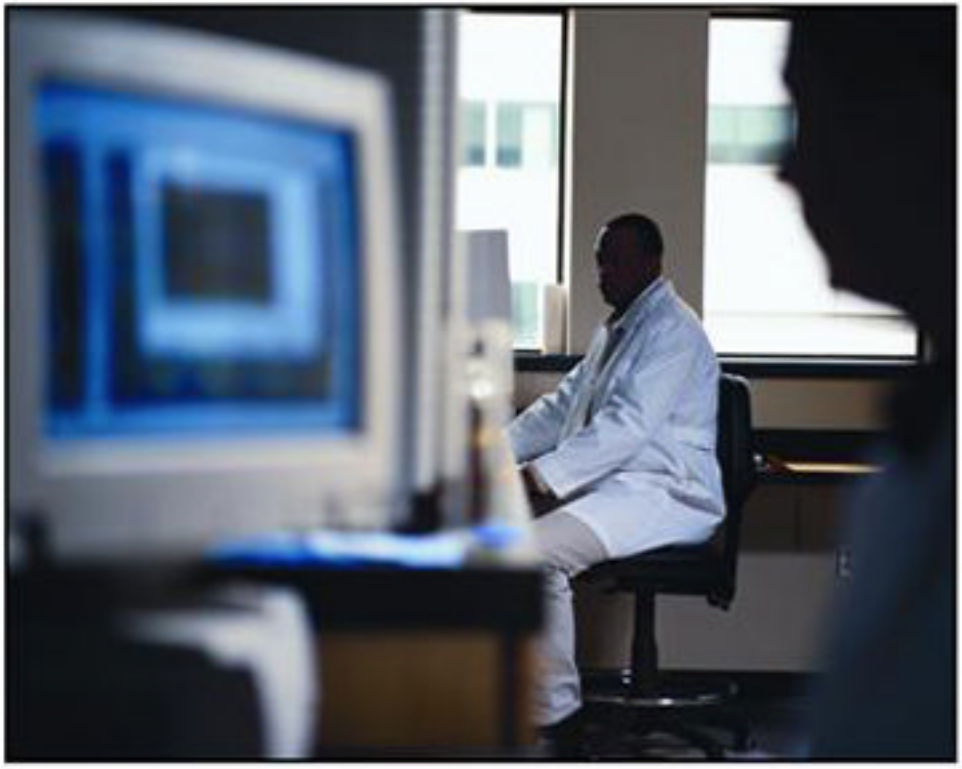
HANDBOOK OF RESEARCH ON

BIOMEDICAL KNOWLEDGE MANAGEMENT

Infrastructures and Processes for E-Health Systems



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Biomedical Knowledge Management:
Infrastructures and Processes for E-Health Systems

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Table of Contents

Detailed Table of Contents

This chapter discusses the role of e-health in creating persistent clinical encounters to extend the scope of health care beyond its conventional boundaries utilizing social networking technology to create what the authors' term 'user driven health care'. It points out the necessity to direct the development of health information systems such that they serve as important vehicles between patient and health professional users in communicating and sharing information other than their role in automated alerts and responses. A project is described that plans to create a system of online sharing of health information in a user driven manner that necessarily becomes persistent due to being stored in electronic health records.

Patient data are increasingly distributed between hospitals using CDs instead of physical films. This introduces problems because different viewers from different vendors are provided, and sometimes viewers are unusable because local software installation is not allowed. In 2004, the authors of this chapter started to facilitate the incorporation of image data from CDs into the normal workflow of the hospital by using commercially available software to perform patient reconciliation based on the DICOM modality work list. In the years after the first introduction, a more comprehensive software system was developed which allows for the fast upload of large amounts of patient image data into the normal workflow. Although direct network connection between institutions is currently being developed and deployed, in the next decade CDs will remain to be used and the integration of the data into the normal workflow is a must. Literature shows that other institutions also started to handle the CDs similarly.

This chapter discusses the role of user-centric and inclusive design methods in healthcare pathways. The rapid uptake of e-health technologies by clinicians and healthcare managers to administer, for example, patient records, has meant that user-centered e-health tools and processes should be adopted to enable those receiving healthcare to become more involved, more proactive in, and more responsible for their own healthcare and its planning. An argument for a user-centered approach as good business practice can also be made. The three case studies described in this chapter are united by a concern for the individual, the end-user, at the heart of healthcare processes, and how design methods, which have a strong emphasis on the consumer or user perspective, can assist the changing requirements for healthcare delivery through an improved, earlier and ongoing engagement with the recipients of health care.

Section 3
Selected Case Studies

Laboratory test results used in health care management can be qualitative or quantitative. These cover several disciplines, the four major disciplines being histopathology, haematology, medical microbiology and chemical pathology. Histopathology and medical microbiology are mainly qualitative assessments, while chemical pathology is predominantly based on quantitative analysis of chemical constituents in blood or other body fluids. Haematology encompasses both quantitative and qualitative assessments, the blood cell parameters being quantitative while blood film reports and bone marrow reports are qualitative. The application of such results to healthcare management includes screening for disease as well as in making a diagnosis and for monitoring response to treatment of a known disease. This necessitates the availability of normal ranges to compare with and decide whether the results are normal or not. Normal means the individual is in a state of good health and a deviation from normal is interpreted as implying ill-health. Data used in these tests are taken from previous studies of Sri Lankan Adults carried out from May 2005 to July 2006.

In the last few years, increasing attention has been paid by the media and the tourist industry to what has become known as ‘medical tourism’ sometimes also called ‘health’ or ‘wellness’ tourism. Before around 2000, these were hardly mentioned by the media at all. However, in one sense, medical tourism has a long history, as some of the information sites on the Internet are eager to point out. People have been travelling in search of medical treatment for millennia, whether in order to visit hot springs as in Poland, Hungary or Japan. Why this sudden interest? This chapter argues that it is due to a combination of factors: the changing distribution of medical services and technologies, the growth of interest among both local medical practitioners in different parts of the world and travel agents, the clever packaging of tourism and medical services as a single product, and the availability of the Internet both to assemble and to disseminate information on these new products. The chapter covers the implications of these cases for the future of medical tourism, and its relations both with the medical and tourism industries.

E-health systems can be used to communicate the risk of significant infectious diseases such as HIV infection to individuals who contemplate taking the risk of the personal behavioral choices they make.

Access to an on-line system which communicates this data in a user-friendly format, can help avoid high-risk behavior by informed individuals who live in different areas with various levels of risk. This chapter presents the case of HIV infection in Japan where many individuals have voluntarily continued a high-risk behavior because apparently they consider the overall risk of infection too low to forgo the personal benefits of risky behavior such as more pleasure, less inconvenience, etc.

Chapter 17

It is argued in this chapter that e-health has the potential to improve the provision of health care and the quality of patient treatment, but it also contains many threats, especially in developing countries where information technologies are generally implemented without any discussion with society. With regard to health information, Brazil is behind some African countries in terms of data recording according to international reports used to publish health care indicators. Most of the hospitals do not have basic information systems for data collection and storage, despite the fact that the country has historically registered very bad health indicators. Moreover, many e-government initiatives, including e-health applications and development are based on the traditional top-down model or market-driven approach to information technology, oriented towards corporate actor interests and health care administration rather than basic population health care needs. This system tends to neglect basic priorities for people lacking education, clean water, food and primary health care.

Chapter 18

This chapter outlines the approach to mental health care developed and currently being implemented by Pathways New Zealand for reducing disease risk factors in patients treated for mental health problems. Pathways New Zealand was formed in 1989 following the closure of the major mental service facility for the Waikato-Hauraki Region of New Zealand, Tokonui Hospital. Since that time Pathways has grown to a national level service offering services to its clients ranging from 24-hour supported accommodation, through healthy lifestyles programs, to outcomes based services including patient access to and involvement in the management of their medical and personal history data (ICAN).

Chapter 19

According to the Australian Department of Health and Aging (n.d.) the adoption of new technologies is crucial in addressing health issues. Currently, wireless technology is used in Australian healthcare with

limited scope, addressing specific aspects of quality of service offered to various stakeholders. While prior studies agree that wireless applications have the potential to address the endemic problems of healthcare, very limited information can be found about the determinants of such applications. Therefore, there is a need to identify factors that may assist in the adoption of wireless applications in healthcare and the factors acting as barriers in the uptake of such applications. This chapter reports on a study designed to elicit these factors using a semi structured interview approach and surveys.

Sleep problems are frequently witnessed in aged care facilities with a large proportion going undetected. Multiple factors are known to contribute many abnormal sleep/wake patterns for residents. A systematic review conducted by Haesler (2004) provided a guide to the direction of future research into sleep in older adults residing in care facilities. This chapter evaluates the effectiveness of implementing the following evidence based recommendation from Haesler (2004): Wrist actigraphy currently represents the most accurate objective sleep assessment tool for use in the population of interest. Factor analysis was utilized to study the patterns of relationship among many dependent variables, with the goal of discovering something about the nature of the independent variables that affect them. Wrist actigraphy showed a disparity between the actual bed time and wake time. One clear difference detected using the device was the increased detection of sleep during the day.

Sleep disorders causing excessive daytime sleepiness are estimated to affect six percent of the population and has traditionally been under diagnosed. Sleep disorders symptoms may lead to an increased likelihood of suffering work and vehicle related accidents as well as affecting the physical and mental well being of the sufferer. A sleep diary documenting sleep hygiene habits over a period of time is an important tool in the diagnoses of sleep disorders. This project was to develop an online sleep diary, bringing benefits of presenting the information earlier to the physician in a format which allows the quick assimilation of information from the diary. The information is also in an electronic format facilitating the transmission to an electronic health record and the building of a database of sleep patterns. An online sleep diary allows a patient to self-monitor their condition allowing them to assess treatment and lifestyle changes on sleep patterns.

Foreword

Knowledge is of two kinds: we know a subject ourselves, or
we know where we can find information upon it.
-- Samuel Johnson

More than ever, we depend heavily on knowledge – both our own knowledge and knowledge prevalent in domains of our interest. Knowledge, like physical and financial assets, has to be preserved and used. And we need to harness and exploit the collective knowledge as it can fill the gaps in individual knowledge. Given that human knowledge is perishable and volatile, knowledge management using computer-based tools and systems augmented with artificial intelligence techniques assumes greater significance.

This book, Biomedical Knowledge Management: Infrastructures and Processes for E-Health Systems, is a timely and a valuable addition to a small set of books in the area of knowledge management in healthcare and biomedical sciences and engineering.

This book covers a variety of topics at the forefront of e-health and biomedical systems, including: telemedicine, electronic health records, e-prescription, systems that analyze and extract meaningful information from free text medical records, use of modeling and artificial intelligence and data mining techniques for data analysis, innovative applications that extend the scope of health care beyond conventional practices and online decision support system for medical practitioners, as well as human factors in e-health systems.

As Goethe has advised, "Knowing is not enough; we must apply!". In that sprit, this book also presents a number of insightful case studies discussing practical applications and real-world experiences. It provides a balanced nexus among research and practice, one complementing and contributing to the other.

Taken together, chapters in this book provide a number of interesting perspectives on e-Health systems and biomedical knowledge management and provide valuable insights that would enable researchers and practitioners to take best advantage of developments reported here and to address problems and issues that deserve further study.

I believe you – whether you are a researcher, an academic, or someone interested IT applications in healthcare – find the book a very valuable resource.

A little knowledge that acts is worth infinitely more
than much knowledge that is idle.
-- Kahlil Gibran

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Preface

Key challenges facing healthcare providers today include an aging population, demanding patients, medical errors and rising costs. These challenges are now being addressed through the application of practical solutions to operational problems and the development of more responsive and efficient health policy using eHealth techniques. This timely book overviews the development of eHealth from a number of perspectives including historical, policy and social viewpoints, and describes the current state of play in terms of eHealth research and the development of innovative ICT systems and services that process, integrate and use all relevant biomedical information for improving health knowledge. It also provides the reader with up-to-date knowledge of the eHealth practices related to prevention, diagnosis, treatment, and personalisation of health care in a number of jurisdictions around the world.

A commonly accepted definition of eHealth is:

"*an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology*" (Eysenbach 2001).

eHealth thus describes the application of information and communications technologies (ICT) across the whole range of functions that affect the health sector, from the doctor to the hospital manager, via nurses, data processing specialists, social security administrators and - of course - the patient. Thus eHealth is one of the most rapidly growing areas in health today; use of the Internet and other developments in eHealth is playing an increasing role in consumer health behaviour, and in the delivery of health services. Accessing health information is one of the main uses at present of Internet-based eHealth techniques. National health services are investing significant resources in the development of programs which will bring profound changes to the organisation and delivery of healthcare, including shared electronic records, electronic prescribing and electronic booking of appointments, and ultimately a much more intimate practitioner-patient relationship. The rate of change and innovation in this area is such that research efforts have so far lagged behind and little work has been carried out to investigate the impact of eHealth developments on public health and health services. This book is designed to remedy that situation.

For our purposes in this book eHealth is therefore best examined in terms of its social as well as technical ramifications, and especially its political and economic (or political economy) contexts at and between different service levels, including the local, the regional and the global. However, only very limited systematic research has been carried out to inform eHealth policy and practice in this sense. It was one of the objectives of this book to address this deficiency.

CHAPTER OVERVIEW

Chapter 1 develops an integrated view of telemedicine and biotelemetry applications. The objective of the chapter is coherent with the objective of the book, which includes techniques in the biomedical knowledge management. Telemedicine is the use of modern telecommunications and information technologies for the provision of clinical care to individuals at a distance and the transmission of information to provide that care. The medical systems infrastructure underpinning this form of medicine, consisting of the equipment and processes used to acquire and present clinical information and to store and retrieve data are explained in detail. An investigation of telemedicine applications in various fields is presented and the likely enormous impact of telemedicine systems on the future of medicine is discussed. For example, bioelectric and physiological variables could be measured by biotelemetry systems. Developing a biotelemetry system and the principal operation of such a system are presented, and its components and the telemetry types are explained. The author suggests that the content of the chapter will assist the medical sector and the general reader in gaining a better understanding of the techniques in the telemedicine and biotelemetry applications.

Chapter 2 shows that there is a treasure trove of hidden information in the textual and narrative data of medical records that can be deciphered by text-mining techniques. The information provided by these methods can provide a basis for medical artificial intelligence and help support or improve clinical decision making by medical doctors. In this paper the authors extend previous work in an effort to extract meaningful information from free text medical records. The chapter discusses a methodology for the analysis of medical records using some statistical analysis and the Kohonen Self-Organizing Map (SOM). The medical data derive from about 700 pediatric patients' radiology department records where CT (Computed Tomography) scanning was used as part of a diagnostic exploration. The patients underwent CT scanning (single and multiple) throughout a one-year period in 2004 at the Nagasaki University Medical Hospital. This approach led to a model based on SOM clusters and statistical analysis which may suggest a strategy for limiting CT scan requests. This is important because radiation at levels ordinarily used for CT scanning may pose significant health risks especially to children.

Chapter 3 documents how the proliferation of Internet and Information Technologies (IIT) has led to many innovations in the healthcare industry. Among such innovations are the Electronic Medication Administration Record (eMAR) and the Bedside Medication Verification (BMV), both of which have been widely implemented by hospitals around the world. In this regard, the goal of this chapter is threefold. It first describes the underlying work-flow utilized in these systems by comparing it with traditional methods of medication administration. Then it investigates the adoption and implementation of eMAR and BMV in hospitals in the United States, the conversion from traditional medication administration to eMAR documentation, and how utilization of eMAR and BMV can promote patient safety. The chapter concludes with the exploration of future trends in medication administration through the utilization of eMAR and BMV, and highlights future research directions in the field.

Chapter 4 outlines how Health Level Seven (HL7) and Digital Imaging and Communications in Medicine (DICOM) standards are strongly influencing Electronic Health Records (EHRs) standardization. In this chapter, the authors present a web-based application, TeleOftalWeb 3.2, to store and exchange EHRs in ophthalmology by using HL7 Clinical Document Architecture (CDA) and DICOM standards. EHRs are stored in the native Extensible Markup Language (XML) database, dbXML 2.0. Application architecture is triple-layered with two database servers (MySQL 5.0 and dbXML) and one application server (Tomcat 5.5.9). Physicians can access and retrieve patient medical information and all types of medical images through web browsers. For security, all data transmissions are carried over encrypted Internet connections such as the Secure Sockets Layer (SSL) and Hypertext Transfer Protocol over SSL

(HTTPS). The application verifies the standards related to privacy and confidentiality. The application is being tested by physicians from the University Institute of Applied Ophthalmobiology (IOBA) in Spain.

Chapter 5 presents an overview and analysis of electronic prescriptions. Medical prescriptions are currently typically handwritten or printed on paper and hand-delivered to pharmacists. Paper-based medical prescription is generating increasing concern as the incidences of prescription errors have been increasing and causing minor to serious problems to patients, including deaths. Most of the problems of paper-based prescription can be avoided by electronic medical prescription, also variously known as electronic prescription, e-prescription, or electronic transmission of prescription. Though the basic concept of e-prescription is simple, e-prescription has not yet been widely adopted, despite advances in information and communication technologies – it is, in fact, just in early stages of adoption in a few countries only. To facilitate wider adoption of e-prescription, several technical and non-technical issues need to be addressed. Beginning with an introduction to e-prescription, the chapter examines various aspects of the e-prescription system, and describes and evaluates various e-prescription models and systems. The chapter then discusses technical and non-technical issues in implementing e-prescription, and concludes with our recommendations.

Chapter 6 shows how some common health methodologies in everyday life are not based on modern scientific knowledge but rather a set of experiences that have established themselves through years of practice. As a good example, there are many forms of alternative medicine, quite popular, however difficult to comprehend by conventional western medicine. The diagnostic and therapeutic methodologies are very different and sometimes unique, compared to that of western medicine. How can these be verified and analyzed through modern scientific methods? The authors present a case study where data-mining was able to fill this gap and provide us with many tools for investigation. Osteopathy is a popular alternative medicine methodology to treat musculoskeletal complaints in Japan. Using data-mining methodologies, it is possible to overcome some of the analytical problems in such an investigation. The authors studied diagnostic records from a very popular osteopathy clinic in Osaka, Japan that included over 30,000 patient visits over 6 years of practice. The data consists of careful measurements of tissue electro-conductivity differences at 5 anatomical positions. Data mining and knowledge discovery algorithms were applied to search for meaningful associations within the patient data elements recorded. This study helped the authors scientifically investigate the diagnostic methodology adopted by the osteopath.

Chapter 7 outlines how, in the wake of continuously escalating healthcare costs, health management in the workplace has gained new momentum as employers strategize how to optimize the health of their workforce while containing healthcare costs and dealing with ethical issues. Gaining acceptance as a viable tool to aid employers is a process called Predictive Modeling. On the surface, Predictive Modeling may contribute significantly to delivering the right interventions to the right person at the right time by identifying high risk individuals, and under-users and over-users of health services. This chapter discusses the ethical principles of non-maleficence, beneficence, justice and autonomy, as well as value judgments and human rights as applied to Predictive Modeling to guide professionals and employers in health management decisions.

Chapter 8 discusses the role of e-health in creating persistent clinical encounters in order to extend the scope of health care beyond its conventional boundaries by utilizing social networking technology to create what the authors' term 'user driven health care'. It points out the necessity to direct the development of health information systems such that they serve as important vehicles between patient and health professional users in communicating and sharing information other than their role in automated alerts and responses. A project is described that plans to create a system of online sharing of health information in a user driven manner that necessarily becomes persistent due to being stored in electronic health records.

Chapter 9 documents how patient image data are increasingly distributed between hospitals using CDs instead of physical films. This introduces problems because different viewers from different vendors are provided, and sometimes viewers are unusable because local software installation is not allowed. In 2004 the incorporation of image data from CDs into the normal workflow of the hospital by using commercially available software to perform patient reconciliation based on the DICOM modality work list was begun. In the years after this initial introduction, a more comprehensive software system was developed which allows for the fast upload of large amounts of patient image data into the normal workflow. Although direct network connection between institutions is currently being developed and deployed, in the next decade CDs will remain to be used and the integration of the data into the normal workflow is a must. The literature shows that other institutions also started to handle CD based media in a similar fashion.

Chapter 10 discusses the role of user-centric and inclusive design methods in healthcare pathways. The rapid uptake of e-health technologies by clinicians and healthcare managers to administer, for example, patient records, has meant that user-centered e-health tools and processes should be adopted to enable those receiving healthcare to become more involved, more proactive in, and more responsible for their own healthcare and its planning. An argument for a user-centered approach as good business practice can also be made. The three case studies described in this chapter are united by a concern for the individual, the end-user, at the heart of healthcare processes, and how design methods, which have a strong emphasis on the consumer or user perspective, can assist the changing requirements for healthcare delivery through an improved, earlier and ongoing engagement with the recipients of healthcare.

Chapter 11 describes a web-based decision support system called TeleDerm that has been developed with the aim of helping general practitioners diagnose skin ailments from a knowledge base while allowing incremental updates of the knowledge base as cases occur. The authors outline the two major challenges in developing the TeleDerm system: developing a general practitioner query process that is easily accessible and building knowledge validation in a case-based reasoning system. The chapter provides a detailed description of approaches to address these problems which involve the use of artificial intelligence classification and reasoning techniques. The system was deployed in a large scale trial in the Eastern Goldfields Health Region of Western Australia and the chapter presents the results and feedback obtained from an evaluation by the general practitioners involved.

Chapter 12 outlines the fundamental user issues identified in the design stage of a Stroke Information System (SIS) for the Hospital Information Management System (HIMS) in the secondary care and above phase of TACMIS (Total Access Care and Medical Information System – see Chapter XXIII). TACMIS is a total, integrated and inclusive healthcare information system design solution reflecting the core ideas of DAITS (Design for Disability, Aging and Access to Inclusive Information Tools, Technologies and Systems); creativity; cutting edge research; and being global. Being a subsystem, HIMS-SIS is developed in alignment with TACMIS, the main system architecture and information system concept, and is designed to allow stakeholders and professions involved within stroke special care unit practice to inform staff from nonmedical professions in order to improve healthcare quality. This may also make improved treatment affordable by many if not all. Finally, initial investigations on how large volumes of patient data could be transformed into useful knowledge using intelligent information processing methodologies are outlined.

Chapter 13 documents how e-health systems and digital libraries deal with human health, requiring fast responses and real-time decision-making. Human intervention can be seen in the whole life cycle of biomedical systems. In fact, relations between patients, nurses, lab technicians, health insurers, and physicians are crucial in such systems, and should be encouraged when necessary. However, there are some issues that affect the successful implementation of such infrastructures. Man-machine interaction

problems are not purely computational and need a deep understanding of human behavior. Many integrated health knowledge management systems, have employed various knowledgebases and ontologies as their conceptual backbone to facilitate human-machine communication. Ontologies facilitate sharing knowledge between human and machine; they try to capture knowledge from a domain of interest; when the knowledge changes, the definitions will be altered to provide meaningful and valid information. In this chapter, the authors review and survey the potential issues related to the human factor in an integrated dynamic e-health system composed of several interrelated knowledgebases, bio-ontologies and digital libraries by looking at different theories in social science, psychology, and cognitive science. The authors also investigate the potential of some advanced formalisms in the semantic web context such as employing intelligent agents to assist the human user in dealing with changes.

Chapter 14 shows how the application of laboratory test results can be used in healthcare management that includes screening for disease as well as in making a diagnosis and for monitoring response to treatment of a known disease. Laboratory test results used in health care management can be qualitative or quantitative. These cover several disciplines, the four major disciplines being histopathology, haematology, medical microbiology and chemical pathology. Histopathology and medical microbiology are mainly qualitative assessments, while chemical pathology is predominantly based on quantitative analysis of chemical constituents in blood or other body fluids. Haematology encompasses both quantitative and qualitative assessments, the blood cell parameters being quantitative while blood film reports and bone marrow reports are qualitative. The application of such results to healthcare management includes screening for disease as well as in making a diagnosis and for monitoring response to treatment of a known disease. This necessitates the availability of normal ranges to compare with and decide whether the results are normal or not. Normal means the individual is in a state of good health and a deviation from normal is interpreted as implying ill-health. Data used in these tests are taken from previous studies of Sri Lankan Adults carried out from May 2005 to July 2006.

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Chapter 16 shows how e-health systems can be used to communicate the risk of significant infectious diseases such as HIV infection to individuals who are contemplating taking the risk of the personal behavioral choices they make. Access to an on-line system which communicates this data in a user-friendly format, can help avoid high-risk behavior by informed individuals who live in different areas with various levels of risk. We present the case of HIV infection in Japan where many individuals have voluntarily continued a high-risk behavior because apparently they consider the overall risk of infection too low to forgo the personal benefits of risky behavior such as more pleasure, less inconvenience, etc. We discuss how a user friendly e-health system can provide geographical risk data that are extracted from HIV epidemiological surveillance. This can provide individuals with a rational incentive for be-

havior change in high-risk areas. It is hoped that such a system helps with the control of not only HIV, but also other agents of disease in situations where individual choices play a significant role in the risk of exposure/disease.

Chapter 17 argues that e-health has the potential to improve the provision of health care and the quality of patient treatment, but it also contains many threats, especially in developing countries where information technologies are generally implemented without any discussion with society. With regard to health information, Brazil is behind some African countries in terms of data recording according to international reports used to publish health care indicators. Most of the hospitals do not have basic information systems for data collection and storage, despite the fact that the country has historically registered very bad health indicators. Moreover, many e-government initiatives, including e-health applications and development are based on the traditional top-down model or market-driven approach to information technology, oriented towards corporate actor interests and health care administration rather than basic population health care needs. This system tends to neglect basic priorities for people lacking education, clean water, food and primary health care.

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Chapter 19 notes that according to the Australian Department of Health and Aging the adoption of new technologies is crucial in addressing health issues. Currently, wireless technology is used in Australian healthcare with limited scope, addressing specific aspects of quality of service offered to various stakeholders. While prior studies agree that wireless applications have the potential to address the endemic problems of healthcare, very limited information can be found about the determinants of such applications. Therefore, there is a need to identify factors that may assist in the adoption of wireless applications in healthcare and the factors acting as barriers in the uptake of such applications. This chapter reports on a study designed to elicit these factors using a semi structured interview approach and surveys. The study is structured in two specific phases. The first phase involved a semi structured interview with selected healthcare professionals to understand various factors involved in the adoption of wireless applications as applicable to Australian healthcare. The second phase involved administering a survey to generalize the findings of phase one and to capture the views of the wider population.

Chapter 20 shows that sleep problems are frequently witnessed in aged care facilities with a large proportion going undetected. Multiple factors are known to contribute many abnormal sleep/wake patterns for residents. A systematic review conducted by Haesler (2004) provided a guide to the direction of future research into sleep in older adults residing in care facilities. This chapter evaluates the effectiveness of implementing the following evidence based recommendation from Haesler (2004): that Wrist actigraphy currently represents the most accurate objective sleep assessment tool for use in studies of this

phenomenon. Factor analysis was utilized to study the patterns of relationship among many dependent variables, with the goal of discovering something about the nature of the independent variables that affect them. Wrist actigraphy showed a disparity between the actual bed time and wake time. One clear difference detected using the device was the increased detection of sleep during the day.

Chapter 21 focuses on the fact that sleep disorders causing excessive daytime sleepiness are estimated to affect six percent of the population and has traditionally been under diagnosed. Sleep disorders symptoms may lead to an increased likelihood of suffering work and vehicle related accidents as well as affecting the physical and mental well being of the sufferer. A sleep diary documenting sleep hygiene habits over a period of time is an important tool in the diagnoses of sleep disorders. This project was to develop an online sleep diary, bringing benefits of presenting the information earlier to the physician in a format which allows the quick assimilation of information from the diary. The information is also in an electronic format facilitating the transmission to an electronic health record and the building of a database of sleep patterns. An online sleep diary allows a patient to self-monitor their condition allowing them to assess treatment and lifestyle changes on sleep patterns.

Chapter 22 contends that there is growing interest in the way that communication between doctors and patients affects important aspects of patient care and health outcomes. However, there is not much research on quantifying the effect of specific training programmes in communication skills for doctors. The aim of this chapter is to describe a research project that addresses this issue by first asking patients to provide feedback to doctors on their interpersonal skills. A set of training objectives is then discussed with individual doctors based on patient feedback. A training programme is subsequently undertaken by doctors, who are re-assessed by patients to determine the effectiveness of the feedback and training. The results indicate significant improvement on re-measurement. The chapter discusses the reasons for this improvement and the implications for providing personalised interpersonal skills training programs that target those skills that have been specifically identified by patients.

Chapter 23 shows how TACMIS is an inclusive solution to the management of health care and medical information. Its design is based on a detailed process analysis of patient journeys and the pathways of clinical care of stroke patients as they progress from acute care, through rehabilitation to discharge and independent living, often with a residual disability. The findings are the work of a team based in the Discovery Research Laboratory at Ritsumeikan University in Japan. The clinical analysis was conducted at King's College Hospital in London and in several care institutions for the disabled and the aged in Japan.

Finally, Chapter 24 outlines how Information Technology (IT) applications for medical services in Japan have developed in line with two major national level factors. One is the "E-Japan Project" which was proposed and implemented to revitalize the Japanese economy by introducing IT to a wide range of industries and sectors of the society and by promoting establishment of IT infrastructure. The other is the serious concern over the fast rising healthcare expenses in the face of the rapidly aging society in that country. The first major efforts under this project, therefore, were made for productivity improvement and cost reduction in the health insurance bill claiming procedure and other related fields. These initiatives were followed by the construction of medical information sharing and processing systems first and then later developed further for regional collaborations among medical institutions. Other examples of IT applications in the Japanese medical services are also discussed, notably that which can be found in telemedicine to cope with the currently serious shortage of medical doctors.

Section 1

Biomedical Knowledge Management Systems

Chapter 1
Telemedicine and Biotelemetry for E-Health Systems:
Theory and Applications

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ABSTRACT

This chapter develops an integrated view of telemedicine and biotelemetry applications. The objective of the chapter is coherent with the objective of the book, which includes techniques in the biomedical knowledge management. Telemedicine is the use of modern telecommunications and information technologies for the provision of clinical care to individuals at a distance and the transmission of information to provide that care. The medical systems infrastructure underpinning this form of medicine, consisting of the equipment and processes used to acquire and present clinical information and to store and retrieve data are explained in detail. An investigation of telemedicine applications in various fields is presented and the likely enormous impact of telemedicine systems on the future of medicine is discussed. For example, bioelectric and physiological variables could be measured by biotelemetry systems. Developing a biotelemetry system and the principal operation of such a system are presented, and its components and the telemetry types are explained. The author suggests that the content of the chapter will assist the medical sector and the general reader in gaining a better understanding of the techniques in the telemedicine and biotelemetry applications.

INTRODUCTION

Literally, telemedicine means medicine at a distance. Telemedicine has been defined as the electronically-transmitted rapid exchange of medical information between sites of clinical practice for the purposes of relief and/or education. Telemedicine is also defined as the use of electronic information and communication technologies to provide and support health care when distance separates the participants. A broader definition is the use of telecommunication technologies to provide medical information and services (Chen et al, 1999; Foster et al, 1998; Güler & Übeyli, 2002a; Moore, 1999). Telemedicine

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includes diagnosis, treatment, monitoring and education of patients using systems that allow ready access to expert advice and patient information no importance where the patient or relevant information is located. The fundamental concepts of telemedicine technology including: Basic principles of telecommunications and internetworking of computer systems, use of communications software, forms of telecommunications. The use of telemedicine systems in hospitals, clinics, long-term care facilities and home care is becoming well established and evolving in effectiveness and efficiency (Garshnek et al, 1997; Stanberry, 2001). Telemedicine can therefore be divided into three areas: Use for decision making; remote sensing; and colloborative arrangements for the real time management of patients at a distance. Each of the three areas are limited to aspects of medical diagnosis, patient care and education (Merrell & Doarn, 2007; Sood et al, 2007).

Biomedical telemetry is a special field of biomedical instrumentation that often permits transmission of biological information from an inaccessible location to a remote monitoring site. When direct observation is impossible, biotelemetry can be used to obtain a wide spectrum of environmental, physiological and behavioural data (Güler & Übeyli, 2002b; Hines, 1996; Jones & Normann, 1997; Ziaie et al, 1997). The purpose of biotelemetry includes the capability for monitoring humans and animals with minimum restraint and to provide reproduction of the transmitted data. If measurements and monitoring techniques are applied to restrained humans and animals, stress of immobilization causes alterations of measured variables. According to this concept, the advantage of biotelemetry is the measurement of physiological variables in conscious, unrestrained humans and animals. The method of biotelemetry is offering wireless, restraint-free, simultaneous, long-term data gathering (Axelsson et al, 2007; Lee et al, 2007; Mussivand et al, 1997). Measurements which have been done in biotelemetry can be determined in two categories:

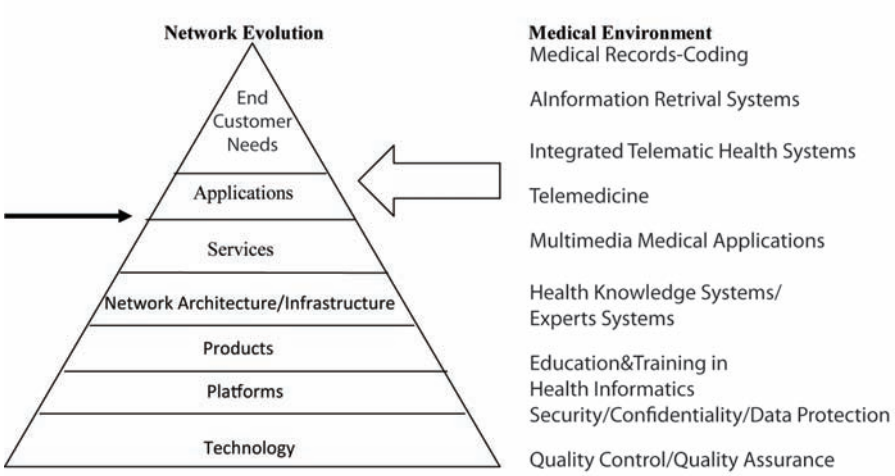
1. Bioelectrical variables, such as electrocardiogram (ECG), electromyogram (EMG) and electroencephalogram (EEG);
2. Physiological variables that require transducers, such as blood pressure, gastrointestinal pressure, blood flow and temperatures. By using suitable transducers, telemetry can be employed for the measurement of a wide variety of physiological variables (Rocchitta et al, 2007; Welkowitz et al, 1976).

TELEMEDICINE TECHNOLOGIES

The use of telecommunications and information technology is central in providing health services- regardless of location. The investigation, monitoring and management of patients and the education of patients and staff using systems which allow ready access to expert advice and patient information, no matter where the patient or relevant information is located (Chen et al, 1999; Garshnek et al, 1997). In addition to the aspects covered by these definitions, telemedicine involves a combination of topics from the fields of telecommunication, medicine and informatics. The application of telecommunication technology to health care requires integration of technology, tools and training with medical care practices and problems, although it is not necessary to be an expert in all these components to effectively use a telemedicine system. Telemedicine achieve its potential to improve delivery of health care in rural or remote areas only through cooperation among health professionals, computer system developers, telecommunication providers and educators.

Telemedicine includes transfer of basic patient information over computer networks (medical informatics), diagnosis, treatment, monitoring and education of patients using systems that allow access to expert advice and patient information. During these processes location of patient or relevant information is not important. The fundamental concepts of telemedicine technology, including:

Figure 1. An abstract mapping of medical applications to network evolution (source: After Pombortsis, 1998)



- Basic principles of telecommunications and internetworking of computer systems;
- Use of communications software, including electronic mail and browsers for the World Wide Web;
- Forms of telecommunications, including videoconferencing, remote data monitoring and file transfer, applicable to medical care in remote or rural environments.

Communication networks are becoming increasingly large in size and heterogeneous in nature. Recent advantages in communication technologies have contributed to an explosion of new products and services directed at the medical environment. An abstract mapping between medical applications and network evolution is given in Figure 1 (Pombortsis, 1998). The general goal of using communication technologies in medical environments is to improve the overall quality of health care at an affordable cost. This requires close interaction between health care practitioners and information technologists to ensure that the proposed technologies satisfy current user's needs and anticipate future ones.

The practice of telemedicine may be broken into two categories: Store-and-forward and interactive. Store-and-forward technology is a low cost method of transmitting images by computer. This technology is most frequently used for transmitting radiological pictures and is used by most of the hospitals and clinics. Interactive telemedicine implies face-to-face interaction with a patient, health professional or both. This requires videoconferencing technology at both sites, which is usually between a large medical center or hospital and another facility (usually rural) requiring a specialist's opinion (Brown, 1998).

Telemedicine can also be synchronous or asynchronous and increasing numbers of programs provide both services. Synchronous services occur in real time and primarily include audio, interactive full motion video and still images. Synchronous services are often used for live patient consultations and for large group continuing education and meetings when interactive communication is required. Systems used for synchronous communication may include specialized telemedicine about interactive video units, interactive video room systems, computer-based desktop videoconferencing units, videophones. These may be supplemented

with peripherals including electronic stethoscopes, other electronic scopes, view boxes, combination of telemonitoring devices, graphics stands and more. Sometimes hand-held mobile and wireless systems are used for records, prescriptions and orders. Asynchronous services are viewed at different times than the time of transmission and generally consist of still images, e-mail and video clips. Asynchronous telehealth is more often used when the patient does not need to be present for interactive communication and for independent continuing education. Store-and-forward technologies used in asynchronous services are mostly PC based (Moore, 1999).

TELEMEDICINE INFRASTRUCTURE

The telecommunications infrastructure provides the technology to move information electronically between geographically dispersed locations. Participating sites are linked through electronic networks. The telecommunication medium utilized by telemedicine programs is determined in large part by the available local infrastructure. These can include satellite, microwave link or terrestrial lines (either twisted copper phone lines or fiber optic cable) (Murakami et al., 1994). The medical systems infrastructure consists of the equipment and processes used to acquire and present clinical information and to store and retrieve data. Acquisition and presentation technologies include teleconferencing, data digitizing and display (remote X-ray, laboratory tests), text processors (scanners, fax), or image processors (video cameras, monitors). Data storage and retrieval include storage devices (disks, tape, CD-ROM) along with technology to compress, transmit and store data. The applications are based on a variety of networks, ranging from the ordinary telephone network to specialized networks.

Telemedicine therefore involves a spectrum of technologies including computer technology, digital imaging, videoconferencing, remote monitoring, file sharing, networking and telecommunications (Conner et al., 2000). Technology is necessary to support long-distance communications. Electronic devices like telephones, TV cameras or computers allow people to create information that is then transmitted through media such as cables, satellite systems or computer networks. Most of these systems interpose switches or routers in the medium that relay information from one intermediate point to another, deciding along the way how to get an electronic message to its intended destination in the best manner (Chen et al, 1999; Ruskin et al, 1998; Sargsyan et al, 1999; Sheng et al, 1999; Takeda et al, 1999; Tanrıverdi & Iacono, 1999).

The Internet allows any computer with an internet connection to communicate with any other connected computer, no matter where each of them are. Internet supports telecommunications in number of ways. Composing, sending and receiving electronic mail between users has been possible. A user can also make copies of files from other computers onto their own by using programs for file transfer such as FTP. The foundation of the World Wide Web is organized group of computers (sites) accessible from internet containing files that can be viewed by using browser software (Ruskin et al, 1998; Sargsyan et al, 1999). With the rapid development of internet and internet based applications, telemedicine can potentially provide important health care coverage for remote and rural area where specialized medical expertise is lacking. Using internet based telemedicine application, the records and vital signs of patients in remote or rural areas can be made available to medical experts in major medical centers for real-time evaluation or diagnosis (Bellazzi et al, 2001).

In order to do this effectively, asynchronous transfer mode (ATM) is the preferred technology in medical communications. Many medical applications require the higher bandwidth and guaranteed qualities of service supported by ATM. Interest first came from the carriers and the manufactures

of wide area network (WAN) equipment and then interest is growing in the application of ATM technology to local area networks (LANs) and campus area networking environments, as well as to desktop area networks. In a typical scenario there are several different networks carrying voice, data and video. An ATM based network can be used to consolidate these into one network, with the initial candidate networks being data and video, and voice networks being the last added (Gomez et al, 2001; Moore, 1999; Pombortsis, 1998).

The Integrated Services Digital Network (ISDN) provides various telecommunication services through one common interface to the subscriber line. Enhanced features for data communication is a particularly important service of ISDN. The services include telephony, telex, teletext, facsmile, videotext, videophony, videoconferencing and data communication (including mail, conferencing, databases, etc.). In the health sevices, use of ISDN for the exchange of administrative information has great potential. Making an appointment for an X-ray examination may be an example. The primary health care clinic's system for medical records can establish a connection to the local hospital's booking system while the patient is still at the practitioner's office. Then the patient, the practitioner and the clerical officer at the hospital cooperate on deciding a suitable time and make the appointment. Then necessary information on the patient can be transmitted. After a completed examination, the X-rays and the radiologist's diagnosis can be transmitted back to the primary health clinic system for medical records (Tanrıverdi & Iacono, 1999).

The integration of fixed and mobile networks also makes new applications possible for telemedicine. Mobile information and communication systems in clinical routine have the potential to greatly improve communication, facilitate information access, eliminate double documentation and increase quality of patient care. With a view to providing paramedical care within moving vehicles, a telemedicine technique using mobile satellite communication is proposed. In a moving vehicle, a color image, an audio signal and physiological signals, such as ECG and blood pressure are obtained from a patient. They are multiplexed and transmitted to a satellite. In a fixed station, the signals received from the satellite are demultiplexed and presented to a medical doctor or automatic monitoring system. The instructions from the doctor are transmitted back to the mobile station via satellite. The usage of mobile satellite communication in telemedicine makes some particular applications more possible: emergency medicine in moving vehicles, emergency medicine during disasters, physiological monitoring of pilots and/or astronauts, etc. In addition, there will be many new applications of telemedicine using mobile satellite communications developed as this technology becomes more widely used (Murakami et al, 1994).

Videophony and videoconferencing over ISDN and internet are useful tools for communication within the health services. Videoconference standards emerged at the end of the 1980s to work over synchronous communication networks, such as ISDN. Videoconferencing is an effective way for people to meet and work together, without being at the same place. It may also be a useful tool when transmitting medical information in the form of video sequences. Videoconferencing connects a group of hospitals on a 'one-to-many' basis, whereby a single hospital acts as a chairman of the conference. The chairing hospital will decide if any of its participating hospitals will become its conferencing partner at any time by channeling the partner's video and audio signals to appear alongside it on the main screen. Any other hospital in the group can join in at any time during the conference (Callas et al, 2000; Klutke et al, 1999).

Finally, teleconsultation is a consultation between two or more physicians about the diagnostic work-up and therapeutic strategy in the treatment of an individual case by means of modern telematics. Teleconsultations can be used in two modes:

Live consultations via videoconferencing systems and store-and-forward consultations via the Internet. Through communication among doctors or between doctors and other related personnel, the knowledge of experts can be transmitted to non-specialists to support medical care (Moore, 1999; Sood et al, 2007).

APPLICATIONS OF TELEMEDICINE

The wide scope of applications for telemedicine include patient care, education, research and public health to diagnose, deliver care, transfer health data, provide consultation, educate health professionals. Telemedicine has become an integral part of medical care in space flight (Hines, 1996). In addition to these applications, telemedicine is utilized in a growing number of medical specialities by health providers (Brown, 1998; Chen et al, 1999; Ruskin, et al, 1998). Home health service is one of the fastest growing areas of health care in many countries. Among the reasons for this rapid growth are several factors, including an aging population, patient preference for care provided in their own homes and earlier discharge from acute care settings (Chae et al, 2001; Ruggiero et al, 1999; Sood et al, 2007). Linking patients and physicians through internet may increase the involvement of patients in supervising and documenting their own health care, processes that may activate patients and contribute to improved health (Mandl et al, 1998). Telemedicine may even be useful in developing more cost effective methods of providing health care in private clinics or organizations which present difficult computer integration and communication challenges due to their size and geographic distribution (Broens et al, 2007; Whitten et al, 2007).

The doctors and/or support people who are working in the medical field often have geographical disadvantages. Their support systems constantly attempt to providesthem with the most up-to-date information. Telemedicine can therefore also be used for educating health professionals in rural or remote communities and to give them access to specialized information that might be difficult to obtain otherwise. Internet teleconferencing software can be used to hold virtual meetings, during which participants around the world can share ideas. For example, anesthesiologists have rapidly adopted teleconferencing as part of scientific meetings and educational activities (Broens et al, 2007; Sood et al, 2007). Distant learning may be used for educating patients, as well as health care personnel. In addition to this usage, patient records from multiple remote sites could be searched for symptoms similar to those observed in a patient. This could greatly enhance the chances of correct diagnosis of particular illness and possible suggest courses of treatment that had been successful in other patients. Telemedicine can also be used in public health programs to assist local organizations in health related campaigns such as accident, pre-natal care, etc. (Moore, 1999).

Telemedicine can also enhance efforts for disaster response. Disasters are catastrophic events that can overwhelm a community's emergency response capacity, threatening health and safety of the public and environment. In the pre-disaster situation, telemedicine could be employed in the education and training of health care personnel and the general community in disaster management practices. Telemedicine could support disaster plan implementation, modification, assist with management of critical resources, and provide consultation from within and outside the disaster area. In post-disaster rehabilitation, telemedicine can provide a variety of traditional medical consultations and continue to provide support to both resource management and continuing assessment activities. It can also provide urgently needed specialist health care in instances of natural disaster (Garshnek & Burkle, 1999).

This is because in many areas ambulances and emergency rescue teams are equipped with telemetry equipment to allow physiological data

to be transmitted to a nearby hospital for interpretation. Through the use of telemetry equipment, physiological data can be interpreted and treatment begun even before a patient arrives at the hospital. However, to be effective, the system must be capable of providing reliable reception and reproduction of the transmitted signals under *any* conditions, including that of natural and man-made disasters. Emergency medical care has become an important part of the overall health delivery system (Anantharaman & Han, 2001; Benger, 2000; Binks & Benger, 2007).

Telemedicine is also not a new concept to space flight. Since its very beginning space medicine has used communications and information processing technologies. Remote monitoring of crew, spacecraft and environmental health has always been an integral part of the US National Aeronautics and Space Administration's (NASA's) operations, as it has been of other space travelling nations. Faced with the prospect of astronauts needing medical attention in space, NASA began remote monitoring of astronauts in the early 1960s (Garshnek et al, 1997). During long-duration missions biomedical data transmitted to earth from space included astronaut heart rates, body temperature, ECG, oxygen and carbon dioxide concentration (Hines, 1996). In many respects operational boundary conditions in space medicine such as remoteness, telediagnostics and biotelemetry are characteristics of telemedicine applications for remote communities on the earth (Williams et al, 2000).

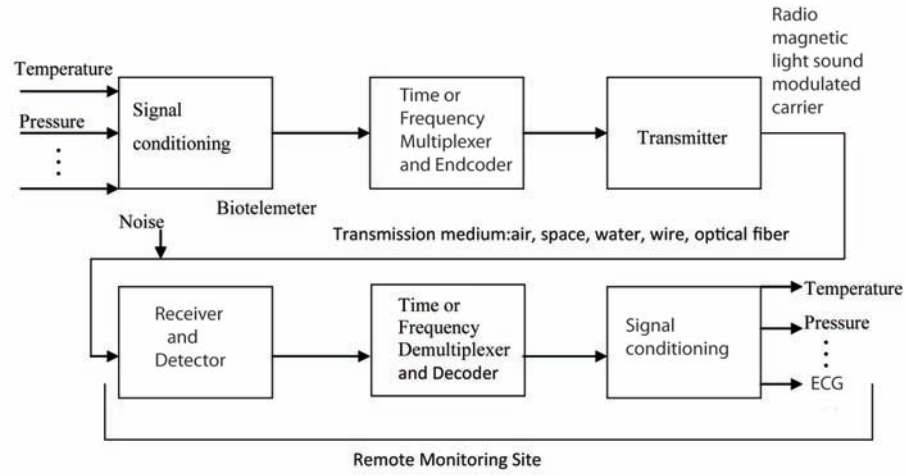
Telemedicine is thus used by health providers in a growing number of medical specialities including: Cardiology, pathology, radiology, endoscopy, pediatry, orthopedics, dermatology, psychiatry, pharmacy, surgery, obstetrics, diabetic patients management, ophthalmology, otolaryngology, space medicine, etc. (Güler & Übeyli, 2002a; Moore, 1999; Sood et al., 2007).

THE COMPONENTS OF A BIOTELEMETRY SYSTEM

Size, cost, circuit complexity, power requirements (and operational lifetime), type of transducer, nature of data to be transmitted and performance are important in the design of a telemeter. First of all, a simple system is described to illustrate the basic principles involved in telemetry. The stages of a typical biotelemetry system are shown in Figure 2 (Güler & Übeyli, 2002b), and can be divided into functional blocks as transmitter and receiver (Lee et al, 2007; Welkowitz et al, 1976). Physiological signals are obtained from the subject by means of appropriate transducers. Then, signal is passed through a stage of amplification and processing circuits that include generation of a subcarrier and modulation stage for transmission. The receiver consists of a tuner to select transmitting frequency, a demodulator to separate the signal from the carrier wave and a method of displaying or recording the signal.

The transmitter generates the carrier and modulates it. The receiver is capable of receiving the transmitted signal and demodulating it to recover the information. Information to be transmitted is impressed upon the carrier by a process known as modulation. The distance the transmitted signal can be received is called as the range of the system. The range of the system depends on the power and frequency of the transmitter, the relative locations of transmitting and receiving antennas and the sensitivity of the receiver. There are several important factors that telemetry users should be familiar with when using antennas. Some of these are: keep clear of the antenna when taking a bearing; do not stand within 1/2 wavelength of the antenna elements; protect the antenna elements to prevent them from being bent out of shape; and keep all metal objects from interfering with the antenna. In this way, confusion will be reduced and success in tracking will be increased (Lee et al, 2007).

Figure 2. Block diagram of a biotelemetry system



Transmitting devices built for patient use must be light weight and compact enough to ensure adequate user comfort. In some cases it is desirable to implant the telemetry transmitter or receiver subcutaneously. The transmitter is swallowed or surgically implanted in the subject. These systems provide monitoring and collecting data from conscious freely moving subjects. Conscious subjects provide data free from the effects of anesthesia. This is important as it has been clearly shown in the literature that anesthetic agents can change blood pressure, heart rate, peripheral vascular resistance, thermo-regulation, gastrointestinal function and other body functions. The highest quality data is therefore be best collected by implanted units. The function of the instrumented implant and the external system components are described by Graichen et al (1996). However, there are some important requirements for the usage of implantable telemetry. Implantable units must have relatively small size and light weight, and their internal power source has to be capable of use for a long time in many cases. Even so, miniaturization and the long-term use of implant electronic systems for medical applications have resulted in a growing necessity for an external powering system.

Another requirement is encapsulation of the unit. There remain unmet needs in packaging, as well as in the development of potentially useful materials and techniques for packaging implantable electronic devices or systems for use in chronic situations. Problems of packaging solid-state transducers, where the volume and weight of the packaging material exceeds that of the operational unit are noted (by Park et al (1994). The use of implantable units also restricts the distance of transmission of the signal. Body fluids and skin greatly attenuate the signal and because of this an implanted unit must be small. Therefore, most units have little power and the range of their signals is quite restricted. This disadvantage has been overcome by picking up the signal with a nearby antenna and retransmitting it. If applications involve monitoring over relatively short distances then retransmission is not necessary.

TYPES OF TELEMETRY

There are two types of biotelemetry units: Single channel and multichannel unit. In general, more than one channel of physiological information is

studied. The simplest encoding can be used for telemetering a single channel of slow data. Pulse interval modulation or pulse width modulation can be used for a single slow variable. Telemetering a single channel of fast data requires quite different encoding because the carrier must be continuously varied. Either its amplitude or its frequency may be modulated (Welkowitz et al, 1976). A multiple subject biotelemetry system is composed of an implantable system, which consists of a command receiver, a subject selection receiver, a conditioner and a transmitter and external systems, such as a power command signal transmitter and a subject selection signal transmitter, as shown in Figure 3 (Park et al., 1994). As indicated in Figure 3, such a system is capable of accepting signals from a variety of sensors.

Biomedical data has been telemetered through every medium between two sites including air, space, water and biologic tissue by using a variety of modulated energy forms like electromagnetic waves, light and ultrasound. In general, biotelemetry systems involve the use of radio transmission. A radio frequency carrier is a high efficiency sinusoidal signal propagated in the form of electromagnetic waves when applied to an appropriate transmitting antenna. Radio telemetry is an excellent tool for gathering data on the biology of animals and their interactions with the environment they inhabit (Salvatori et al, 1999). Infrared (IR) telemetry also has a very wide field of application. IR radiation enables transmission of different physiological parameters from moving subjects like patients in intensive care units, wards, newborn babies in incubators and animals in biological and hospital laboratories. In a typical IR biotelemetry system, the patient carries a battery-powered transmitter and one or more small arrays of infrared light-emitting diodes (IRLEDs) that send encoded data to remotely located photo detector-based receivers (Santic, 1991). Acoustic energy can also be used to send a signal over a distance. Ultrasonic ranges from 30-100kHz are above most animal auditory ranges and transmitted with low energy loss through seawater or gel media (Voegeli et al, 2001).

APPLICATIONS OF BIOTELEMETRY

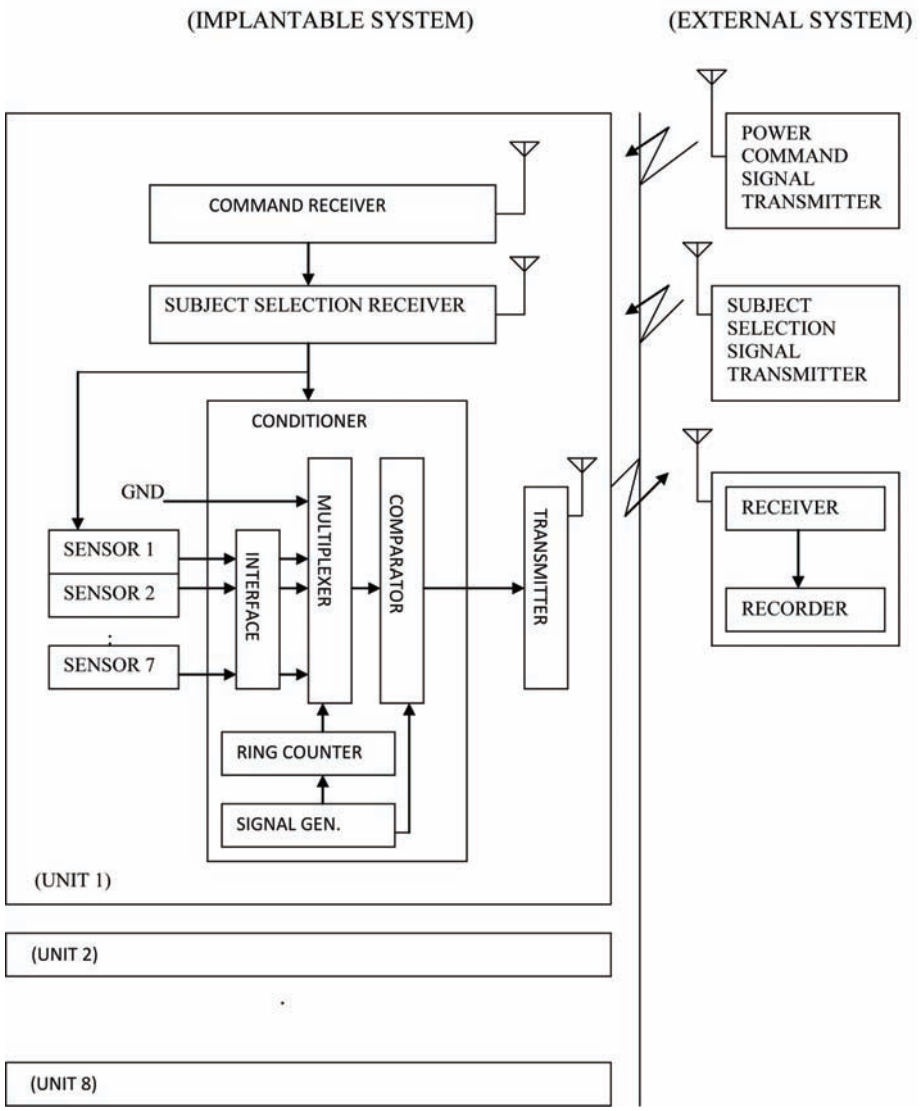
As we have seen, during space travel biomedical data transmitted to earth from space included astronaut heart rates, body temperature, ECG, oxygen and carbon dioxide concentration. Telemetry was employed to establish an understanding of and monitor the health and well-being of astronauts while they were in space. In the early days of human space flight, NASA for example used biotelemetry to provide biomedical data from orbiting astronauts to medical personnel. So NASA has been involved in the development and application of biotelemetry since the Agency's beginnings (Güler & Übeyli, 2002b). Because of the great distance from the earth, systems and procedures were developed to support medical operations inflight. All astronauts wore a biosensor harness, which provided for transmitting critical physiological data back to the earth from space craft and lunar surface. This real time telemetry was also available to monitor astronauts in the event of illness inflight.

Advanced biosensors and biotelemetry systems are used in sensing a wide variety of phenomena in the body and transmitting this information to receivers near the body. These sensors can provide remote, continuous biomedical monitoring of patient data (Rocchitta et al, 2007). A pressure/temperature pill-transmitter is the first of a family of implantable and/or ingestible pill-transmitters that will measure a variety of physiological parameters. The pill-shape and small size of the transmitter, its ultra-low power consumption, long lifetime and the powerful capabilities of data analysis software make this system unique. Applications of these pill transmitters are very common and go beyond fetal surgery. A complete biotelemetry system can be designed for the telemetry of various physiological signals such as ECG, EEG, etc.

The main advantage of such biotelemetry systems is that they provide an easy and practical way for the long term monitoring of various physiological signals from a patient's body while maintaining a low implementation cost (Axelsson et al, 2007; Jaana et al, 2007).

The use of telemetry to monitor a swimmer's rectal core temperature has been developed and measurements taken from swimmers have been analysed (Finlay et al, 1996). Progress in the development of an implantable telemetry system for assessing blood oxygen saturation and hematocrit is described. The key element of the system is an optical sensor which employs optoelectronics and on-chip signal processing electronics to measure light backscattered by blood. Long-term monitoring of central haemodynamics with implanted monitoring systems might be valuable in managing heart failure patients (Ohlsson et al., 1996). Alongside these uses emergency medical care has also become an important part of the overall health delivery system. In many areas ambulances

Figure 3. Block diagram of a multiple subjects telemetry system **(***Source: Park et al., 1994)*



and emergency rescue teams are equipped with telemetry equipment to allow electrocardiograms and other physiological data to be transmitted to a nearby hospital for interpretation (Anantharaman & Han, 2001).

A compact, low power, implantable system for in vivo monitoring of oxygen and glucose concentrations has been developed. The telemetry instrumentation system consists of two amperometric sensors: one oxygen and one glucose biosensor and two potentiostats for biasing the sensors, an instrumentation amplifier to subtract and amplify sensor output signals and a signal transmitter subunit to convert and transmit glucose dependent signals from the sensors to a remote data acquisition system (Salehi et al., 1996; Beach et al., 1999). A system has also been designed to simultaneously acquire ECG and respiration and send them to a receiver over a telephone line. Respiration is acquired by measuring the transthoracic impedance between two electrodes (Reisman, 1984).

Remote biotelemetry systems can also provide power, remote monitoring and control (Mussivand et al, 1997). A single channel implantable microstimulator for functional neuromuscular stimulation can be inserted into paralyzed muscle groups by expulsion from a hypodermic needle, thus reducing the risk and discomfort associated with surgical placement. The device receives power and data from outside by radio frequency (RF) telemetry (Ziaie et al., 1997). The walking (gait) analysis telemetry system (walking analyzer) consists of miniature sensor/transmitters that are affixed directly over the leg muscle group being studied. The muscle activity sensed by the electrodes is transmitted to a computer by biotelemetry process. This system is used to determine the degree and location of abnormal muscle activity and in prescribing treatment. A system for measuring force in both legs and crutches or cane during walking uses a special sensor based on infrared radiation changes to achieve force measurement in the crutches or cane. To extend a patients free mobility, an infrared telemetry system is applied (Lackovic et al, 2000).

The most reliable operation of IR biotelemetry has been found in hospitals and in biological laboratories (Hagihira et al., 2000). An IR diffuse telemetry system for ECG and temperature transmission will typically consist of a basic patient unit with IR receiver and transmitter because biological data and signals have to be transmitted and commands to the basic patient unit have to be received (Santic, 1991). A wireless biotelemetry system for the transfer of digital data through intact skin tissue has been developed to provide a safe and noninvasive communication between implanted medical devices and the outside of the body. With the development of more powerful telemetric data transmission technologies, such a method could be extended in the near future to a truly ambulatory urodynamic recording with real-time on-line facilities, either at home or in the clinic, and usable for both adults and children (Mohseni et al, 2005; Neihart & Harrison, 2005).

A through-water ultrasonic data telemetry system burst-mode frequency shift keying (FSK) has been developed. The system can be adapted for the transmission of data from various sensors, but it has been designed principally for monitoring the respiratory rate, heart rate, temperature and depth of a free-swimming diver over a range of up to 300 meters (Woodward & Bateman, 1994).

Different biotelemetric applications have been adeveloped for wide variety of animal species since the 1950s. Information about wild-life biotelemetry activity with some historical perspective are described by Long & Weeks (1980). For many species, determination of habitat selection is based on habitat-use data obtained through radio telemetry (Rettie & Mcloughlin, 1999). Some species of animals are currently used in biomedical research through radio telemetry systems consisting of implantable transmitters and receivers. Implantable devices are used to monitor various physiological parameters in mice, hamsters, rats, rabbits, ferrets, dogs, cows, sheep, bears and other species.

Implants that measure ECG waves have flexible leads extending from the housing similar to those used in heart pacemakers. When measuring telemetered ECG, sensing leads are placed under skin at locations similar to surface electrodes. For EEG measurements, the transmitter leads can be connected to screw electrodes or deep electrodes to monitor various sites within the brain. For EMG measurements, the transmitter leads can be connected to fine braided stainless steel wire to be threaded through or buried in the muscle. On the other hand, implants that measure temperature generally have a sensor imbedded in the electronics module. When measuring core temperature, the device is often placed in the peritoneal cavity. This is because core body temperature is often a critical measure in studies of behavioural and physiological control of metabolism and body temperature regulation (Beach et al, 1999; Rocchitta et al, 2007; Axelsson et al, 2007). A wireless telemetry system to assess heart rate, core temperature and gross locomotor activity in freely moving rats while performing a behavioural task allows measurement of these variables. The telemetry system consists of a small implantable transmitter and a receiver connected to a computer, with data acquisition controlled by a computer board and software package (Mussivand et al, 1997; Mohseni et al, 2005).

CONCLUSION

Telemedicine represents a combination of expertise and technology that delivers medical services and information over distance. Telecommunications technology delivers this information in the form of voice, data or video imagery. Most of the existing literature on telemedicine has taken as its primary focus the utility and efficacy of the technology itself, as it is applied to particular clinical problems and settings. This is primarily a clinical literature that is about establishing the safe practice of medicine using a diverse set of communications technologies. Since the rapid growth in telecommunications and computer technology over the last decade, telemedicine has become an important part of medical development, with the potential to greatly improve the quality of future health care.

Biomedical telemetry is a special area of biomedical instrumentation that permits transmission of physiologic information from an inaccessible location to a remote monitoring site. The goals of biotelemetry include the capability to monitor humans and animals with minimum restraint and to provide faithful reproduction of the transmitted data. Size, cost, circuit complexity, power requirements (and operational lifetime), packaging, transducers, nature of data to be transmitted and performance are important parameters in the design of a backpack or implanted biotelemetry unit. It seems likely that future development will be in the further miniaturization and integration of biotelemeters and transducers, improved power sources and improved packaging. Techniques and applications of biotelemetric methods continue to expand and are limited only by the imagination of the investigators in using new technologies as they evolve. Since the rapid growth in technology different applications of biotelemetry can be used for data gathering from a remote location, and these have been described in this chapter.

FUTURE RESEARCH DIRECTIONS

There are several barriers inherent in overcoming distance in delivering health care – these are technological, political and professional. Some of these barriers are described in the following:

1. **Infrastructure Planning and Development**: It is unusual for health care applications to be considered in planning and developing new telecommunications and information technology. Policy makers at the regional and national level must consider needs and

solutions for multiple agencies and activities. Lack of uniform policies and standards creates problems for health care organizations. Absence of policies also creates confusion about patient privacy rights and how to enforce them;

2. **Economic Impact**: Competition for telecommunications services, particularly in rural areas, has resulted in arbitrary boundaries between service areas and high costs for transmission services of the power needed to support telemedicine. There is no clear policy at the national level anywhere that allows the costs of telemedicine systems to be reliably covered, but public and private payers are reluctant to set reimbursement policy at a lower level until more viable applications for telemedicine are developed;
3. **Security and Confidentiality**: While the Internet is a marvelous medium for transmitting information between remote computers, it is notoriously susceptible to security problems. Since confidentiality of patient information is a foundation of medical care in most countries, the problems of keeping information transferred between computers away from unauthorized access must be solved. Special consideration and care must be taken to ensure the safety of patient and medical data;
4. **Speed of Communication**: The Internet carries millions of pieces of information every minute and demand gets larger all the time. Some critics have predicted the eventual collapse of the Internet from the traffic it is forced to carry. Even when operating at full speed, it is difficult for internet media to transmit large amounts of information (like that needed for videoconferencing) at sufficient rates to avoid delays and degradation of the images or sound. New networking media must be developed that is capable of carrying more information at faster speeds.

While these challenges are difficult, they can be overcome with cooperation among health care professionals, technology specialists and governments. Such cooperation is the key to telemedicine's achieving its potential to improve health care.

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KEY TERMS AND DEFINITIONS

Applications of Biotelemetry: Transmitted biomedical data included heart rate, body temperature, ECG, oxygen and carbon dioxide concentration. Telemetry was employed to establish an understanding and monitor health and well-being of the subjects.

Applications of Telemedicine: The wide scope of applications for telemedicine includes patient care, education, research and public health to diagnose, deliver care, transfer health data, provide consultation, educate health professionals.

Biotelemetry: Biomedical telemetry is a special field of biomedical instrumentation that often permits transmission of biological information from an inaccessible location to a remote monitoring site. When direct observation is impossible, biotelemetry can be used to obtain a wide spectrum of environmental, physiological and behavioural data.

Telemedicine Infrastructure: The telecommunications infrastructure provides the technology to move information electronically between geographically dispersed locations. The telecommunication medium utilized by telemedicine programs is determined in large part by the available local infrastructure. These can include satellite, microwave link or terrestrial lines (either twisted copper phone lines or fiber optic cable).

Telemedicine Technologies: The use of telecommunications and information technology is central in providing health services- regardless of locations. Telemedicine involves a combination of topics from the fields of telecommunication, medicine and informatics. The application of telecommunication technology to health care requires integration of technology, tools and training with medical care practices and problems.

Telemedicine: Literally, telemedicine means medicine at a distance. Telemedicine is defined as the use of electronic information and communication technologies to provide and support health care when distance separates the participants.

Telemetry Types: Biomedical data has been telemetered through every medium between two sites including air, space, water and biologic tissue by using a variety of modulated energy forms like electromagnetic waves, light and ultrasound. Telemetry types are defined according to the transmission medium.

Chapter 2
The Use of Artificial Intelligence Systems for Support of Medical Decision-Making

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ABSTRACT

There is a treasure trove of hidden information in the textual and narrative data of medical records that can be deciphered by text-mining techniques. The information provided by these methods can provide a basis for medical artificial intelligence and help support or improve clinical decision making by medical doctors. In this paper we extend previous work in an effort to extract meaningful information from free text medical records. We discuss a methodology for the analysis of medical records using some statistical analysis and the Kohonen Self-Organizing Map (SOM). The medical data derive from about 700 pediatric patients' radiology department records where CT (Computed Tomography) scanning was used as part of a diagnostic exploration. The patients underwent CT scanning (single and multiple) throughout a one-year period in 2004 at the Nagasaki University Medical Hospital. Our approach led to a model based on SOM clusters and statistical analysis which may suggest a strategy for limiting CT scan requests. This is important because radiation at levels ordinarily used for CT scanning may pose significant health risks especially to children.

INTRODUCTION

Text-mining is applied in various fields to extract useful and previously unknown information contained in databases and texts. In the field of bioinformatics significant efforts are being made in genome sequencing, protein identification, medical imaging, and patient medical records. This study continues the efforts to mine patient medical records that consist of clinician notes in the form of free

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text. Harris et al (2003) developed a system to extract terms from clinical texts. Using natural language processing techniques, i.e., a parser, the MedLEE system, Jain et al (1996) turned free-text from patient records into an output with structured information. For example, this system may identify patients with tuberculosis based on chest radiographs. To do this it uses a corpus of controlled vocabulary developed from a collection of medical reports. This, as well as similar work discussed below such as BIRADS UMLS, SNOMED, are useful in converting clinician notes as free text into some form of structured codes for medical diagnosis purposes. They use natural language parsers and a domain vocabulary (knowledge base) developed either using a corpus or stored expert knowledge.

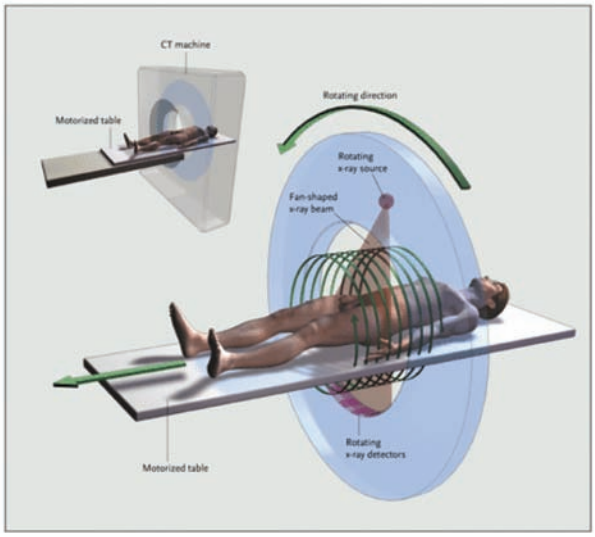
The gold standard in text mining is natural language processing, which aims to include semantic information in the text mining task. The full realization of this goal is still on the distant horizon however serious efforts have already achieved some success. These include AQUA, PROTEUS-BIO, and SemRep. AQUA (A Query Analyzer) is an underspecified semantic interpreter that was originally formulated for processing MEDLINE queries. PROTEUS-BIO applies to web documents on infectious disease outbreaks. It mines semantic predications relevant to this domain and stores them in a database. The database is then available to users. SemRep is being developed to recover semantic propositions from biomedical research literature. It again focuses on MEDLINE citations. SemRep utilizes underspecified syntactic analysis and structured domain knowledge. In addition to investigations that consider semantics, non semantic approaches are yielding significant progress as well. Vector space models, neural networks, kernel methods, decision trees and rule induction, and probabilistic models are all being used for classification without strong emphasis on semantic characteristics and are yielding promising and interesting results as applied to text mining.

BACKGROUND

The advent of computed tomography (CT) has revolutionized diagnostic radiology (Figure 1). Since the inception of CT in the 1970s, its use has increased rapidly. It is estimated that more than 62 million CT scans per year are currently obtained in the United States, including at least 4 million for children (Brenner & Hall, 2007). The increase in the use of medical radiation, especially in diagnostic CT scanning has raised many concerns over the possible adverse effects of procedures conducted in the absence of any serious risk/benefit analysis, especially where these procedures are carried out on Children (UNSCEAR, 2000). According to a survey conducted in 1996 (White, 1996) the number of CT scanners per 1 million population was 26 in the United States and 64 in Japan. The growth of CT use in children has been driven primarily by the decrease in the time needed to perform a scan — now less than 1 second — largely eliminating the need for anesthesia to prevent the child from moving during image acquisition (Frush et al, 2003). Overuse of diagnostic CT radiation, which deliver radiation doses 50 to 200 times higher than most X-rays, can lead to an increased risk of cancer. Additionally, it may lead to an unnecessary rise in health care costs (Roebuck, 1999; Ghotbi et al, 2005; Walsh, 2004).

In this system a motorized table moves the patient through the CT imaging system. At the same time, a source of x-rays rotates within the circular opening, and a set of x-ray detectors rotates in synchrony on the far side of the patient. The x-ray source produces a narrow, fan-shaped beam, with widths ranging from 1 to 20 mm. In axial CT, which is commonly used for head scans, the table is stationary during a rotation, after which it is moved along for the next slice. In helical CT, which is commonly used for body scans, the table moves continuously as the x-ray source and detectors rotate, producing a spiral or helical scan. The illustration shows a single row of detectors, but current machines typically have multiple rows of

Figure 1. The basics of CT



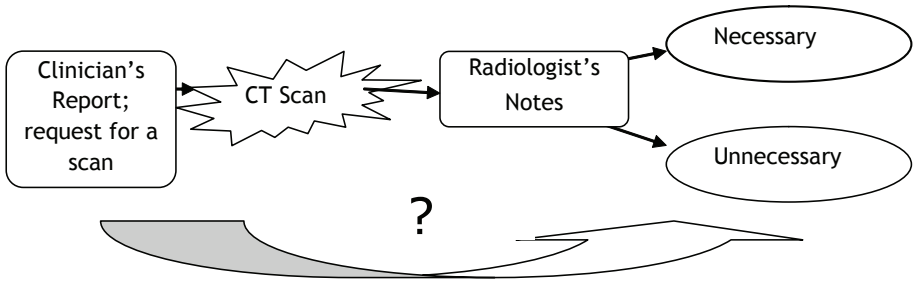
detectors operating side by side, so that many slices (currently up to 64) can be imaged simultaneously, reducing the overall scanning time. All the data are processed by computer to produce a series of image slices representing a three-dimensional view of the target organ or body region (White, 1996).

Originally, prior to our investigation into the use of ANN based approaches, researchers at Nagasaki Hospital attempted to reevaluate the efficiency of CT scanning in both the diagnosis of acute appendicitis and also when used to detect possible injuries after acute head trauma using conventional methods (Deboeck & Kohonen, 1998a). As a result of that study a recommendation was made to the two departments studied. The recommendation was to employ guidelines and algorithms which present a stepwise set of clinical diagnostic methods and tools. The intention of this recommendation being that CT scans be reserved for patients that may be expected to benefit from them. However, in other departments, due to the lack of such a stepwise approach to diagnosis, many unnecessary CT scan have been and continue to be undertaken, and sound clinical judgment is generally postponed until viewing the results of a CT scan. This was the initial impetus for our current work. The standard procedure adopted for requesting a scan at the Nagasaki Medical University Hospital as well as other medical practices and classification by field expert is outlined in Figure 2.

In the past much concern has focused on the lack of digitalized patient records, but with the digital revolution in full sway this is becoming a non-issue (Walsh, 2004). Using medical records obtained from Nagasaki Medical University Hospital Radiology Department's CT scanning database we preprocessed these records and emerged with a dictionary of 900 features (i.e., words) which were then used to search for clusters which could represent factors with predictive significance.

In our previous work (Claster et al, 2007) we employed Kohonen Self Organizing Mapping to analyze a sample of 50 of the free text medical records (clinician notes) out of a collection of 982 records obtained from the Nagasaki University Hospital. In the present study all 982 records were considered. In both the original study and the present study because of the free text nature of the data, the use of conventional analysis techniques became impracticable, as there were 900 words or features involved. In the prior 50 record study we sought to look deeper into factors which might indicate

Figure 2. Schematic diagram showing the standard procedure followed at Nagasaki Medical University Hospital and the expert classification on the necessity of a CT scan



unnecessary scanning. In the present study, in addition to extending our work to the full 982 patient records we also develop a methodology for testing the analysis. We have used a k-fold validation design to test the proposed methodology. Finally we apply a novel approach to decision tree algorithms by focusing on the clusters discovered at the SOM layer of the analysis.

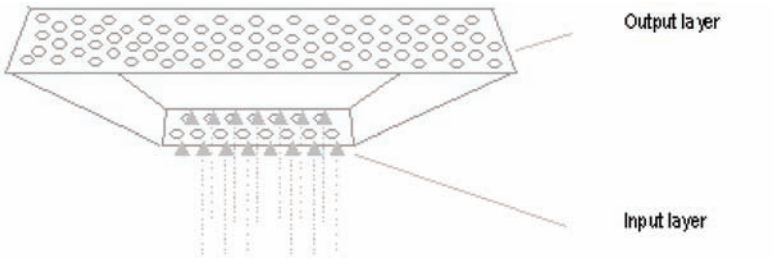
CT SCAN DATA AND SOM BASED TEXT MINING

A thorough understanding of the indicators for the request to do a CT examination requires the analysis of huge amounts of text data in the medical records. Because of the unstructured form of these records, use of traditional statistical methods showed limited promise in isolating factors that could accurately predict the patterns of CT scan usage. Unstructured text is a candidate for SOM text mining. A SOM is a feed forward neural network (Figure 3), which uses an unsupervised training algorithm to perform non-linear regression. Through a process called self-organization the network configures the output data into a display of topological representation, where similar input data are clustered near each other. At the end of the training SOM enables analysts to view any novel relationships, patterns or structures in the input vectors. The topology preserving mapping nature of SOM algorithm is highly useful in projecting multi dimensional data sets into low dimensional displays, generally into one- or two-dimensional planes. Thus SOMs can be used for clustering as well as visualization of multi dimensional data sets (Deboeck & Kohonen, 1998b).

The SOM techniques are successfully applied to visualize and cluster large volumes of complex statistical data sets of many real world problems such as pattern recognition, image analysis, process monitoring and control, and fault recognition. As SOM methods are based on an unsupervised training algorithm, they could be used for data clustering without knowing the class membership of the input data (Simula & Vesanto, 1999). Traditional methods (i.e. simple statistical methods) that are useful in summarizing low-dimensional data sets (mean value, smallest and highest values), are seen to be less effective in visualizing multi-dimensional (i.e. multivariate) data sets (Deboeck, 1998; Deboeck & Kohonen, 1998b).

The self-organizing map (SOM) algorithm, first introduced by Tuedo Kohonen in 1982 was developed from basic modeling information of the human brain's cortical cells, as they were known from the neuro-physiological experiments of the late twentieth century. The processing of synaptic connections between the cortex cells in the human brain is based upon the nature of the sensorial stimuli; hence different patterns of sensorial signals converge at different areas within the brain's cortex cells. Because of this different individual neurons or groups of neurons become sensitive

Figure 3. Simplified diagram of a SOM



to different sensorial stimuli, and neighboring neurons also learn to respond to similar patterns of signals (i.e. visual, auditory, somatosensory, etc). Despite this realization our knowledge on the associative areas of signals and the other different tasks involved with the rest of the cortical area is relatively poor. Only ten percent of the total cortical area is described as involved with primary sensorial signals. The planning of actions is assumed to take place in the frontal lobe.

Kohonen's SOM applications to real world problems range across many disciplines, mainly in the field of knowledge discovery. SOM ability to discover implicit knowledge from numerical data displaying the input vectors on low dimensional grid structures is significant. The following are some of the major identified areas of SOM applications (Deboeck & Kohonen, 1998a):

1. Classification, clustering, and/or data reduction;
2. Visualization of the data;
3. Decision-support;
4. Hypothesis testing;
5. Monitoring system performance;
6. Lookup of (missing) values;
7. Forecasting.

Traditional statistical methods consist of limited abilities for revealing structures, relationships and novel patterns in low dimensional data sets. Two to three dimensional data sets can be visualized by using simple two- to three-dimensional graphs. But with multi dimensional data sets, plotting a vector or analyzing the relationships between different vectors by simple graphs is not possible. Thus other methods are needed to visualize such multi dimensional data sets.

In existing data visualization methods, the different components contributed by each and every dimension are integrated into the one final result. The major drawback experienced with conventional methods is that they are unable to reduce the amount of data within large sets, as processing becomes incomprehensible. However, they can be used to display simple summaries of data sets (Deboeck & Kohonen, 1998c). Data clustering is one such operation through which similar data items are categorized or grouped together and it is one of the best possible methods available for reducing large volumes of data for visualization purposes. Clustering is described as similar to information processing in humans and preferred over projection methods. The goal of projection methods is to represent the input data in a chosen low dimensional space, where certain properties of the structure of original data are preserved as faithfully as possible to the original values. Thus these projections can be used to visualize a high dimensional data set if a sufficiently enough low dimensionality is chosen for output display. Clustering can be automated to classify different categories and automation also reduces bias and errors in the grouping process. Traditional clustering methods can be classified into two basic types: hierarchical and (ii) non-hierarchical. On the other

hand, projection methods can also be classified into two basic types: linear and (ii) non-linear.

In our example a commercial software package called Viscovery SOMine was employed to model the data. This provides a visualization tool that maps high dimensional inputs onto a two-dimensional map for easy visualization of the inputs that enhance detection of new knowledge in the form of patterns.

CT Scan Data Preprocessing

Medical records were examined by breaking each patient record into its constituent words. We used a standard method of weighting the words which gives consideration to the frequency at which a word occurs in a document and also the overall frequency that the word occurs within the entire corpus. This method is known as tf-idf (see below). This allows us to recode text data as numerical data and thus makes it amenable to analysis with Kohonen mapping procedures. Our hypothesis is that information contained within the narrative text of medical records may determine whether a particular medical procedure (CT scans) would prove to be unnecessary.

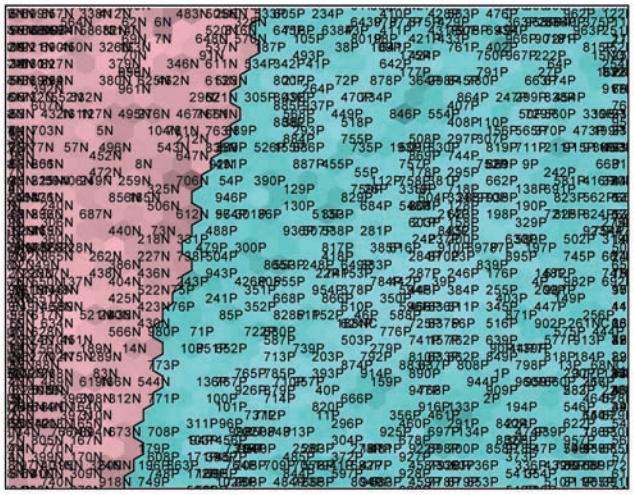
Of the 1024 pediatric patient records extracted from the Nagasaki University Hospital, clinician notes and their outcome classified as either necessary or unnecessary scan by a medical expert from the radiologist comments were used in this SOM based clustering. The original clinicians' notes in Japanese were initially translated into English for this purpose. We then removed standard stop words (i.e. 'a', 'able', 'about', 'above' etc.,) as well as common medical terms identified by a physician (i.e., 'abduction', 'advance', 'vessel') from the clinician notes. The 42 records that came out blank through this process were removed altogether from this analysis. Consequently, a matrix of word x record no. was created in which the rows consisted of all the words in the text corpus of patient records, to apply the tf x idf formula discussed in the methodology section. For further details on the process and formula see Claster et al (2007). From this matrix, words that were found to be useless in the analysis were again removed and a new matrix of word x patient record numbers was created. The records that lost all the words in the process were labeled as 'no comments'. The records that had radiologist notes unclassifiable either as necessary or unnecessary by the medical expert were also tagged with 'no comments'. Using the final matrix we created a 2000 node SOM (Figures 4 and 7). The validation performed on the SOM clustering is discussed in the next section.

METHODOLOGY: CLUSTER EXPLORATION, MODEL DEVELOPMENT AND TESTING

An expert in the medical field (in this case a physician) indicated whether each particular scan was necessary or unnecessary and thus we had a classification for the data. Viscovery SOM discovered clusterings on the dataset ranging from 2 clusters to more than 30. When we explored the 2-cluster SOM (Figure 4) we were able to identify a cluster of records that were 98% necessary (C1) and a cluster of records that were 97% unnecessary (C2) - where necessary and unnecessary refer to whether a CT scan was deemed necessary or not by the expert. The two cluster profiles are shown in Figure 4.

We analyzed each cluster and developed a methodology (described below) to weight a word in the text according to how often it occurred in either cluster of the 2 cluster SOM (Figure 2; note: this does not refer to tf-idf but a weighting used for another purpose described below). In short this can be described as: a word appearing only in the cluster C1 was given a high positive weight and a word appearing only in the cluster (C2) a high negative weight. Then the word weights for all the words contained in a particular record were summed to determine a record classification value ("rc") for that record. This record classification value was

Figure 4. SOM of physician's CT referral rationale (text being mined) segregated into positive versus negative outcome clusters



then used to predict whether a particular record belonged to the class of necessary scans or to the class of unnecessary scans. A K-fold cross-validation procedure was later employed as a means of model verification (Table 1).

Model

The tf–idf weight (term frequency–inverse document frequency) is a statistical measure used to evaluate how important a word is to a document in a collection or corpus. The term frequency is given by:

$$tf_i = \frac{n_i}{\sum_k n_k}$$

with n_i being the number of occurrences of the considered term, and the denominator is the number of occurrences of all terms. The inverse document frequency is given by:

$$idf_i = \log \frac{|D|}{|\{d : d \ni t_i\}|}$$

with |D| the total number of documents in the corpus and $|\{d:d \ni t_i\}|$: the number of documents where the term t_i appears (that is $n_i \neq 0$). Then *tfidf=tf·idf*.

Now define a word prediction vector for word w_i by defining jth component of the word prediction vector ("wpv_{ij}") for word w_i in cluster j as:

$$wpv_{ij} = \sum_{\substack{\text{all records} \\ \text{in cluster } j}} \frac{(t_f - idf)}{n_{i,j}}$$

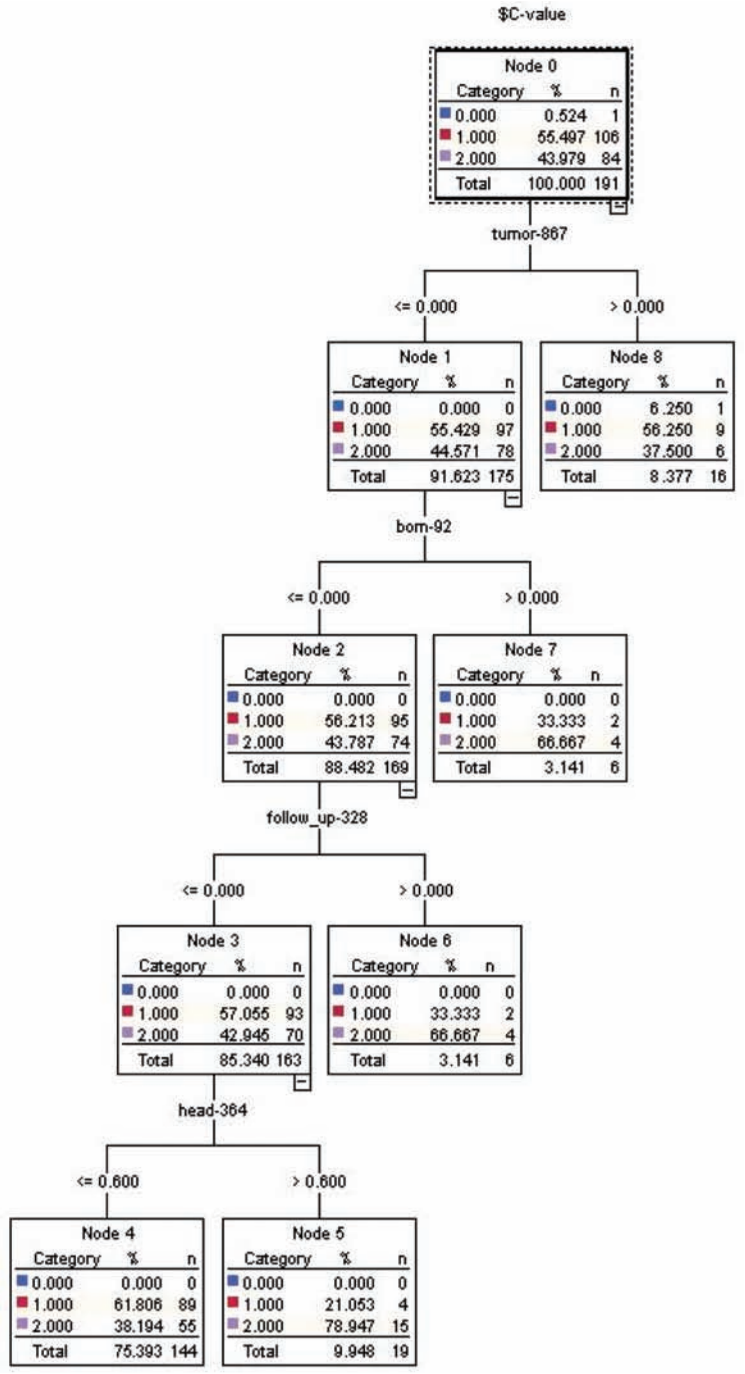
In other words, wpv_{ij} is the mean of the tf-idf over all the records in the jth cluster for word w_i.

Next letting K_i be the cluster with the maximum wpv_{ij} for word w_i (over all j clusters), define the word prediction weight ("wpw_i") for word w_i over all clusters to be:

$$wpw_i = wpv_{iK_i} - \sum_{\forall j \neq K_i} wpv_{ij}$$

(note, that in our case there are just two clusters 1 and 2, and therefore this becomes just wpv_{i1} - wpv_{i2} which will be either positive or negative).

Figure 5. C5.0 chart for cluster C1 (expanded view). For example, node 2 indicates that when tumor <= 0 then 55.4% of the records were necessary and 44.6% were unnecessary



These word prediction weights, wpw_i, are used to establish an overall value for any record. This gives us a way of taking a new document and assigning a value (and therefore a classification as a necessary or unnecessary CT scan) based on the following scheme.

Table 1. Averaged results of K-fold cross validation

		Predicted Classification	
		necessary	unnecessary
Actual Classification	necessary	506	105
	unnecessary	108	253

Define the record value v as:

$$v = \sum_{\substack{\forall w_i \text{ in the} \\ record}} wpw_i$$

Then define rc to classify a record as necessary or unnecessary by

$$rc = \begin{cases} necessary & if \;\; v \geq 0 \\ unnecessary & if \;\; v < 0 \end{cases}$$

Model Testing

The above classification model was tested in a K-fold cross-validation procedure. We subdivided the data into 3 subsets and the cross validation process was carried out 3 times, after which the results of the folds were averaged.

RESULTS

In previous work we were able to identify through the methods of text mining explained earlie, a series of keywords within the CT scan referral rationale. The statistical strength assigned to the keywords led to their separation into three sets which had a strong association with a positive finding by radiologists, a strong association with a negative finding by radiologists, or a weak association with both a positive and a negative finding (Figure 6).

Classifying and Testing

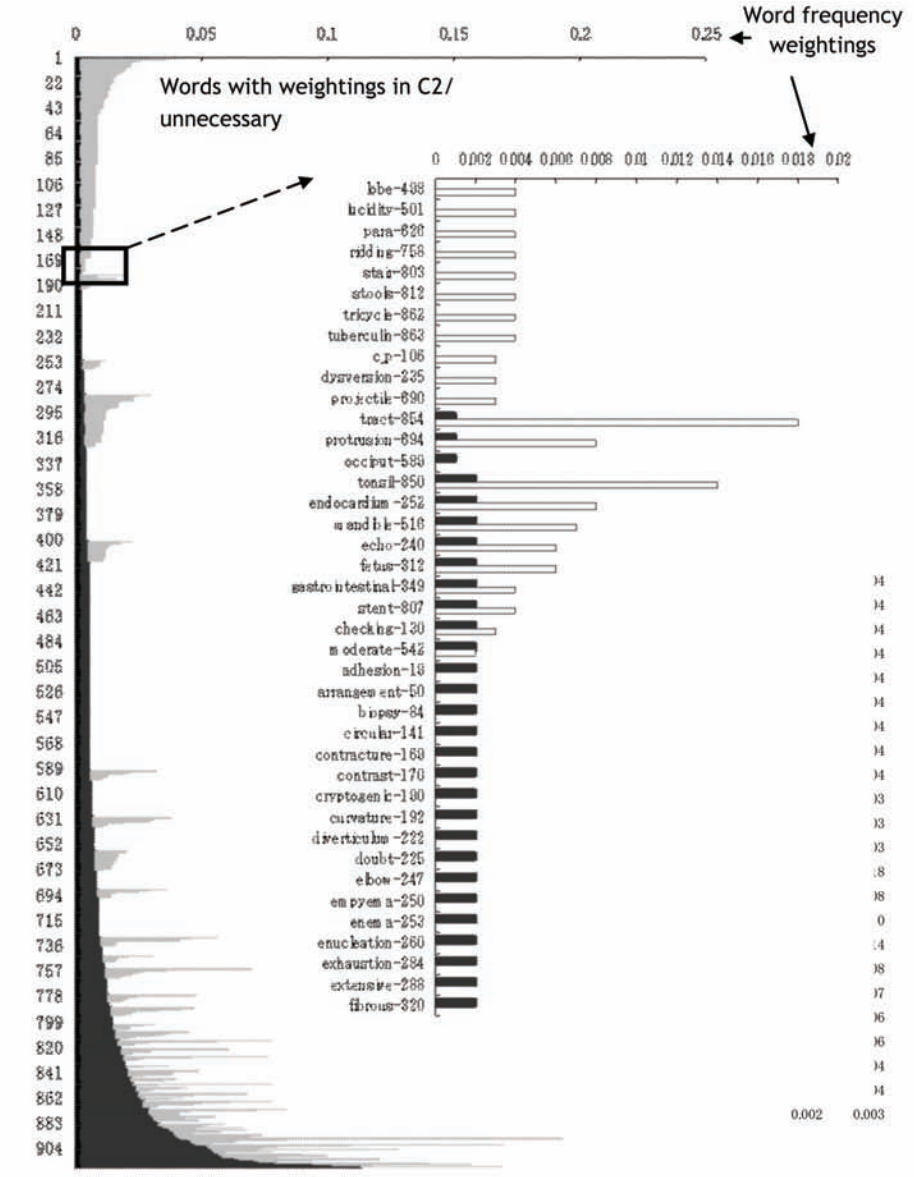
We conducted a 3-fold cross validation procedure and arrived at Table 1. This table shows a false-positive error rate of 11% and a false-negative error rate of 11% and an overall error rate of 22%. Although this accuracy is substantial we may improve upon it by the elimination of words which occur in higher frequencies in both clusters. Modification of the wpv_{ij} weight assignment may also contribute to a reduction in either false positives and/or false negatives.

Additional preference was given to have the positive and negative notes clustered together. Cluster C1 contains 98%P (necessary scans) and Cluster C2 contains 95% N (unnecessary scans).

Clusters

We investigated the subgroups within C1 (necessary) and C2 (unnecessary) clusters to see whether these subgroups could be developed into a C5.0 charts. Based on SOM clustering suggestions (generated with *Viscovery* commercial software) C1 and C2 clusters were further divided into 25 and 9 subgroups respectively (Figure 7) and then their word groupings (Figure 8) were analyzed for any possible scenarios of developing a C5.0 chart. Most of the groupings appeared to consist of a uniform and unique set words relating to a particular type of disease (ENT, pulmonary) accident (involving a vehicle, fall from a tree, etc) or birth defects. For example, clusters 30 and 31 of C1 have words relating to neural disorders (see Figure 8). Similarly, cluster 32 words relate to orthopedic (lower facial).

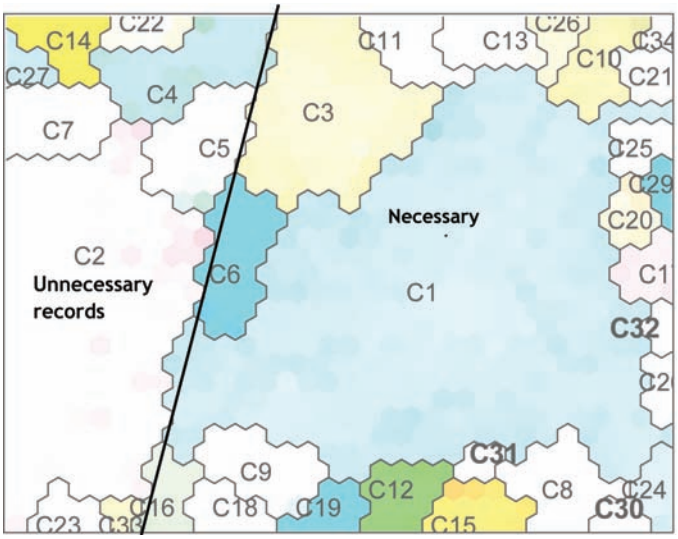
Figure 6. C1 (necessary) word weights (mean, minimum, maximum and sum). C2 (unnecessary) word weights (mean, minimum, maximum and sum)



The grey areas represent mean word frequency weightings in C2 unnecessary scan. The black areas represent those of C1 necessary scan, according the areas with both represent those weightings present in both C1 and C2.

We ran a C5.0 algorithm to produce a decision tree (Figures 5 and 9). C5.0 is a commercial classification algorithm used to generate a decision tree using the idea of information entropy. It is not restricted to producing binary trees. It is hoped that a tree could provide feedback to a medical practitioner that may be included as one factor in the decision to request a CT scan and we will explore this in future work.

Figure 7. Positive records further subdivided into 25 clusters and negative records subdivided into 9 clusters



CONCLUSION

This discussion shows that medical doctors may be able to consider some pre-test factors as predicted strength of the test, before requesting a CT scan for children. Our analysis gives a preliminary methodology for predictive record classification. The 11% false-negative rate is large but there are strategies for pruning this error rate.

Figure 8. Constituent words (including record number, word, weights, and necessary/ unnecessary classification) within clusters 30 to 34

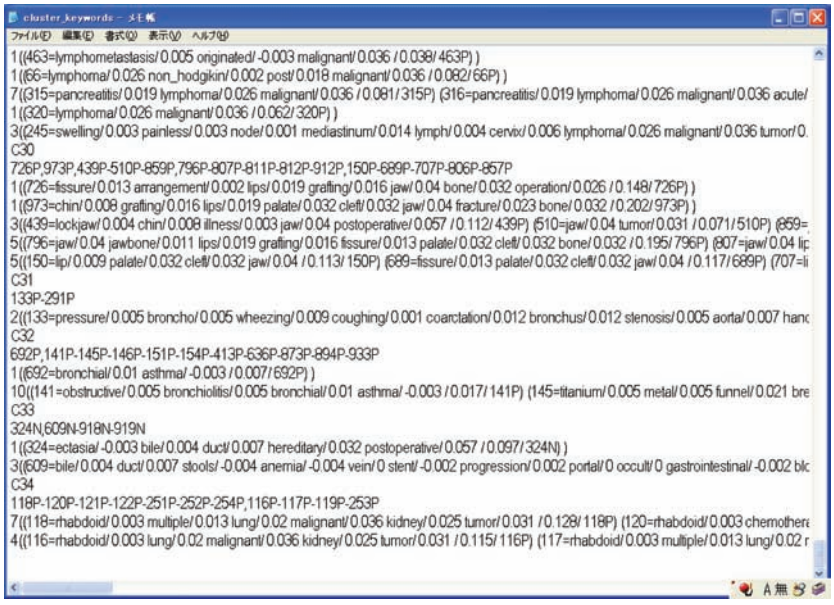
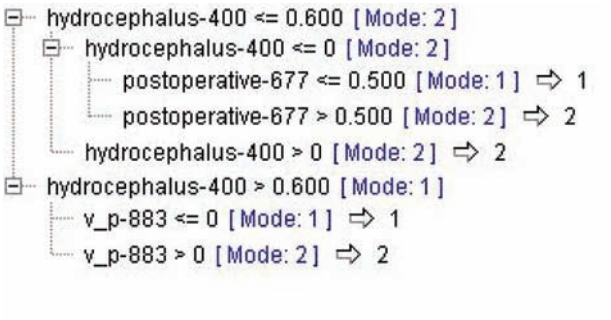


Figure 9. C5.0 chart for subgroup cluster number 30. 1 indicates the predication of a necessary scan and 2 indicates the prediction of an unnecessary scan



Future Work

Further research is underway to study an additional 10,000 records. With these records we hope to explore other weighting systems and by including time series analysis to develop an expanded hybrid methodology to include seasonal effects in order to achieve improved accuracy. Using the same data, we will compare the current methodology with a neural network classification scheme as well as modifying the SOM clustering to a K-means clustering algorithm. Additional research is underway to measure the effectiveness of SOM based decision charts. We believe it is possible to design a form of text mining system that helps with such decision making when a medical doctor is considering whether or not a CT scan may be helpful in reaching a diagnosis. This text mining system can be fed with the hospital's own data so that patterns of association between clinical information and radiological findings are determined, and help with decision-making further on.

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Chapter 3
Digitizing Healthcare:
Electronic Medication Administration Record (eMAR) and Bedside Medication Verification (BMV)

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ABSTRACT

Proliferation of the Internet and Information Technology (IT) has led to many innovations in the healthcare industry. Among such innovations are the Electronic Medication Administration Record (eMAR) and the Bedside Medication Verification (BMV), both of which have been widely implemented by hospitals around the world. In this regard, the goal of this chapter is three-fold. It first describes the underlying work-flow utilized in these systems by comparing it with traditional methods of medication administration. Then it investigates the adoption and implementation of eMAR and BMV in hospitals in the United States, the conversion from traditional medication administration to eMAR documentation, and how utilization of eMAR and BMV can promote patient safety. The chapter concludes with the exploration of future trends in medication administration through the utilization of eMAR and BMV, and highlights future research directions in the field.

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INTRODUCTION

It is estimated that the United States spends two billion dollars each year as a result of medical errors. Medical errors also attribute to a total of 7,000 deaths in the United States alone annually (Paoletti et al, 2007). The estimated rate of bodily harm or death in 2002 was 3.5 incidents per 1,000 administered medication doses (Goth, 2006).

Hospitals have been utilizing traditional paper-based medication administration records for years. However, the traditional method encompasses multifaceted steps that are time consuming and prone to promote errors. There could be up to 65 steps involved in the complete process of medication administration from prescription to the patient administration (Douglas and Larrabee, 2003). During the process of bedside medication administration, it is important for healthcare providers to administer the correct medication to the proper patient. Along with verifying the correct patient and medication, the medication dose, the route of medication administration and the timing of its administration need to be confirmed. These are referred to as the *Five Rights of Medication Administration* in the healthcare field.

Proliferation of the Internet and the diffusion of Information Technology (IT) have led to many innovations in the area of healthcare, including the Electronic Medication Administration Record (eMAR) and the Bedside Medication Verification (BMV). eMAR incorporates a complex collaboration of medicine, pharmacy, nursing, and other allied health professions to formulate a workable document regarding patient medications, and is essentially a patient medication profile and electronic record that is complete, dynamic, and functions in real-time. Infrastructure for the system usually involves a wireless network installed in a hospital, several bedside computers, bar coding on employee identification badges, on patient identification wristbands, and on medications. Data available through the system consists of patient's medical history, including past operations of the patient and allergies, as well as employee information participating in the implementation of the system. The system also integrates important information on medications, such as appropriate dosage and possible medication interactions. Finally, eMAR's dynamic features allow healthcare professionals to enter medication orders and update patients' condition and needed care in real time.

BMV is a system that is tightly integrated with eMAR by using a bar code mechanism. Bar codes are placed on medications, the patients' hospital identifying wristbands, and employee badges. Utilization of bar code scanning assures validation of accurate medication administration by facilitating data entrance and update by the personnel in the system. Implementing the eMAR system along with the BMV together facilitates correct and efficient medication administration in hospitals, while enhancing patient care, outcome and safety.

This chapter examines the adoption and implementation of eMAR and BMV systems in hospitals around the United States, the conversion from traditional medication administration to eMAR documentation, and how utilization of eMAR and BMV systems can promote safer medication administration in hospitals. The chapter concludes with the exploration of future trends and research in medication administration through the utilization of eMAR and BMV.

BACKGROUND

Being an innovative application of Information Systems to the healthcare field, eMAR and BMV are made up of five interrelated components: hardware, software, data, procedures, and system users. Hardware consists of medication carts and laptop computers with wireless networking capabilities. Software is available through several major vendors, including the IntelliDot Corporation, LifeCare Technology, Inc., Medical Information Technology, Inc., Mediware Information Systems,

Inc., and Omnicell, Inc. Data is a compilation of the patients' medical history, laboratory test results, medical diagnosis, medication prescriptions, and on-site scanning of patients and medications at the time of delivery. Finally, system users include hospital staff, doctors, nurses, pharmacists, as well as patients who are the subjects of the data involved (Caesar and Hutchinson, 2006).

Utilization of a bar coding system in healthcare was first envisioned during the early 1980s (Simpson, 2003). Nevertheless, development of the first systems occurred in the mid-1990s pioneered by the U.S Department of Veterans Affairs (Cummings et al, 2005). The Food and Drug Administration (FDA) of the United States mandates that pharmaceutical manufactures provide a bar code; however, they do not require hospitals to utilize a bar code system (Goth, 2006). In 2002, 1.5% of hospitals were utilizing BMV in the United States, and by 2005 the percentage had increased to 9.4%. Larger hospitals, with 400 beds or more, showed an increase in utilization from 3% in 2002 to 17.2% in 2005 (Paoletti et al, 2007). Implementation of the BMV is estimated to prevent 25,000 medical errors a year in the United States, according to the FDA of the United States (Wickham et al., 2006).

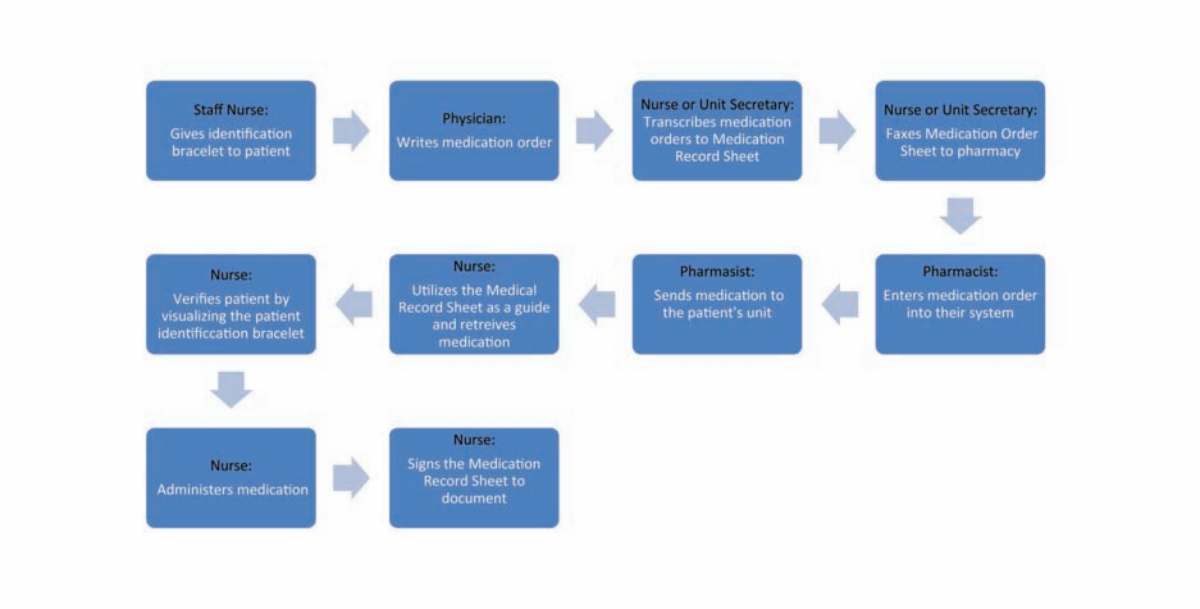
Medical error studies have shown that 39% of mistakes occur in the physician ordering stage, including illegible handwriting and omissions. Pharmacists detected 6% of these errors and 42% were detected by nurses. Patient bedside administration accounted for 38% of errors, of which only 2% were correctly identified. Order transcription accounted for 12% of errors, and the remaining 11% are due to inaccurate medication dispensed from the pharmacy to the patients' unit floor stock. (Douglas & Larrabee, 2003; Galvin et al, 2007). eMAR and BMV systems are actually being initiated in hospitals in order to decrease and ultimately eliminate such medication administration errors in hospitals. Indeed, correct and consistent use of bar coding decreased written transcript errors by 17%, reduced medical errors by 86%, and positively provided patient identification 100% during blood transfusions (Douglas & Larrabee, 2003).

eMAR has the ability to deliver warnings, which could alert the healthcare providers of potential medications administration errors in real time. When the nurse scans the bar code on the medication at the patient's bedside, the eMAR system would alert the nurse with a visual warning if a medication were to be delivered to the wrong patient, at the wrong time, or consisted of the wrong medication, amount, or route of delivery. eMAR would also notify the healthcare personnel if the patient's drugs were contraindicated. Reports on potential errors made, and prevented errors could be documented by the eMAR system as well (Douglas & Larrabee, 2003). The benefits of eMAR and BMV further include a decrease in waste of resources as a result of medical error, easier documentation and information retrieval, valuable means by which to negotiate with drug companies, and subjective perception that the hospital is safer because of these innovative practices (Goth, 2006; Rabert and Sebastian, 2006).

Today, medication administration without the utilization of eMAR and BMV systems would include the following basic work-flow in a hospital (Figure 1).

An admitted patient would have a generated identification wristband applied, which would provide the patient's name, sex, birth date, medical record number, date of admission and account number. The physician would handwrite medication orders, which would be faxed to the pharmacy and transcribed onto a medication administration sheet by a nurse or unit secretary. The pharmacy would enter the medication order into their system. If the medication were not previously in stock on the patient's floor, it would be dispensed to the floor with the patient's name and identifying information on it. The medication sheet would be used as a guide for the registered nurse when dispensing medication. The registered nurse, pharmacist and physician are all responsible for

Figure 1. Traditional medication administration



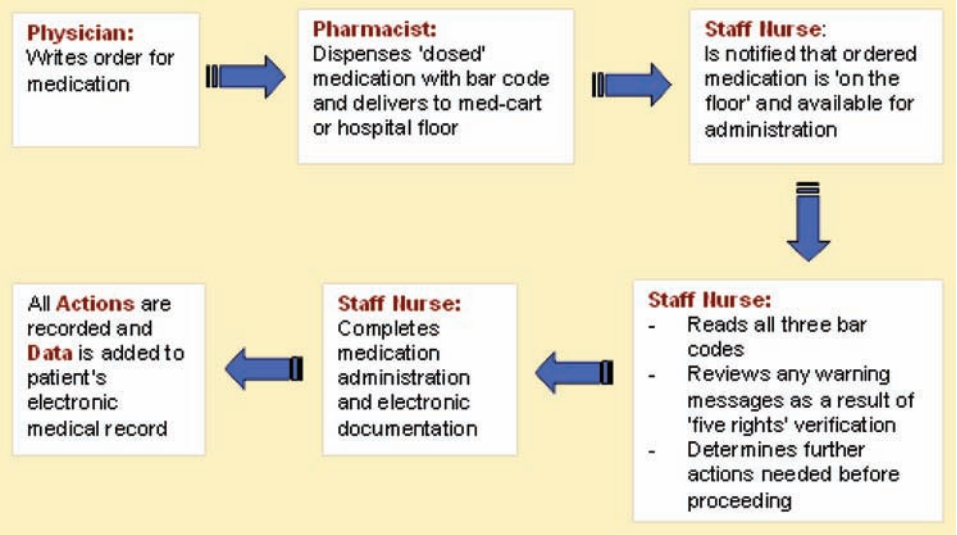
having comprehensive knowledge regarding the medication in terms of its use, dose, timing, route of administration, side effects, and interactions. The nurse would retrieve the medication from the medication room, usually from a pyxis, or unit dose machine. The medication would be inspected for the *Five Rights of Medication Administration*. Next, the nurse would check the patient's identification wristband to verify whom she will be administering the medication to. Finally, the nurse would sign the medication sheet documenting that she gave the medication and at what time. As can be observed from the figure above, the traditional method of patient medication administration is lengthy, time consuming, and allows for the possibility of medical error. Implementing an eMAR and BMV system in medication administration can easily address and help correct all of these issues, as detailed in the next section.

The Value of eMAR and BMV to Promote Patient Safety

Although both eMAR and BMV utilize complex technologies, their implementation by healthcare personnel involve simple steps, as depicted in Figure 2.

The process starts when a nurse gives a patient a wristband that has an identifying bar code on it. The physician writes medication orders on the patient's chart. The orders are scanned to the pharmacy by the nurse or medical secretary. Requested medications are individually labeled with a bar code and dispensed to the nurse's medication cart by the pharmacist. The nurse has her own computer on wheels, called COW for short, which is basically a cart with a computer and a bar code scanner on top. Under the cart are draws filled with medications for patients. When the nurse administers a medication to the patient, she enters a password on the computer, pulls up the patient's name, and views the doctor's orders for the medications needed. The nurse then gathers the patient's medications from the draw and scans the

Figure 2. Steps in a typical EMAR application



bar code on the label of the medication. Finally, she scans the bar code on the patient's wristband for accurate identification. This process reviews the "Five-Rights of Medication Administration," and will alert the nurse of any deviation from the medication order. The nurse administers the medication to the patient after correct medication verification has occurred, and electronically documents her actions. During the entire process, valuable time is saved as it requires a much shorter amount of time than with the traditional medication administration system.

Combining software decision support enhances the effectiveness and value of eMAR and BMV by providing critical information necessary for the nurse prior to administration of medication. For example, knowing a patient's potassium level value in the blood before administrating a medication may prevent serious cardiac complications. A scanned bar code would alert the nurse on the computer screen of the patient's potassium blood level value, and provide the necessary information needed to decide whether to hold that dose; otherwise, overdosing with potassium could sometimes be lethal. Having such a useful technology like eMAR and BMV in a healthcare organization reassures the patient of a safer environment, and can serve as a recruitment tool for new nurses. Not only do patients want to obtain care in these facilities, but also nurses want to be employed there (Staggers et al, 2007).

The use of bar coding is sometimes viewed as strictly technology. However, a broader view of bar coding can be seen as a tool for managing information and disseminating knowledge. Bar coding enables quick generation of accurate data, which enables one to make decisions based on valid and reliable information. There are numerous advantages of implementing bar coding in hospitals, including ease of use, timely feedback, and improved productivity. In addition to these apparent advantages, bar coding technology provides two main functions necessary for ensuring quality care and patient safety; namely, validation and tracking. The validating function of eMAR and BMV is an effective method for verification of the 'Five Rights of Medication Administration'. The ability to validate an action via bar coding reduces medication errors and waste, and helps construct the necessary documentation to meet the requirements of the Joint Commission on Accreditation of Healthcare Organizations and Insurance

Companies. The Joint Commission has established the accuracy of patient identification as one of the six National Patient Safety Goals (Simpson, 2003). The purpose of these safety goals is to promote specific improvements in patient safety. With the ease of swiping a patient's wristband, one obtains positive patient identification, correct medication prescribed by the doctor at the right time, and it identifies the nurse administrating the drug. The entire process provides the tracking function to help prevent possible medication errors. With the traditional system, nurses may occasionally fail to appropriately document medication given to a particular patient, which could lead to an over medicated patient. Besides, they may be rushed or distracted, and fail to check patient's identification wristband or doctor's orders. Instead, they may rely on their memory or the memory of a confused or medicated patient.

The other goals established by the Joint Commission include improving the effectiveness of communication among caregivers, to improve the safety of using medications, to reduce the risk of healthcare-associated infections, to accurately reconcile medications across the continuum of care, and to reduce the risk of patient harm due to falls (The Joint Commission, 2007). By instituting eMAR and BMV systems, three of these mandatory goals are easily met by hospitals.

INTEGRATION OF EMAR AND BMV IN TO CURRENT HEALTHCARE PROCESSES

Implementing eMAR and BMV is a unique form of automation, which streamlines data verification involved in medication administration. It assists hospital staff in performing their tasks and responsibilities more accurately and efficiently. Its implementation is relatively simple when compared with more complex rationalization of procedures, such as Business Process Reengineering (BPR) and paradigm shifts. Although the underlying technology for the eMAR and BMV systems have existed since the 1990s, many organizations have not yet converted to put them to use, mostly because of the large initial expense of implementing these systems.

The conversion strategy adopted for implementing eMAR and BMV may vary by organization. Most often, however, eMAR and BMV is introduced through a pilot study, which introduces a new system to a limited area of the organization. When the conversion is complete and the system is working smoothly in the targeted area of the organization, it can then be installed throughout the rest of the organization (Laudon & Laudon, 2006). This type of conversion projects through a pilot study is becoming a growing trend among healthcare institutions in the United States. For example, in the case of a 240-bed regional referral hospital (name suppressed for privacy reasons), an eMAR and BMV system was introduced to a 24-bed medical-surgical step-down unit. Each nurse in the hospital was given a two-hour system orientation, and there was a designated "super user" for each shift to act as a staff resource (Douglas & Larrabee, 2003). During the pilot implementation phase, the actual system was tested and evaluated. Both benefits and potential problems were identified, and they were considered when overall organizational conversion took place.

At the time of the conversion, there were several problems faced by institutions implementing eMAR and BMV. The first major hurdle was the lack of bar codes on medication. To tackle this issue, hospitals developed their own bar coding standards which would allow for more accurate use of eMAR and BMV (Douglas & Larrabee, 2003). Another problem involved frustrations from using the eMAR software for the first time. It took some time for nurses to learn and adapt to the new processes initiated by the use of the eMAR and BMV system. Hardware problems were also common: laptop cords were too short, wristband bar codes were too long and therefore difficult to read, medication carts could not easily access

isolated units, and nurses had to stand to use the system which created a strain on their posture and health. Most importantly, however, medication administration time has surprisingly increased as a result of the eMAR and BMV conversion initially (Caesar & Hutchinson, 2006).

Although these problems may seem discouraging, they could be easily fixed and solved. For example, bar codes can be produced and stamped on medications at the hospital's pharmacy, 'super users' and software vendors may collaborate with eMAR and BMV users to mitigate frustrations, longer laptop cords can be purchased, systems can be designated to isolated units only, and occupational therapists may help the hospital staff with their posture. Indeed, the long term benefits of eMAR and BMV systems have proven to outweigh the total cost of implementation and conversion (American Health Consultants Inc, 2005). Medication administration errors have been significantly reduced and timely administration has improved. The initial troubles of adapting to the new system were overshadowed by the ability to improve patient safety (Eisenhower et al, 2007).

There have been other case studies featuring success stories. For example, the Lancaster General Hospital in Pennsylvania implemented an eMAR and BMV system with a goal to reduce medication administration errors by 50%, and they were quite successful. The overall error rate in their medication administration had decreased by 54% at the end of the conversion. Successful implementation of this system was also evident from a consistent bar code scanning compliance rate exceeding 90% (Paoletti et al, 2007). The majority of nurses at the Lancaster Hospital were consistent in utilizing the bar code scanner to verify a patient with the correct medication.

Another success story of eMAR and BMV implementation has occurred at the Spaulding Rehabilitation Hospital in Aurora, Colorado. In 2002, this facility implemented patient safety initiatives focusing on reducing medication errors through use of technology. By 2005, after the continuous implementation of eMAR and BMV, the hospital realized 37.8% overall decrease in medication errors examined (Caesar & Hutchinson, 2006). The Sacred Heart Medical Center in Spokane, Washington, a 623-bed tertiary center has also reported that they were able to prevent a total of 969 medical errors in 20 random days. This corresponds to an average of 49 errors prevented per day with the overall prevention rate of 10.4 errors per 1,000 medication administrations occurred during the implementation of eMAR and BMV in the hospital (Galusha, 2005).

Although the success and benefits of eMAR and BMV are well documented, there are few cases where their use was not as helpful as expected. For example, the Good Samaritan Hospital, a 500-bed facility in Cincinnati, Ohio, had difficulties with the implementation of the system. High resistance to change from the nurses, the cost of the system to the organization, and difficulties with the software vendor's design of the system contributed to the failure of implementation. One particular problem occurred when a nurse went to look at the orders on the computer and only a partial view was seen on the screen. In addition, some of the medication orders were missing. This apparent problem created more work for the nurses to sort through the orders on all patients, which was time consuming and potentially led to medication errors. The problem in this particular case actually stemmed from the shortcomings of the technology itself; the screen size for viewing the medication orders was too small, preventing some of the orders from being seen by the nurse. Needless to say, such a technical problem can be easily eliminated by providing bigger screen monitors or increasing the physical memory size of the system.

Apart from the aforementioned difficulties faced by the Good Samaritan Hospital, nurses working in fast-paced areas, such as labor and delivery, found the eMAR and BMV system too multifaceted for their standardized medications, because the system unnecessarily required them to

go through "too many hoops" especially for cases where the turn-around time of patients should be short (Galvin et al, 2007). The turn-around time relates to how long a patient stays on a hospital unit, which can be as quick as five minutes for an injection or require hours of observation to determine if one is in labor.

For the same reasons mentioned above, some units in a hospital may not find the implementation of the eMAR and BMV systems practical, especially in areas where there are emergency situations and critical care issues. These areas include the operating room, emergency department, labor and delivery, and the intensive care areas. Here medications need to be given rapidly, and the use of eMAR and BMV would delay the entire process. In these situations, further refinement of the eMAR and BMV systems may be needed.

CONCLUSION

Today, medication administration by healthcare providers is multifaceted and perilous, which can jeopardize patient safety. Inaccuracies may occur throughout the traditional administration system process, which includes several healthcare providers. Verifying the 'Five-Rights of Medication Administration' for patient safety can be improved with the use of technology, such as the eMAR and BMV systems as discussed in this chapter. The bar code system utilized by the eMAR and BMV provides an efficient modality to the delivery of patient medications accurately. The system incorporates all healthcare providers involved with the medication administration. It manages and disseminates information to validate medication administration, to avoid potential errors, and to document these occurrences.

Hospital implementation of eMAR and BMV systems requires financial and personnel commitment. Learning and adopting this new process can include adjustments to potential difficulties, which should be anticipated to prevent them. Instituting a pilot study with super-users, and incorporating the hospital's own bar code system can facilitate a smooth transition. The success from the establishment of these systems definitely offers a benefit to both hospital healthcare providers and patients. Most importantly, the system provides a consistent and important component of healthcare, which improves patient safety by decreasing medication administration errors.

FUTURE TRENDS AND RESEARCH DIRECTIONS

The future in using eMAR and BMV systems to help promote patient safety and care would require that the infrastructure be able to support different medical applications. Although these systems are currently used for medication administration only, their focus could be extended to include other dimensions of patient care, such as recording vital signs and laboratory values of patients. This may include a patient's temperature, pulse rate, blood pressure, and respirations. For instance, it is necessary to know a patient's blood pressure and pulse rate before administering certain cardiac medications. Instead of the nurse retrieving this information on a flow sheet at the nurse's station, she would be able to see it on her computer screen before administering a drug.

Another useful medical application related with the eMAR and BMV systems would be to better control intravenous fluid rates by nurses based on laboratory values. For example, when a patient is receiving intravenous magnesium, which is used to stop preterm labor, it is critical that the patient's blood level of this drug stays within a certain parameter. As it works today, the nurse obtains the value after a blood draw from a laboratory, and adjusts the rate of the intravenous infusion accordingly. Instead of waiting for the laboratory to call back with the results, the eMAR and BMV systems could incorporate designing a standardized algorithm to automatically change

the rate of the intravenous fluid based on the laboratory value obtained. The system would also signal the nurse of the change in the intravenous rate, and alert her for the time that the next blood should be drawn. This would allow accuracy and decrease the human error factor.

Apart from the expected practical applications and improvements in the eMAR and BMV systems as detailed above, more academic research on this important area is definitely needed. Future studies may utilize case-based research by intensively reporting new implementations of these systems in hospitals around the world. Such studies will enable us to better understand the success factors as well as the reasons for failures in these implementations for individual cases. Future research may also utilize established statistical methodologies in order to analyze cross-sectional, time-series, or panel data collected from the individual case studies regarding the use of these systems. The results from such empirical works may help us observe the correlations between relevant variables chosen, the effect of time on these variables, and major differences across implementations of eMAR and BMV in different hospitals or countries around the world, all of which may not be obvious otherwise.

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KEY TERMS AND DEFINITIONS

Automation: The use of an information system to perform certain activities in a business process automatically. Automation by its nature reduces human involvement in a process and facilitates data entering into the system.

Bedside Medication Verification (BMV): BMV is a bar code scanning system used in conjunction with the electronic medication administration record (eMAR). Bar code scanning is utilized to assure validation that a medication administration action is accurate. BMV provides an easy and effective way for entering data to be used in a medical process.

Computer on Wheels (COW): These are computers usually accessible on a cart that would also include a bar code scanning mechanism, medications, and other important medical supplies. COWs play an important role in eMAR and BMV systems.

Electronic Medication Administration Record (eMAR): eMAR is a patient medication profile and electronic record, which is complete, dynamic and functions in real-time. It includes the provider orders, medication lists, administration details, allergies, and safety alerts to increase patient safety.

Five Rights of Medication Administration: These are the expected steps to administering medication, which when applied correctly will decrease the probability of medical mistakes. These rights are *(i)* right patient, *(ii)* right route, *(iii)* right dose, *(iv)* right time, and *(v)* right medication.

Joint Commission on Accreditation of Healthcare Organizations (US): An accrediting body for healthcare organizations that uses standards and policies to promote patient protection, including medication administration safety.

Medication Administration Record: A written paper record, which documents medications that are given or planned to be applied to a patient. The record includes the patient's name, patient's allergies, the medication, dose, the time of administration, the route of administration, and the name and signature of the nurse who administers the medication.

Medication Administration: The entire process of providing medication to a patient in a medical facility. This process begins with a diagnosis and concludes upon timely delivery of the medicine to the patient. This is traditionally a lengthy and complicated process, which increases the risk of medical mistakes.

Medication Error: A medical mistake made by a health professional unintentionally, which may or may not cause harm to a patient. The

medication error generally stems from breaking the rules of the 'Five Rights of Medication Administration'.

Pilot Study: An established method of implementation for an information system, by which an organization tests a new system in a controlled division of the organization. If successful, the organization will then adopt the information system throughout its remaining divisions.

Chapter 4
Electronic Health Records System Using HL7 and DICOM in Ophthalmology

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ABSTRACT

Health Level Seven (HL7) and Digital Imaging and Communications in Medicine (DICOM) standards are strongly influencing Electronic Health Records (EHRs) standardization. In this chapter, we present a web-based application, TeleOftalWeb 3.2, to store and exchange EHRs in ophthalmology by using HL7 Clinical Document Architecture (CDA) and DICOM standards. EHRs are stored in the native Extensible Markup Language (XML) database, dbXML 2.0. Application architecture is triple-layered with two database servers (MySQL 5.0 and dbXML) and one application server (Tomcat 5.5.9). Physicians can access and retrieve patient medical information and all types of medical images through web browsers. For security, all data transmissions are carried over encrypted Internet connections such as the Secure Sockets Layer (SSL) and Hypertext Transfer Protocol over SSL (HTTPS). The application verifies the standards related to privacy and confidentiality. The application is being tested by physicians from the University Institute of Applied Ophthalmobiology (IOBA), Spain.

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INTRODUCTION

Telemedicine is a general concept that includes diagnoses, examinations, medical meetings, collaborative operations and nurseries (Xiang et al, 2003). It uses common technologies that provide a conduit for information exchange between physicians, nurses and patients (Kugean, 2002). There are many different disciplines in telemedicine, such as teleradiology, telemonitoring, teleconsultation, teleconference, teleophthalmology and telepsychiatry (Brauer, 1992). Teleophthalmology is the use of information and communications technology to enable the delivery of ophthalmology services between geographically separated individuals (Health Canada, 2007). Some teleophthalmology objectives are: to make eye care service accessible and affordable by reducing travel cost and for the patients, to enable people in remote areas to have access to specialised eyecare facilities and to act as an interface between physicians to share their experiences. Teleophthalmology is highly suitable for treating speciality diseases like Glaucoma, Diabetic Retinopathy (RD) and Corneal Ulcer. Since all these diseases can be diagnosed by looking at the fundus image, a digital fundus camera attached to a computer and supporting software alone is required in treating these diseases (Thulasi et al, 2007).

Information systems in telemedicine provide storage, retrieval, connection, and evaluation of the healthcare information. Some of these systems are the Electronic Patient Records (EPRs) and the Electronic Health Records (EHRs). EPR stores and administrates all the medical data about a patient (Horsch & Balbach, 1999). EHR is a secure, real-time, point-of-care and patient-centric information resource for physicians (HIMSS, 2003). EHR usually contains, without being limited to, observations, care plans, comments, and, as a whole, act as a long-term accumulator of information about what has happened to the patient. The term EPR focuses only on relevant information for specific medical problem episodes. EHR must enable the communication of healthcare information to support shared patient care, improved quality of care and effective resource utilisation (Ferreira et al, 2004). Some benefits of the EHR systems are their universal access, coding efficiency and efficacy, easier and quicker navigation through the patient record (Smith & Newell, 2002). There are several barriers to their adoption such as training, costs, complexity and the lack of a national standard for interoperability (Gans et al, 2006).

The telemedicine applications and services often involve many institutions using different systems and technologies. This complicates the necessary technical standardization (Holle & Zahlmann, 1999). International, European and national organizations are concerned with standardization of EHR such as the ISO Health Informatics Standards Technical Committee (ISO/TC) 215, CEN Technical Committee (CEN/TC) 251, openEHR, Health Level 7 (HL7), Extensible Markup Language (XML), Integrating the Healthcare Enterprise (IHE), Digital Imaging and Communication in Medicine (DICOM), American National Standards Institute (ANSI) to name but a few (Bott, 2004).

DICOM is a standard that is being used for the exchange and storage of medical images and related information all over the world. This format has been recognized as the de facto standard for storage, transferring and sharing of cardiac images along different modalities like magnetic resonance imaging (MRI), nuclear medicine, computer tomography (CT), digital angiography (XA), digital radiology (Marcheschi et al, 2003). One of the advantages of DICOM is that only a part of the defined keys is specified (Neri et al, 1998). After radiology, ophthalmology is one of the biggest users of digital imaging and therefore DICOM is likely to be a significant development in the future for ophthalmic imaging. In turn, HL7 is dedicated to the development of standards for the message-oriented exchange of information between health information systems. The idea of using the same mechanism for the specification

in the exchange of EHR components is obvious and so the concept Clinical Document Architecture emerged (Dolin et al, 2001). It specifies XML documents as EHR components based on a three layer approach. The development of HL7 and DICOM standards has also been of great benefit in telemedicine services and applications. HL7 has been the standard for communication between clinical databases for many years and DICOM has not grown much beyond radiology. It requires the entire EHR system to function in both HL7 and DICOM.

In this chapter, we present a web-based application (TeleOftalWeb 3.2) designed to store and exchange EHR in ophthalmology by using HL7 Clinical Document Architecture (HL7-CDA) and DICOM standards. Moreover, we give a general vision about the current situation of the most important EHR standards to exchange healthcare information such as ISO/TC 215, CEN/TC 251, openEHR, HL7, DICOM and IHE. This web-application ensures interoperability among different applications and institutions. EHRs have been built on Java Servlet and Java Server Pages (JSP) technologies. Its architecture is triple-layered with two database servers (MySQL 5.0 and native XML) and one application server (Tomcat 5.5.9). The application is platform-independent thanks to use XML and Java technologies. Physicians can access and retrieve patient medical information and images through Web browsers as Mozilla Firefox, Microsoft Internet Explorer and others. Furthermore, they can view, modify and store all types of medical images in different formats like DICOM, JPEG, GIF, etc. For security, all data transmissions were carried over encrypted Internet connections such as Secure Sockets Layer (SSL) and Hypertext Transfer Protocol over SSL (HTTPS). The application verifies the standards related to privacy and confidentiality, and is being tested by ophthalmologists from the University Institute of Applied Ophthalmobiology (IOBA), Spain.

BACKGROUND

EHR has been a key research field in medical informatics for many years. EHR is a history of all observations and decisions about the care of a subject, and as such, it exhibits a kind of 'clinical integrity', meaning that no matter what part of it is viewed, a complete clinical story is available. The primary purpose of the EHR is to provide a documented record of care that supports present and future care by the same or other physicians. This documentation provides a means of communication among clinicians contributing to the patient's care. The primary beneficiaries are the patient and the physicians (ISO/TC 215, 2002). Making EHR interoperable will contribute to more effective and efficient patient care by facilitating the retrieval and processing of clinical information about a patient from different places. To address the EHR interoperability problem, there are several standards under development such as HL7, DICOM, ISO/TC 215, CEN/TC 251, OpenEHR, the industry initiative IHE to name but a few (Eichelberg et al, 2005).

HL7

Founded in 1987, HL7 is a non-profit American National Standards Institute (ANSI) accredited Standards Developing Organization that provides standards for the exchange, management and integration of data that supports clinical patient care and the management, delivery and evaluation of healthcare services. HL7 standard is used for many different medical environments. For example, there are mobile clinical information systems using HL7 to integrate the patient data (Choi et al, 2006). HL7 Document is intended to be the basic unit of a document-oriented EPR. The patient medical record (PMR) is represented as a collection of documents. It is a widely used standard for the electronic interchange of clinical, financial and administrative information among heterogeneous computer systems. The HL7 stan-

dard has gone through many different revisions and releases, and different vendors offer varying levels of support for the different versions. Currently, there are two message protocols supported by HL7: Version 2 and Version 3, the first parts of which were approved in 2004 by the ANSI.

HL7-CDA, previously called Patient Record Architecture (PRA), defines structure and semantics of medical documents for the purpose of exchange. CDA documents are encoded in XML and they derive their meaning from the HL7 Reference Information Model (RIM) and use HL7 Version 3 Data Types. The HL7-CDA is a XML-based document markup standard that specifies the structure and semantics of EHR for the purpose of exchange. ANSI/HL7 CDA R1.0-2000 is the first nationally certified XML-based standard for healthcare (Alshuler, 2000).

A CDA document is a contextually complete information object that can include text, images, sounds, and other multi-media content. Moreover, it stands alone, outside the environment in which it was created or communicated. In general, each clinical document template consists of XML fragments, which are the units of re-use among document templates. Thus, XML fragments are used to assemble clinical document templates. Clinical document templates correspond to structured forms that are filled out by healthcare professionals in the context of a telemedicine session e.g. request for consultation, diagnostic report, progress note, etc (Chronaki, 2001). HL7-CDA defines XML-based document markup that standardises the structure and content of clinical documents for exchange. HL7-CDA principal goal is to facilitate the continuity of patient care across disparate organizations by creating a human-readable, machine- and application-independent format for the EHR exchange. This promotes the longevity of clinical records and minimizes barriers to creation and use.

CDA distinguishes three different levels of granularity as shown in Table 1, where each level repeatedly adds more markup to clinical documents, although the clinical content remains constant at all levels (Eichelberg et al, 2006).

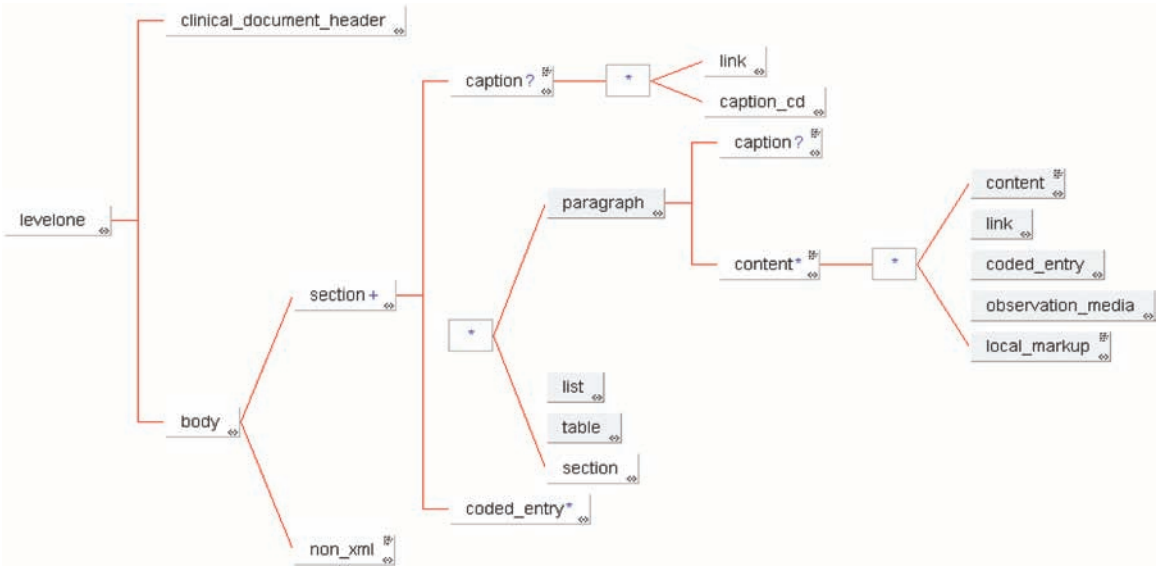
There is only one CDA Level One Document Type Definition (DTD) for all types of clinical documents. CDA Level One is specified by three components: the CDA Header, the CDA Level One Body and Reference Information Model (RIM) data type DTD. The CDA Level One Body is specified in the CDA Level One DTD and is derived from document analysis. RIM data type DTD is an XML implementation of the abstract data type specification. It used by both the CDA and the HL7 Version 3 message specifications. A HL7-CDA document is comprised of a header, referred to as the 'CDA Header', and a body, which at CDA Level One is referred to as the 'CDA Level One Body'. The CDA Header identifies and classifies the document and provides information on authentication, the encounter, the patient, and the provider. The body contains the clinical-related information that we want to exchange.

Although CDA Release Two, which has been approved as an ANSI standard in May 2005, does not distinguish these three levels any more (Table 1), the basic architecture with structured documents of different granularity remains. The CDA specification prescribes XML markup for CDA Documents: CDA cases must be validated

Table 1. Levels of document granularity in CDA release one and release two

CDA Release One	*CDA Release Two*
CDA Level One	***Unconstrained CD specification***
CDA Level Two	***CDA specification with section-level templates applied***
CDA Level Three	***CDA specification with entry-level templates applied***

Figure 1. CDA schema



against the CDA Schema and may be subject to additional validation. The CDA Schema is shown in Figure 1.

The CDA Level One Body is comprised of nested containers. There are four types of containers: sections, paragraphs, lists and tables. Containers have contents and optional captions. Contents include plain text, links and multimedia. CDA document is a defined and complete information object that can exist outside of a messaging context and/or can be a MIME-encoded payload within an HL7 message. The CDA is only the first example of HL7's commitment to the advancement of XML-based e-healthcare technologies within the clinical, patient care domain. The CDA scope is the standardization of clinical documents for exchange. A HL7-CDA structure may include texts, sounds, pictures and all kind of multimedia contents. It can refer to external documents, procedures, observations and acts. It includes information about authors, authenticators, custodians, participants, patients and so on (Treins et al, 2006).

DICOM

DICOM is a cooperative standard. It was developed from 1990 to 1996, mainly by the American College of Radiology (ACR) and the National Electrical Manufacturers Association (NEMA) committee in the United States, with contributions from European standardization organizations, the Japanese Industry Radiology Apparatus (JIRA), the Institute of Electrical and Electronics Engineers (IEEE), HL7 and American National Standards Institute (ANSI) as well as from European manufacturers and societies. This standard allows the exchange of medical images and related information between systems from different manufacturers (Neri et al, 1998) and defines data structures and services for vendor independent exchange of medical images and related information.

DICOM format has been recognized as the de facto standard for the storage, transferring and sharing of cardiac images along different modalities like Magnetic Resonance Imaging, Nuclear Medicine, Computer Tomography (CT), Digital Angiography and Digital Radiology.

In many medical environments there is a large need to have cardiac images available in formats (i.e. GIF. BMP or JPEG), which are compatible with widely used office automation applications (Marcheschi, 2003). In the year 2000, an extension to the DICOM standard was officially released that covers medical reports and other clinical data. Structured Reporting (SR) is a general model for encoding medical reports in a structured manner in DICOM's tag-based format. The DICOM SR standard sets out rules that define how structured documents that contain health information should be composed, stored and transmitted. These documents can contain embedded references to other DICOM instances such as images, waveforms, audio files and other structured reports and also references to regions of interest within images and waveforms (Bortoluzzi, 2003).

DICOM is a success for radiology and cardiology and it is now beginning to be used for other clinical specialities. The US Department of Veterans Affairs has been instrumental in promoting this technological advancement. Their goal is to incorporate all the patient's data into the EHR. DICOM is making this easier for everyone. The work involved in extending DICOM to the clinical specialties such as ophthalmology (Kuzmak, 2003).

The interests and needs of ophthalmologists can be best served by establishing global standards to govern the communication of images and data, which increasingly will be done in digital formats for speed, accuracy and convenience. A digital imaging standard will allow users to communicate readily, no matter what specific technology they use, and a system of globally agreed ophthalmological definitions can be applied through it. The DICOM standard is recognized in the United States and throughout the world as the medical imaging standard (Quality of Care Secretary, 1997). The American Academy of Ophthalmology (AAO) is committed to supporting and working with these entities to assure that these standards reflect the needs and interests of ophthalmology and eye care. On June 22, 1998 in Amsterdam, the AAO convened an open organizational meeting for a new Working Group on Ophthalmology Standards to focus on issues related to standards for ophthalmic imaging and digital communications. There were a total of 30 participants, representing various vendors, ophthalmologists, ophthalmic photographers and academic medical centers. The group will be focusing on the standards development activities related to digital imaging and terminology in eye care. The Working Group is formally recognized within the DICOM Committee structure as Working Group 9 (Ophthalmology).

ISO/TC 215

ISO/TC 215 has defined the EHR and also produced a technical specification (ISO 18308) describing the requirements for EHR Architectures. It provides standardization in the field of information for health. It ensures compatibility of data for comparative statistical purposes and to reduce duplication of effort and redundancies. The EHR architecture must describe standardized structural elements in order to enable automatic processing and interoperability. This structure should not dictate the work patterns or system required to operate an effective health service, rather it should ensure that conforming EHR should be available in many settings (ISO/TS 18308, 2003).

CEN/TC 251

CEN/TC 251 is the body within Europe with a mandate to develop standards for Health Informatics. It is a workgroup within the European Union working on standardization in the field of Health ICT. The goal is to achieve compatibility and interoperability between independent systems and to enable modularity in EHR systems. This standard considers the EHR to be the persistent longitudinal and potentially multi-enterprise or multi-national record of health. Moreover, it pretends the care

provision relating to a single subject of care (the patient), created and stored in one or more physical systems in order to inform the subject's future health care and to provide a medico-legal record of care that has been provided. Various mechanisms have been developed to optimally represent details of statements in a record system (Rossi, 1998). Magdalena et al (1999) describe a telemedicine based approach to a computer-aided healthcare system. All its modules comply with European CEN/TC 251 standards (Magdalena, 1999).

OpenEHR

OpenEHR is the next generation public specifications and implementations for EHR systems and communication, based on a complete separation of software and clinical models. It is dedicated to the development of an open, interoperable health computing platform, where a major component is clinically effective and interoperable EHR. It does this by researching clinical requirements, and creating specifications.

Baretto et al. (2004) examine the problem of achieving a close relationship of EHR content with other components of a clinical information system (guidelines, decision support and workflow), with particular emphasis on integrating the EHR with workflow. We use the openEHR architecture, which allows the extension of a core reference model via archetypes, to refine the detailed information recording options for specific points in the workflow and to represent the chain of instructions that is the workflow itself. This case study shows the contribution guideline content and its derived workflow can have on problem specific EHR structure and demonstrates the potential for a constructive interaction of workflow support and the EHR. Fernandez-Breis et al. (2006) present an ontological approach to promote interoperability among CEN and OpenEHR compliant information systems.

IHE

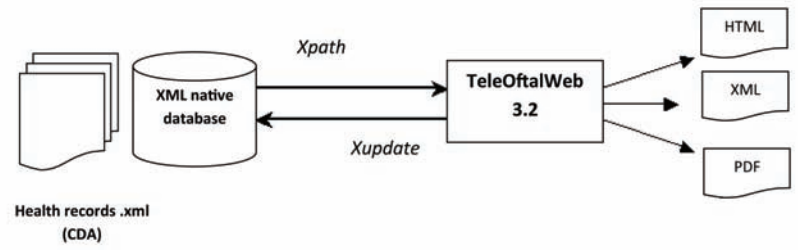
IHE is an initiative to integrate existing standards into a comprehensive best-practice solution. It does not create new standards, but rather drives the adoption of standards to address specific clinical needs. IHE does this by creating a framework for passing vital health information seamlessly across the entire healthcare enterprise. It is an important initiative strongly supported by the industry: more than 110 companies developed IHE-compliant systems between 1999 and 2004 and participated in the cross-vendor testing events organized by IHE, including most of the market leaders.

Currently, clinical information is stored in all kinds of proprietary formats through a multitude of medical information systems available on the market. This results in a severe interoperability problem in sharing EHR. To address this problem, an industry initiative, called IHE has specified the 'Cross Enterprise Document Sharing (XDS)' Profile to store healthcare documents in an ebXML registry/ repository to facilitate their sharing. IHE has also specified the interfaces of healthcare applications and the messages exchanged by restricting the well known standards such as HL7 and DICOM (Dogac, 2006). XDS specifies guidelines for sharing clinical documents across healthcare organization boundaries.

There are now eight 'domains' in IHE, only one of which is ophthalmology. The IHE Eye Care initiative was formed in 2005. The AAO is the principal sponsor of the initiative. The mission of the IHE Eye Care initiative is to bring together information technology stakeholders and healthcare professionals to implement standards for communicating patient information efficiently throughout healthcare facilities.

IHE Profiles provide a common language for purchasers and vendors to discuss the integration needs of healthcare sites and the integration capabilities of healthcare IT products. They offer developers a clear implementation path for communication standards supported by industry

Figure 2. Application architecture



partners. They are carefully documented, reviewed and tested. In Eye Care there are three profiles: Eye Care Workflow (EYECARE), Eye Care Evidence Document (ECED) and Eye Care Displayable Report (ECDR). EYECARE manages eye care workflow including ordering, scheduling, imaging acquisition, storage and viewing. ECED creates, stores, retrieves and uses objects to record Eye Care evidence. ECDR creates, stores and retrieves displayable (PDF) clinical professional reports (AAO et al, 2007).

A WEB-BASED APPLICATION TO EXCHANGE AND STORE EHRS: TELEOFTALWEB 3.2

Application Overview

TeleOftalWeb 3.2 has been built on Java Servlet and JSP technologies. The relational database MySQL has been changed into a native XML. The EHR are stored in the native XML database. Figure 2 shows the application architecture. It is triple-layered with two database servers (relational and native XML) and one application server. The client application (standard web browser) consists of a web interface based on JSP running on the web server. The server application communicates with the databases to retrieve the data. In communication with the native XML database, we used the languages XPath and XUpdate. XPath is employed to find information in an XML document. It operates on the abstract, logical structure of an XML document rather than its surface syntax. XUpdate makes heavy use of XPath for selecting a set of nodes to modify or remove. It provides open and flexible update facilities to modify data in XML documents. The XML-based architecture described in the CDA v1.0 standard has been used to define the health information format.

System Specifications

The software requirements in TeleOftalWeb 3.2 are the following:

- The development environment was NetBeans IDE 4.1 of Sun Microsystems. Java was the basis application programming language. We included all tools and Application Programming Interface (API) as Javascript, JSP, Java Servlets and Java Database Connectivity (JDBC);
- The application is platform-independent thanks to using XML and Java Technologies. The evolution of Java Technology brings more features to the Java development tools. This facilitates the creation process of telemedicine applications and reduces the time of developing programs (Fedyukin et al, 2002);
- Combining Java and XML leads to the attractive dual portability of code and data. Wherever Java programs can run, they can also access XML information. This enables

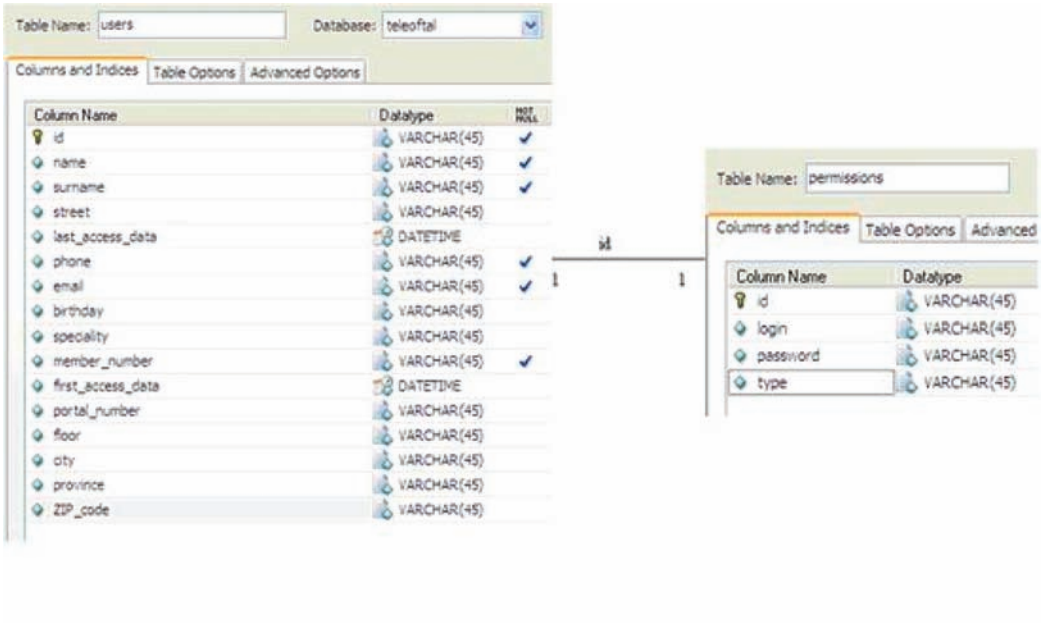
Java and XML information to interoperate efficiently and effectively on different platforms (Fan, 2005). We used XML to store and exchange the EHR. Some advantages of XML are: easily readable, self-describing and interoperable. Moreover, there are several types of object-based parser components available for this language. XML parsers work the same way on virtually every platform;

- We chose free open-source applications and database servers. For the manager module, we used a relational database to store the personal data. The database manager has been MySQL Server 5.0 with the Connector/J-3.1.11. We applied a native open-source XML database, dbXML 2.0 to manage and store the EHR and images. We employed Tomcat 5.5.9 to process the requests: JSP and Java Servlets. Java programming techniques were used to implement the system. The users can access and retrieve medical information and images through Web browsers as Mozilla Firefox, Microsoft Internet Explorer and others;
- For security, all data transmissions were carried over encrypted Internet connections such as SSL and Hypertext Transfer Protocol over SSL (HTTPS). These protocols were employed in Wei (2006).

Data Modeling

There are two types of database systems to store XML data: relational and native XML. The relational databases consist of a set of tables. Each table is a set of records. MySQL is a multi-threaded, multi-user and SQL relational database Server (RDBMS). In some telemedicine applications, the authors use MySQL databases. For example, according to Hung and Zhang (2003) MySQL relational database system was set up to store the blood pressure (BP) readings, electrocardiogram (ECG) data, patient records, clinic and hospital information, and doctors' appointments with patients. In the MySQL database, we stored all the

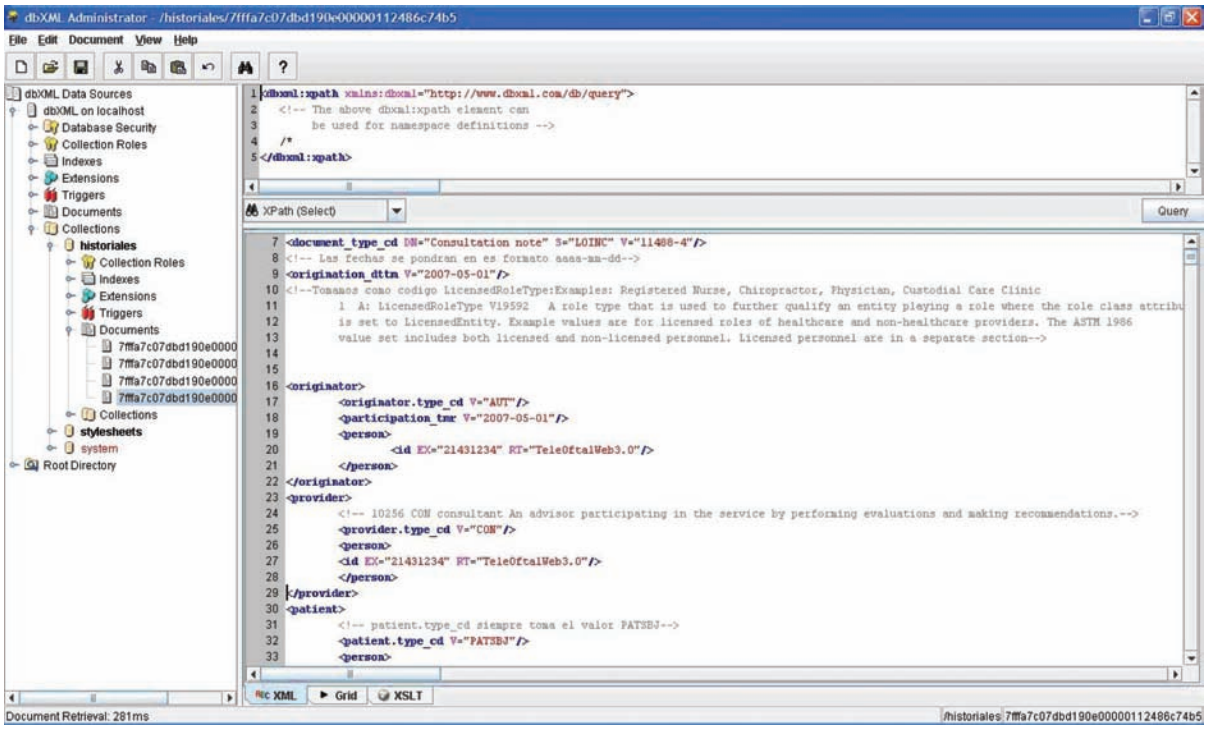
Figure 3. User data modeling in the MySQL database



user data and access information to web application. It has two tables: "users" and "permissions". The table "users" contains personal user data. The user identification, user name, password and user type appear in table "permissions". The primary key is the same in both tables (identification number). The data modelling in the MySQL database is shown in Figure 3.

The native XML databases allow the storage and indexing collections of XML documents in both native and mapped forms. They define a logical model for an XML document. They are not required to have any underlying physical storage model. A native XML database is not required to have any particular underlying physical storage model. It can be built on a relational, hierarchical, object-oriented database, or use a proprietary storage. XML/XPath query language operates over XML documents and produces XML documents (Marcheschi, 2004). XPath models an XML document as a tree of nodes. The name of a node is modeled as a pair consisting of a local part and a possibly null namespace Uniform Resource Identifier (URI). In this application, we used the native XML database dbXML 2.0 to store XML data and all their components. DbXML is a proprietary database developed by the dbXML Group. It uses a model-based storage strategy to store XML documents in the database system. We employed XPath to address parts of the XML documents. Figure 4 shows the manager interface of the dbXML 2.0. It stores and indexes collections of XML documents in both native and mapped forms for highly efficient querying, transformation and retrieval. It is a native XML database written in Java. DbXML manages documents in collections. Many collections can be created and managed at one time. Collections can also be laid out in a hierarchical fashion, in much the same way that an operating system's directory structure works. A single collection may be associated with multiple indexes, extensions, triggers and child collections.

Figure 4. Manager interface in the dbXML 2.0 database



XML documents can be stored as binary streams but will not benefit from tokenization, compression and indexing. DbXML supports four query languages: XPath, XUpdate, XSLT and FullText. XPath is a terse path syntax that is similar in some ways to UNIX or DOS directory paths. It allows the returned results to be filtered based on location and predicated evaluation. XUpdate is also a transformation with some of the same goals as XSLT, but its syntax is simpler, and its purpose is to modify the content of documents in place. XSLT is a transformation language that converts XML into other forms. FullText is a search engine style query with the ability to search on many words with ANDed and ORed set evaluation. The results of a full text query can also be filtered using an XPath expression.

EHR are stored in the native XML database according to the ANSI/HL7 CDA R1.0-2000 template. In Figure 4, we can also see the CDA Level One DTD. It allows any valid document type code and section code. There is only one CDA Level One DTD for all types of clinical documents.

Technically, CDA Level One is specified by three components: the CDA Header, the CDA Level One Body and Reference Information

Figure 5. CDA Header in TeleOftalWeb 3.2

```
<levelone>
<clinical_document_header>

<id EX="XXXIDHISTXXX" RT="TeleOftalWeb3.0"/>
<document_type_cd V="11488-4" S="LOINC" DN="Consultation note"/>

<origination_dttm V="XXXFECHACREACXXX"/>
<originator>
        <originator.type_cd V="AUT"/>
        <participation_tmr V="XXXFECHACREACXXX"/>
        <person>
                <id EX="XXXIDDOCTXXX" RT="TeleOftalWeb3.0"/>
        </person>
</originator>
<provider>
        <!-- 10256 CON consultant An advisor participating in the service by performing evaluations and making recommendations.-->
        <provider.type_cd V="CON"/>
        <person>
        <id EX="XXXIDDOCTXXX" RT="TeleOftalWeb3.0"/>
        </person>
</provider>
<patient>
        <!-- patient.type_cd = PATSBJ-->
        <patient.type_cd V="PATSBJ"/>
        <person>
                <id EX="XXXDNIXXX" RT="TeleOftalWeb3.0"/>
                <person_name>
                        <nm>
                                <GIV V="XXXGIVXXX"/>
                                <FAM V="XXXFAMXXX" />
                        </nm>
                </person_name>
                <addr>
                        <STR V="XXXSTRXXX"/>
                        <HNR V="XXXHNRXXX"/>
                        <ADL V="XXXADLXXX"/>
                        <CTY V="XXXCTYXXX"/>
                <STA V="XXXSTAXXX"/>
                <ZIP V="XXXZIPXXX"/>
                <CNT V="XXXCNTXXX"/>
                </addr>
                <phon V="XXXPHONXXX"/>
                <local_header descriptor="email">XXXEMAILXXX</local_header>
        </person>
        <birth_dttm V="XXXBIRTHXXX"/>
        <administrative_gender_cd V="XXXGENDERXXX" S="2.15.840.1.113883.5.1"/>
        <local_header descriptor="numeroSS" >XXXSSNUMXXX</local_header>
</patient>
<local_header descriptor="compartidos">
        <local_header descriptor="person">
                <local_attr name="V" value="XXXIDDOCTXXX"/>
                <local_attr name="type" value="owner"/>
        </local_header>
</local_header>
 </clinical_document_header>
```

Figure 6. CDA Level One Body in TeleOftalWeb 3.2

```
<body>
 <!-- ********************************************************************************************-->
 <!--                                  REVISIONS                                                   -->
 <!-- ********************************************************************************************-->
 <section>
   <caption>Revisions</caption>
   <section>
            <caption>Filiación</caption>
            <paragraph>
                 <content>
                      <local_markup descriptor="patient">
                           <local_markup descriptor="person">
                                <local_markup descriptor="id">XXXDNIXXX</local_markup>
                                <local_markup descriptor="person_name">
                                     <local_markup descriptor="nm">
                                          <local_markup  descriptor="GIV">XXXGIVXXX</local_markup>
                                          <local_markup descriptor="FAM">XXXFAMXXX</local_markup>
                                     </local_markup>
                                </local_markup>
                                <local_markup descriptor="addr">
                                     <local_markup descriptor="STR">XXXSTRXXX</local_markup>
                                     <local_markup descriptor="HNR">XXXHNRXXX</local_markup>
                                     <local_markup descriptor="ADL">XXXADLXXX</local_markup>
                                     <local_markup descriptor="CTY">XXXCTYXXX</local_markup>
                                     <local_markup descriptor="STA">XXXSTAXXX</local_markup>
                                     <local_markup descriptor="ZIP">XXXZIPXXX</local_markup>
                                     <local_markup descriptor="CNT">XXXCNTXXX</local_markup>
                                </local_markup>
                                <local_markup descriptor="phon">XXXPHONXXX</local_markup>
                                <local_markup descriptor="email">XXXEMAILXXX</local_markup>
                           </local_markup>
                           <local_markup descriptor="birth_dttm">XXXBIRTHXXX</local_markup>
                           <local_markup descriptor="administrative_gender_cd">XXXGENDERXXX</local_markup>
                           <local_markup descriptor="numeroSS" >XXXSSNUMXXX</local_markup>
                      </local_markup>
                 </content>
            </paragraph>
       </section>
<!-- ********************************************************************************************-->
<!--                                  IMAGES                                                      -->
<!-- ********************************************************************************************-->
<section>
   <caption>Images</caption>
   <list>
        <item>
        </item>
   </list>
</section>
 </body>
</levelone>
```

Model (RIM) data type DTD. The CDA Level One Body is specified in the CDA Level One DTD and is derived from document analysis. In our web-based application, TeleOftalWeb 3.2, the CDA Header can be seen in the Algorithm 1. The CDA Level One Body in our application is shown in Algorithm 2.

Manager Module

The manager module interface is shown in Figure 5. The manager can access the web platform and has to introduce the login and password. In Figure 6, we can see several application users. The two user roles are: manager and user. The application manager can do the following actions:

- Create new users;
- Show the user information;
- Erase users;
- Modify the user information;
- Show the user statistics. They are the number of patient records (own and shared);
- Show the user patient records;
- Search users by different criteria such as surname, identification number, type of user and member number.

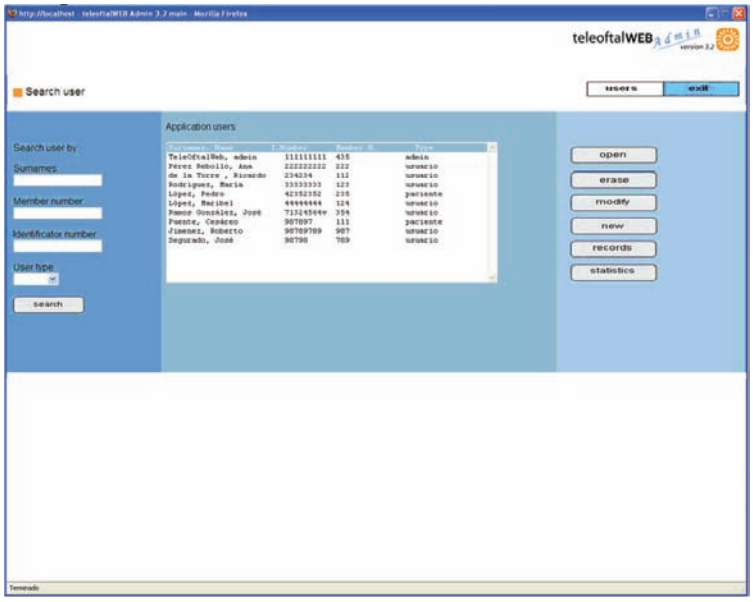
User Module

The authorized users can access this module. They have their login and password. The access is similar to the manager module. The users can do the following actions:

- Create new records (see Figure 7). They have to introduce the necessary data: patient affiliation information, patient precedents, medical exploration and diagnostic;
- Erase and search records;

Figure 7. Manager Module

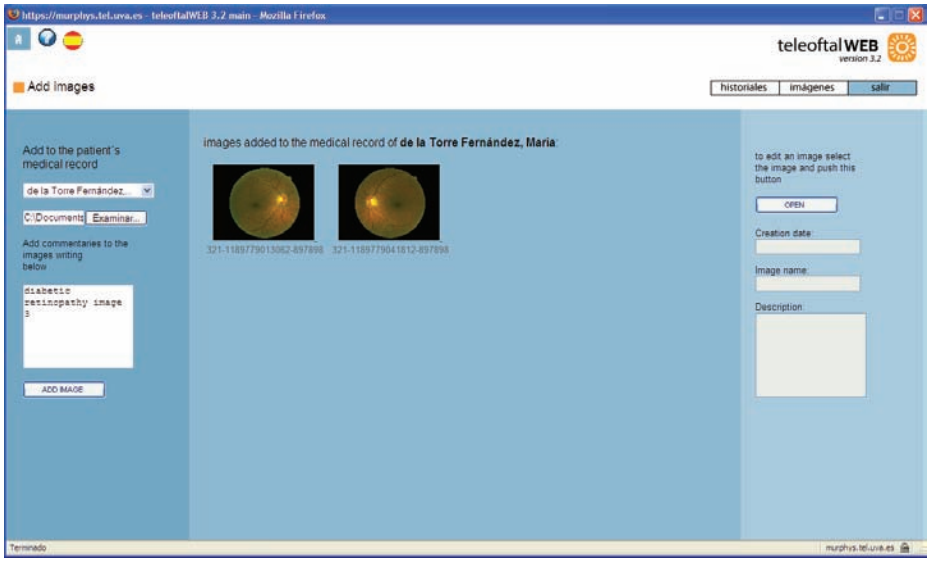
Figure 8. Application Users Module



- Create new revisions in a record;
- Erase and search revisions;
- Add new images in different records (see Figure 8). The images editor shows images and allows us to change their shape and colour, to make them bigger or smaller. Other basic actions can be done. The physicians can add new images in an EHR. These may

Figure 9. Create a new record in the application

Figure 10. Add images in a record

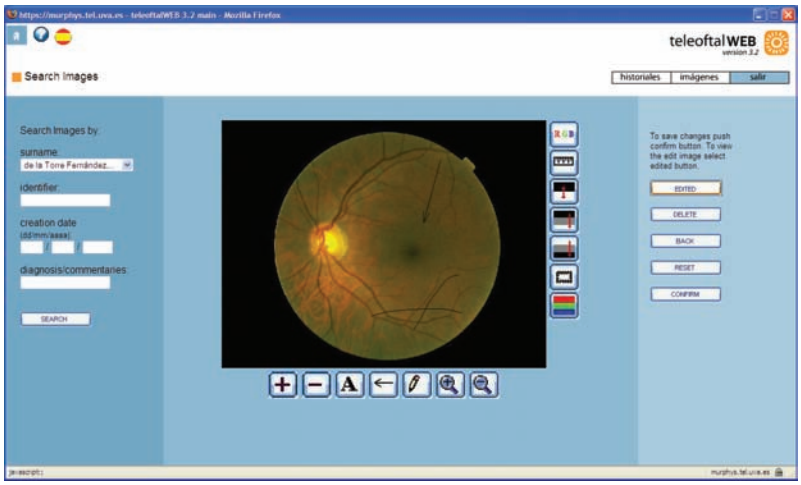


be in different formats such as DICOM, JPEG, GIF, BMP, TIFF amongst others;

- Edit and erase images; and
- Search images according to different criteria: image identification number, surnames, image creation date and comments. Figure 9 shows this action.

We use Extensible Stylesheet Language Formatting Objects (XSL-FO) to format XML data. XSL-FO is a complete XML vocabulary for laying out text on a page. An XSL-FO document is simply a well-formed XML document that uses this vocabulary. The EHR output format is a Portable Document format (PDF). An EHR in PDF

Figure 11. Images editor with a DICOM image



format can be viewed in Figure 10. It is a necessary process to get from your XML document to a PDF printable document.

First, the XML must be fed to an XSLT processor with an appropriate stylesheet in order to produce another XML document which uses the XSL-FO namespace and is intended for an XSL-FO formatter. The second stage is to feed the output of the first stage to the XSL-FO formatter, which can then produce the end product: a printable document, styled for visual presentation (Pawson, 2002).

CONCLUSION

TeleOftalWeb 3.2 has been developed to store and exchange EHR in Ophthalmology by using HL7-CDA and DICOM standards. Other applications have been presented using XML-based Clinical Document Architecture to exchange discharge summaries (Paterson, 2002). There are several EHR applications in different medicine areas such as oncology (James et al, 2001) and emergency departments (Amouh et al, 2005). In the telematic system for oncology, they use a data warehouse as EPR server. The authors do not present a standardization process for the EHR. In our application, we applied EHR standards. The information system designed for emergency department has been implemented by prototyping a web-based. It is a multiplatform and multi-user system, using the Java programming language. We apply XML and Java technologies to interoperate efficiently and effectively on different web platforms.

Dalley et al (2005) describe a functioning model that permits access to an EHR. An SQL 7.0 database and Apache 4.0 Web Server are used. In our application, we chose free open-source databases. They do not use XML and Java technologies. Physicians and researchers must be the ones to benefit from integrating EHR with data collection and analysis in clinical trials. The extensive use of HL7-CDA standard is desirable, not only in a cardiology environment but also for all fields present in medicine (Marcheschi et al, 2004). In this chapter, we apply it in an ophthalmologic application.

According to HFMA (2006), there are important barriers in the EHR adoption such as the lack of national information standards and code sets. Moreover, the lack of available funding and interoperability can be presented. We are trying to solve some of these problems of EHR adoption in Ophthalmology. Web-based applications allow for improved data access for patient data

management. The advantages of our web-based application are: its adaptation to the standards HL7-CDA and DICOM. The application facilitates the interoperability between institutions and applications, and verifies the standards related to privacy and confidentiality. Moreover, the transactions are secure. Web-based applications also allow for improved data access for patient data management. The physicians can analyze the patient records everywhere. They only need a computer with Internet access, although web-based application speed depends on the Internet connection and the number of users in the system. When this number is high, the application speed is lower.

FUTURE RESEARCH DIRECTIONS

Diabetes mellitus is a leading cause of vision loss in industrialized countries. Diabetic retinopathy is the most common diabetic eye disease and a leading cause of blindness in adults. It is caused by changes in the blood vessels of the retina. In some people with diabetic retinopathy, blood vessels may swell and leak fluid. In other people, abnormal new blood vessels grow on the surface of the retina. The retina is the light-sensitive tissue at the back of the eye. Diabetic retinopathy has features which make it ideal for disease management by telemedicine. In our research, several Teleophthalmology services for specialists have been developed in cooperation with the IOBA, in order to improve the training of ophthalmologists in the retinal area. We will continue developing new telemedicine applications in teleophthalmology and studying the EHR standards such as HL7, DICOM, ISO/TC 215, CEN/TC 251, etc.

Our application (TeleOftalWeb 3.2) uses a native XML database: dbXML 2.0. This has one disadvantage for scientific evaluation: an additional module or parser must be implemented. We are working in the migration of all information from XML native and relational databases to Oracle 10g in order to solve this problem.

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KEY TERMS AND DEFINITIONS

DICOM: Digital Imaging and Communications in Medicine. It is a standard for handling, storing, printing, and transmitting information in

medical imaging. It includes a file format definition and a network communications protocol. DICOM files can be exchanged between two entities that are capable of receiving image and patient data in DICOM format. DICOM enables the integration of scanners, servers, workstations, printers, and network hardware from multiple manufacturers into a picture archiving and communication system.

HL7: Health Level 7. It is an all-volunteer, not-for-profit organization involved in development of international healthcare standards. HL7 promotes the use of such standards within and among healthcare organizations to increase the effectiveness and efficiency of healthcare delivery for the benefit of all. It collaborates with healthcare information technology users to ensure that HL7 standards meet real-world requirements, and that appropriate standards development efforts are initiated by HL7 to meet emergent requirements.

ISO: International Standardization Organization. It is a worldwide federation of national standards bodies. The work of preparing International Standards is normally carried out through ISO technical committees. Each member body interested in a subject for that a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work.

Java: Is an object-oriented applications programming language developed by Sun Microsystems in the early 1990s. Java applications are typically compiled to byte-code, although compilation to native machine code is also possible. The language itself derives much of its syntax from C and C++ but has a simpler object model and fewer low-level facilities.

JSP: Java Server Pages. It is a Java technology that allows software developers to dynamically generate HTML, XML or other types of documents in response to a web client request. The JSP syntax adds additional XML-like tags, called JSP actions, to be used to invoke the functionality. It lets you separate the dynamic part of your pages from the static HTML.

RIM: Reference Information Model. It specifies the grammar of HL7 messages and, specifically, the basic building blocks of the language and their permitted relationships. The RIM is not a model of healthcare, although it is healthcare specific, nor is it a model of any message, although it is used in messages. At first sight the RIM is quite simple.

SQL: Structured Query Language. It is a computer language designed for the retrieval and management of data in relational database management systems, database schema creation and modification, and database object access control management. SQL is a standard interactive and programming language for getting information from and updating a database.

XML: Extensible Markup Language. It is a general-purpose markup language. It is classified as an extensible language because it allows its users to define their own tags. Its primary purpose is to facilitate the sharing of structured data across different information systems, particularly via the Internet.

Chapter 5
Electronic Medical Prescription:
An Overview of Current Status and Issues

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ABSTRACT

Even today most medical prescriptions are typically handwritten or printed on paper and hand-delivered to pharmacists. Paper-based medical prescription is generating major concerns as the incidences of prescription errors have been increasing and causing minor to serious problems to patients, including deaths. Most of the problems of paper-based prescription can be avoided by electronic medical prescription, also variously known as electronic prescription, e-prescription, or electronic transmission of prescription. Though the basic concept of e-prescription is simple, e-prescription has not yet been widely adopted, despite advances in information and communication technologies – it is, in fact, just in early stages of adoption in a few countries only. To facilitate wider adoption of e-prescription, several technical and non-technical issues need to be addressed. This chapter presents an overview of electronic prescription. Beginning with an introduction to e-prescription, it examines various aspects of the e-prescription system, and describes and evaluates various e-prescription models and systems. The chapter then discusses technical and non-technical issues in implementing e-prescription, and concludes with our recommendations.

INTRODUCTION

Traditionally, medical prescriptions by doctors have been typically handwritten or printed by computer on paper and hand-delivered to pharmacists. Paper-based medical prescription is, however, causing increasing concern as incidences of prescription errors have been increasing causing minor to serious problems to patients, including deaths. Most of the errors of paper-based prescription could be eliminated or minimized by electronic transmission of prescription (ETP), also known as electronic prescription or e-prescription. Though e-prescription is simple and straightforward, it has not yet been

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widely adopted; it is, in early stages of adoption just in a few countries. Several technical and non-technical issues hinder its widespread adoption.

In this chapter, we present an overview of electronic prescription, providing a snap-shot of its current status and highlighting its issues and barriers. We identify the limitations of the paper-based prescription system, and describe the e-prescription system and discuss its benefits. We then present different e-prescription models and systems that are in use and evaluate them. We also examine technical and non-technical issues in implementing e-prescription, and offer our recommendations.

MEDICAL PRESCRIPTION: CURRENT PRACTICES AND THEIR LIMITATIONS

Even today, handwritten or printed paper-based medical prescription is the most common way doctors prescribe medicines to patients. In this traditional system, patients visit their heath care provider for consultation, and after assessment of the medical condition of the patient the doctor writes or prints off a prescription on a paper. The prescription is then signed and given to the patient; the patient or his/her authorized representative presents the prescription to a pharmacy of his/her choice for getting the prescribed medicines. In most countries, where pharmacies use computer-based system, the pharmacist enters the medication details into the system and gets usage labels for the drug printed. The patient or his/her representative receives the drug and signs on the prescription form confirming the receipt of the medicines.

Though the paper-based prescription system has been in practice for decades, it is susceptible for several types of errors at each step in the process. These errors are the result of a myriad of difficulties such as lack of medical information integrity and sharing, drug cross-reactivity and complications, incorrect or inadequate physicians' knowledge about the new medications, slow prescription ordering and dispensing process, security and privacy issues, lack of standardization of technologies and protocols used, and administrative and organizational issues such as pharmaceutical benefits and billing process. Incidences of prescription errors have been increasing contributing to minor to serious problems to patients, including deaths. Fatal health problems can arise due to adverse drug effect (ADE) resulting from erroneous prescription, illegibly written prescriptions, errors in dosage and unanticipated drug interactions, communication errors committed during ordering, dispensing and administering of drugs, and dosing mistakes such as incorrect dose of drug and incorrect frequency of drug intake, and lack of reliable health information.

For instance, ADE was identified to be the sixth leading cause of mortality (Lazarou et al., 1998). According to the Australian Department of Health and Aging (2006), estimated 400,000 ADE incidents occur in Australia each year. ADE related incidences occur in hospital settings due to errors in dosing or order. Estimates reveal that annually between 44,000 and 98,000 people may die as a result of medical errors (Australian Department of Health and Aging, 2006; Thomas, 2001). Medical statistics confirms that this erroneous practice happens to 2 to 7 patients out of 100. Every year there were about 150 million inquiries from pharmacies to physicians discussing prescription problems (Richards, 2003). According to the study conducted by the Institute of Medicine (Caine, 2003; Weinstein, 2005) annually around 7,000 American citizens die due to medication errors that could have been avoided if only the prescriptions were handled properly by the health professionals. The main causes of the above deaths were wrong dosage, unexpected drug reactions, lack of knowledge of the formulary slip-ups, and unreadable paper prescriptions. Additional expenses due to these avoidable mistakes account for US $77 billion every year (Caine, 2003; Weinstein, 2005).

Other problems associated with the traditional paper-based prescription system are: fraudulence; prescription pad theft and altered prescription dispensation, data integrity, administrative workload, efficiency and patient exemption/identification (Mundy & Chadwick, 2002).

So, medical prescription system needs to be improved. Electronic transmission of prescription (ETP) aims to avoid or minimize these problems and improve the efficiency of healthcare system. Research scholars, healthcare professionals, and industry leaders are advocating the switch from paper-based prescription system to an ETP system as a most effective means of addressing the problems of paper-based prescription (Australian Department of Health and Aging, 2006; Tierney, 2003). Next, we describe the principles of electronic prescription and discuss its advantages.

ELECTRONIC PRESCRIPTION

Electronic prescription, or e-Prescription, is computer-based drug prescription to patients. It is the transmission and processing of medical information electronically starting from the actual prescription of the drug by the doctor to the patient and finally closing of the transaction at some prescription processing agent (Mundy & Chadwick, 2002; Schiff and Bates, 2000). E-prescription, or electronic transmission of prescription (ETP) is defined by these sources as being: the electronic transmission and processing of medical information contained within medicinal prescriptions through all components of the prescription system, from the initial prescribing of the drugs, through dispensation to the patient, to the eventual close of transaction at some prescription-processing agent (Mundy & Chadwick, 2002). The E-prescription system checks various steps in the prescription processes such as the selection of the drug, prescription checks and information about drugs and prescriptions.

As a means of providing fast and accurate transaction processing, e-prescription is expected to be a core part of health care and national e-government infrastructure in the near future. Many of the errors of paper-based prescription discussed in the previous section are preventable (Halkin et al., 2001) and can be effectively addressed through e-prescription. Several studies confirm elimination or reduction of the errors in medical prescription as a result of adoption of ETP. For instance, a Harvard University study reports that errors in drug-prescription were reduced by around 55% when the physicians started using ETP (Richards, 2003). A study conducted by Kember Associates in UK (Mundy and Chadwick, 2002) points out that about 60% of the pharmacists trust that electronic prescription helps them to reduce the time needed for the dispensation of the drugs. About 55% of pharmacists strongly recommend e-prescription, as they were convinced that it will lessen patient time required for obtaining prescribed drugs. All these factors have paved the way for the implementation of the ETP in UK (Mundy & Chadwick, 2002). At the Harvard Hospital which has embraced the ETP, prescription errors came down from 140 to just 25 per 100 patient days, but on the whole, this form of medical error in the US result in 44,000 to 98,000 deaths annually.

Estimates on financial savings resulting from adoption of e-prescription have also been made. For instance, in Germany it is estimated that e-prescription can lead to annual savings of over 1 billion Euro (Salmivalli & Hilmola, 2006). Another study estimated that the potential savings of US $27 billion per year in the US through reduction of adverse drug events and in improved workflow (Leavitt, 2007). Implementation of e-prescription is highly regarded by advocates of e-prescription technology (Ateniese & Medeiros, 2002). The potential benefits of e-prescription systems are discussed in detail in the next section.

Advantages of E-Prescription

A fully operational e-prescription system offers a range of benefits to patients, GPs, and dispensing staff such as pharmacists and other health care stakeholders. The benefits include improved safety, prevention of abuse, efficiency, cost control, and improved delivery of health survives-cross the full spectrum of health care, from patient to medical provider to pharmacy to insurer. The benefits of e-prescription are further elaborated below:

- **Better communication with stakeholders:** The use of ETP system would enable better communication among the stakeholders such as the GPs, pharmacies and help us go paperless. The errors that arise due to miscommunication between the stakeholders can be greatly reduced by electronic communication;
- **Increased efficiency and decreased costs:** ETP can result in considerable reduction in the cost of administering the prescription. Resource savings and efficiency gains are the major benefits. This is mainly due to a reduction in the repeat prescriptions and prescription queries from pharmacies. Pharmacists will also benefit from faster payment cycles. The time saved as a result of ETP can be utilized for patient management and clinical duties. According to a study (Mundy & Chadwick, 2002), 60% of pharmacists believed that the introduction of e-prescription system would lead to time savings within the dispensation process and 55% of pharmacists believed e-prescription would result in shorter patient waiting times to get their prescribed drugs;
- **Reduced fraud:** The ETP is believed to decrease fraudulent acts in the health care service particularly through introduction of an electronic authorization and exemption system and reallocation of resource savings from ETP towards fraud reduction;
- **Reduced medication and transcription errors:** The introduction of ETP would reduce the medication errors due to illegibly written medical prescriptions. Other advantages of the ETP include decreased patient waiting time and observance of the local policies of the health care system (Mundy and Chadwick, 2003b; Bell et al., 2004);
- **Reduced overheads on repeat prescription:** The introduction of the ETP system can reduce the number of travel patients make to their GP to collect repeat prescriptions as repeat prescriptions account for an estimated 70% of the prescriptions issued by medical practitioners in the UK;
- **Improved quality:** Quality refers to conformity to prescription standards for the drugs prescribed and other data included in the prescription form such as signature, drug quantities, and drug guidance information. The ETP ascertains that transmitted prescriptions conform to prescription standards. For instance, the presence of electronic signature is always assured; otherwise, the system will refuse to accept it. Computer based prescription is found to produce a lower error rate than manual prescribing (Mundy & Chadwick, 2003a);
- **Improved medical practice:** Putting an ETP system into work will improve the medical practices performed by the medical professionals including GPs, the pharmacists and the Prescription Pricing Authority (PPA). The GPs make use of the electronic prescription system to estimate and make judgments about their practice; it helps them to reduce the instances of lawsuits, and to ensure quality in their treatment. The ETP reduces the administrative workloads of the pharmacies and enables the PPA to issue proper medical alerts to the society;

- **Improved public health:** To improve public health, in many developed countries health system constantly seeks to pursue the ETP. This will take place through greater and timely access to services and cost reductions in the form of decreased wastage and greater efficiency (Mundy & Chadwick, 2003a).

Though ETP offers several advantages, there are barriers and limitations such as patients' data privacy and security, implementation cost, legality and common standards that prohibit the widespread implementation of an ETP system. These issues are further discussed below. In the next section we review popular e-prescription models and systems.

E-PRESCRIPTION MODELS AND SYSTEMS

A few different models and systems for e-prescription have been proposed and are being used. In this section, we review them. Typical e-Prescription process is as follows: the doctor who wishes to prescribe drugs to a patient sign-in into a portable electronic gadget or to a healthcare information system to access the patient's medical records that are stored electronically. He then reviews the patient's state of health, decides on the drugs to be given and prepares an e-Prescription. Prior to prescribing the drugs, the doctor checks for any potential adverse effects of the drugs, reactions, contradictions, and allergies. The doctor also reviews the entitlements under the patient's health plan. Then the physician decides on the dosages of the drugs. The doctor can also selects the pharmacy for medical dispensing from the prearranged medical store lists and sends the prescription to the selected pharmacy via email or fax. After this, the patient collects the drugs from the pharmacy (Mandhania & Kulkarni, 2004).

Good progress have been made in related areas, such as the representation and exchange of computerized medical information (Beuscart-Zephir at al., 2004; Wang et al., 2004), and use of the Internet for online prescription and dispensation of drugs. These developments are reported in several practitioner reports and public national plans for e-prescription and quite a few countries are currently in the process of establishing electronic prescription systems. Academic research on electronic prescriptions, however, remains relatively scarce (Hypponen et al., 2005).

In the following, we outline different approaches undertaken for the ETP system. Though different countries adopt diverse healthcare systems and their objectives to implement the system are often vary, generally the key motivations and reasons for implementation of ETP remains the same: reduction of medication errors and improving efficiency.

Status of E-Prescription

Electronic prescription has been practiced or piloted in several countries. For instance, in some States of the USA electronic prescription systems have been in use for the last few years. Users of e-prescription have been small cluster groups of selected physicians and pharmacies who have all been signed up to the same system provider (Mundy & Chadwick, 2002). A review report (BJHC Report, 2007) shows that only about 9% of hospital in the US ha computerized prescription system. Some hospitals have stand-alone systems, while others have computerized prescriptions as part of an electronic medical record system. Some systems send prescriptions by fax or e-mail, and these systems do not entirely fulfill the definition of electronic prescription system that we use (Mundy et al., 2003).

In the UK, the government has been reforming the National Health Services (NHS) and has modernized NHS IT systems at a cost of £6.2bn (NHS Statistical Report, 2007). As part of the

plan a system for electronic prescription has been implemented. As a result, millions of prescriptions have now been transmitted electronically. Legislation allowing the electronic transmission of prescriptions was approved in 2001 and after that the health services commissioned three pilot programs which we will discuss later in this chapter. Finland also uses electronic prescription. Currently, about 90% of major health care units and about 30% of second grade health care units are making use of the system (Sugden & Wilson, 2004; Boonstra, 2003). Moreover, the Finnish GPs are making use of telemedicine systems to obtain access to patient medical data through telephone inquiries.

The Netherlands commissioned a project on electronic prescription support system in 1999. Primary goal of the project was to improve the quality of prescribing in general practice, and secondary goal was to establish a reduction in the cost involved with general practice prescriptions. According to Boonstra (2003), this system, however, was a failure and was not widely accepted by its users, GPs. In Denmark an e-Prescription system called MEDPRE has been in operation since 1995. Until 2005 about 35% of prescriptions were sent electronically (Mundy & Chadwick, 2002). Patients are given the choice to select their preferred pharmacies for getting the prescribed medicines and the Danish GP sends an e-copy of the same prescription to the patient's preferred pharmacy.

In 1995 an e-Prescription system called PharmaNet was introduced in British Columbia, Canada. Similar projects such as WellNet and a smart system for Health, ePhysician (Cornwall, 2002), have been established. The Australian government has also opened the door for implementing e-prescription system by implementing changes to National Health (Pharmaceutical Benefits) Amendment Regulations 2006. Work is currently underway to develop a key standard, to finalize jurisdictional legislative amendments, and to establish a national health information regulatory framework. Currently a small trial is being undertaken in Darwin that is being conducted in an aged care setting (Australian Department of Health and Aging, 2006).

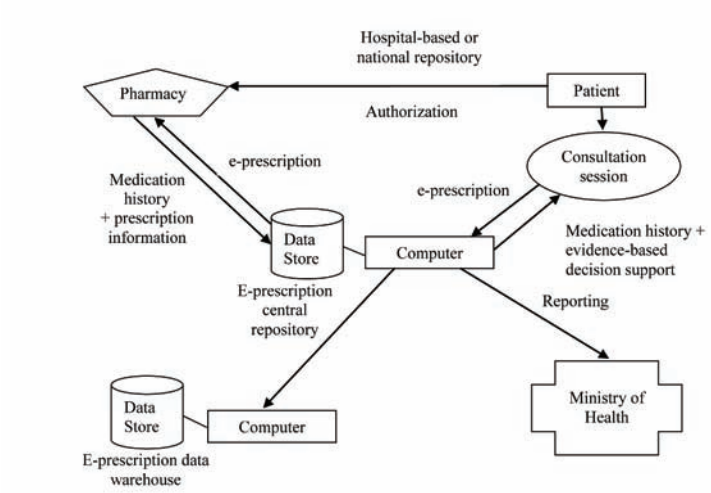
Computer-based messages can be electronically manipulated, stored and combined with other information and transmitted through telephone wires or wireless networks. Email is tied into the system that runs the business-data base, data warehouses, enterprise resource planning, internet commerce and customer support. Many states and private health care organizations are issuing smart health cards that contain the card holder's health history, emergency data and health insurance policy details. The smart cards contain a microprocessor (chip) and can store a considerable amount of information and can conduct processing. Smart cards are being used to transport data between computers replacing floppy discs. Adding a small transmitter to a smart card can allow businesses to locate any employee and automatically route phone calls to the nearest telephone.

Pilot Models of E-Prescription

An e-prescription service scoping model (Mundy & Chadwick, 2002) which characterizes face-to-face interaction between the patient and the physician as well as the use of workstations is presented in Figure 1. The pilot model also includes the use of smart card and electronic kiosk technology for patient authorization to pharmacists and for the patient's access of the e-prescription repository. Prescriptions made by physicians can be verified by the Ministry of Health. As smart cards contain all the information and details of a person's identification and data, they can be used for verifying identification of the patient being authorized by the GP.

As the success of e-Prescription models depends on security measures such as authentication, access control, confidentiality, and encryption, a high level of honesty and commitment by the provider is needed in order to gain the trust of the

Figure 1. E-prescription service scoping model



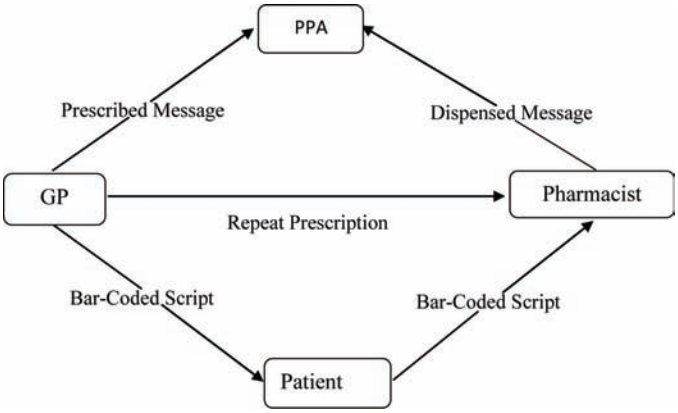
patients. The confidentiality of data means that only authorized individuals could access, decode, encrypt, decrypt, and read the data stored. Incorporating computer security mechanisms, as early as 1997, the UK NHS piloted three ETP models (Murthy and Manoj, 2004; Sugden & Wilson, 2004) - Transcript Consortium, Pharmacy2U Consortium, and SchlumbergerSema Consortium (Flexiscript) - which are briefly discussed below.

Transcript Consortium Model

The Transcript Consortium model shown in Figure 2 uses a two-dimensional barcode on a paper prescription that the patients deliver to a pharmacy of their choice. Bar-coded prescriptions contain the prescription data and digital signature. The pharmacist scans in the barcode, validates the digital signature, and dispenses the drugs. In acute cases the patient is issued with a bar-coded script which the patient uses to obtain their medication from any pharmacy. For repeat prescriptions, the patient must nominate the pharmacy from where he/she wishes to collect their medications. The GP sends a prescribed message to the PPA electronically and in the case of a repeat prescription, prescription data is also sent to the pharmacist by email. On arrival at the pharmacy, repeat prescriptions are ready for collection by the patient. In acute cases, the patient hands over the bar-coded script to receive his medications. The pharmacists send a dispensed message to the PPA electronically for payment after dispensing the prescribed drugs to the patient. The PPA makes payments to the pharmacy based on the dispensing messages and paper prescription forms received for that dispensing period. The PPA issues prescribing information based on the electronic messages and paper prescription forms signed by the GP.

Several methods and mechanisms are used to fulfill the security requirements. One of the primary mechanisms is encryption. An encrypted message is sent to the PPA. The patient then gives the e-prescription to the pharmacist of his choice who would scan the bar-coded paper and dispense the prescribed medicines to the patient, while simultaneously sending the prescribed prescription to the PPA. The health agency then stores and uses every message received from the pharmacy as reference for its future payment and to the prescriber to give feedback regarding the prescription. The advantages of this model are that it:

Figure 2. Transcript consortium model



- Uses digital signature that prohibits duplication of e-prescription plus a unique number and a validity time. Repeat prescription will have a unique number;
- Partially protects against fraudulent claims of lost prescription since patients are not given a prescription except in acute cases where patients are provided freedom for pharmacy selection for their prescribed medication.

The model has, however, the following disadvantages:

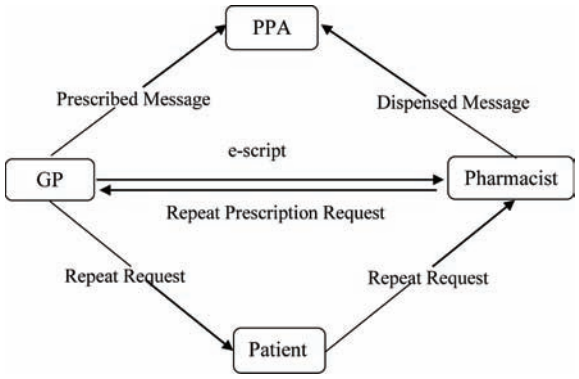
- As no authorization system is included, confidentiality is low; even unauthorized users can access the system;
- Patients can't change their chosen pharmacy for dispensing drugs;
- The software of the model prevents prescription duplication. However, duplication prevention may not be consistent from time to time.

The Pharmacy2U Consortium Model

The Pharamcy2U model, shown in Figure 3, uses direct messaging from the GP to the nominated pharmacy for repeat and acute prescribing. The decision as to which pharmacy would be chosen is the privilege of the patient, which is often influenced by the proximity of the pharmacy to the patient's residence, or other personal reasons. The chosen pharmacy is discussed and agreed upon during patient's consultation with his/her physician. After the consultation, the GP sends a prescribed message to the PPA and prescription data to the pharmacist. Both are sent electronically. Acute and repeat prescriptions are ready for collection by the patient at the nominated pharmacy. If a patient requests a new repeat prescription, the pharmacist passes this information on to the GP, who verifies, electronically whether the patient is eligible to receive the medication. The pharmacist dispenses the medication to the patient. The pharmacist sends a dispensed message to the PPA electronically for payment. The PPA makes payments to the pharmacy based on the dispensing messages. The PPA issues prescribing information based on the electronic messages.

The advantage of this model is that it uses digital signature that prohibits duplication of e-prescription plus a unique number and a validity time. Repeat prescription will have a unique number. This model has, however, the following disadvantages:

Figure 3. Pharmacy2u consortium model



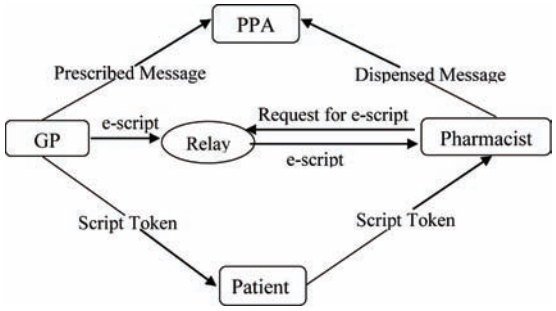
- Patients can't change the chosen pharmacy. The GP encrypts the prescription only for the first chosen pharmacy.
- The software for the model prevents prescription duplication. However, duplication prevention may not be consistent from time to time.
- This model partially protects against fraudulent claims of lost prescription, since patients are not given a paper-based prescription.
- It uses one directory server to store all users' public key certificates for both encrypting and validation of signatures.

The SchlumbergerSema Consortium Model (Flexiscript model)

The SchlumbergerSema Consortium model, shown in Figure 4, works as a relay approach as the prescriber sends a digitally signed encrypted prescription to a prescription data store. An electronic script is forwarded to the relay. The GP also sends electronically the prescribed message to the PPA.

This model also gives paper prescription with an identification number and barcode of the digitally signed prescription to the patient. The patient presents the identification (ID) number to the pharmacist to retrieve the data from the data store. The data store decrypts and re-encrypts the data code upon the pharmacist's demand. The barcoded script is presented to the pharmacist when the medication is collected. On verification, the pharmacist dispenses the medication to the patient. The pharmacist sends a dispensed message to the PPA, electronically, for payment. The PPA makes payment to the pharmacy based on the dispensing messages and paper prescription forms received for that dispensing period. The PPA issues prescrib-

Figure 4. The SchlumbergerSema consortium Model



ing information based on the electronic messages and paper prescription forms signed by the GP. The advantages of this model are:

- It uses digital signature that prohibits duplication of e-Prescription plus unique number and a validity time. Repeat prescriptions will have unique numbering;
- A duplicate prescription with the same unique number is automatically rejected by the system.

This model suffers from the following disadvantages:

- As no authorization system is included, confidentiality is low because unauthorized users can access the system. Prescription is encrypted for the central store, but is decrypted there after the patient has chosen the pharmacy. Hence, anybody who has access to the central store, and pharmacists, can view the patient's health data. However, access is blocked if a specified number of attempts are used up;
- Not enough documented information to justify its initiatives to stop fraudulence against duplication;
- Has only one prescription store where all prescriptions are stored whose, malfunction, therefore, makes the whole system fail. Uses only one private key server where prescribers must download their signature keys before prescribing.

In addition to the above 3 UK NHS Pilot systems, a fourth system, called the University of Salford ETP model has been proposed.

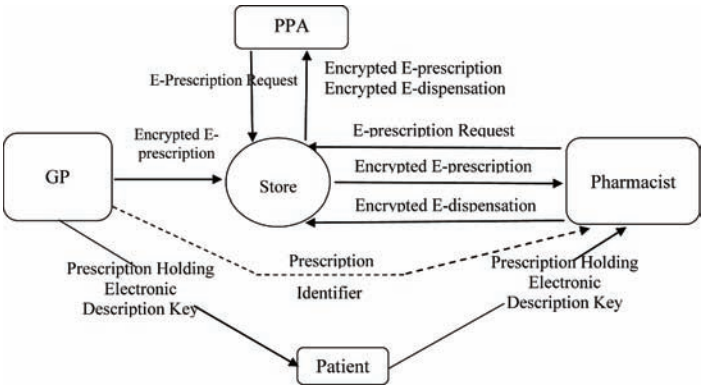
The University of Salford ETP Model

The Salford model, shown in Figure 5 and designed by the University of Salford (Mundy & Chadwick, 2002), works as a relay system just like the SchlumbergerSema Consortium model. After the physician digitally signs the prescription, it is automatically sent to the prescription store. It contains a symmetric key encrypted code for PPA retrieval and decryption. The patient is then given a paper copy of the prescription together with a reference barcode, and a symmetric key barcode to retrieve and decrypt the prescription in the prescription store. The patient would have to bring and hand over the prescription to the chosen pharmacy so that the pharmacist could dispense the medicine after decryption, and send the data to the PPA and to the prescription store. From time-to-time, the PPA retrieves dispensed and indisposed (expired) medicines for the prescription store.

If a patient prefers a pharmacy of his choice, the physician sends an e-mail message to this pharmacy together with the encrypted code for the latter. This would allow fast and easy retrieval of the prescription even before the patient would claim it from the pharmacy. The system could be utilized for repeat and new prescriptions. Also, when a patient claims a free prescription this model could automatically check it, which eases the pharmacist's responsibility. The advantages of this model are:

- High security authorization embedded in the system;
- Provides freedom of choice to patients up to the time of dispensing, without sacrificing confidentiality;
- Uses digital signature that prohibits duplication of e-prescription plus a unique number and a validity time. Repeat prescription will have unique number;
- Duplicate prescriptions with the same unique prescription are automatically rejected by the system;
- Locks the prescription records, and automatically sends a message to patient stating that the needed prescription has been dispensed. Hence, it prevents the pharmacist

Figure 5. University of Salford ETP model



from dispensing same prescription and also prevents the patient from claiming that no dispensing has been made. This reduces fraudulent prescriptions;

- Uses a prescription store which is planned to be configurable. The system is widely available so that any number of prescription stores can be utilized, up to one per prescribing doctor if needed. This eases accessibility.

Of the four e-Prescription pilot models described above, it seems that the Salford model has a high level of security and is a better model than the other three models for the following reasons:

1. By implementing the Salford model, the Healthcare authorities can prevent unauthorized access of medical data/records and misuse of it as high security authorization is imbedded in the system;
2. In this model, patients have freedom to select pharmacies up to the time of dispensing without sacrificing confidentiality;
3. Thirdly, this system, to a great extent, will curtail the misuse of fraudulent ways of obtaining prescription medicines because digital signature of the GPs in the system prohibits duplication of e-Prescription. As double safeguard, the system has a unique number and a validity time for the prescriptions;
4. Duplicate prescriptions with the same unique number are automatically rejected by the system;
5. The system uses a prescription store which can be configurable. Due to this the chance of data getting lost is low. It also helps in easy access.

Though the above model has a number of potential benefits, it is not flexible enough to provide the service information availability at the point of care with the patients on frequent travel who may need to visit doctors in different cities or even countries; some patients may need to seek appropriate medical treatment beyond local facilities. This difficulty can be minimized by adoption of other models presented here using a smart card (Zoreda & Oton, 1994; Yang et al., 2004; Anderson & Balas, 2006) containing the medical and insurance information, which the patient can always carry around. It is apparent that the introduction of this technology would significantly simplify the process of drug precipitin as it enables the doctor to bypass several bureaucratic and time-consuming procedures if they needed to get access to required information from central databases. More over, the smart card technology

would relieve the doctor from the inconvenience and annoyance caused by the occasional blockage of network traffic. On the other hand, the patient could deliver the smartcard, which the pharmacists could use to decrypt and to extract the prescriptions.

In addition to being a data storage device, the smart card enables the patient to sign electronically the electronic prescription pads, declaring the patient's authorization to the prescription so as to collect the prescribed medicine (Yang et al, 2004). This proof of authorization will be used by the pharmacy to collect payment from the patient's health plan account administrated by the corresponding insurance organization.

Recent developments in telecommunication technology such as the General Packet Radio Service (GPRS) and Wireless Fidelity (WiFi) have enabled ubiquitous interconnectivity, access to the Internet and World Wide Web, and opened up a realm of new possibilities for more flexible e-prescription solutions. As a consequence, more recently, e-prescription solutions that are wireless based have been piloted. Thus, solutions based on smartcard, where repeat prescriptions are transmitted wirelessly to the patient's doctor (Bobbie et al., 2003), have been piloted as point-of-care systems. In this system, prescriptions are written on a personal digital assistant (PDA) at the point of care, and transmitted wirelessly to a predefined pharmacy (Ki´el & Goldblum, 2001).

All these wireless solutions suffer from one or both of the two major drawbacks (Ghinea et al., 2006). First, they are not generic (they suited for specialized scenarios, such as repeat prescriptions, where problems encountered in the more general case of prescribing medicine, such as potentially toxic drug interactions do not occur). Secondly, they are not truly ubiquitous since they involve only wireless data upload, in a given, localized, setting, such as surgery or the patient's home, with all subsequent data communication taking through a wired medium. To address these limitations, they have developed a wireless prototype solution for an ETP based on Jini technology (Knoll et al, 2000) to enhance the prescription services to clinicians and patients alike. Jini is a service-oriented framework that enables the entities in a distributed environment to define, discover, and advertise their services in a robust and impromptu manner (Sun Microsystems, 1999). According to Ghinea et al, (2006), this solution is more secure, and ubiquitous; and was highly rated by both clinicians and users.

E-PRESCRIPTION: ISSUES AND BARRIERS TO IMPLEMENTATION

Earlier we identified key barriers and limitations of ETP that hinder its widespread implementation. Compared to other industry sectors, such as finance and commerce, the adaptation and integration of information technology in the health sector is unfolding much more slowly (Thomas, 2001). According to Leavitt (2007) in the USA in any given year physicians write over 3 billon prescriptions; however, only 5 to 18% of physicians use e-prescription. The Institute for Safe Medication Practices (ISMP) reports that less than 5 percent of US physicians prescribed electronically in the year 2000 (American Institute for Safe Medication Practices, 2001). Another study (Spil et al., 2004) reveals that in the Netherland less than 28% of the GPs use ETP. A more recent survey conducted by the Harvard School of Public Health (Anderson, 2007) found that use of e-prescription by primary care physicians was 9 percent in the USA, 8 percent in Canada, 44% in Australia, 52% in New Zealand, and 87% in the UK.

These findings clearly indicate that despite the potential benefits of ETP, the acceptance or adoption rate of this system has been very slow. This raises a legitimate question: why ETP systems are not being implemented on a wider-scale globally. In this section we address this question by discussing the perceived potential barriers to implementing ETP.

Issues and Limitations of E-Prescription

There are a number of obstacles for the implementation of an e-prescription system. They include:

- **Threat to privacy and security.** One of the most talked about barriers is the threat to privacy and security of patient information. Some fear that hackers might be able to crack personal medical information that would eventually leak to the public. The professionals using computerized systems doubt whether the companies making the e-prescription software are giving adequate importance to the security of the patient medical information stored in the system and accessed by different stakeholders. There are possibilities for the misuse of the system. The companies designing the ETP system must take appropriate measures to ensure adequate security of patient information and to make abuse of the system extremely hard;
- **Commitment of senior management and clinician.** Another barrier is the lack of commitment of senior management and clinicians to the e-prescription system. Positive attitude of the users of ETP system are key to the successful implementation and use of the systems. Those who are used to the traditional paper-based systems might obstruct the implementation of electronic prescription. Some of these people still prefer the traditional paper based prescription and some others have teething troubles in adopting the new technology (Mundy & Chadwick, 2003a);
- **Cost of transformation.** Changing from the paper-based prescription into an e-prescription is expensive due to the fact that purchasing costs of hardware and software needed to implement the program could be high. According to industry estimates, even the basic e-prescribing machinery costs from USD1500 to USD4500 per physician. On the other hand, advanced systems that offers features like alerts and reminders will cost around USD29000 per doctor in the initial year and USD4000 annually thereafter. An average complete EMR system costs about USD2500 per license with a yearly fee of USD90 per license for quarterly updates of the drug database after setup costs. A majority of health professionals are unwilling to embrace the new technology due to the high total cost of implementation (Ateniese & Medeiros, 2002; Mundy & Chadwick, 2003a; Bell & Friedman, 2005; Corley, 2003);
- **Legality.** Legal issues surrounding e-prescriptions should be understood and addressed adequately. Fraudulent on-line pharmacies issuing drugs to the patients without valid prescriptions from doctors are currently rampant. In fact, a study on internet pharmacies (Mundy & Chadwick, 2003b) reports that 19.6% of them dispensed prescriptions without a legitimate physician consultation and approval. Another study (Fung et al., 2004) reveals that about 13% of online pharmacies have been giving medications without a genuine doctor's prescription. Another report shows that some states in US still have regulatory barriers to electronic transmission of the prescription (eHealth Initiative Report, 2004);
- **Technicality.** The introduction of e-prescription system requires that stakeholders – doctors and pharmacists - to acquire basic computer hardware and software needed to run the system. These systems should also be able to access the database needed to decode the messages contained in e-prescriptions. Unfortunately, even the basic computers are not available in many pharmacies, placing the adoption of

E-prescription in question. System complexity and compatibility is also a major concern and barrier. A survey found that 86% of the physician surveyed stated that vendor's inability to deliver acceptable products as a significant barrier to implementation of IT in their practice (Anderson et al., 2006). Interoperability represents a major problem as there are many vendors offering incompatible systems. Standardization in ETP development is particularly a major concern in US where IT adoption decisions are made independently and there are a few if any incentives to share information concerning patient care (Schiff & Bates, 2000). Another study shows that ETP system has not been embraced by the stakeholders for inconsistencies and complexities between ETP products (Laura & PharmD, 2005);

- **Barriers in implementation process.** Developing e-prescription software is challenged with many issues: local adoption, ease of use, system flexibility, and health professionals' support. Designers, implementers and users of e-prescription system should not compromise on their dedication, commitment, honesty, credibility, and expertise. Unfortunately, there seems to be absence of these values among some people currently working in the process of implementation are supposed to possess. Moreover, there are no effective systems to monitor the avoidable harmful effects that could result from such implementation (Ateniese & Medeiros, 2002; Anderson, 2007; Sarasohn-Kahn & Holt, 2006);
- **Professional and patient issues.** The stakeholders of e-prescription are not properly educated on the many benefits of e-prescription and on the precautionary measures they should take. There are no concerted efforts to empower the stakeholders. Physicians are reluctant to take up the technology and are very slow in integrating the system into their workflow. Studies indicate that only 14% of doctors are using any of the e-prescription tools. Only half of the GPs are aware of the benefits of the system according to the US National Audit Office (NAO), and 61% are pessimistic about the plan (National Audit Office Report, 2005). Some of the reasons for the stated pessimism are: doctors' hesitancy or shyness to incorporate the technology into their work, extra work, lengthened consultation hours, and doubts that current health disparities will be increased. A number of doctors only see the financial benefit of the other stakeholders such as the pharmacies or prescription processing agents, being largely ignorant about the benefits they are going to reap. Due to protection and confidentiality issues, a number of patients simply do not find the system practicable. This is due to their unfounded fear that technical malfunction might happen anytime and their medical records will get affected or unsecured;
- **Difficulty of marketing.** The marketers of the e-prescription system find it very hard to sell it especially to small and middle-range GPs for they view its application as highly expensive; hence they could not afford it. A Deloitte Research survey indicates that 96% of GPs who are comfortable using the Internet on a daily basis do not feel the same when it comes to working on the e-prescription program, for they think that it will increase their administrative workload (Mullich & Paul, 2001). The stated problems aggravate the marketing difficulties of the e-prescription system. More so, unstable market conditions constrain the GPs from spending time, money and effort in adopting the system (Kilbridge & Gladysheva, 2001).

Overcoming Barriers to Implementation

To fully and successfully embrace e-prescription the barriers discussed above must be resolved satisfactorily. Introduction of the technology in a sector like healthcare involving many different stakeholders is not an easy task. Nevertheless, the stakeholders should take powerful steps to surpass the perceived barriers. We recommend the following measures to overcome the major barriers:

- **Overcoming Privacy and Security Issues.** The stakeholders as well as the patients who are advocates of e-prescription should brainstorm about the measures to resolve the privacy and security issues. In protecting the privacy of the patient's health records, smartcards, discussed earlier, are playing a vital role. The introduction of smart cards contributed to the development of e-prescription. The smartcards that contain the current and updated personal medical data, surgery and insurance information, and other relevant health data can be carried by the patient themselves. Another way of keeping the confidentiality is by using a barcode system. The barcode contains symmetric key to encrypt the e-prescription. Another method to reserve the privacy of a patient is to apply a pseudo name from his insurer and to sign the prescription under that pseudo name (Mundy & Chadwick, 2003a; Ball et al., 2003; Mundy & Chadwick, 2003b);
- **Commitment of Senior Management and Clinicians.** It is crucial that senior professionals and clinicians should possess the right attitude to put this venture into widespread practice. Information dissemination is important so that the senior management and the clinicians using the system will be aware of the major benefits that they and other stakeholders will enjoy when the system becomes operational. They can be educated about the reduction in administration workload, clerical work and above all, the substantial reduction in medication errors and saving of time that could be achieved by the adoption of the system (Mundy & Chadwick, 2003a);
- **Overcoming Cost of Transformation.** A marketing strategy of short-term free trials could be taken in order to introduce the system to target stakeholders. Certain incentives could be offered in order to motivate physicians to apply the new system. Once the system is introduced to physicians, implementers could take advantage of the opportunity in convincing the doctors that the cost of technology supersedes the benefits stakeholders could derive from it (Mundy & Chadwick, 2003a). For example, New Zealand, Australia and the U.K. that have introduced government funding programs to stimulate adoption and use of EMRs (Harris Interactive Health Care Report, 2001);
- **Financial Incentives.** These may also accelerate adoption of ETP and other IT applications. In US, a number of purchasers, health plans, and employers are initiating a quality-based reimbursement program (Bates, 2005). These programs reward practices for specific quality improvement actions or use of specific IT applications. Similar programs have been implemented in some other countries as well;
- **Legality.** Government support is highly needed in order to implement e-prescription systems. In many countries their legal systems present barriers to IT adoption in health care. For example, in the US, various laws related to fraud and abuse, antitrust, federal income tax, intellectual property, liability and malpractice and state licensing create a climate of uncertainly for

health care providers in implementing IT (U.S. Government Accountability Office, 2004). In the US, only 39 states legally support an e-prescription system, while other states are trying to take off the unfavorable legislations that prevent the implementation of e-prescription system By-laws should be drafted in favor of e-prescription and its stakeholders. For example, the Australian Government has removed Commonwealth legislative barriers to electronic prescribing and dispensing of medicines by implementing changes to the National Health (Pharmaceutical Benefits) Amendment Regulations 2006. UK government has approved legislation to implement e-prescription in 2001;

- **Technicality.** Technical issues should be satisfactorily addressed. Standardization for the ETP products and electronic transmission is necessary to overcome some barriers of wide-spread adoption of ETP systems. Certification of vendor's applications for more uniform products with user-friendly interfaces may help to accelerate implementation of ETP. In the United States, consistent appraisals of the system are taking place, with hundreds of physicians giving their valuable feedback. An e-prescription software provider, OnCallData, has been religiously revising the e-prescription database every week following the advices of the customers (Hypponen et al., 2005).

E-PRESCRIPTION IMPLEMENTATION STRATEGY

The introduction and utilization of e-prescription is an enormous task as far as logistics and distribution are concerned. While implementation is taking place, maintaining patients' safety and choice are of paramount importance. In order to achieve this, implementation in four phases has been proposed in (Connecting for Health, 2005).

Implementation Phases

Implementing e-prescription in different phases would prepare the users to become familiar with the system and reduce errors in implementation and use. We are used to paper-based prescription for getting medicine from the pharmacy. Hence, making our health data accessible to every healthcare professional could be a scary and stressful thing to imagine. Our health record is confidential and we want only we or the few chosen people to have access to its information. Any unauthorized person accessing our health data could also disconcert patients who deeply care about the security and confidentiality of their medical records. Therefore, phased approach for implementation is highly recommended.

Every phase gives light to its introduction to stakeholders. It specifically educates and prepares not just the stakeholders, but more so the creators of the system in order to properly develop, implement, and maintain it. Each phase could give more time to its creators to re-evaluate every stage for validation purposes; hence, errors could be minimized or be avoided and benefits would be maximized.

There are two releases of software used in the implementation of ETP. Under Software ETP release 1, the phases involved are the initial implementers (phase 1) and the nationwide deployment (phase 2) while the transition (phase 3) and full ETP deployment (phase 4) are under ETP release 2. The objectives of the former are to verify the technical stability and safety of the system, while comparing it to the usual prescribing and dispensing method. This would guarantee that full potential of the system is being maximized as far as its benefits are concerned and potential hazard would be avoided.

Phase 1: Initial Implementation

The initial implementation, or phase 1, is done by a live trial using a paired GP and pharmacy sites.

It could then be reviewed by the two participants for comments, suggestions, and advice. After all, aside from the patients, they are the direct users of the system. Hence, it would be more practical if several such trials can be done by the mentioned players.

Phase 2: Nationwide Implementation

Nationwide deployment aims to maximize utilization of the system on a number of locations. During the first two phases, functionality is evaluated, although no digital signing would be made yet. The usual prescription paper would have a barcode that should be scanned whenever purchase is being made. The bar-coded prescription could be taken to any pharmacy for dispensing, regardless of whether the pharmacy is using the system or not.

Phase 3: Transition

The main objective of the third phase is to bring e-prescription in lieu of the paper-based prescription. Digitally signed prescription is utilized, patient can freely nominate a preferred pharmacy, and the electronic reimbursement is provided. However, paper based prescription would still be needed in some instances. Please take note that education and training of its users have to be implemented in this phase. The PPA will make the reimbursement for every electronic prescription dispensed.

Phase 4: Full ETP

Full ETP stage expects that majority of its users operate the new system, and minimize the paper prescription. A digitally signed prescription must take place during this last phase which completes the implementation service.

CONCLUSION

E-Prescription promises to offer several benefits to its different stakeholders. It will, to a great extent, reduce the problem of medical and transcription errors if implemented properly. Information technology has already brought about major improvements in healthcare delivery, ranging from better and faster diagnoses to expedited research and development of new drugs, to more accurate monitoring of critically ill patients and many more. Implementation of the ETP system will add to these services and provide a platform for overall implementation of e-Health.

In this chapter, we have presented an overview of electronic prescription. While a number of pilot projects have demonstrated electronic prescription's potential for enhancing the effectiveness and efficiency of health care services, there are a number of technical and non-technical issues that need to be addressed for rapid wide-scale adoption of it. There is no simple solution to accelerating its adoption and use for quality improvement. Given the multifaceted nature of the barriers, a range of policy incentives will help speed up ETP. Interoperability and open standards are key factors for successful adoption of ETP systems. To reduce the cost and facilitate easy implementation, an ETP system should adopt prevailing information infrastructure and telecommunication capabilities in the health care industry.

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KEY TERMS AND DEFINITIONS

Adverse Drug Effect (ADE): refers to is a harmful and undesired effect resulting from a medication and it is called also as "side-effect" meaning secondary to a main or therapeutic effect. It could be due to medical error such as an unsuitable or incorrect dosage and/or drug. Adverse effects may cause medical complications of a disease or procedure and negatively affect its prognosis. Adverse effects may cause a reversible or irreversible change.

Electronic Medical Record (EMR): is medical or health record of a person in digital format. It is a systematic documentation of a patient's medical history and care. As medical records are intensely personal documents, there are many ethical and legal issues surrounding them such as the degree of access by third parties including doctors, emergency services and other stakeholders, appropriate storage and disposal, and implications of hacking into medical records and inappropriate use.

Electronic Transmission of Prescription (ETP): is the transmission of medical prescriptions from doctors (or other prescribers) to pharmacies and other dispensers and/or electronic notification to the reimbursement agency.

E-Prescription: is the electronic transmission and processing of medical information contained within medicinal prescriptions from the initial prescribing of the drugs, through dispensation to the patient, to the eventual close of transaction. E-prescription system checks various steps in the prescription processes such as the selection of the drug, prescription checks and information about drugs and prescriptions.

Medical Prescription: is an order by a qualified health care professional to a pharmacist or other therapist for a treatment to be provided to their patient. It is a legal document which instructs the preparation and provision of the medicine and the prescriber (person who writes the medical prescription) takes responsibility for the clinical care of the patient and the outcomes of the prescription.

Chapter 6
Data-Mining Techniques for an Analysis of Non-Conventional Methodologies: Deciphering of Alternative Medicine

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ABSTRACT

Some common methodologies in our everyday life are not based on modern scientific knowledge but rather a set of experiences that have established themselves through years of practice. As a good example, there are many forms of alternative medicine, quite popular, however difficult to comprehend by conventional western medicine. The diagnostic and therapeutic methodologies are very different and sometimes unique, compared to that of western medicine. How can we verify and analyze such methodologies through modern scientific methods? We present a case study where data-mining was able to fill this gap and provide us with many tools for investigation. Osteopathy is a popular alternative medicine methodology to treat musculoskeletal complaints in Japan. Using data-mining methodologies, we could overcome some of the analytical problems in an investigation. We studied diagnostic records from a very popular osteopathy clinic in Osaka, Japan that included over 30,000 patient visits over 6 years of practice. The data consists of some careful measurements of tissue electro-conductivity differences at 5 anatomical positions. Data mining and knowledge discovery algorithms were applied to search for meaningful associations within the patient data elements recorded. This study helped us scientifically investigate the diagnostic methodology adopted by the osteopath.

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INTRODUCTION

Growing acceptance of alternative medicine by the public has convinced third party organizations to increase the level of insurance coverage and has caused the U.S. Congress to rule for establishment of the National Center for Complementary and Alternative Medicine (NCCAM) at the National Institutes of Health (NIH) (Jonas, 1998; Nahin & Straus, 2001). However, these methodologies are still considered largely unsubstantiated by many practitioners of conventional western medicine. The problem many of these investigators are faced with is the difficulty in performing trials of an intervention not based on clinical practice as well as trials of multifaceted interventions that are too complicated for a conventional study design (Miller et al, 2004; Lewith, 2003). Can data-mining help explore non-conventional methodologies such as those used in alternative medicine in the light of science? NCCAM has been seeking the advice of the scientific research community in this regard.

Western medicine has benefited from inquiry into non-traditional healing practices whether it has been through the study of chemical agents or through the study of physical modalities like acupuncture. Complimentary/alternative medicine (CAM) is gaining more popularity in the US, Europe, Australia and elsewhere (Eisenberg et al, 1998; Cassileth et al, 2001). Probably the popularity of complementary /alternative medicine has increased because of some dissatisfaction with modern medicine or with the economics of clinical care surrounding the management of ill-defined chronic conditions (Imanishi et al, 1999). The following classification has been suggested for the main CAM modalities (Gordon et al, 1998): manual therapies (e.g. chiropractic, osteopathy, acupuncture, acupressure, and massage), oral therapies (e.g. herbal medicines, homeopathy, diets, and vitamins), mind–body therapies (e.g. meditation, relaxation, biofeedback, and hypnosis), movement-based therapies (e.g. Tai chi), and support therapies (e.g. counseling, support groups, prayer, and other religious practices). Manual therapies are by far the most widely used CAM modalities (Koes et al, 1992; Eisenberg et al, 1993; MacLennan et al, 1996; Astin, 1998; Druss & Rosenheck, 1999). Although there are many issues that arise in categorizing the use of diagnostic modalities as western versus non-western, we will not concern ourselves with such classification issues in this paper any further

BACKGROUND

In Japan, Chinese herbal medicine (kampo) which was originally introduced in the 5th and 6th century has been significantly modified by Japanese practitioners over a long time. Kampo was excluded from authorized medical practice about 100 years ago but is still, along with acupuncture, electro-acupuncture and moxibustion widely practiced and popular. In Japan, non-western medical treatments are sought for various ailments and illnesses in spite of the fact that medical practice in Japan is one of the most advanced in the world.

Modern osteopathy was probably started in the late 1800s by an American physician called Andrew Still. Osteopathy is now a quite established profession in the U.S.A. with many osteopaths diagnosing and treating medical problems using manual touch. They get training on how to feel (through palpation) the body´s anatomy, the texture and motion of tissues, the flow of fluids and its structural makeup. In osteopathy, the body´s innate power to heal itself is emphasized, and it is believed that previous physical trauma leaves its touch on the body's structure. The osteopaths generally try to develop a strong sense of touch to detect physical problems, and to apply the exactly right amount of pressure to treat dysfunction in the motion of the tissues, restore movement of fluids and to release compressed joints and bones.

In Japan, a particular type of osteopathy that has its roots in the martial arts practice of Judo

is also widespread and in contrast to most other non-conventional medical practices has achieved acceptance into the medical health system. In fact, some alternative practices in this area are recognized by the national health program and are covered by insurance plans. There are many schools of thought in osteopathy and some practitioners develop their own unique way of palpation and detection of anatomical problems.

We were informed of a very popular osteopathy practice in Osaka, Japan which also kept electronic records of the patients on their computers. Therefore we contacted the main practitioner and got an opportunity to visit the practice, hear about the methodology of examination and diagnosis, and also collect the large amount of recorded data. We also explained our data mining methodology and the fact that we were interested in a non-biased study of the data and any patterns of associations among them which could help decipher the methodology and make it more understandable to conventional care. The sorts of data that were available and their way of interpretation will be explained in the following sections.

The data gathered consisted of electro-conductivity measurements taken at five anatomical positions which include the neck, armpits, wrists, knees, and ankles. These recordings were used as a diagnostic tool by the osteopath practitioner to isolate the primary problem area of the patient. The practitioner would take readings from the right and left side of the patient at each of these five locations and would consider the measures of difference between the left and right at all locations in one series of recordings. The location which showed the greatest imbalance would be deemed as the initial problem location. From that location, the practitioner would approach to introduce "energy" and physical manipulations to help the patient.

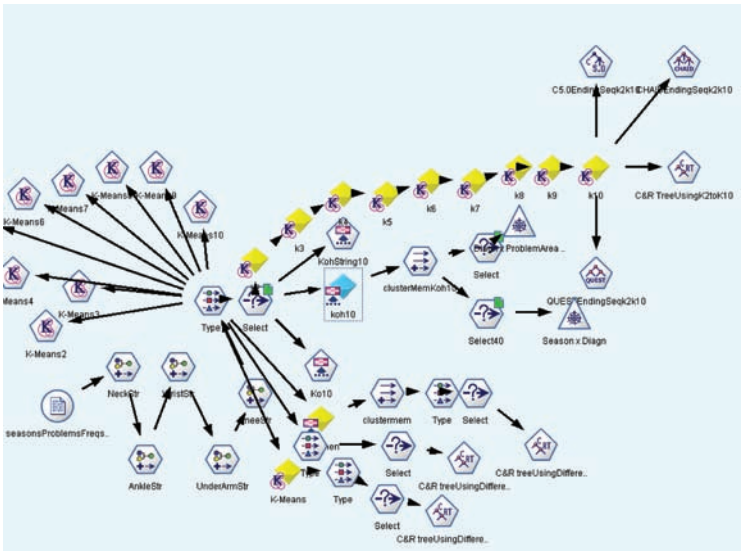
Although our efforts fell short of clinical verification, we were able to identify useful patterns using self organizing maps, decision trees, and association and sequence rule mining approaches. We also studied the attributes of a considerable number of users of osteopathy services which can be useful in the delineation of the social position of this alternative medicine modality in Japan.

DATA MINING METHODOLOGY

We explored the data using self-organizing maps (SOM) and web graphs. A self-organizing map (SOM) is a type of artificial neural network that is trained using unsupervised learning to produce a low-dimensional, discretized representation of the input space of the training samples, called a map. The map seeks to preserve the topological properties of the input space. This makes SOM useful for visualizing low-dimensional views of high-dimensional data, akin to multidimensional scaling. The model was first described as an artificial neural network by Teuvo Kohonen, and is sometimes called a Kohonen map. We also explored the sequential patterns in the data using a sequential form of an association algorithm. Together with the practitioner we defined a 'balanced' state. We were able to find sequences of readings with a support of greater than 30% and confidence level of 70%. These association rules identified a few likely sequences of readings that lead to this balanced state. We then built a predictive decision tree using the C5 algorithm which included inputs from the association rules, the original data, and the clusters obtained from the SOM maps.

We used Self-organizing maps to analyze the electro-conductivity readings. The practitioner provided us with approximately 32,077 patient visit records. At each visit the practitioner used an electronic measuring machine which was purchased locally in Japan and modified to enable convenient measurements in the doctor-patient setting. The readings consisted of both a resistance measurement (RES) and a pulsed direct current (PDC) measurement for unidirectional currents, taken at the left and right sides of each of the five anatomical locations on the patient. The range

Figure 1. The Clementine workspace: Each node represents a step in the analysis. In our analysis we used both K-means and Kohonen clustering algorithms. Kohonen maps and K-means are often considered to be equally stable and accurate



of electro-conductive difference at each of these locations was 8.31, the mean was 0.07, and the standard deviation was 0.99. The readings were all distributed in an almost normal distribution with the largest skew coefficient being -0.19

Based on the suggestion of the practitioner we used only the electro-conductive measurements for our initial investigation. The data was then normalized and categorized based on measurements taken from a normal distribution and using the mean and standard deviation from each location. This produced measurements for each location that were categorized within the set {-3, -2, -1, 0, 1, 2. 3} where -3 indicated the most extreme imbalance towards the left and 3 indicating the most extreme imbalance to the right. We tried various Kohonen SOM maps and measured their silhouette coefficients.

In this Chapter we present the results of analytical investigation using Clementine data mining package. This package proved to be a convenient tool for step by step exploration of the data. It provides a visual map of the process of exploration. Figure 1 shows a visual map of the steps in our investigation. Each 'node' represents either a step in the process or else a particular visualization of the data.

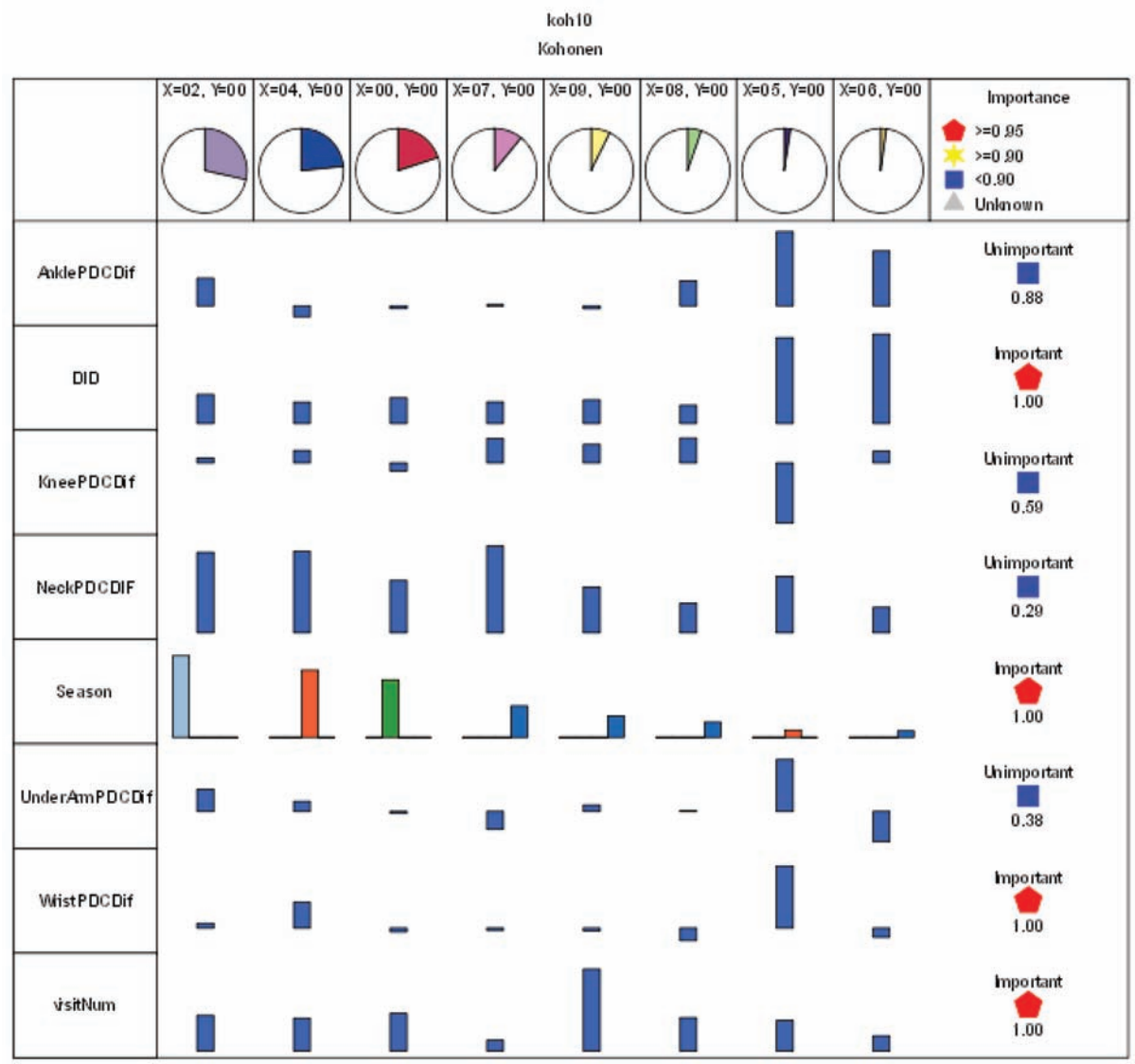
Kohonen Self Organizing Maps (SOM) and Clementine Web Graphs

We explored the Kohonen clusters from 2 to 15 clusterings (Figure 2). We then used the silhouette coefficient (Knuth, 1973). The silhouette coefficient is a measure of the clustering quality that is independent from the number of clusters (Kaufman& Rousseeuw, 1990). It measures the cohesiveness of the items within a group as compared to the dissimilarity of the points within different clusters. The silhouette coefficient was largest for 8 clusters at 0.72. This indicates a clustering result with very good separation among clusters, viz. Data points are very close to the center of their cluster and remote from the next nearest cluster. We also tried using the K-means algorithm. The results differed from Kohonen but the silhouette coefficients did not vary as much and the highest silhouette coefficient was 0.4 with 5 clusters.

We identified certain clusters as having distinct characteristics. In particular two clusters were identified as having a large number of summer visits. In one of those clusters the problem areas were located in one group of locations (writs, underarm, and knee) whereas the other cluster had a different set of problem areas (neck and underarm).

Clementine has a visualization technique referred to as a web graph. It visualizes associations

Figure 2. Kohonen SOM for 8 clusters: In Clementine clusters are named with their x and y coordinates of the associated nodes.. Cluster x=04, y=00, and cluster x=05,y=00 were both identified clusters of patient visits in the summer but differed in other characteristics. Web graphs revealed relationships within the clusters. Cluster x=05,y=00 had patients with a problem area primarily located in the wrist, underarm, or knee, whereas cluster x=04, y=00 had patient visits where the problem area was measured as being located primarily in the neck and underarm (Source: Authors)



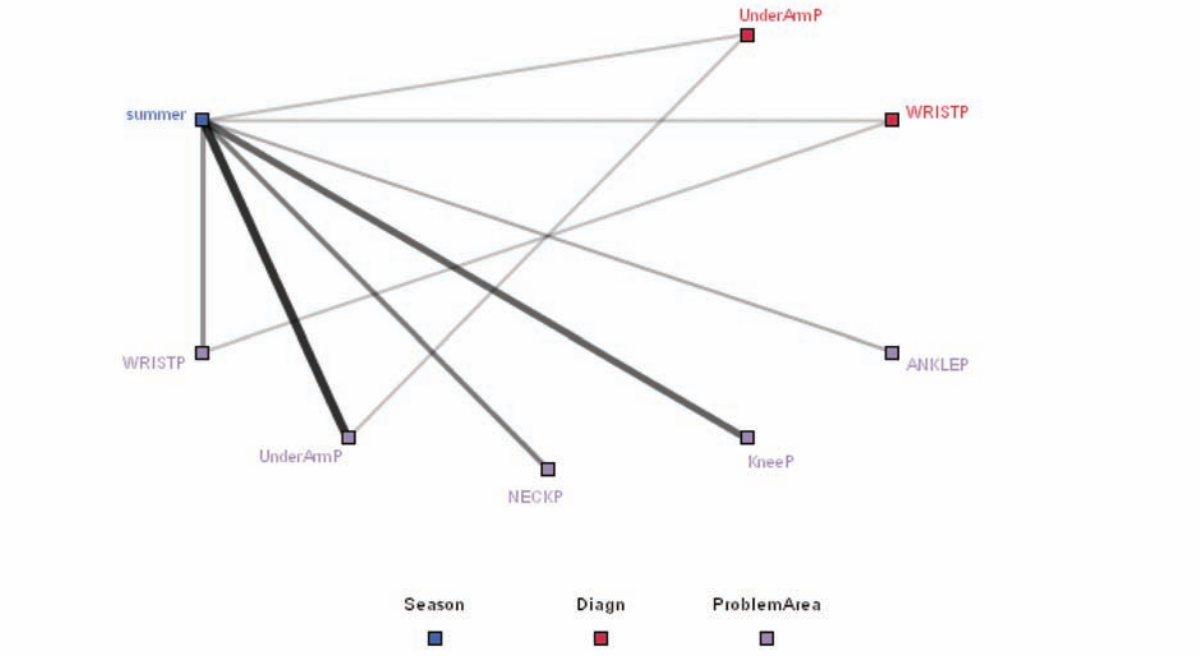
between different values of a collection of (at least 2) nominal variables. Darker lines in the web graph indicate stronger relations between outcomes that are connected by the line. For example, as seen in the graph in Figure 3 there are dark lines connecting a value of the season variable (summer) with 3 separate outcomes a variable indicating the problem area (knee, neck, and underarm). This is because this was a web graph of cluster x=04, y=00, whereas Figure 4 is a web graph of cluster x=05, y=00. In cluster x=05,y=00 summer was associated with underarm and neck problem areas.

Underarm was overall the most prevalent problem area measured and so the practitioner will focus on the neck versus the wrist in these two clusters. The practitioner wanted to use this to distinguish between two possible types of patient visits and look for variations between responses to treatments in the summer between patients who have neck located problems versus knee or wrist problems. Thus the clustering and further exploration of different groups discovered through clustering may lead to focused and more effective treatment.

MODELING THE DATA TO PREDICT A BALANCED STATE

We used C5.0 algorithm to predict whether the patient's next visit would result in a balanced state (see the decision tree presented in Figure 5 below). A balanced state was defined to be a visit where the maximum imbalance across all the readings was within 0.25 standard deviations of the mean. The inputs to the model are Problem Area, visit number, and season. The output is the yes/no variable indicating whether a balanced state had been achieved. The correlation between a balance state, thus defined, and the lack of symptoms

Figure 3 Clementine web graph: This is a web graph of the data from cluster three variables (season, diagnosis, and problem area) are pictured and their possible values. Diagnosis was the original location of the problem area as measured by PDC and problem area was the location at the current visit. We see the boldest lines connecting summer and underarm, summer and neck, and summer and knee



was only 61%. It is hoped that this model may help to better understand patients who reached a balanced state and yet still had symptoms. C5.0 produces a decision tree which can provide an intuitive model for predictions. Consultation with the practitioner lead us to believe that this would be the best choice for reasons pertaining to its usability by the practitioner since unlike neural networks which are presented as "black box", decision trees present the practitioner with an intuitive feel for the model. The predictions for the outcome "No" (meaning 'not balanced' as defined above) did not come with as high an average confidence level as those of 'Yes'. The confidence for 'Yes' was above 75%.

The output variable is a dichotomous nominal variable, whether the measurement is characterized as balanced (Yes) or not balanced (No). The pair of numbers in brackets to the right of each branch of the tree indicates (number of records, confidence). From the C5.0 decision tree we can discover various rules. For example, the model predicts that if the problem area is in the knee then there is 75 percent chance that the next visit will result in a balanced reading; on the other hand, if the problem area is in the neck, the season is spring, and the number of visits to the practitioner is greater than 32, then the next visit will result in a balanced reading with 100 percent confidence; again on the other hand, if the problem area is neck, the season winter, and the number of visits less than 5, then there is a 75 percent chance of a balanced state, etc. These rules should help the practitioner to get more insight into the prognosis and treatment of their patients.

Figure 4. Clementine web graph: This is a web graph of cluster x=04, y=00. This cluster had patient visits where the problem area was measured as being located primarily in the neck and underarm

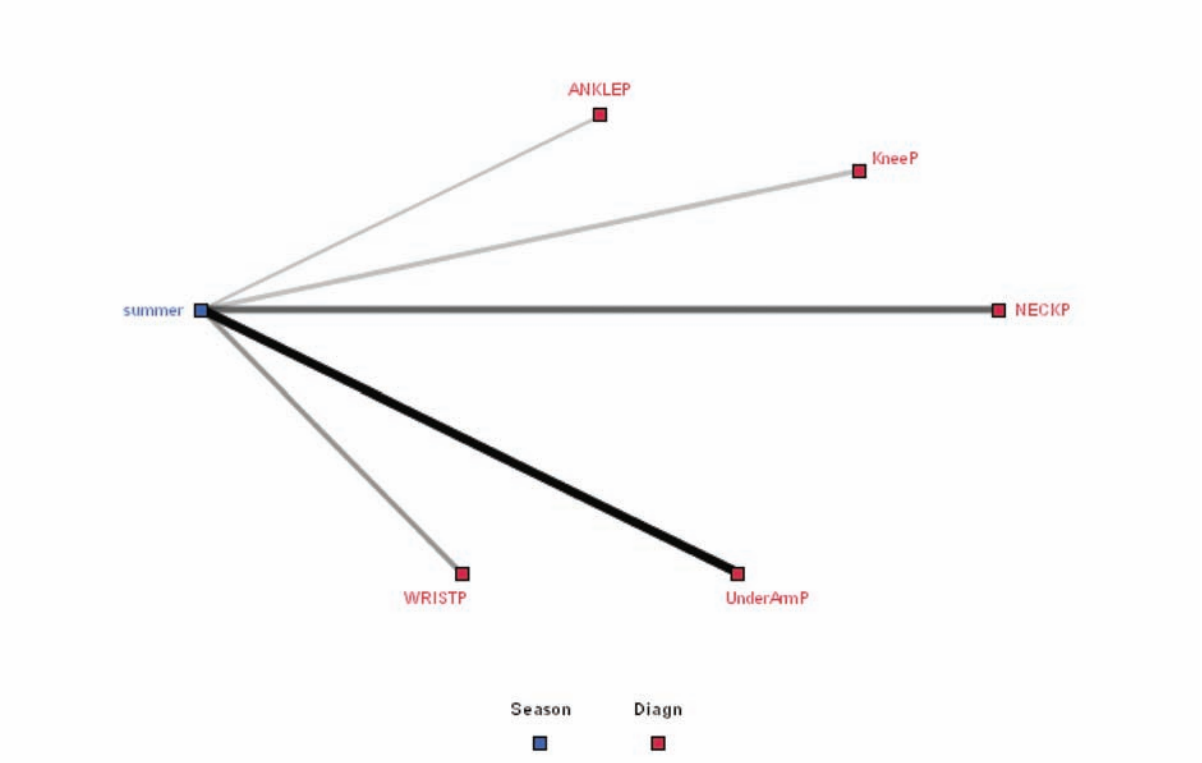


Figure 5. C5.0 decision tree

CONCLUSION

Alternative medicine includes a variety of different practices; however, they share a common feature in that modern clinical methods cannot be used to properly comprehend them without causing a lot of controversy and disagreement on both sides. Although it has been suggested that modern study methods can investigate but the experts of the alternative medical practices may disagree with this approach. Even the definitions of health vary. However using data mining techniques we endeavor to analyze the methodology without interfering with the practitioner. Meanwhile, many of these alternative medicine modalities are built upon overwhelming set of data in respect with their breadth and detail. We offered an example from a popular osteopathy clinic in Osaka which contained tens of thousand of measured data. Clustering of these alternative patient records helped us to see groups of similar patients or symptoms. In our study we found two groups of patients who exhibited similar symptoms in certain seasons. On one hand, we were able to examine this unorthodox methodology based on a series of data mining methods including Kohonen networking, decision analysis trees, etc.

On the other hand, the alternative medical practitioner can use the gained knowledge to better understand the associations discovered amongst patients. They can develop modifications in treatment methods for different groups in order to see if they respond uniformly within the groups. Similar explorations can be made for other seasons or across other variables.

Building a model for alternative healthcare is a daunting task because of the novelty and complexity of the data and because the stakes are so high. On the other hand, because the stakes are so high there is strong impetus to formulate such models. In our work, there was an inherent limitation on our access to clinically comparable data such as the medical complaints of the patients and clear indications of a response to modern treatments modalities. However, we were able to examine the possibility of building a model based on the

concepts of the osteopath practitioner himself in respect with balance and imbalance. With this improvised definition of balance we were able to build a model which could help the practitioner to predict a prognosis of the problem and whether the next state of the patient would be more balanced based on the current state.

The approach of this osteopathy methodology is somewhat unique in attempting to blend the intuitive 'energy' approach of complimentary, traditional medicine with scientific record keeping and measurements. We hope to continue a discussion of the findings with the practitioners of this osteopathy clinic and to encourage a measurement across more variables like initial patient complaint, age, gender, and other physical bodily measurements. With additional data such as these, the model building can be more significant.

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Chapter 7
Ethical Issues of Health Management Predictive Modeling

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ABSTRACT

In the wake of continuously escalating healthcare costs, health management in the workplace has gained new momentum as employers strategize to optimize the health of their workforce while containing healthcare costs. Gaining acceptance as a viable tool to aid employers is a process called Predictive Modeling. On the surface, Predictive Modeling may contribute significantly to delivering the right interventions to the right person at the right time by identifying high risk individuals, and underusers and overusers of health services. This chapter discusses the ethical principles of nonmaleficence, beneficence, justice and autonomy, as well as value judgments and human rights as applied to Predictive Modeling to guide professionals and employers in health management decisions.

INTRODUCTION

The role of workplace-based health management is more important than ever as employers seek solutions to control escalating healthcare costs. According to Hewitt Associates employer health care costs in the United States have risen 76% over the past five years with 83% of healthcare spending attributable to chronic health conditions. Review of claims data indicates that 1 percent of the population is responsible for 30% of healthcare cost and 10% for 70% of cost, mostly due to chronic and complex conditions (Berk & Monheit, 2001). The challenge for those responsible for health management is early identification of those at risk and the ability to steer them to interventions and treatment that reduce risk and improve health status (Hewitt Associates, 2006).

While it is relatively easy to identify those that are current high users of healthcare services through insurance claims data, identifying the transitional population - those who are currently healthy or light users of services but are eminent high users, is more complex. Predictive Modeling

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is a tool to identify people at risk, potential high users and also underusers of healthcare services, and noncompliant patients. As we explore what can be accomplished with Predictive Modeling it is also important to discuss what we should do ethically. Predictive Modeling is inextricably intertwined with health management in this chapter because there is no value to Predictive Modeling except for the purpose of assisting an individual achieve or regain optimal health. The purpose of this chapter is to discuss the ethical implications of Predictive Modeling for those responsible for the management of the health status or cost of defined populations.

BACKGROUND

First the chapter will define Predictive Modeling, Health Management and Ethics and then discuss a framework for application of ethics to Health Management Predictive Modeling.

Predictive Modeling

Predictive Modeling (PM) is defined by Jonathan Weiner, PhD of Johns Hopkins Bloomberg School of Public Health as 'a process that applies available data to identify persons who have high medical need and are *at risk* for above-average future medical service utilization' (Carlson, 2003). Predictive Modeling is currently a diverse field and generally utilizes algorithms derived from regression analysis, decision trees, rule-based systems or neural networks to identify high risk individuals. The overall goal is to improve health status while reducing cost (Axelrod & Vogel, 2003). Uses include (Tremblay, 2005):

1. Identifying healthy persons whose health is likely to decline;
2. Reducing inconsistency in care;
3. Predicting who is likely to be non-compliant with prescribed treatments and medications;
4. Identifying patients with high risk for actionable chronic diseases such as diabetes, congestive heart failure (CHF), asthma, chronic obstructive pulmonary disease (COPD), and depression.

Factors such as age, gender, total co-payments at drug initiation, total medication burden, and initial compliance with prescribed care are predictive of long term compliance (Carlson, 2003). Limitations of PM are that it must use readily available data and generally does not include affective constructs such as attitudes and beliefs. As adoption of PM applications becomes more widespread it is incumbent upon health management professionals to use ethical guidelines as a framework in deciding when to use it and how to use it. A review of the basic tenets of ethics in relation to PM provides a guideline for recommending and designing programs.

Health Management

Health management is a core discipline of our nation's health initiative that assists individuals in making informed decisions on health issues that affect themselves, their families and communities for the purpose of improving health status. Health managers use environmental supports including social, political, economic, organizational, policy and regulatory resources that influence behavior or more directly health. (Breckon et al, 1998; Liss, 1999). Historically, the place of employment is a key organizational site for health management in conjunction with the purchase and provision of work-based health insurance. Health management initiatives involve the behavior change of individuals to improve self-management of care (Robinson & Yegian, 2004).

Ethics

Regardless of the profession, certain values guide and direct how others are dealt with and health management is no exception. Cribb & Duncan (2002) cite two primary ways that ethics assist health managers. First, health policy and practice is adopted from clear ideas regarding ethical concepts, assumptions and arguments. Secondly, the ethical defensibility of intervening in individual behavior is supported by ethics. Guidelines employed to explain ethics, called ethical principles, apply to situations to help determine whether or not they are right or wrong. Four ethical principles that apply to PM for health management are nonmaleficence, beneficence, justice and autonomy. In addition value judgments and human rights will be discussed.

ETHICS IN HEALTH MANAGEMENT PREDICTIVE MODELING

A closer exploration into the meaning and characteristics of these ethical principles provides a better understanding of how ethical principles can guide decisions related to health management and Predictive Modeling.

Nonmaleficence

Simply stated, the *Principle of Nonmaleficence* dictates that whatever else one does, no harm should be done. Ethically, this principle necessitates the avoidance of any act that might needlessly harm a person. This contrasts with negligence in which a probable and unreasonable risk of harm or act of carelessness is willfully exercised upon another. Standards of care should be exercised to avoid or lessen harmful risk to others.

At the heart of the ethical issue as it relates to PM is intention. Is PM being instituted to help at risk employees maintain or return to health or in a way that could harm the employee? Predictive modeling could be harmful to employees if it is used to increase their insurance premiums or to withhold or terminate employment. Female gender and aging are known predictors of cost even controlling for gender specific utilization factors and other factors (Green & Pope, 1999). Employers (particularly those self-insured) could use PM to reduce healthcare costs by reducing the number of employees at risk for high cost conditions such as diabetes, heart disease, or cancer. PM also holds the risk of violating the employee's right to privacy as it could render an individual uninsurable or unemployable. At issue is what happens to the PM data once it is determined. Close adherence to confidentiality guidelines are necessary minimize this risk.

Beneficence

Beneficence is an act of goodness or kindness beyond what another may expect or require. Beyond just not being harmful, the health management initiative should also provide benefit. The health professional has an obligation to contribute to the individual's welfare and ensure that the benefits are well worth the risks. Health management PM initiatives can be beneficial to both the individual and the employer. PM used to identify non-compliance with asthma treatment could benefit the individual if intervention could help reduce acute attacks, but the employer may also reap benefit through decreased sick days.

Early detection can optimize recovery; minimize disability and increase years of healthy life (McCain, 2001). Employees also benefit by being identified as having risk prior to onset of illness by having preventative choices.

Distributive Justice

The third ethical principle, justice, is the availability to all of an equitable share in health opportunity. Distributive justice provides each person with an equal opportunity to achieve positive health status

according to need, effort, contribution, merit and free-market exchanges (Berk & Monheit, 2001). The ethical principle of distributive justice would dictate that the benefits of predictive modeling and health management be available to all.

Lack of access to needed health services is in itself an ethical issue (Mondragon & Brandon, 2001; Wilensky, 2003,) and uninsured individuals may be at the highest risk (Hadley, 2007). While PM used for commercially insured populations as well as government covered individuals such as Medicaid can be instrumental in increasing appropriate use of services, it does not assist the uninsured members of our society. According to Mondragon and Brandon (2001), justice is relatively neglected in the United States as citizens focus more on autonomy rather than justice.

Autonomy

The last ethical principle explored is autonomy which is the capability of individuals to exercise freewill in making rational and informed decisions. Each individual should be given the opportunity to act intentionally, with understanding, and without influence from an outside source that might alter their action. In essence, individuals who are mentally competent should be left alone unless they are bringing harm to others (Seedhouse, 2001). However, there are incidences when individuals cannot act reasonably on their own behalf and have limitations or lack understanding of their current circumstance.

Are employers obligated to protect personal freedoms while advocating for the health and well-being of the workplace as a whole? One of the most fundamental ethical concerns in the field of health promotion is the potential for coercion and manipulation people to behave in healthy ways (Breckon et al, 1998; Buchanan, 2000). Buchanan accuses health promotion of prioritizing health behavior change rather than seeking to reach a common understanding about the quality of life. He states 'plans for meeting the nation's health objectives verge on designs that treat people as means to an end…[often] toward ends not of their own choosing' (Buchanan, 2000, 68). The challenge is in balancing the greater good for all versus valuing freedom of choice of the individual (Breckon et al, 1998, 51).

If PM is used to inform at risk individuals about interventional options for potentially impending health crises it does not violate autonomy. But PM can also be used to monitor compliance with prescribed treatment. Using PM for the purpose of monitoring compliance with a prescribed course of action or treatment may violate the autonomy of individual choice, particularly if a punitive action is used to increase compliance. It is at this juncture that the health managers must decide whom they are serving – the individual, employers, managed care organizations or society as a whole?

Value Judgments

Ethical principles guide health management professionals in making value judgments in the process of promoting the health of an individual or a community. These decisions are not always clear or easy. For example, autonomy would support an individual's right to smoke cigarettes. Distributive justice indicates the need to provide clean air for all and to protect the public from the harm of second-hand smoke.

Greenberg and Gold (1992) state that the resolution of an ethical dilemma, defined as a situation where two or more ethical principles are applicable and in conflict with one another, should be based upon value judgments, placing one ethical principle above an other. However, additional problems are presented when basing the morality or immorality of ethics on individual values. People have different opinions about what is right or wrong, good or bad depending on background, culture, religion and life experiences. Values are not formed solely through life experience, but also bestowed from one generation

to the next, in which the interpretation of those values change and evolve over time (Buchanan, 2000).

One way to recognize a judgment based solely on individual values is to view the implications and reason given for the judgment. According to Rachels (1999) a moral or value judgment must be supported by good logic. Ethical questions can only be answered correctly by having the weight of reason on its side. This explanation of value judgments leans heavily on the natural law theory, defined by Dolhenty (2004) as moral principles common to all humankind and recognized only by human reason.

Predictive Modeling is predicated upon value judgments that assign a positive or negative status to behaviors, attributes, demographics, and clinical values. But whose values are applied? When PM is implemented on behalf of an employer (or a government) the values of that organization should be applied. Specific organizational value statements relating to how health status is viewed and handled in the organization will provide guidelines for PM and prior notification to employees regarding how health status is viewed and valued by the organization. Employees can then make an informed decision regarding employment in that organization. Handelsman et al (2002) agree however that little can be done when ethical principles are put in opposition against one another. Therein, lay the importance of ethical reasoning whereby the best possible solution is based on valid ethical principles, prudent thought, and cultural sensitivity.

Human Rights

Human rights, like ethics, are concerned with individual rights and interest. Human rights are founded in moral principle belonging to all people simply because they are human. Human rights and health are interdependent (Easley et al, 2001). The right to individual health and well-being derives from conventional human rights, such as the right to healthy working conditions, a safe environment and clean water while, at the same time, gives equal measure to the dignity of the individual, rights to education, free speech and the ability to participate in the political process. Human rights, from a universal perspective, are known as life integrity rights and include the following: the right to life; the right to personal inviolability – not to be hurt; the right to be free of arbitrary seizure, detention and punishment; the freedom to own one's body and labor; the right to free movement without discrimination; and the right to create and cohabit with family (Geiger, 2000). To say that health is a human right suggests that there is a covenant to which such an entitlement should be respected, defended and promoted (Gostin, 2001).

Predictive modeling in relation to human rights can thus be viewed as a contradiction. On one hand it could be said that the individual's right to freedom of one's own body favors personal choice and privacy. On the other hand, the individual choice of health may be dependent upon information provided through PM.

CONCLUSION

The purpose of this paper was to discuss ethical principles in relation to Predictive Modeling. Health Managers could benefit by using the framework described in Table 1 to evaluate the ethical considerations in providing a PM program. Health Managers must decide if PM is being used for the benefit of the employee as well as the employer and that mechanisms are in place to protect the individual from harm. McCain suggests that health professionals who object to using PM based on ethical intrusion, may find that it is less ethical to withhold use of a beneficial process that is superior to clinical judgment alone (McCain, 2001).

Breckon (1997, 89) states that ethics are relative; there is no one right or wrong act. The author adds, '…the act that produces impartial justice

Table 1. Evaluation of ethical issues of the predictive modeling health management program Evaluate the positive and negative aspects of ethical issues

Ethical Issue	Negative Neutral Positive
Nonmalefence	
Potential to create dissention at work	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Potential for harm to employees	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Beneficence	
Potential for benefit to employees	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Potential for benefit to employer	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Justice	
Identifies underutilizers	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Identifies overutilizers	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Autonomy	
Program is coercive	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Program is manipulative	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Value Judgment	
Program is logical	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Program supports organizational value statements	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Human Rights	
Program allows freedom over one's body	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5
Individual health dependent on risk identification	-5 -4 -3 -2 -1 0 +1 +2 +3 +4 +5

for the greatest number of people is the best that can be achieved and is therefore ethical. When an act only benefits a few, ethical questions emerge'. Sindall (2002) on the other hand, implies that ethics within the realm of health promotion is lacking, suggesting that the discipline is complacent when it comes to its own moral credentials. Others have stated that ethical principles in health promotion and health management have not been as relevant as those same principles when applied to biomedical issues (Mondragon & Brandon, 2001).

Fuch (1998) describes the importance in finding the proper balance between individual and collective responsibility. If too much emphasis is given to individual responsibility, society recreates the jungle, whereas all the freedom and insecurity the jungle implies is gained. In contrast, if too much emphasis is placed upon societal responsibility, a zoo is created, purchased at the expense of freedom. Fuch (1998:29) warns that in our zeal to increase levels of health, we must be careful not to impinge upon other valuable rights such as the individual's right to be left alone. While controlling health behaviors may lead to increased life expectancy, '…a well run zoo is still a zoo and not a worthy model for mankind'.

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KEY TERMS AND DEFINITIONS

Autonomy: Autonomy is the capability of individuals to exercise freewill in making rational and informed decisions.

Beneficence: Beneficence is an act of goodness or kindness beyond what another may expect or require.

Distributive Justice: Distributive justice is the participation of all in an equitable share of opportunity.

Health Management: Health management assists individuals in making informed decisions on health issues that affect themselves, their families and communities for the purpose of improving health status.

Human Rights: Human Rights refer to those religious, cultural, philosophical and legal rights or freedoms endowed to every person.

Nonmaleficence: The principle of nonmaleficence states that whatever else one does, no harm should be done. This principle necessitates the avoidance of any act that might needlessly harm a person.

Predictive Modeling: Predictive Modeling is a process which uses statistical analysis of data to identify a need, analyze a problem or forecast an event. In healthcare it has been used to identify underusers and overusers as well as those at risk for future health crises.

Value Judgment: A value judgment is an opinion based upon subjective beliefs or attitudes as opposed to objective or empirical evidence.

Section 2

Applications:

Extending the Scope of Health Care Beyond Conventional Boundaries

Chapter 8
Persistent Clinical Encounters in User Driven E-Health Care

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ABSTRACT

This chapter discusses the role of e-health in creating persistent clinical encounters to extend the scope of health care beyond its conventional boundaries utilizing social networking technology to create what the authors' term 'user driven health care'. It points out the necessity to direct the development of health information systems such that they serve as important vehicles between patient and health professional users in communicating and sharing information other than their role in automated alerts and responses. A project is described that plans to create a system of online sharing of health information in a user driven manner that necessarily becomes persistent due to being stored in electronic health records.

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INTRODUCTION

In the pre-globalization motorization era when physical distances mattered, the practice of medicine was confined to individual health care experts who seemed to know all about their individual patients. In the absence of specialists (if at all the only competition was the barber-surgeon) the wise community physician's knowledge was not just confined to pills and potions (which came in various colors), but s/he also knew all about how her/his patients led their lives. With time all that changed, and now the present day expert dispenses advice to a global consumer and uses findings that may be generalized to all humans (on the basis of quantitative research which is considered to be evidence-objective, absolute and rational).

The resulting fragmentation – resulting from specialization and sub-specialization – characterizing 'modern medicine' has reduced each health professional's knowledge about individual patients to only those fragments he needs to know and that match his area of expertise. In many instances the life of present day health care giver is often far removed from the lives of his patients unlike his know all, do all predecessor who used to share the lives of his patients in more ways than one. It is unlikely that the present day expert can shed a tear for his patient when he dies because he doesn't know his patient to merit as much but it is still possible with the practitioner who values her knowledge of individual patients derived from her local settings. The wise physicians' anecdotal wisdom although negligible in a global society was of immense value in their local communities where they were seeped in information about the details of their patient's lives that gave them a non mathematical but perhaps a grounded narrative and equally fair impression of what suited their individual patient needs (Biswas et al, 2007).

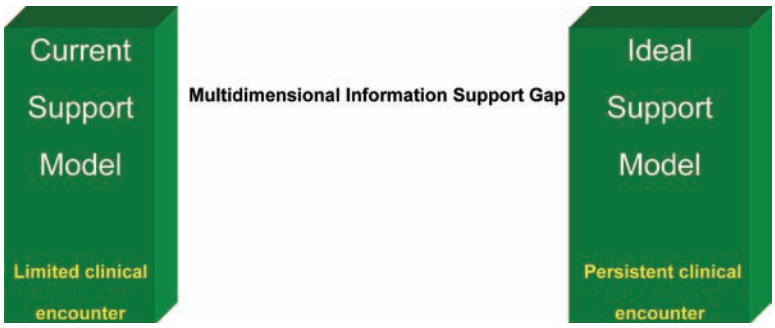
The traditional patient and health professional clinical encounter has evolved into a series of fragmented exchanges of information, often between several professionals. The information exchange between professionals often excludes the patient and is usually limited to a synthesized 'factual' written account. The synthesized 'factual' written account however fails to convey much of the subtleties gained through the information exchanges in the encounter, and which ultimately build a most valuable tacit knowledge base about a patient. (Sturmberg, 2007) Yet the encounter could actually evolve into an informational collaborative process, persistent in virtual space and time. A persistent clinical encounter has immense potential advantages for the patient as well as health professional.

Medicine is in fact a collaborative effort in problem solving between individual patients and their health professionals. This collaboration also involves others who are directly or indirectly related to the patient and health professional (for example, the patient's relatives, the practice staff and the physicians' institutions etc) who provide the necessary support to the two primary collaborators. In this Chapter we suggest viewing such an integrated approach to health care as 'User driven health care' that may be defined as:

'Improved health care achieved with concerted collaborative learning between multiple users and stakeholders, primarily patients, health professionals and other actors in the care giving collaborative network across a web interface' (Biswas, 2007).

And needs to be differentiated from the presently more ubiquitous 'consumer driven health care', which is essentially a strategy for users/consumers to decide how they may pay for their own health care through multiple stakeholders like employers who provide the money and insurance companies who receive the premiums.

Figure 1. From current limited clinical encounter to an ideal persistent clinical encounter



PERSISTENT CLINICAL ENCOUNTERS AND CONTINUITY OF CARE

An individual patient who sees her/his physician for a chronic problem like diabetes for example may be called back on an average for a follow up after 2-3 months. In this interval between physician visits, the patient on his/her own is expected to continue a judicious diabetic diet, maintain an optimal exercise schedule and dutifully consume all his/her medicines on time (and presumably also have an understanding of correct dosage). Any confusion or queries on the patient's part would be solved on the next visit unless it can be prescheduled (which is not always easy). Of course, apart from these usual information needs that are compromised there may be other emotional information needs that would go unexpressed.

As information needs keep being suppressed there may be a gradual build up of patient dissatisfaction from sources other than the worsening of the disease. Timely answering of patient informational needs that would have resulted in a better-educated diabetic may have prevented this. Patient education has long been a recognized positive factor in successful management of diabetes and good education may result from problem based experiential learning that begins with addressing patient's information needs (Biswas, 2007). Therefore, to understand a given individual patient's information needs we require an informational continuity about the person and his/her disease. Documented information tends to focus on the medical condition but knowledge about the patient's preferences, values, and context is equally important for bridging separate care events and ensuring that services are responsive to needs. This type of knowledge is usually accumulated in the memory of providers who interact with the patient (Haggerty, 2003). A persistent clinical encounter would involve accumulation of knowledge not just in the human memories of individuals (that is inherently perishable and worse corruptible) but also in a shared web space that can be accessible for asynchronous interaction between the individual actors in the clinical encounter. Such a well-documented clinical encounter for each individual patient can serve as a foundation to continuity of care and learning.

Continuity of care, in its traditional form, presumably consisted of the same doctor looking after a patient from the beginning to the end of an illness. It would have been even better if the same doctor was involved in any subsequent illnesses, a sort of cradle to grave care package. Patients would get to know and trust their doctor, forming a comfortable relationship for both. The nearest any doctor has come to this model is the general practitioner, but with the introduction of large group practices and realistic working hours it is no longer always possible to see the same doctor (Sturmberg, 2007). At the other end of the spectrum, anesthetists, radiologists, and accident

and emergency doctors have always accepted the single consultation or intervention as the rule rather than the exception. Continuity of care in general practice – though it is a defining characteristic of the discipline (McWhinney, 1989; Starfield, 1998; Sturmberg, 2007) - is under threat; while for consultants in hospitals it has probably not existed for some time, if ever. In the case of the acutely sick patient, where a clear perspective of the developing situation may be crucial to the management of the patient, it might seem that there could be no substitute to continuity of care (Bulstrode, 1995).

Haggerty et al (2003) in a review have described the concept - and reality - of continuity of care that crosses disciplinary and organizational boundaries. Continuity is the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context. Continuity of care is distinguished from other attributes of care by two core elements - care over time and the focus on individual patients. Continuity of care is achieved by bridging discrete elements in the care pathway -whether different episodes, interventions by different providers, or changes in illness status - as well as by supporting aspects that endure intrinsically over time, such as patients' values, sustained relationships, and care plans. For continuity to exist, care must be experienced as connected and coherent. For patients and their families, the experience of continuity is the perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future, (Haggerty et al, 2003).

Health Information Sharing Systems for Continuity of Care

For care givers, the experience of continuity relates to their perception that they have sufficient knowledge and information about a patient to best apply their professional competence and the confidence that their care inputs will be recognized and pursued by other providers (Haggerty et al, 2003). At present the stage is already set for health information sharing (HIS) to grow in India as in the west with a large number of hospitals (including those run by charitable trusts) increasingly getting interlinked by web-based HIS.

A hospital information system (HIS) can be defined as an integration of administrative, financial and clinical information systems of a hospital, with specialty or department specific sub-systems also known as modules. Author JG's hospital Health Information Systems includes the following modules: System Manager, Application Master, Master Patient Index, Duplicate Registration Check, Inpatient Management, Outpatient Management, Appointment Scheduling (includes wait listing), Accident & Emergency, Medical Records, Patient File Tracking, Order Entry & Results Reporting, Pharmacy, Radiology Information system, Operation Theatre Management System, Laboratory Information System, Blood Transfusion Services & Blood Donor Management, and Clinician Access. Of particular interest is the Clinician Access module which provides users with a single point access to all the information residing in the electronic medical record (EMR). It facilitates viewing the list of inpatients under the doctor's care, patients waiting for consultation in the OPD, history of the patient chronologically listing out each encounter (patient's visit and consultation) with hyperlinks to the clinical details for each of those visits. The user can update/view the pre-consultation observations, place orders for diagnostic imaging procedures and lab tests. All these features are available to the users based on their roles/responsibilities and access privileges. Doctors place orders for lab investigations, imaging procedures, look up the reports released by say the radiologists/pathologists in the HIS, wait list patients for surgery, request for blood, nursing/ward staff assign beds for patients, transfer them, perfusion details recorded at the OT's, discharge

summaries printed out, signed and given to the patient. All these activities/transactions right from the registration, admission to discharge are through the HIS.

From a functional perspective, the HIS consists of components that support the following distinct purposes:

1. Patient management;
2. Departmental management;
3. Care delivery and clinical documentation;
4. Financial and resource management; and
5. Managed care support.

HIS also harbor logic modules with sufficient knowledge to make a single clinical decision. The health knowledge base may contain contraindication alerts, management suggestions, data interpretations, treatment protocols, diagnosis scores etc. For example, when a doctor prescribes the patient penicillin, the logic module will check for contraindications. If the patient has a recorded allergy to penicillin, an alert is generated. This decision support system in clinical institutions has been in use for many years.

However these systems emphasize increasing automation through human computer interaction whereas health and healing require human to human interaction (that just needs to be augmented by computers). The human interaction aspect, with a focus on the person and his unique illness experience, is fundamental to medical care, to healing and to cost efficiency, and cannot be overemphasized. This is particularly important for the rapidly rising number of patients with chronic illness who have most to gain from well directed personal and technical care (Martin, 2007). This importance of human to human interaction and its augmentation by technology is illustrated below with a single day hospital ward scenario from a hospital physician consultant's e-diary (Note that care giver logs are often just telegraphic information):

1. Relooked Bed 11…student's request. 50 yr Male, Nephrotic syndrome with diabetes mellitus and with his diabetic foot dripping pus on the bed. No dressing since yesterday? Blood sugar values?
2. Bed 10, 60 yr Male, collapsed suddenly, cirrhosis with end stage, didn't want to resuscitate but had to for protocol as we had missed out on the DNR earlier. Students had an exercise.

Another note a month later:

3. This was a month back I think…can't be sure…time flies so fast on the daily ward rounds. Most of my E-logs remain unutilized. In fact I first started making e-logs on my PDA chiefly to identify my information needs as a physician before I gradually started realizing even patients had similar needs and we needed to have an integral solution for both.

Relevance of Daily E Logs to Solve Individual Patient/Health Professional User Needs

The academic physician-consultant (author of these real log examples) had seen the diabetic man in Bed 11 earlier on his morning consultation rounds but he realized that this patient's blood sugar control had been overlooked only after a medical student requested him to have another re-look. He made a point in his mind to inform this to his junior colleague, the medical officer who would remain in the wards (also at the same time making the telegraphic note about the patient in Bed 11 in his personal diary). Suddenly, at that point in time, the patient in Bed 10 collapsed and he had to participate in his CPR that was emotionally and physically draining and he was relieved to escape to the out patient department (OPD) for the day.

SHARING AND COMMUNICATING VALUABLE INDIVIDUAL PATIENT DATA

If this data were on a web portal (a kind of virtual hospital filing system) as soon as the physician entered it into his personal digital assistant (PDA), the data would have matched with his other colleague's data for the day regarding this particular patient. His junior colleague (Medical Officer/ Senior Resident) doing just a file review on his PDA would have noticed the note and acted on the diabetic man's blood sugars if it was high. Controlling it better may have benefited the wound more than the systemic antibiotics that he was already on (and which had doubtful local benefit although again it is an issue that may be debated). This technology offering a convenient local solution to improving hospital communication among in-house health professionals is evolving at present in many hospitals.

Medical Students as a Vital Force in E Learning and Improvement of Patient Care

The government generally thinks that it spends too much money in Undergraduate Medical training perhaps as these student doctors apparently do not serve while they learn. However it is the medical student who has the time to listen in detail to their chosen individual patient (they do not have to see and are not responsible for all the ward patients unlike their overworked houseman/resident seniors). Medical student logs on their individual patients can be a vital source of detailed narrative data on individual patients which their consultant might often enjoy reading and also benefit from daily. The medical student who pulled the consultant to the bedside may as well have entered his thoughts about his patient on his PDA-elog that would have automatically been reviewed by the consultant or his Medical officer (Senior Resident).

Individual Patient Learning and Communicating from Global Experiences

We need a global solution for all varieties of individual users. Perhaps a diabetic patient in another part of the world on keying his concerns about his own foot ulcer would find a match in this incident and drop a word of sympathy for our diabetic in bed 11. Another person in another part of the world could become aware of the importance of a do not resuscitate (DNR) form for his dying father with end stage disease. Another diabetic with a mild foot ulcer on reading bed 11's note could become aware of the need for better sugar control in his own situation and may remind his physician about his increasing sugars (perhaps the emotional appeal in narratives may make for better patient learning?). Not that his/her physician is not knowledgeable about the importance of controlling blood sugars in foot ulcers but perhaps it is sometimes human for physicians to make errors of omission (especially under pressure) and unfortunately it is perhaps human to even want to cover up our errors (covering up is incidentally another word for creating privacy).

We also need to increase more transparency in patients and physicians so that both parties can benefit continuing to learn from each other. Having said that it would still be important to maintain patient anonymity and there are methods of anonymous information sharing where patient identity would remain secure. In fact, most health care professionals/individual patients can generate a variety of beneficial examples in shared e-logging in health care regularly maintaining their own daily process logs for which one may still have time if it is done on the job and the information needs generated from these may be identified by web based user driven solutions.

For each and every individual patient who suffers it is possible to electronically document her/his clinical encounter with the entire social

Table 1. This section has been separated as it is speculative but it has been included for curious readers who may want to browse through for remotely testable ideas

EHRs (Electronic health records) need to start as a simple free text entry platform for the individual user with minimal interference from the software which may irritate health professionals as well as patients who are utilizing EMRs mainly for data storage and communication particularly in their own style with which they are used to and which need not necessarily always follow a standard. The maximum value of EMRs lie in its ability to foster knowledge sharing and learning and this can be achieved with a simple free text storage that can be updated by the user be it the patient, patient's relative, health professional. The present dissatisfaction with EHRs among practicing health professional users may lie in its software's automated interference with individual user's capacity to create meaningful data in their own terms through free text (or sketches). Free text open ended entries promote creativity in the user whereas drop down developer designed windows stifle it. As currently conceptualized, evidence-based medicine cannot adequately accommodate concepts that resist quantitative analysis and therefore cannot logically differentiate complex human beings with natural intelligence from machines with artificial intelligence. Our present day computer based clinical decision support systems suffer due to the same reasons. Medicine needs a more robust knowledge based system capable of recognizing patients and clinicians as persons. One that is more likely to be driven by natural intelligence than artificial. A truly person-centered medical epistemology requires a revised conception of medical uncertainty and recognition that clinician–patient interactions are central to medicine. (Henry et al, 2007) It is necessary to debate if we really need logic modules for automated drug allergy alerts or we need to be alerted by a care giving collaborative network of users that may be accessing and modifying an individual patient user's EHR? Perhaps we need a judicious mixture of both but at present the emphasis unduly lies on automated software that require universal standards to tackle interoperability. Humans have their own standards in communication and their own tacit ways of understanding each other. We need to utilize this potential human base of dedicated users (patients, health professionals) instead of discouraging them with software that force them to conform to automated standards.

network that supports her/his healthcare. This persistent documentation in individual personal health records (PHRs) made accessible to all stakeholders (that include innumerable patients and caregivers) would serve as a valuable learning resource that may enable improved decision-making utilizing meaning derived from multiple dimensions of the clinical encounter. (Pauli & White, 1998; Sturmberg, 2007; Martin, 2007; WHO, 2007)

CREATING PERSISTENT CLINICAL ENCOUNTERS THROUGH USER DRIVEN E- HEALTH CARE TO ANSWER MULTIDIMENSIONAL INFORMATION NEEDS IN INDIVIDUAL PATIENTS

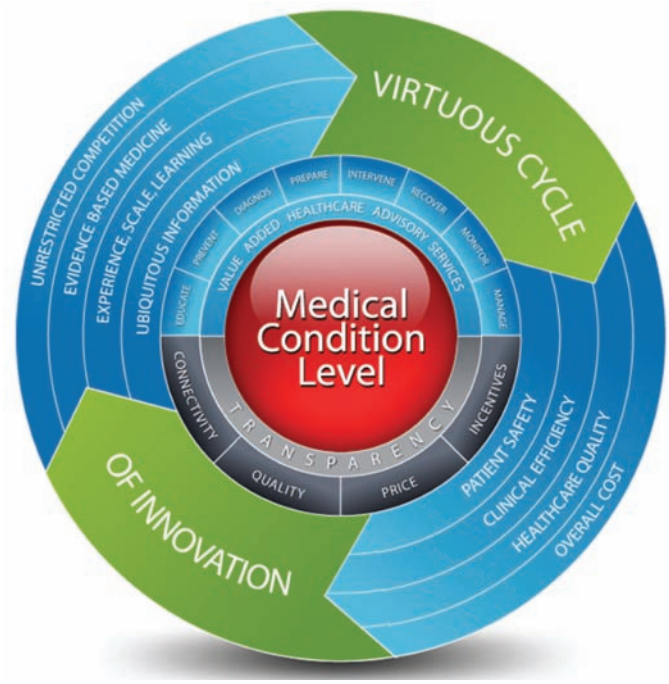
A web-based solution to integrate healthcare E-learning needs could lie in a simple forum model already in use at present in various web sites using what is loosely termed as Web 2.0 technology. In web sites using this technology user-generated tags allow the site to evolve, enabling individual users to conduct more precise searches, make previously unacknowledged associations between facts, and explore a diverse undercurrent of themes to synthesize learning.

It has been recently named Health 2.0 with reference to health care and has been described to be all about Patient Empowered Healthcare whereby patients have the information they need to be able to make rational healthcare decisions (transparency of information) based on value (outcomes over price).

The Four Cornerstones (Connectivity, Price, Quality, and Incentives) of the Value Driven Healthcare movement begin to create a virtuous cycle of innovation and reform. Transparency serves as a key catalyst in this process by creating positive sum competition that can deliver better outcomes at a lower cost (Shreeve et al, 2007). As more information becomes available as a result of increased transparency, there will be a wave of innovation at all points along the full cycle of care (Fig 2), which includes phases where health care providers Educate, Prevent, Diagnose, Prepare, Intervene, Recover, Monitor, and Manage the various disease states (Shreeve et al, 2007).

Each and every human has the capacity and likelihood of performing both roles of caregiver

Figure 2. Explaining health 2.0 (Copyright 2007 by Scott Shreeve, MD. Made available under the creative commons non-commercial attribution 2.5 License)



and care seeker (patient) in their lifetimes. The illness experience posts would automatically generate related posts depending on the keyword-tags they use to represent their posts and this would enable every user posting his/her individual experience to go through similar relevant lived experiences of other individuals. This would be a tool delivered remotely, often anonymously, and yet may foster a sense of belonging and intimacy. In this way any individual user feeding input into the net can receive automatic feedback that can grow as individual users for this web based solution grow as they keep feeding their own data regularly. This may function purely on the power of human collaborative intelligence or distributed knowledge arising from the wisdom of the crowd (Surowiecki, 2004) rather than pure artificial intelligence and yet may prove to be much more efficient.

Each and every individual may be the author of his own destiny (as well as his own web log) that reflects his experiential life processes and decisions that can shape his future. User driven health care is an attempt to help make those decisions. It is a proposal to document valuable individual experiences of patients, physicians and medical students in a practicably feasible grassroots manner that has till now regularly gone undocumented and has been lost to the medical literature that may have actually benefited from it. The present version of *Pub-Med*, a popular evidence based resource (http://www.ncbi.nlm.nih.gov/sites/entrez) utilizing the Web 2.0 technology displays related publications as soon as a user clicks on to read an article abstract after entering his/her search terms. However this evidence based resource is chiefly concerned with empirical collective experimental data and even the case reports available on the site do not offer the richness of the individual lived experience that addresses our previously discussed dimensions of the clinical encounter. Pub-Med is a limited information source as most of the articles have restricted access to the full text version.

Introducing and Sustaining the Conceptual Model in Routine Clinical Practice

Regular experiential informational input may be posted on to a web based forum along with a copy to the individual user's password protected web account that would function as an E-portfolio if s/he were posting as a caregiver and one to his/her private personal health record if s/he is posting as a patient. The individual user could even do this through email and every post made by mail could easily open a new post on to the forum. All this information sharing could be optionally kept anonymous, as usernames could be made impersonal (again depending on user choice).

Once individual users key in their unique experiential information that could also reflect pathophysiologic rationale, patient values and preferences, system features including resource availability, societal and professional values they would be presented with related individual experiences mashed up with empirical data immediately at the click of a mouse. Later it would be up to the individual to derive meaning from these multiple dimensions of information – though for patients this may only be possible in conjunction with their doctor. To date this experiential information may exist in difficult to search web logs but most parts of our day-to-day innumerable clinical encounters remain undocumented. As a result the present day user is far from optimal satisfaction with the information on the net.

A few physician led companies have already made considerable headway in this direction. SERMO is a web based US company that uses a forum model to develop experiential knowledge networks among US physicians while ' Patient opinion ' is a UK based setup that aims to access the collective wisdom of patients using Web 2.0 tools where patients can share their stories and rate the care they receive down to ward and department level. This patient opinion aspect of user driven health care is about conversations, democracy and improving services by making the individual voice more audible. Curbside.MD is another US based company that goes one step beyond Pub-Med in data mining and presentation by utilizing semantic fingerprinting to let users key in natural language queries in their search engine, which returns a variety of useful empirical evidence arranged as, all research, systematic reviews, guidelines, review articles, images etc. It also has begun fingerprinting of individual health profiles and matching similar profiles.

Even if one could collate a larger variety of experiential information on the net, it would still be confined to PC literate individuals and to bridge the digital divide we along with our technical collaborators (see operational model) are trying to develop a mobile SMS (short messaging system) portal for data entry into the web repository. An individual at his leisure or even while waiting in queue to meet his/her physician may SMS their thoughts and queries about their disease onto the forum that could be responded to by anyone on the web. All this information sharing could be optionally kept anonymous, as usernames could be made impersonal (again depending on user choice). SMSes to the web may display only the individual user's mobile numbers.

CREATING PERSISTENT CLINICAL ENCOUNTERS THROUGH USER DRIVEN HEALTH CARE PROJECTS

This section describes a project to create persistent clinical encounters through user driven E health care underway in Malaysia, in which the authors are involved. An operational model was created to plan a trial on a sample diabetic population utilizing a randomized control trial (RCT) design, assigning one randomly selected group of diabetic patients to receive electronic information intervention and analyze if it would improve their health outcomes in comparison to a matched diabetic population who would only receive regular medical inter-

vention. Diabetes was chosen for this particular trial, as it is a major chronic illness in Malaysia as elsewhere in the world.

The Role of Individual Patients, Health Professionals and IT Collaborators in the Trial

As this was a multidisciplinary user driven project it was necessary to clearly define certain user roles although there is scope for these to evolve further after the pilot phase.

Role of Patients Participating in the Project

Patients who have consented to be willing participants in the trial period will be randomly allocated to either receive the mobile phone intervention with current standard therapy or receive current standard therapy alone. All participants in the study trial will have their baseline characteristics entered in a structured manner into a web database designated as personal health record (PHR). The patients receiving mobile intervention would receive weekly SMSs enquiring about their present symptom status, self monitored blood pressure, blood glucose values if any, current diet, exercise patterns and any other complaints they would like to convey. All responses and interaction would be automatically recorded into the non-structured portion of their web-based record. Patients may communicate either through text or voice messages.

Role of Physicians Involved in the Project

Patient entries to the mobile web database will be reviewed by one of the physicians involved in the study and s/he will make appropriate adjustments to the patient's management according to standardized diabetes management protocol (ADA, 2007; Malaysian Clinical Practice Guidelines, 2004). S/He will also be instrumental in supervising entry of all the individualized data into a standard format to be later entered into a web-based repository that can serve as the individual patient user's standardized personal health profile that may be accessed by appropriate health care givers and controlled by the patient and his/her health care provider. S/he will also monitor the non-structured patient generated health profile for day-to-day patient queries, thoughts etc. S/he will respond to patient queries and comments to the best of her/his expertise and refer appropriate information needs to medical information specialists/other health professionals who will try to enrich each individual patient profile with the addition of appropriate evidence based data at relevant areas in the profile. During each visit of the patient s/he will access the patient's personal record on her/his computer and provide a print out of the PHR (latest version with changes) if necessary.

Role of the Research Assistant/ Clinical Care Co-Coordinator

S/he will be instrumental in entry of all the individualized data into a standard format supervised/guided by the physician after ensuring a record of proper informed consent. S/he will be an important liaison between patient and health care providers, which includes physicians, diabetic educators, dieticians and even mobile web support staff. S/he will arrange for mobile phone based continuity of care by ensuring appropriate weekly and monthly, individualized phone and SMS reminders and discussion. These reminders and discussions with patients are primarily aimed at assessing patient compliance to treatment of which diet, exercise and drugs are equally important components. S/he will ensure this assessment is done weekly in mobile phone users apart from the standard 3 monthly face-to-face assessments on hospital visits, which would be same as for the matched control group. S/he may help the other health care providers to address patient

queries sent by patients to the mobile phone support network by collecting their answers and giving them back to the patient with the help of the mobile network support staff. S/he will also help the mobile network web support staff to create and maintain the individual patient's personal health profiles by ensuring appropriate entry of proper and relevant data.

Role of Mobile Phone Based Web Support Staff

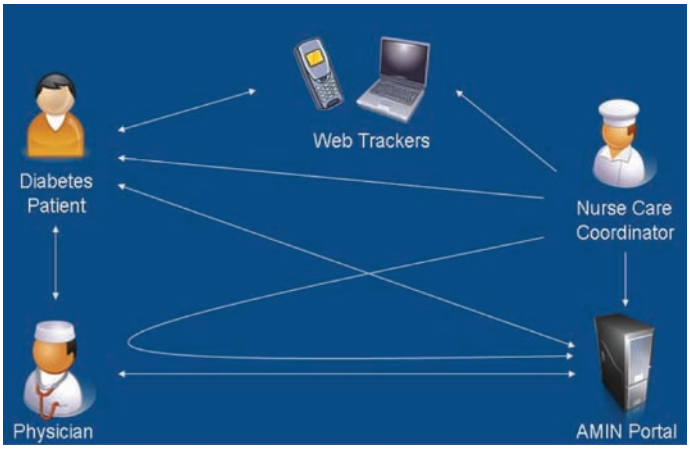
The proper functioning of mobile phone intervention in the lives of the selected patients will be developed and maintained by web support staff who regularly monitor and update the individual patient web profiles based on the data provided by the patient, health care provider and research assistant. S/He will ensure that authorized users only with valid personal identification, user name, passwords etc use the system.

Prototype Development

The structured and non-structured information log for patient centric support to manage and control disease allows patients to overcome limitations in the time spent with physicians. This system provides continuous virtual connection with physicians and support group. The diabetes support system is designed to provide care to patients in the areas depicted in Figure 3. Patients will have access to support and care through their mobile phones at all times. This is to allow patients to monitor, manage and control their own health at anytime and place. Support and alert messages are sent to mobile phones to disseminate and collect information from patients as depicted in Figure 3. The collected information is published in an online web log anonymously to provide support and help to patients who are suffering from the same disease and have similar disease related problems. The organizing of the structured and non-structured information is done based on the patient centric model.

There are other benefits. This system allows getting connected with users who share the same common goals and challenges (but would be otherwise difficult to locate), along with care givers who can contribute usefully at their own time. It also maintains privacy and confidentiality of patient and empowers them to manage their own health. Search and other utilities will be added to facilitate fast access to information.

Figure 3. The Role of various collaborators in answering multidimensional informational needs (AMIN)



Network Architecture

The prototype mobile application is designed to interact with Mobile Internet Platform (MIP) to send and receive short messages. The architecture shown in Figures 4 and 5 is applicable to all mobile phone users irrespective of mobile services providers. The above initial prototype was further modified to introduce the unified communication engine that would support both

Figure 4. Interaction between patient and care provider models

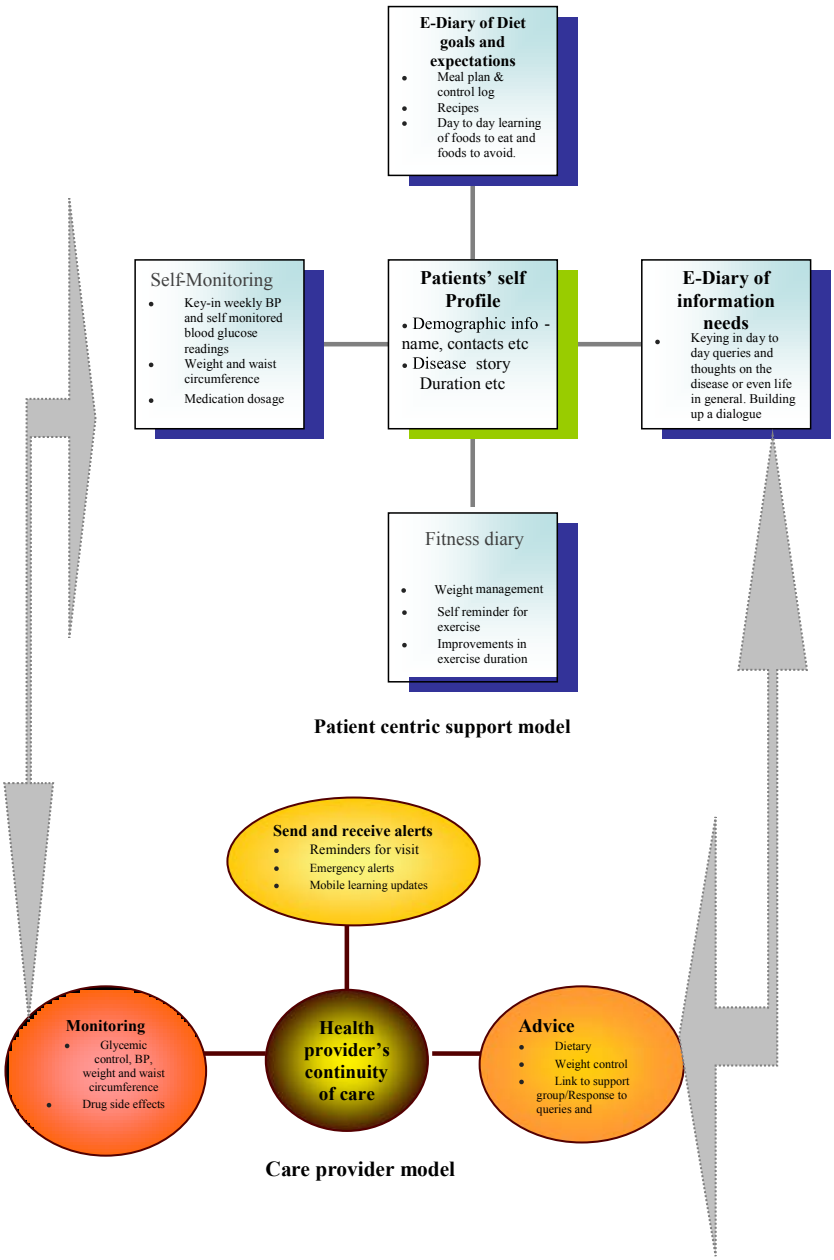
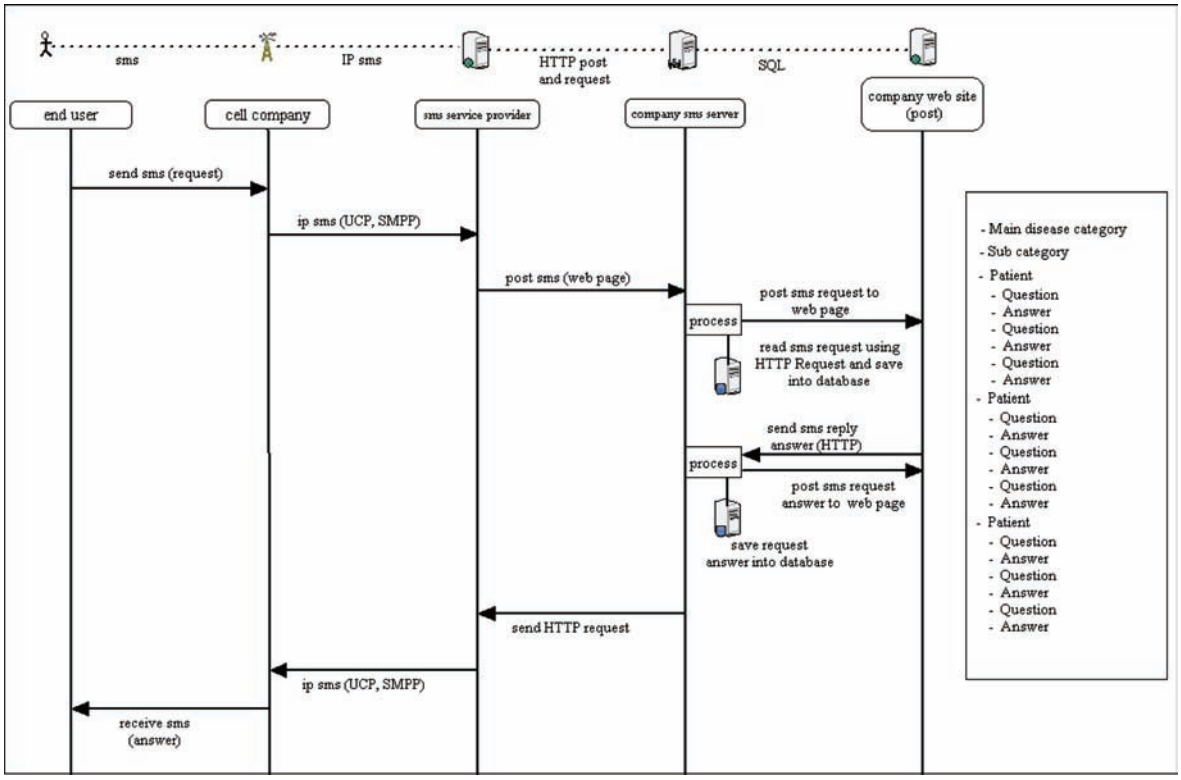


Figure 5. Mobile web log network architecture



voice and data inputs especially for structured data. Users could choose to use phone, mobile phone, PC/laptop or an embedded system to work with the proposed health portal.

ANSWERING MULTIDIMENSIONAL INFORMATIONAL NEEDS (*AMIN*)

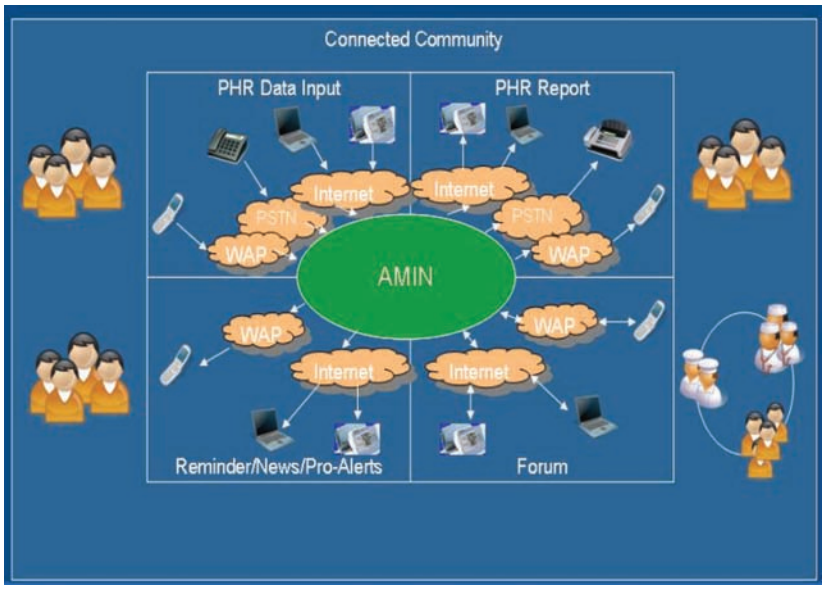
Patient needs: To address the problem of multidimensional information needs we plan to use a Web based-learning solution being perhaps tested for the first time (Figure 6). The following quote may explain the background to the term, *multidimensional* information needs and our enthusiasm to address it:

'...the need for information is often much more than a question about medical knowledge... are looking for guidance, psychological support, affirmation, commiseration, sympathy, judgment, and feedback. This "information need" is particularly poorly explored, and yet it may well be the most important need and the biggest stumbling block to a technical solution' (Smith, 1996).

To address this problem we propose maintenance of non-conventionally structured personal disease logs. Regular short messaging services (SMSs/Emails) from individual diabetics conveying their daily thoughts on their disease would be kept in a personalized repository in the web for those in the intervention group:

1. Thought partner matching for a learning community creation—Thought partnerships in different diabetic patients with similar needs as expressed in their e-logged thoughts could be identified by web based matching

Figure 6. AMIN (answering multidimensional informational needs) solution framework



using text tags. This aims to promote shared learning in individual diabetics with similar needs gradually leading to an improved learning community of diabetics;

2. Informational needs on SMS, conveyed explicitly as health queries, could be manually responded to by health professional monitors. Medical informational specialists (previously designated Medical library scientists) other than physicians could monitor the discussion between patient-patients and patient to physician with valuable evidence based inputs to the gradually developing structure on the individual health record.

CAREGIVER NEEDS

All personalized data generated from the patient's regular SMS/Email interaction with the mobile web support system would be structured into a personalized health record (PHR) with the following components:

1. Structured summary of the patient's health status *(mostly monitored/maintained/modified by health professionals)* based on
   a. Basic information on identification, insurance, allergies, advance directives etc. (format);
   b. Latest Problem list along with patient's care plan (Investigations and treatment listed serially according to priority of action to be taken);
   c. Hospital admission discharge summaries in the past;
   d. Present hospital record (if admitted at present)
2. Non-structured evolving narratives inserted by the patient, thought partners or care givers at various points of time (with date). *This structure would simulate the* ***discussion-*** *structure of a wiki at present;*
3. Non-structured PHRs (Personal health profiles) created /modified either by patient/thought partner or personal physician could also be labeled and stored here for future needs. *This structure would simulate the* ***article*** *structure of a wiki at present.*

Personal Health Records (PHR) are a medical knowledge-based characterization of a user of a medical information service. Such a technology facilitates convenient and personalized access to knowledge produced by medical practice--the primary knowledge construction process. Therefore, a personal health record enables exchange, debate, and reasoning about personal experiences with disease and the health care system, as a secondary knowledge construction process (Sittig & Hazelhurst, 1999). The PHR as described above must reflect the following attributes (Personal Health Working Group Summary, 2003):

1. Each person controls his or her own PHR;
2. PHRs contain information from one's entire lifetime including information from all health care providers;
3. PHRs are accessible from any place at any time;
4. PHRs are private and secure;
5. PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from and who has viewed it;
6. PHRs permit easy exchange of information across the health care system.

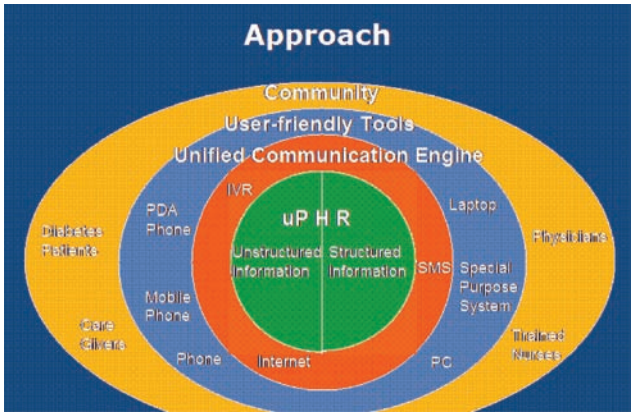
The initial elaborate entry for the individual users PHR can be made by the patient user through his/her mobile phone with a direct telephonic interaction with a web support staff/research assistant who would fill up relevant details into a structured online database that could be downloaded into the mobile as per need.

At present the health record structures in the Malaysian health system are predominantly paper based with the attendant disadvantages of information of a single patient in multiple paper files that are difficult to trace and maintain. The patient often doesn't carry any substantial information about his past medical history. All this is expected to change soon with implementation of electronic health records (EHRs) in most Malaysian health care set-ups. Complimentary to this, our introduction of the proposed mobile phone based PHRs in diabetics (to start with) aims at trying to eliminate the present problem of information tracing confounding medical decision-making. These PHRs would not only be in the mobile phones of individual users but would also remain safe in a web-based individual health record bank (IHRB) (Shabo, 2005).

FUTURE DIRECTIONS

On completion of the test phase this web-based solution to integrate healthcare e-learning needs

Figure 7. The overall approach to AMIN



can be opened to the world in a simple forum model. Regular experiential informational input may be posted on to the forum along with a copy to the individual user's password protected web account that would function as an E-portfolio if s/he were posting as a caregiver and a private personal health record if s/he is posting as a patient. The individual user could even do this through email and every post made by mail could easily open a new post on to the forum. Most PC users in recent times spend their Internet time predominantly in their mailbox and integrating this solution into the mailbox would target this population.

Finally the digital divide would only be effectively bridged as the basic mobile phone is phased out and the personal digital assistant (PDA) combined with mobile phone and PC functionality takes over boosted with WIMAX (Worldwide Interoperability for Microwave Access) technology for continuous easy online access).

CONCLUSION

This chapter discussed the role of e-health in creating persistent clinical encounters to extend the scope of health care beyond its conventional boundaries and strengthening the foundations of healing through a long-term trusted professional-patient relationship utilizing social networking technology to create what the authors' term user driven health care. It pointed out the necessity to direct the development of health information systems such that they serve as important vehicles between patient and health professional users in communicating and sharing information other than their role in automated alerts and responses.

A project was described that plans to create a system of online sharing of health information in a user driven manner and which necessarily becomes persistent due its getting stored in electronic health records. This is an operational model of user driven health care developed in an attempt to optimally answer multidimensional needs, utilizing post EBM approaches, in individual patients and health professionals. This may allow them to achieve better health outcomes through inter individual collaboration between multiple stakeholders in the care giving and care seeking collaborative network (see conceptual model). AMIN, which is an acronym for answering multidimensional informational needs, is a Web 2.0 enabled and moderated forum to support users' unstructured queries, thoughts and journals by returning related thoughts and text with each entry made by users. It is an integrated system to simplify and streamline the diabetes monitoring process and support users' unstructured queries, thoughts and journals.

This operational prototype, which still continues to evolve, has been shared with other future stakeholders particularly in the government healthcare system and is expected to considerably improve communication and transparency between multiple users and stakeholders, primarily patients, health professionals and other actors in the care giving collaborative network across a web interface.

ACKNOWLEDGMENT

The first author assumes complete responsibility for the views expressed in this Chapter. We acknowledge the technical contributions of Waqar Aziz in developing the software interface for the solution discussed and the technical liaison maintained by Lim, Chia Ni, Tan, Eng Hoo, and Tan, Eng Hoo, Jia Yu, HonX and Ang, Koon Liang. We are thankful to the Ministry of Health, Malaysia for having gone through our proposal demonstration and at this point eagerly wait for the next step in this collaborative venture that is executing the operational model into a validation model. This write up has been shared extensively in emails and web portals and ideas contained within it are being considered for publication in completely different contexts (for example as an

illustrative process description for a chapter on collaborative E-learning). The appendices mentioned in this article may be obtained from the corresponding author by email.

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Chapter 9
Incorporating Radiological Patient Data Acquired at Other Hospitals into the Local Workflow

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ABSTRACT

Patient data are increasingly distributed between hospitals using CDs instead of physical films. This introduces problems because different viewers from different vendors are provided, and sometimes viewers are unusable because local software installation is not allowed. In 2004, we started to facilitate the incorporation of image data from CDs into the normal workflow of the hospital by using commercially available software to perform patient reconciliation based on the DICOM modality work list. In the years after the first introduction, a more comprehensive software system was developed which allows for the fast upload of large amounts of patient image data into the normal workflow. Although direct network connection between institutions is currently being developed and deployed, in the next decade CDs will remain to be used and the integration of the data into the normal workflow is a must. Literature shows that other institutions also started to handle the CDs similarly.

INTRODUCTION

Transfer of radiological image data between different institutions is an important issue in the diagnosis and treatment of patients. The reasons for the transfer of radiological image data can be for the radiologist to perform a second opinion consult or to have old image data readily available for comparison with new image data acquired at the own institution. Furthermore, the image data can also be relevant to other physicians outside radiology to obtain relevant prior clinical information about a referred patient without having to redo examinations. With the advance of digitalization of radiology departments, the interchange of radiological image data between

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institutions is shifting towards shipment of CDs instead of physical film. Frequency of the transfer of image data strongly depends on the activities of the institution and the experts employed by the institution. A large university hospital with many referrals and many experts whose expertise is requested for second opinions will have a relatively higher throughput of radiological image data from outside than a small community hospital.

Although the shift from physical film towards CD for the transfer of radiological image data is a positive change in terms of costs and ease of shipping, it also has its disadvantages. One of the main problems is how to integrate these CDs into the normal workflow. Although most CDs are equipped with a dedicated viewer, these viewers are different per vendor and thus, users have to learn to operate many different software packages at a sufficiently high level. Furthermore, some of the software packages also require software installation on the local workstation, which is not always possible because of restrictions on software installation, imposed by the local IT department for security reasons. Sometimes, the CDs even do not contain any viewing software at all and only hold the DICOM images either with or without a proper dicomdir file.

The aim of this chapter is to provide insight to the reader about the current practice and possibilities in inter-institutional image data exchange. This concerns enormous amounts of image data that have to be transferred back and forth between institutions on portable media. In the near future, this will increasingly shift to the use of secure data transmission over the ever present internet, possibly in combination with large data centres containing regional or even nation-wide PACS archives of all patients. However, these initiatives are still sparse and most of them are not developed for the large amounts of data exchange as required in day-to-day radiology. Therefore, the main data transfer in radiology both for clinical and scientific applications is still done using portable media such as CD or DVD.

The possibilities and the advantages and disadvantages that come with image data transfer on portable media will be covered, based both on our own experiences in a large university hospital in the Netherlands and on the current status in literature and technique. Furthermore, a look into the near future will be made to explore the possibilities that are emerging in secure data exchange using so-called tele-medicine solutions.

BACKGROUND

In the majority of the hospitals the handling of the CDs is a major concern. Large amounts of CDs are shipped on a daily basis and they all have to be read by the receiving physician. Recently, Onken et al. reported on the situation concerning the exchange of radiological images on DICOM CD in Germany (Onken, 2007). In their paper they describe the test protocol they used to determine whether DICOM CDs provided by German radiologists comply to the DICOM and IHE rules or not. To achieve this they devised a three-stage testing protocol which can be found on the website of the initiative (www.dicom-cd.de. Using their, very restrictive, testing scheme they showed in a study of 65 CDs from 27 different vendors and 44 different products and versions that 74% presented with a violation of the specifications and 5% was defective or did not contain any DICOM files at all. Only 9% complied with all requirements, and 12% was usable but not fully compliant. Although the requirements set forth by this initiative are very restrictive and maybe not representative for the situation or requirements outside Germany, the study does show that the usability of CDs with radiological images can be a major problem. Especially since the results state that of the 80% of CDs failing the tests, the majority did not fail a test requirement, but failed to conform to the DICOM standard.

Besides the non conformance to the standards, reading CDs in a clinical setting can be hampered

by the following problems (Khorasani, 2006; Ooijen, 2005a):

- The viewing software on the CD is unknown to the reading physician because of which reading takes more time and possibly required functionality (e.g. measurements) is not available or cannot be found. These factors might results in a non optimal evaluation of the image data;
- The viewing software on the CD doesn't work. The viewing software requires local installation on the hard drive of the personal computer of the physician, which is not always allowed by IT security officers and therefore impossible. Subsequently, the physician is unable to read the image data;
- The Image quality of the images is dependent on the quality of the computer screen. Mostly CDs are viewed on workstations that do not have diagnostic computer screens;
- The CDs get lost or damaged and have to be requested again from the source institution.

As a consequence of the problems with the evaluation image data from CDs, unnecessary repeat scans can be requested because the previous scans from the CDs can not be used. This increases the burden on the patient and possibly also the radiation dose to which the patient is exposed. A small study of 77 CDs was conducted in the Netherlands in 2005 (Ooijen 2005a) in which information was recorded about the software viewer on the CD including the version number and the software vendor. Of these 77 CDs, 76 contained a viewer that either ran directly from the CD or required installation on the local machine. The 76 viewers were from 8 different vendors and included 11 different software versions. Major vendors used for the CD production proved to be Kodak (26%), Merge (22%), Agfa (18%) and AccuImage (17%). The remaining 17% was from the other 4 vendors. Several groups have implemented different, although often similar, solutions for the incorporation of the data contained on CDs into the normal workflow (Feron, 2007; Hackländer 2006; Lu. 2007; Ooijen, 2005a; Ooijen 2006b).

Involvement of Standards

Because of the increased use of CDs for image data distribution, standards and initiatives such as DICOM (Part 10) and Integrating the Health Enterprise (IHE) have included descriptions of the use of CDs for image data transport and the way they should be constructed. In this, DICOM only just defines the minimal requirements for the DICOM file format. IHE takes this a step further and besides conformance to the DICOM standard also covers the way the CD should be structured, the possibility of optional clinical data viewing and the implementation of data security.

To define this, the PDI (Portable Data for Imaging) profile has been developed within IHE. This profile aims to describe how CDs should be constructed such that media containing DICOM data and possibly also web browser readable data can be created and read anywhere. The structure of a CD should be a DICOMDIR file in the root with a subdirectory containing all DICOM images. Optionally other components such as index.htm, readme.txt and a directory of web files may be added. Rules for the content used in IHE connections are the following:

- DICOM Part 10 compliance. IHE_PDI web content corresponds exclusively to the DICOM content, although it need not represent the entire DICOM content. Other content will not be placed in DICOM or IHE_PDI directories, but may be placed in other locations on the CDROM;
- Do *not* assume that an application on the media will automatically be launched. IHE recommends that media readers not automatically run software on the media;

- Web content use of XHTML and JPEG formats is restricted to ensure interoperability;
- No compression should be used.

Furthermore, each viewer enclosed on a CD should indicate any DICOM file found that is not readable to the viewer and automatic execution of the viewer should preferably be disabled for security reasons. Although the IHE definitions are available, many companies are providing software and hardware for publishing DICOM CDs and they all have their own level of conformance to the IHE profile. Furthermore, in some countries rules are stricter than defined by the IHE (Onken, 2007).

IMPLEMENTATION OF A DECENTRALIZED UPLOAD SYSTEM

To solve the problems with evaluation of the image data from CDs that still remain regardless of the fact that standards were under development or finished, we included the image data from the CDs into the normal hospital workflow of a large, 1400 bed, university medical center in the Netherlands (Ooijen, 2006a; Ooijen, 2007). Figures for 2005 in our hospital were 31,458 hospitalizations, 115,019 first out-patient visits, 417,911 consults of which 31,970 at the emergency department, and 13,952 day care treatments. For many of these patient visits previous image data is required which could also be acquired outside our institution and thus has to be retrieved from the source. Only a couple of years ago the image data would still be sent to us on physical film, but nowadays, all image data is send digitally on CD. All the CDs that were sent to our institution for that purpose placed a high burden on the physicians and came with a difficult and complex workflow. Therefore, integration into the normal workflow was the only option.

To achieve this, all DICOM files from the CD are read, the DICOM header is changed (reconciliated) to comply with the patient ID and accession number used in our institution and the image data are either stored into the PACS or the webserver. The adaptation of the patient ID of our institution is required because, although a nation wide healthcare identification number has recently been implemented in the Netherlands, all hospitals still work with their own patient ID. Based on remarks in recent literature, this also appears to be the case in other countries (Feron, 2007).

In our solution only second opinion cases are stored into the PACS, all other image data are only stored on the web-server and will be automatically deleted after two years. To perform this, most ideal, procedure a software tool was developed at our department that handles all the image data transfer and reconciliation and which allows the decentralized preparation of the CDs. This means that any department can upload the image data from the CD using a standard PC running our application when providing a valid patient ID. After this upload, the image data will be transferred to the radiology department and handled by dedicated staff. The two main advantages in this are the increased speed because no time is wasted on sending the CDs through internal mail and the fact that the CD physically remains at the sending department and thus is available locally in case of emergency.

Implementation Details

A software package was developed at our department. This software package named DICOM Uploader allows reading all DICOM files from a CD on any workstation within our institution. After scanning the CD, the patient name and the available studies are displayed. The physician can then choose the relevant studies and after providing the in-house patient ID and some additional information, the selected studies will automatically be pushed to a server at the radiology department.

The big advantage is now that the CD remains at the physician and does not have to be sent to the radiology department. Thus, the physician can always access the data from the CD when needed in case of emergency.

At the radiology department, the data are retrieved from the server automatically using the DICOM Uploader software and stored on the local hard drive. After this, the same tool can be used to perform patient reconciliation is using a Dicom Modality Worklist (DMWL) capability. This reconciliation is performed during the transfer to the indicated DICOM node. After the transfer is completed, this is recorded in the DICOM Uploader software and the data are automatically removed from the ftp-site. Using the same DICOM Uploader software package, the physician who uploaded the CD can also track whether his/her CD has already been stored into the requested DICOM node or what the status is of the request.

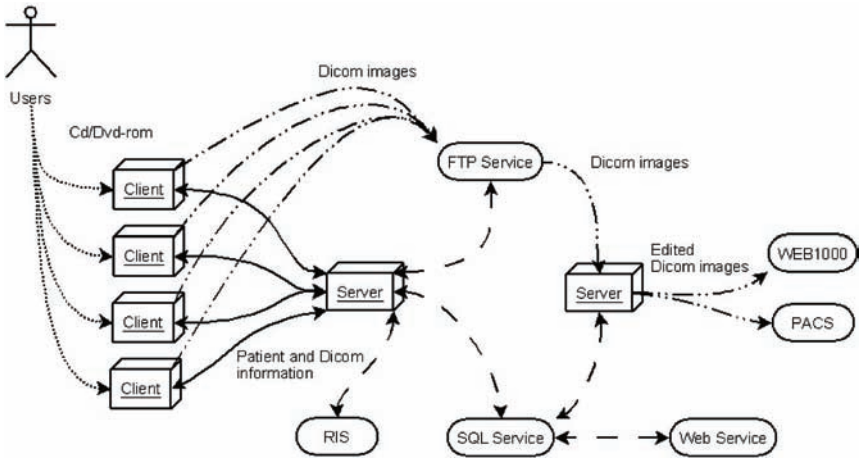
Implementation Overview

The DICOM Uploader software is build using a client and server model, this allows the simultaneous handling of clients. The client application provides three different basic functionalities including uploading CDs or DVDs, displaying detailed status overview of upload requests including advanced searching capabilities, and processing and reviewing requested uploads. The Server application is built on a modular framework containing several management modules for functions such as user management, request management etc. The most important modules will be discussed later in more detail below.

User authorisation is not part of the DICOM Uploader client or server applications, but is handled by a web server used to manage the users and rights. Statistics and graphs are built as web pages, which also allow to quickly add implementations of new statistics and graphs in the future. As shown in Figure 1 multiple client applications are connected to one server application. Multiple clients can initiate an upload action at the same time without decrease in performance.

When a user initiates an upload the files on the CD or DVD will be scanned for the DICOM patient information which the server uses to verify the patient identification with the information from the local RIS (*Radiology Information System*) to check if the upload is valid and the entered patient ID and name correspond to a possible entry in the RIS. When the verification is valid the client application will send the image data to

Figure 1. Dataflow overview of module interactions



the configured FTP service and the request will be available for processing.

This processing must be initiated by dedicated radiology users that are authorised to use this functionality. They can open the processing overview in the client to see the available requests and initiate an automated process. In this process the image data headers will be modified with the new local patient information from the RIS and study information by selecting an entry from the DMWL. After this, the server application will schedule the request for archiving to the appropriate DICOM destination. In the following sections we will discuss the interface of the DICOM Uploader client software and describe the various functionalities.

Login Screen

When the DICOM Uploader client is started a user authorisation form is being opened. The user is requested to enter username and password. When the user is authorised the application is dynamically modified to only show the functionality the user is allowed to perform.

Main Menu

When the user is authorised the main menu will be opened with at the maximum the following functionalities, depending on the authorisation level of the user:

- Upload a CD or DVD;
- Show an overview for request statuses;
- Show an overview to process requests;
- Logout.

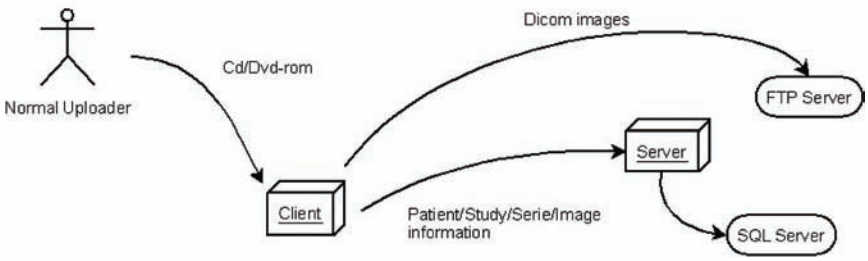
Uploading DICOM Data

The uploading part of the DICOM Uploader Client is designed for easy usage which allows using this application after only a very short training session over the phone. Figure 2 shows how this upload process is designed.

The whole process consists of the following steps:

- The user is asked to enter the CD or DVD in one of the drives available in his/her system (*the software is designed to be able to handle more than one drive*);
- The software is then scanning the inserted medium for available DICOM image data to upload and shows the user the available patient names (*when two or more patient names are found the user is asked to select the right patient)*;
- The software copies the patient DICOM image data to a temporary directory on the local machine and shows the user all the available studies. The user is then asked to select the relevant studies that need to be uploaded;
- The details of the relevant studies from the selected patient are shown for confirmation and the user is asked to enter the patient number of the local RIS record (*the*

Figure 2. Dataflow overview when uploading a CD/DVD



new patient identification number) and also select the DICOM archive destination; Optionally the user can also include remarks for the processing users. For example if the request should be handled with priority;

- The client application then initiates the request upload activity on the server which verifies the entered patient number against the RIS (*this Server to RIS connection is done by a HL-7 connection*).

When the patient's name, birthday, gender has similarities with the DICOM header patient details, a weighting is applied for the different properties which generates a value indicating the accuracy of the match. When the result from the similarity measures combined with the weighting system is below 80% the user is asked to verify the patient information manually (*only if the specific user is authorised to do a manual verification, if not the upload will be refused and the CD has to be handled by an authorised user).*The patient DICOM image data is uploaded to the defined FTP server and upon completion of the upload, the request is finalised for processing.

Status Overview

The request status overview can be used to easily find old or new requests by specifying a patient identification number or by selecting a day count. When a patient identification number is specified a historical overview is shown with all current and old requests from that particular patient. The history day count functionality is used for a quick overview of the processed requests of the past few days while the patient identification method is frequently used to check historical data and is used most of the time to reply to questions users about previous uploads of that particular patient.

Status Details

When a user wants to see a detailed overview of a request he can open a detail form from within the status overview. This detail form shows the current request status, the processing authorisation user and detailed process information with timestamps of processing events and reports. Also an overview is shown of the requested studies with all the required information.

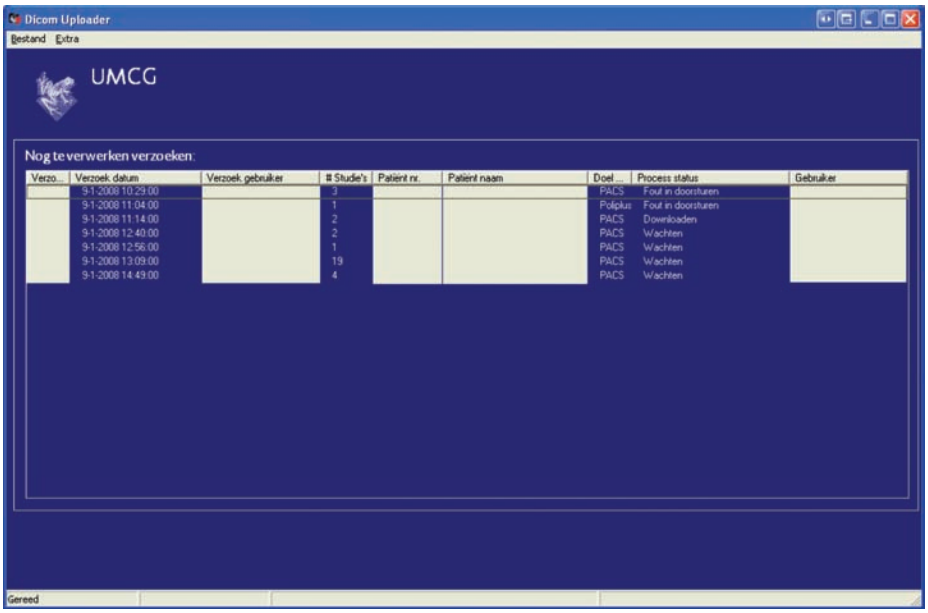
Processing Overview

Figure 3 shows a screen dump of the processing overview form. This processing overview shows the currently available requests that are waiting to be authorised for processing. From here a processing authorised user can easily see who uploaded a request, which patient the data is from (both patient identification number and name are given) and what destination it needs to be archived to. When a request is already authorised to be automatically processed it is still shown in this list with an indication of the user that authorized the upload.

Every request has to go through the following request process statuses to reach the end of the processing cycle:

- Open (*The request is new and has to be authorised for processing*);
- Waiting (*The request is authorised for processing but is waiting in a queue to be handled*);
- Downloading (*The DICOM image data belonging to the request is being downloaded by the server*);
- Processing (*The headers of the downloaded DICOM image data are being modified to correct the patient identification number and the accession number based on the DMWL to be correctly stored into the new DICOM archive location*);

Figure 3. Request processing overview screenshot



- Transmitting (*The modified DICOM image data is being archived to the desired destination*);
- Failure (*For all the processing statuses there is a failure status to indicate where the problem is located, when this occurs the processing user is required to manually handle the request*);
- Finished (*The request is correctly processed and archived and will not be visible anymore in the processing overview*).

Processing Details

Figure 4 shows a screen dump of the processing details form. Using this form the user can authorise a processing action for the request or change the process status, destination archive, and remarks manually. When a request has the "Open" status the server automatically requests the needed DMWL (*DICOM Modality Work List*) entries to allow reconciliation. (*This server to DMWL server connection is realised through a DICOM protocol*).

After the available DMWL entries are listed for a particular request, the processing user can select the correct DMWL entry of the request and the functionality to start automatic processing will be enabled. When a request is already in one of the stated processing statuses, besides the Open status, the process cannot be interrupted nor modified unless a failure process status arises.

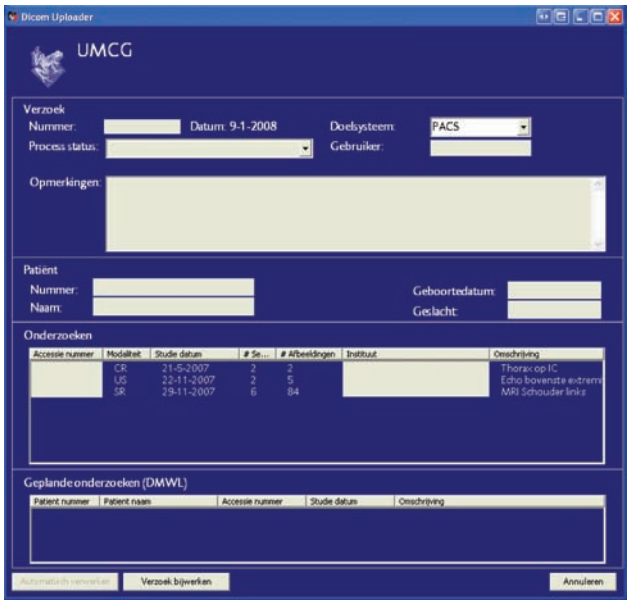
Technical Implementation

One of the requirements when designing this software tool was to allow easy further development of the tool with easy extension of the server software with extra functionality. This requirement was met by using a dynamic Framework of modules for the server design.

Technical Framework

Figure 5 shows the basic design of the DICOM Uploader server. The application starts at the DICOM Uploader Server object, from here the server creates Resource Management, Session

Figure 4. Request process details overview screenshot

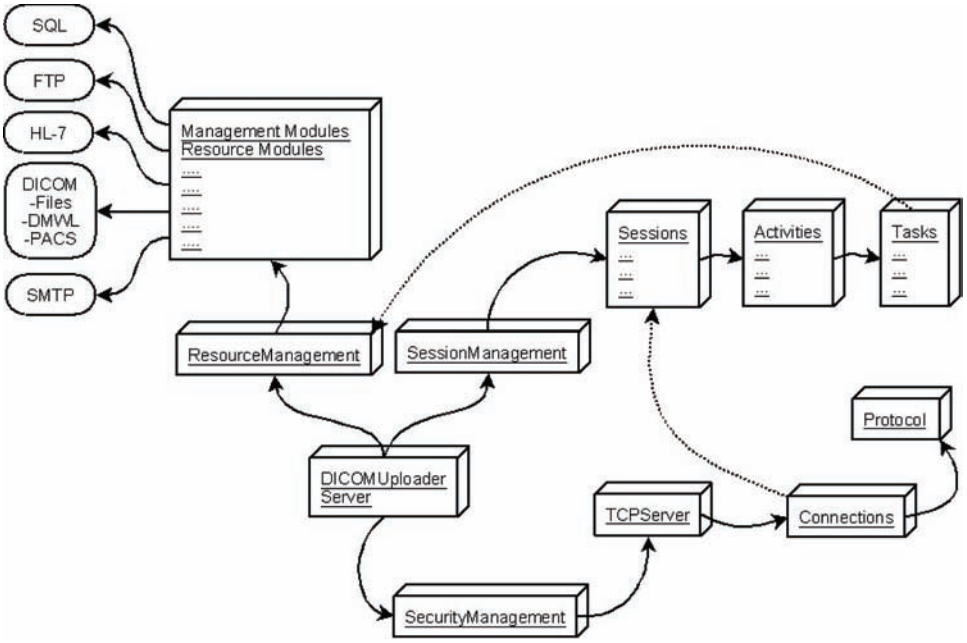


Management and Security Management. For safe operation and future functionality the Security Module supervises the TCPServer connections from al the Clients. When a client connects with the server it will be authorised by the Security Management if the user has the right authorisation. After this the connection will be forwarded to the Session Management and the client can start the various activities (for example an upload activity). Activities will be executed with multiple tasks that execute certain actions from the pool of resource modules. The eleven most important resource modules are:

- User management (*used for authorisation*);
- Request management (*Handles the requests*);
- Request processing management (*Handles the process of a request, by using multiple management modules*);
- DICOM files management (*Handles the image files and modifies the image headers*);
- DICOM transmit management (*Handles sending image files to multiple DICOM receive Nodes*);
- FTP management (*Handles the files on the FTP Service*);
- HL7 management (*Handles the communication to a Radiology Information System to verify the requests that are being uploaded and processed*);
- SMTP management (*Handles sending E-mails to users to inform them about process statuses*);
- DMWL management (*Handles the DICOM Modality Work List service*);
- Scheduling management (*Handles the scheduled tasks such as request processing and FTP cleanup*); and
- Logging management (*Handles the logging of all events in the server application).*

Every management module has access to resource modules and can therefore execute the various tasks available to handle the clients. The design described above allows for quick implementation and configuration by the use of XML

Figure 5. Basic modular design overview with services



oriented configuration for every management or resource module. For instance, if the server needs to connect with a MySQL Database, MS-SQL Database or different FTP servers it can be configured to work with these services. When the server can not handle the load of al the processed requests anymore, this design also allows multiple instances of the server to process multiple requests at the same time. At the University Medical Center Groningen in the Netherlands there is currently a double setup with two server instances to handle the upload requests and request processing separately.

This design also implements a scheduling management for certain tasks that need to be executed on a time interval. For example the FTP server holds all the uploaded requests for processing. When these are processed they are not deleted directly, instead a scheduled task will automatically delete the processed requests after a configured time to allow a reprocessing during this time in case of possible unknown failures in the destination archive.

Usage Statistics

The graphs in figures 6 and 7 show the number of CDs uploaded at our institution with a subdivision of the number of CDs uploaded by the radiology department versus by other departments (figure 6) and a subdivision by storage in the PACS or in the Electronic Patient Record (EPR) (figure 7). A trend of a shift of uploading to the departments outside radiology is clearly visible (figure 6) and the amount of data stored into the PACS is relatively stable (figure 7). If we assume an average data content per CD of 200 MegaByte, then the number of CDs stored per month currently requires an average of approximately 150 x 200 Megabyte = 30 Gigabyte per month added to the PACS resulting in an average of 12 x 30 Gigabyte = 360 Gigabyte per year (which in our case results in about 3.6% of our current total annual data storage of about 10 TB/year). The institutional webserver has to approximately store an additional 550 x 200 Megabyte = 110 Gigabyte per month resulting in a total of about 1.7 Terabyte per year (0.36 TB forwarded from the PACS + 1.32 TB direct storage).

The current figures show that average number of CDs per month was 505 CDs/month in 2006 and 722 CDs/month in 2007. Other authors even report numbers up to 400 CDs per week (Feron, 2007) in their institution.

User Satisfaction with the System

To evaluate the value of incorporation of the CDs into the normal workflow, a questionnaire was sent when the new procedure was running for a couple of months in 2006 to all users to evaluate the satisfaction with the current facility and to evaluate possible improvements (Ooijen, 2006b). Several quality parameters on speed and satisfaction were rated on a 5-point scale (1=bad to 5=excellent). Replies were obtained from 17 different respondents from 10 different departments, accounting for an average of 76 CDs per week. Mean (median) results showed a score of 3.6 (4) for handling time, 3.4 (4) for archival of second opinion data, 3.8 (median 4) for archival of external data onto the web server, and 4.5 (median 5) for the overall performance of the current procedure. These results clearly show that, although some improvements can be made, storage of the study data from CDs from outpatients into PACS and web server provides for an existing need. Using this service, physicians can access the data with ease and familiarity. User satisfaction with the provided solution is high.

Clinical Relevance

The increased clinical value of the integration of the patient image data from CD into the clinical workflow is demonstrated by the increased level of patient care by providing all relevant prior examinations at sufficient diagnostic quality. Furthermore, the CDs are no longer being shipped around the hospital but remain with the referring physician who can always directly access the

Figure 6. Graph showing the number of CDs uploaded per month subdivided into CDs uploaded by the radiology department and CDs uploaded by other departments

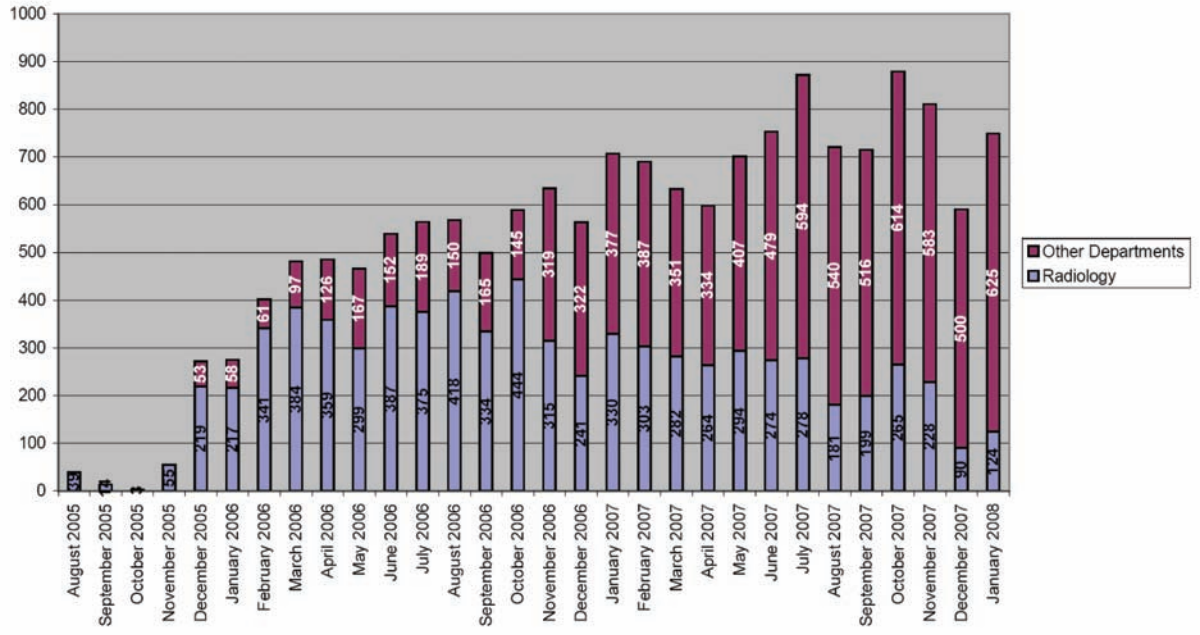


Figure 7. Graph showing the number of CDs uploaded per month subdivided into CDs uploaded to be stored into the picture archiving and communications System (PACS) and CDs uploaded to be stored in to the electronic patient record (EPR)

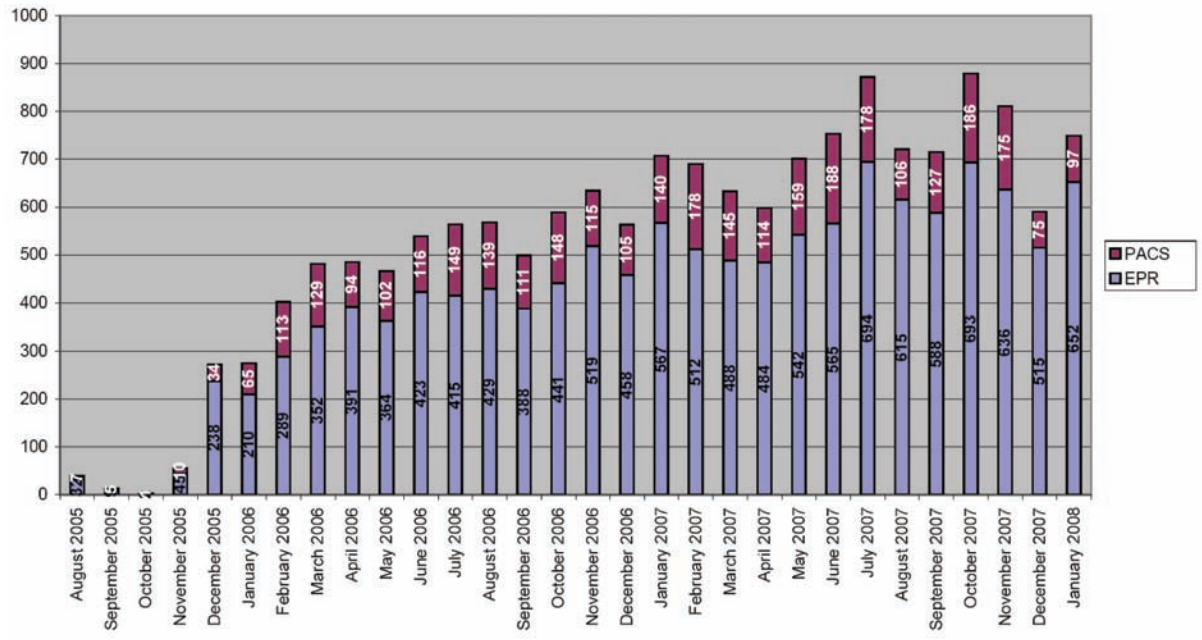


image data from the CD in emergency cases and CDs cannot get lost. Another, somewhat smaller, advantage is the ability to track the status of the upload and being able to supervise the process.

DISCUSSION AND CONCLUSION

Generally, a main point with the data exchange between institutions remains that the source of the data should always be recognizable. Not only for possible referral, but also because difference in image quality, scanning protocols, and incorrect examinations can occur. In such cases it must be clear that the data does originate from another institution. In our case we solved this by entering the study descriptions "EXTERNAL DATA" and "SECOND OPINION" into the radiological information system. This study description is given to all imported data. Other implementations like by Feron et al. (Feron, 2007) use a similar approach with identification of external data in the study description.

A presentation by Lu at the annual SIIM meeting of 2007 (Lu, 2007) raised an important question which is also valid in our research, the balance between recreating every RIS study code for every study on the CD and a single code for all outside studies. Currently, this balance is mainly set by the available time since recreating every RIS study code by hand is very labour intensive. Furthermore, new study codes have to be made indicating that the study was acquired at another institution to avoid confusion (Feron, 2007).

A shortcoming of our system which is also still apparent in the solutions of other institutions (Hackländer, 2006) is the manual entry of the studies in the RIS. This issue was already tackled by Lu et al (Lu, 2007) where they generate an HL7 order based on the modality and body part

as included in the DICOM header of the studies that are sent for upload. Feron et al (Feron, 2007) propose a solution where they automatically generate a more generic code for the whole study and afterwards a employee of the radiology department will manually attach the correct study description. Using this approach they claim that the data is already available under a generic name and the employee of the radiology department can adjust this afterwards without any time pressure.

Problems that can still occur with the use of portable data are CDs containing proprietary, non-DICOM, formats which cannot be processed, and CDs that fail to upload to the PACS. In all cases these are CDs that do not conform to the IHE profile for Portable Data for Imaging (PDI).

Trends Towards Telemedicine

A current trend is the transition to telemedicine in which patient image data will be made readily available at a location different than the location where the image data were acquired. Large projects are running in multiple locations in regional, national and international setups (Engelbrecht, 2007; Tachakra, 2007). However, a limitation of most of those projects is that they focus on a central database which runs parallel to the own hospital systems and thus image data are not integrated but 'merely' available. Furthermore, another limitation is that some of these projects do not concern full transfer of radiological data but limit themselves to text extended with a limited number of images similar to the content of most electronic patient records.

One step further is advocated by, for example, the Globus MEDICUS project (Erberich, 2007) in which it is proposed to use grid technology to construct a large medical imaging grid which functions as a inter-institutional PACS. Using this methodology multiple sites can be connected together through secure protocols using the standard available world wide web connections. Using these connections, a virtual PACS system is defined in a grid. Within this grid, the location of the imaging data is known within the grid and any party within the grid can access any data to which access is allowed transparently from his or her own workstation. Authorization to access data in the grid is covered by role-based access rules to ensure the privacy and security of the medical data contained in the grid.

CONCLUSION

The current practice still involves handling CDs and this will probably remain like this for the coming years. Implementations such as the one described here will allow keeping up with the increasing amounts of CDs. Results in user questionnaires and production numbers really show the success of the implementations. Current implementations in different institutions allow fast and easy integration of patient image data from CDs into the normal clinical workflow. It is shown that this increases the level of patient care by providing all relevant prior examinations at sufficient diagnostic quality.

Future Research Directions

The current practice of image data distribution using CD and DVD will lead to further development of the IHE profiles involved. Furthermore, in the next few years all vendors of CD publishing software and hardware will be forces to conform to the IHE profiles and the problems now existing with the import of the image data will decrease significantly.

Although using CD, or currently even DVD, is now commonplace, the future will show an increased direct digital connection between hospitals which will bring a whole new challenge concerning the synchronization of databases and questions like whether image data should be copied or only references to the image data should be available outside the institution. To solve this many vendors

are advocating their own solution to the problem varying from a large central data centre that can be accessed by a web client to a direct copy of the image data into the other institutions PACS using a secure connection. All these different solutions have their own advantages and disadvantages.

Within our research, the future directions are already starting to get shape. Main issues are the automatic entry of the visits on the CD into the RIS. Furthermore, current research is focused at the implementation of the same procedure outside the hospital walls and to allow other hospitals to directly upload their data into our system without all the overhead concerned with burning CDs. In 2008 this software and his architecture is extended with new and better functionalities to automate this whole process even more. The need for CD and DVD media is still growing but new technologies, such as the still growing usage of VPN (*Virtual Private Networking*) over the Internet, will lead to the near eradication of the CDs and DVDs for image data distribution.

A more difficult topic will be the internationalization of healthcare. A trend which is already visible to some extent in Europe is that patients will start to get patient care not only from a different hospital in their on country, but also from hospitals abroad. This will again provide difficulties with the interchange of image data because of the inconsistencies between databases, especially the patient ID will again be a major problem. Therefore, besides the current nationalization of patient IDs, a internationalization or even globalization may be advantageous in the future.

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APPENDIX A

Key Terms and Definitions

Transfer of radiological image data between different institutions is an important issue in the diagnosis and treatment of patients. To solve the problems with evaluation of the image data from CDs that still remain regardless of the fact that standards were under development or finished, we included the image data from the CDs into the normal hospital workflow. Using this service, physicians can access the data with ease and familiarity. User satisfaction with the provided solution is high.

Although the IHE definitions are available, many companies are providing software and hardware for publishing DICOM CDs and they all have their own level of conformance to the IHE profile. The increased clinical value of the integration of the patient image data from CD into the clinical workflow is demonstrated by the increased level of patient care by providing all relevant prior examinations at sufficient diagnostic quality.

Although direct network connection between institutions is currently being developed and deployed, in the next decade CDs will remain to be used and the integration of the data into the normal workflow is a must. Enormous amounts of image data have to be transferred back and forth between institutions on portable media. In the near future, this will increasingly shift to the use of secure data transmission over the ever present internet, possibly in combination with large data centres containing regional or even nation-wide PACS archives of all patients.

Chapter 10
User-Centric and Inclusive Design Methods:
Implications for E-Healthcare

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ABSTRACT

This chapter discusses the role of user-centric and inclusive design methods in healthcare pathways. The rapid uptake of e-health technologies by clinicians and healthcare managers to administer, for example, patient records, has meant that user-centered e-health tools and processes should be adopted to enable those receiving healthcare to become more involved, more proactive in, and more responsible for their own healthcare and its planning. An argument for a user-centered approach as good business practice can also be made. The three case studies described in this chapter are united by a concern for the individual, the end-user, at the heart of healthcare processes, and how design methods, which have a strong emphasis on the consumer or user perspective, can assist the changing requirements for healthcare delivery through an improved, earlier and ongoing engagement with the recipients of health care.

INTRODUCTION

With the rapid uptake of e-health technologies by clinicians and healthcare managers to administer, for example, patient records, it is of equal importance that user-centred e-health tools and processes be adopted to enable those receiving healthcare to become more involved, more proactive in, and more responsible for their own healthcare and its planning. Design methods and processes, with

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their strong emphasis on the consumer or user perspective, can assist the design and delivery of healthcare to ensure that decisions made are more representative and equable, and foster positive new relationships between health professionals and their patients. This chapter discusses the role of user-centric and inclusive design methods in healthcare pathways through three case studies.

CONTEXT

The Age Shift

The ageing of populations is a phenomenon occurring throughout much of the developed world due to reduced total fertility rates and an increase in life expectancy. This is characterised by an increase in the proportion of the elderly, which is growing at a faster rate than the population of the world as a whole. The numbers of older people has tripled over the past half century and will more than triple in the next. The 20th Century saw life expectancy rise in the developed world by 30 years. Projections by the United Nations (2006) show that by 2030 at least half of the Western population will be over 50, with a life-expectancy for 50 year olds of a further 40 years, and that by 2050 the proportion of 65+ in the EU will comprise approximately 28% of the total population. Ageing in some regions will be particularly acute: in 2004, China's elderly made up just 11% of its population, but by 2040, the UN predicts (Jackson & Howe, 2006) that this will increase to 28%, a larger proportion than for the US. Alongside changing demographic and improved healthcare there has been an accompanying shift from a predominance of infectious to chronic diseases. As populations age, the numbers affected by associated impairments increase, and pathologies tend to be complex in the geriatric domain (Isaacs, 1965). In older populations, the diversity and range of physical, sensory, and cognitive capabilities are higher as is the likelihood of co-morbidity.

Drivers in Healthcare Policy

Change Towards People-Led Policies

This change in population demographics and associated health conditions has been one of the drivers of change in healthcare policy and delivery. The consumer of healthcare has traditionally been seen as the passive recipient; however, with recent policy changes as well as the introduction of the idea of the 'expert patient' there has been a move to acknowledge the patient perspective to a much greater extent. Although patients and professionals may share the same goals, *i.e.* the successful management and treatment of the patient, they do not necessarily agree on the important routes to those goals. One can often see healthcare organised for the convenience of the management of an organisation or its clinical staff and most solutions are geared towards either of these ends. However, in many regions there is a shift towards prioritising more the end-beneficiary and to encourage people to take more responsibility for some of their health outcomes by creating a patient-led service (NHS Scotland, 2005a). One example of the shift in thinking is a desire to bring the views of the public and patients into planning, delivery and development of NHS services (NHS Scotland, 2005b) with the aim that patients 'experience a smooth and quick journey of care' (NHS Scotland, 2006).

Patient Pathways

By their very nature, healthcare services are complex systems, and the means to achieve this priority shift requires user-centered processes and methods, and ones that can deal with complexity. Traditionally, many of these complex systems have tended to be articulated in writing, but this historical approach has proved inadequate. However, while clinical models and technologies for managing and sharing patient information (primarily clinical) have evolved significantly, the tools to

engage healthcare consumers with *their* priorities and perspectives are still relatively rudimentary, if they exist at all: very often the individual is disenfranchised from decisions about his/her care and not empowered to assist more effectively in his/her own recovery.

Social scientists have investigated the patient's perspective in healthcare for some years, primarily using qualitative methods but the concept of patient pathways, as a tool for facilitating improved healthcare delivery as a vital part of healthcare reform, appears to be relatively recent. Visual process maps appear to offer an improved way to, *e.g.,* portray patient pathways or journeys through healthcare but the way these are visualized is still in its infancy. In 2002, for example, design consultancy IDEO redesigned the DePaul Health Centre USA, and developed a Patient Journey Framework, primarily concerned with the physical orientation of ambulatory patients making a journey through a health centre (Metropolis, 2002). This considered and presented both the clinician's and the patient's understanding of that journey, two mutually valid and complementary perspectives. In a 2004 scoping study on design issues for patient safety, maps of medication and information flow were created (Clarkson, 2004). These included a patient-centred map of the healthcare system, a map for self-prescribed drugs administered at home, and a map for prescribed drugs administered by the patient. In these maps, the patient is at the centre 'surrounded by healthcare professionals who might interact directly with them. Further out lies a layer of equipment, software, and medication stock. The outermost layer comprises companies and organisations involved in the healthcare supply chain.' These patient maps describe the relationship of patients to systems of equipment, medication, and companies.

In 2005, the Scottish Executive (SE)'s Centre for Change and Innovation (CCI) developed models of Patient Pathways of Care (PPC) (NHS Scotland, 2005b). It was claimed that the impact of mapping out the whole pathway and process, and reducing the number of elements in the process, appeared to have produced some very profound changes resulting in a significant reduction in patient waiting times, which can only be good for quicker patient diagnosis and treatment. There was encouragement by the SE for General Practitioners (GPs) to utilise these new pathway models, where it was expected that GPs discuss with their patients where they fitted on a pathway, what they could expect to happen next, and to discuss available options. On closer examination, however, these PPC's represented a pathogenic-centric, rather than a patient-centric view, describing a set of clinical areas such as cardiology, dermatology, orthopaedics, and urology, and described e.g. the clinical stages of diagnosis, referral and treatment.

In a more recent exercise, by the National Rheumatoid Arthritis Society (NRAS), mapping the patient's journey with rheumatoid arthritis, acknowledgement was made of the need to make sense of the often-complex journey in negotiating the healthcare system, and of 'how confusing, stressful and sometimes convoluted the experience can be to the patient' (Oliver et al, 2007). The NRAS 'maps' summarise patients' contact with the healthcare system, with consultants, and various tests, but also include a summary of patients' own comments about their views of certain consultations and treatments (e.g. frustration at being rushed, poor communication, health benefits from a certain change in lifestyle, etc.), and also the financial consequences to the patient (e.g. loss of pay, sickness benefit, travel costs for treatment, prescription charges, etc.). These inclusions in this form of mapping are significant as, alongside clinical information, they represent a fundamental shift in consideration of issues that are important to the patient.

In addition to increasing the efficiency and security of sensitive information about patients, the development of any e-health system and technology will require to provide the means to engage and benefit from the knowledge and

experience of its healthcare consumers: they are an under-utilised resource, and if not adequately factored into healthcare systems, these systems will never be optimised, and may well fail to achieve their goals.

The Changing Nature and Role of Design

Inclusive Design: From Margin to Mainstream

Within the world of design, there has been a tradition of designing for older and disabled people, but this was, until relatively recently, seen as largely outside the concerns of mainstream design. However, a recent and increasingly valid movement in design has challenged and is changing this view. Firstly due to advocacy from disabled veterans returning from the Vietnam War to create 'barrier-free' environments, and then from disability rights campaigners demanding 'accessible' environments and services, the concept of 'inclusive design' has gained momentum and emerged as a strong philosophy to embrace the needs of these groups – and others - within mainstream design. Inclusive design is manifest under many different banners such as, e.g., 'inclusive design' (ID) in the UK, 'universal design' (UD) and trans-generational design in the US, UD in Japan, and 'design-for-all' in Europe. UD has been embraced to a significant extent in Japan, driven by the recognition of the need to address significant challenges deriving from the changing profile of population demographics: Japan is now a 'super-ageing' society, i.e. more than 21% of the population over the age of 65, and such a large sector cannot be ignored.

Inclusive and User-Centred Processes and Methods

Following on from this growth in an 'inclusive' philosophy, design has broadened its focus from predominantly a product-focus to one which also includes processes and systems that are 'inclusive' and 'participatory'. This shift also recognises the latent expertise and experience within 'lay' individuals who may help provide insights and perspectives previously unavailable into the planning and design of healthcare provision processes. In its Red paper, the UK Design Council's 'Health: co-creating services' project (2006) focussed on health in the community and explored two areas, 1) diabetes and 2) encouraging activity and exercise, and two key processes, 1) 'co-design' and 2) 'co-creation', engaging individuals to help provide the key to solutions that might work. Philips Design, in developing healthcare technologies and products, used insights obtained from people at the early stages and throughout its innovation process collecting data by 'multiple encounter' 'people research' techniques (Rameckers and Un, 2005). An anthropological tool, the 'cultural probe' (Gaver et al, 1999), now widely adopted by the design community, has been adapted, in some cases, for healthcare settings (Crabtree et al, 2003). Simultaneously, there has been the growth in user-centred research methods typified by the Methods Lab (Aldsersey-Williams et al, 1999).

What characterizes these processes and methods that have evolved from the design and social science professions is that they are designed to engage end-users and to get close to and understand users' perspectives, needs, motivations, and values. A pressing question here is how these methods in design can be more widely recognised and employed to understand and provide for future patient needs and goals in e-healthcare scenarios, and to improve healthcare services. Not only will tomorrow's populations be older but, in a consumerist society, they will be more demanding in how they choose to live and accommodate age, disability and illness. This will require not only effective healthcare strategies for adapting to the large range of limitations and rehabilitation requirements of an ageing population, but also flexibility in the means to enable

active, healthy ageing, socialisation, independence (DTI, 2000), and to maintain dignity and a sense of well-being.

CASE STUDIES

The following three case studies are united by a concern for the individual end-user at the heart of healthcare processes and how design methods, which have a strong emphasis on the consumer or user perspective, can assist the changing requirements for healthcare delivery through an improved, earlier and ongoing engagement with the recipients of healthcare. The first case study is concerned with the visual mapping of pathways of health and healthcare and exploring how these can more holistically represent a number of different perspectives to include the patient's and that will allow a more strategic approach to the design of products, environments and services. The second demonstrates a means of sharing, more widely, specialist biomechanical data on older people's muscles and joints as they perform daily living activities, achieved through an innovative visualization method. This enables a range of specialist disciplines concerned with older adults' health and wellbeing, as well as older adults themselves, to engage in a discourse shaping the design of the built environment and healthcare pathways. The third case study is concerned with the design of Information and Communication (ICT) product interfaces, taking into account generation effects particularly amongst older users, which has implications in e.g. self-medication and self-monitoring in e-healthcare.

Case Study 1: Design and Healthcare

The following case study was concerned with bringing the two fields of clinical healthcare and design together and exploring some of the issues surrounding mapping healthcare pathways. The *Ideal States* (Macdonald, 2007) research cluster was formed in Glasgow between individuals in the two fields of design and clinical healthcare, both concerned with people-centric processes and practices and in how to respond to healthcare and quality-of-life issues associated with an ageing population. The cluster ensured that advocates for its older subjects, such as carers, public health and human factors professionals, were represented in some of the activities. Cluster members included the head of a department of medicine, a professor of geriatric medicine, a professor of women's health, a project manager for a stroke therapy evaluation programme at a local hospital, a senior consultant in human factors, a sociologist, an academic architect, and a design researcher.

The local socio-cultural context was crucial to this research activity in that the west of Scotland faces the same spectrum of health and social issues as the rest of the world's post-industrial economies, but in a more virulent form (Hanlon, 2004). The research study was grounded within this context, with the ageing population and associated chronic disease, in particular stroke, providing the focus. The cluster's title, 'Ideal States' referred to the aspiration of the two separate fields to collaborate more effectively to the benefit of a healthier community. Its aims were:

1. To identify ways to better understand one another's fields, and by so doing;
2. To explore how and in what ways the two fields could effectively collaborate to bring mutual benefit, through design thinking, to those individuals experiencing ageing, change in health, illness and disability; and
3. From the outset to engage designers, clinicians, healthcare professionals, and patients in this discussion.

Inclusive Process

The cluster was keen to continually reference the discussion back to the specific context of healthcare in its community: it was important to

the cluster that the voice of the subjects, *i.e.* older and disabled people, was introduced early on. Interestingly, a very simple technique, now commonplace in design research, was used to promote discussion in one of the many workshops that took place. Subjects were provided with a disposable camera and questionnaire and asked to document what enhanced or provided an obstacle to their quality-of-life during a typical day and then to discuss the findings at a subsequent group session. The subjects' photos were video-projected at a scale large enough (2-metres wide) to allow group discussion and comment. Common issues were identified, as well as those unique to each individual. This approach generated a sustained level of interest for the duration of the project with the healthcare professional members of the research cluster. Carers were also asked to participate in the same activity, which provided a complementary perspective. Clinicians were witnesses to the issues and agenda decided, for once, by their 'subjects'.

Focus on Stroke

Because of the enthusiasm of its geriatrician, the Ideal States cluster agreed to explore patients' pathways through their experience of strokes. Stroke pathology is complex, and the west of Scotland has a particularly high incidence of this chronic disease. Early attempts to describe a patient's pathway through the onset, acute and rehabilitation phases of strokes revealed how inadequately this was currently being described. However, it was felt that if this could be described in a visual format it could be shared between different fields of expertise and with non-specialists. This lack of existing useful mappings proved an incentive, particularly on the design side, to really understand what happened to a patient as s/he progressed through healthcare from one stage to the next, and to be able to describe that to patients.

Mapping Pathways

The cluster's early pathway mappings tended to describe somewhat simple and linear pathways and did not reflect the complexities of pathology, need and expectation, or the full context of healthcare and the professional and human relationships within these. Given that, as previously stated, pathways tend to be described by clinicians these tend to be described from a pathogenic-centric point of view. In one discussion about strokes for example, it was revealed that a stroke team's contact with a patient in a rehabilitation ward apparently accounts for only 45 minutes of a patient's 24 hour day; the patient may be left in their bed for 60% of the time and spend most of his or her time alone. It was recognised that this non-contact time was not 'designed' in any effective way to actively engage the patient in purposeful activity and as a means of hopefully assisting recovery. During a survey of patient mappings, one also recognised that the patient's voice would become increasingly important to hear as the patient moved out of the acute phase, through rehabilitation, into the community and back home. Given that healthcare managers often lead the introduction and development of e-health systems, the patient voice and perspective will need to be factored into any e-health system.

Case Study 2: Visualizing Data and Information on Older Adults

This second case study describes the development of a tool to visualise biomechanical data obtained from the functional demand on the joints of older people and then portrayed in an innovative visual manner (Macdonald et al, 2007). This was originally conceived as a tool to assist designers when designing products, environments and services for frailer older adults. However, it has been found to have the potential to facilitate discourse across the range of professionals who have an interest in the healthcare and well-being of older people, and

to enable older people themselves to participate in this discourse.

Context

In order to reduce the cost 'burden' for their care and to improve their quality-of-life and well-being, it is essential that older adults are able to live as independent a life as possible where they can have control of their environment, satisfaction in their daily living activities, and enjoy greater social inclusion, quality of life and well-being. While the physical changes caused by the ageing process cannot be arrested as yet, it is possible to alleviate the implications of the ageing process by changing attitudes to health and exercise, by increasing understanding of the effects of daily living activities on older adults, and through the appropriate design of the environment and products with which the older adult interacts.

In the last two decades there have been numerous research programs associated with four facets of ageing including fitness, joint range of motion, muscle strength and cognitive ability. For example, a reduction in quadriceps muscle strength (an impairment) will affect the ability to climb stairs (a loss of functional ability) which in turn will reduce the quality-of-life due to problems with stairs (a loss of participation) (WHO, 2001). Similarly, atrophy will affect a person's ability to reach, hold and manipulate objects. Overall fitness classification is a popular indication of the activity level of which an older adult is capable (Wood et al, 1999). However general fitness does not necessarily imply an ability to function normally within the physical environment. This can only be determined by studying the older adult undertaking functional tasks related to daily living. The functional demand (how hard the muscles are working relative to their maximum strength) placed on older adults during the normal activities of daily living is of concern to a broad range of health professionals and designers, as well as clients and their carers.

Capturing Data

A Health Promotion England report (DTI, 2001) indicated that the main causes of fatal accidents for those aged over 65 years were from falls on stairs and steps (62%), transits between two levels such as rising from a chair (15%), and mobility on the same level (13%). Accordingly for this project, the decision was taken to focus on the measurement of hip and knee strength for the lower limbs. Accordingly, data was captured from whole body movements of 84 older adults in the 60+, 70+, and 80+ age categories during activities of daily living using a 3D motion capture system together with reaction forces measured by force platforms. A prototype tool was developed to convey visually the complex biomechanical functional movement and strength data produced from functional demands on the muscles and joints of older adults while performing a range of daily living tasks.

Understanding Data

The users of this data were originally conceived as being designers of facilities for older people. Understanding functional demand is of particular importance in the case of designing for older people to ensure that products are usable and match capability without causing injury (Rowe et al, 2005). To date, there has been very limited information available for designers about the functional demand. However, what information that has been available, e.g. numerical data or graphs of joint moments, joint angles and functional demand data, was found to require skill in interpretation and a level of biomechanical comprehension and training beyond most of the design community which the researchers wished to reach, involve and educate, and if there was a level of comprehension, then it was time consuming to interpret the data. In addition to the general lack of information, any information that is available is too often presented in a format that is at best

onerous to use, at worst incomprehensible, and fails to recognize the needs of the designer or the processes of design. As the interaction between people, products and environments is a dynamic process, the typically static representation of information in statistical tabulation formats proves of questionable value to a designer. There is a real risk of a designer misapplying what information is available, which at present requires specialist knowledge, interpretation and calculation. Current information sources also tend to ignore the design environment and tools with which they work, particularly the predominant use of CAD software in the design process.

Other Tools and Models Used in Design

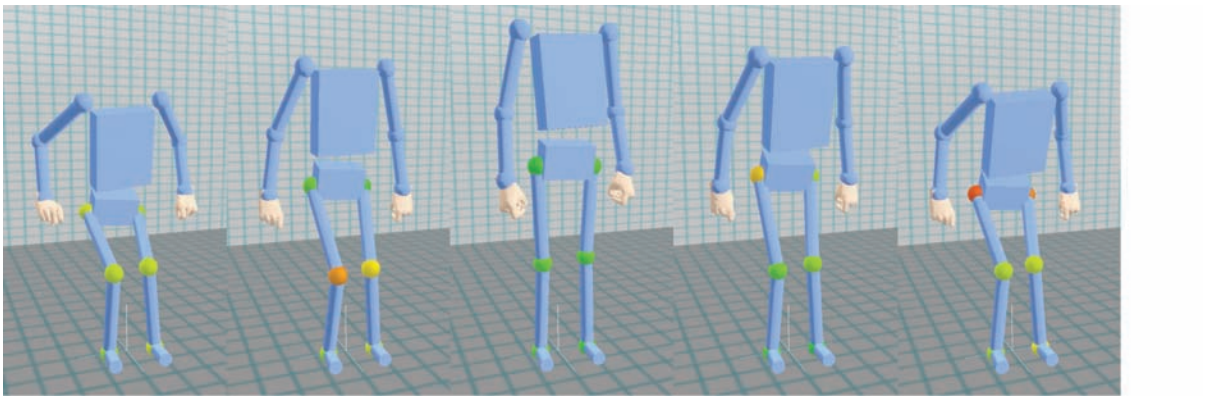
The lack of capability information for designers and tools and strategies to apply it have also been recognized in recent research, for example, HADRIAN, which works in conjunction with an anthropometric CAD package, is a multivariate database containing data on anthropometry, joint mobility, reach volumes, and posture-based task capabilities for 100 people, the majority of whom are older or disabled (Porter et al, 2004). The data are maintained as individual data sets used to inform design decisions by highlighting the capability issues of individuals within the population. The database also contains task capability data on a range of kitchen tasks performed by subjects, lifting and moving weights defined by comfort maximums reflecting the maximum weights these individuals were likely to lift. The ability to perform tasks and the way in which tasks were performed was recorded and converted into postural codes that could be used to predict behaviour for similar tasks in different situations. Another, more conceptual, tool is the 'inclusive design cube' model (Keates and Clarkson, 2003). This is a means of describing the whole population in terms of functional (mobility, sensory, and cognitive) capability and providing a visual record of the level of inclusion/exclusion for each capability. Used during a seven-level design process its aim is to minimize the numbers in the population excluded by any design, by facilitating the consideration of the full range of functional capabilities of the users who wish to use them.

The Glasgow Prototype

To achieve the usability and accessibility of the data, and to create visualisations which could be taken to designers for subsequent evaluation, a prototype software tool was developed, implemented in Visual C++ and OpenGL, which displayed real-time generated 3D animated visualisations of each of the individual participants performing the daily living activities. The animated human model consisted of simple cylindrical or block representations of the body segments from the VICON model rendered frame by frame in three dimensions. The tool enables the viewer to select a participant (selection by age and gender) and an everyday living task and view a 3D animated model of the participant performing that task. Reanimating the motion capture data provides the viewer with the opportunity to alter the viewpoint to any angle and zoom in or out to examine the motion.

In order to express the functional demand visually, each segment was connected to the next segment by a node representing the joint as a variable-colour sphere. Functional demand was represented on a continuous colour gradient from green through yellow to red. A green colour was shown where functional demand was below 40%. At higher functional demand but still within acceptable limits (between 40% and 80%), the shades of colour of the sphere ranged from green/yellow to orange. Finally, if the joint was experiencing functional demand levels deemed to be unacceptable (above 80%), the sphere was shaded red. If the viewer requires any details of the forces which are being represented, s/he can select the joint to obtain the numerical values, direction of the forces, etc. This 'traffic light' system was thought to be

Figure 1. (a-e) The visualisation method displays the functional demand at the joints of the lower limbs. Using a 'traffic light' system, red indicates points of greatest stress during a sitting task



a clear and immediate way of allowing designers to understand, without specialist knowledge, the functional demands placed on individuals while performing daily activities.

This concept is illustrated in Figures 1a to 1e, which are taken from an animation of an older adult participant during the sitting task. On rising from the chair, the right knee displays green showing that it is moving well within his capability, but in the middle phase of the movement briefly shows an orange colour, corresponding to medium demand. As the participant sits back down on the chair however, the red colouring at the hip joints shows very high demand.

Already in discussions with biomechanics researchers, several guidelines and 'rules of thumb' have been identified that would be of value to designers when considering the limitations of older users. Integrating these guidelines into the tool will give further context and explanation of what is happening in these movements during everyday tasks. A good analogy here is work (Pirkl and Babic, 1988), which describes the physical changes in capability of the senses and motor movements with age, the functional effect, the problem this causes and how these are interpreted into a series of strategies and guidelines for the designer to allow them to determine the design characteristics of potential solutions for products, interfaces and environments that are able to safely accommodate the functional limitations of older users.

Further Value from the Visualisations

An interesting outcome of the prototype tool is that the viewer obtains a glimpse into the experience of the user. As the animations of the individuals performing the tasks are from motion capture, the motions have a 'life-like' quality. There are differences, often subtle, in the way that different individuals perform the same motion, which have a corresponding effect on the stresses at the joints, and care must be taken in their interpretation. An example of this is where the functional demand is shown to be asymmetric – high demand on the right knee may be due to the person compensating for a problem in the left leg, causing him/her to put more pressure on his/her right.

Although originally intended as a tool for designers, the early feedback and evaluation of this method of visualizing the acquired data has been encouraging is beginning to suggest that this tool has the potential to be of value across the wider range of disciplines of all those involved in the provision for and professional care of older adults. This began to become apparent at two events at the conclusion to the first phase

of the project, the initial results and findings to all those individuals, organizations, and professions who had been involved in the project. This included the various healthcare professionals, bio-engineers, designers, and the subjects (older adults) themselves. For those who had had no previous knowledge or understanding of the work of the project, and for those with no specialized knowledge of biomechanics, muscle strength or functional demand, the visualization of the data through the animated 3D model using the 'traffic light' system proved highly effective. An understanding of where in a movement cycle the greatest functional demand was placed on the joint was gained in a very short space of time by the broad range of disciplines – including lay people - with a minimum of explanation. For example, a designer can quickly understand the effect of the weight of an object whereas a physiotherapist can quickly understand how much load could be tolerated during exercise.

Information about functional demand is presented in a way that allows each discipline to discuss its implications from their particular perspective. This is illustrated by a discussion between two physiotherapists (P1 and P2) commenting on the visualizations. P1: *'...when he's sitting down he's going asymmetrical...'* P2: *'..he's put more on that hip...'* P1: *'...he's keeping this right knee flexed, because he's probably got OA in that knee...so he's a wee bit rotated...'* P1: *'... but he's probably also got it on there, because if you look again, that stays green. That one changes slightly to yellow...'* P2: *'He's loading his right hip..'* P1: *'... but there's more force going down through his left ankle. Because he's off-loading it...and then he gets to fully standing...and then there's a bit of internal rotation...you can get [that] with hip problems as well. So with him if you were going to design something...let's assume he has OA in his right knee, clinically...he's not going to be able to put 100% functional performance through his right knee. He's only able to do 70% before pain inhibits him. So any adaptation isn't going to change anything on the affected side but may improve things on the unaffected side... reduce the loading.'*

From pilot studies it appears that this visualisation method will also be useful in facilitating discussions between bioengineers, designers, human factors experts, health scientists, health and social care providers, and older adults and their carers, and has the possibility of allowing fresh cross-disciplinary insights to emerge about the effects of functional demand on older adults. This may allow the interrogation of issues that have an effect on the way that not only the built environment and a wide range of products are designed including devices that would improve muscle strength in older adults, but also in care strategies, with the ultimate goal of improving quality of life in older adults.

Case Study 3: Designing for Age and Generation Effects in Products for Older Populations

Case Study 3 is concerned with researching the design of Information and Communication Technology (ICT) product interfaces, where age-effects and generation-effects are differentiated, particularly amongst older users, with implications for the design of product interfaces for self-medication and self-monitoring in e-healthcare.

Ageing Effects

With ageing populations there are tremendous opportunities to develop e-healthcare products and e-services to support an independent lifestyle for an older population (Heok, 1994; Mohd, 2002). Changes in physical, sensory and cognitive functions affect the way in which we interact with our environment, in particular in the way we use products and services to conduct our daily life. Studies (Ricability, 2001) have shown that with increasing age, disabilities and impairments become more severe. As we grow older, these

cognitive, physical and sensory functions decline and this rate of decline varies between individuals (Gregor and Newell, 2001). A reduction in joint movement and muscle strength and the ability to control rapid and accurate movements are some of the physical changes observed as one ages. Sensory changes, in particular visual changes, include reduced ability to perceive contrast and impaired near-vision (Hitchcock et al, 2001). Cognitive changes include the reduction of the ability to plan and remember to perform future tasks (prospective memory) particularly in tasks where no external reminders are provided, or self-initiation is required. The ability to display selective attention, which is the extraction of relevant information from distracting ones, also declines with age (Hawthorn, 2000; Carmichael, 1999).

Although research suggests that people with different capabilities can benefit from using technology to lead a better quality life (Dewsbury et al, 2003; Intel, 2007), it is important, however, that users, to the greatest extent possible, are empowered by technology. This principle is important if products and services (especially in the area of self-medicating and self-monitoring healthcare) are to be designed to enable and promote independence. To achieve this, an understanding of the dynamically changing physical, sensory, cognitive capabilities, lifestyle needs and desires, and choice and application of appropriate technology interfaces will require to be taken into account. This will require an understanding of how products and services will meet people's clinical and functional needs yet help address people's aesthetic and lifestyle aspiration, as well as providing a greater sense of individual well-being (Macdonald, 2003). However, many approaches currently used in designing product and technology interfaces concentrate only on the effects of ageing, and while an important factor to integrate into designs, it is not the only factor to be considered.

Memory, Learning and Generation Effects

Cognition and prior experience are key factors in determining how easy or difficult a product is to use. Of particular concern is how the acquisition of knowledge, memory and prior experience affect the learning about and operation of a product or a technological interface. Experience is acquired knowledge and the greater the knowledge base of a person, the easier it is for them to understand, encode, integrate and remember new and relevant information. All this information is stored in the long-term memory which has three components: episodic, procedural and semantic memory (Hawthorn, 2000). Episodic memory is for specific events, procedural memory is concerned with how tasks are accomplished, and semantic memory involves holding information about the meaning of the things that are around us.

As we age, certain cognitive abilities deteriorate, namely processing speed, working memory, attention and automated response. These cognitive processes are influential in the performance of complex tasks that require high cognitive demands: a decrement in these abilities could place an older person at a disadvantage. For example, the decline of processing speed affects not only the ability of older people to respond but is also responsible for the decline of working memory especially when dealing with complex tasks (Salthouse & Babcock, 1991). Slower rates of processing have also been linked to age differences in reasoning, spatial abilities, and attention (Salthouse, 1993).The performances of speed, reasoning and memory (except vocabulary, i.e. semantic knowledge) show an almost linear decline beginning from early adulthood, e.g., in the performance of computer data entry tasks older participants input significantly less data than younger and middle aged participants (Czaja & Sharit, 1998). Results also indicate that although older people's skill level will increase with practice, but given equivalent training, it will still be lower than that

of younger people. One theory suggests that older adults find ICT products more difficult to use than younger adults because of the differences in their mental models of ICT interfaces and interaction procedures (Molenbroek, 2001).

A mental model is defined as 'the model people have of themselves, others, the environment and the things with which they interact. People form mental models through experience, training and instruction' (Norman, 1999). The implication here is that the models that individuals have learned and used before of how to operate or interact with products may not always apply to current ICT products.

The importance of this prior formative experience with technology has a great impact in the way a user handles present day technology. People who have used or experienced certain technologies during their formative period, estimated to be when they were between 10 and 25 years old, can also exhibit similar usage behaviour in later years (Weymann & Sackmann, 1993). They recognized this grouping of people as a 'technology generation' and they proposed that different technology generations behave differently with technology, displaying a 'generation effect' due to the way they learnt to interact with and use technology during their formative period. One reason older people have difficulties with current ICT products may be because they belong to a different technology generation. Consideration and understanding of users' prior knowledge could consequently make products less complex for them and therefore less difficult to use (Carroll et al, 1988). The exploitation of familiarity, in particular prior skills, can be a 'basis for universal design' and there has been little work done on familiarity and its impact on human and product interface interaction (Turner & van de Walle, 2006). As a consequence, in order to design e-products and e-technologies that are inclusive and promote independence, besides taking into account the ageing effects in physical, sensory and cognitive functional decline, this generation effect, in particular relating to technological interfaces and interactions, must also be considered.

Generation Timeline Tool

The designer, as the one who mediates between technology and people through good design, is faced with the challenge of embodying ever-new technologies and features into products and services in a usable and understandable way. However, there appears to be a lack of tools to help the designer understand the way an ageing population copes with, in their eyes, potentially ever more complex and alien technologies and their associated interaction protocols.

User interface complexity, age-related changes affecting abilities, and generation-related differences in prior experience of technology all may play a role as to why older people have more difficulties than younger people when using ICT products. In order to understand in depth why older people have more difficulties than younger people when using ICT products, a technology timeline chart, the *Generation Timeline Tool* (GTT) was designed to assist research into people's past experiences and familiarity with technological products (Lim & Macdonald, 2005). For this GTT, a visual timeline was constructed from visual archives showing a variety of everyday domestic consumer products such as radios, cameras, telephones, vacuum cleaners and TVs from 1930 to 2004. The following were then added as a series of visual overlays:

1. The points on the timeline at which different types of technologies emerged and were embodied in these products;
2. A conceptualization of different technological eras along this timeline into the 'mechanical' (M) before 1930, the 'electro-mechanical' (EM) c1930 to c1960, and the 'digital-software' (DS) era after 1960;
3. The changing profile of the population along this timeline (i.e. the proportion of young to old); and
4. 'Generation profiles' that clarified the span of types of technologies (M, EM, or DS)

likely to have been experienced by people of certain ages which allowed a correlation between their current age and likely prior usage and familiarity with different product and interaction types. To complement this GTT, subjects under research were shown a set of Visual Prompt Cards (VPCs) illustrating products from each decade to stimulate discussion.

The 'Generation' Concept – Results From Experiments

An exploratory case study was carried out using a semi-structured interview method, the VPCs, and the GTT, and the research was formulated to understand people's prior experience and familiarity with technological products from different eras (Figure 2). A content analysis of the interviews revealed that interviewees aged 46 and older belonging to the EM generation had more difficulties with operational procedures (relating to interaction structure linked to menu-based interactions commonly found in present day ICT products) compared to interviewees aged 45 and younger from the DS generation. For difficulties with functionality, the EM generation had more difficulties compared to the DS generation. Most difficulties mentioned arose because of unnecessary features and functions ('features-bloat'). A comparison of statements also indicated that interviewees from the EM generation were more affected by difficulties due to unfamiliarity and lack of experience with present day devices than those from the DS generation.

As some participants appeared to have difficulties with menu-based interactions or multi-layered menu interfaces, a cross-sectional study was conducted to investigate the relationship between age groups and problems with different types of interfaces, from EM analogue to DS menu-driven. Thirty-five volunteers between the ages of 19 and 83 were asked to complete tasks for the operation of a camera, a telephone and a radio both from the EM and DS eras. Efficiency and effective measures as recommended by ISO 9421-11 were used. The efficiency measure was the time taken to complete a task while the effective measure was the percentage of users completing the task successfully. In the efficiency measure, it was found that there is a general continuous increase in the time to complete the tasks as age increases. This indicates that there was an age effect for task duration performance. In the effectiveness measure, the 56–65 and 66-and-above age groups (those in the EM generation) had a lower rate of successful interactions with products having two or three 'layers' of menu interface compared to those from the DS generation. Analysis of the results suggests a generation effect in the 46–55 and 56–65 age groups, where older participants have a generation-related lack of experience with newer types of user interfaces. Interestingly, those in the 46–55 age group, which was classified as the EM generation (assuming that when they were 10–25 years to be the formative age when learning about technologies) had no unsuccessful completions in multi-layered tasks for either the camera or telephone. This could indicate that either the formative period hypothesis is incorrect or the participants in that age group had to overcome or learn how to operate new types of technological interface. Using the GTT and the formative age (i.e. 10–25 years old) theory, only those who were 46–55 years old at the time of conducting the research would have experienced some multi-layered interface menus towards the end of their formative age period. However, if the formative period is extended until they are aged 30 (Rubin et al, 1998), then they would have had more experience with multi-layered interfaces.

A survey conducted among the 35 participants regarding their familiarity or experience, in terms of ownership or usage, with other products similar to those used in the experiments showed that, with the exception of analogue radios and telephones, the 56–65 and 66-and-above age groups had less experience compared to other age groups had less prior experience with digital cameras, digital

Figure 2. Discussion with older person using the Generation Timeline Toll (GTT) and the Visual Prompt Cards (VPCs) to determine preferred technological interfaces

telephone and digital radio compared to other age groups. For the 46–55 years old age group, their experience with digital phones was comparable to those from the younger age groups which may explain their competence with layered interfaces even though they are from the EM generation. The 46–55 year old age group can be seen as a transition group between the EM and DS generations.

Rapid technological change and the difficulties that different generations interacting with ICT products is exemplified in the paradigm-shift in the design of telephones. These have shifted from traditional landline to mobile technologies and very clearly illustrate the issues in design that can lead to exclusion of significant sectors of the population. Where there were once analogue interfaces, with dials or push buttons, these have now been replaced by multi-layered menu-driven interfaces with multi-function buttons. Japanese manufacturers have been very alert to the idea of a generation effect. In its 'super-ageing' society (over 21% of the population is now over 65), and given the evolving market, Japanese carriers have increasingly sought to provide customers with phones designed using UD principles for the most overlooked sectors: the younger and older age groups.

DISCUSSION: DESIGN AND E-HEALTH

Issues arising from each of the case studies above are now discussed with relevance to biomedical knowledge management infrastructures and processes for E-Health systems. In Case Study 1, the visual mapping of pathways of health and healthcare had the potential to enable a clearer and more holistic representation and discussion of different perspectives: these can include the patient's viewpoint. This in turn may facilitate a more strategic approach to the design of systems of products, environments and services. Case Study 2 showed the potential for information, previously buried in the domain of one field of expertise, to be shared amongst key stakeholders and older adults themselves. This visualisation method has already demonstrated that it can enable a discourse to emerge between different fields and so influence decisions about design and healthcare: it has the potential to shape new forms of patient-healthcare interaction. Case Study 3, with its concern with ICT product interfaces, discovered and acknowledged issues potentially affecting the successful operation of self-medication and self-monitoring products or ICT e-healthcare interfaces.

The rudimentary mappings produced in the Case Study 1 cluster workshops proved highly significant, as these could begin to allow the cluster to identify new approaches to healthcare design. For instance, by providing designers with a visual overview of the healthcare pathway, one could begin to think about how design interventions, in the broadest sense, could be mapped onto that pathway. This in turn has the potential to begin to enable designers to think about how responses to what are normally perceived as separate and unconnected design problems could be thought of more as a mutually interdependent system of products and services. Using this approach, different types of equipment, furniture, information, medical packaging, and interiors could be considered in terms of their relationships to another as a total system helping to deliver an improved service. Another aspect of this approach was to begin to identify where, to what extent, and how patients could be engaged at different stages of the pathway, not just as a 'subjects' but as members of the design team, involving them more as contributors and partners in a participative design process, ultimately asking them the question 'how would you design your ideal pathway?'

A fundamental, perceptual shift in understanding occurred within the Case Study 1 cluster when what had been assumed to be person- or patient-centric representations of pathways were in fact understood to be described from a clinician's perspective – i.e. pathogenically, focused on the disease pathway. A subsequent survey revealed another prevalent mapping, that of healthcare managers who were principally concerned with efficiency flow through the healthcare system, and with reducing the number of elements in the chain of events and patients' waiting time, and ultimately cost. Almost exclusively, advances in e-health systems tend to be about a) the secure management of the volume and variety of patient record information, b) issues of accessing this accurately by the complex web of individuals and services to support an individual's pathway through healthcare, and c) in making this as efficient and as cost effective as possible. However, there is another challenge and opportunity for the development of e-health tools which is to present clearly communicated and understandable views of pathways from the variety of constituent perspectives, *e.g.,* healthcare clinician, healthcare manager, patient, carer, *etc.,* all of which are equally and simultaneously valid, and in formats which can manage the complexity of that information. Such a tool as described in Case Study 2 could be used in a variety of ways, for instance, to provide a means of engaging patients more effectively to obtain a better understanding of their needs, values, motivations, and goals. Indeed, by increased empowerment, this could offer them a more pro-active role alongside, *e.g.,* physio - and occupational therapists, bioengineers, and exercise scientists. Having previously produced a first generation proof-of-concept of this form of visualised data tool, the current phase of research (2007-2009, supported by a UK ESRC research grant in its New Dynamics of Ageing programme) is its careful and systematic evaluation by all those involved in providing or determining care for older adults - bioengineers, designers, health scientists, health and social care providers, human factors experts, and – equally importantly - older adults. There is sufficient data to allow a systematic evaluation not only of individualized issues such as the previously mentioned coping strategies but also common generic issues, and to determine their implications for many aspects of the design of the built environment and care strategies.

This multi-user (key stakeholder) -centred approach will also be explored focussing on malnutrition amongst older people in hospitals during 2008-2010, supported by a UK ESRC research grant in its New Dynamics of Ageing program. The aspiration of this research is to understand, radically question and rethink the expectations, means and the quality of nutrition within a food-delivery service for geriatric patients. The design of this service will focus on the confluence of the

'food journey' with the 'patient experience' and consider all aspects of improvement of quality of the production, delivery and experience of consumption of food for patients by engaging the total 'feeding family' (comprising food producers, dietician, speech therapist, occupational therapist, caterers, nursing staff, geriatricians, patients, carers, hospital management, and ward volunteers), together with novel applications of technologies and design, and the use of participative, co-design, and service design processes and methods. The focus is the hospital environment, but the approach has the potential for home, care home and community applications.

One of the intentions in researching this prototype is the design integration of monitoring technologies, e.g., how can automated inventory technologies be better exploited to maintain food quality and evaluate patient consumption? This raises issues identified in Case Study 3 in relation to the design of interfaces and interactions for IT technologies. Current procedures for monitoring food/nutrient intake of patients are insufficiently accurate and so adequate monitoring does not take place. If the technology is able to, at a technical level, monitor change in food quality, or quantity eaten, it has – ideally and at another level - to be operable by range of individuals who may have different types of experiences of different types of technological interface.

The argument for a user-centred approach as good business practice can also be made. A user-centred as distinct from technology-centred approach to the design of easy-to-use mobile phones and associated support services for all customers can show some startling results. For example, in Japan in the 60-64 age sector only 45% owned mobile phones in 2004 (Macdonald, in press). However, by 2005 this was 53%, and by 2006, 69.3%. Undoubtedly this was due to the appearance on the market of innovative products that understood and catered for the particular needs and capabilities of this sector. The first of a new type of design Japan specifically designed and marketed for the older user, as distinct from a phone that had adaptable features, appeared in 2004. Its marketing literature literally and visually spelled out the analogy between this new mobile and older landline-based phone interfaces with which these particular customers were more familiar and was very simple to operate. This was followed by ones with similar features over the next two or three years (Macdonald, in press). Given that patient safety and medication compliance is a significant issue in healthcare treatment, there is much to be learnt in designing from this successful approach to appropriate product interfaces for new technologies.

CONCLUSION

Although design researchers are the authors of this chapter, the last words come from a medical clinician. In Case Study 1 it was interesting to note how the perceptions of the clinical members of the cluster changed over the duration of the project which helps to articulate their appreciation of the value of design thinking and approaches and which could be further exploited within this e-health context:

'Design thinking seems to be 'boundary-less' or at least to cut across traditional boundaries in medicine. That is one of its strengths, and this approach can assist the patient or the staff perspective with more ease than someone who works in the medical world. The design perspective therefore brings clarity to medical problems'.

and

'design places a strong emphasis on obtaining and acting on the consumer or user perspective. While this is widely recognised within healthcare as a critical component in planning, it has not yet been fully assimilated. Design has a number of approaches and methods that could assist the

changing requirement for healthcare delivery through an improved earlier and ongoing engagement with the recipients of healthcare. Designers are also used to working with the users in a collaborative manner far more closely than medics with patients (the experiential approach). The design perspective tends to approach the user and ascertain what they would like out of the situation, which may be better health, but the route map may be different' (Macdonald, 2007).

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KEY TERMS AND DEFINITIONS

Ageing Effect: An ageing effect is described as an age-related change in abilities that affect performance across different age groups. Age-related changes may be physiological, cognitive and/or sensorial. Performance could be operationalized as task duration and/or the number of errors made.

Functional Demand: In the context of Case Study 2, functional demand is described as how hard the muscles are working relative to their maximum strength. This is calculated as the external moment expressed as a percentage of the maximum available isometric strength available at a limb joint at a particular angle.

Generation Effect: A generation effect is defined as the difference between behaviour and attitudes towards technology shown by different birth cohorts due to the effects and experience of technological changes that occurred during the formative development stage of an individual's life.

Chapter 11
Telederm:
A Web-Based Decision Support System for Medical Practitioners

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ABSTRACT

In this chapter we describe a web-based decision support system called Telederm that has been developed with the aim of helping general practitioners diagnose skin ailments from a knowledge base while allowing incremental updates of the knowledge base as cases occur. We outline the two major challenges in developing the Telederm system: developing a general practitioner query process that is easily accessible and building knowledge validation in a case-based reasoning system. We provide a detailed description of our approaches to address these problems which involve the use of artificial intelligence classification and reasoning techniques. The system was deployed in a large scale trial in the Eastern Goldfields of Western Australia and we present the results and feedback obtained from an evaluation by the general practitioners involved.

INTRODUCTION

The past two and a half decades have seen a significant increase in the use of Artificial Intelligence (AI) methods to enhance the provision of medical services such as expert systems. More recently, research has focused on developing medical decision support systems to meet the needs of General Practitioners (GPs) in rural and remote areas, in order to reduce the number of patient referrals and the travel costs for patients. The research has been inspired by advances in telecommunication technology that has allowed the establishment of telemedicine services for the delivery of health care and the exchange health care information over the Internet (Perednia & Allen, 1995; Wootton & Craig, 1999). This can significantly benefit rural and remote patients, because without the availability of telemedicine, they

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must travel large distances to visit a city-based specialist or consultant, which can be expensive, time consuming and inconvenient.

This chapter focuses on Telederm, a teledermatology system developed in cooperation with experts in the dermatology field to assist GPs with their decision making processes, and on the challenges involved in developing a decision support system that can be used by GPs with little computing knowledge. Dermatological complaints such as rashes are an important part of a GPs case load as 15% or so of patients suffer from skin problems. It is also well suited to a telemedicine approach because of the reliance of the diagnosis on historic data about the patient and images of the skin, both of which can be easily stored and transmitted over the Internet. It can benefit from AI because of the potential for interpretation of the historic data and the images. To our knowledge there have been no other attempts to incorporate AI techniques in order to provide automated decision support to GPs in analyzing patients with dermatological conditions. There are systems available that aid the diagnosis process, such as Dermis and Dermatlas, but these are mainly repositories of images and other information about dermatological complaints using relatively simple search methods.

In our research we have identified three major challenges in developing medical decision support systems. The first challenge is the need to shorten the length of the query process, and thus reduce the time required to reach a diagnosis. Medical practitioners can be reluctant to use such systems because of time constraints (Liaw & Schattner, 2003). The second challenge concerns the disparity between the types of questions asked by medical practitioners and those asked by decision support systems. This concerns the presentation of questions that closely model GP-patient interaction during traditional face-to-face consultations. For example, a decision tree classifier generates a number of separate yes/no questions as it homes in on the solution, and it is important to convert these into the more user-friendly questions commonly used during traditional consultations. The third challenge concerns the dependency of the diagnostic performance on the quality of the cases stored in the knowledge base. For example, it is usual in a Case Based Reasoning system (CBR) for new cases to be added incrementally without checking the consistency of the knowledge base. However, in medical decision support systems where the correct decision is critical, updating (without supervision) can lead to significant problems including misclassification that may result in incorrect diagnoses.

The overall objective of our research has been to build web-based tools to enhance the quality of healthcare in rural and remote areas using information and communication technologies (ICT) technologies by developing a decision support system that is usable by GPs in the real world. The specific objectives of this research were threefold:

1. The investigation into the establishment of a web-based diagnostic system to provide dermatological services to rural and remote GPs, in order to reduce the number of patient referrals to city-based consultants and hence associated travel and other costs for patients;
2. The investigation and development of methods to assist GPs, who may not be familiar with aspects of complex computer based reasoning, in diagnosing patients with dermatological problems;
3. The development of techniques that aid dermatology consultants in validating the knowledge in the CBR system, and interactively supervise the knowledge updating process. This includes techniques to aid the consultant in dealing with electronic referrals from the GPs for those cases they cannot diagnose with the Telederm system.

BACKGROUND

Advances in ICT and AI have increased the provision of health care across large distances and have provided decision support to assist medical practitioners with their decision making, known as telemedicine. These changes significantly benefit patients who live in rural or remote areas because without the availability of telemedicine they must travel large distances to visit a city-based specialist and this can be expensive and inconvenient. Recent research has focused on developing domain specific medical decision support systems to meet the needs of medical practitioners in remote areas. The development of such systems has involved the adoption of various techniques ranging from, but not limited to, CBR, machine learning and data mining.

Telemedicine

Advances in telecommunication technology allowed the establishment of telemedicine in the mid-1990s to deliver health care and exchange health care information across distances (Perednia & Allen, 1995; Wootton & Craig, 1999). Since then, telemedicine has become popular among the medical communities, and has been practiced in many hospitals and clinics to provide health care to patients (Merrell, 1995). It was estimated that in 1998, the US had over 130 active telemedicine programs. The average number of teleconsultations per program was 428 and this increased to 608 in 1999 (Grigsby & Brown, 2000).

Telemedicine has the benefit of reducing costs and improving the provision of health care services to rural and remote patients. It is particularly useful in underserved populations where the level of health care provided is inadequate and patients can have difficulty visiting specialists. For example, in situations such as nursing homes (Zelickson & Homan, 1997) and prisons (Norton et al, 1997) telemedicine is well suited because of the restricted movement of the patients. Telemedicine has been practised in various domains such as dermatology (Clay, 2002; Tait & Clay, 1999; Wootton & Craig, 1999), radiology (Chartier, 2002; Roine & Ohinmaa, 2001; Zdravkovi´c et al, 2002), pathology (Brauchli et al, 2005; Yagi & Gilbertson, 2005), neurology (Wootton & Patterson, 2005) and oncology (Zdravkovi´c et al, 2001). The communication process in telemedicine can be performed either in real-time using video-conferencing or by a pre-recorded method known as store-and-forward (Perednia & Allen, 1995). Video-conferencing between medical practitioners enables a real-time consultation to take place. Store-and-forward refers to the transfer of digital images and clinical information in a time and place independent manner to the medical specialists for offline analysis.

Store-and-Forward

Store-and-forward is a commonly used technique amongst medical practitioners for communicating medical information in a cost effective manner (Burg et al, 2005). It is commonly used for transferring digital images and clinical information from one location to another over the Internet using email systems.

There are two advantages of using the store-and-forward method. First, it is more efficient compared to video-conferencing since the domain specialist, general practitioner (GP) and patient do not need to be available at the same time. This enables medical practitioners to compose and read emails when it is convenient, thereby saving time and giving them the flexibility when handling patient cases. Second, it supports medical diagnosis to the rural and remote communities more conveniently using the Internet and readily available equipment (digital cameras for example) in a less expensive way. Therefore, in most cases, store-and-forward should always be considered before using real-time video consultation since it is cheaper and easier to use.

Video-Conferencing

Another widely used communication technology in telemedicine is video-conferencing that uses a synchronous video and audio transmission. It enables a live and interactive consultation between a remote specialist, the patient and their GP. Patients need to be present during video consultation so that appropriate information (e.g. symptoms) can be gathered. The technology helps to model the traditional consultation, and is appropriate when a face-to-face consultation is required such as for psychiatry in which the real-time behavior of the patient is of interest. However, for a video consultation session, the above steps still apply except that the domain specialist relies on the GP for information such as patient history. Also, even when the conclusion is reached at the end of the video consultation session, it is up to the GP to make the final decision.

Despites the benefits of using video-conferencing during medical consultation, there are some disadvantages compared to the store-and-forward technique. Video-conferencing requires coordination between the specialist, GP and patient. This makes it less convenient for the parties involved. Also, the image quality provided across the network using video-conferencing may not be clear compared to digital images taken by a digital camera although advances in video technology is making the video images more acceptable.

Teledermatology

Teledermatology is a subspecialty of telemedicine and is defined as the practice of dermatological services at a distance (Wootton & Oakley, 2002). Traditionally, patients with dermatological problems consult their GP. If the GPs cannot confidently diagnose their patients, they seek advice from their peers and dermatology consultants, who are normally located in the nearest city, by referring their patients to the city-based consultants. For patients who live in rural or remote areas, this can be expensive and inconvenient because they must travel large distances. There has recently been rising interest in the use of web-based diagnostic tools to aid GPs in diagnosing their patients. In the case of dermatological diagnosis, specialized communication systems have been developed to enable activities such as emailing and video-conferencing between GPs and dermatology consultants (Tait & Clay, 1999). In teledermatology, the store-and-forward method is used for sharing information in a time (asynchronous) and place independent manner consisting of various web pages that enable the GPs to enter clinical information, including text, and attach digital images of the skin lesions. The pages and the attachments can then be sent to the consultant for offline analysis. These processes can be done independently at times more convenient to the patient, GP and consultant. A stand-alone store-and-forward software package, TELED (Tait & Clay, 1999), was developed to aid GPs in communicating with dermatology consultants. The software guided the GP through a series of screens to request information by clicking on boxes and making choices. This was then formatted for email delivery to the consultant as an HTML file for viewing using a web browser.

Case-Based Reasoning

At the core of our research has been the use of the AI approach called case-based reasoning (CBR). A CBR system solves new problems by using or adopting solutions that successfully solved old problems. A major drive behind CBR research has been the desire to develop technology to make AI systems more effective (Leake, 1996). There has been a substantial amount of work done in CBR, with early systems beginning to be deployed in the early 1980s. The effectiveness of CBR has seen the approach used in a wide variety of systems for classification, diagnosis, prediction, assessment, process control, planning, the design of mechanical objects, and for expert systems in the domains of law and medicine (Kolodner, 1993).

CBR is a cyclic and integrated process of solving problems. Aamodt & Plaza (1994) have outlined the four steps used in CBR as follows:

1. Retrieve the most similar case or cases;
2. Reuse the information and knowledge in the case-base to solve the new problem,
3. Revise the proposed solution if necessary; and
4. Retain the cases for future problem solving.

To develop a CBR system that is effective, it is critical to have a knowledge base that contains quality cases as it is the quality of the cases that determines the performance of the CBR systems. For a medical diagnosis system, the instances for training and reasoning need to be selected and provided only by domain experts and must not contain any ambiguities. The data collection process is a critical part of the knowledge elicitation required for CBR and is a task that is both difficult and time consuming. The domain expert usually has difficulty articulating or explaining to the knowledge engineer any procedural tasks which he performs subconsciously, routinely and automatically. In order to provide explanations of his problem solving activities, the expert has to reconstruct the declarative knowledge that he once possessed. The reconstruction only provides an approximation of the original declarative knowledge and may not represent how he actually solves the domain problems.

PROBLEMS TO BE ADDRESSED

GP-Patient Query Process Problem

The first problem we investigated was that of developing a web-based query process that helps the GPs reach the correct diagnosis. Two issues were of high significance in our research:

1. The difference between the type of questions asked by the GPs and those asked by the web-based diagnosis system; and
2. The length of the query process.

In the normal diagnostic process, GPs have a set of questions that they regularly use when dealing with dermatological cases. However, the CBR system is evidence based and as a result, the questions generated by the CBR system can often be different from those typically used by the GP. Therefore we needed to develop a system that offers the GP the option to query the patient using either the CBR generated questions or a set of generic questions that would be familiar to all GPs.

GPs also typically have heavy workloads and the time required to use the system to reach a diagnosis was a critical aspect in the usability of the system from the point of view of the GPs. A major factor in the query process is the number of questions required to be addressed by the GP when attempting to reach a diagnosis. Unfortunately most AI techniques typically generate complex decision structures and the challenge in our research was to develop an approach that would allow the system generated questions to be as short as possible.

Knowledge Validation Problem

The second problem we addressed in our research was that of incremental learning from the cases observed by the system, specifically the problem of knowledge validation. Typically in a CBR system, new cases are added to the knowledge base in an unplanned order. In most cases, CBR systems are allowed to learn by themselves. This means new cases are added incrementally without checking the consistency of the knowledge base. However, in medical decision support systems where the correct decision is critical, automatic updating is not recommended and updating should only be carried out by domain experts. Automatic updat-

ing (without supervision) can lead to significant problems including misclassification which may result in incorrect diagnoses. This is expensive in the best case (false diagnoses) and fatal in the worst case (missed diagnoses).

It is important that the results generated by the system are reliable because, in most cases, the final decisions are made by GPs who may not be domain experts and may have limited knowledge in the field. A CBR decision support system that is not 100% accurate is of little practical use and GPs would have no incentive to use it. Therefore, it is crucial for the domain experts to constantly check the consistency of the knowledge base.

Although CBR is a popular approach, relatively little effort has gone into investigating how new knowledge can be validated, with most research having been focused on classification and retrieval. The consistency of the knowledge base is an important issue that still needs to be addressed. For this reason, a knowledge validation process is necessary for dealing with the inherently imperfect data collected over time, because inconsistencies in data occur (because of subjective assessment e.g. redness of a lesion) and adversely affect the performance of a diagnostic system.

OUR APPROACH

In developing Telederm we have attempted to address the two problems outlined in the previous section. We first developed an advanced but easily accessible decision support system that caters for both rural and remote medical practitioners, to help them diagnose dermatological problems with their patients, as well as expert users. The significance of this research is that Telederm can help reduce the number of patient referrals and hence associated travel costs for patients. We have implemented two distinct GP query methods that have been incorporated into a web-based CBR diagnostic system with the intention to suit different user preferences. The first approach, the Specific Question (SQ) approach, uses a decision tree classifier to generate a set of classification rules to guide the query process. However, while the decision tree approach provides results that are easy to understand and interpret by all users, it can also generate long sequences of questions that can often be a drawback for time poor GPs. As a result, a second method, the General Question (GQ) approach, was developed to streamline the query process so that a GP can reach a diagnosis with fewer steps, and thus reduce the time required. In addition, we developed an attribute mapping technique to improve the representation of the information (questions and answers) presented to GPs and consultants during the query process. The technique involves transforming the generated attribute-value pairs from the decision tree classifier to a more user-friendly attribute grouping and naming scheme. This allows the GPs and consultants to work more efficiently with Telederm. The technique automatically identifies relationships hidden in the dataset. The significance of this research lies in the unavailability of such an automated decision support system in the dermatology domain at the time this research was conducted.

In addition to the GP query system we have also developed a set of automated validation tools to help the dermatology consultants check the consistency of the knowledge base thus addressing the problem of knowledge validation. This part of the work is particularly significant, since relatively little effort has gone into investigating how new knowledge can be validated in CBR systems, with most research focused on classification and retrieval. However, a knowledge validation process is needed to deal with misinterpreted and imperfect data as inconsistencies in the data will reduce the performance of the diagnostic system and lead to mistrust. We have developed two approaches to help the consultant with the knowledge validation process. The first approach involves extracting and displaying misclassified instances generated by the decision tree classifier. This approach

also identifies any ambiguous features that may cause the inconsistencies. The second approach uses formal concept analysis (FCA) to determine the conceptual differences between the reasoning before and after the latest case has been added to the knowledge base. These are presented as a graphical representation of lattices, a summary description highlighting the conceptual variations, and a dissimilarity metric.

We will describe in detail the query and knowledge validation approaches that have been developed to assist the GPs and consultants in the effective analysis of the case data.

THE TELEDERM SYSTEM

The work we describe is focused on decision support techniques for the development of a Web-based system - Telederm - or dermatological diagnosis. Importantly, Telederm does not replace GPs, but instead assists the decision making process, and reduces the number of patients referred to dermatology consultants in the city, thus reducing medical costs. To attract more GPs and consultants to use it on a regular basis the system needs to be easily accessible. This would result in an increase in the system usage, which would eventually decrease the number of patients traveling large distances to visit dermatology consultants.

The research and development process was very sensitive to the needs of the GPs and consultants and was designed to be integrated into the normal diagnostic process used by GPs and consultants. In particular the system was developed to be a decision support tool and certainly not intended to replace the GP. As such it was expected that the GP would invoke the system if they couldn't quickly diagnose a complaint. By answering questions and seeing the possible diagnoses given the answers, the GP should be able to firm up the diagnosis. If they can't, then they can refer the case to a consultant by sending them the answers as well as images and other information. The consultant can then either respond by email with a diagnosis, or request to see the patient.

The Telederm system consists of two subsystems: the GP subsystem and the consultant subsystem. Telederm makes use of CBR, a popular classification scheme in medical diagnosis (Watson, 1997) that stores knowledge as a collection of cases describing the diagnosis and the associated attribute values for each case. A suggested classification is obtained by comparing the attributes of the unknown diagnosis with those of existing cases in the knowledge base and selecting the diagnosis with the closest matching attributes. CBR has the advantage that cases can be incrementally added to the knowledge base over time to improve comprehensiveness and decision making.

System evaluation was an important part of this research. A grant was obtained from the State and Commonwealth Research Issues Forum (SCRIF) initiative administered by the National Health and Medical Research Council (NHMRC) to address the development of electronic services for rural and remote communities. The funding was used in this research to enhance teledermatology services in an attempt to overcome apparent resistance to using the Store and Forward approach and to function as a decision support tool for GPs to aid in diagnosis. The Eastern Goldfields Medical Division of General Practice (EGMDGP) was specifically targeted on the SCRIF grant application as the trial area for the Telederm system. The trial was organized by the EGMDGP as part of the Australian Eastern Goldfields Regional Reference Site (EGRRS) Project that aims to provide GPs in rural and remote areas with access to broadband technology and the infrastructure to support a range of services to improve health care delivery. In particular, the teledermatology trial was to evaluate the usefulness of the Telederm application.

A domain expert was involved in validating the developed techniques as well as evaluating the whole Telederm application. The GPs were

invited to take part in the trials and to assess the usefulness of the Telederm application. The experience and knowledge they have are important in determining the appropriateness of the Telederm system. The domain expert, Dr. Chris Clay, has been a dermatology consultant at the Royal Perth Hospital, Australia and in private practice since 1991. He has been active in the College of Dermatology at both State Faculty and College level having been the Western Australian Faculty Director of Postgraduate Training and the State Faculty Secretary. Dr Clay played an important role in this research because of his computing experience and knowledge of dermatology. He has been responsible for providing dermatology data used in this research, evaluating proposed techniques, and providing dermatology knowledge such as information on diseases and current issues relating to dermatology. He services the Kalgoorlie area in the Goldfields via visits on a regular basis. This gave him the opportunity to contact GPs regularly to discuss the Telederm application. Hence, Dr Clay was also a good conduit for recruiting GPs, and spoke on their behalf regarding the Telederm application and related issues.

The GP Subsystem

Apart from the knowledge validation tools used by the consultant we also describe the techniques that are available to the GPs to query the Telederm system. The important issues that need to be addressed are the length of the query process and the disparity between the types of questions asked by GPs and those asked by CBR systems. Techniques were developed, based on investigation and collaboration with the dermatology consultant involved in this research, to address these issues.

The diagnostic process involves the system asking the GP questions about patient symptoms and history, and determining the most likely diagnosis based on the given information. The system is designed to be used effectively by a GP in the presence of a patient during diagnosis, so that the information can be gathered directly from the patients. At each stage of the query process, the system provides a GP with the following information:

- The number of questions remaining to be answered;
- The number of possible diagnoses left based on the information given so far; and
- The characteristics (questions and answers) that have been selected by the GP.

At any point during the diagnosis process the GP has the option of continuing with the query process or exiting the process either by deciding on the most likely diagnosis or contacting an expert via the email facility that is inbuilt in the system.

Telederm uses the decision tree classification approach for inducing classification rules. The rules are generated using the validated data stored in the knowledge base. The system provides two different approaches for performing a diagnosis. The SQ approach presents the GP with questions generated by the decision tree. The GQ approach extends the SQ approach. It uses seventeen general questions, to guide the query process and eliminate irrelevant questions so that the length of the query process can be shortened. For example, it is generally faster and more user-friendly for the system to ask the GP a general question such as 'Where does the lesion occur?' rather than a number of separate 'yes/no' questions, such as 'Does the lesion occur on your leg?' and 'Does the lesion occur on your arm?'. Thus, the GQ approach improves question representation and minimizes the length of the query process. The system provides GPs with immediate access to information about other patients with a similar medical condition. This is done using the ranking option that extracts and displays existing dermatological cases with similar symptoms to the current case. If a GP cannot reach a diagnosis, the system enables

them to send information (a case history and images) to a consultant who can assist in reaching a decision. Importantly, Telederm can learn and gain experience as a result of adding new cases. This closely models the way human experts learn. The diagnostic process results in new cases being generated. A GP can instruct the system to store the new generated case to the database or discard it. The new case added to the knowledge base is marked as 'unchecked'. The unchecked cases need to be verified by the consultant before they are used for updating the knowledge and rules in the decision support system.

The Specific Question Approach

The SQ approach uses 'yes/no' and other forms of binary answers generated by a decision tree to guide the query process. When a GP selects the SQ mode, the system disables the GQ mode related questions and answers, and only displays the specific questions and answers generated by the decision tree. The decision tree uses IF ... THEN ... ELSE logic, so each question only has two outcomes. For example, the system asks 'Does the affected site occur on the upper arm?' and displays the possible answers 'yes' and 'no' for the GP to choose from. The decision tree can also produce questions that have numeric outcomes. For instance, the GP could be asked 'How long since the beginning of the current illness?', and the possible answers would be >10 weeks or ≤10 weeks. The SQ approach only allows one answer to be chosen at a time according to the ordering of the decision tree, because the selected answer is used to determine the next question to ask. The system fetches the next most disambiguating question based on the answer chosen by the GP. The process continues until a leaf node (i.e. a diagnosis) is reached. Then the system returns this, the most likely diagnosis, at the end of the query process.

At each stage of the process, the selected questions and answers are displayed in the 'Selected characteristics' section, while a list of possible diagnoses shown on the right is shortened. This information provides a history of the entered characteristics, and it enables the GP to decide whether or not to continue the query process. However, there are inefficiencies associated with the SQ approach that can lead to poor query representation and efficiency.

The General Question Approach

The GQ approach is a modification of the SQ approach, and it was investigated to address the following inefficiencies in the normal decision tree query approach:

1. The decision trees ask a number of separate 'yes/no' questions which poorly model GP-patient consultation in real life situations. This could adversely affect question representation and may result in poor interpretation by the GP;
2. In a decision tree, the same attribute can occur at more than one level. This results in the same question about an attribute being asked multiple times, which makes for an inefficient query process; and
3. In a decision tree, the normal query process always starts from the root of the decision tree with the same question.

However, discussions with the dermatology consultant involved in this research revealed that this way of querying is inefficient. Ideally, the system should not be using a single fixed starting question which does not allow a GP to select questions that are appropriate to the current patient's condition. For example, the query always starts with the same question, such as 'Does the lesion occur on the mouth?' Hence, a GP may be less inclined to use the system. To develop the GQ approach, the consultant defined seventeen general questions typically used by a GP in the real world during the patient diagnosis.

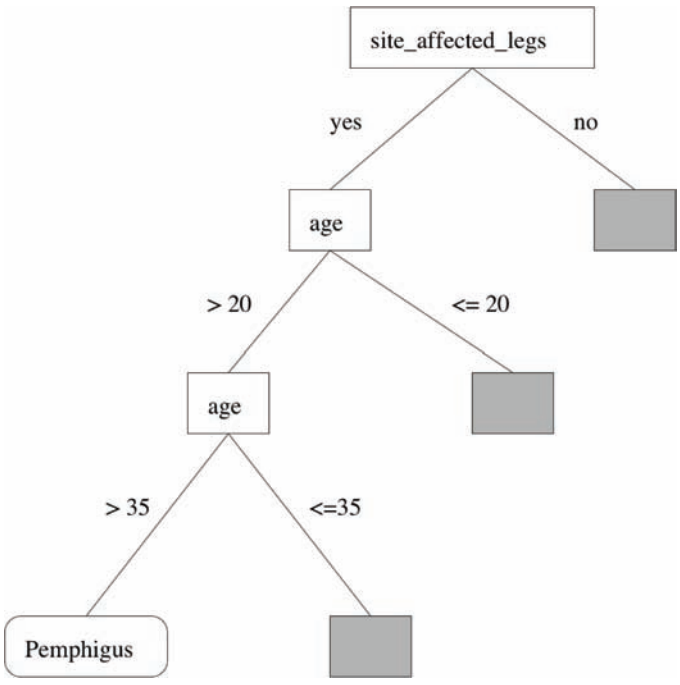
The attribute-value pairs of decision rules are then formulated into simpler rules based on the seventeen general questions and are used during the query process.

The GQ approach has three advantages over the SQ approach. First, it improves the GP-patient consultation and helps to shorten the query process by eliminating the redundant questions in the decision tree (repeated questions that can be answered with one response).

For example, Figure 1 shows a decision tree containing an attribute age that appears more than once at different levels. In this case, if we apply the SQ approach, the same question would be asked multiple times. This is impractical, because we get decisions based on the same attribute occurring at more than one level in the tree, e.g. a rule concerning the age of a patient. At one level it may be > 20 years old, further down it is > 35 years old. A general question asking for the age of a patient would satisfy both decisions. Second, it eliminates irrelevant questions. This is achieved by determining the lowest common parent node of the selected attributes and filtering out the irrelevant nodes accordingly. Note that the number of questions X is usually less than N, the depth of the tree, as many nodes in a tree are concerned with the same attribute. The worst case is where X = N. Third, it gives a GP flexibility in the way they handle the querying. Generally, it is preferable to initially acquire partial information from the GP regarding the patient's current condition through the use of general questions, and then present the subsequent questions related to the given information. However, the success of the GQ approach is highly dependent on the amount of initial information provided by the GP. The more information the GP specifies at the initial stage of the query, the fewer questions there are left to be answered. This means they will get a diagnosis in a fewer number of steps.

In addition to these two query approaches, we enhanced Telederm by including two further avenues of interpreting the data. First, the system

Figure 1. A example of a decision tree that contains a repeated attribute (age) at different places in the tree (source: the authors)



provides a ranking option, one of the functions of Telederm, which provides differential diagnoses to help a GP with decision making. It provides examples of other dermatological cases relevant to the current patient's conditions, enabling a GP to compare the current case with those stored in the system. A GP may choose to view other dermatological cases that possess similar features to those they have entered regardless of whether the query process has been completed. The ranking of the matches is determined by comparing the currently entered features with the existing cases' features stored in the database, and listing them according to their similarities. The system ranks and displays the closely matching cases at the top of the list. A GP may view a full description of a case's symptoms to better understand how it may relate to the current case by selecting it from the list.

Second, an email facility is provided to enable effective communication between a GPs and a consultant. Telederm has two email options. The first can be used as a normal communication tool like any other email system. The second can be used to send a logged history of GP-system interactions to the consultant for offline analysis. The latter method is only available once the GP invokes the query process using the diagnostic system. At the end of the query process, the logged case history containing GP-system interactions can be viewed by the GP as a final check before contacting the consultant. The GP's decision to email the consultant depends on whether the GP is confident about the diagnosis. If the GP needs a consultant's advice, the email button is used to generate an email page. The log file is automatically attached to the email. The GP can include extra information not covered by the query system in the text of the email as well as images. Providing the consultant with the case history would help them decide the correct diagnosis.

Consultant Subsystem

Knowledge validation is a crucial part of the Telederm system, as it helps the consultant to interactively supervise the CBR system to ensure the validity of both the old and new cases stored in the knowledge base. The aim is to enable the quick and effective handling of inconsistent and ambiguous cases by the dermatology consultant. Human supervision ensures that the decisions and learning are correct, and prevents contradictory cases from being involved in the classification process. Hence, we developed a knowledge validation tool that helps the domain experts, who may not be familiar with aspects of machine learning and computing, to maintain and interactively validate the knowledge base.

Generally, the dermatology consultant will instruct the system to re-train the classifier to update the classification rules whenever the knowledge base is updated. Re-training is needed to add the new case to the system. However, the re-trained classifier must be re-validated to ensure that all cases in the database are still classified with 100% accuracy; if the results of re-training the classifier show perfect classification (no ambiguities) no further action is required by the consultant. However, if the re-training results show any misclassification (ambiguity), then the consultant is required to use the knowledge validation tools to resolve the inconsistencies.

We have developed two validation approaches that have been implemented to check and handle inconsistent data in the Telederm system knowledge base: the Misclassification and Formal Concept Analysis (FCA) approaches.

The Misclassification Approach

The Misclassification approach is useful for dealing with human errors (such as in data entry) and misclassification caused by a classifier. In general, the classifier built from the data is not guaranteed to be completely accurate on the training data itself.

However, the classifier must have 100% accuracy in order to maximize its expected accuracy when classifying new cases hence the database must not contain cases that are inconsistent or ambiguous. This functionality helps the consultant to identify and view misclassified cases as well as case attributes that cause the ambiguities. The validation process has two steps. First the decision tree rules are generated based on the cases in the knowledge base. In the second step, the system identifies all instances misclassified by checking their assigned class against the known true class. Whenever a misclassified instance is found the following information is presented to the user:

1. For each rule whose labeled class matches the case's true class, the common attributes to the case and the rule are displayed; and
2. The labeled and true classes are displayed.

Misclassified cases are referenced by instance IDs so that the consultants can view and handle (modify or reject) the cases accordingly. After checking the misclassified cases, the consultant may decide to exclude some of the cases from the knowledge base, if the ambiguity cannot be resolved, and move them to the pending repository for later reference. Alternatively, the consultant can add new attributes or modify existing ones to justify the cases and reduce the anomalies. For example, the two diseases *Eczema* and *Keratosis Pilaris* possess similar characteristics. They are both scaly and associated with family history. In such cases, the consultant needs to add more features, such as itch or no itch, locations, responds to treatment and number of lesions, to disambiguate them.

The Formal Concept Analysis Approach

The second validation technique uses formal concept analysis (FCA) to validate the consistency of the existing and new knowledge. The FCA approach uses concept lattices to represent the conceptual changes to the knowledge base when new cases are added to the database. However, what is critical for the user is to have a simple, fast and effective way to visualize the differences. An algorithm is used to determine the level of conceptual variation between the two lattices. Lattice nodes are highlighted to indicate the changes in characteristics used for describing the diagnoses. However, this representation can be problematic when the lattices become too large (too many diagnoses and attributes) to be interpreted by the consultant. In such cases, it is desirable to provide other methods of displaying information to help the consultant in performing knowledge validation to overcome the lattice visualization problems. These methods include a summary description highlighting the conceptual changes, and a metric that provides an overview of the level of variation between the current and previous lattices.

In the graphical representation of the knowledge using concept lattices, concepts in a lattice are grouped according to the common attributes shared amongst them. Top nodes always contain general attributes that cover a large number of classes, and lower nodes contain specific attributes that cover fewer classes. Generally, each node in a lattice represents a concept. By representing the concepts as nodes, the consultants can easily view the relationships between the characteristics and the corresponding diagnosis.

A concept lattice is built automatically from a context table (Wille, 1982). The table consists of attribute-value pairs generated by the decision tree algorithm. The algorithm automatically extracts disambiguating attributes and partitions continuous attribute values into discrete values. This is because context tables need to use discrete or binary values to represent the relations between attributes and objects. The automatic creation of a context table addresses the prior lack of support for automated knowledge acquisition when building conceptual graphs to represent a knowledge base. Generally, the building of such graphs is based on

interviewing the domain expert, or directly from the cases stored in a database.

The binary relations between the diagnoses and the characteristics within the context tables determine the concepts in the lattices. Using lattices to show the changes in the concepts offers three major advantages. First, the consultants have the flexibility to select specific parts of the lattice to view, and ignore the parts that they consider irrelevant. This allows them to quickly identify the changes. Second, the hierarchical structure of the conceptual groupings can be interpreted intuitively. Third, the changed concepts can be represented as different colored nodes to highlight the changes for quick reference. Note the consultant involved in the research has confirmed the usefulness of lattices as a means to present conceptual variations.

Comparing the previous and current lattices involves identifying which concepts have been changed after adding new cases. The conceptual changes are illustrated using the colored nodes, as can be seen from Figure 2. For example, nodes 1, 3 and 4 are the added concepts. In this particular example, node 1 is an intermediate node that represents a general concept. A general concept has fewer constraints and contains fewer characteristics describing a diagnosis. Thus, it covers more diagnoses than its child nodes, nodes 3 and 4. In Figure 2, node 1 only contains one characteristic: *Pruritus* and it matches two diagnoses: Lichen Planus and Eczema. Nodes 3 and 4 contain more characteristics and so are more specific than node 1.

Often the concept lattice grows too large to be effectively displayed on a single screen and can overwhelm the user with too much relevant information. Telederm offers two alternatives to the graphical FCA analysis. The first is the summary description method that uses text to define the changes occurring in the concepts. The summary description provides the following information:

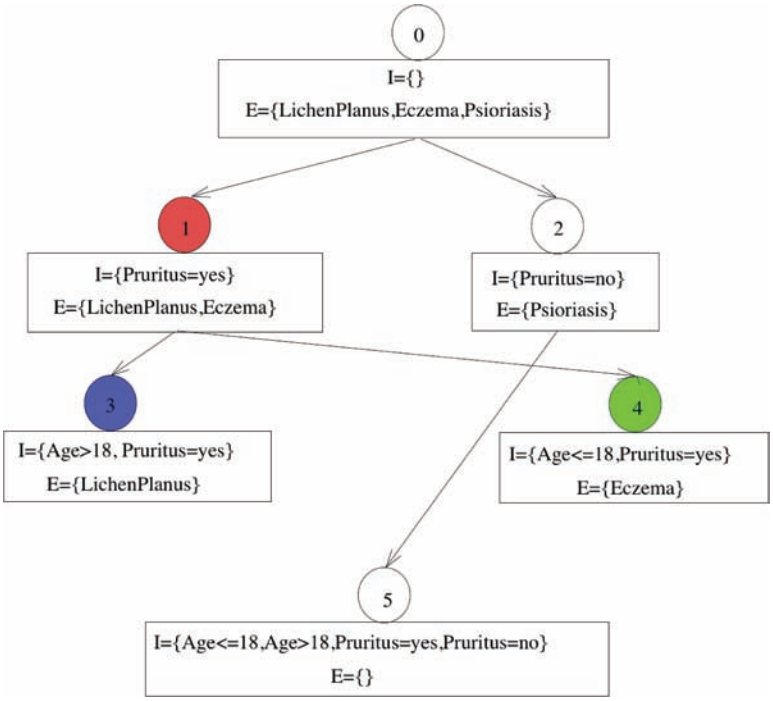
- The number of missing, added and unchanged concepts. This provides a brief indication of the conceptual changes;
- The diagnoses that have been affected and the possible characteristics used to describe each of them as a result of knowledge base updates. The changes can be referenced to the lattices by graph labels (previous graph and current graph) and node identifiers; and
- The diagnoses added or removed, and the possible characteristics that are used to describe each of them. Once again, the changes can be referenced to the lattices by graph labels and node identifiers.

Finally, in Telederm a dissimilarity metric is used to represent conceptual change. Unlike the summary description, the dissimilarity metric attempts to quantify the changes occurring in the concept with a single numerical value and thus provides a simple measure of the overall changes. It can also be used as an indicator of the consistency of the knowledge base. The measure of conceptual variation between two concepts C_{v1} and C_{v2} when a new case is added is dependent on the following factors:

1. The number of diagnoses that were affected;
2. The ratio of characteristics of each diagnosis that was affected;
3. The level in the lattices at which the concept variations occur. The closer the changes are to the top of the lattice, the more significant they are; and
4. The number of new diagnoses added to or removed from, the lattices.

The Telederm system knowledge base is updated as new cases are added to the database by the dermatology consultant. Cases that have been validated by the consultant are labeled *checked* in

Figure 2. The current graph consists of seven cases. Nodes 1, 3, and 4 represent the concepts that changed (source: the authors)



the database. As part of the validation process, a newly added case is labeled *unchecked* before the consultant validates it. The *unchecked* cases are those that need to be validated by the consultant before they are used for classification and learning in the Telederm system. The *unchecked* cases are then combined with existing *checked* cases already in the database for training and generating concept lattices. If the system determines that the validation results do not show any ambiguity (i.e. consistent with previous knowledge), the new cases are relabeled as *checked* by the consultant. The system then uses all the validated cases to build and update the classification model for classifying future cases. However, if the validation results do show ambiguity according to the system, the consultant needs to revise the newly added cases or add them to a repository for later reference.

EVALUATION

The evaluation process involved collecting feedback from GPs via questionnaires, interviews and logs. The results collected from the trial were analyzed and used as an indicator to determine the effectiveness of the system and its ability to assist GPs with their decision making. The EGRRS Project was funded by the 2003-04 Australian Federal Department of Health and Ageing Budget which allocated $9.2 million in funding over two years to the Access to Broadband Technology initiative. The Australian Government also funded $35 million to the Broadband for Health Program to provide broadband Internet access to GPs.

The involvement of practitioners is vital to this research because the proposed techniques and the developed system need to be validated and assessed to ensure their effectiveness in a real world situation. GPs in the Eastern Goldfields including Kalgoorlie, Boulder, Kambalda, Norse-

man and Esperance were invited to participate in the teledermatology trial as part of the EGRRS Project. These GPs have previously referred patients with dermatological problems to Dr Clay for examination.

The dataset was acquired from the consultant, consisting of cases for patients resident in Western Australia who were referred to the consultant by their GPs. This is an important dataset because the cases referred to the consultant are, by definition, those the GPs could not diagnose and hence are ideal to base the decision support system on. This leads to the observation that commonly occurring complaints were not needed as these were diagnosed by GPs without the need of a consultant. Some rare and serious complaints were not considered as few cases were available and complaints such as melanomas were felt too serious to be included.

The consultant data was acquired in two ways. One of the ways involves using an on-line form, provided by the Data Management tool, to allow the consultant to directly enter cases into the database. The form covered a total of 17 topics consisting of 28 specific questions. These questions were considered important while examining patients with dermatological problems as they are commonly used in the real world by GPs and dermatologists during patient consultation. The advantages of using the online form was that the consultant can easily update the existing cases that are stored in the dataset, and the temporarily unused cases can be moved to a repository by deselecting the "Include in knowledge base" option (located at the bottom of the form). The second data acquisition method requires the consultant to manually complete a form regarding the patient's condition during the patient consultation. The information on the paper form was then entered into the database. Each paper form was manually referenced to a case ID that was automatically generated by the Telederm system as a result of adding a new case. This allowed the consultant to cross reference the electronic and paper records of the case at a later stage. Importantly, each form contained the consultant's diagnosis that best represented the patient's condition.

The final dataset contains patient details, symptoms and the consultant's diagnoses. Each patient was given an identification number, and episode numbers were used for multiple consultations for the same patients. The data had 17 general attributes describing 17 topics and consisted of cases describing 51 different diagnoses. As commonly occurs in many real world datasets, this dataset contained missing attributes and these were indicated with "?". Data collection was a continuous process and new cases were being submitted by the GPs to the consultant for examination, and subsequently added to the knowledge base to continuously enhance the system.

Evaluation Process

The first part of the evaluation process determined the effectiveness of the techniques through a series of experiments. A measure of success of a diagnostic system is how many steps or actions are required by the GP to reach a diagnosis. The approach that uses fewer steps to query the system is more effective as it helps shorten the query process. In the experiment, a decision tree was generated from cases in the dataset and was used to guide the query process in the Telederm system. The experiment involved using the logs generated by real GPs during the query processes in the trial period. The system automatically produced a log file that contained a case history for each query. The symptoms contained in each log file were used as input to test both the General (GQ) and Specific (SQ) diagnostic modes. The mode that involved fewer steps to reach a diagnosis was defined to be the most appropriate.

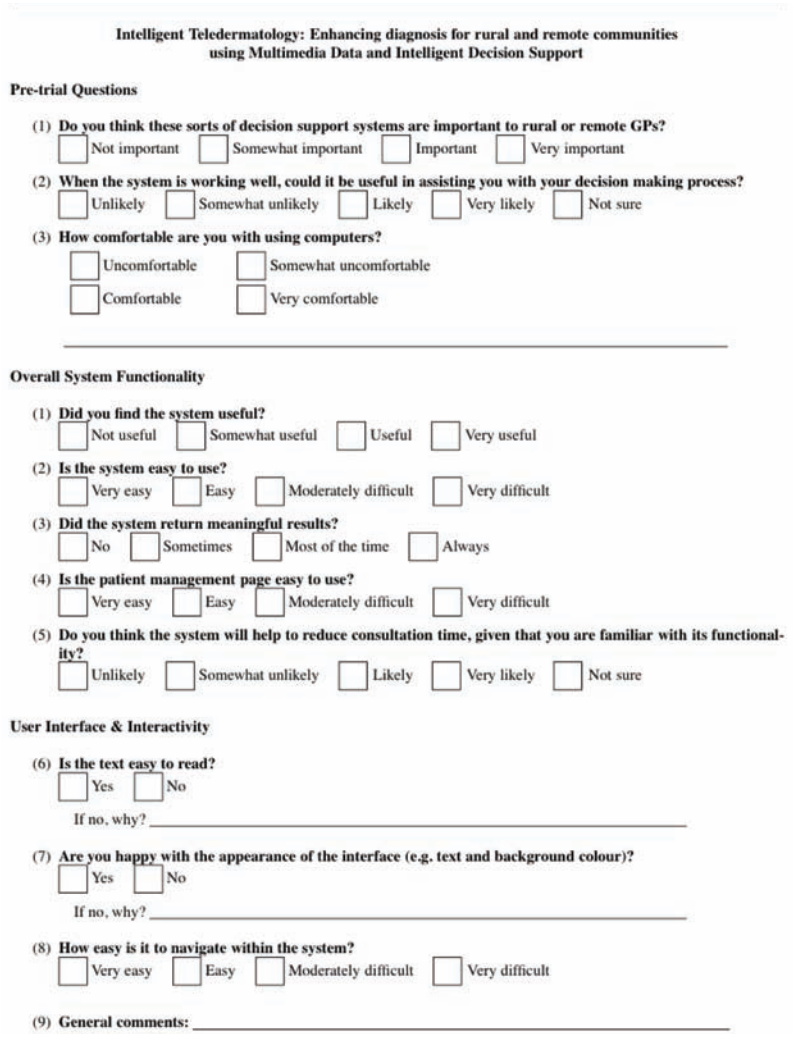
The second part of the evaluation process determined the usefulness of the Telederm system in assisting GPs to diagnose their patients in clinical situations. This involved setting up a trial as part of the EGRRS Project, and recruited all 53 GPs

in the Eastern Goldfields region to participate. The Eastern Goldfields were targeted due to the presence of the EGRRS Project that enhanced the connectivity between the local GPs and the consultant. All GPs taking part in the trial had personal computers in their surgeries and were expected to use the services as part of their normal daily activity.

Before evaluation, the system had to be trained with real data. This was captured from actual consultations by the consultant, many of which were referrals from the GPs in the Goldfields. The data was captured manually by the consultant on custom forms and entered into the CBR knowledge base along with the diagnosis. The consultant subsystem was used by the consultant to ensure consistency in the knowledge base and data. The system had, at the time, 31 specific questions, and 267 cases for 64 diseases. The classification by the decision tree was 100% accurate on these cases.

The trial involved GPs using the system in real situations for a period of six months. All actions performed by the GPs on the system were logged, allowing their usage to be analyzed. As the trial

Figure 3. Questionnaire A (source: the authors)



Intelligent Teledermatology: Enhancing diagnosis for rural and remote communities using Multimedia Data and Intelligent Decision Support

Pre-trial Questions

(1) **Do you think these sorts of decision support systems are important to rural or remote GPs?**
☐ Not important ☐ Somewhat important ☐ Important ☐ Very important

(2) **When the system is working well, could it be useful in assisting you with your decision making process?**
☐ Unlikely ☐ Somewhat unlikely ☐ Likely ☐ Very likely ☐ Not sure

(3) **How comfortable are you with using computers?**
☐ Uncomfortable ☐ Somewhat uncomfortable
☐ Comfortable ☐ Very comfortable

Overall System Functionality

(1) **Did you find the system useful?**
☐ Not useful ☐ Somewhat useful ☐ Useful ☐ Very useful

(2) **Is the system easy to use?**
☐ Very easy ☐ Easy ☐ Moderately difficult ☐ Very difficult

(3) **Did the system return meaningful results?**
☐ No ☐ Sometimes ☐ Most of the time ☐ Always

(4) **Is the patient management page easy to use?**
☐ Very easy ☐ Easy ☐ Moderately difficult ☐ Very difficult

(5) **Do you think the system will help to reduce consultation time, given that you are familiar with its functionality?**
☐ Unlikely ☐ Somewhat unlikely ☐ Likely ☐ Very likely ☐ Not sure

User Interface & Interactivity

(6) **Is the text easy to read?**
☐ Yes ☐ No
If no, why? _____

(7) **Are you happy with the appearance of the interface (e.g. text and background colour)?**
☐ Yes ☐ No
If no, why? _____

(8) **How easy is it to navigate within the system?**
☐ Very easy ☐ Easy ☐ Moderately difficult ☐ Very difficult

(9) **General comments:** _____

progressed, a better understanding was gained of the system and its improvement on the diagnostic accuracy through the acquisition of additional data and feedback from the GPs.

In evaluating and assessing the Telederm system, the following qualitative and quantitative methods have been used as there are a number of characteristics that need to be evaluated. The first evaluation method involved the use of questionnaires to gain a better understanding of the GPs' perceptions, technical adaptability, and the usefulness of the system. There were two sets of questionnaires. Participants were asked to complete questionnaire A (see Figure 3), at the beginning of the trial. It consisted of questions concerning their perception of decision support applications prior to using the system, the system functionality, and the user interface. Towards the end of the trial period, participants were asked to complete questionnaire B (see Figure 4), consisting of questions regarding the usefulness and effectiveness of the system.

The second evaluation method involved interviewing participants to acquire other information that they considered important. A structured interview was conducted with each participating GP, to confirm and discuss their responses to questionnaire A. The discussion aimed to reveal other issues regarding the system that were not covered in the questionnaire. The interview responses were collected, analyzed, and used to facilitate the improvement of the system functionality. The system was modified accordingly to suit different users' preferences. Hence, this improved the usability of the system.

The third method involved the examination of the logs of interactions between the GPs and the system. The logs were examined to assess the effectiveness of the system in assisting GPs to diagnose their patients. Each log contained

Figure 4. Questionnaire B (source: the authors)

Intelligent Teledermatology: Enhancing diagnosis for rural and remote communities using Multimedia Data and Intelligent Decision Support

Post-trial Questions

(1) **Did you find the system useful?**
☐ Not useful ☐ Somewhat useful ☐ Useful ☐ Very useful

(2) **Did the system help you reach a diagnosis?**
☐ No ☐ Sometimes ☐ Most of the time ☐ Always

(3) **Do you prefer to use the Specific or General approach?**
☐ The Specific approach ☐ The General approach

Why? _____

(4) **Rank the options below in term of their usefulness.**

	Not useful 1	2	3	Very useful 4
Ranking option	☐	☐	☐	☐
Emailing option	☐	☐	☐	☐
Selected characteristics	☐	☐	☐	☐
Remaining diagnoses	☐	☐	☐	☐

(5) **How comfortable are you in using the system compared to the beginning of the trial?**
☐ Uncomfortable ☐ Somewhat comfortable ☐ Comfortable ☐ Very comfortable

(6) **Are you likely to use the system again?**
☐ Very unlikely ☐ Unlikely ☐ Likely ☐ Very likely

(7) **General comments:** _____

information including a case history describing a patient's symptoms, the diagnosis mode that was used, whether the GP had completed the whole query or exited before reaching a diagnosis, and the time it took to get to a firm diagnosis. The information contained in the logs was used to provide answers to the following questions:

- Which GPs used the system?
- How many times in total did each GP use the system within the trial period?
- How many times per day did each GP use the system?
- How long did each GP spent on each diagnosis?
- When did each GP use the system? and
- How many questions did the GP answer before exiting the system without reaching a diagnosis?

Results and Discussion

Anecdotal evidence from these visits revealed some opposition but also some enthusiasm for the system along with the other services provided in the trial. The two questionnaires A and B were used to obtain information about the experience of the GPs before and after using the system. The first questionnaire was given to the GPs before the start of a 6 months trial period. Feedback from questionnaire A indicated that a significant proportion of GPs found Telederm to be useful, and were satisfied with its functionality and performance. A summary of the results obtained is shown in Figures 5 and 6.

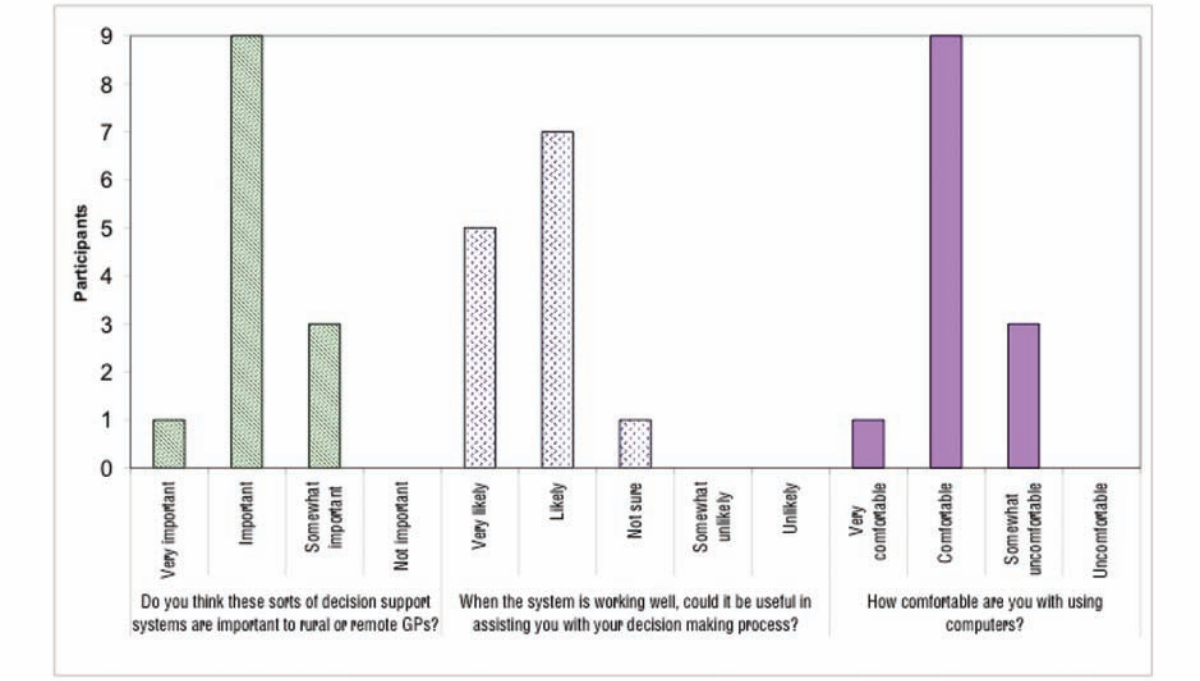
The results show that there is a significant proportion of GPs (70%) who consider such systems to be important to rural and remote GPs. The feedback also shows that 92% of GPs felt that Telederm was likely or very likely to be useful in assisting them with their decision making process. Among the respondents, 69% were comfortable with using computers. These results suggest that the GPs were generally enthusiastic towards the use of decision support systems. The results also indicate that a definite relationship exists between the GPs' level of comfort with using computers and the importance assigned to decision support systems. Specifically, 77% of the respondents who considered decision support systems to be important, 80% were comfortable with using computers. However, the results also suggest that for those who considered such systems to be unimportant, it is unlikely they felt comfortable using computers. The relationship suggests that further uptake of decision support systems is possible if GPs are given adequate training on the use of computer systems. In terms of usefulness, 67% of the respondents found the system useful or very useful, 25% found the system somewhat useful, and only 8 percent found the system not useful. The same proportions of respondents found that the system returned meaningful results always or most of the time, sometimes and never, respectively.

In terms of its usability, 83% found the system easy to use and 17% found it moderately difficult to use. However, the GPs differed on whether the system would help to reduce consultation time. 50% of the GPs felt that the system would be likely or very likely to help reduce consultation time, 8 percent were not sure, and 41% felt this would be unlikely or somewhat unlikely.

The results from the post trial questionnaire (B) are shown in Figure 7. A large majority of GPs reported that the system did help them reach a diagnosis. 56% of the GP respondents reported that the system did help them reach a diagnosis most of the time, 33% reported that the system did help reach a diagnosis sometimes, and only 11% reported that the system did not help reach a diagnosis. It is important to note that the 11% could then refer the patient to the consultant as they had not made a decision. The feedback also suggests that a large proportion of GPs preferred to use the GQ approach rather than the SQ approach.

In addition, on the post-trial questionnaire (B), GPs were asked to comment on their level of comfort in using Telederm compared to the beginning

Figure 5. Questionnaire A: result set 1 (source: the authors)



of the trial. The results were used to determine the GPs' ability and willingness to become familiar with the system in order to use it effectively. 45% of the respondents reported that they felt comfortable in using Telederm compared to the beginning of the trial, and 55% felt somewhat comfortable.

Figure 6. Questionnaire A: result set 2 (source: the authors)

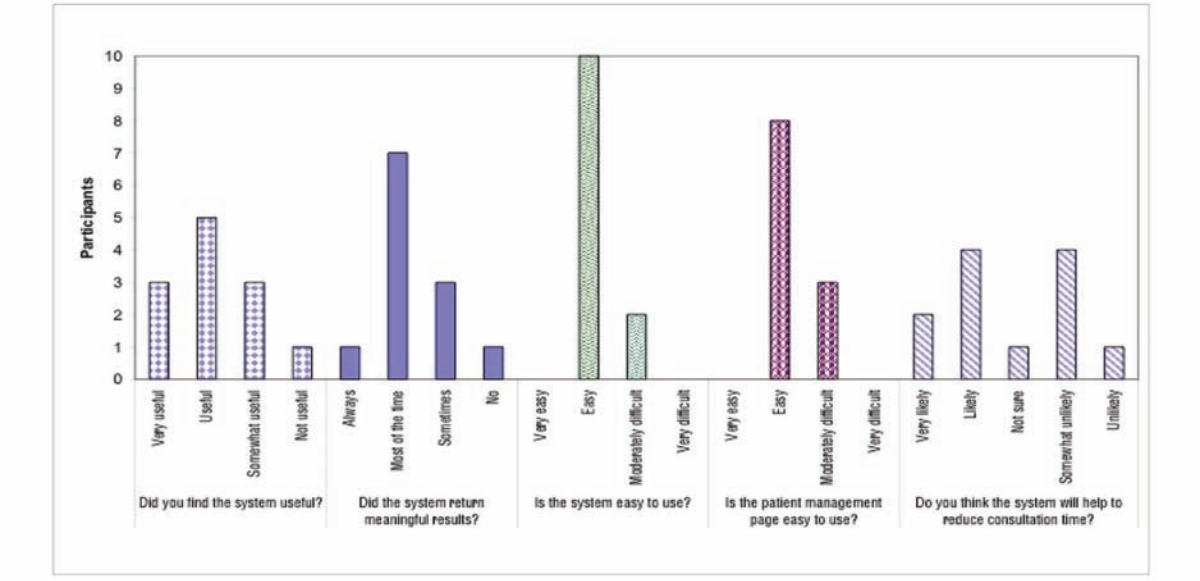
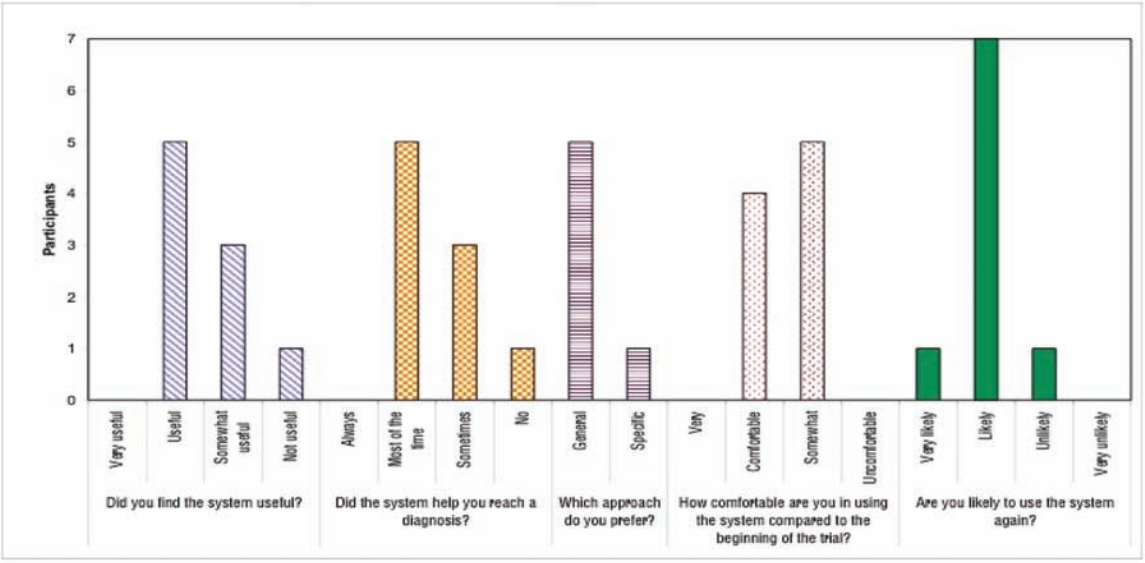


Figure 7. Post trial questionnaire results (source: the authors)



The results suggest that most GPs were willing to become familiar with Telederm. However, based on the feedback, we believe that the level of comfort may improve with more training and practice. 89% of the GPs indicated that they are likely to use the system again.

Finally, the Goldfields trial GPs ranked the benefit of the 12 systems made available (including Telederm). Out of the 53 GPs, 25 responded. The result was that Telederm was ranked about the middle depending on the criterium. We believe this is a good result considering the system was quite complex compared to many of the others, many of which were databases of drugs and other knowledge sources.

CONCLUSION

In this chapter we have described the challenges to developing an effective web-based decision support system and our proposed to solutions to address these challenges. Two major challenges were identified: the first was to develop a query system that was accessible to the GPs and required only minimal time to use and, the second was to develop a system that allowed valid incremental updates of its knowledge base.

To address these challenges we developed Telederm, a web-based decision support system aimed at helping GPs in remote areas to diagnose dermatological conditions. Our proposed solution offers the GPs two approaches to query the patients on their symptoms. The first solution we developed involved the use of a specific question (SQ) approach that assumed that the GP will follow the query process suggested by the CBR system, step by step. However, our feedback on that approach indicated that another approach that minimizes the number of questions was needed. Hence we developed an alternative approach (GQ) that allows the GP to shorten the query process by using more general questions. In addition, we also addressed the problem of knowledge validation that is associated with incremental learning. Since the system's accuracy is critical we proposed a set of knowledge validation tools that offer the experts several alternatives to determining the consistency of the knowledge in the database.

The system was evaluated for a period of more

than two years and this included a large scale trial in the Western Australian Goldfields. The feedback from the trial indicates that it was positive but it did highlight that GPs knowledge of computers and their reluctance to rely on remotely generated information as major factors in overall acceptance.

FUTURE WORK

The current Telederm system is effective in dealing with text based data but feedback from the consultant has indicated that image data is a very important aspect of the diagnosis process. In our future work, we intend to extend Telederm to allow the decision making to include images provided to GPs. We also plan to develop methods to speed up the query process (better human computer interface, image analysis etc.) and thus help the GP with their diagnoses.

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APPENDIX

KEY TERMS AND DEFINITIONS

Artificial Intelligence
Case Based Reasoning
Computer Vision
Data Mining and Knowledge Discovery
Decision Support Systems
Distributed Stream Analysis
Formal Concept Analysis
Geographical Information Systems
Image Processing
Pervasive Computing
Quality of Service in Ad-Hoc Mobile Networks
Smart Homes
Supervised Machine Learning
Surveillance Systems
Telemedicine

Chapter 12
A Stroke Information System (SIS): Critical Issues and Solutions

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ABSTRACT

Fundamental end user issues identified in the design stage of a Stroke Information System (SIS) for Hospital Information Management System (HIMS) in the secondary care and above phase of TACMIS[1], depict the 'gloomy trend' in introducing Information and Communication Technologies (ICT) to the health sector observed across the world and understanding this trend is vital to the future of eHealth '. TACMIS is a total, integrated and inclusive healthcare information system design solution that reflects DAITS[2] core ideas, namely, creativity, cutting edge and being global. In align with the architecture and concept.of the main system TACMIS, the subsystem HIMS-SIS design as well consists of functions that provide stakeholders and nonmedical professionals involved within a stroke special care unit practice, with access to information stored in this subsystem. The SIS functions are especially introduced to inform staff from the so called nonmedical professions in order to improve healthcare quality. This may also make improved treatment affordable for many if not all. At the end of this chapter, some initial investigations on how to transform large volumes of patient data into useful knowledge using intelligent information processing methodologies are outlined.

INTRODUCTION

Stroke Information System (SIS) design issues relating to the system's end users belonging to professions categorised as other than allied to medicine in TACMIS (in a stroke special care unit practice) depict the general gloomy trend observed across the world in introducing Information and Communication Technologies (ICT) to the health sector and understanding this trend is vital to the future of *eHealth*. SIS is an integrated information system design being developed for Hospital Information Management Systems (HIMS) in the *secondary care and above phase* of TACMIS (see Figure 1

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and for further details refer to Chapter 20). Self care: Patient Empowerment and Environmental Control System (PEECSS), and Community care: Socio-economic and Health Care Support System (SEAHCSS) are the other two phases (sub systems) and corresponding information systems of TACMIS. All these systems reflect DAITS core ideas, namely, creativity, cutting edge and being global. Hence, the main focus of HIMS-SIS initial design research was to identify the issues and then to formulate potential solutions, such as integrated information systems, models, and products to equip health sector professionals with concise and precise information on patient care. However, special emphasis was given to look into ways and means to equip the nonmedical staff with information that would be of use to bettering healthcare services relentlessly bearing in mind the rapid growth of the world's ageing population. Thus, the SIS design team in the initial stages of the design looked at the possibilities of including universal design (UD) principles for improving every aspect of the health sector, with an overall aim of delivering quality and efficient services at affordable costs to many ordinary citizens. The major issues encountered in introducing modern ICT capabilities to HIMS and SIS within a stroke special unit practice portray the issues in the whole of the health sector experienced in many countries such as, the United States, the United Kingdom, Canada, European Union countries and the Pacific Region supported by well-known corporate enterprises and is discussed in detail. Finally, the chapter concludes with some initial investigations into how heuristics, such as artificial intelligence, could be introduced to analysing large volumes of stroke clinical data for producing concise information for use by nonmedical staff.

TACMIS FOR STROKE CARE

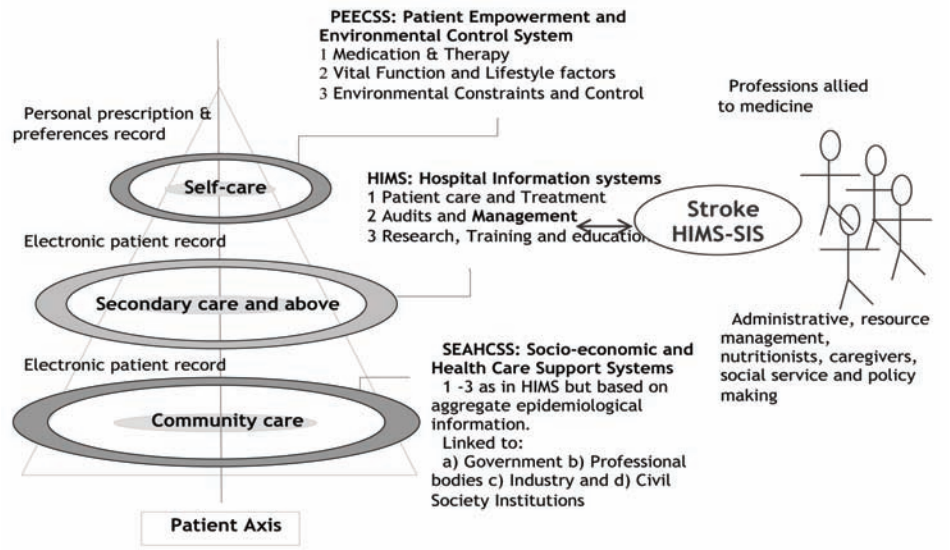
Stroke care in recently introduced special unit practices is used for the initial prototyping and information system implementation of TACMIS as well as HIMS-SIS and the reasons for this are:

a. Stroke care issues, such as disability, therapy, rehabilitation in nursing/care home setups, exemplify the basic healthcare issues associated with the rapid growth of the worlds ageing population, especially in the next two decades (for details see Chapter 20);
b. Stroke in developing countries is rated as the second major killer next to heart attack by the World Health Organisation. Six million people die of stroke annually, whereas for heart attack the recent annual death rate is around seven million (World Health Organisation, 2006); and
c. In developed countries, stroke is the third leading cause for death also raising significant concerns over the burden of the disease, such as long term care, on state and private healthcare institutions as well as insurers (Gordon et al, 2004; Sharma et al, 2005; Sharma & Gehring, 2004).

Stroke Special Unit Practice and Information Sharing

The special stroke unit practice introduced with an aim of providing inclusiveness, information integration and sharing is yet to serve all staff within the clinical professions of TACMIS. The stroke special unit features, such as information sharing and participation in decision making processes relating to patient treatment, progress and disease outcome, are achieved through some radical changes recently adapted by staff from professions allied to medicine. Such recent changes differ significantly in the way professionals allied to medicine perform their daily functions and duties in general. In this special unit practice, most of the staff, namely consultants, senior as well as junior medical registrars, nurses, speech and physiotherapists, all of them are present when an indoor patient's daily progress is assessed. In so doing any decision on a patient treatment or

Figure 1. HIMS-IIS within TACMIS core architecture (electronically reformatted) **(***Source:Cassim, 2005b: 1)*



activity in patient stroke recovery path is made in consultation with all the professions involved. However, this ground breaking practice is yet to fulfil its main aim. At this point in time it does not include in the processes, professions who are classified as other than allied to medicine, such as administrative, resource management, bed managers, drug store managers, nutritionists, caregivers, social services and policy makers and the like. Unless and until the so called nonmedical professions within clinical care management are included in the information sharing group, the special unit practice cannot be described as truly "integrated and inclusive" of an ideal knowledge-intensive information society from an universal design perspective. The inclusion of staff from the professions other than allied to medicine is increasingly becoming significant to bettering the management of rare skills, resources and healthcare funds (Thematic Network, 2006) and in meeting the needs of the world's rapidly ageing society.

HIMS-SIS features that permit staff from professions allied to medicine to share vital information on patients could as well facilitate service providers and patients harness the real benefits of the stroke special unit practice especially, in delivering/ obtaining quality services i.e., better treatment, and care at affordable costs. SIS enhances the possibilities of realising the true potentials that integrated and inclusive information systems can offer, as seen in other sectors, such as banking, airline ticketing and reservation systems, and supply chain management. Introducing ICT capabilities into various mainstream functioning continue to enforce many reforms and unprecedented changes in the management of many other sectors, and even in the way we lead our daily lives. To the contrary, the health sector does not reflect this scenario and the recent trend in almost all developed countries is seen as of major concern. The health sector has as well come under severe criticisms for misappropriation of funds, mainly due to huge administrative costs, such as 41% of the total healthcare budget in the USA. Hence, the health sector needs urgent and immediate reforms that embrace the potentials of ICT mainly to cut down the extra expenditure incurred that hinder patient benefits (Lenz, 2007).

It is becoming increasingly evident that unless healthcare systems are not fully integrated in the near future there will be major break downs in the delivery of even the bare minimum/ basic care for the world's ageing population, as all the medical advances have to rely on a paper based information system. Incidentally, the lack of suitable IT-based models has also made any beneficial feedback action on operational control approaches rare in the health sector (Cannataro et al, 2007; Grant et al, 2006; Maloney, 2006).

Recent reports on healthcare crises experienced from around the world and the measures to introduce latest ICT functionalities to patient information systems to overcome the crises within the sector evidence the gloomy future of eHealth in general. Despite a few encouraging examples on the use of electronic patient records (EPR) there is ample evidence that indicate a slow and rather depressing trend in the implementation of integrated information systems in the sector and these examples and the general issues relating to the trend are elaborated upon here.

Firstly, the implementation of EPRs in many US states has enabled medical professionals to ensure that care for acute patients is extended while in clinic and into community living and this is one of the core functionalities in TACMIS. In Oregon, a State in the US, the medical community there has made good and swift progress in adapting electronic health records (EHRs) to improve health care quality and safety for all patients. The effort to introduce electronic integrated health records for Medicare patients by about 150 of the State's physicians with small to medium sized offices gained support from *Acumentra* Health, Oregon's Quality Improvement Organisation. The implementation of this information system was aimed at ensuring the physicians that their patients received recommended care for chronic illnesses, such as diabetes, concurrently reducing the health care cost by eliminating staff time needed for handling paper based records (dBusinessNews Portland, 2006).

Similarly, many other States in the US and the UK Government as well have made preparations to introduce integrated information systems to permit patient data sharing across secure networks for a wider range of professions. One such example is the efforts made by Department of Health and Human Services (HHS) in the US that promoted the use of technology to improve patient safety. With the use of such new systems doctors and health care providers availed themselves with faster, reliable and secure access to EHRs wherever and whenever required. They even anticipated setting standards for ensuring security and privacy for protecting patient information. To oversee that the widespread adaption of interoperable EPRs is carried out, the US Federal Government established an Office for Health Information Technology. The following are the four primary responsibilities of this Office:

- Serve as senior adviser to the President and the Secretary of Health and Human Services on health information technology programs and initiatives;
- Develop and maintain a strategic plan to guide nationwide implementation of interoperable EHRs in the public and private healthcare sectors;
- Coordinate the spending of approximately $4 billion for health information technology programs and initiatives across the federal government; and
- Coordinate outreach activities to private industry and serve as the catalyst for healthcare industry changes (Symantec, 2006:1).

Meanwhile, across the Atlantic the UK Government has taken a number of initiatives to speed up progress on the implementation of EPRs. One of the initial plans was to begin pilots for uploading patient information onto a summary care system by as early as 2007. In order to deliver this massive NHS (National Health Services) plan a multi-billion pound information infrastructure was to

be created. This was expected to improve patient care by increasing the efficiency and effectiveness of clinicians and NHS staff with the following steps set in place to achieve this:

- Creating an NHS Care Records Service to improve the sharing of consenting patients' records across the NHS;
- Making it easier and faster for GPs and other primary care staff to book hospital appointments for patients; and
- Providing a system for electronic transmission of prescriptions ensuring that the IT infrastructure can meet NHS needs now and in the future as well (UK Dept of Health, 2006:1).

Some latest developments concerning the EU countries are seen as significant in that they show a constructive approach to implementing integrated EPR systems consisting of modern ICT capabilities as in the TACMIS concepts discussed earlier in this chapter. The following concepts are considered as important for the integration of the Health Information Systems in Germany:

- The shift from paper-based to computer-based processing and storage, as well as the increase of data in health care settings;
- The shift from institution-centered to departmental and, later, hospital information systems towards regional and global HIS;
- The inclusion of patients and health consumers as HIS users, besides health care professionals and administrators;
- The use of HIS data not only for patient care and administrative purposes, but also for health care planning as well as clinical and epidemiological research;
- The shift from focusing mainly on technical HIS problems to those of change management as well as strategic information management;
- The shift from mainly alpha-numeric data in HIS to images and also to include data on the molecular level; and
- The inclusion of new technologies that are on a steady increase, for now to include ubiquitous computing environments and sensor-based technologies for monitoring patient health remotely (Sargeant 2008:1).

Given the initiatives taken in 2006 it is also interesting to see some very recent developments in the implementation of integrated EPR systems designed to overcome the issues faced by health carers and providers, imposed by the world's ageing society:

'Microsoft's move into the European healthcare market is generally seen as constructive and observed very cautiously by the other developed nations. Microsoft has today moved fully into the European healthcare market with the launch of *Microsoft Amalga*, its new unified intelligence system for hospitals at the cohnIT healthcare show in Germany. Amalga is designed to enable hospitals - or groups of hospitals/clinics - to access data sitting in isolated clinical, financial and administrative systems without replacing existing software. Microsoft also announced plans for a European Amalga early adopter programme, which will enable it to work with customers to deploy Amalga in various healthcare settings' (Sargeant, 2008:1)

Amalga represents one of Microsoft's new ventures into other software fields (or sectors, in this case the health sector) and it is described to have many components covering everything from handling patient care records to tracking down research projects and finance department tasks. This software is for use in the clinic, and is designed to draw data out of other health-care systems and software used by hospitals into a database and then present it in an intelligible way for medical professionals. For example, Amalga can bring up a patient record and link it

to an X-ray along with other clinical data stored in different systems:

'The goal is to give doctors a faster way to compile the information they need to treat patients and speed up hospital administration. Microsoft said Amalga can manage more than 40Tb of live data, enabling it to quickly respond to queries. The software is built on Microsoft's .NET Framework and uses the company's SQL Server database' (Kirk, 2008:1).

It is very clear as described in the above health-IT news reports that Amalga is a total solution with a multi-modular hospital information system architecture especially designed for the emerging EU markets. Amalga as well has features such as bed management, human resources and picture archiving for radiology. The picture archiving features called Amalga Radiology Information System and Picture Archiving and Communication System can also be used as stand-alone systems (Kirk 2008).

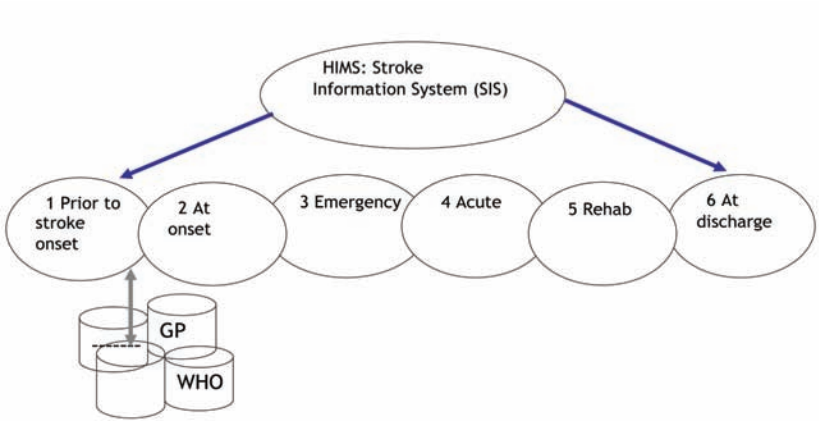
It then appears, while the EU Health sector moves towards something similar to TACMIS total solutions, the UK's initiatives seem to be less positive, having some promising prospects with more state funding but however still with fundamental and niggling security issues yet unresolved. Nonetheless, there are some positives, one of them is the recent announcement by the Scotland's NHS, which is to upgrade its IT systems and equipment following a £525 million cash injection from the Scottish government. Some £324 million is to be spent across Scotland to build new so called 'fit-for-purpose' facilities and to improve equipment. The remaining £201 million is to be spent on specific projects, including eHealth, primary care, and primary and community - care premises that are equivalent to the goals of Self Care and Community Care phases of TACMIS. This shows that the need to feed in summarised relevant patient information to other healthcare systems to ensure patients receive continued care and support throughout their life when they are into community living. It is also interesting to note that the financial boost would be used to upgrade computer equipment used by the health authority. UK Health Secretary Nicola Sturgeon anticipates that the cash would improve the service for local people. In addition she reiterated that:

'The record funding I am announcing today will enable NHS boards across Scotland to continue with their building programmes to ensure we have a health service infrastructure that is fit for the 21st century' (Computerworld, 2008:1).

The disheartening fact in this regard is that the government admitted that it had much more work to do in resolving issues relating to patient security and confidentiality concerns, associated with allowing pharmacists to access patient Summary Care Records (SCRs) (King, 2008). In the meantime, UK-based healthcare IT vendor *iSoft* very recently announced of a partnership with US-based *Sentillion* to deliver a single-sign-on (SSO) solution for healthcare organisations. The solution would provide SSO context management and user provisioning solutions i.e., Vergence SSO/context management suite and Sentillion's next-generation SSO solution expreSSO, developed exclusively for healthcare organisations. iSoft is renowned for its expertise in clinical systems; this is said to be complimentary to Sentillion's, that is described as pedigree in delivering world-class identity and access management solutions to healthcare. The partnership between iSoft and Sentillion is aimed at helping healthcare organisations maximise their investments in clinical information systems by providing the technology needed to improve clinician workflow while improving security audit-ability and compliance (Means, 2008).

Even though the overall current trend in introducing ultra modern ICT to the health sector with world leading IT corporate partnerships especially designed to cater to clinical, audit, management and also with capabilities to extend

Figure 2. EMR penetration figures for 2006 - commonwealth fund survey (by it component). Source: Maloney 2006, 32



required summaries on patient details to community, emergency and carer systems, the sector needs radical changes. The health sector needs to involve i.e., provide access to, all of its professionals in the information systems to improve the sector to make the most of ICT potentials. For example, in New Zealand which showed the world's highest Electronic Medical Records penetration figures for 2006 (Figure 2), doctors are still stressed out, one of the main reasons for this being excessive paperwork and red tape for processing ACC and insurance claims (Maloney, 2006 ; Matheson, 2008).

Given this background on recent issues and the major trend in the heath sector in introducing ICT capabilities, the following section summarises the issues and then presents the solutions suggested to resolve the issues within a stroke care unit practice.

HEALTH CARE ISSUES AND DATA CAPTURE SOLUTIONS

The following are the issues identified concerning the availability and sharing of relevant data within the HIS, the information system for the secondary care and above phase of TACMIS, with a special emphasis on the different stroke pathways, disability, therapy, rehabilitation and care and literature reviewed for this study:

1. Attitude to information sharing: Despite growing public concerns over security issues relating to information sharing, the Scottish Consumer Council study indicated that participants of a recent survey conducted, were more supportive towards sharing NHS information, in the form of an emergency care summary (ECS) extracted using latest technologies for ambulance staff, accident and emergency departments and NHS 24. However, expressed mixed views on sharing the information with community pharmacists. The ECS sharing, mainly aimed at making core information on patient details, such as medication and allergy, available to medical staff in out-of-hours and centers, especially to make care quicker, safer and more effective, was implemented with continued funding from the Scottish Government (Computerworld, 2008). The latest situation reveals that there are still some security issues that remain unresolved (King, 2008);
2. Information on stroke outcome and its related factors: Stroke outcome depends on many

complex factors that can be broadly classified into three major categories, namely patient characteristics, stroke attack and treatment, within clinical care. Despite the many randomised cohort studies carried out on stroke clinical care, Sharma et al (2005) found that information on how these three factors could be related to each other for disease prognosis to be limited. The latter study was based on an extensive literature reviewed for the study on acute stroke treatment;

3. Narratives between clinical professionals and patients: The extraction of useful information embedded in narratives between medical/ other clinicians and patients was identified as a challenge that needed special emphasis and addressing; this was stated in the analysis conducted by TAMICS research team members affiliated to the Discovery Laboratory based in Japan and the United Kingdom. The team found that significantly valuable information on critical decisions made relating to life or death situations in stroke care was being lost or not recorded in the current systems, and made suggestions on how to explore data mining/ management for this purpose;
4. CT/ MR scan notes: Recent technological advances made in medical imaging have created exceptional benefits as well as chaos. With highly sophisticated medical imaging techniques such as 4D ultra sound, high-speed MR scanners and 16 slice CT devices delivering very high resolution pictures, radiologists, paediatricians, cardiologists, stroke experts and many other medical professions are able to diagnose and prescribe treatment faster and more accurately with increased confidence resulting in better outcomes. However, these advanced medical imaging techniques have increased huge volumes of radiology data (in the magnitude of terabytes and even petabytes) that need to be captured, stored, retrieved instantly, transferred seamlessly, securely, and be intrusion free, all of which require intelligent use of technologies. Despite these complex and costly issues, today medical imaging systems have evolved into what could be described as amazingly efficient and viable setups. In the current imaging systems as soon as a diagnostic image is acquired it is coupled electronically with the patient record as the two systems are integrated. With this aspect, the selection of useful data to the professions allied to medicine from significantly high volumes of medical information is a critical factor to the SIS design team as current CT scan images and brain mapping techniques are seen to be significantly useful in establishing the stroke outcome with greater accuracy. For example, depending on the location, type of artery and infarction/ haemorrhage details, stroke outcome could be described to a greater extent, such as required length of indoor patient stay in a hospital;
5. It is obvious that making patient storke information available in a summary form to staff from nonmedical professions would enable the staff to allocate and budget resources needed for the treatment as well as care. More research is warranted to establish the information needs of medical staff so that collective analysis on data in different formats i.e., medical lab test results in text as well as alpha numeric, radiologists notes in text formats and narratives between clinical professions and patients are developed based on user requirements;
6. Specialist notes and burden of input: Even though currently available clinical information systems accommodate capturing specialist notes, such as brief medical notes, in digital formats, there are still practices with staff possessing technophobia issues that hinder the use of such facilities. This is a major concern, also identified by the

TACMIS research team as 'a major burden of input'; and

7. Inadequate integration within stroke facilities: Fragmentation of stroke care caused by inadequate integration of various facilities, agencies and professionals who need to function in close collaboration with an aim of providing effective care, was identified as a major cause for obstacles in consistently translating scientific advances into clinical practice (Lubitz & Wickramasinghe, 2006).

HIMS-SIS ISSUES AND SOLUTIONS

The following are some solutions suggested for the implementation of IT in the health sector to resolve the fundamental challenges and issues identified in the HIMS-SIS design and in the worldwide trend so far discussed in this chapter:

1. Security and access to information: Security over information sharing, access levels, overriding authority and related issues have evolved along side with that of the information systems themselves, the former being considered as part of the system design and implementation. Currently, there are standard conventions that have been refined over the last six decades and a related set of generic codes applied to medical information systems will be adapted for SIS in setting access levels and authority. Furthermore, data elements relevant to professions allied to medicine will be selected for this purpose and the methodology sort for this task is discussed later under proactive use of emerging data/text mining technologies;
2. Burden of input: Also identified by the TACMIS team as a major issue in the initial studies and state-of-the-art speech recognition and optical/ intelligent character recognition software available in the market would need to be used to transform hand written notes and conversations between clinicians and patients. SIS will consist of modules and interfaces to add such software and devices used to address the issues however they would be dealt separately in order to have the SIS core systems abreast of technological advances as stated in TACMIS. Sound and text captured through these special devices, such as e-pen and e-pad, would be transferred into flat text files and further intelligent data/ text processing methodologies would be run to select useful data from them;
3. Data selection for sharing: The specific issue relating to HIMS-SIS is the selection of relevant data elements useful to professions allied to medicine for extending patient benefits. The solution for this is discussed in proactive use of emerging technologies;
4. Proactive use of emerging data/ text mining technologies: This is the most vital component of the SIS design and it needs collaboration between professionals from IT and stroke care. In this case, implicit knowledge in stroke severity, treatment, outcome and care from professions allied to medicine as well as that of nonmedical would be incorporated into an efficient and effective information system useful to staff from both professions. As discussed in the earlier section, information on stroke factors, outcome and how the two are related to each other is limited, hence initiallyconventional computer systems analyst tools would be used to identify available data sources. The chosen data sources would then be normalised and case studies would be carried out using data mining techniques with processes/ stages of a typical knowledge discovery application;
5. With regard to integrating CT scan image results into the SIS analysis, text mining techniques elaborated in (Chapter X of this volume) can be explored to extract keywords

from the radiologist notes made on scan images. Extracted keywords either with weights/ codes would be then included into the SIS. Increasingly, CT scan images are found to be indicative of stroke outcome, prognosis as well as risk factors, such as silent stroke attacks without any diagnostic clinical symptoms but with radiological evidence of infarction;

6. Furthermore, the use of unsupervised and supervised artificial neural network as well as Bayesian Belief net techniques should be investigated to classify stroke outcomes and their related risk factors. In the next section, data collected for such an investigation is discussed.

STROKE PATIENT DATA FOR SIS

Data captured on stroke patients, be it stroke in special units or other emergency medical service centres, could be broadly classified into four main categories. They are:

1. Patient characteristics and history;
2. Stroke attack symptoms and treatment;
3. Treatment received; and
4. Outcome.

The sources that are useful in drawing data for stroke related cohort studies could be classified as:

1. Death certificates
2. Hospital records
3. Public Health Centers
4. General Practitioners

The data identified for HIMS-SIS based on the above issues and solutions, is included in Table 1. Using this data relating to stroke patient severity and outcomes, SIS stroke outcome classes could be established. With expert advice and intelligent information processing techniques, the major contributing and risk factors could be grouped for each of the SIS stroke outcome classes established to inform staff from professions allied to medicine. The knowledge obtained through computational intelligence would enable the non-medical professionals to make better management decisions in order to improve stroke patient care, such as treatment suitable from the options available, and the type of care and resources needed. The stroke outcome classes established can be applied to disease prognosis *and* to future resource and budget allocations as well. The following are the main steps of the approach:

1. Kohonen's Self-Organizing Neural Network Techniques: Initially, SOM based clustering techniques would be investigated to find the different stroke outcome classes based on patterns/ relationships within stroke factors from the SIS data as SOM techniques can be used with data sets even without their class membership. In addition, integrating keywords extracted from CT and MRI scan results and radiologist notes, further relationships between stroke attack variables, patient characteristics, risk factors and stroke outcome could be studied;
2. Supervised neural networks: Once classes within stroke outcome data are identified, using supervised neural networks (such as back propagation) stroke prognosis could be made; and
3. Bayesian belief networks: With more information on stroke outcome and its related factors, Bayesian belief net techniques could be applied to establishing the probability of stroke attacks for a given patient under varying degree of conditions relating to patient risk factors. Based on stroke patient conditions possible outcome could be predicted to plan, organise and mange patient care and rehabilitation.

Table 1. Stroke data analysis

Patient characteristics & History	Stroke attack (sign) variables	Treatment	Outcome
Patient Id	Symptoms; head ache, paralysis	Received	Rankin Scale Grades
Demographic	Laboratory data		Barthel score
Age	Blood glucose level		
Sex	Physical examination		
Job (level of stress)	Blood pressure		
Weight & Height (obesity)	Neurological examination (Glasgow coma scale)		
Accompanying disease/ medical conditions	CT & MRI scan image results/ radiologist notes		
Diabetes			
Hypertension			
Arteriosclerosis			
Life style			

Rankin Scale Grades Grade-Description
0 No symptoms;
1 Minor symptoms that do not interfere with lifestyle;
2 Minor handicap - symptoms that lead to some restriction in lifestyle but do not interfere with the patient's capacity to look after himself;
3 Moderate handicap - symptoms that significantly restrict lifestyle and prevent totally independent existence;
4 Moderately severe handicap - symptoms that clearly prevent independent existence though not needing constant attention; and
5 Severe handicap - totally dependent patient requiring constant attention night and day

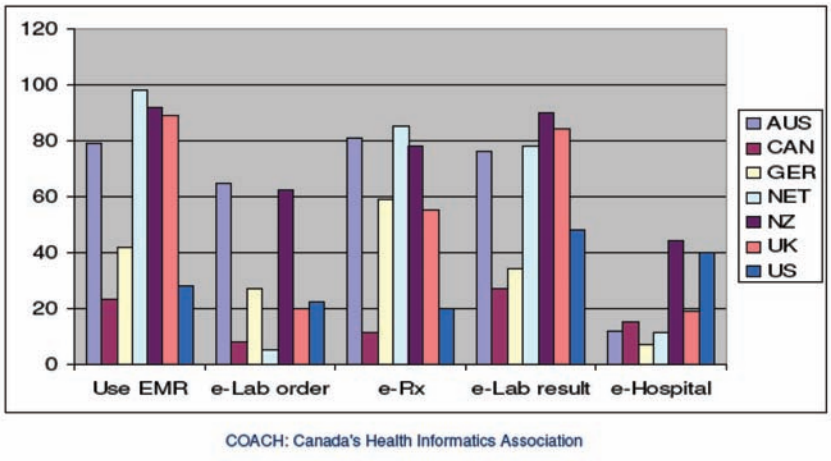
There are significant details on CT scan image mapping/ radiologist notes that relate to the brain area of infarction/haemorrhage and vessels affected, hence SIS will have facilities to add new knowledge and create classes as and when new information becomes available on stroke attacks and outcome.

Finally, SIS will explore new ways and means on how best useful knowledge might be obtained for stroke prognosis and care management by mining medical research publication systems, such as PubMed. Ultimately, professions other than those allied to medicine will be equipped with useful and new knowledge on stroke care to better manage this problem, and in turn to extend extra benefits to stroke patients not just in clinical care but throughout patient life either independent or with enduring disability in community care/ nursing/rest homes.

Based on that specifics relating to information integration and sharing, HIMS-SIS, the multi modular system design developed using information from electronic patient data and manual recording systems is outlined herein. The different modules included in this design are based on the typical stages of a stroke patient journey within HIMS, (see Chapter 20), the secondary care and above phase in TACMIS. The stages included in this information system are: 1) prior to stroke onset; 2) at onset; 3) emergency; 4) acute; 5) rehabilitation; and 6) at discharge (Figure 3).

The HIMS-SIS design discussed in this chapter can be seen to be in align with TACMIS core concepts, such as inclusiveness, integration using cutting-edge techniques to information gathering and processing within stroke special unit practice. Advanced optical character recognition (OCR) techniques, such as electronic pen and electronic note pads, are suggested for use to enter stroke care details, such as patient notes, treatment and response data that are generally handwritten in paper based systems, into electronically acces-

Figure 3. HIMS-Stroke Information System (SIS) and modules based on major stages of a stroke patient in secondary and above care of TACMIS



sible formats. Data mining and other techniques to transform stroke data and scores generally used to assess the disease severity and outcome into formats for the secondary care and above phase of TACMIS have been elaborated. HIMS-SIS implementation aspects and recent approaches thus far investigated in the development of this integrated information system have also been discussed, with stroke data also listed.

FUTURE WORK

Research is already underway to analyse stroke data from King's College, UK to establish the relationships between stroke type, treatment and outcome using the methods discussed in this Chapter. Information for sharing with Self Care and Community Care phases**:** for this, the data required from SIS for creating two separate summary feeds to the other two stages of TACMIS will be worked out. The self care phase summary would consist of details for the patients/ carers either in nursing/ elders homes or in their own homes with their family members. The details designed for self care include: patient details, medications, next appointment, therapy and emergency contact details. The community phase summary will consist of patient details, emergency treatment, allergies and GP/ specialist summary/ contact details.

CONCLUSION

Based on the current situation revealed from the recent ventures and partnerships discussed in this chapter, it is clear that the health sector is, a long way away from harnessing the true potentials of information and communications technologies as seen in other sectors such as banking, air ticket reservations, etc. The main reason for this seems to be related to delays in resolving information sharing issues in the implementation of technologies even with highly secured integrated information systems and models specially designed to the health sector. This is disheartening given the burden the sector is faced with due its continued use of isolated and paper based information systems The benefits of information sharing even between professions categorised as allied to medicine, can be seen in the stroke special care unit practice in which vital information on patients is shared in order to provide the required treatment, therapy and care at the appropriate time to aid in fast and

full recovery or almost normalcy. In the special stroke unit practice all medical personnel are able to access patient information but not the professions who are categorised as the other that allied to medicine.

In view of the shortcomings related to lack of information sharing in the heath sector, an integrated information system design solution especially designed to cater to the nonmedical professions in stroke care, such administrative, resource management, bed managers, drug store managers, nutritionists, caregivers, social services and policy makers alike was elaborated. The chapter as well looked into the critical issues and solutions in developing a SIS. The issues are the same and can be observed in the health sector across the world. The chapter provided a detailed description on potential solutions within an integrated information system framework especially on how ICT usability, diversity, proactive use of emerging technologies could be implemented for supporting knowledge-intensive societies along with benefits to patients and end users. SIS design parameters conform to the HIMS framework, the information system of the secondary care and above phase of TACMICS (Cassim, 2005a) an inclusive and integrated information system design concept prototyped within a stroke special care unit practice. Stroke was chosen for this project as the disease is a leading cause of death and besides its less terminal outcomes, such as disability and the level of care required, exemplify the likely characteristics of the world's ageing population in the next few decades. Furthermore, many recent studies on evidence-based stroke care clearly point out that there is a need for integrated care systems for improving treatment and care, especially to translate advances made in this regard. SIS design as well demonstrated functions to fill the knowledge gap in stroke outcomes and related factors such as patient characteristics, stroke attack, treatment and risk factors.

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ENDNOTES

1 Total Access Care and Medical Information System

2 DAITS: Design for Disability, Aging and Access to Inclusive Information Tools, Technologies and Systems

Chapter 13
Human Factors in Dynamic E-Health Systems and Digital Libraries

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ABSTRACT

E-health systems and digital libraries deal with human health, requiring fast responses and real-time decision-making. Human intervention can be seen in the whole life cycle of biomedical systems. In fact, relations between patients, nurses, lab technicians, health insurers, and physicians are crucial in such systems, and should be encouraged when necessary. However, there are some issues that affect the successful implementation of such infrastructures. Man-machine interaction problems are not purely computational and need a deep understanding of human behavior. Many integrated health knowledge management systems, have employed various knowledgebases and ontologies as their conceptual backbone to facilitate human-machine communication. Ontologies facilitate sharing knowledge between human and machine; they try to capture knowledge from a domain of interest; when the knowledge changes, the definitions will be altered to provide meaningful and valid information. In this chapter, we review and survey the potential issues related to the human factor in an integrated dynamic e-health system composed of several interrelated knowledgebases, bio-ontologies and digital libraries by looking at different theories in social science, psychology, and cognitive science. We also investigate the potential of some advanced formalisms in the semantic web context such as employing intelligent agents to assist the human user in dealing with changes.

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"When dealing with people, remember you are not dealing with creatures of logic, but with creatures of emotion, creatures bristling with prejudice, and motivated by pride and vanity"

Dale Carnegie (1888-1955)

INTRODUCTION

During the last two decades, many advances in healthcare have required the development of artificial intelligence (AI) techniques in the biomedical domain. Several biomedical systems, such as Acute Care Systems, Medical Decision Support Systems, Educational Systems, Quality Assurance and Administration, Laboratory Systems, Medical Imaging, and so forth, are recruiting large digital libraries, knowledge-bases and ontologies (Gruber, 1993) as their backbone to facilitate human-machine communication and capture knowledge from the domain of interest. When the knowledge changes the definitions will be altered to provide meaningful and valid information. E-health systems and digital libraries deal with human health, requiring fast responses and real-time decision-making. These systems usually have a very complex structure, with many elements tightly coupled to one another and organized in distributed, lattice-like networks. In such structures, changing one component can have unpredictable effects on the whole system. As can be seen from state-of-the- art change management in existing biomedical knowledge-bases and digital libraries, this problem is inadequately addressed by available tools and algorithms, mostly because dealing with change is mainly a social, linguistic, and philosophical problem, rather than computational one. A key issue in managing current dynamic biomedical systems relates to users' behavior and the cultural and disciplinary assumptions (Forsythe, 1998), which can determine the success or failure of a system. The change management phase in current systems is largely addressed implicitly, and followed with human supervision and intervention.

Human intervention can be seen in the whole life cycle of biomedical systems. In fact, relations between patients, nurses, lab technicians, health insurers, and physicians are crucial in such systems, and should be encouraged when necessary. The human contribution improves rationality and plays an important role in controlling the quality of the results. However, there are several applications where human intervention is difficult, impossible, or simply undesirable (Flouris et al, 2006) (e.g., due to security issues). Also, differences in background knowledge, views, or preferences are other obstacles for consensus between people. In this sense, a result might not be accurate or reproducible. In addition, the system's outcome might be highly dependent on human behavior, which makes it difficult for evaluation in terms of efficiency or correctness.

The existing well-known biomedical systems and digital libraries usually affect large and heterogeneous groups of people, with different levels of background knowledge and dissimilar interests. Therefore, an efficient user-centered approach, along with psychological and organizational proficiency should be taken to reduce the behavioral side-effects and successfully manage changes in healthcare applications. An ideal e-health system should be able to automatically coordinate human factors, processes, tools and knowledge-bases while coping with different changes. There are some issues that affect the successful implementation of such infrastructures. In this paper, we review and survey the role of the human factor in a dynamic e-health system, and we address following issues:

- The organizational and social impacts of human-driven changes in e-health systems;
- Different sources of change;
- Human errors due to change and alteration;

- Responding to change in a dynamic e-health environment;
- Safety;
- User interface issues;

We also investigate the potential of some advanced formalisms in the semantic web context (such as using intelligent agents to assist computational inferencing) to assist the human user in decision making and dealing with changes.

BACKGROUND

A large body of literature exists on the importance of human-machine interactions in various domains of interest. Life science and biomedical fields are challenging domains in knowledge management. Biomedical data are highly dynamic, and the large biomedical knowledge sources contain complexly interrelated elements, with various levels of interpretation. Considering the dynamic nature of current volatile digital libraries, which need real-time decision-making and proper action from human agents, the concept of change and the ability to cope with various alterations play important roles in biomedical knowledge bases. Lorenzi & Riley (2000) presented an overview of change management efforts in informatics showing the roles of people and the organizational issues (i.e., the interruption of a known routine) that were counterproductive to the implementation and management of major information systems.

Based on their research, the main reasons for system failure can be categorized under miscommunication, cultural barriers, underestimation of complexity, inadequate or low-quality training, lack of organizational change management strategies, and weak leadership. Considering the dynamic nature of current knowledge-bases, which need real-time decision-making and proper action from human agents, the concept of change and the ability to cope with various alterations play important roles in biomedical knowledge-bases. Lewin (1947) with his social psychology perspective focused on the motivational concepts that underlie an individual's behavior. He believed that psychological needs in humans cause tension until they are fulfilled. Lewin indicated three major conflict situations: the choice between two positive goals of equal strength, two equally negative goals, or opposing positive and negative forces of different strengths. Lewin's field theory, commonly used in healthcare systems, allows one to identify different types of conflict situations and to analyze the effect of a change in a knowledge-based environment (Lorenzi & Riley, 2003).

TYPES OF USER-DRIVEN CHANGES

Watzlawick et al (1974) used two theories to explain first-order and second-order changes, namely the theory of groups and the theory of logical types, from philosophy and logic. A first-order change is defined as the logical extension and incremental improvements of past and current practices in a given system, leaving the system's core belief relatively unchanged (Examples such as recovery from system failure, and generating new reports). A second-order change occurs when the system itself is changed. This change usually involves a redefinition or re-conceptualization of the ideas, tasks, domains, or roles in an organization. First-order change involves improving the existing procedures, while second-order change alters the core methods of conducting business, or even the basic business itself. The change from paper-based medical records to electronic medical records represents a second-order change in biomedicine (Lorenzi & Riley, 2000). Golembiewski et al (1976) added a middle-order level of change, to represent a middle ground for changes greater than first-order that do not affect the strategic goal and nature of the system.

For any alteration in a system, users, designers and developers can play various roles, which will influence their conceptualization about the

change and their reaction to it (Lorenzi & Riley, 2000). So, in making decisions and taking action within dynamic biomedical systems, the users' behavioral aspects associated to each role should be controlled.

HUMAN ERROR IN CLINICAL SYSTEMS AND CHANGE MANAGEMENT

Studies (Lorenzi & Riley, 2000) on people working with health-related systems imply that due to high stress and pressure in the field they are relatively more resistant in confronting with changes. Changes can potentially increase the chance of error in a system by routine disruption. One factor urging system change is the need to deal with human error, present in all stages of a system's life cycle. Human error should be considered in clinical application development's life cycle, along with many other aspects of design. Studying human error provides valuable information for analyzing human behavior and reveals user requirements and misunderstandings. Human error is defined by Barfield (1993) as an error caused in some way by the user of the system, in contrast to a system error, where there is a physical fault in the system. Based on the user's mental model, he grouped the errors into two categories: errors of action (error in the translation between a user's intention and their action) and errors of intention (the user doing the wrong thing on purpose). This classification is comparable with Norman's categorization of errors (Norman, 1988) into mistakes and slips: if a person has intent to act that is inappropriate, it is a mistake; if the action was not what was intended, it is a slip. In order to deal with human error, Norman highlighted the needs for better consistency in describing the errors and better feedback for capturing and reporting them (Lorenzi & Riley, 1994). In dynamic environments with several external and environmental parameters such as evolving e-health systems, the rates of unintentional errors can increase greatly. Bés (1997) and Decortis (1993) have worked on the effects of temporal characteristics on users' activities in dynamic environments. Decortis stated that temporal errors can originate from incorrect estimates about the sequence or duration of actions and/or failure in choosing the right time to act, in anticipation of an event or in synchronization of collective actions (Decortis, 1993). In addition, De Keyser (1995) identified other sources of temporal errors, such as the absence of high-quality indicators to highlight the change, the presence of micro-changes too short to be received, and the existence of distracters capturing the users' attention (Bés, 1999). Heifetz et al (2002) made the distinction between two methods for change management: the technical method that can be understood and addressed with available knowledge (mostly used for managing first-order change) and the adaptive method that is beyond the existing and available techniques of operation.

Several efforts such as (Forsythe, 1998) and (Lorenzi & Riley, 1994, 2000, 2003) have been made for applying knowledge of human and organizational behaviors derived from psychology, sociology and cognitive science to the implementation and management of healthcare systems.

Safety

The six principles was defined by Committee on Quality of Healthcare in America (2001), to be followed by any e-health knowledge-based system to provide high-quality services, focus on safe, effective, patient-centered, timely, efficient, equitable environments. User and patient safety is a challenging issue that needs to be addressed with proper real-time control and feedback mechanisms in the systems. User interfaces can play a vital role in this case by providing appropriate forms of messages and warnings in a timely manner. The number of potentially hazardous errors can be reduced by employing intelligent safety devices, accurate alerts, and effective user-friendly interfaces.

To cope with changes in the constantly evolving knowledge-based e-health environments, one must have a formal model of human reactions to change, enabling cognitive error analysis. Beitler et al (1995) designed an interface that provides a virtually simulated multimodal user control environment, based on the knowledge of a reactive planner to allow "autonomous planning as well as planning through human-machine interaction". The system acts like a human agent and can be used in situations unsafe for people. This approach is especially useful in assisting people to perform repetitive tasks, which potentially increase the chance of error for human.

Trust and Security Issues

Kini et al (1998) observed various aspects of human trust in computer-dependent systems, according to personality theory, sociology, economics, and social psychology. They defined trust as "a belief that is influenced by the individual's opinion about certain critical system features". Their study does not support the problem of trust between humans and processes involved in knowledge-based interactions, but focuses on the human factor as the "truster" instead of system. Gambetta (2000) defined trust as an estimation that can be determined by the probability of an action being successfully performed. Jøsang et al (2007) look at trust in a user-centered framework where '*one party is willing to depend on something or somebody in a given situation with a feeling of a relative security, even though negative consequences are possible'*. In this sense, human-agent interactions play important roles in the security process, which usually includes authentication, authorization, and confidentiality. Relying only on human factors in the security process, especially in complex health systems, may lead to unpredictable, inaccurate, and inconsistent results that often may not be reproducible. So, in modern e-health knowledge bases, security management must be carried out automatically, with minimal human intervention.

User Interface Issues

Since biomedical knowledge bases and applications are most often used by lab technicians, nurses, and physicians, a formal logical language is not well-suited. Therefore, special attention is given to the design of the operational user interface, based on natural language processing and intuitive graphical representation. Currently available tools do not provide complete support for dealing with the complexity of evolving medical systems, which go beyond the capabilities of existing user interfaces. One method for dealing with the representation of changes in user interfaces is to employ ontology in capturing the knowledge about evolving concepts. In this way, changes to the user interface can be made by changing the underlying ontology. Taboada et al (1996) and Gupta et al (1999) undertook two efforts devoted to modeling user interface for biomedical applications. Pohl et al (2007), Leitner et al (2007), and Carrigan et al (2007) also recently demonstrated their advances in the usability of user interfaces of available information systems in medicine and healthcare. In general, a user interface based on human factors is a key to the acceptance of a system (Nielsen, 1993) in medicine. In creating a graphical user interface (GUI), the level of expertise and the operational habits of the medical staff should be considered.

Hartson & Boehm-Davis (1993) specified behavioral and construction domains for implementing a user interface. The behavioral domain includes the design and development of the interactive part of an interface, and the construction domain includes the development of the graphical environment. The development process of a usable GUI is not possible without active participation of physicians, psychologists, and other end-users of an e-health system. It also requires the consideration of important human factors, such as intuitiveness, functionality, accessibility, flexibility, and adaptability of the user interface. However, design criteria based on human factors do not

automatically guarantee a solid, usable interface (Taboada et al, 1996). As the GUI development for dynamic environments is always an iterative process (Hartson & Boehm-Davis, 1993), it requires the occasional modification of initial system specifications based on new requirements or newly obtained knowledge.

For defining any behavior change procedure, we first need to specify behavioral patterns to capture current behavior, the behavior upon change, and the advantageous replacement behaviors. For this purpose, we introduce our agent-assisted framework, meant to assist humans in performing changes automatically.

AN AGENT-ASSISTED FRAMEWORK FOR PARTICIPATIVE CHANGE MANAGEMENT

A dynamic health knowledge-base usually deals with spatial and temporal data, metadata, documents, and data warehouses while working in an integrated web-based system that includes databases, ontologies, and software agents. To overcome some of the existing challenges in current knowledge-based systems, there is an emerging trend to design systems based on human behavior and needs (Brazier & Treur, 1994; Duribreux-Cocquebert & Houriez, B, 1996).

Recruiting intelligent agents can assist users in coping with change in evolving environments. Change management starts with specifying the type of potential change. Then an individual can act alongside agents to capture, represent, and manage the alterations. In this approach, special attention should be paid to agent-human interactions. Intelligent agents are able to discover, identify, and collect information about a variety of actions under changing conditions from multiple distributed resources (Devedžic, 2001). They have ability to work rationally, to capture different alterations in frequently changing environments, and to react appropriately to these changes (Li et al., 2005). In our proposed RLR (*R*epresentation, *L*egitimation and *R*eproduction of a change) framework (Shaban-Nejad & Haarslev, 2008), we have used four types of agents, the Change Capture agent, Learner agent, Reasoning agent, and Negotiation agent, to assist an ontology engineer in coping with change in dynamic knowledge-bases. Figure 1 demonstrates the interactions between the agents and the human factor. The collaboration between human and software agents can lead towards participative evolution which is defined as managing incremental change through collaboration (Dunphy & Stace, 1990).

Change Capture Agents

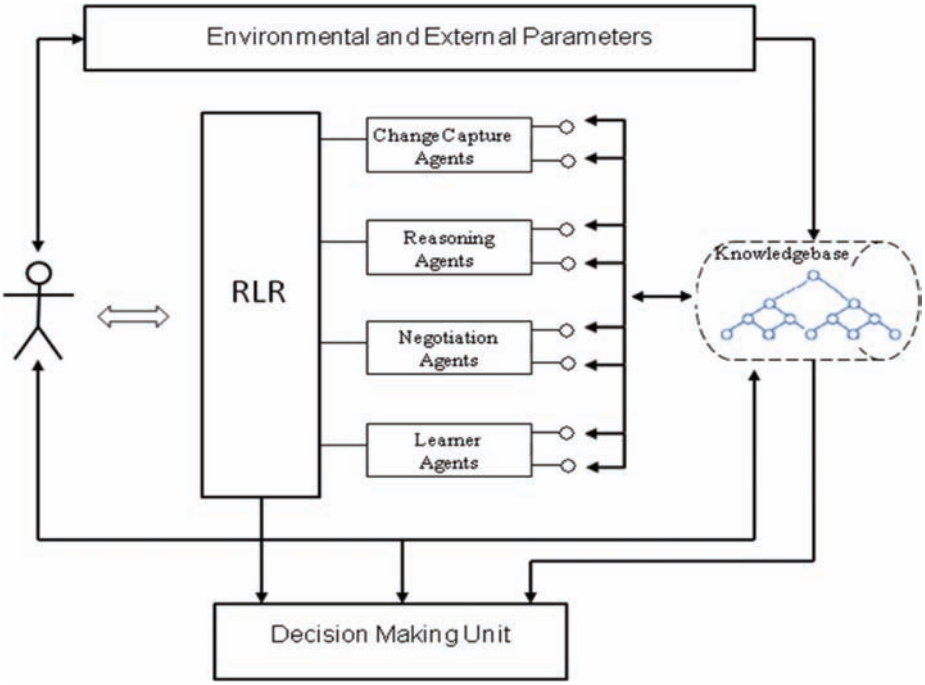
These work like triggers in database and can find, capture, and track different alterations in a knowledge-based system, by processing the associated change logs. These agents perceive the changes – either random or scheduled- in the real-world and report them as new facts to update the new knowledge. In the RLR framework, we have defined three different types of change-capture agents: action control agents, explorer agents, and log-reading agents.

Action Control Agents (ACA): consist of user activities and legal operations for capturing and storing (within change logs) basic changes such as deletion, insertion, and updates to knowledge-base elements.

Explorer Agents (EA): capture changes by processing and reading accumulated data in change logs within a specific time period and submit proper messages for the corresponding services.

Log-Reading Agents (LRA): read the information stored in the log files within two time points and send them to a learning agent in order to create patterns for different changes.

Figure 1. The decision making mechanism for user-centric change management



Learner Agent

One approach to minimizing the side-effects of a change is to concentrate on a limited number of changes until they gradually become part of the routine. In this way, the system can improve its learning abilities over time and adapt to new conditions. With active human and machine participation in the change management process, the necessary skills for bootstrapping the whole process can be achieved by the adaptive learner agents. As a knowledge-based system is used and evolves, the designed change logs accumulate invaluable data and information about various types of changes. An intelligent learner agent can then exploit these records of changes that happen frequently in a process to develop a pattern, which can be used to predict - with a realistic degree of certainty - the rate and direction of change.

The learning agent starts with a limited, uncertain knowledge of the domain and tries to self-improve; it relies on adaptive learning, based on the semantics provided by the ontological backbone. The adaptive learning agent plays an important role in the reproduction phase, where we look for patterns to bootstrap the process of change management.

Reasoning Agent

The new inputs (based on different changes) for a system force an agent to revise its conceptualization accordingly, by reasoning out the consistency of the change through the use of both prior and new knowledge. A reasoning agent controls and verifies the logical consistency of a system, by revealing inconsistencies, hidden dependencies, redundancies, and misclassifications. We use RACER (Haarslev & Moller, 2001) as a description logic reasoning agent, along with other semi-formal reasoners in the RLR framework.

Negotiation Agent

Negotiation happens when agents have conflicting interests and a desire to cooperate to settle the conflict (Rahwan et al., 2003). In RLR infrastructure, the negotiation agent handles all the negotiation between agents to determine the best approach for implementing a particular change. The final decision for confirmation, deletion, or modification of a proposal can be made by human experts based on the application's goal. In RLR, the negotiation is defined in accordance to the conceptual model of argumentation (van Eemeren et al, 1996) and an argument is described as a piece of information that allows an agent to backup and justify its negotiation stance or to influence that of another agent (Rahwan et al., 2003).

FUTURE TRENDS

With the increasing popularity of open source knowledge-based systems and advances in web-based applications and technologies, such as intelligent agents, online annotated knowledge-bases, and search engines, as well as in the popularity of collaborative media including blogs, social networking systems, wikis, podcasts, and RSS feeds, the current World Wide Web is heading towards its next incarnation, Web 2.0 (O'Reilly, 2005). Web 2.0 offers many facilities for e-health, such as satellite conferences, personalized learning environments, and blog meetings for educator and learners. A new trend in online biomedicine, e-health 2.0, will facilitate intelligent interaction between the users and computers. It will allow for active participation and contribution by different users, enabling them to add/modify information and knowledge to/from online biomedical knowledge-based networks through web interfaces. Also with advances in neural network and so called ambient intelligence (Riva et al, 2005), which rationally support human in performing various tasks, users will be more in charge and have direct influence in driving and defining the needs. It seems that research on the role of human factors as fundamental constructors of the social semantic web and e-health will continue to aid in the success of e-health 2.0. There is also a growing need to re-engineer our conceptualization of users, developers, trust, security, and traditional user interfaces for new mobile and dynamic e-health applications.

For overcoming issues related to user-interface, recent advances in brain-computer interface (BCI) (Lebedev & Nicolelis, 2006) and human ergonomics (Bridger, 2008) offers promising results, which will enhance the quality of user-centric modelling.

DISCUSSION

As dynamic knowledgebases are becoming huge and complex, operations have to be automated, that needs a fine-tuned collaboration between human (user, operator or developer) and machine. The man-machine interaction problems are not purely computational and need a deep understanding of human behavior. To understand and analyze underlying behavioral issues in modern health systems, we studied some of the theories in social science, psychology, and cognitive science. This will enable us to apply knowledge of human behavior to the implementation and management of knowledge-bases in a healthcare environment. Life sciences in general and the health industry in particular are still highly dependent on human factor playing various roles, so it won't be sufficient to focus entirely on technology and machinery for modelling and implementing knowledge-based systems without considering various human behavioral aspects. To enhance the quality of our knowledge-based systems, human behavior and its limitations should be reflected in any defined change management strategy. In frequently evolving systems and knowledge-bases, this case would be even more critical. For example

in modern e-health systems, security management must be carried out automatically, with minimal human intervention. Our proposed multi-agent change management framework presents a collaborative, realistic and future-oriented approach to facilitate human-agent interactions in dynamic environments.

The RLR framework acts as a basis for a web based decision making and recommender system which allows different users to control and analyze the consequences of their actions in a knowledge-based system. Then they can follow the most beneficial or the least harmless recommended actions to perform a change. Due to the multi-disciplinary nature of research on dynamic knowledge-bases, any advances in this field would be highly dependent on those in various others, such as human-computer interactions, user interface design, neural network, knowledge-base integration, translation,, alignment, and prediction of the semantic closeness of concepts in different knowledge-bases.

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KEY TERMS AND DEFINITIONS

Action Control Agents (ACA): Consist of user activities and legal operations for capturing and storing (within change logs) basic changes such as deletion, insertion, and updates to knowledgebase elements

Explorer Agents (EA): Changes by processing and reading accumulated data in change logs within a specific time period and submit proper messages for the corresponding services.

Learner Agent: Exploit the records of changes that happen frequently in a process to develop a pattern, which can be used to predict the rate and direction of change.

Log-Reading Agents (LRA): read the information stored in the log files within two time points and send them to a learning agent in order to create patterns for different changes.

Negotiation Agent: Handles the negotiations between agents to determine the best approach for implementing a particular change.

Reasoning Agent: Controls and verifies the logical consistency of a system, by revealing inconsistencies, hidden dependencies, redundancies, and misclassifications.

RLR: A multi-agent framework for Representation, Legitimation and Reproduction of changes

Section 3

Selected Case Studies

Chapter 14
The Use of Laboratory Test Results in Health Care Management

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ABSTRACT

Laboratory test results used in health care management can be qualitative or quantitative. These cover several disciplines, the four major disciplines being histopathology, haematology, medical microbiology and chemical pathology. Histopathology and medical microbiology are mainly qualitative assessments, while chemical pathology is predominantly based on quantitative analysis of chemical constituents in blood or other body fluids. Haematology encompasses both quantitative and qualitative assessments, the blood cell parameters being quantitative while blood film reports and bone marrow reports are qualitative. The application of such results to healthcare management includes screening for disease as well as in making a diagnosis and for monitoring response to treatment of a known disease. This necessitates the availability of normal ranges to compare with and decide whether the results are normal or not. Normal means the individual is in a state of good health and a deviation from normal is interpreted as implying ill-health. Data used in these tests are taken from previous studies of Sri Lankan Adults carried out from May 2005 to July 2006.

INTRODUCTION

Laboratory test results used in health care management can be qualitative or quantitative. These cover several disciplines: the four major disciplines being histopathology; haematology; medical microbiology; and chemical pathology. Histopathology and medical microbiology are mainly qualitative assessments, while chemical pathology is predominantly based on quantitative analysis of chemical constituents in blood or other body fluids. Haematology encompasses both quantitative and qualitative assessments, the blood cell parameters being quantitative, namely, Haemoglobin (Hb). Red Blood Cell count (RBC), Mean Corpuscular Volume (MCV), Mean Corpuscular Haemoglobin (MCH),

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Mean Corpuscular Haemoglobin Concentration (MCHC), Packed cell volume (PCV), White blood cell count (WBC), Differential Count (DC) and Platelet Count (Pl. Count)., while blood film reports and bone marrow reports are qualitative.

In the developing countries good quality automated laboratory equipment to measure the various biochemical and haematological parameters are now often available, and laboratory results are accurate and show precision. Their application to healthcare management includes screening for disease as well as in making a diagnosis and for monitoring response to treatment of a known disease. This necessitates the availability of normal ranges to compare with and decide whether the results are normal or not. Normal means the individual is in a state of good health. A deviation of the test results from the normal is interpreted as implying ill-health.

THE REFERENCE RANGE

Laboratory results are conventionally compared with established physiologically normal values, such values being often derived from text books. For any individual, the ideal reference value for a test result would be that obtained when that individual is healthy. Test results for the normal and abnormal can overlap, and a value within the accepted normal range may be pathological for a particular subject. For this reason, more recently, the concept of normal ranges has been replaced by the concept of reference ranges and test results of patients have been compared with the reference ranges. Ideally, each laboratory should establish its own data bank of reference values and reference ranges.

A reference individual is one selected using defined criteria and picked from a population that includes all individuals who meet those criteria. A reference sample is a number of such reference individuals. Reference values are test results obtained by testing the reference sample or population. They can be subject to statistical analysis, and they will show a certain distribution. Leaving out the lowest 2.5 percent and the highest 2.5 percent at either end of the observed range, the central 95% of the observed values is known as the reference interval (Bain, 1995). Reference ranges for a particular test for a select population are determined from groups of comparable subjects assumed to be representative of the population being dealt with, namely a reference population, of defined criteria such as age, sex, non-smokers, non-alcoholics, non- pregnant (if female), not on regular drugs and free from chronic disease. The technique and timing of sample collection and posture of the subject at the time the sample is taken must be standardized. Whether the subject is ambulant or resting in bed also may affect the test results. Samples should be collected at the same time of the day, in fasting state, with the subject in standardized position i.e. either seated or recumbent with the arm semi-flexed and with minimum stasis (Lewis et al, 2001).

Statistical Procedures

In order to determine the reference range, the set of results for each variable is recorded graphically. The application of the Gaussian curve to describe biological variables was popularized by the English naturalist Sir Francis Galton, cousin of Sir Charles Darwin (Amador, 1975. Usually the data will fit a certain type of graph. Normal results usually produce a symmetric (Gaussian) type of graph. If the values fit a Gaussian distribution their arithmetic mean and standard deviation are calculated. From these the 95% confidence interval i.e. mean +/- 2 Standard Deviations (SD) is calculated. The result thus obtained gives the reference range of the particular test for the population being studied. If the graph is asymmetrical with a skewed distribution (non-Gaussian), the data should be converted to log values and these used to draw the graph. Then the geometric mean and SD are calculated, and the 95% confidence

interval may be determined. Finally, the results are then converted to their antilog and expressed as the reference range.

When the type of distribution cannot be incorporated into a graph, a non-parametric method of analysis is used. Here, the data are ranked according to increasing numerical values. The total number of results is taken as n; and subsequent calculations are based on n+1. The lower reference limit will correspond to the rank number at which 2..5% of n+1 results occur, and the upper reference limit is the rank at which 97.5% of n+1 results have accumulated. The values between 2.5 percent and 97.5% give the 95% confidence interval. A reasonably reliable result can be obtained with a small number of test values (as low as 40 tests) if the results fit a Gaussian curve, but a larger number (120 or more) is required if the graph is non-Gaussian or non-parametric calculation. All industrialized or developed countries have determined their own reference ranges. Developing countries such as Sri Lanka have yet to determine the reference ranges for their indigenous populations.

HAEMATOLOGICAL REFERENCE RANGE PARAMETERS FOR SRI LANKAN ADULTS

Establishing reference ranges on a population sample is a difficult and expensive procedure. Nevertheless, laboratories should as far as is possible try to establish their own reference ranges not only on indigenous reference populations, but also applying similar sampling techniques and laboratory methods. A well recognized and unbiased sample of normal subjects commonly used for determining reference range is volunteers presenting for their annual health screen. We have here used such a reference sample to determine reference ranges for haematology variables in Sri Lanka. Data from volunteers who presented themselves for their annual health screen at a large private hospital in Colombo are used for the purpose. These data supply the reference ranges of haematological parameters for a segment of the population, namely, healthy, well nourished adult Sinhalese people of either sex, living at the same altitude (i.e. at sea level) in Sri Lanka and serve as the reference range for all adult Sinhalese. This can then be used as an example for working out the reference ranges for other groups of reference populations.

For Sri Lanka, it is important to recognize that the results of haematology variables may be different for the rural folk whose dietary habits, life style, beliefs etc. are different from the urban elite, or educated people living in cities. Similarly, the elderly may require a different set of reference ranges as their nutritional status and sub clinical disease may affect the reference range. Reference ranges for pregnant women would have to be worked out separately, preferably using women attending antenatal clinics. In normal pregnancy, there is an increase on erythropoietic activity, and at the same time plasma volume expands causing a progressive fall in Hb, PCV and RBC. These return to normal about a week after delivery. MCV increases slightly in the 2nd trimester. Thus, during pregnancy, data should be collected at 2 weeks, second trimester, prior to delivery and 1 week after delivery.

For the paediatric group, the normal ranges for most haematologic parameters are quite different from that of the adults. Dramatic changes occur in haematological values during the first few weeks of life and continue throughout the child's growth and development. Nutrition of the child exerts a critical effect during periods of rapid growth. As haematological measurements are frequently used as a screening procedure to detect abnormalities in the child, recognition of these variables in the paediatric age group will avoid unnecessary laboratory investigations when they are unwell. To determine reference ranges for haematological parameters, it is necessary to take into consideration narrow age groups, as the haematological values change

a great deal in the infant. Hb RBC and PCV are highest in the neonate. After the neonatal period, Hb falls steeply reaching a minimum by about the 2nd month. The RBC and PCV also fall and the red cells may become microcytic. Thus physiological iron deficiency of infancy would develop at about 2 months and does not alter much thereafter up to about 3 years. Hence, data should be obtained from reference groups at birth (cord blood), Day 3, 1 month, 2 months, 3 years and 12 years. Up to the age of 12 years there is no necessity to consider the two sexes separately.

Sample Selection

The subjects were adult males and females, who presented themselves for their Annual Health check at Asiri Surgical Hospital, Colombo by prior appointment. The final sample included 506 males aged between 19 and 90 years, and 460 females aged between 20 and 76 years who appeared to be in good health and had normal biochemistry. The data presented here were collected from a prospective study carried out from May 2005 to July 2006 where the subjects were selected from their response to a questionnaire (Figure 1) in which information about their socio-economic background, age, nutrition, exercise, smoking, alcohol consumption, past medical history, any medications they regularly use, marital status and in case of a female, whether pregnant, were sought. In addition to information obtained from the questionnaire, their state of health was determined by clinical examination and laboratory biochemical tests. If their MCV and/or MCH were below the accepted normal, (MCV < 76) and (MCH < 26), Thalassaemia trait or iron deficiency were ruled out by checking Hb A2 level, and testing for Hb H inclusions and/or serum ferritin level.

The exclusion criteria were: heavy smoking (more than 5 cigarettes a day for over six months); high alcohol consumption (three or more drinks a day for three or more days a week); body mass index under 18 or over 26; chronic illnesses such as asthma, renal disease, chronic liver disease; and grade III hypertension. These

Figure 1. The questionnaire

A study to determine the reference ranges for l blood cell parameters for Sri Lankans

1. Name.
2. Age
3. Sex
4. Ethnic origin
5. Height
6. Weight
7. Marital status
8. No. of children Are you pregnant?
9. Profession/job
10. Diet -Veg/Non-Veg
11. Smoking yes/no < 10/ day > 10 /day. How long?
12. Alcohol consumption.
13. Life style
14. Place (a) urban (b) Rural
15. Exercise
16. Rest (a) Physical (b) Mental
17. Past medical history: Asthma, Hypertension
    Diabetes Renal disease Allergies
    Cardiac disease Liver disease
    Heavy menstruation
18. Family history of anaemia / haemoglobinopathy
19. Are you taking any medications regularly?

were determined from demographic and health information obtained from the questionnaire and findings from a clinical examination which was carried out by the clinician on every candidate, telechest and laboratory investigations of other systems, namely, renal functions, liver functions, fasting blood sugar, thyroid functions, and ESR.

The inclusion criteria were: apparently healthy persons with no known past history of chronic illness; no family history of anaemia or haemoglobinopathy; and the patient not being on regular medications.

Methodology

Candidates were seen by appointment. They were asked to present themselves at the health screen clinic between 8 and 9 am after an overnight (12-14 hours) fast. They were interrogated and examined clinically by the clinician having studied the details supplied on the questionnaire. After this they had to go to the outpatients' laboratory between 9 am and 10 am. Venous blood was collected from an antecubital vein into a vacutainer tube by a clean venepuncture done with minimum stasis, while the patient was seated with the forearm bent at the elbow. Samples were delivered into a potassium EDTA bottle, a plain bottle, a citrate bottle and a fluoride bottle. These samples were transferred to the main laboratory of Asiri Hospital, within 1 hour of collection, and examined within the next hour.

Haematological tests were done on a haematology auto - analyser (model Abbot Cell-Dyne 3500 and 3700) which incorporates both laser light scattering and impedance technology. Tests carried out were FBC, which included (RBC, WBC, Differential count and platelet count) Hb, PCV, MCV, MCH, MCHC and RDW. Of these Hb, RBC, WBC, Platelet count and MCV were direct measurements, while PCV, MCH, MCHC and RDW were automatically derived data from these results. Quality control of the tests was carried out daily, by testing the first two samples of each day, on a Cell –Dyne 3400 as well as on the Cell-Dyne 3700 (each tested twice for accuracy and reproducibility). If results of these two samples

Table 1a. Males: descriptive statistics for haematologic indices

Measure	n	Median	S D	Ref, interval (Mid 95%)
RBC	503	5.14	0.41	4.3 - 5.9
HB	503	14.83	0.94	12.9 - 16.7
PCV	502	44.42	2.71	39.0 - 49.8
MCV	503	86.41	5.52	75.3 - 97.4
MCH	503	29.04	1.96	25.1 - 33
MCHC	503	33.33	1.30	30.7 - 36
RDW	502	13.62	1.62	10.3 - 16.8
WBC	503	7.32	1.76	3.8 - 10.9
N	503	3.84	1.25	1.4 - 6.3
L	502	2.52	0.75	1.0 - 4.0
M	503	0.55	0.30	-0.1 - 1.1
E	503	0.35	0.24	-0.1 - 0.8
B	503	0.07	0.05	-0.0 - 0.2
Pl.	503	247.4	47.65	152 - 342

Table 1b. Females: descriptive statistics for haematological indices

Measure	N	Mean	SD	Mid 95% Range
RBC	460	4.53	0.34	3.8 - 5.2
Hb	460	12.8	0.85	11.2 - 14.6
PCV	459	38.8	2.49	33.8 - 43.8
MCV	460	85.8	4.11	77.6 - 94.0
MCH	460	28.5	1.67	25.2 - 31.8
MCHC	460	33.1	0.98	31.2 - 35.1
RDW	460	13.7	1.48	10.7 - 16.6
WBC	459	7.3	1.76	3.6 - 11.0
N	460	3.9	1.36	1.2 - 6.6
L	460	2.5	0.74	1.1 - 4.0
M	460	0.5	0.30	-0.1 - 1.0
E	460	0.3	0.26	-0.2 - 0.8
B	460	0.1	0.05	-0.0 - -0.1
Platelets	459	276	56.9	162 – 390

did not show precision, previous week's external quality control sample was re-tested, and if there was any discrepancy, readings were adjusted accordingly. External quality control was done every fortnight using Riqas (Randox International Quality Assessment Scheme).

ESR was done manually. Liver functions, renal functions, thyroid functions i.e. T4/TSH, lipid profile and fasting blood sugar were done from the other samples (plain blood and fluoride samples) on one of the automated biochemistry analyzers: Hitachi 911, 912 or 917.

Results and Data Processing

Results were recorded in an Excel program. Data processing involved displaying the cumulative results for each of the parameters, namely Hb, RBC, PCV, MCV, MCH, MCHC, RDW, Platelet count, WBC, N, L, E, M, B, separately for the two sexes. Histograms were plotted and all of them showed Gaussian distribution. The best fitting Gaussian curves were drawn, and the mean and standard deviation determined. Using Formula 2.5 and 97.5 percentiles the middle 95% confidence interval was calculated (Tables 1a & 1b). The statistical

Table 2. Medians and 95% confidence intervals of red cell indices for Sri Lankan adults common to both genders

Measure	N	Min	Max	Mean	S. Dev. Devia	Lower CI	Upper CI
MCV	963	26.6	98.0	86.1	4.9	76.3	95.9
MCH	963	23.8	53.0	28.8	1.8	25.1	32.5
MCHC	963	12.3	36.2	33.2	1.2	30.9	35.5
RDW	962	1.5	18.3	13.7	1.5	10.6	16.8

Table 3. Results of tests to determine the statistical significance of blood cell indices between male and female groups

	SEX	N	Mean		
RBC	1.00	503	5.14		
	2.00	460	4.53		
HB	1.00	503	14.83		
	2.00	460	12.88		
PCV	1.00	502	44.42		
	2.00	459	38.82		
MCV	1.00	503	86.41		
	2.00	460	85.79		
MCH	1.00	503	29.04		
	2.00	460	28.52		
MCHC	1.00	503	33.33		
	2.00	460	33.14		
RDW	1.00	502	13.62		
	2.00	460	13.71		
WBC	1.00	503	7.32		
	2.00	459	7.32		
N	1.00	503	3.84		
	2.00	460	3.95		
L	1.00	502	2.52		
	2.00	460	2.55		
M	1.00	503	0.55		
	2.00	460	0.47		
E	1.00	503	0.35		
	2.00	460	0.31		
B	1.00	503	0.07		
	2.00	460	0.07		
PL	1.00	503	247.41		
	2.00	459	275.89		

Key: Male = 1.00 Female = 2.00

significance of the difference in means between the two sexes were worked out applying Student's t-test (Tables 2 & 3). Age related data for males and females were calculated separately (Table 4), and presented graphically (Figures 2, 3 and 4). The reference ranges of blood cell counts and red cell parameters from Europeans, Chinese and Australians were also compared with our results (Table 5).

DISCUSSION

Selection of a reference sample is a central issue in determining laboratory reference ranges. We have selected a sample of healthy adults by using a group of persons from among those who presented themselves for their annual health screen. By applying strict exclusion criteria, minimizing

Table 4. Age related data for RBC, Hb and PCV for males & females

Males	RBC	Hb	PVC
All ages (N=489)	5.13 ± 0.03	14.85±0.08	44.56±0.28
15-25 years (N=10)	5.38 ± 0.17	15.11+0.41	45.69+0.94
26-35 years (N=88)	5.26 ± 0.08	15.19+0.18	45.37+0.53
36-45 years (N=132)	5.29 ± 0.07	15.10+0.14	45.06+0.38
46-55 years (N=147)	5.11 ± 0.06	14.75+0.15	44.31+0.43
56-65 years (N=81)	4.82 ± 0.00	14.36+0.22	43.69+1.11
66-75 years (N=31)	4.85 ± 0.13	14.54+0.28	43.17+0.89
Females			
All ages (N=448)	4.54 ± 0.03	12.88+0.08	38.82+0.23
15-25 years (N=11)	4.44 ± 0.22	13.20+0.11	39.73+1.28
26-35 years (N=47)	4.60 ± 0.09	13.11+0.25	39.44+0.68
36-45 years (N=112)	4.57 ± 0.06	12.94+0.16	38.92+0.47
46-55 years (N=128)	4.51 ± 0.05	12.80+0.16	38.59+0.43
56-65 years (N=101)	4.54 ± 0.06	12.93+0.13	38.96+0.44
66-75 years (N=49)	4.49 ± 0.10	12.84+0.25	38.79+0.80

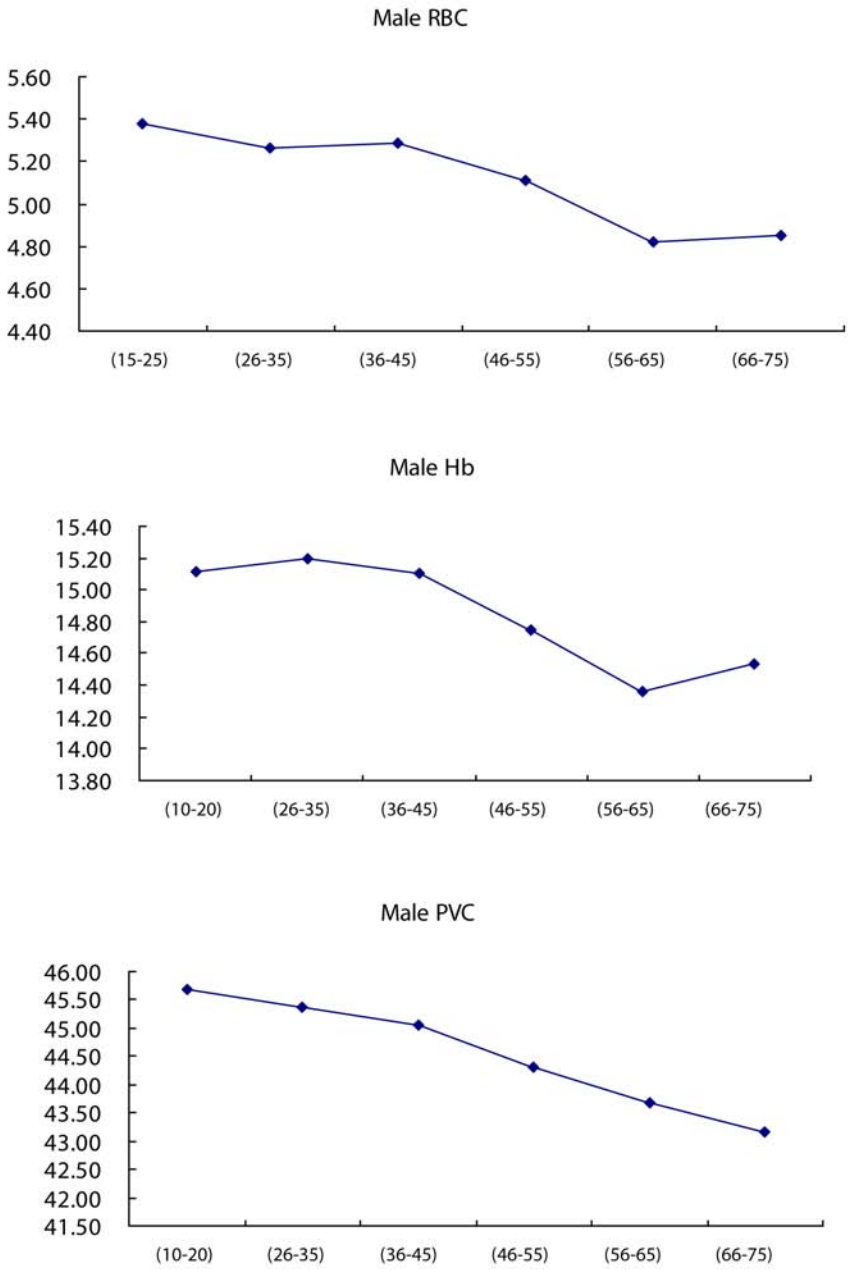
bias from variation in lifestyle, nutrition, medications and disease by getting them to answer a questionnaire, clinical examination and laboratory investigations such as liver function tests, renal functions, thyroid functions, fasting blood sugar and lipid profile, and also by using a relatively large sample, a normal healthy group of subjects was selected. The time of sample collection, the method of sample collection, the posture when collecting blood samples, and the sample handling variables were all standardized, and testing was done with strict quality assurance in the same laboratory. The results were analysed as indicated and the 95% confidence interval was determined from the mean +/- 2 SD.

The descriptive statistics given in Tables 1a and 1b show the 95% confidence interval of all haematological indices separately for males and females respectively. The reference ranges for the main haematological parameters for adult male and female Sri Lankans are Hb 14.8 ± 1.8 g/dl; RBC 5.1 ± 0.8 X 10^9/l; PCV 44.4 ± 5.4 for males and Hb.12.9 ± 1.6g/dl; RBC 4..5 ± 0.6 X 10^9/l and PCV 38.8 ± 5.0 for females. These confidence intervals show a statistically significant difference between males and females, values being significantly higher for males than females (p value < 0.0001) (Table 3). This finding has been reported by several workers from other countries (Kelly & Munan, 1977; Williams et al, 1983; Lugada et al, 2004; Yip et al, 1984) and is accepted as normal. In our study, there is also a statistically significant difference in platelet counts between males and females (p value < 0.0001) the values being higher for females. This sex difference has been observed by the Australian study (Tsang et al, 1998) as well, but was not reported in the European (Lewis et al, 2001; Amador, 1975) and Chinese studies (Arumanayagam et al, 1987). The mean values for MCV, MCH, and MCHC were similar for the 2 sexes (Table 2) and are in agreement with the findings of other workers (Bibile et al, 1949).

Age Related Trends

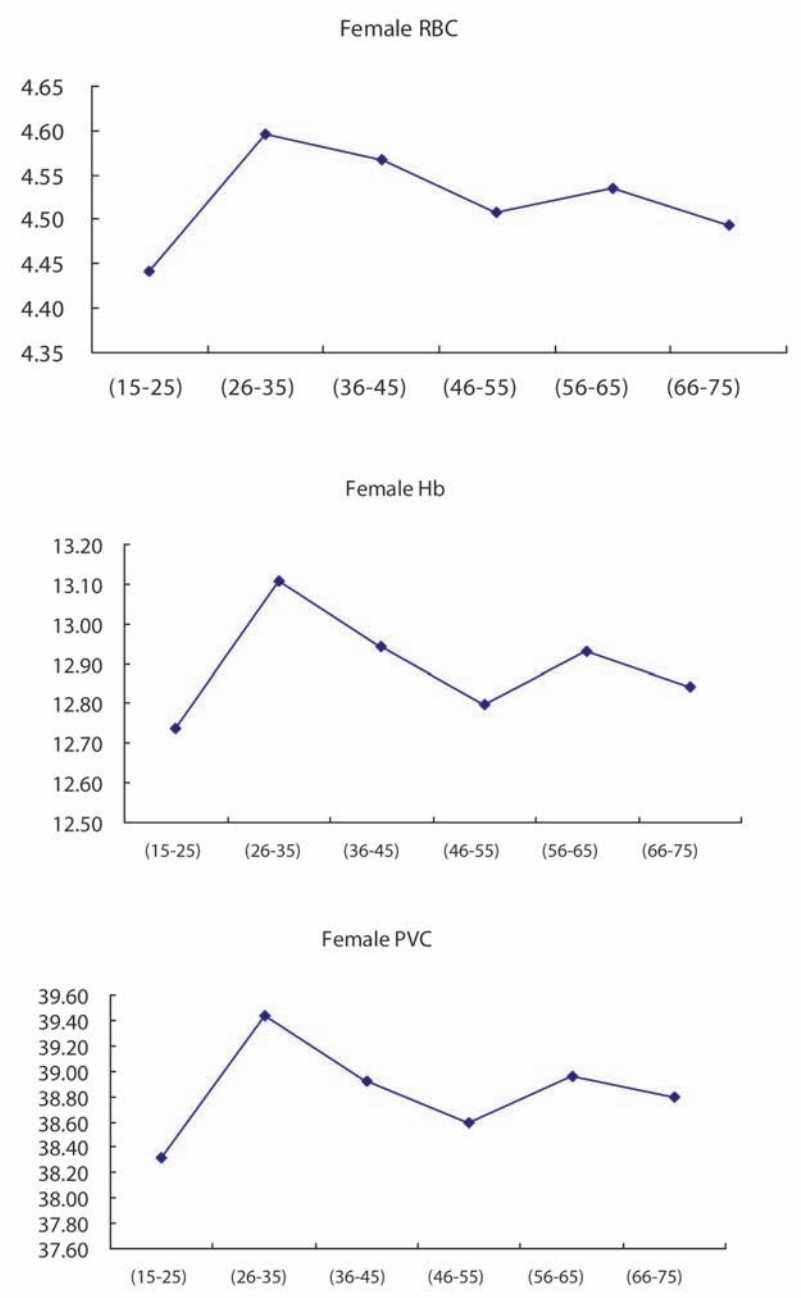
Table 4 and Figures 2 & 3 outline the results for this variable. As expected, the average erythrocyte count (RBC) Haemoglobin (Hb)

Figure 2. Age-related graph (male)



and Haematocrit (PCV) for all ages are higher in males than females. In both sexes, the maximum levels of median RBC, Hb and PCV are found at the end of the second decade. In males the maximum level of Hb, RBC and PCV is reached by the beginning of the second decade, while in females the rise is sharp and maximum is reached between the second and third decade of life. Thereafter, in males, the three parameters appear relatively constant through the 3rd

Figure 3. Age-related graph (female)



and 4th decades, until about the age of 45 years when there is a smooth decline in Hb and RBC reaching the lowest levels at around 60 years. The PCV declines further until the 7th decade and then shows a rising trend.

In females, there is a sharp rise of all three parameters in the second decade, maximum being reached between the second and the third decades of life. After that, there appears to be a slow decline of Hb, RBC and PCV during the

Table 5. Reference values (95% confidence interval) compared with other studies

Males	**Hb(g/L)**	**Hct (L/L)**	**RBC (10^12/L)**	**MCV (fL)**	**MCH (pg)**	**MCHC (pg)**	**RDW (%)**	**Platelet (10^9/L)**	**WBC (10^9/L)**
Lewis et al	130-170	0.40-0.50	4.5-5.5	83-101	27—32	31.5-34.5	11.6-14.0	150-400	4.0-10.0
Bain	133-167	0.39-0.50	4.32-5.66	82-98	27.3-32.6	31.6-34.9	9.9-15.6	168-411	3.7-9.5
Tsang et al	133-175	0.39-0.51	4.2-5.9	80-99	27-34	-	-	153-382	3.9-9.5
Arumanayagam et al	142-159	0.41-0.48	4.61-5.13	88-96	30-33	32.6-34.8			5.47-9.15
Bibile et al (Sinhalese)	139.		5.22						
Present study	130-167	0.39-0.5	4.33-5.96	76-96	25.-32	31-36	10-16	152-342	3.8-10.8
Females									
Lewis et al	120-150	0.36-0.46	3.6-4.6	83-101	27-32	31.5-34.5		150-400	4.0-10.0
Bain	118-148	0.36-0.44	3.9-5.0	82-98	27.3-32.6	31.6-34.9	9.9-15.5	188-445	3.9-11.1
Tsang et al	122-161	0.36-0.47	4.0-5.4	80-87	27-33			163-414	3.6-9.4
Arumanayagam et al	113-151	0.34-0.45	3.8-5.1	81-99	27-34				3.8-10.8
Bibile et al (Sinhalese)	129		4.47						
Present study	112-145	0.33-0.44	3.85-5.2	76-96	25-32	31-36	10-16	162-390	3.6-11.0

latter part of the 4th and early part of 5th decades and a rise occurs around 45 and 55 years probably coinciding with menopause and finally a fall after 75 years.

CONCLUSION

Our reference ranges on the whole are comparable with those of other studies done on different populations (Table 5). This finding upholds the observations of other workers (Bain, 1995). However, the general belief locally is that Sri Lankan reference ranges on the general population are lower than the Western figures. This probably upholds that the contributory factors for the optimal haematological results are good nutrition and good health. However, the majority of subjects in Sri Lanka cannot achieve this optimal level of nutrition. As such the reference ranges for different groups of subjects would have to be determined by using the general population as the reference population rather than a choice elite group of people because for deciding whether a laboratory result would indicate ill-health or deviation from the normal, we need to go by the reference range of the general population.

Table 6 gives the comparison of white cell counts and differential counts between present study and that of Europeans (Lewis et al, 2001). They are also comparable except that Sri Lankan results show a significant increase of the eosinophil count.

This study involves only one cohort of the population, our objective being to illustrate how reference ranges are determined. These reference

Table 6. Comparison of white cell counts and differential counts in the present study with those of Lewis et al

Measure	Lewis et al	Present study
WBC (10^9/ l)	4.0–10.0	4.0–11.0
N (10^9/l)	2.0-7.0	1.2-6.6
L (10^9./l)	1.0-3.0	1.2–4.0
M (10^9/l)	0.2-1.0	0.2-0.8
E (10^9/l)	0.03-0.5	0.1-0.6
B (10^9/l)	0.02-0.1	0.02–0.1

ranges would be suitable for the well nourished healthy adults of high and middle income groups living at sea level. Further studies incorporating a wider reference population from different parts of the country, rural as well as and of different age groups should be carried out. Pregnant mothers, the elderly population 70 to 80 years, 80 to 90 years and above which comprises an increasing section of the general population at present, and should be studied. The paediatric age groups require special attention as they would need to be studied as narrow age groups as highlighted earlier.

Although this is an expensive exercise, in order to establish a sound health program it is an essential analysis and each laboratory should strive to establish its own data bank of reference ranges.

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Chapter 15
Sun, Surgery and Cyberspace:
The Role of the Internet in the Rise of Medical Tourism

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ABSTRACT

In the last few years, increasing attention has been paid by the media and the tourist industry to what has become known as 'medical tourism' sometimes also called 'health' or 'wellness' tourism. Before around 2000, these were hardly mentioned by the media at all. However, in one sense, medical tourism has a long history, as some of the information sites on the Internet are eager to point out. People have been travelling in search of medical treatment for millennia, whether in order to visit hot springs as in Poland, Hungary or Japan. Why this sudden interest? In this Chapter I argue that it is due to a combination of factors: the changing distribution of medical services and technologies, the growth of interest among both local medical practitioners in different parts of the world and travel agents, the clever packaging of tourism and medical services as a single product, and the availability of the Internet both to assemble and to disseminate information on these new products. The chapter covers the implications of these cases for the future of medical tourism, and its relations both with the medical and tourism industries.

INTRODUCTION: THE RISE OF MEDICAL TOURISM

In the last few years, increasing attention has been paid by the media and the tourist industry to what has become known as "medical tourism" sometimes also called 'health' or 'wellness' tourism. Before around 2000, these were hardly mentioned by the media at all, as a search of the LexisNexis database of major world sources shows (Table 1). According to LexisNexis, the number of news items from major news agencies and newspapers which mentioned it rose from zero around 1990, to over 2000 at present, and most of this increase has occurred since 2003.

In one sense, medical tourism has a long history, as some of the information sites on the Internet are eager to point out. People have been travelling in search of medical treatment for millennia, whether in

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Table 1. Number of references to "medical tourism" in major English language news sources, 1992-2008

Year	Number
1992	8
1993	14
1994	26
1995	14
1996	12
1997	35
1998	103
1999	26
2000	49
2001	95
2002	151
2003	234
2004	548
2005	737
2006	1349
2007	2335
2008 (January-August)	1850

Source: LexisNexis, Major English Language News Sources (Retrieved 30 August 2008).

order to visit hot springs as in Poland, Hungary or Japan (Kapczynski & Szromek, 2008; Geoghegan, 2003; Clark, 1994), bathe in or drink the local waters with supposed healing properties as in Bath (Sanati, 2003, Haley et al. 2005), visit shrines or the tombs of saints as in Catholic Europe (Gesler, 1996), or seek out local healers with regional or international reputations, as in contemporary Africa (Probst, 1999). But however these earlier forms of medical tourism are described, it does appear that in recent years the industry has boomed to a quite unprecedented extent, and has been recognized as a distinctive sector within both the tourism and medical industries.

Why this sudden interest? In this paper, I argue that it is due to a combination of factors: the changing distribution of medical services and technologies, the growth of interest among both local medical practitioners in different parts of the world and travel agents, the clever packaging of tourism and medical services as a single product, and the availability of the Internet both to assemble and to disseminate information on these new products. Indeed, without the Internet, the industry could probably not have taken off at all. The kinds of instant research into medical procedures and their relative prices in different parts of the world would have been impossible for most people in the pre-Internet era when they would have been reliant on newspaper archives, libraries and conventional telephone and postal services for assembling this kind of information. Anything based on scholarly research is by definition several years out of date, allowing for the cycle of research, writing and publication. Meanwhile in the world of medical tourism, whole industries can mushroom in the time it takes to get the average article published in a conventional journal. The Internet has short-circuited the delay in compiling information, allowing this new industry to take

off and at the intersection between medicine and tourism flourish in just a few years.

After considering just what we mean by medical tourism, and how far it can be considered a form of tourism at all, this chapter looks at the main causes of the phenomenon, and surveys the main services on offer. The various web sites disseminating information on medical tourism can be broadly divided into three types: portals, which offer instant access to information on a wide variety of medical services in a number of different countries; country sites, which promote their own versions of the industry; and sites relating to particular types of treatment. The final section looks a the role of the Internet in generating debate about medical and health tourism, and the ways in which they have been absorbed into a more general debate about migration and access to health services, using the example of the United Kingdom. Paradoxically, the new media in the developed countries have responsible for both publicizing medical tourism as a fashionable option for wealthier citizens, and suggesting that health tourism is reducing the access of the local population to medical services of local residents because of an influx of outsiders. Based on these examples, I consider the future of medical tourism against the background of the present financial crisis, and how it is likely to fit in with the rest of the medical and tourism industries in the years to come.

MEDICAL TOURISM AND LIFESTYLE MIGRATION

The growth of modern medical tourism has been so rapid that there is as yet surprisingly little scholarly work on it; early articles in the tourism literature include Goodrich & Goodrich (1987), while more recent surveys include Connell (2006) and Page (2008), and there are a growing number of references to the phenomenon in the medical literature, such as Bies & Zacharia (2007), McReady (2007), and Srivastava (2006), as well as in particular countries (Lautier 2008). However, to date the Wikipedia definition is as good a starting point for this discussion as any. The authors of the Wikipedia Medical Tourism page define the field as follows:

Medical tourism (also called medical travel, health tourism or global healthcare) is a term initially coined by travel agencies and the mass media to describe the rapidly-growing practice of traveling across international borders to obtain health care.

Such services typically include elective procedures as well as complex specialized surgeries such as joint replacement (knee/hip), cardiac surgery, dental surgery, and cosmetic surgeries. As a practical matter, providers and customers commonly use informal channels of communication-connection-contract, and in such cases this tends to mean less regulatory or legal oversight to assure quality and less formal recourse to reimbursement or redress, if needed. Leisure aspects typically associated with travel and tourism may be included on such medical travel trips. (http://en.wikipedia.org/wiki/Medical_tourism. Retrieved 13 September 2008)

As the Wikipedia page acknowledges, this is a rapidly growing practice which makes use of the differential prices of medical treatment in different countries of the world. The range of services listed is also suggestive. First, there are chronic conditions related to joints (especially hips and knees), and to dentistry. These may be painful but are unlikely to be life threatening, at least in the short term. Second, there are more life-threatening conditions related to vital organs such as the heart, liver or kidneys, which if left untreated can soon prove fatal. Interventions may include complex surgery and/or transplantation, which, for one reason or another, may not be available in the patient's home area, or at least at a price the patient can afford. Third, there are interventions

such as cosmetic surgery, which from the point of view of life expectancy may not be clinically necessary, but which may result in an improvement in the psychological state of the patient. Finally, there are a range of less intrusive therapies and interventions involving massage, aroma, diet, and hot or cold water treatments which may have little clinical effect, but which also make some clients feel good, at least temporarily. Wikipedia also makes the point that one reason why these treatments may be more widely available or cheaper in places other than the travelers' home areas is that they are subject to less regulation. Medical tourists, in other words, have to exercise care in deciding where to go for treatment.

The final point in the Wikipedia definition is that the medical treatment may be packaged along with more conventional tourism attractions, such as good hotels, scenery, climate, food, recreational activities, or local culture. How much of course depends on the medical condition of the traveler. There may be another continuum involved here. At one end are cases in which the *raison d'être* for the travel may be almost entirely medical. The heart transplant or hip replacement patient is unlikely to go swimming or playing golf very often during his or her treatment. A pleasant hotel bed with a nice view out of the window may be more appreciated than proximity to tennis courts or opportunities for rock climbing. On the other hand, the client in search of massage, yoga, aromatherapy, hot springs or mud bath beauty treatments might well value these kinds of amenities much more, and make more regular use of them. In other words, the clientele for medical tourism ranges from completely healthy individuals on the one hand to the terminally ill on the other. This helps explain the extraordinary number of products now available in the medical tourism sector, and the large number of countries that appear to be jumping onto the bandwagon. The next section considers the main reasons inherent in the global medical system that stimulates them to so jump.

THE CAUSES OF THE MEDICAL TOURISM PHENOMENON

A number of circumstances in the global economy along with the tourism and medical markets seem to have conspired to produce this boom. In his survey, Connell (2006) mentions factors such as high costs and waiting lists in the patient's own countries, coupled with the development of technology in developing countries, the falling costs of international transport, and Internet marketing. It may be convenient to treat these and other factors under the headings of supply and demand.

Supply Factors

The supply factors include the growth of the medical and tourist industries in a number of developing and newly industrializing countries. This is particularly so in the "miracle" economies of East and Southeast Asia, some of which have experienced two decades or more of double digit annual rates of growth, raising them from the lower echelons of the third world to something approaching first world standards of living. This began with Japan, followed by the tiger economies of South Korea, Taiwan, Hong Kong and Singapore. More recently, they have been joined by Thailand, Malaysia, the eastern coastal regions of China, and the more prosperous parts of India (Garekar, 2005). As they have developed, all of these countries have improved their medical sectors dramatically. New technologies have come onto the market, an increasing number of graduates trained at medical schools overseas have returned home to set up their own hospitals and clinics, and the emergence of an increasingly large and wealthy local middle class has led to a concomitant increase in demand.

Currently in the Asian region, Singapore, Malaysia, India, and Thailand are among the countries most enthusiastically promoting their medical products and services worldwide, and in some fields they have become world leaders.

Singapore is attempting to establish itself as the leading medical hub in Southeast Asia, while Malaysia has been promoting medical tourism as a major export industry since 1997. Indeed, Malaysia alone accounts for nearly half of the world-wide coverage of the field in the LexisNexis database, because of the government's adoption of medical tourism as an important plank in its development policy. There is a certain amount of rivalry between the two countries as well, with Malaysia trying to offer similar services to tourists, but at lower cost (Cheesman, 2001). For typical coverage of the industry in India, see Ramesh (2005); on Thailand, see e.g. Morris (2001).

At the same time, these countries have also been promoting their tourist industries. Singapore, Hong Kong, and parts of Thailand, Malaysia and Indonesia (Bali) have become big players in the international tourist market. They are selling a combination of the local environment (eco- and beach tourism), and the local culture (heritage and cultural tourism), as well as the generalized tourist experience in the form of five-star hotels and good shopping facilities. The prices for branded goods are often cheaper in these locations than in North America, Western Europe, Australia or Japan. Hong Kong and Singapore have become major hubs in the international air networks, and the stopover trade is an essential part of the local tourist industry. One of the attractions of both cities is that many of the attractions can easily be visited in a short stay of two or three days, while recovering from the jet lag from long haul flights to and from other parts of the world. No surprisingly, these countries have also begun to see medical and health services as additional sources of income. Indeed, because the medical tourists may well stay longer in the locality than ordinary tourists, buying expensive services while they recuperate, they are seen as a major potential addition to the local tourist market. Connell (2006) also concludes that the stimulus to the travel industry in general from medical tourism can be considerable.

Demand Factors

Demand factors depend largely on the supply and cost of medical services elsewhere in the world. As the newly industrialized countries with their expanding middle classes are investing in new medical capacity and technology, the older industrialized countries of the West are increasingly finding that their own medical sectors are under strain from a number of different directions.

In the United States, the costs of the mainly private medical system have escalated rapidly in recent years, even as the number of people covered by medical insurance schemes has tended to fall as a percentage of the population. Remarkably for the richest economy in the world, something like a sixth of the total population, or around 45 million people, have no medical coverage at all (Common sense has a voice, http://www.areavoices.com/commonsense/?archive=2006-04), while others have insufficient cover in the case of major illness. The reasons for this are complex. One underlying long-term cause stressed by Castells (1996) is the changing nature of the labor market, and the replacement of full-time with casual labor. Despite the long economic growth in the 1990s, many of the rewards went to the rich through tax cuts and compensation packages involving generous stock options, while a majority of even middle class households were seeing their incomes fall. The result was to take on more jobs, with the result that many workers are holding down two or three part-time jobs, none of which are linked to medical insurance. Another reason is the prevalence of malpractice suits, forcing up the costs of insurance for the medical practitioners, costs which are passed on to the consumer in the form of higher premiums (GAO, 2003). A third reason is the increasingly high-technology nature of modern medicine, requiring elaborate and sophisticated equipment, the costs of which have to be offset against patient fees (e.g. Stiller, 1989). A final reason is that the medical practitioners have tended to raise their own incomes, to pay for

the increasingly high costs of their training, their rising cost of their own medical insurance cover, and to ensure the continuance of their standards of living after retirement – when they themselves will face hefty medical bills.

In countries such as the United Kingdom, where the state has provided basic health care for the entire population for the last 60 years, the system is also under strain, again because of the increasingly high-tech nature of the enterprise, the high levels of compensation for medical practitioners, and the preference for politicians since the 1980s to try and cut taxes rather than increase investment in public services. Those who can afford it have increasingly resorted to private medical insurance, and many of the practitioners have set up their own private practices because they are more lucrative than work in the state sector. This is particularly so in dentistry, where costs are among the highest in Europe for private patients, many people have increasingly difficulty in finding a dentist to work on their teeth under the National Health scheme at all (Patients Association, http://www.patients-association.org.uk/FAQS/19). The results of the strains in the system include overcrowded hospitals, with a consequent increase in the risks of patients suffering from infections contracted there, and long waiting lists for operations such as hip or knee replacements. These patients are increasingly willing to look elsewhere for quicker and cheaper treatment, outside the country if necessary, and indeed they are being encouraged to do so by the state (Wilson, 2001).

Travel and Medical Care

In the case of Europe, their search has been made easier by two other factors: the expansion of the European Union into Eastern Europe, and the falling cost of air travel, thanks to the rise of the budget airlines, flying our of secondary local airports as well as the national capitals. Until the rise in the price of oil in the Spring and Summer of 2008, the airfares of budget airlines had generally fallen thanks to competition – to the point at which it is often cheaper to fly elsewhere in Europe than travel by train within a single country. It is not surprising, therefore, that there has been a boom in medical tourism from the UK to countries like the Czech Republic, Poland and Hungary, where the training, professionalism and equipment of the practitioners are similar to those in the UK, and where the practitioners often speak excellent English, but where the costs of treatment are often much lower.

Where there is sufficient demand, the tourist companies often see a business opportunity, and arrange packages for transport, hospital accommodation and treatment, plus the necessary period of recuperation and relaxation in a local hotel. Given the often quite substantial savings on the medical costs, the whole package may still work out considerably cheaper than having the treatment in the patient's home country. And the further afield one is prepared to go, the more substantial the savings may be.

India in particular has cashed on several competitive advantages: the prevalence of English, the fact that many practitioners were themselves trained in the West, the lower cost of labor, and the lower cost of accommodation. When this is coupled with the exotic tourist attractions in the form of local culture and environment, it is not surprising that so many patients are heading in this direction.

Who Offers What? The Geography of Medical Tourism

Not all countries with good medical facilities are necessarily cashing in on medical tourism. As mentioned above, many western systems are under strain with escalating costs and contracting coverage for the local population, and are therefore attracting few tourists. Top specialists in particular fields may attract an international clientele to their private practices, but this does not really constitute a flow of medical tourists *per*

se – only the movement of a small, rich clientele willing to pay for treatment by top specialists.

Japan is a particularly interesting case, in that its medical services are among the best in the world, as reflected in the exceptionally high expectation of life. It also has a huge domestic tourist market, of which one of the major attractions on the fringes of medical tourism is the country's hot springs. But it but attracts very few medical tourists from elsewhere. This can be easily explained. First, despite recent high-profile government campaigns in the mid-2000s led by former Prime Minister Junichiro Koizumi, Japan still attracts surprisingly few international tourists at all. The Japanese tourist industry is largely domestic, and this applies to the kinds of medical and wellness tourism centering on the hot springs industry as well. In Beppu, the largest hot spring resort in the country, around 90% of the tourists are domestic. Of the foreigners, most come from neighboring countries such as South Korea and Taiwan. Very few come from the West.

The other reason for the lack of medical tourists in Japan is probably the structure of the local medical insurance industry. Most Japanese belong to health insurance schemes either run by their employers or the state which pay for most of the medical expenses incurred. Typically schemes pay two-thirds of the cost of medical treatment, and the remaining accumulated bills can be written off against income tax at the end of the financial year, which may reduce them by another 40%. However, foreigners without their own insurance coverage would have to pay the full cost, which may mean that treatment is little if any cheaper than in their own countries. In other words, the local conditions within Japan make it unlikely that anyone but the fairly rich would want to visit the country for the purposes of medical tourism – unless seeking out the treatment from a particular specialist, as mentioned above. In any case, most of the hospitals in Japan are not particularly attractive. Many are aging concrete structures dating from the post-war boom period of the 1960s and 1970s. However effective at controlling and healing disease they are, these rather utilitarian settings are hardly the high-tech architectural fantasies of which medical tourism television commercials are usually made. Korea and Taiwan have similar characteristics, though Korea at least has been promoting its skills in cosmetic surgery in recent years. This has been helped by the increasing visibility of Korean popular culture in the region, from electronic gismos to television soap operas. It may also be helped by the substantial fall in the value of the Korean Won in the global financial crisis at the time of writing (November 2008). Certainly, the massive appreciation of the Yen against other major currencies has probably reduced the likelihood that outsiders will look to Japan for treatment even further.

The main medical tourist destinations therefore are generally newly industrializing countries that have invested a lot more recently than Japan or the West in signature hospital buildings and advanced technology, plus the recreational facilities necessary to serve the tourist part of the equation. Because they have developed more recently, their medical practitioners are more likely to have been trained abroad, and are therefore more likely to speak English than those in Japan. They have been able to market their tourist facilities successfully internationally already, rather than just relying on the domestic market. The major air hubs of Southeast Asia are particularly well located in regards to this, and Singapore, Kuala Lumpur and Bangkok have all invested heavily in the medical tourism market (Chen, 2007).

With the increasing number of players in the market, a degree of regional specialization in the medical tourism market is also starting to appear. In Europe, generally the Eastern European countries are offering a range of standard medical services similar to those in Western Europe or North America, claiming a similar level of professionalism but cheaper prices. The picture changes in the Mediterranean and the Middle East, partly because the tourism element of the package starts

to loom larger, and partly because of a different range of treatments available depending on the hot springs and mineral resources of the region. Turkey and Malta are combining treatments with their traditional role as tourist destinations (Mendinck, 2002). Malta has remade itself once since the days when its main role was that of a large British naval base in the days of empire. Now that it has joined the EU, its economy is still based on tourism, but it is also marketing its medical expertise in sectors such as dentistry ('Malta popular with UK medical tourists', http://www.treatmentabroad.net/medical-tourism/news/november-2007/malta-popular-with-uk-medical-tourists/). Meanwhile, Israel is combining its own high-tech medical expertise with the thermal and mineral bathing facilities available around the Dead Sea (Erixon & Davis, 2008, Siegel-Itzkovich, 2008). Indeed, was one of the very first players to spot the potential of medical tourism, from the early 1990s onwards. While the various conflicts in the region are getting in the way of marketing their medical products, recent advertisements from Israel stress that these are happening far away from the high-tech hospitals of Jerusalem and Tel Aviv. Israeli hospitals are also aggressively marketing via the Internet (Siegel, 2007).

The tourism elements are also very prominent in the case of the Southeast Asian destinations, and the treatments also tend to be different. Even though Singapore as the most advanced country in the region can provide world-class medical services of all kinds, the emphasis in Malaysia and Thailand, in their marketing at least, is on rejuvenation, beauty treatments, and – closely linked with these – cosmetic surgery. Thailand in particular has an international reputation in the niche market for sex change operations, with transgender patients coming in from all over the world, in addition to a relatively large local clientele (Talbot, 2001).

India is perhaps the largest provider of medical services in the region, and has perhaps the lowest costs. These are marketed particularly strongly in the UK because so many doctors are either English-speaking and/or trained in Britain, the old Commonwealth countries, or in America (Ramesh, 2005). In addition to these services, India can also provide a wide variety of exotic tourist locations, plus the traditional medical sector. Here conventional medical treatments shade off into yoga, meditation and other Indian techniques in the intersection between medicine, ritual and religion, and based on a long indigenous tradition of religious pilgrimage.

THE ROLE OF THE INTERNET

It is the contention of this chapter, however, that it would have been very difficult to develop these facilities as rapidly as they have been developed in the modern world without a facility such as the Internet. As with any other kind of research, the Internet has greatly simplified the task by giving access not only to information on individual health providers, but also to portals which provide instant access to a wide variety of services in a range of countries, and to press material which comments on and reviews the claims of the medical tourism industry itself.

Some of the most informative medical tourism sites on the Internet are those promoting the industry by providing access to multiple sources of data, both in terms of the services and the countries in which they are being offered. A major site in the UK for instance is the *TreatmentAbroad* site (http://www.treatmentabroad.net), which offers a mass of general information, links to recent press coverage (see below) and even an on-line screen for generating quotes for different types of treatment in different countries. This site is run by Intuition Communications, which describes itself as the 'UK's leading web publisher in the healthcare sector,' and has links with the UK's private medical providers. It also carries advertisements for healthcare schemes from the larger insurance companies, a synergy of

interest groups, all of which presumably benefit from the dissemination of this information. The site has a general page on medical tourism and a downloadable guide. The guide deals with topics such as basic considerations and costs, checking out doctors and hospitals, guarantees, comparisons of different provides, things not to do, the practicalities of going abroad, and what to do if something goes wrong. The site also provides lists of treatments and countries providing them (divided into cosmetic surgery, elective surgery, dentistry, infertility treatment, diagnostic imaging, and medical spa treatment), a country-by-country list of destinations, an indexed guide, information on costs, patient stories, and a list of recent articles from the press. There is also a listing of jobs for health service professionals. A useful search engine provides instant lists of providers in particular countries – for instance, a search for dentists in Poland gave particulars of seven practitioners, including contact information.

A similarly informative site for North American patients is provided by healthbase.com, under the trademark 'Healthcare Beyond Boundaries' (http://www.healthbase.com). This site provides an alternative definition of medical tourism based on their services. It is 'the process of traveling abroad to receive superior medical, dental and cosmetic care by highly skilled surgeons at some of the most modern and state-of-the-art medical facilities in the world … all at a fraction of the price in the USA, UK and Canada'. It claims that 'For millions of patients in the USA, it is the only way to get the needed or desired medical treatment, without wiping out their entire life-savings'. Once more the home page contains a wealth of buttons for further information: free registration, testimonials from satisfied customers (complete with video clips from national TV networks), details of the company and its policies, its international network of partner facilities, medical plans for employers involving treatment abroad, and contact information. Another series of buttons gives access to information on specific procedures in different areas of medicine such as orthopedic, spinal procedures, cardiac surgery, bariatric (gastro-intestinal) surgery and laparascopic surgery. The healthbase.com site is also a useful portal to some of the other medical products listings on the Internet, including country listings of facilities, virtual tours, blogs (many of them consisting of information on particular procedures posted by the healthbase.com team itself), and testimony from satisfied customers. On many pages in the site, there are buttons to click in order to register or obtain a free quote. As with the Treatment Abroad site, there is also a collection of Healthbase press releases and articles from the press on topics related directly or indirectly to medical tourism, the earliest dating from January 2005.

Interestingly the healthbase.com site also offers a whole page devoted to Michael Moore's documentary on American medicine and its woes, *SiCKO*, including his trip to Cuba with sick people in need of treatment. The review ends, 'Unfortunately SiCKO does not offer any solutions to the problems posed in the film. But, what it does do is make you feel angry and confrontational enough to go out and demand some answers and solutions from the powers-that-be'. It then adds in a separate box, 'One solution is Medical Tourism with Healthbase. Click here to register for FREE' (emphases in original).

MEDICAL TOURISM AS MORAL PANIC

In addition to making available information on medical and health tourism, the Internet has also provided an invaluable sounding board and forum for various interest groups to press their cases in relation to the possible problems arising from it. A good example of this is the debate surrounding supposed 'health tourism' into the UK from other countries and the costs to the country resulting from it. This has continued unabated several years,

even while the international and legal environment has been changing around it, and shows no sign of ending soon.

This debate has to be seen within the wider context of immigration and the expansion of the European Union to include many of the former communist countries of Eastern Europe. The British National Health Service has provided 'free' medical care, paid for out of the national insurance and pension system, since the early post-war period, but its state of health, and how it compares with the systems in other countries, is a perennial topic of national political debate. The problem for the British welfare system with the expansion of the EU is the possible arrival of foreigners from other parts of Europe in search of medical and other welfare benefits. There is little evidence that this is happening on any significant scale, though there is a constant stream of anecdotal evidence supplied by the right-wing media that the system is being abused by foreigners, and accusations by the opposition Conservative Party that the Labour Party government is not doing enough to curb this abuse. Even though many in the Labour Party are inclined to take a liberal view on immigration (not least because Britain's ethnic minorities tend to vote Labour), the Labour government which has been in power since 1997 still has to take into account the fact that public opinion as a whole has generally been in favor of restricting immigration and the rights of immigrants. A final complicating factor is the devolution of power in Wales and Scotland, so that they have been able to pursue their own welfare and health policies separate from those of the English and the national parliament in Westminster.

This debate is relevant to medical and health tourism because 'health tourists' have become the targets of much of the debate, and part of urban folklore as well as mainstream political discourse. They have been the subject of a number of moral panics, promoted by the conservative press which has skillfully exploited the fears of the local population that their welfare services, always seen as under stress, will be overrun by foreign nationals demanding medical care and benefits. For a good discussion of this issue, see the Guardian editorial of December 31 2003, 'In place of fear'.

The issue came to the fore in the spring and summer of 2003, with the news that the government was considering tightening the rules of access to the health system to stop it from being abused by foreigners with no legal claim to its services. Government ministers asserted that this abuse was costing the British taxpayers up to 200 million pounds a year, and that they were considering how the rules could be tightened up. The general view was that in future only those with a valid work contract in the UK would be eligible for free care. Other groups such as 'failed asylum seekers', those whose applications for political asylum had been turned down but who were still in the UK were to be denied access (Brooks, 2003). The claims of abuse were backed up by anecdotal evidence of pregnant women arriving in the UK just before the birth of their children, and foreigners coming to the UK on business bringing sick relatives with them so that they could receive NHS treatment. There was a statement from the Health Secretary, John Reid that 'foreigners who use the National Health Service will have to pay for their treatment in advance'. He was quoted as saying 'If there are bona fide tourists dropping ill in the street, of course we will do what we have to do, but we are not mugs. There is a difference between being civilized and being taken for a ride'. ('Health tourism rules unveiled', BBC News, 30 December 2003).

These assertions led to a furious response from pressure groups working with asylum seekers and immigrant groups, and health professionals concerned at the practical and ethical implications (see e.g. Hawkes, 2005; Carter, 2006; Feldman, 2006; Frauenfelder, 2006; Bralo, 2008; Williamson, 2008). Much of this debate took place on the Internet, or could be tracked via the Internet through press, interest group and discussion web sites. First they quoted their own anecdotal

evidence to suggest that the level of abuse of the system cited by the government and those arguing for immigration control was greatly exaggerated. A leaked report from Newham General Hospital in East London put the figure much lower. An initial estimate had suggested that health tourists cost the trust about a million pounds a year, but a later study could only identify 17 ineligible patients, being treated at as cost of 32,000 pounds out of a budget of over 100 million pounds ('Are Health tourists draining the NHS?', BBC News, May 14 2004).

Other doctors expressed concern about having to discriminate between patients, or demanding payments and delaying treatment which could put patient lives at risk. The chairman of the British Medical Association's international committee, Dr Edwin Borman, noted that there was 'little definitive evidence that foreign visitors presented a significant problem to the NHS' and that the 'medical profession is not willing to become a state agent, and police a system which, in any way, might interfere with … an ethical patient-doctor relationship' ('Medics balk at NHS tourism plan', BBC News, Monday, 29 December, 2003).

There was also anger concerning allegations that foreign immigrants to the UK were bringing in more than their fair share of dangerous diseases and infections, including TB and HIV. These were made most famously by the Daily Mail in an article by James Chapman entitled 'Our NHS, not the World Health Service' (Chapman, 2005). This reported a pledge by the then Conservative leader, Michael Howard (ironically himself the son of immigrants) to introduce compulsory TB and HIV tests for non-European citizens before their arrival in the UK. The article asserted that unqualified patients accounted for 10% of cases in GP surgeries, that two-thirds of sufferers from TB were born abroad, and that 80% of those with heterosexual HIV infections had been infected in Africa. The average number of new HIV cases under the Conservatives up to 1997 had been 2,672, but this had increased to 4,213 under the subsequent Labour government.

Other groups quickly presented contrary evidence. A study of thousands of immigrants in Kent revealed very few cases of TB (Patterson, 2003) and questioned whether screening was at all cost effective. Other research suggested that immigrants on average, far from demanding expensive treatment soon after arrival, only looked for medical attention after three years in the UK. Health Ministry officials were forced to concede that they had little or no evidence on the extent of the problem, while many health professionals raised doubts both about the practicality of distinguishing between legitimate or illegitimate patients, or the ethical propriety of denying sick patients treatment, with the danger that more people would thereby become infected. There were also concerns about whether a crackdown would be a beneficial use of resources, given that it would lead to few if any savings. One cynical view expressed by an official of the British Medical Association was that 'Certain ministers seem to want to highlight this issue from time to time, usually when there is another story that they don't want to hit the news' ('Are Health tourists draining the NHS?', BBC News, May 14 2004.) Other specialists pointed out that denying foreigners care would do little to solve the problems of waiting lists in other areas, and that it would also demonize them in the eyes of the public and health workers.

In the event, the government put forward proposals for consultation in 2004, but kept very quiet about the response of professionals to them after that. In the spring of 2008, they had still not released the results of the consultation or introduced legislation, and in any case the legal and international environment were both changing fast. By this time, in a landmark case, the High Court had decided that denying care to a Palestinian man on the grounds that he was not qualified to receive it was illegal, though the government was given leave to appeal ('Asylum seeker NHS ban 'unlawful'', BBC News, 11 April 2008). The European Union was moving towards a more flexible

system in which EU citizens could shop around for treatments in any of the member states (Laurance, 2007). And the Welsh Assembly declared that, unlike England, it would not deny failed asylum seekers medical attention ('Failed asylum seekers' free NHS', BBC News, 20 May, 2008). The government position was therefore looking increasingly untenable, thanks to the chorus of disapproval, orchestrated not least by the interest groups concerned on the Internet, and despite the consistently hostile anti-immigration stance of the popular press. However, the government was still being urged to crack down on 'transplant tourism' (New Scientist, 2008), so the more general debate seems set to continue.

CONCLUSION

What are the implications of these cases for the future of medical tourism, and its relations both with the medical and tourism industries? As we have seen above, while some countries are promoting the development of the sector as an export industry, people in others like the UK see it as a threat to their medical services, couched in a zero-sum discourse: medical capacity is limited and any of it which is used by the foreign "health tourists" however defined will automatically reduce the services available to "legitimate" local patients. As we have also seen, this is a discourse which is contested by the health care professionals themselves, both on the grounds that it is unethical and may well help spread disease, but it is a powerful one when it comes to selling newspapers and mobilizing political support. Politicians of either liberal or conservative persuasions are therefore likely to listen to it.

For the time being, it is likely that the countries which are investing in medical tourism as an export resource will continue to do so in the short term, though there are already some strains and tensions visible (e.g. Idris, 2008). In Malaysia for instance, which has established itself as one of the larger players in the market, there are already worries about lack of medical capacity for the growing local middle class consumers given that trained English-speaking professionals can move elsewhere in the world for higher salaries than those on offer locally. Singapore has more proactive, and is recognizing a wider range of foreign degrees, in order to be able to both recruit foreign professionals more easily, and make available services to suit an increasingly internationalized clientele .

One might predict that as local prosperity rises and therefore costs increase, the medical tourism countries will have the options of either moving up market, or moving out of medical tourism to concentrate on providing better services to their own residents. Countries that need the foreign exchange will try to stay in the market longer than those that do not.

However, all this is based on the assumption that the global financial crisis of late 2008 has no long lasting effects. If it does, how might it affect medical tourism? On the one hand, consumers worried about savings and medical bills in the advanced countries might well look abroad for treatment increasingly often, in order to save money. On the other hand, investment in treatment facilities in these countries could slow down, due to decreased liquidity and increases in the cost of borrowing, to say nothing of the relative movements of exchange rates. At the time of writing it seems that the values of the Japanese yen and US dollar have held relatively steady, while the values of the Euro and Pound have declined relative to both of them. Therefore countries pegged to the dollar could well see their prices rise in the short term, relative to countries with no such peg. The rapid fall in the Korean won, for instance, has been mentioned above.

As for the developed countries, as centers of excellence and cutting edge research, they will always have available a cadre of top specialists who will attract a wealthy clientele from around the world able to pay privately for the best ser-

vices. On the other hand, opening up their mass medical services to foreigners from less developed countries could, if unregulated, continue to create moral panics among local administrators, media and politicians. In the case of the UK, the development of Eastern Europe and a rising standard of living throughout the euro zone might eliminate some of the pressures on the British system, as well as creating more opportunities for the British to shop for services elsewhere in the EU. However, this could equally well be offset by the recent rapid decline in the value of the pound against the euro.

Overall, the present trend towards regional specialization in different types of medicine will most likely continue, and the service providers will continue to advertise their wares on the Internet. What does seem certain, given the nature of the medical market, is that the Internet and successor technologies with the capacity to assemble and deliver information quickly are likely to play an important role both in the continuing globalization of medical services, as well as in the construction of discourses and the political debates surrounding them for the foreseeable future.

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Chapter 16
The Use of Public Health Surveillance Data for Preventive Control of Diseases that Depend on Individual Risky Behavior:
The Case of HIV Infection in Japan

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ABSTRACT

E-health systems can be used to communicate the risk of significant infectious diseases such as HIV infection to individuals who contemplate taking the risk of the personal behavioral choices they make. Access to an on-line system which communicates this data in a user-friendly format, can help avoid high-risk behavior by informed individuals who live in different areas with various levels of risk. We present the case of HIV infection in Japan where many individuals have voluntarily continued a high-risk behavior because apparently they consider the overall risk of infection too low to forgo the personal benefits of risky behavior such as more pleasure, less inconvenience, etc. We discuss how a user friendly e-health system can provide geographical risk data that are extracted from HIV epidemiological surveillance. This can provide individuals with a rational incentive for behavior change in high-risk areas. It is hoped that such a system helps with the control of not only HIV, but also other agents of disease in situations where individual choices play a significant role in the risk of exposure/disease.

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Table 1. The numbers of all new (2005 & 2006) HIV cases in Japan by route of exposure, gender, & Japanese/non-Japanese citizenship. The significant number of infected men and of sexually transmitted route of infection (including both homo & heterosexual contact) is worth consideration

Route of exposure	Japanese citizens (88%)		Non-Japanese citizens (12%)		Total	
	2005	*2006*	*2005*	*2006*	*2005*	*2006*
Heterosexual	161	173	42	50	203	223
Homosexual	514	571	15	33	529	604
Drug abuse	2	1	1	3	3	4
Mother-newborn	0	1	1	0	1	1
Other routes	9	29	2	11	11	40
Unknown	55	61	30	19	85	80
Total (Men/Women)	741 (709/32)	836 (787/49)	91 (60/31)	116 (76/40)	832 *(769/63)*	952 *(863/89)*

INTRODUCTION

The first cases of HIV infection/AIDS in Japan were discovered in 1985, and were related to the use of contaminated blood products imported to Japan in the 1980s. This exposed many hemophiliacs to the infection so that as of August 1995, 1,803 of the estimated 5,000 hemophiliacs in Japan were discovered to be HIV infected. These constituted the majority of the total number of HIV $^{+}$ cases (62% of 2,893 cases), and AIDS patients (52% of 1,026 cases) in Japan at the time. Subsequently, screening of all donated blood and blood products for HIV infection has changed the situation significantly so that the most common route of infection in Japan is now through unprotected sexual contact. Table 1, extracted from data released by the Japanese Ministry of Health, Labor & Welfare shows the shares of different routes of exposure to HIV infection in Japan in 2005 & 2006.

Although biologically the risk for sexual transmission of HIV infection is higher from men to women than women to men, the number of infected males is significantly higher (about 10 times). This discrepancy is mainly attributed to the higher frequency of high-risk sexual behavior among men, such as anal sex among homosexuals and lower adherence to condom use even among heterosexuals. On the other hand, Japanese women rarely engage in very high-risk behaviors such as intravenous drug use and receptive anal sex; more importantly, they are more prone to insist on using condoms to avoid the risk of pregnancy which can at the same time protect them against infection with the HIV virus.

Female workers at 'snack pubs' may be sometimes compelled to have sex and not to use condoms by the clients. However, professional 'soap-land' sex-workers are periodically self-tested for HIV and fired if positive. Apparently, a disclosure of HIV infected sex-workers in any premises would discourage potential customers from visiting the area and severely damage the sex business in the whole neighborhood, as has occasionally happened and been reported by the mass media in the past. Such instances show that even the relatively risk prone customers of these businesses are sensitive to risk data and although they may seem to be less concerned with preventive efforts at low-risk situations, they may respond to higher levels of risk they perceive from the media.

Some researchers in the field of economic epidemiology have compared health related risk data to economic data of financial stock markets, and the changing behavior of risk-taking individuals to the sell/purchase of stock shares by stock holders. However, we believe that currently there is a difference in access to the risk information between these two risk markets. The stock market provides a daily list of the stock prices and associated investment risk data to its customers, while access to HIV infection rates and associated risks are commonly limited to the annual number of new infections at the national level and may be further broken into the numbers at each prefecture, but not any further. Here, we propose a more real-time distribution of the health risk data on a relatively more detailed geographical map that functions as a telemedicine application to warn potential risk-takers about the need for preventive and/or protective measures. It should be noted that the overall risk of HIV infection in Japan is very low compared to most countries worldwide; an informed risk-taker may respond to this information by accepting high-risk behavior. However, the local risk in some metropolitan areas of Tokyo, Nagoya, Osaka, as well as during outbreaks elsewhere increases to higher levels that can motivate risk-takers in using protective measures.

BACKGROUND

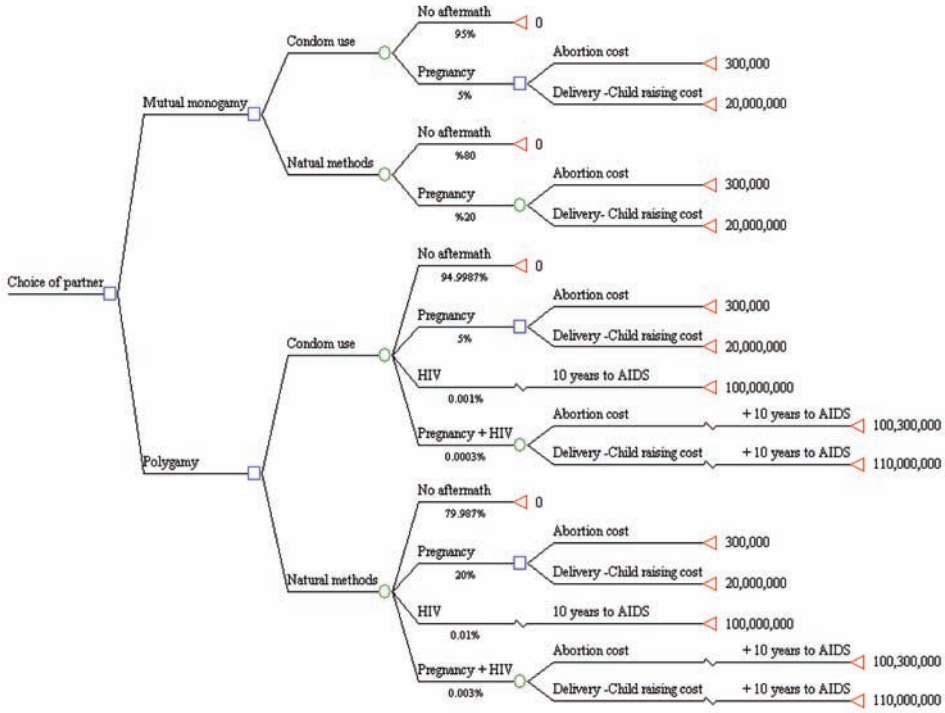
Having sex with another person involves some risk of infection unless it is between non-infected couples who observe a mutually long-term monogamous relationship, whether hetero- or homosexual. Many people get involved in more diverse sexual behaviors which involve having multiple partners or polygamy, apparently to derive more utility. This utility can be gaining a greater amount of sexual pleasure, using sex in an attempt to preserve social bonds to other people, or a desire to experience sex of an unusual kind. Therefore safe sex is a relative concept that usually implies the use of condoms and/or staying committed to one partner, but may not necessarily mean either.

In an economic sense, sex appears as a trade between two (or more) people the utility of which may be decreased by safe sex practices (Philipson & Posner, 1993). Accordingly, the commitment of an individual to safe sex practices depends on a few factors including how significant the risk of non-commitment would be. This is the main mechanism that explains why there are fewer women affected with HIV infection than men; the reason is that often women are directly dealing with an added risk of pregnancy too. This is especially true in Japan where hormonal contraception is still quite limited and using condoms is the most common way of contraception.

DECISION TREE ANALYSIS

We used the decision analysis tree method to study this issue. First we estimated the preventive effectiveness of condoms against pregnancy at 95% and against HIV infection at 90%. We also estimated the costs of adverse outcomes in the form of an unwanted pregnancy and infection with HIV, respectively. Clinics in Japan charge about 100,000 Yen for an abortion; we added two times this amount to compensate for the costs of absence from work, pain and suffering, and other costs. We also estimated the cost of raising a child till the legal age of 20 years in Japan to be 20,000,000 Yen, which is 10% of the average lifetime earnings in Japan. Twenty million yen was also chosen as a proxy of the value of the total life years of a Japanese citizen; we took the damage or cost of HIV/AIDS to be 50% of this value. Then we drew a decision analysis tree to study the possible outcomes and their associated economic costs on individuals who choose different levels of risky sexual behavior (Figure 1). Figure 1outlines a decision analysis tree used to demonstrate the ap-

Figure 1. Decision tree analysis of health related sexual activity



proximate probabilities and costs (in Japanese Yen) of different health outcomes following one year of heterosexual behavior choices in Japan. In each case we considered a one year period of heterosexual life per different individual choice in respect to the number of partners (mutual monogamy vs. polygamy) and contraceptive method (condom vs. no protection or withdrawal), and we appointed to each the associated risk of pregnancy and HIV infection for this period of time. For simplicity, we chose not to consider the very rare situation that a Japanese HIV infected mother delivers an HIV infected baby. Risk estimates are calculated based on the results of other studies, many of which are published (Weller, 1993; Pinkerton & Ambramson, 1997; Davis & Welle, 1999).

Although the cost of HIV infection is very large, the annual risk of infection for an average Japanese citizen not observing mutual monogamy is still relatively small, from 0.001% to 0.01% depending on condom use. While the cost of HIV/AIDS is very large, about 300 hundred times higher than an unwanted pregnancy resulting in abortion, its probability/risk of happening is 2000-5000 times less.

As regards to performing a sensitivity analysis to assess the impact of our assumptions on the results, we realized that our estimates for the annual risk of HIV infection are in fact at the highest possible range; in many non-metropolitan areas in Japan this risk is close to zero. Among approximately 50 million Japanese at the age range of 15-44 (49,938,116 for 2003 estimates), there may be about 10,000 HIV $^{+}$ individuals with a gender distribution of about 85% male-15% female. Now, considering that about 60% of the infected males belong to the homosexual community, there may be only about 3400 male and 1500 female HIV $^{+}$ individuals among so many people who face the above heterosexual behavior choices.

THE INFLUENCE OF RELATIONSHIP STYLE ON RISK

There are also no concrete data or estimates on the frequency of committed vs. non-committed monogamous relationships. In respect with the rates of actual condom use, apparently only about 20% of regular couples (mutual monogamy) and 30% of casual partners (polygamy) are consistent users of condoms (Kihara et al, 2001). These statistics have many implications in our analysis. First, the relatively low level of condom use explains the relatively high number of induced abortions in Japan (Goto et al, 2000), and also depicts the relatively high perceived value or utility of unsafe sex practices among Japanese citizens.

An important point to consider is that while usually men bear all the costs of using condoms (buying them obviously is not but a small fraction), women bear all or most of the abortion costs. Therefore men who derive a higher utility (sexual pleasure) from unsafe practices (not using a condom, polygamy, anal sex, etc) are relatively more risk-taking than women, however women face the costs of an unwanted pregnancy and therefore are rationally more risk-averse than men. This risk-averse stance provides women with an incentive for protection against pregnancy as well as HIV infection even though biologically they are more susceptible than men.

The average 10 year length of time for the HIV incubation period would necessitate two further studies: one is a time trade off study to estimate the preference weight of Japanese individuals as a quality of life assessment in an asymptomatic HIV^+ state, and the other is to introduce an annual discount factor (generally 5%) for the economic losses that occur after AIDS appears (the future costs multiplied by 0.6139). In US studies, having HIV on average was assessed to reduce quality of life by 26% (Lenert, 2002). Corrections can be done to use these two factors of economic loss in Japan, but it would be better to do such an analysis based on independent time trade off studies from those in the USA.

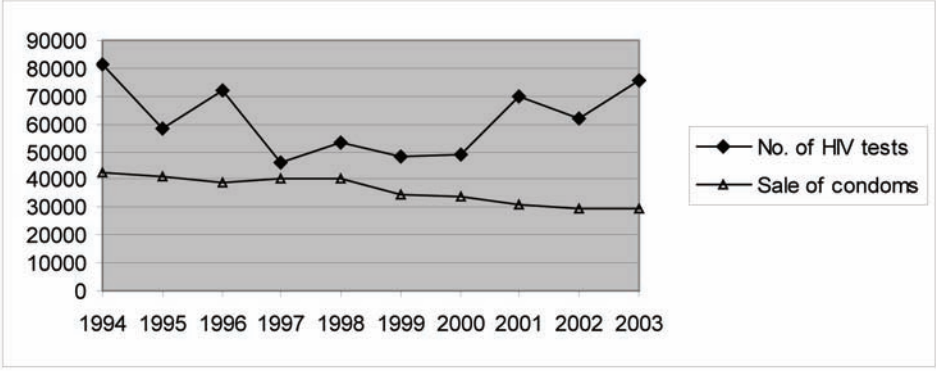
Generally speaking, individuals looking for sex act rationally by considering the "expected cost" (The term "expected utility" is more familiar; for example it is economically rational if a gambler risks 50 dollars (or less) to try and win a $ 1000 prize when the chance of winning is only 5%) of infection against the assumed utility, and choose some degree of relatively safe/unsafe practices. The use of condoms is the strategy that "liberals" promote in discussions of safe sex education. 'Conservatives' on the other hand, encourage abstinence or monogamy as the only safe sexual behavior (Bearman & Bruckner 2004; Watson & Watson, 2004) and insist on the fact that sex with condoms is not 100% safe. Many studies have shown that promotion of abstinence is less successful than promotion of condoms because most people accept some level of risk in pursuit of the utility of sex. This raises the important question of how public health policy can help fight an infection which is transmitted through voluntary risk-taking behavior.

Our opinion is to let concerned individuals be informed about the risk of infection in different areas by providing them with electronic access to a geographical map which is drawn based on the most recent epidemiological data. But before explaining this model, it would be useful to explain what the alternative policy is and why it may not stand to expectations.

Health Screening

Many health officials insist on the use of HIV screening tests in the fight against HIV infection. HIV testing can affect the sexual behavior that individuals choose; for example some couples in Western countries who plan a mutually monogamous sexual relationship apply for HIV testing to eliminate worries over HIV infection. However, such instances of 'partner observed tests' are very rare among Japanese couples. There are many rea-

Figure 2. The number of HIV tests performed by Japanese public health centers per year (from 1994-2003). The intermittent surges in the number of HIV tests apparently follow public health campaigns designed to fight HIV spread while the sale of condoms (in grosses) has been declining at the same time period



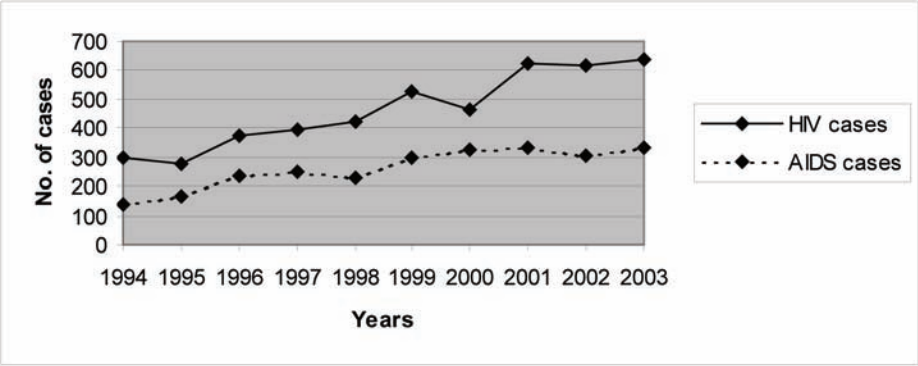
sons why, including the relatively low prevalence of HIV infection and the socio-cultural attitudes that exclude such directness. HIV test/screening in Japan is not partner observed; even a negative test result may not be presented because it may be interpreted as a confession to having indulged in high-risk behavior. Therefore the individual's own reaction to an HIV test result and its effect on his/her behavior (Ciccarone et al, 2003) is more important:

1. When the test result is negative, it may create a false assurance that the person's level of risky sexual behavior has not and therefore possibly will not expose him/her to HIV infection. He/she may continue to have the same level of (or even increase) risky behavior but rarely finds the incentive to control risky behaviors that have existed prior to the test;
2. If the test result is positive, any *further* risky behavior may have a very small added cost for the individual as he/she is already infected. Such an individual may choose not to inform the current or future partner about his/her HIV^+ state, though an altruist person (with a personal goodwill not to hurt others) may resort to safe sex with the current or future partner. Japanese HIV/AIDS experts estimate that around 50% of HIV^+ cases follow the second option.

Considering the very few number of positive results among performed HIV tests (88, 99 and 84 per 10,000 test in 2001, 2002, and 2003 respectively; Figure 2, Figure 3), and the time constraint on public health officials to provide the necessary counseling to the remaining individuals with negative results, it could be argued that the public subsidies for free HIV tests might even increase high-risk behavior in the community.

Meanwhile, the negative result of the test is only valid up to the time of performing the test, and with just another act of risky sex happening afterwards, the test needs to be repeated after a couple of months for a negative result to be reliable, as the body needs some time to make antibodies that are detected by the test. Moreover, false negative results during this window period, that is ironically a hyper-infective period, create a false sense of security and may lead to dangerous risky behavior. Therefore, instead of HIV screening, blinded sero-surveys of sentinel target populations (those attending STD clinics, etc) have

Figure 3. The reported number of new HIV+ and AIDS cases reported at the same time interval as in Figure-1. Please also note that as HIV tests are done anonymously, there may be a duplication of its data and an overlap with new cases of AIDS



been recommended as an epidemiological tool for surveillance of HIV infection in the community (Ciccarone et al, 2003).

CONCLUSION

While HIV infection in Japan is nowadays mainly spreading through voluntary individual behavior, personal choices in taking/avoidance of the risk of infection are underestimated and the voluntary role of individuals in their sexual behavior has not received enough attention. The epidemiological features of HIV/AIDS in Japan has provided us with opportunities to examine the role of personal behavior elements as well as policies that make use of individual risk averseness, and their impact on the spread of this infection. Infectious disease surveillance can be promoted using E-health systems such as through issuing of warnings for pre-epidemics and epidemics. We have examined the case of HIV infection in Japan where people taking risky behavior can receive and respond to the risk information very similar to the response to investment risk data of a stock market business.

The lower prevalence of HIV/AIDS in Japan compared with other developed countries has resulted from a far lower intensity of high-risk drug use/sexual behavior in the general population and the predominant role of condoms in contraception. But the incidence has been rising among high-risk groups and there are worries it may change the whole community trend. As voluntary high-risk sexual behavior is responsible for the great majority of new HIV infections, we examined the economic rationality of the Japanese heterosexual behavior in the face of uncertainty and their level of risk taking/averseness, using a decision tree with approximate levels for the risks and costs of different choices.

Given the current situation of HIV/AIDS in Japan, HIV prevention policies and programs could stress more on behavior modification towards a low risk lifestyle, as the most important factor in HIV spread in Japan is the voluntary sexual behavior of individuals who choose risky sex practices. These individuals 'rationally' react to the risk data they receive through public channels; they have already been changes like the recent trend in the sex industry towards more use of condoms and private self-testing. Here, we suggest that the bulk of heterosexual risky behavior can be changed by providing local risk data through a public E-health system. However, we are certainly not denying the role of traditional public health programs to fight HIV infection. Public health programs should

aim at other promotional activities to change risky behavior especially among susceptible young teenagers who may not be well-informed to act rationally. Moreover, the most high-risk group in Japan showing the least risk-averseness remains the homosexual community; their level of risky behavior is not expected to decrease significantly unless there are changes in their level of satisfaction from social life as homosexuals in Japan (Isomura & Mizogami, 1992).

Individuals can choose to lower the infection transmission risk by consistent use of condoms, or to change their partner seeking behavior to monogamous relationships and avoidance of sex with high-risk partners. Personal incentives can be provided by the public health system through its already existing mechanisms. The surveillance system for issuing weekly warnings over new cases of infectious diseases (Murakami et al, 2004) is a good example. If HIV warnings are issued for the public, the potential "risk takers" receive them as risk data, similar to those of stock market changes. The main advantage of such warnings is the potential for customization up to the local level.

HIV/AIDS is still a relatively small problem in Japanese society but with the rapidly changing patterns of freer sexual behavior in the new generations of young Japanese, the < 20 age group may become more susceptible. Scarcity of information on safe sex in schools needs to be tackled to avoid misinformed agents into risky and costly trades through deception or persuasion. Inadequate sex education programs offered at schools are held responsible for the increase of teenage unwanted pregnancies and venereal infections. With the continuous change of sexual trends in younger generations towards an earlier age of starting sexual activity and more frequent changing of partners, such information can be vital in decreasing the rate of unwanted pregnancies as well as venereal infections including HIV. Studies suggest that if sex education is started before puberty, it helps with staying abstinent and using protection when sexual activity is started (Kirby et al, 1994). Sex education to teenagers can also be provided by E-health systems.

Such a program may be implemented based on a blueprint provided by the WHO HealthMapper surveillance and mapping application. From 2003, the system supported surveillance of HIV/AIDS/STIs. It provides the public health user with a simple data management interface and is meant for use by public health administrators at national and district levels. It is compatible with the same mapping engine (MapObjects) used for ArcView and can therefore be used in conjunction with other ESRI Inc. products. However, it may require some modifications as it was initially designed for Africa and South-East Asia. An alternative implementation could be as a web service. Such a system design would encompass a database (storing the data), the web server (holding the web service) and a proxy (to ensure good security standards). Depending on security concerns, database and webserver would be separated so that the server could be accessible by the public but not the database. A system of identification of reports could be developed to overcome the problem of duplicate notifications which may be substantial in the Japanese system. The issue is that there are currently two systems to report new HIV infections in Japan. One is based on the anonymous test results at the public health centers all around Japan. Any positively identified individuals are reported anonymously to the surveillance system and the individual is also confidentially informed of his/her HIV positive status. These individuals will most probably refer to hospitals for further work-up and preventive treatment and are reported again, though now with a name.

Although the primary purpose of this system would not be for academic research, it would be of additional benefit if the interface was provided not only in Japanese but also in English as this would make the data available for international usage. Two types of maps could be incorporated, one for absolute numbers (total number of cases on a ward basis) and one for showing incidence. Depending

on variables, the supplied maps could also display gender of the infected cases, information about the location, and other information supplied by the incidence reports. Temporal as well as spatial displays should be considered. Graphs such as number of cases per week based on ward or other city divisions over the past few weeks, months and years should be provided as well as the trend or moving average graphs.

All displays should be intuitive, user-friendly, and easily understood by the public. The graphic display of data plays a critical role in visualization and exploratory data analysis. Appropriate use of color for data display allows interrelationships and patterns within data to be easily observed. Thus a gradual color scale to indicate "hotspots" may provide users with a more intuitive experience. An increasing number of countries including the US, Canada, England, Thailand, Ireland, and France have systems to publish national surveillance data in the public domain through the internet. Our recommendation focuses on HIV but in terms of the implementation of the system much can be gained by a review of these implementations. It is recommended that a step-by-step implementation of the project can test these designs in an experiment where users attempt to draw inferences about 'hotspots'.

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Chapter 17
E-Health in Brazil:
Less Care for the Poor?

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ABSTRACT

It is argued in this chapter that e-health has the potential to improve the provision of health care and the quality of patient treatment, but it also contains many threats, especially in developing countries where information technologies are generally implemented without any discussion with society. With regard to health information, Brazil is behind some African countries in terms of data recording according to international reports used to publish health care indicators. Most of the hospitals do not have basic information systems for data collection and storage, despite the fact that the country has historically registered very bad health indicators. Moreover, many e-government initiatives, including e-health applications and development are based on the traditional top-down model or market-driven approach to information technology, oriented towards corporate actor interests and health care administration rather than basic population health care needs. This system tends to neglect basic priorities for people lacking education, clean water, food and primary health care.

INTRODUCTION

It is argued in this chapter that e-health has the potential to improve the provision of health care and the quality of patient treatment, but that it also contains many threats, especially in developing countries where information technologies are generally implemented without any discussion with society. As a result of this, the literature has mentioned that while e-health has the potential to empower patients and stimulate participation it also has the dangers to disseminate inaccurate information and inappropriate use of health care resources (Sadan, 2002; Leaffer, 2001). On the other hand, in Canada Alvarez has stated that e-health solutions 'while exciting and promising, also present new challenges particularly in regard to acceptable standards, choice of technologies, overcoming traditional jurisdictional

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boundaries, up-front investment, and privacy and confidentially' (Alvarez, 2002).

With regard to health information, Brazil has been left behind some African countries in terms of data recording according to international reports used to publish health care indicators. Most Brazilian hospitals do not have basic information systems for data collection and storage, despite the fact that the country has historically registered very bad health indicators. For instance, infant mortality rate is quite high and there are inequalities in the distribution of health resources, as well as the fact that for many years Brazil used to register the highest cesarean section rates in the world (Rodrigues, 1987; 1988). In addition, many e-government initiatives, including e-health applications and development are based on a traditional top-down model or market-driven approach to information technology, which is oriented towards corporate actor interests and health care administration rather than to basic population health care needs. This has the effect of neglecting basic priorities for people lacking education, clean water, food and primary health care.

In the late 1980s the country contemplated health care reform, implying that the country would have the most comprehensive health care system in the world. Unfortunately, there is a deep abyss between the language of the law and its application in Brazil. In practice, it is hard to describe the functioning of the Brazilian health care system when the provision of health care services for the poor seems to have reached the most degraded level in all its history.

The implementation of Information and Communication Technologies (ICTs) in the developed world is usually carried out the supposition that there is a need to improve the quality of available services in traditional non-electronic formats, and guaranteed to everyone. In other words, the services already exist, and there are hopes that their provision can be improved by the utilization of information technology tools. This is not always the case in developing countries where services, in most cases, are unavailable and consequently not guaranteed to everyone. While in the former case there are examples of success and failure in the application of information technology, in the latter investments in IT are made but it is hard to talk about technology success.

Despite the limited provision of health care in Brazil, especially for the poor population, and the lack of basic infrastructure in term of information systems for the registration and storage of basic health information in hospital and health centers, there is a national project to implement a national health card. It seems that the official technical knowledge of executives and bureaucrats in the public sector subjugates other knowledge from society concerning the implementation of information technology through the use of the traditional top-down model or the 'tool-approach'. Therefore, the time has come for a comprehensive analysis of the Brazilian health card project given the comments that it will be expensive, in addition to the reports of delays, dependability problems, and that it is serving more the interests of corporate actors than the population. Furthermore, the technology seems to be inappropriate because in many instances the software and hardware packages do not speak to each other. In other words, there are problems of interoperability and the project architecture may have to be redefined after consultation with many segments of the Brazilian society, especially academics, nursing and medical professionals.

The current scenario now is that investment in information technology in government, especially in the health sector is increasing while spending in important social programs for the poor are decreasing. The purpose of this study is to describe how the approach to e-health in Brazil is developing. In other words, an attempt is made to use an interpretive perspective to answer the question on how is the National Health Card system has been implemented in Brazil, and what does this implementation mean for those who are touched by it.

E-HEALTH AND THE SMART CARD

Over the past few years the use of emerging IT methodologies and techniques such as electronic health records, digital radiology, telemedicine and the health care smart card, has become the key for delivery of health care services and for the management of the health care business. These systems are being introduced in response to cost and organizational problems facing health care providers everywhere. The rapid propagation of these technologies in the health sector, with the potential to favor management and exchange of relevant data may improve medical decision-making considerably, but this proliferation also creates many challenges and lots of disappointment. Specifically, it may be argued that the general overestimation of technological capability on a world-wide basis has meant that we not experienced the revolution in health care applications that some authors claim is possible. The IT revolution has penetrated so fast and increased the pace of change on a superficial level, but it is taking too long to reach its full promise. In addition, the structures of society, people and existing institutions have not changed, and many resist the changes necessary to ensure effective implementation of new technologies. In addition, in terms of ICT use even in the public sector, the pressure is to leave the market forces alone so that they can work their magic. Therefore, the market-driven approach to IT, especially in the areas of government and health care, does not address the real market and political failures that continue to slow and limit the implementation of a strategy to boost policies in areas where the government is in a position to play a key role.

Therefore, in the public health sector or public administration there is no distinction between economic imperatives and community legal, political and democratic values, and in the mainstream literature on e-government, for instance, especially in the discourse of the New Public Management, efficiency and effectiveness (economic) values are emphasized even if 'nevertheless other values like political and democratic values or legal security belong to the core of public administration' (Snijkers, 2005). However, in the public health sector the distinction between economic, legal, political and democratic values has to be made. Legal values are concerned with legislation as the guiding principle in public administration; economic values deal with efficiency, effectiveness, flexibility and customer orientation – the citizens as a customer of public services; and democratic values are concerned with transparency, accountability and social equity, so that all citizens should be able to influence and participate in decision making processes and be treated in an equal manner (Snijkers, 2005).

The implementation of new IT-based techniques in the developed world is almost always carried out under the supposition that there is a need to improve the quality of services already available in traditional, non-electronic formats, and guarantee these changes to everyone. In other words, the services already exist, and there are hopes that their provision can be improved by the utilization of information technology tools. This is not always the case in developing countries where services in most cases are unavailable and, consequently not guaranteed to everyone. While in the former case there are of course examples of success and failure in the application of information technology, in the latter investments in IT are made, but it is hard to talk about technology success. Failure is almost self-evident.

The literature has shown that information policy in health care, especially in developed countries is concerned with standardization in both health information and communication technologies. It is worth mentioning that everything evolves around the medical record as a 'distributing and colleting device' that is the fundamental and constitutive element of medical practice (Berg, 1996). For more than a decade in many countries, medical information has been treated within an informational architecture of record, involving a mixture

of Electronic Health Records, Electronic Patient Records and Health Smart Cards. In this context, research on the effectiveness and drawbacks of electronic health records (EHRs) has been quite attractive in contemporary health care studies. Thus, 'EHRs are predicted by some to enhance the effectiveness and efficiency of health care and play a key role in health systems reform. Yet, by their very nature, EHRS raise concerns regarding the privacy, confidentiality and security of health information' (Office of the Privacy Commissioner of Canada, 2005). In that sense, the literature is abundant on this topic and registers quite different results (Berner et al, 2005; Berg, 1999; Ellingsen, 2002; Lium et al, 2006).

Smart Cards

Over the past ten years smart cards have become increasingly important in a number of sectors all over the world: mobile communications, banking, corporate uses and transport. Now they are taking their place in healthcare and in other e-Government applications. In general such cards can be used to store data, to prove identity and act as a key to access information. In health care smart cards have been used to store patient personal and medical data generally for proving entitlement to health care and, as the technology advances, smart cards can be used in many other electronic schemes. The concept of the smart card is though abstract and loose, and describes any card with a capability to relate information to a particular application through methods such as magnetic stripes, optical memory, and/or microprocessor access.

In order to enable an individual technology such as health smart cards, it is required that medical information codes be standardized, that doctors' offices and other health providers have smart card readers, that all health care providers agree to use the system, that privacy issues are dealt with, and that people have guaranteed access to health care. In short, these are issues that sellers of health smart cards alone in the marketplace cannot resolve because it all depends on consumer and government involvement. But, government involvement means that although the smart card or 'credit-card-sized personal computer' has the capacity to store medical information that can provide benefits to both the user and the practitioner, it can also be used as a technology of surveillance and control, overriding human freedom and ethical norms. In this respect the introduction of a health smart card in Canada (*Quebec Health Card Act*) could be seen as an indication of a move 'towards a radical modification of public services principles for health care' in flagrant contradictions of the principle of universality (Prémont, 2002).

In consequence, commentators such such as Premont (2002) have recommended the abolition of the health card project due to the dangers of information sharing to individuals' privacy and the astronomical costs that could dissipate public funds to the benefit of academic and medical circles. Furthermore, in documents published by the Centre for Bioethics, it was argued that 'the money that will be spent on developing and implementing the card should be put directly to use in providing services to the public where the need is most urgent'. Investment in this technological product should be 'delayed until it has been thoroughly and conclusively tested elsewhere' (Centre for Bioethics, 2002).

In April 2006, the Australian Government announced plans to proceed with a new access card for health and welfare services. This Access Card system is, in effect, a national identity card system with a unique personal identification number linked to a centralized database, containing information about almost every Australian. The Electronic Frontiers Australia – EFA organization has stated that this Access Card system poses risk of increased fraud, 'including identity fraud and identity theft, because it involves centralizing all personal information on one database and issuing a single form of identification. Such a plan is fundamentally flawed because it produces a 'honeypot effect – a highly attractive and richly

rewarding target for criminals', and that such centralization is likely to increase identity theft and fraud (EFA, 2006a). In other comments the EFA stated that Government 'claims that the Access Card system is similar to card systems implemented in a number of other countries for accessing health and/or social services. However, none of the smart card systems in the listed countries are similar to the Australian Government's planned access card system. The most similar is South Africa's planned multi-purpose national ID smart card system which is plainly a Big Brother mass surveillance and information sharing system. If the Australian Government's plans are remotely similar to the South African system, Australians concerned about their security and privacy should be very afraid'(EFA, 2006b).

Finally, the campaign in Australia against this health smart card seems to be quite intense, involving many people and institutions such as the Australian Medical Association (AMA) that has said: 'Lives may be at risk under a plan to allow patients to include their own health information on the federal government's proposed smartcard' and that 'it would be risky for the medical profession to rely on the information, particularly if a patient was unconscious or otherwise unable to confirm the details' (Australian IT, 2006).

In the United Kingdom the project to create a *National Electronic Patient Record* (EPR) in the National Health Service (NHS), the world's largest IT program, is beset by worries, cost overruns, and critics urging Britons to boycott it. By uploading millions of personal medical records to a central national database, the government says the system will revolutionize management of the NHS, while critics are calling it 'data rape' (The Guardian, 2006a). Recently, a group of academics and representative of several medical organizations expressed their concerns about the security of information on the care records systems. According to the national doctors newssheet The Register (2006), 'Doctors have spoken out against the controversial £12.4bn NHS IT system that is over budget and behind schedule', claiming that patient confidentiality is being put at risk by the system. Writing in the British Medical Journal, a number of doctors have also said that it is unwise to put the medical records of the entire population on one computer (The Register, 2006). On the other hand, *The Guardian* noted that Ross Anderson, Professor of Security Engineering at Cambridge University has said: 'If enough people boycott having centralized NHS records, with a bit of luck the service will be abandoned' (The Guardian, 2006b).

Further to this, we should be conscious about the subtle but significant maneuvering that is taking place in e-health. With the standardization of the medical record, creating the 'language of health', it is evident that what is important about the record is not its content but its form (Freeman, 2002). By erasing the dialectic used by a patient and their doctor, there is no doubt that 'the individual patient is being separated from the individual physician' (Freeman, 2002).

Given these comments it must be noted that the national health card in Brazil is a simple magnetic card used primarily to prove identity. However, it can become a health smart card that envisages a number of uses beyond the core of identification for health care. As these extra uses increase, they can complicate the project and increase the risk of failure. The further use that is being proposed for the national health card is the storage of patient records. It is this use that can result in system failures, and the loss of confidentiality and privacy.

Despite well-documented public concern often shared by clinicians in many countries about the confidentiality of medical records, it seems that the medical professionals in Brazil have been relatively muted. The extension of data sharing and data integration, as proposed by the Brazilian national health card project, should be a matter of concern by the general public, including the mainstream media and politicians. In addition, the compatibility between data sharing and privacy

protection is not an easy matter. It is amazing how often data sharing has been proposed prior to any discussion on information privacy. Also, the government has not yet introduced legislation and other safeguards in order to avoid the situation that the national health card, in the near future, can evolve into a national smart card.

The time has come to improve the Brazilian health card project based on the above concerns. It is common to find people saying that it took more than two years for them to receive the health card after registration, while many people have never received it. Furthermore, the technology seems to be inappropriate because in many instances the software and hardware do not speak to each other. In other words, there are problems of interoperability and the project architecture may have to be redefined after consultation with many segments of the Brazilian society, especially academics, nursing and medical professionals.

HERMENEUTIC RESEARCH AND THE HEALTH CARD

The hermeneutic approach for the analysis of organizational change and information systems development and evaluation has been used frequently (Scott et al, 2005; Ammenwerth, 2003; Berg, 2001; Klecun & Cornford, 2005). Because this study deals with the problem of finding the concepts or meanings of the health smart card, we draw on hermeneutics for the research design. Broadly speaking, the research methodology is based on hermeneutic inquiry. Hermeneutics is a method of textual analysis, and means *to interpret*. Hermeneutics is an artful form of understanding and a process of exposing hidden meanings (Butler, 1998; Klein & Myers, 1999, Myers, 1994). However, after a quite extensive literature review on hermeneutics, electronic medical records, and official documents on the Brazilian health cards, it is surprising that this research work is in its very initial stage. In addition, despite of quite abundant literature on electronic health records, not much work can be found on the electronic health smart card, even in the developed world. This is quite a new technology, therefore the very preliminary answers to the research question that have emerged during this study, rather than being articulated at the outset, are based on documents and textual analysis, not empirical work.

In order to know the dimensions of the Brazilian health card project, and the priority given to it to the detriment of other programs, it was necessary to compile some data that could initially given us some idea about its development against other health and social programs. It is necessary to have some understanding on how the national health card has been implemented, in order to be able to answer the question: what does this implementation mean for those who are touched by it? Thus the second part of this research work requires the use of interviews, in order to provide a deeper analysis of the problems of social exclusion, digital divide, empowerment and alienation - topics that can be well treated by the interpretative perspective.

So, in this very preliminary stage it is acknowledged the limitations of trying to capture all aspects and contexts of the health card on different levels. In the hermeneutic study it seems that we are in the first circle, trying to peeling off some biases and seeking to understand the 'little bits' that make up the whole. The present study can thus be seen as being part of a continuous process of refining our understanding of the health card studying its different manifestation, moving from the 'parts' to a wider context.

In February 2000, the Brazilian health card or the national health card, as it is called, was introduced in Brazil. The initial plan was to introduce the health card in 44 municipalities in 10 Brazilian States, most of them situated in the richer areas of the country. As in some other countries, one of the main objectives of the national health card is to simplify and to process reimbursement claims. As it was mentioned before, this identification card,

Table 1. Expenditures on e-health versus other social programs (value in million us$)

EXPENDITURE	2001	2002	2003	2004	2005
Implementation of the National Health Card	16,538.9	22,156.5	13,403.5	23,491.4	30,810.2
Oncological Cancer Prevention/Treatment	10,587.9	9,756.6	9,278.0	N/A	N/A
Population Vaccination	14,430.6	9,617.7	5,152.0	2,664.6	3,080.4
Adolescent Social Re-Insertion in Conflict with the Law	7,024	7,725	4,472.2	2,961.7	4,633.4

Source: SIAFI/TCU

Conversion of the Brazilian currency, real (R$) into US$: The Annual Average was calculated based on the daily official rate as registered by the Brazilian Central Bank. Years: 2001 = 2,3522; 2002 = 2,9285; 2003 = 3,0715; 2004 = 2,9257; 2005 = 2,4341

that keeps the patient's number and name, not only allows the patient to have access to medical care in any part of the country but can facilitate data integration stored on an electronic record.

The implementation of the national health card therefore required a quite sophisticated infrastructure of hardware and software that is able to read the card and to give electronic access to patient information. In short, with the implementation of the card, it is possible to create a national central database, with data from patients attended at the local level, facilitating data sharing and integration. In 2006, the government was planning to register more people and to distribute fifty million cards.

For this reason, investments in the national health card are increasing considerably over the years, requiring an infrastructure in terms of software, hardware and networks systems that should continue to be enhanced. However, due to resource limitation and the lack of access to health care, it is expected that the chances of the national health card system working reliably remains remote. Table 1 shows that the introduction of e-health in Brazil may have contributed to reduce expenditures in other important social programs. While expenditures made by the Ministry of Health increased over the years with the implementation of the national health card (smart card), expenditures in other social programs decreased. During the last few years, the Ministry of Health is spending more money with the health card than with clinical and biomedical research by national institutes. The same happens in terms of research in tropical medicine, tuberculosis and other endemic diseases. The constant changes in accounts classification in the national budget make it difficult to follow an historical expenditure analysis.

No doubt, the health card may be a very important instrument for the electronic patient record facilitating the storage and exchange of health care information among medical professionals and health care institutions in benefit of the patient, but in the developing world it may be seen as a toy for the rich that can be used only in the developed world. As a result there are many factors to confirm that the National Health Card is not a public health priority, partly because of insufficient knowledge about the goals and functions of this system – and almost complete lack of knowledge on how it is working and the lack of participation of the medical professions on its development. This is a top-down project based on the tool approach to technology.

There are many things in which the Brazilian health care project is similar to the IT projects cited here, in terms of a national central database, standardization, and data sharing and integration. Some of the implications related to these topics have been mentioned, and must be clear that once data are transferred on to a central database, without patient permission, records can be shared, and it is not clear who might access them. In this

case, there is a control over ICT moving from the local level to a centralized system. This could potentially make systems insufficiently flexible to take account of useful variations in local working practices. Others issues that seems to affect information technology in both developed and developing countries are: inadequate funding, insufficient skilled staff and the competition of other priorities may mean that although ICT systems have been implemented, the benefits delivered will not be as great as they might have been.

CONCLUSION

It is a paradox to come across so many information technology projects failures at a time when new approaches to information systems development have been proposed, requiring more stakeholders' participation. In all the projects mentioned above the evidence is that the problems of architecture, design and treatment of data have to be revised. In the UK IT project it has been stated that health service staff are 'heavily demoralized' over the lack of information and communication, apart from having concerns about confidentiality and the lack of resources for staff training. A recent survey in the UK revealed 'that 71% of healthcare professionals place IT security at the top of a list of current issues likely to remain a concern over the next three to five years' (The Observer, 2006). In addition, the lack of staff involvement is symptomatic of the NHS' failure to listen to its staff responsible for delivering patient care. New information systems methodologies have shown that the success of an IT project should take sufficient account of the need for consultation to ensure that systems can help end-users do their work better and easier.

The national health card project in Brazil is falling behind schedule in key areas, and it may be heading for failure before a new system is proposed. The time has come for a discussion of a health information technology policy in Brazil. Unfortunately, there is no clear information technology policy for the country as a whole. With regard to the health sector, there is an urgent need to improve health information quality that may curb bad resource allocation and corruption, and improve the access and quality in the delivery of health services, especially for the poor population. While in the UK the Observer has reported that the money spent already in the multi-billion pound IT project 'could have been used to run 10 district general hospitals for a year' (The Observer, 2006), the few million pounds spent already in the Brazilian health card project could have been used to improve the bad health conditions of the poor. In the UK, it is also mentioned that the biggest civilian computer project in the world is to face the biggest IT failure in the NHS history.

A review of the literature has shown that there are many barriers to e-health and e-government such as poor technical design, technological infrastructure, lack of trust, workplace and organizational inflexibility, digital divides, financial inhibitors, in addition to leadership failures in all states of information technology development (European Commission, 2006; Ebrahim & Irani, 2005). It is expected that the Brazilian authorities should learn these lessons and recognize the urgent need for a discussion, after full consultation, with health care organizations and professionals, especially in the medical, nursing and computer science areas, in order to propose the appropriate health care information architecture for the health sector.

With regard to e-health in Brazil, the official technical knowledge of executives and bureaucrats in the public sector seem to subjugate other knowledge from society in the attempt to implement information technology. The use of the traditional top-down model or the 'tool-approach' to information technology no longer works, except to attend the interests of corporate actors and health care administration rather than the basic health care needs. It should become clear, though, that e-health, as many other information technology initiatives, has a politics and it is never neutral. Again, the

political dimension has to be well understood in order to see the democratic promise of ICT. There is no sign that the health smart card is opening a space for public deliberation, or contributing to improve transparency and accountability in the provision of health care. There has always been a lack of transparency in public administration in Brazil, resulting in public services becoming less accountable and senior bureaucrats more encouraged to waste resources, tolerate inefficiency and mistakes, and corruption.

It is mentioned that the literature on many ICT projects seems to be very often an empirically-disconnected speculation, infused with utopian optimism or dystopian techno-skepticism and/or cynicism. In addition, it is noted that many of these projects are directed to the advantage of corporate actors serving to reinforcing structures that have difficulty in attracting the most deprived and excluded in society (Conway et al, 2003). Studies on e-health in the European countries have emphasized the importance of studies on citizens' expectations about the provision of e-health services. Future strategies should ensure that e-health services are implemented with care, in order not to consolidate or create new inequalities in health care. It will be of great importance to follow up on studies of European citizens' use of e-health (Andreassen et al, 2007).

We understand the limitations of this work and the urgent need for more empirical research work on e-health in Brazil. It has been found that e-government, for instance, has increased efficiency and reduced corruption in Brazil, but at the lower level of administration. While the e-government apparatus facilitates the reduction of corruption amongst small bureaucrats, there is an invisible power that escapes from citizen perception, and is visible only to higher bureaucrats or political and economic elites. Therefore, e-government has reinforced and increased government power control over lower bureaucracy, but this control does not reach the areas in which there are high public resource transactions, where the political elite, legislators and the high bureaucracy still maintain power (Sanchez, 2003).

E-health in most cases is thus oriented towards corporate actor interests and health care administration rather than the basic population health care needs, The next round of this research work is to develop knowledge about invisible areas in terms of health care, hearing the voices of those who never were heard in order to confirm if e-health in Brazil means less care for the poor. However, it is understood that there are many hopes for the potentiality of e-health, especially because the internet is free and open. Brazil is a country with many priorities and many needs, especially in terms of health care. Any e-health strategy or project should be developed not to widen the gap between the well off and the less well off in a society with such huge existing inequalities.

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Chapter 18
Mental Health Management in New Zealand:
The Pathways Model for Client-Based Treatment

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ABSTRACT

This chapter outlines the approach to mental health care developed and currently being implemented by Pathways New Zealand for reducing disease risk factors in patients treated for mental health problems. Pathways New Zealand was formed in 1989 following the closure of the major mental service facility for the Waikato-Hauraki Region of New Zealand, Tokonui Hospital. Since that time Pathways has grown to a national level service offering services to its clients ranging from 24-hour supported accommodation, through healthy lifestyles programs, to outcomes based services including patient access to and involvement in the management of their medical and personal history data (ICAN). Gavin Cooper, Pathways Housing Management Coordinator for the Waikato-Hauraki Region, in conjunction with the Waikato Institute of Technology (WINTEC) has developed a holistic system for the treatment of environmentally induced mental illness that includes chemical treatment, exercise programs, self-help training and community support. The results of a two year program of research into the impact of this program are reported on in this chapter, and its suitability for wider adoption discussed. These comments are partly based on research statistics provided by the Centre for Sports Exercise Science (WINTEC) and Mike Dove, Team Leader Residential, Pathways.

INTRODUCTION: PATHWAYS NEW ZEALAND

'Creating mental health and wellness opportunities that enable individuals to live their dreams'

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Pathways New Zealand was established in 1989 at a time when support for the traditional mental health support system in New Zealand, which involved long periods of incarceration and the use of drug therapy as the preferred method of treatment for people diagnosed with a range of mental disorders was declining. The mental health system was domi-

nated by a few large institutions like the former Tokonui Hospital (New Zealand Government mental health system institution for the Waikato Region from 1912 to 1997), and/or large group houses. Pathways New Zealand is registered as a Charitable Trust under the New Zealand *Charitable Trusts Act 1957*, and is effectively a Non-Government Organization (NGO) operating side-by-side with Government, local government and other welfare agencies. Its primary purpose is to provide high quality accommodation, in the community, and a range of support services that are based in everyday living environments. The fundamental concept being that mental health patients needed to be able to reintegrate in the community to achieve full normalcy.

This recovery model has continued to evolve and Pathways has been able to extend its range from the Waikato Region (based on the City of Hamilton, 2 hours south of Auckland) to the rest of the Country. The model itself relies on introducing clients to good independent housing, instilling a shared belief in recovery, and community-based recovery rather than the incarceration or ghetto-style isolation that characterised the former system of mental health care. One of the challenges was to ensure that client support services moved beyond 24 hour supported accommodation alone to a wider and more diverse range of services, while it was imperative to prove to the client and to the wider community that people do recover from mental illness in order to reduce the stereotypes surrounding this form of illness. Services rapidly became focussed on supporting clients to live well in their own homes; a by product is of course that fewer and fewer support staff are needed for other forms of accommodation, so Pathway's resources can be devoted to other services as outlined below.

As a result Pathways services have an explicit outcomes orientation, assisting clients to live for themselves, and with their families. When this is combined with increasing use of internet and other ICT-based tools, a true independence for the client may be reached. In this, Pathways' origins as a group made up of community-based organisations and individuals concerned about homelessness and lack of support for clients of the mental health system following the closure of Tokonui Hospital in the Waikato has played a big role. The intention of the government at the time to provide little continuing support to take the hospital's place meant that its clients were essentially to be dumped into the wider society without support, or families where they existed were to take over the support role without assistance. No safe houses were to be provided, simply a half-way house solution – the *Henry Burnett Centre* in Hamilton – where medication could be introduced, patients stabilised, and *then released* into society. While this service could in fact take up to one year, it was not the continuing support that the client and the community needed.

The advent of Pathways brought long-term services, valued partnerships with client's families (a very important focus in the rehabilitation of clients), and new innovations in treatment and support as its hallmark from the beginning, but the flexibility derived from being a loose organisation of like-minded people and groups has been the major impetus to success in a community-based framework of support for people with mental health problems. Best practice services mean coping with rapid change and not having a 'one size fits all' approach to the services offered, flexibility is thus the key to survival and growth of the organisation as well as to improving the welfare of the client. Pathways is in effect a client of the Henry Burnett Centre, in that patients are released to its care and support instead of directly to families or to their own devices. As a provider of long-term residential and other lifestyle choice services, Pathways was thus a key ingredient in the new-style mental health care system introduced after 1999.

That this model works and is preferred in health care service delivery is also borne out by the creation of the post-2002 medical system in New Zealand based on Primary Health Organizations

(PHOs) (Ministry of Health, n.d.). PHOs are the government's *local structure* for delivering and co-ordinating primary health care services under District Health Boards, and bring together doctors, nurses and other health professionals (such as Maori health workers, health promotion workers, dieticians, pharmacists, physiotherapists, psychologists and midwives) in the community to serve the needs of their enrolled (clients must sign up) populations. These organisations vary widely in size and structure and are not-for-profit. The first PHOs were established in July 2002 and there are now 81 around the country. The Minister of Health released minimum requirements that guided the establishment of PHOs, and set out standards that they must meet. These include a requirement that PHOs will give communities and enrolled people the opportunity to have their say about the services provided, exactly the model that Pathways uses. PHOs in turn get a set amount of funding from the government to subsidise a range of health services. The funding is based on the numbers and characteristics (e.g., Age, Sex, and Ethnicity) of people enrolled with them; the Waikato District Health Board contains 4 PHOs covering some 330,000 enrolled clients (95%) of the regional population. That funding pays for:

- Providing care and treatment when people are ill
- Helping people stay healthy
- Reaching out to those groups in their community who have poor health or who are missing out on primary health care.

OUTCOMES FOCUSSED SERVICES AND EVIDENCE BASED PRACTICE

Pathways New Zealand offers a number of support programs for its clients, who are mainly people whose ability to operate within mainstream society is compromised due to their mental and physical state. These programs range from direct respite care to employment.

Supported Living

The support choices currently offered to clients are:

Mobile and Enhanced Mobile Support

Mobile support provides the kind of tailored service that enables service users to live independently, yet at the same time retain whatever level of support they feel they need. This means that the service varies according to individual need. The Enhanced Mobile Support service is a recent critical innovation within this service, providing a comprehensive and intensive support service in client's homes as an alternative to 24 hour residential support services. Mobile support teams also work with other community networks and act as facilitators for community inclusion.

Respite Options

Respite services are available in a variety of settings across all regions, ranging from *planned respite* (if in individual housing, then move into supervised group facility) where clients can have a situational break from the environment in which they live; through *crisis respite*, where unexpected problems can be addressed short of hospitalisation in 24-hour supported accommodation; to *acute respite,* which is the community based alternative to acute hospital care but is a neutral 24-hour environment to aid wellness.

Residential-Based Support Solutions

For many, this service is a critical step in their journey toward independent living. Some clients require both accommodation and intensive support. These services are mostly provided through groups of accommodation units. The staffing levels

and mix of roles will vary in each location according to service user needs, with the most intensive being able to provide skilled, professional staff, 24-hours a day.

Housing Management

Keys Living Choices

Keys Living Choices is a new housing service operating independently under the Pathways organisation. Separately managed from Pathway's mental health support services, Keys grew out of an earlier concept – the *Supported Landlord Bureau* – that was piloted in Hamilton in 2001. This service is designed to break down the link between the level of support clients choose and the place they choose to live. It provides both a step from residential-based support into independent living and a choice for people who simply need affordable, secure, quality accommodation. Essentially, there are three aspects to Keys:

- A landlord managing housing stock and tenancies on behalf of Housing New Zealand
- A housing facilitator assisting clients who have diagnosed mental illness to find and keep a home of their own
- Keys also provides advocacy services to clients in their relationship with the government welfare services through Work & Income New Zealand, practical support to get a house set up for independent living (automatic payments for rent, power, phones etc), budgeting advice, and help with sorting out tenancy issues (including mediation if necessary)
- Transitional Housing that supports recovery – safe, affordable, and clients learn skills that help them cope with the New Zealand housing market.

Life Management

Workwise

In 2000 at the annual meeting of Pathways personnel and clients (a *Hui,* or group discussion meeting), service users sent a clear message to management about the direction they wanted the organisation to take – provide real jobs and real pay to clients if they wished. A separate organisation was called into being to assist clients into mainstream employment – Workwise. This organisation is now a separate legal trust that engages in employment facilitation, the establishment of new businesses that provide sustainable income streams and real jobs at a variety of levels and in a variety of areas throughout the country. It also functions as a specialised employment agency for its clients (finding fulltime factory and building & construction jobs for example).

In addition to this service Pathways offers a transition to employment program through two agricultural enterprises – Hamlin Road Farm (20 acres of land, organic vegetables, flowers and free-range eggs), and the Waihi Garden Project – several small plots of agricultural land are developed by clients for household produce, but under an overall business plan for organic farming certification. Currently classified as 'spray-free', the gardens are creating both a healthy workplace environment and pride in the outcomes from the point of view of the client. The nature of the business allows for tailoring work to suit the client and their development of the necessary self-esteem for moving to mainstream employment.

Workforce Management

The Blue Print Centre for Learning

The quality of professional care provided by Pathways is predicated on the skills and attitudes of its workforce. Accordingly, the Blueprint Centre for Learning was established in 1999 to meet

demand for training with the introduction of the first specific qualification for mental health support workers (The National Certificate in Mental Health (Mental Health Support Work)). For non-government organizations this qualification presented a significant challenge and at the same time, inspired the development of an innovative new training service. Blueprint delivers a diverse range of training at all levels, to all kinds of health, mental health, addiction and social sector agencies – with the same passion for real outcomes. In addition to education and training, Blueprint Centre for Learning is also recognized as a hub of sector expertise, undertaking workforce research and evaluation projects for both government and non-government agencies.

Originally established under the Pathways Trust to meet the needs of its staff, Blueprint soon became a separate entity in response to the unexpected level of demand for high quality mental health education. On 1 December 2007, Blueprint changed from a Trust to a registered company with charitable status, *Blueprint NZ Limited*, trading as Blueprint Centre for Learning (Blueprint New Zealand, 2007).

Healthy Lifestyles

The concept of Healthy Lifestyles has emerged as a leading area of interest for Pathways in recent years. Data on the health of clients show that people with serious mental illness smoke more than other groups, have higher rates of diabetes, are heavier, exercise less, take more medication, and die younger when compared to New Zealand population demographics as a whole. Pathways services are officially smoke free and some control is extended to other areas of difficulty like diabetes, but it took a program of research into the effects of mental patients lifestyles to galvanize both the organization and its clients in this area of its work.

A joint initiative between Pathways Waikato–Hauraki service and the Waikato Institute of Technology (WINTEC) Centre for Sports and Exercise Science, this program, discussion of the results of which forms the core of this Chapter, involved exercise and education designed to offset major weight gain for clients on the newer anti-psychotic medications developed in recent years. The program also helped to build relationships between staff and clients while also increasing the social skills of clients themselves.

The Use of Information Technology

Information technology is a vital part of the quality management and service provision in the Pathways operation, but more importantly, provides an opportunity (pathway) for the training of clients in modern ICT use. Three software systems are in use: the first is CIMS, which is used to track rents and utility payments by Keys Living Choices, in other words primarily an in-house financial and payments accounting system which is not transparent to the client, although it is to staff. The second is a much more sophisticated central support service technology entity called PHACTS described below. The third is TABS, used primarily for recording in-house training and as a comprehensive employee induction and training management system.

At the core of support service technology in Pathways is PHACTS, a system developed by the organisation to record individual information on and for each client. This software enables Pathways to fully coordinate individual service plans electronically and to phase out paper files. The system is accessible across the entire Pathways network; security attributes are set to information determined by role and region. The network is also linked to the Ministry of Health's Mental Health Information National Collection database (MHINC). This fully integrated network ensures information integrity, allows for standardised file management, and data retrieval. New business intelligence software is used to extract meaningful outcomes data, analyse service outcomes,

and ultimately provide a more streamlined and responsive service. A key tool for staff is contained within the system; the Supported Services Manual contains best practice policies and procedures and is available online and hyperlinked, allowing fast access to this management resource.

But perhaps the most important system resource contained within PHACTS is the one added in 2005, *ICAN*. For several years before this Pathways had explored ways of making it possible for clients to directly contribute to, retrieve and manage their own personal records during their time with Pathways. The result was ICAN. This system allows service users to create their own case notes (how *they* are feeling and experiencing, not how the medical profession or Pathways staff might interpret their emotional condition), connect to databases containing their own health notes, to connect with family, friends, health professionals, support staff and psychiatrists and friends through the internet, and to access all this through any computer, anywhere. The use of ICAN has led to a revolution in everyday practice, both on the part of the service provider and of the client. Cooperation in recording progress against individuals' goal plans and notes, and through such conversations interconnecting the two has been a very positive feature of this system.

The ICAN Network is a portal that also enables users to gain access to the Microsoft Office programs Word, Outlook, Excel and PowerPoint. The ICAN Network also provides the link to PHACTS, where clients can read, review and contribute to their own case notes. Word allows clients to write letters, keep a diary, create cards and invitations, insert pictures or photos, and even write assignments if studying. Outlook is the email program and Excel can be used to create financial documents and accounts, to set-up mailing lists, and to create graphs. Clients are provided with a username and password for log on purposes, and access the following screen at this point (Figure 1). Access to every-day operating software and a message center is available.

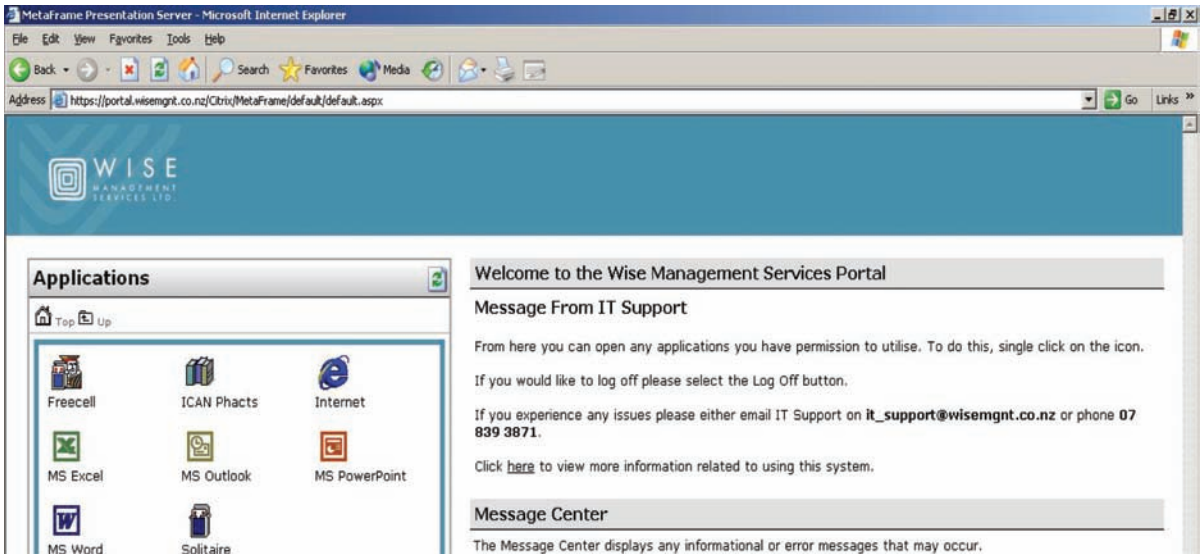
PHACTS is also the program that contains the electronic record of a client's documentation during their time with Pathways. With full access to PHACTS through a password system clients can read their health records and add their own information to those records. Through this software clients can communicate with health professionals, support staff and psychiatrist, and when they leave Pathways they can take their health records with them. The following features can be accessed through PHACTS:

- Personal Details tab (this entire tab, including the New, Modify and Delete buttons, is read only. The client is not able to alter details, or enter new information for security reasons. The exception is the contacts button, which is active – see Figure 2)
- R&D tab
- Notes tab (to access the Client tab)
- Daily tab under the Notes tab
- Medical Tests tab under the Notes tab
- Medication tab
- Plans/Reviews tab
- Essential Information tab
- Movements tab
- Financial tab
- A Miscellaneous tab
- Entry tab
- Exit tab
- IAC tab.

THE HEALTHY LIFESTYLES WEIGHT-LOSS PROGRAM

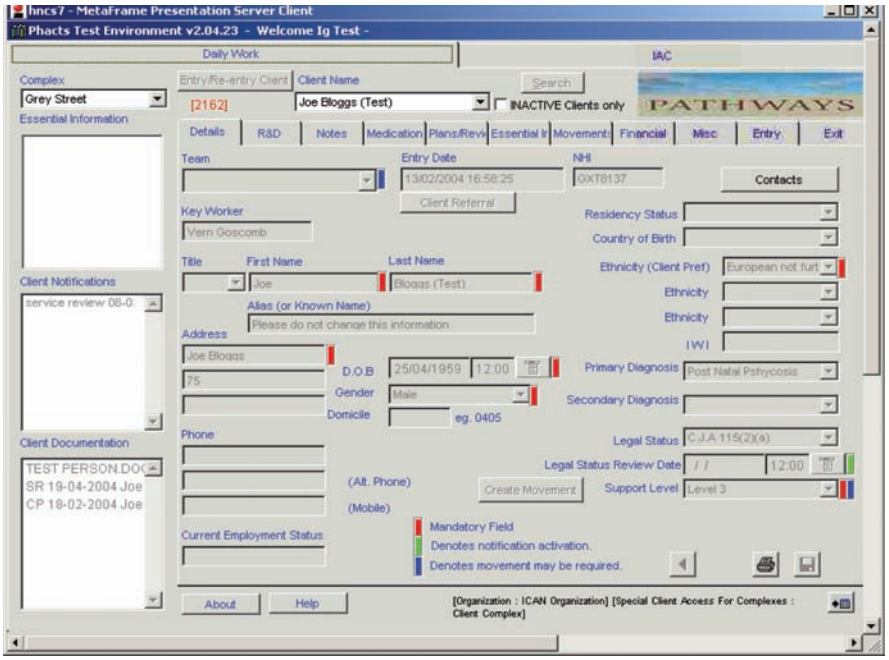
As part of the ICAN and Healthy Lifestyles programs and the recording of client-based data under PHACTS it was noticed that Pathways New Zealand clients on certain atypical antipsychotic medication complained of weight gain (Figure 3), amongst other problems. The medications that are found to be effective in specific psychotic

Figure 1. ICAN opening screen **(***Source: Pathways ICAN Manual 2007 (with permission))*



conditions are also found to be associated with significant co-morbidities such as weight gain, hyperglycaemia and type II diabetes (Allison et al, 1999). In consideration of the fact that life style behavior could attenuate the secondary health concerns in psychotic clients, Pathways Hamilton Office began from 2004 implementing a 12 month fitness and education research program designed by G. Cooper and M. Dove and implemented by WINTEC Centre for Sports and Exercise Sci-

Figure 2. Phacts client information screen (Source: Pathways ICAN Manual, 2007(with permission))



ence as part of its on-going research program into healthy lifestyles as an intervention idea for mental health clients. This has now gone through 2 iterations, and the results are reported on below. The research project consisted of giving advice from fitness professionals and nutritionists too clients as well as recording of pathological data on client health conditions. Clients wrote about themselves and their experiences/progress through the ICAN software. In 2006 the fitness education program became part of the primary mental health healthy lifestyles program *Help 4U* developed by the Hamilton PHO (Ministry of Health, 2004).

The medical background to the study is that clients with mental illness have death rates (Handiside, 2004):

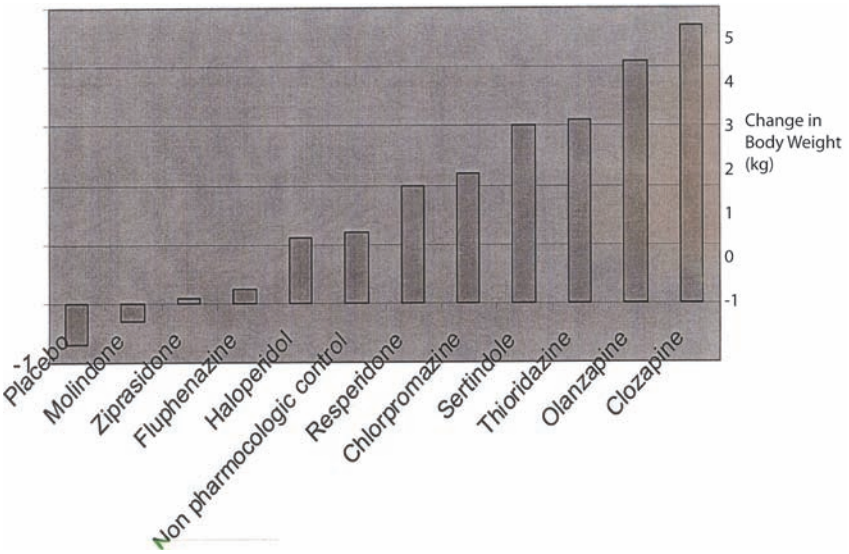
- 2.2 times the normal population from heart disease
- 1.5 times from all-cause cancers
- 3 times from diabetes
- 5 times from influenza
- 2.8-4 times the normal population from respiratory illness of all types.

The purpose of the project described here was therefore to assess the various metabolic, physical and mental functioning factors that might be associated with antipsychotic drug intake for clients currently managing diagnosed mental illness. Weight management strategies were offered to patients by qualified health professionals and pathways staff also participated in the program, which was financed by the New Zealand Government through the Waikato District Health Board and supported by Pathways and local GP's/Pharmacists (the Breakthrough mechanism).

Methodology

The first healthy lifestyles program was envisaged as a 12 month protocol in 2004 to manage the acute weight gain associated with antipsychotic drug intake by WINTEC in conjunction with the Hamilton office of Pathways. The 12 months was to include a preliminary phase (3 months of preparation), an intervention phase (6 months), and a follow up phase (3 months). In. the final design the follow up or post-intervention (PI) phase lasted 12 months, making the total program

Figure 3. estimated weight gain at 10 weeks of the use of antipsychotic drugs (Source: Shanks, 2007)



18 months in duration. In the first program there were 57 subjects in total, with 32 'experimental' subjects (clients) and 25 'control' subjects (support workers):

- Preliminary Phase

This consisted of a monthly visit to the Centre for Sport and Exercise Science at WINTEC. During this visit 7-day food intake and physical activity measures (recall and Pedometry), psychological functioning (self attributes questionnaire SEES), blood glucose, insulin and cholesterol levels, blood pressure, body mass index (BMI), and body size measurements were taken from records submitted by patients. These measurements became the 'baseline' levels of each patient's health endeavours.

- Intervention Phase

Following the preliminary phase participants underwent a pre-screening examination from a medical practitioner, completed 2 supervised sessions of physical activity per week, were prescribed a fitness program by personal trainers, were provided with a pedometer and encouraged to record at least 10,000 steps per day in addition to their supervised workouts. Once every 2 weeks they attended a wellness workshop to discuss progress and obtain information and other resources with facilitators were knowledgeable about physical activity, nutrition and psychological skills training for adherence to lifestyle changes. During this visit to WINTEC nutrition scale (NAKS) and health measures were applied to each subject, including medical examinations, wellness workshops, physical activity, and a six-minute walk test at the start and end of intervention to detect changes in the subject's level of fitness.

- Follow Up Phase

During the follow up phase interaction with the client was restricted to 3, 6 and 12 monthly recording of the same measures as for the two previous phases.

The second healthy lifestyles program was began on 30/08/06 and finished on 28/02/07. Promoted as *'Help 4U'*, it involved a core intervention phase of 10 weeks, preceded and followed by preliminary and post-intervention phases as for the first trial, designed and implemented by the Hamilton PHO on the basis of the original research and undertaken at WINTEC. Total enrolees were 52, and all were clients of the medical or Pathways systems. Ages ranged from 20 to 69 (Table 1), with 34 participants of European ethnicity and 15 Maori (3 did not disclose their ethnicity). Pathways clients were 32 (19 home-base and 13 general), and the others came from living and housing trusts (7), Medical Centres (8), and mental health support centres (5). The problems revealed by these clients

Table 1. Demographics of the 2nd sample

Age (n=52)	Male	Female	Total
20-29	5	4	9
30-39	10	11	21
40-49	6	6	12
50-59	6	2	8
60-69	-	2	2
Total	27	25	52

Source: Shanks 2007.

are given in Table 2. Clients were informed that the cost of dental treatment would be minimised through Work & Income New Zealand.

Following GP checks and blood tests, 11 participants were informed that they also had high glucose levels, 10 were informed of high cholesterol levels, and a number of minor physical conditions treated.

Results

The results obtained from the *first set* of patient trials were as follows:

- Significant decreases in weight were observed, but these were not maintained (3% for clients, 1% for staff) during intervention. At 12 months Post Intervention weight gain was 1.3% for clients and 2% for staff
- Significant increases in physical activity were recorded and maintained. The mean distance walked during the six minute test was 588 meters, up from 524 meters at the beginning of intervention, but clients reported a 70% increase in all forms of physical activity by the second 3 months of the intervention phase
- Body Mass Index declines were recorded
- Total cholesterol levels decreased significantly during intervention (8.78% at 6months) but by 12.35% at 12 months Post Intervention (PI); LDL cholesterol decreased by 11.82% and 16.37% at 6 & 12 months PI; HDL increased by 5.03% at 12 months PI
- Significant decreases in blood pressure (Mean Arterial Pressure – MAP – of 9.95%) were recorded at 12 months PI
- No significant differences in fasting blood glucose concentrations or in *Prolactin* (in male clients) from baseline levels were observed
- While there was no significant change in nutrition knowledge throughout the intervention period, dietary *practices* during intervention changed considerably for both clients and the staff control group, with energy intakes being significantly greater during intervention and PI
- Significant increases in positive wellbeing were observed and maintained after intervention, and very large *decreases* in fatigue (up to 65%) were reported throughout the entire investigation.

Table 2. Medical and other conditions reported before the program

Condition	Number
Asthma	11
Diabetes	3
High Blood Pressure	3
Epilepsy	1
Hepatitis/Hepatitis C	3
Depression	16
Intellectual Disability	3
Arthritis	1
Bone Complications	1
Cerebral Palsy	1
Dental Treatment Needed	27

Source: Shanks 2007

Results from the 'Help 4U' program are outlined in Table 3. These data show that, as for the first trial, the patients who enrolled largely stayed in the program. This result and the ongoing demand for places in the nutrition groups shows that there is awareness of the importance of weight control in the mental health patient population. Many stated that they feel fitter and have taken command of their walking program themselves. Participants are also relaxing more at the activities and pushing themselves further on their own. Similar results to the first trial in terms of weight reduction, blood pressure reduction, and slightly lower reductions in cholesterol and Body Fat indexes were observed.

DISCUSSION AND CONCLUSION

Care for individuals presenting with symptoms related to mental illness is a government health and community issue that is becoming more difficult to manage in many countries. The programs described in this discussion have indicated a set of suitable and successful protocols to facilitate long term health and wellness through cognitive behavioral management, physical activity and nutritional assessment. Both the housing intervention and the 'wellness' study/intervention have led and continue to lead to improvements in health and in ability to cope in society amongst the group that Pathways supports.

Even though improvements in the health of Pathways clients were attenuated over time after completion of the intervention programs, ongoing community support (including outpatient care) and physical activity as part of 'daily living' may be a more appropriate intervention in their lives than the drugs used in the past. Also, Pathways clients generally demonstrated similar improvements in health in the WINTEC study as did support workers, indicating that they are as able to *change* their behavior to improve health as is the general population. And in relation to this the increasing use of ICAN has demonstrated both a willingness to use and a realization of the benefits of interactive media such as the internet and email. A significant increase in knowledge for both clients and their support systems is the result.

Of all the participants in the first program, 62% completed (29), 8 withdrew for reasons beyond their control, while 10 did so voluntarily. In the second program 71% completed (37), while 15 did not complete (28%); 10 for mental and physical health reasons, 4 for personal reasons, and 1 was lost contact with. In both programs weight loss was found not to be a good indicator of success in such interventions. The decreases in weight

Table 3. Results of the help 4u program initial phase 30/08/06 – 28/02/07(n=52)

Condition	Before	After			
		Stopped	Reduced	Same	Increased
Smoking	41	22	5	14	-
Dental	27	15	-	12	-
Weight	-	-	22	4	26
Clinical Parameters					
Blood Pressure	-	-	32	5	15
Glucose Levels	-	-	5	46	1
Cholesterol	-	-	14	26	12
Body Fat (BMI)	-	-	12	2	13

Source: Shanks 2007.

recorded were not maintained and there was a significant increase in mean weight relative to baseline 12 months Post Intervention, nevertheless lasting improvement in health overall were recorded (recorded via pedometers and the six minute walk test). Thus physical activity seems to have the most benefit, but pedometry may not be the best method of recording this. As a result, the Hamilton PHO continued with the original program beyond the 2nd trial, and out of this has come the appointment of permanent, full time lifestyle facilitators and aerobic instructors.

Lasting improvements in some important aspects of health like cholesterol levels and blood pressure *can* be achieved by such interventions, but results may be affected by the masking from prescribed blood cholesterol lowering agents now being taken as part of the increased awareness of health experienced by all patients. Overall, though evidence for favorable cholesterol profiles and decreased blood pressure was quite strong during these tests. And, even though higher levels of psychological distress were reported during the first part of each intervention *because* the programs were forcing a change that otherwise does not usually happen, the magnitude of positive feelings especially that of decreased feelings of fatigue after completion each time were both surprising and welcome.

The increases in feelings of wellbeing found by the first study were duplicated in the second. A number of patients stopped drinking alcohol, 5 enrolled in courses at educational institutions, 6 found part-time work, and many started cooking for themselves. On the medical side there appear to be fewer GP visits and less use of medications, while the healthier shopping choices, greater social contacts being made, team work improvements, and greater self esteem are very noticeable. On the downside, 10 weeks of the intervention program was not long enough, participants are really the only ones that are able to determine how long they need to be involved in the group situation, and all stated that a longer period was needed. Many signed up for a follow-on nutrition program as proof of this. The other major problem was lack of transport; in order to improve attendance it was necessary to arrange collection and transport to/from the classes.

In a reflection of the importance of transparent knowledge transfer between clients and the medical profession the experiences gained through these programs have led to new joint programs between Pathways New Zealand and the professional services. General practitioners, psychiatrists, occupational therapists, social workers and many non-government support services have all referred new patients to the healthy lifestyles program. The ICAN and PHACTS frameworks have made it possible for the mental health support system to be driven by clients, with the additional important factor of family involvement being possible. Not only have Pathways clients achieved the results outlined above, but local GPs through the Hamilton District Primary Health Organisation have also begun recommending that people without a history of mental health problems join the Help 4U program. These programs thus confirm the Pathways approach to mental health support and the new approach to mental health management in New Zealand post 2002; one based securely in client-based and client-determined treatment. As the Pathways founders noted:

'The shape of the future lies with all of us and our responsibilities are clear; be brave – discard old ways of working and services that are no longer meet the needs of service users. Create new paths.' (Julie Nelson, Chair, Pathways Trust, 2007, 4).

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KEY TERMS AND DEFINITIONS

Keys Living Choices: Keys Living Choices is a new housing service operating independently under the Pathways organisation. Separately managed from Pathway's mental health support services, Keys grew out of an earlier concept – the **Supported Landlord Bureau:** That was piloted in Hamilton in 2001. This service is designed to break down the link between the level of support clients choose and the place they choose to live. It provides both a step from residential-based support into independent living and a choice for people who simply need affordable, secure, quality accommodation.

Mobile and Enhanced Mobile Support: Mobile support provides the kind of tailored service that enables service users to live independently, yet at the same time retain whatever level of support they feel they need. This means that the service varies according to individual need. The Enhanced Mobile Support service is a recent critical innovation within this service, providing a comprehensive and intensive support service in client's homes as an alternative to 24 hour residential support services. Mobile support teams also work with other community networks and act as facilitators for community inclusion.

Residential-Based: Support Solutions: For many, this service is a critical step in their journey toward independent living. Some clients require both accommodation and intensive support. These services are mostly provided through groups of accommodation units. The staffing levels and mix of roles will vary in each location according to service user needs, with the most intensive being able to provide skilled, professional staff, 24-hours a day.

Respite Options: Respite services are available in a variety of settings across all regions, ranging from *planned respite* (if in individual housing, then move into supervised group facility) where clients can have a situational break from the environment in which they live; through *crisis respite*, where unexpected problems can be addressed short of hospitalisation in 24-hour supported accommodation; to *acute respite*, which is the community based alternative to acute hospital care but is a neutral 24-hour environment to aid wellness.

The Blue Print Centre for Learning: The quality of professional care provided by Pathways is predicated on the skills and attitudes of its workforce. The Blueprint Centre for Learning was established in 1999 to meet demand for training with the introduction of the first specific qualification for mental health support workers.

Workwise: In 2000 at the annual meeting of Pathways personnel and clients service users

sent a clear message to management about the direction they wanted the organisation to take – provide real jobs and real pay to clients if they wished. A separate organisation was called into being to assist clients into mainstream employment – Workwise. This organisation is now a separate legal trust that engages in employment facilitation, the establishment of new businesses that provide sustainable income streams and real jobs at a variety of levels and in a variety of areas throughout the country.

Chapter 19
An Exploratory Study to Understand the Drivers and Inhibitors for the Successful Adoption of Wireless Technology in Australian Healthcare Systems

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ABSTRACT

According to the Australian Department of Health and Aging (n.d.) the adoption of new technologies is crucial in addressing health issues. Currently, wireless technology is used in Australian healthcare with limited scope, addressing specific aspects of quality of service offered to various stakeholders. While prior studies agree that wireless applications have the potential to address the endemic problems of healthcare, very limited information can be found about the determinants of such applications. Therefore, there is a need to identify factors that may assist in the adoption of wireless applications in healthcare and the factors acting as barriers in the uptake of such applications. This chapter reports on a study designed to elicit these factors using a semi structured interview approach and surveys. The study is structured in two specific phases. The first phase involved a semi structured interview with selected healthcare professionals to understand various factors involved in the adoption of wireless applications as applicable to Australian healthcare. The second phase involved administering a survey to generalize the findings of phase one and to capture the views of the wider population.

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INTRODUCTION

The last three decades of investment in the information and communication technology sector have had dynamic effects on healthcare. Such investments have resulted in increases in productivity, a high quality of services and the development of new processes. Despite this, the healthcare industry did not enjoy flexibility as the industry was always operating under limited resources. Recently, the strategists, operators, decision makers, and other stake holders have realize the potential of information communication technology (ICT), especially in wireless technology and see an opportunity window to address some issues healthcare sector is facing. It is suggested the ICT have the potential to address the issues such as quality of care, reduction in cost, shortages of human resources, reduction in errors, reduction in funding, and high satisfaction levels among customers and employees. For example, a patient registering in a hospital may be issued with electronically readable code and staff with wireless devices can enter critical information directly into the hospital network. Through wireless devices, a patient's body can be connected to various items of hospital equipment to record medical data, such as blood pressure, heart function can directly be monitor, recorded, and analyzed by doctors internally and externally. Through wireless networks, doctor can order tests, prescribe medicines, and request for other services directly from the patient's bed.

The Australian healthcare industry is operating under the umbrella of high expectations, reducing funding, aging populations, pressure from industry regulatory bodies, pressure to integrate new technological development in the exiting business processes, and a need to ensure the ability to provide customized care and other associated activities, wherever, whenever, at a competitive cost, at the point of care in a highly competitive environment. Under such a circumstance healthcare providers are operating with limited resources, constant calls for reductions in operating costs, and demands to redesign their workflow systems in order to accommodate the dynamic environment of healthcare industry. Therefore, adoption and utilization of new technological developments is very critical for the survival of healthcare in Australia. In this situation, it appears that the reduction in hardware/operating costs, the increased functionality and the increases in the ability to transmit high speed secure data gained from new wireless technologies are able to address most of the concerns of the healthcare provider.

ADOPTION AND BACKGROUND

Earlier models of technology adoption come with criticism. For example, in terms of the Theory of Reasoned Action (TRA), irrational decisions, habitual actions and other unintentional behaviours are not explained (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). TRA is also limited by its reliance on self reported information to determine the subject's attitude and the data reported may be subjective in nature (Ajzen & Fishbein, 1980; Farhoomand et al., 1990; Fredricks & Dossett, 1983; Tan & Teo, 2000). The Theory of Planned Behaviour (TPB) is also limited in that it describes the attributes of adoption at the individual unit of analysis rather then at the organisational level. This precludes its use when dealing with an adoption based on primarily, organisational units (Ajzen, 1985; Ajzen, 1991; Ajzen & Driver, 1992; Ajzen & Madden, 1986; Cheung et al, 1999; Madden et al., 1992; Randall & Gibson, 1991).

The Technology Acceptance Model (TAM) was predominantly tested with students who have limited computing exposure, administrative and clerical staff who do not use all ICT functions found in software applications. Applicability of TAM to specific disciplines such as medicine appear to have not yet fully established (Burton-Jones & Hubona, 2005; Davis, 1989; Davis et al., 1989; Darsono, 2005; Hu et al, 1999; Hu et

al, 2002; Legris et al, 2003; Riemenschneider et al, 2003; Venkatesh & Brown, 2001; Venkatesh et al, 2003). In terms of Unified Theory of Acceptance and Use of Technology (UTAUT), three additional reported indirect determinants such as self-efficacy, anxiety and attitude towards using technology need further study (Carlsson et al, 2006; Cody-Allen & Kishore, 2006; Li & Kishore, 2006; Lubrin et al, 2006; Robinson, 2006; Venkatesh et al, 2003).

Likewise, the Diffusion of Innovation (DOI) Model is limited, its processes not uniform, it may not hold true due to its linearity, and unstructured, emergent phenomena, and it is too complex to be expressed in a step-like model. Diffusion processes are focused on describing observed diffusion patterns in terms of pre-specified trend or distribution functions. There are no references to technical, organizational or social context, or different industry contexts (Baskerville & Pries-Heje, 2001; Hamblin et al., 1973; Mahajan and Peterson, 1985; Moseley, 2000; Rogers, 1983, 1995, 2003; Vuarin & Rodriguez, 1994).

In the healthcare literature the concept of wireless technology is discussed by many studies (Dyer, 2003; Hamalainen et al, 2007; Handy et al., 2002; Simpson, 2003; Sausser, 2003; Wisnicki, 2002). For example, Wisnicki provides details of how broadband technology, a component of wireless technology, can be used in healthcare. The discussion provided by Wisnicki (2002) involves the high cost of setting up a wireless technology in a healthcare setting, improvements to patient care using this technology and potential cost-effective quality of service to patients. Sausser (2003) provides information on how to improve clinical quality using wireless technology including challenges for maintaining security and privacy. Sausser (2003) also discusses the concept of portable devices for data collection purposes by providing an argument on benefits that can be realized using these devices. Simpson (2003), while critiquing the nursing domain stresses the need for the innovative use of IT to improve patient care. He points out that new wireless technologies can help to address some of the chronic problems encountered including saving nurses' time, skilled nursing care and home healthcare. Dyer (2003) on the other hand, provides details of how text messaging using wireless devices can be effectively used to remind patients of their appointments. He reports the idea behind a radically new system of managing patient care in conjunction with modern telecommunication applications using wireless devices to improve the quality of patient care. Common to all these studies is the use of emerging wireless applications in healthcare and potential benefits that can be achieved.

While many other studies in the healthcare literature echo similar sentiments, none of these studies have examined the potential challenges of using wireless applications. It appears that almost all studies have taken this crucial aspect for granted and did not research, for example, the impact of factors such as compatibility, integration, support and training, configuration, and security issues. While some studies have indicated existing problems in collecting patient data and provided some theoretical solutions, these studies have seldom analyzed the changing nature of information systems using wireless applications. For instance, Sausser (2003), Tseng & Heui-huang (2007), and Wu et al (2007) mention the advantages of using mobile technology in collecting patient data, but do not provide an in-depth analysis of their strengths, weaknesses, or influences and how critical these factors are for successful implementation and usage of wireless technology.

To comprehend the issues related with data collection using wireless applications, several information technology studies were also reviewed. Our review indicated that this area (wireless technology) is not fully researched in information systems. For example, (Redman, 2002) states that wireless technology is in its infancy stage and warns of the potential pitfalls of IT providers rushing to implement the technology. Shah (2001) warns of the slower speed of wireless networks

compared with desktop computers and highlights the potential problems that could be encountered by healthcare from this situation. The relatively high costs to initially set up these wireless networks is mentioned by Shroefer (1999). The lack of real time connectivity due to the mobility of the device and the problems associated with such mobility is highlighted by (Stevenson, 2001). The size of the screen and hence the problems that may be encountered in displaying data due to screen size while capturing data is stressed by Toms (2000) and Kang et al (2007). The problems that may be encountered due to the lack of provision for high quality graphic display on wireless devices are highlighted by Atwal (2001). Bevan & Mittman (2002) discuss the potential problems of capturing data using wireless devices due to the 'hard-to-see display' nature of these devices. While the studies mentioned above warn of the problems that could be encountered while using wireless applications, they also tend to agree that the usage capabilities of these wireless applications are growing and hence these hardware related problems will disappear in a few years time. What can be realized from this review is that the bulk of the studies have paid attention on the 'hardware' or 'physical' component of wireless devices, as this appears to be a focal point of interest to many authors now. Other studies refer to the 'implementation' or 'management' of these wireless technologies in healthcare organizations, as cost appears to be a determining factor in such implementations. None of the studies appear to have examined the 'usage' aspects of wireless applications. Consequently the overreaching aim of this study is to explore and identify the drivers and inhibitors for adoption of wireless applications in the healthcare industry for data management. Therefore the research question addressed in this study is as follows:

'What factors influence the uptake of wireless applications in healthcare environment?'

RESEARCH DESIGN

The research design for the study reported in the Chapter involved both qualitative and quantitative techniques. The qualitative techniques were employed to get 'first hand' information from nurses using a semi structured interview approach. This is essential because the literature is limited in this aspect. The quantitative method involved developing a survey instrument to obtain nurses' perceived opinion on various factors impacting the adoption of wireless technology, as found from the interviews. The data were collected in two stages that are six months apart. In the first stage, data were collected from nursing staff involved in patient care about their adoption and usage behavior of data collection using current technologies. In the second phase, respondents were contacted again for a follow-up survey to understand their changing views and behavior pattern. Three specific hospitals were identified for this purpose where wireless devices are used for data collection purposes. The hospitals were derived from government, private and regional sectors respectively.

While many techniques are available to capture perceptions and attitudes of usage of technology, this study employed an interview and a survey technique (Zikmund, 1994). This included open-ended responses to obtain factors that are not constrained by a pre-determined identification of constructs found in traditional surveys, as well as to determine the importance of the pre-determined factors. Given the exploratory nature of this study, these two techniques are considered important.

The instruments of this research constitute two broad categories of questions. The first categories of questions were related to the adoption and usage of wireless devices in hospitals for data collection purposes. The second category consisted of demographic variables. Open ended questions were included in the instrument to obtain unbiased and non-leading information. Prior to administering the questions, a complete peer review and a pilot

study were conducted in order to ascertain the validity of the instrument. A two stage approach was used in administering the instrument, where the first stage gathered information about the key factors influencing nurse decisions to use wireless applications and the second stage on the importance of those key factors. This approach was followed in this study in order to complement the open ended questions so as to determine the importance of the individual factors determining the adoption and usage of wireless devices and applications. This is not reported in this chapter, as the outcome has already been published.

For the purpose of this chapter the second stage data collected through the survey were analyzed through SPSS, by using the factor analysis technique to identify drivers and inhibitors for the adoption of wireless technology in healthcare environment. Findings pertaining to these are presented here.

Qualitative Data Collection and Data Analysis

In this stage of the research a set of 30 interviews were undertaken. In order to ensure the interviews were conducted on time, the local health district was approached through one of the authors of this paper and suitable candidate groups were identified. After obtaining ethical clearance from both the principal University and the Health District, a research associate from the Health District was contracted to undertake the interviews. The interviews were conducted in such a fashion as to minimise any disruption to nurses' work schedule, ensure comfort of nurses in answering questions, minimise any travel time by interviewees, synchronise the 'interview' language with participants and to prompt nurses when unknown aspects were encountered by participants.

Participants for the interview were selected from the nursing staff in Queensland Health. The participants were initially screened for suitability as only nurses working with technology were considered for this purpose. Any nursing staffs involved with administration only were eliminated from the interview to avoid any unforeseen bias. Nurses with a vast background were chosen (pharmacy, oncology and emergency departments). As the nurses belonged to the Health Department, no further screening was employed for sampling. Prior to the interviews, their line managers were approached for permission to release staff for interviews. Initially a consent letter was distributed to obtain consent for interview and the list of people interviewed was provided to the Health District. The interview was recorded using a digital recorder and catalogued as per ethics requirements. These interviews were then transcribed for data analysis.

The instruments of this research consisted of two broad categories of questions. The first category of questions was related to the adoption and usage of wireless devices in hospitals for data collection purposes. The second category consisted of demographic variables. Open ended questions were included in the instrument to obtain unbiased and non-leading information. Prior to administering the questions, a complete peer review and a pilot study were conducted in order to ascertain the validity of the instrument. A two stage approach was used in administering the instrument, where the first stage would gather information about the key factors influencing users' decision to use wireless applications and the second stage on the importance of those key factors. This approach was followed in this study in order to complement the open-ended questions so as to determine the importance of the individual factors determining the adoption and usage of wireless devices and applications.

The data was analysed using the NVivo software application. Prior to the analysis of data, the interviews were transcribed using university services. The transcribed interviews ranged from 8 pages to 17 pages in length, covering a total of 260 pages of rtf format file. Two experienced transcribers were involved in the process of converting

Table 1. Organized facilitators and inhibitors of the adoption of wireless hand held technology (source: the authors)

FACILITATORS	**INHIBITORS**
Volume of Information	User Friendly
User Friendly	User Friendliness
User Friendliness	Unreliable
Reduction of Documentation	Testing
Quicker Response	Short Staff
More Timely Recording	Secure
Mental Health	Reliance
Medication Schedule	Problems
Medication Errors	Schedule
Managing Data	How does it work
Intensive Activities	Health Policy
Health Policy	Coverage
Handover Reports	Confidentiality
Fantastic Benefit	Awareness
Falls	
Cut Down on The Paperwork	
Current Competence	
Benefits	
Avail Liability of More Time	
Alert Clinicians	
Adverse Event	
Advantages	
Access Massive Amount of Information	
Remote Monitoring	

the interviews into a computer file. Once the files were transcribed, they were read while listening to the conversation in order to verify accuracy of transcription. Any parts that were missing during the transcription process was filled in as the researchers possessed sufficient knowledge of various technical terms used in this domain. The files were then printed and scanned for facilitators and inhibitors. These themes were identified on paper and then used as nodes in NVivo while examining the text files.

Once the themes were identified as free nodes using NVivo, the text snippets were examined again to aggregate the nodes into groups. Initially over 200 free nodes were realised and they were grouped into facilitators and inhibitors by examining the text passages again. They were grouped into the two major categories as trees and a simple correlation analysis using the table facilities was also performed on the various nodes.

Results

The analysis using NVivo confirmed that the following facilitators and inhibitors can be extracted from the data collected from nursing participants. Our aim was to identify the factors impacting wireless technology adoption. We did not attempt to classify them in an order of priority. However, we will be conducting more data analyses to classify them in proper groups and this exercise is beyond the scope of this project. The following tables list the facilitators and inhibitors of wireless technology adoption in nursing.

Quantitative Data Collection and Data Analysis

A survey instrument was developed from the findings of the stage one and 200 questionnaires were distributed among the healthcare professionals in the state of Queensland. Out of 200 questionnaires

Table 2. Reliability statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items
.877	.892

only 179 useable questionnaires were received. Responses from the survey were transcribed into a spreadsheet file and a visual basic interface was used to generate the numerical code to analyze the data by SPSS. Initially data was review for missing or incorrect values, descriptive analysis techniques were used to review the data from the SPSS as well. In-order to ensure the reliability of the instrument a reliability test was run on the complete instrument and the group of selected variables. The reliability test of Cronbach's alpha was performed through the SPSS and value of 0.892 was received, which indicate high reliability (Manning & Munro, 2007; Hair et al, 2006).

Further, a data reduction technique, Factor Analysis, was used for the exploratory analysis. As can been seen from Table 3, four factors: *efficiency, organizational, communication,* and *reporting* factors were identified for the adoption of wireless technology in the healthcare environment. How these are intermediated by the attitudes of health professionals is outlined in Figure 1.

DISCUSSION

It can be seen from the above data analysis that Australian healthcare professionals are quite concerned about change management and if this is not handled appropriately, it can have negative effect on the adoption of new aids like wireless technology in the healthcare environment. At the same time it can also be seen that Australian healthcare professionals are keen to adopt wireless handheld technology that has specific advantages or a perceived usefulness, indicating their awareness of its use in error reduction, in raising quality of care, and in clinical performances. Australian healthcare professionals thus see the technology as having positive potential in the

Figure 1. Initial framework for the adoption of wireless handheld technology in healthcare environment

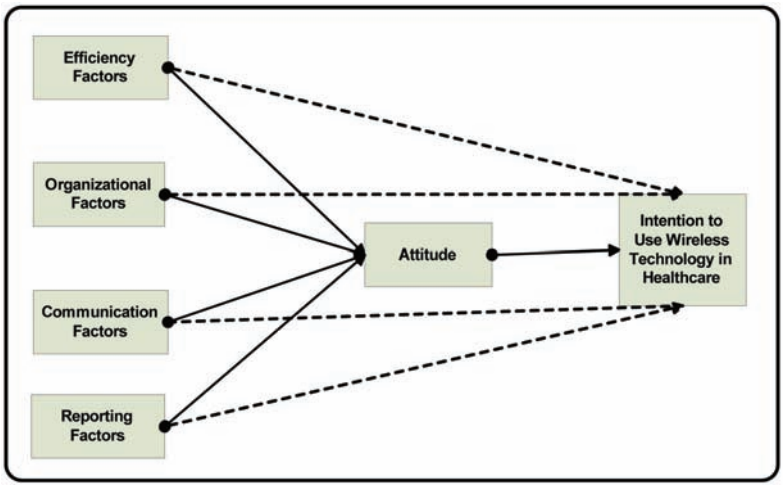

Table 3. Organized facilitators and inhibitors of the adoption of wireless hand held technology (source: the authors)

	Component			
Descriptions	**Efficiency Factors**	**Organizational Factors**	**Communication Factors**	**Reporting Factors**
Reduce-Workload	.785			
Improve-Public-Image	.655			
Improve-Clinical-Performance	.769			
Save-Time	.821			
Save-Effort	.820			
Reduce-Overall-Cost	.747			
Reduce-Medical-Errors	.837			
More-Contact-Time-With-Patients	.840			
Improve-Clinical-Workflow	.941			
Efficiency-In-Communication	.839			
Better-Quality-Of-Service	.882			
Improved-Delivery-Of-Information	.856			
Delivery-Of-High-Quality-Info	.896			
Reduce-Inaccuracies	.836			
Easy-Access-To-Data	.784			
Positive-Impact-On-Patient-Safety	.840			
Solutions Barrier		.671		
System Migration Barrier		.541		
Benefit Evaluation Barrier		.578		
Time For Training Barrier		.564		
Poor Technology Barrier		.644		
Incomplete Health Std Barrier		.777		
Lack Of Support Barrier		.638		
Legal Barriers		.704		
Security As Barrier		.637		
Device Usage Barrier		.606		
Device Comfort Barrier		.554		
Device Access Barrier		.530		
More-Training			-.780	
Tech-Support			-.716	
Electronic Medical Records			.613	
Obtain Lab Results			.641	
Administrative Purpose			.545	
Patient Education			.547	
Communication With Physicians			.633	
Communication With Colleagues			.660	

continued on following page

Tabel 3. continued

Communication With Patients	.524	
Electronic Prescribing		.826
Daily Scheduling Of Appointment		.532
Billing And Accounting		.804
Disease State Management		.749
Generating Exception List		.680
Note Taking		.544
Drug Administration		.563

Australian environment. It is quite clear that the views and opinions mentioned in this study by the healthcare professionals are either through their personal experiences or others' use of the handheld technology on a limited scale.

CONCLUSION

This chapter examined the potential uses and the identified the potential determinants for the adoption of wireless handheld technology in the Australian healthcare setting. Respondents clearly mentioned that there *are* benefits in using wireless handheld technology; but also that there are substantial challenges that need to be addressed before its wider scale adoption in the Australian healthcare environment. While highlighting the challenges faced, this study concludes that the Australian healthcare professional has a positive image about the use of wireless handheld technology and can see substantial benefits if implemented properly with appropriate support being provided. Future research in this domain needs to examine the implications of wireless handheld technology at an organizational level in the healthcare environment, and its adoptability in unique healthcare settings.

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Chapter 20
The Role of Wireless Technology in Addressing Sleeping Disorders in Aged Care

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ABSTRACT

Sleep problems are frequently witnessed in aged care facilities with a large proportion going undetected. Multiple factors are known to contribute many abnormal sleep/wake patterns for residents. A systematic review conducted by Haesler (2004) provided a guide to the direction of future research into sleep in older adults residing in care facilities. This chapter evaluates the effectiveness of implementing the following evidence based recommendation from Haesler (2004): Wrist actigraphy currently represents the most accurate objective sleep assessment tool for use in the population of interest. Factor analysis was utilized to study the patterns of relationship among many dependent variables, with the goal of discovering something about the nature of the independent variables that affect them. Wrist actigraphy showed a disparity between the actual bed time and wake time. One clear difference detected using the device was the increased detection of sleep during the day.

INTRODUCTION

This chapter focuses exclusively on the effectiveness of strategies to assess sleep disturbances and manage sleep in residents of aged care facilities. Research indicates that there are substantial changes to an individual's sleeping cycles as they age. An accelerated decrease in melatonin levels, a hormone implicated to control the body's sleep-wake cycle has been described by some researchers. In addition, there are a number of age-related sleep disorders, such as sleep apnoea syndrome and periodic limb movement, which may be experienced. For older people living in residential aged care facilities, the risk of sleep disturbances may be exacerbated due to a number of reasons. Environmental elements, such as increased light, noise and disruption to sleep by staff and other residents can substantially impact upon the quality and quantity of resident's sleep. The routines typically adhered to aged care

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facilities mean residents spend much time in bed during the day, which has been shown to interfere with circadian rhythms. In addition, residents are often given short-acting hypnotics or long-acting benzodiazepines to manage sleeping difficulties, despite research indicating that these medications may be counter-productive.

In a wrist actigraphy assessment, a monitoring device containing an accelerometer that measures intensity and frequency of body movement, is worn on the subject's non-dominant wrist. Activity is measured in 1-5 second intervals and data are analysed to determine sleep-wake cycles. Some wrist actigraphy devices have the added benefit of recording noise and light levels, enabling the opportunity to concurrently assess sleep patterns and the sleep environment objectively. Wrist actigraphy was found to offer the most accurate objective sleep assessment tool for use with residents of aged care facilities. Wrist actigraphy offers benefits over EEG in that it can be used in a resident's normal sleep environment (as opposed to a sleep laboratory), is noninvasive, more cost-effective and the data are not influenced by brain wave changes associated with dementia. The main issue appears to be compliance, and regular staff checks to ensure the resident is still wearing the wrist device are highly recommended.

This chapter demonstrates that the introduction of wrist actigraphy into a residential aged care environment can improve the detection of sleep problems. Measures collected prospectively using the wrist actigraphy software included: Sleep Efficiency, Total wake time, Percentage of wake, Wake bouts, Total sleep time, Percentage of sleep, and Sleep bouts.

BACKGROUND

The definition of sleep, among many other things, includes 'a period of rest for the body and the mind' (Haesler, 2004). This definition implies that during sleep, bodily functions are temporarily suspended in order to provide rest to limbs and other organs. Other definitions state that sleeping results in 'a natural occurrence having a psychological and physiological function that activate the restorative repair process of the body'. Both definitions indicate that the human body recovers from various abuses during sleep, but it also appears that the nature and purpose of sleep is not completely established. Theories from previous studies suggest that the primary function of sleep is to restore physical organs of the body and to conserve energy. Adam & Oswald (1984), after examining over 100 studies in this domain established that sleeping is restorative. The main findings include the evidence of protein synthesis and its implication on tissue healing after surgery.

Studies have also established that lack of sleep results in irritation, anger, anxiety, weeping, erratic behavior, impaired cognitive processes, lethargy, reduced motivation and decreased pain tolerance (Adam & Oswald, 1984). This appears to be connected with the ability to perform daily activities.

Prior studies provide details of some form of sleeping patterns. It appears that there are two distinct phases of sleep: non rapid-eye movement sleep (NREM) and rapid- eye movement sleep (REM). NREM accounts for about 70% of the sleep and REM the remainder. Due to its regular nature of electrical activity, NREM is also called as synchronous sleep. At this sleep level, minimum mental activity is taking place, tissue renewal appears to be taking place and this sleep is deep. On the other hand REM is active in mental activities such as dreaming and this sleep appears to be impacting the restorative functions of the brain.

Previous studies have also indicated that sleep progresses in cycles of 60 – 90 minutes duration starting with NREM sleep and cycling through REM sleep. With increased age, it appears that the lighter period of sleep increases and the deeper periods of sleep decreases. Some studies state

that the deeper stages of sleep are particularly affected as the ageing process occurs. Sleeping irregularities can of course occur at any time, but they are more noticeable and increasing as ageing occurs. While ageing alone is not a cause for sleeping disorders, it appears that sleeping disorders are pronounced in aged people. Some reasons attributed to this include emotional illness and periodic leg movement syndrome. Disturbed sleep is a common complaint among aged people and can be of short or long term nature. Prior studies also indicate that in aged people length of time taken to get to sleep, ability to stay asleep, early morning wakening and insomnia result in day time fatigue, tiredness, and increased frequency of daytime sleeping. Further, age related physiological factors also contribute to irregularities in sleeping patterns in aged people.

PROBLEMS IN SLEEP CARE RESEARCH IN AGED PEOPLE

Due to the irregular nature of sleeping disorders, it appears that data collection of sleeping time, sleeping quality and other details associated with sleep becomes a complicated issue. Prior studies have introduced many tools to measure sleep pattern including observations, and self-reported time by the subjects. The factors common to many studies in sleep care appear to be sleep pattern timings, day and night awakenings, and level of sleepiness. In many cases, nursing staff and care givers collect data on the irregular patterns of sleep. However, it appears that due to the physical conditions such as nursing care or home environment, differences were noted in terms of sleeping patterns. Further, due to the cost involved, it appears that the data collection exercise becomes very difficult in this irregular sleeping issue.

However, due to the development of frontier technology such as the wireless technology, it appears that sleeping patterns can be monitored remotely. For instance, by installing certain wireless equipment in a patient's bedroom, it may be possible to remotely monitor body movements and then to determine the sleeping pattern. Similarly, using some laser beams, it is possible to determine the movements of a subject while sleeping to derive a sleeping pattern. The strength of these technologies lie in the fact that the sleeping pattern can be monitored remotely, without the need for staff on site.

WIRELESS TECHNOLOGY SOLUTION FOR SLEEPING DISORDERS

Wireless technology includes the concept of mobile computing, which consists of portable devices that can connect to traditional networks without the utilization of cables. Wireless technology provides increased flexibility and mobility to the use of information technology in today's competitive environment. Current aged care systems, due to the increasing costs and due to the complexities in managing the patient data and associated information such as billing and pharmaceutical information, are not functioning at their expected level (Davis, 2002). This can, in turn, compromised the level of service provided to the stakeholder involved. For instance, a patient may have difficulties in accessing pharmacy information and associated benefits provided by the government to different categories of people, as this information doesn't appear to have been integrated with the current hospital systems. In the other hand, it may be difficult for an external doctor to ascertain whether an operation theatre in a hospital is available to schedule an operation as hospital administrative staff maintains the current systems of scheduling. While it is possible to point out that these problems can be sorted out with proper integration and access to systems (Craig & Julta, 2001), it is also possible to argue that the wireless technology will be able to provide better access to data from anywhere at any time.

This notion, it appears, has prompted aged care organizations to consider wireless devices in their overall information technology development.

The need for wireless technology in aged care can be justified as a solution to the financial crisis encountered in many healthcare systems (Davis, 2002), to address the increasingly complex information challenges (Yacano, 2002), to comply with the rigorous regulatory framework (Wisnicki, 2002), to reduce the medication errors (Turisco, 2000) and to generate affordable healthcare applications that allow for greater mobility and ease of use in entering, sending and retrieving data (Athey & Stern, 2002).

While the use of wireless technology can be justified, it should be remembered that wireless technology can not solve all problems encountered in aged care (Wisnicki, 2002). Even though the technology is rapidly improving and cost involved coming down these devices are still experiencing some practical problems. This includes slower speed compared with the desktop computers (Shah, 2001), lack of real time connectivity due to the mobility of the device (Stevenson, 2001), the limited size of the screen and hence the problems that may be encountered in displaying data, little or no provision for high quality graphic display (Atwal, 2001).

In sleep care, wireless technology can be introduced at many points. For instance, it is conceivable to collect sleeping pattern data using wireless technology based on body movements. It is also possible to remotely monitor sleeping patterns of aged people using wireless technology, resulting in cost savings. Emotional illness can be determined using wireless technology by measuring body temperatures etc. In certain cases, it is possible to use Radio Frequency Tags (RF Tags) to communicate body functions to a computer. Aged people can be monitored for various sleeping related problems at their home using wireless technology and this may reduce the burden on nursing care associated with aged people. While the technology provides solutions to some of the sleep disorder issues, legal issues may prohibit the uptake as discussed below.

A systematic review conducted by Haesler (2004) provided a guide to the direction of future research into the effective diagnosis, assessment and management of sleep in older adults residing in high-level care facilities. Haesler recommended the following as future research into the issues surrounding sleep management:

- The effectiveness of diagnostic tools for sleep disturbance or sleep disorders;
- Effective methods by which resident satisfaction with sleep can be measured, and consideration of resident satisfaction in studies investigating the effectiveness of sleep promotion interventions;
- The validity, reliability and acceptability of long-term wrist actigraphy assessment;
- The most effective time-frame over which behavioral observations should be made to provide an accurate reflection of sleep patterns;
- The long-term sustainability of improvements to sleep from reduction of disruptive night-time nursing care; the long-term effects on skin condition when night-time pressure area care is reduced; the most effective continence aids to use in conjunction with a decrease in night-time care attendance; and residents' acceptance of reduced night-time nursing attendance;
- The effect of aromatherapy on sleep, including the most effective essential oil preparations and administration techniques;
- The effect of bright light therapy on residents with varying types of cognitive impairment, and the effect of the therapy on residents without cognitive impairment, including clarification of issues surrounding the most effective timing, duration and length of therapy sessions; investigation into the feasibility, acceptability and

cost-effectiveness of various light administration techniques;
- The effect on sleep of commonly used sleep promotion strategies including massage, warm baths, music therapy and social activity;
- The effect of melatonin on sleep when used over longer time frames using controlled trials;
- The most effective interventions to incorporate into individualized, multidisciplinary sleep promotion plans;
- The effectiveness of specific medications in the promotion of sleep, and the most effective regimes by which to reduce medication use although not impacting on residents' satisfaction with sleep.

MAIN FOCUS OF THE CHAPTER

It is clear through the results found within this research that wrist actigraphy does have a place in monitoring the sleep of residents in residential aged care. As wrist actigraphy was able to show a significant disparity between the actual bed time and wake time when compared to observational forms of sleep assessment the first clear benefit is the degree of accuracy that this device has over existing assessment methods. Current forms of sleep assessment showed residents to have a higher sleep efficiency when compared to the results of wrist actigraphy. This meant that staffs were of the belief that residents were getting a better quality of sleep than was actually the case. Wrist actigraphy was able to show that the true sleep efficiency on average for each resident was significantly lower than originally depicted. An interesting finding however was that current forms of sleep assessment showed on average a smaller total sleep time when compared to wrist actigraphy. This meant that residents were actually getting a greater total sleep time than was actually being depicted however the quality of sleep was actually quite poor. This meant that there were several undetected factors that were contributing to sleep deprivation within this population that remained undetected.

Night time waking was also a clear difference with a definite increase in night time waking based on wrist actigraphy data. On average residents were waking 75% more often when wrist actigraphy was used as decision making. With further analysis of identified factors it was very clear that known sleep disorders had a definite link to an increase in night time arousals when analyzing wrist actigraphy data. This was not clear when compared to sleep form data. Where night lights where in place with residents there also was a strong link with increased arousals or wake time using wrist actigraphy. This again was not as clear with the sleep assessment data.

LEGAL ISSUES

There are 10 areas of wireless technology specific to aged care that may be impacted by national privacy principles in many countries. These are: collection of data, use and disclosure, data quality, openness, access and correction, identifiers, anonymity, trans-border data flow, data security and sensitive information. These are discussed below in detail:

Collection of Data

According to privacy laws, an organization can collect data only for the purpose and should be 'fair' in the way in which the data is collected. An organization should identify itself to the person from whom the data is collected and can collect personal information 'directly' where practicable. Further the national privacy regulations also state that if the information is collected from someone else about a person, then the involved parties need to be notified. This opens up some new legal challenges in the wireless technology domain.

When the data passes through wireless networks, it goes through many service providers and it is difficult to apply national privacy regulation at this point, as some networks may be 'transparent'. Further, when security breaches occur on the wireless networks, the data become visible to all parties involved and this introduces risks in data handling.

Use and Disclosure

The privacy principle states that an organization can use and disclose information as per the expectations of the user. When it comes to wireless technology, the user may not have any awareness of the potential of the technology and hence the expectation may not be valid as the user has no comprehension of the technology. Therefore, organizations may find it difficult to perform certain functions that are capable of using the technology. Further, in certain conditions, it may be difficult to prevent the disclosure of the user information because of the technical limitations. During these instances, organizations may fail to comply with this principle.

Data Quality

National laws state that an organization must ensure that the data collection process is accurate and the collected data accurately reflects the purpose. While this is theoretically possible, in wireless technology, if the device is not calibrated properly, then inaccuracies may be introduced in the data collection exercise. If the wireless device is manufactured by an overseas company, then due to contractual issues, it may not be possible to accurately caliber the device as often as an organization would like to do so. This lack of frequent calibration would result in poor data quality.

Openness

The Australian privacy laws for example state that organizations must set out clearly how personal information will be managed. When this concept is applied to the wireless technology, there may be issues associated with data storage, where the data is stored, how this is stored etc. When this reaches the vandals, sensitive information is at risk. Further, it is not clear whether the policies should cover the data transfer procedures as well. A major complication that may arise in a wireless domain is due to the transmission of data through various service providers. When the data is sent across different wireless networks, the control information such as the type of encryption used will be stripped from the data for 'transfer' from one network service provider to another to ensure Quality of Service (QoS). At this time, anybody having access to these networks will be able to see the data as transmitted in its raw form. This process is generally termed as the 'WAPGAP' or the Wireless Application Protocol Gap. So, openness, when interpreted in technical terms, can create problems for organizations.

Access and Correction

As per the privacy laws, individuals can have access to their personal information, wherever possible. While this concept is easy to comprehend in theoretical terms, in terms of implementation this introduces some difficulties. For instance, medical records need to be maintained for longer period of time and cannot be destroyed due to the sensitive nature of the data. In the case of aged care, it may so happen that a patient can access their data and interpret a treatment in an adverse manner. In certain instances, care providers may be limited by the facilities available at the time of providing the care and this can be interpreted in an adverse manner by patients and their families. Further, the physical condition of a patient may prevent a care provider to avoid certain

procedures. Any such documented information, accessed by stakeholders, may result in a legal procedure. When this happens, organizations need to bear the cost of defending their actions. Further, in some cases, presenting the data and other evidence may require expensive and time consuming processes. When organizations are found guilty, the correction of medical records may also result in bad publicity.

Identifiers

National privacy principle states that an organization must not use its own identifiers in certain conditions. In physical environment it is possible to do achieve this aim when sensitive data is collected as organizations may be able to hire an external agency to perform the data collection exercises for them. However, when technology such as wireless is used, it may not always be possible to hide the 'identifier' information as national regulations (Communication Authorities) warrant the disclosure of identification for data communication. Therefore, it may not be possible to 'hide' the identity of an organization in a wireless domain.

Anonymity

National privacy principle states that in certain cases individuals have the option of concealing their identity when entering into transactions with organizations. While the concept is valid, in certain specific cases, there may be management problems. When wireless technology is used for communication purposes in the aged care sector, the individual identity is automatically revealed for communication purposes. Therefore, for the technology to be enabled identification is essential. Therefore, concealing identification may not be possible in a technical communication using wireless technology as this identification is essential to pass data between networks and send responses to the originator. Email messages from doctors to pharmacists must have identification for action and hence the concept of anonymity may be difficult to implement in certain specific conditions using the wireless technology.

Trans-Border Data Flow

The privacy principle states that an organization can transfer data pertaining to a patient only under specific conditions, especially when it involves a foreign country. The concept of wireless technology is to support anywhere, anytime and anyhow access to data and messages. When the data transfer occurs in a wireless domain, it is difficult ensure that standards maintained by a service provider in a country are compatible with standards maintained y another service provider in a different country. This includes record keeping standards, procedures, certification associated with the industry practice, technology standards and a range of other issues associated with these. In addition, when things go wrong due to technical issues, it may be difficult to enforce certain conditions as technology implementation differs in many countries. Therefore, trans-border data flow is a complicated issue when technology is involved.

Data Security

In wireless technology multiple security level standards are available. Therefore, data security depends upon the security sophistication of an organization. Further, there is no guarantee that two service providers facilitating wireless services will maintain the same level of security protocols. Therefore, it is difficult to guarantee standards for data security.

Sensitive Information

Privacy principles state that an organization must only collect sensitive information in certain specified conditions. While this is applicable to a

condition where human intervention is allowed, this is not possible when technology is involved as current technology has not yet reached the level of understanding human feelings to the expected level. Further, in certain specified conditions, technology may react differently. For example, in extreme heat temperatures, wireless technology may fail. In certain electro-magnetic induction fields, wireless may not perform well. Therefore, collection of sensitive data may not work well in wireless technology domain. Further, when the sensitive information is linked with privacy principles, any ignorant disclosure of the collected data may result in an adverse reaction.

SOLUTIONS AND RECOMMENDATIONS

Wrist actigraphy should be adopted as a standard sleep assessment tool in aged care residential facilities. This device will lead to a greater detection of sleep issues and will more effectively allow aged care clinicians to measure intervention outcomes. Written sleep assessment forms should be reserved for residents that do not tolerate wrist actigraphy or where the wrist actigraphy has been ineffective due to excessive limb movements. During the course of this research residents that suffer from diseases such as Parkinsons may not benefit from wrist actigraphy.

Sleep hygiene history should be regularly taken and updated to complement to wrist actigraphy recordings. The sleep hygiene factors a paramount in determining contributing factors towards recognized sleep disturbance.

Further research needs to be conducted on the methods used for data collection in these contexts. A wireless interface for example would allow multiple assessments at one time. Currently it is a limitation that only one resident can be measured at a time. The introduction of pulse oximetry to compliment the wrist actrigraphy may also be beneficial as this would add to the data and potential help pin point actual sleep disorders.

CONCLUSION

Clearly the results show positive links between listed sleep hygiene factors and increasing arousals. The sleep assessment form, although still a valuable tool in aged care settings does demonstrate some gaps. It shows great value in detailing sleep hygiene factors, however would not appear to be able to accurately measure a change to sleep patterns that may result as a direct consequence. On the other hand wrist actigraphy, although not an accurate measurement of sleep quality, is able to demonstrate any distinct changes to the sleep cycle which will be valuable where interventions require pre and post measures. Wrist actigraphy would appear to have many benefits over the visual observation form.

One key factor is the reduction in nursing hours required to do the sleep assessment. This frees nursing time for other duties while also being very cost effective. Wrist actigraphy while in place is also constantly measuring the sleep-wake time of the resident at regular intervals of less than 1 minute versus the 1 hour visual observations of the nurse. The results clearly show a clear difference in accuracy of many factors. Particularly concerning are the number of missed arousals, the decreased detection of total sleep time, decreased detection of total wake time, and the greater sleep efficiency detected by visual sleep assessments. In the current climate of residential aged care facilities these research findings would suggest that clinicians are using poor data for decision making. One can only assume that this has and would lead to inadequate or inappropriate interventions to assist the resident.

This chapter has discussed the role of wireless technology in sleep research specific to aged care. While it is possible to apply wireless technology to address some problems encountered in this area,

the assessment specific to legal issues indicates that due to privacy principles organizations engaged in providing aged care should consider the introduction of this technology with caution.

FUTURE RESEARCH DIRECTIONS

This chapter provides a technology solution to monitor sleep disorders among aged people. While the paper merely highlighted how wireless wrist actigraphy can help in the tracking and monitoring of sleep patterns, any future research should focus on issues such as the effectiveness of diagnostic tools using wireless technology for sleep disturbance or sleep disorders as this is not well covered in the literature. Wrist actigraphy can only provide an alert to potential issues. Effective methods of including wireless technology in sleep disorder studies in order to measure satisfaction with sleep, and consideration of satisfaction in studies investigating the effectiveness of sleep promotion interventions need further investigation. The validity, reliability and acceptability of long-term assessment of wireless technology in aged care needs further consideration as many studies appear to have ignored this component in their haste to provide 'urgent' solutions. The most effective time-frame over which behavioral observations should be made to provide an accurate reflection of sleep patterns using wireless technology needs further clarification through research. Issues such as tolerance to the device and the long-term on skin condition when night-time pressure area care is reduced require consideration.

Future research should include a wireless interface that would allow multiple assessments at one time. This is a current limitation as only one resident can be measured at a time. In the future it would be possible for this device to have multiple functions. It may be possible for it to monitor those in high risk categories e.g. heart conditions, respiratory conditions, and obesity. Complimentary measures such as pulse rate, oximetry, and body mass index measures will make this possible. The device itself needs to be improved with both hardware and software capacity in order for this to happen.

Actigraphy algorithms may provide a reasonably accurate estimation of sleep and wakefulness in normal subjects and patients with obstructive sleep apnea on an epoch-by-epoch basis. This simple method for assessment of total sleep time may provide a useful tool for the accurate quantification of obstructive sleep apnea in the residential and home environments. The sources of data outside of the wrist actigraphy device also requires further investigation to assist in decision making without going for formal polysomnography which would require resident travel, sleep hygiene measures, and patient history data.

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KEY TERMS AND DEFINITIONS

Behavioural Observation: Although commonly used to assess resident sleep, numerous researchers have questioned the validity of behavioural observation. As described in many cohort trials, the sleep of older nursing home residents, particularly those with dementia, is punctuated by regular interruptions and it is questionable whether 1–2 hourly observations by nursing staff are sensitive to episodic night wakening.

Percentage of Sleep: Percent of total sleep time in a 24hr period

Percentage of Wake: Percent of total wake time in a 24hr period

Polysomnography: Polysomnography (PSG) is described as the traditional gold standard in sleep assessment. which consists of wiring patients with electroencephalogram (EEG), electroculogram (EOG) and electromyogram (EMG) electrodes, provides readings of brain and muscle activity that is interpreted by trained technologists to provide a record of sleep–wake activity. General consensus maintains that PSG provides the best assessment of sleep; however, this method may be impractical and invalid when used on elderly subjects and those with dementia.

Sleep Bouts: The total number of sleep episodes

Sleep Efficiency: Quality periods of sleep.

Subjective Assessment Tools: Written assessment tools that require documentation at regular intervals based on observation.

Total Wake Time and Total Sleep Time: Total time a person has been awake or asleep within a 24hr period.

Wake Bouts: Total number of wake episodes.

Wrist Actigraphy: Wrist actigraphy assessment requires a monitoring device containing an accelerometer that measures intensity and frequency of body movement to be worn on the non-dominant wrist of the subject. Activity is measured in 1–5 s intervals that are recorded as sum activity level and maximum activity level in 1–2 min intervals. Data are analysed to determine sleep–wake status based on recorded activity levels. Some wrist actigraph devices are designed to record noise and light levels, offering the ability to concurrently assess sleep patterns and the sleep environment in an objective manner. Wrist activity devices have been reported as having 89–95% agreement in sleep–wake status with EEG in both old and young populations.

Chapter 21
Development of an Online Sleep Diary

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ABSTRACT

Sleep disorders causing excessive daytime sleepiness are estimated to affect six percent of the population and has traditionally been under diagnosed. Sleep disorders symptoms may lead to an increased likelihood of suffering work and vehicle related accidents as well as affecting the physical and mental well being of the sufferer. A sleep diary documenting sleep hygiene habits over a period of time is an important tool in the diagnoses of sleep disorders. This project was to develop an online sleep diary, bringing benefits of presenting the information earlier to the physician in a format which allows the quick assimilation of information from the diary. The information is also in an electronic format facilitating the transmission to an electronic health record and the building of a database of sleep patterns. An online sleep diary allows a patient to self-monitor their condition allowing them to assess treatment and lifestyle changes on sleep patterns.

INTRODUCTION

This project is to implement an online sleep diary, a sleep diary is used to record sleep patterns usually for fourteen nights. The person notes the parameters of their nights sleep day-by-day building up a picture of sleep habits known as sleep hygiene. A sleep diary is used by a number of health professionals, including psychologists, physicians and sleep specialists and is the primary diagnostic tool for insomnia and an aid to the diagnosis of other sleep disorders. An online sleep diary has a number of benefits; the data contained within the diary is presented in a summarized readily accessible format available in real time, while building a database of sleep patterns. This Chapter will discuss the importance of sleep, sleep hygiene, the construction of the online diary and its importance.

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THE IMPORTANCE OF SLEEP

Sleep pattern disturbances are common in adult populations. Access Economics Pty Limited (2004) estimated that six percent of the Australian population experience a sleep disorder but only twenty per cent of those affected by sleep disorders are diagnosed. In a study carried out in the United Kingdom on a sample of 2000 patients by Groeger et al (2004) it was found that 58% of respondents reported sleep problems during the previous fortnight, with 18% stating that the sleep they received was insufficient on the majority of nights. Other international studies state sleep disruptions may occur in ten to thirty five per cent of the population (Foresman, 2000; Groeger et al, 2004; Morin et al, 1999; Ohayon & Partinen, 2002). For between 3.2 and 5.5 percent of the population these sleep disruptions result in the problem of excessive day time sleepiness (Akerstedt & Nilsson, 2003; Engleman et al, 1997).

In the Groeger et al (2004) study those respondents which reported that they had gained sufficient sleep believed they had more energy, life satisfaction and success than those not gaining sufficient sleep. The sleep patterns of healthy people aged between 20 and 50 years were studied; 266 respondents filling in a sleep diary for two weeks. The study found that the average time in bed was seven hours 35 minutes during the week and eight hours two minutes in the weekends with no significant gender differences. This relatively small difference between time in bed on weeknights and weekends showed that there was only a slight sleep deficient. Average sleep latency was 10.5 minutes with an average of one awakening per night. Sleep deprivation causes a sleep deficient, this deficit is reduced by sleeping longer than normal, perhaps during days off work. These normal sleep patterns can be contrasted with the sleep patterns of those people with a sleep disorder who have a larger sleep deficit. The sleep diary of these people may show they wake more often for longer and have shorter sleep latency (Arand, 2006).

McFadyen et al (2001) found that Obstructive Sleep Apnea (OSA) patients and partners reported increased material satisfaction as the result of compliant treatment of Continuous Positive Airways Pressure (CPAP). Treatment of narcolepsy, which is a sleep disorder characterized by excessive daytime sleepiness and abnormal rapid eye movement sleep patterns (Billiard, 2007) can be made by using drugs (Niederhofer, 2006), whereas treatment for a disorder such as insomnia may be undertaken using psychology (Morin et al, 1999). The most common sleep disorder is OSA (Access Economics Pty Limited, 2004; Foresman, 2000; Kramer et al 1999; Mulgrew et al, 2007; Young et al, 2002) and the most common treatment for this is by CPAP (Hsu & Lo, 2003; Young et al, 2002). CPAP works by holding open the upper airway during sleep with continuous flow of air preventing collapse and therefore sleep apnea this allows refreshing sleep to occur (Hsu & Lo, 2003).

When a patient is suspected of having a sleep disorder by a primary care physician they may be referred to a Sleep Investigation Unit (SIU). A study by Kramer et al. (1999) found that primary care physicians may under diagnose sleep disorders. They found that the majority of patients referred to a SIU did have OSA, however the percentage of patients referred to a SIU was very small at 0.13 per cent with all patients referred being very symptomatic. This study suggests that support may be necessary for primary care physicians to recognize patients at risk of having a moderate sleep disorder, as well as those at severe risk.

The Boston Consulting Group (2003) believe that sleep is under represented as a health priority, but note that to increase awareness of the importance of restorative sleep and sleep disorders a education program is necessary for the public and for general practitioners. However, as awareness of sleep disorders increases it is likely that there will be a shortage of sleep specialists. If there is a shortage, the sleep specialist's ability to see patients will need to be maximized, and general

practitioners may provide an alternate avenue for the initial treatment of sleep disorders if given support.

Costs of Sleep Disorders

The Boston Consulting Group (2003: 7) report on a national sleep health agenda for Australia reports that the estimated cost of sleep disorders to the Australian society is within the range of three to seven billion dollars a year. These costs include co-morbidities, lost production, transport and workplace accidents and social costs, such as learning difficulties. The amount and quality of sleep also has an effect on how quality of life is perceived, with excessive daytime sleepiness associated with depression and lack of concentration (Groeger et al, 2004). Physically, sleep deprivation may be associated with an increased risk of myocardial infraction (heart attack), type two diabetes and depressed immune response (Akerstedt & Nilsson, 2003).

The term *sleep disorders* describes conditions of which the most common are OSA, narcolepsy, periodic limb movement disorder, idiopathic hypersomnia insomnia, parasomnias such as sleep walking or sleep talking and shift work syndrome (Access Economics Pty Limited, 2004; Douglas, 2001; Johns, 1991). The primary symptom of sleep disorders is excessive daytime sleepiness which may be accompanied by diminished alertness and inability to concentrate on tasks (George, 2001). Excessive daytime sleepiness is when there is an increased predisposition to falling asleep during daytime activity such as sitting and reading or sitting in a public place (Hossain et al., 2005).

Effects of Sleep Disorders

The point at which the excessive daytime sleepiness becomes a problem is when the person suffering from the sleep disorder is more susceptible to adverse consequences from carrying out day to day activities such as driving or performing work related tasks (Sangal, 2006). Dawson and Reid (1997) compared sleeplessness with alcohol use and found that after seventeen hours of wake time the ability to perform a cognitive psychomotor activity performance decreased to the equivalent level of a blood alcohol reading of 0.05. This means that sleepiness is an important contributing factor for driving and work related injuries (George, 2004; Terán-Santos et al, 1999). Johns and Hocking (1997) state that between 16 to 20 per cent of motor vehicle accidents on Australian highways can be attributed to driver sleepiness. Treatment of sleep disorders which eliminates the excessive day time sleepiness returns cognitive psychomotor performance to normal levels (George, 2001), thus reducing the risk of driving and work related incidents to average levels (Ellen et al., 2006; George, 2001; Hsu & Lo, 2003; Yoshino et al., 2006). Douglas (2001) states that everyone who finds that excessive daytime sleepiness causes impairment of work or driving skills or reports a propensity to sleep measured on the *Epworth Sleepiness Scale* of higher than 12 despite having more than seven hours of sleep a night needs an investigation into the cause of the sleepiness.

Sleep Hygiene

Good sleep hygiene helps to ensure good quality sleep. The guideline for good sleep quality comprise having a consistent sleep and wake times, avoiding caffeine, nicotine and alcohol before bedtime, avoiding heavy meals close to bedtime, exercise and sleeping in a darkened quiet room (Stepanski & Wyatt, 2003; The Boston Consulting Group, 2003:6). People who do not follow the sleep hygiene guidelines tend toward having poorer quality sleep, with the degrading of sleep quality being dependent upon the guideline not followed (Stepanski & Wyatt, 2003:223). Brown et al (2002) found that increasing awareness of sleep hygiene through education did impact favorably on the sleep quality of healthy university students,

with Bootzin & Stevens (2005) describing the regularizing of sleep patterns as a powerful means of increasing sleep quality. However the following of good sleep hygiene rules in the presence of a sleep disorder such as insomnia is not enough on its own to remove excessive daytime sleepiness (Stepanski & Wyatt, 2003).

The sleep hygiene of a person is determined by looking at sleep patterns over a two week period, documented in a sleep diary filled in every day. These sleep patterns are expressed for a health professional in a number of standard sleep measures, described in the development of the online sleep diary section. Lifestyle factors such as caffeine and medication use may also be included in a sleep diary, along with indicators of mood on awakening. Better quality sleep information is obtained when a sleep diary is filled out every day. This ensures that the person has the best recall of sleep quality and timing of sleep. In this regard Libman et al (2000) state that a questionnaires looking at respective sleep patterns are susceptible to memory distortion, whereas a sleep diary filled in every day has the ability to capture day to day variations; highlighting variations that may indicate problems such as sleep deficits in sleep patterns. This means that a sleep diary gives a baseline of a person's sleep patterns. In the online sleep diary the user is able to enter the date of the sleep event, however the entry is also date and time stamped to give the physician a guideline to the quality of the sleep information contained in the diary. The disadvantage of a sleep diary is that a person may change their sleep patterns in reaction to the self-monitoring and the imposition of filling in the diary day to day (Libman et al, 2000). However Lacks & Morin (1992) comment that a sleep diary is the most widely used, practical and economical method of gauging sleep patterns.

THE BENEFITS OF A SLEEP DIARY

The benefit of a sleep diary is that it provides a tool to gather the details of sleep patterns using a range of easily understood questions in a simple format. While the gathering of day to day information requires commitment from the patient, the information gathered provides an insight into the patient's lifestyle and sleep habits. This information may allow a physician to suggest lifestyle changes, for instance lowering caffeine intake to reduce sleep disorder symptoms. Another benefit of a sleep diary is that it is less intrusive than a retrospective sleep questionnaire the patient fills in at a clinic. The patient does not need to leave their home and entries can be made as soon as the patient arises if they wish.

The depiction of day to day sleep patterns may also suggest a co-morbid sleep disorder, such as insomnia coupled with OSA. The existence of a co-morbid sleep conditions typically worsens symptoms, this condition occurring in 8 per cent to 43 per cent in older patients of OSA (Smith et al, 2004). The use of a sleep diary allows the physician to diagnose the co-morbid condition and treat the insomnia before treating the OSA, potentially reducing the patient's symptoms to a level where the need for CPAP treatment may be removed.

The Benefits of an Online Sleep Diary

Current practice is that the sleep diary consists of a printed form which the patients fill in sleep information every day. The data contained in the printed sleep diary requires manual calculation to extract the required sleep statistics and is in a format that difficult to quickly assimilate within a consultation and in consequence may not be used effectively. A paper based sleep diary also does not present information in a format that the lay

person can understand. This means that the patient does not have an opportunity to self-monitor their sleep patterns and perform functional analysis of lifestyle changes such as reducing caffeine intake.

An online diary used in a sleep clinic setting has the ability to bring forward information gathering on a patient's sleep hygiene to before a patient's first appointment with a sleep physician. The benefit of this is that there can be a substantial waiting time for an appointment with a sleep physician due to the increasing burden of the disease. Access to an increased amount of patient knowledge early in the patient physician interaction means the physician can better assess the urgency of a patient's need for services. Another benefit to early patient information is that a recommendation that the patient see another health professional during the wait time can be made. For instance a sleep diary coupled with a physician's assessment is the primary diagnostic tool for insomnia (Lacks & Morin, 1992; Morin et al, 1999), so that the sleep physician may be able to recommend the patient visits a psychologist for help with insomnia without the need for an extended physical appointment. This means that the patient is spared an extended wait for service potentially increasing his satisfaction with the service provided and the physician has increased time to see other patients. The provision of increased patient knowledge at the first consultation means that the physician has the opportunity to talk to the patient about their specific sleep hygiene practices during the first consultation making the consultation patient centered rather than general.

The online sleep diary will produce a summary report which may be printed both for the person filling in the diary and a physician. This gives the physician quick and accessible access to information extracted from the sleep diary in a format which has direct utility for assistance in a diagnosis of a sleep disorder. The summary report may also be filed in a patient record to provide a baseline for future sleep diary reports. The facility to export the data contained in the online sleep diary in an eXtensible Markup Language (XML) format will also be provided. This means that organisations other than that hosting the sleep diary can receive patient data in an electronic format. The patient also has access to the information on their sleep patterns presented in a simple graphical format.

Thus patients gain a tool to use in self monitoring their sleep patterns. Wilde and Garvin (2007:343) defines self monitoring as awareness of symptoms that is facilitated by periodic measurements or recordings to provide information for improved self-management. The use of the online sleep diary to self-monitor means that the patients have an opportunity for shared decision making on the management of their sleep disorder with their physician. Vermeire & Hearnshaw (2001) found that shared decision making is an important factor in compliance to treatment, this is important as compliance to CPAP requires commitment from the user.

ONLINE TOOLS USED FOR DEVELOPMENT

An online sleep diary gives the form designer control over the order the form is filled in and an opening to conduct validation of the entered data. Using validation in the sleep diary means that the physician does not need to question the patient about the data contained in the sleep diary, but may accept that the sleep statistics reflect the sleep patterns of the patient. Once the sleep diary is developed each repetition of the form is cost effective, allowing large numbers of respondents or many repeated iterations of the form to be filled in. As the data is captured, automatically stored and may be manipulated by the online form, data analysis is low cost and happens in real time for each form (Wyatt, 2000). The automatic storage of data, gives an opportunity to collect good quality validated data for future research.

In the 2005 to 2006 period 60 per cent of homes had home internet access, which had increased by four per cent from the previous period, with 66 per cent of Australians accessing the internet from any site (Australian Bureau of Statistics, 2006). The percentage of home internet user's show that online forms are a viable alternative to paper based forms for a large proportion of the population. Patients will be asked to complete the sleep diary online on a computer at their home, if this is not available then a machine with the sleep diary application will be made available in the waiting room of the sleep investigation unit, also a free help line will be available so that patients may talk to a sleep investigation unit staff member and as a last resort a paper and pen version of the tools will be made available. The items are answered using the mouse to click on a graphical Likert-like response scale or pick a value from a list, no typing is required.

One of the difficulties of an online IT system is the need to design the system for an unknown user. Users of an online system will access the system through a wide variety of connection mechanisms, with a wide variety of hardware and technical skill levels. This compares to the development of an organizational system development with standardized connection, hardware and a known minimum technical standard (Taylor et al, 2003). Usability must be a primary objective of an online tool, with Guenther (2004) stating that have a clear set of objectives for the user helps to make the online system high value. This project has two different sets of users, physicians and patients, so the online tool has to meet two different sets of objectives and expectations. Calongne (2001) adds that what the user wants to achieve from the site must also be considered. In this project the online systems are tools so that to achieve user satisfaction the online tools must look and feel like a solid health orientated implement. In the patient's case the tool needs to feel like a device that will provide good information to themselves and the physician, while in the physicians case the tool should provide a set of quality information in an easy to assimilate format.

To display information online, equity of access must be considered so that online tools have utility for the sight, hearing and physical impaired, users with little technical expertise must also be catered for. Williams (2000) has listed a number of guidelines to assist in this endeavor, making sure visual elements are large enough to be seen and deciphered is one guideline. He suggests that using elements that contrast highly with the background such as black elements on a white background assists. An uncluttered web page without too many elements claiming attention helps the user to make sense of the page, also using graphics only when necessary to illustrate or add to the site's function (Guenther, 2004; Williams, 2000). The expected age range of the patients is fairly broad and computer literacy is variable. Most of the potential patients are greater than 45 years old and reasonably computer literate but to improve equity of access the sleep diary must be as accessible as possible across the whole spectrum of potential patients.

In the sleep diary interface we have used maximum contrast of black text on a plain white background, with a sans serif font and an uncluttered background. The uncluttered background means that the sleep diary can be personalized with for example an organisations logo without disturbing the readability of the questions. This also means that those patients with slow download speeds are not penalised by the wait for a graphic to download. A user tries to make logical sense of the web page displayed at first glance, so that the design of the page must make logical sense, for instance headings are in the larger font. Design elements which are related need to be gathered together graphically, for example a question is contained within a boarder, with the graphical treatment of these elements consistent and predictable throughout the web site (Williams, 2000). A linear web site plan also helps to orientate the user so that they are aware of where in the web site they are (Guenther, 2004; Williams, 2000).

The heuristic evaluation rules for websites detailed by Sharp et al (2007) were employed. The website has internal consistency, with phases carrying the same meaning throughout the web site with simple dialog. To aid internal consistency, formatting of pages fonts, font sizes and font colors are consistent. Shortcuts have not been used, as the sleep diary has a simple linear format which must be followed to gather complete information. The user's memory load is minimized with no information being required to be remembered from one part of the web dialog to the other. Validation will exist within the web forms so that for example a wake time before a sleep time can not be chosen, validation will also check each page for completeness. The feedback from the sleep diary is the presentation of the sleep pattern graphic representing sleep patterns. To give the sleep diary internal locus of control a sleep day with incomplete data will be discarded.

DEVELOPMENT OF THE SLEEP DIARY

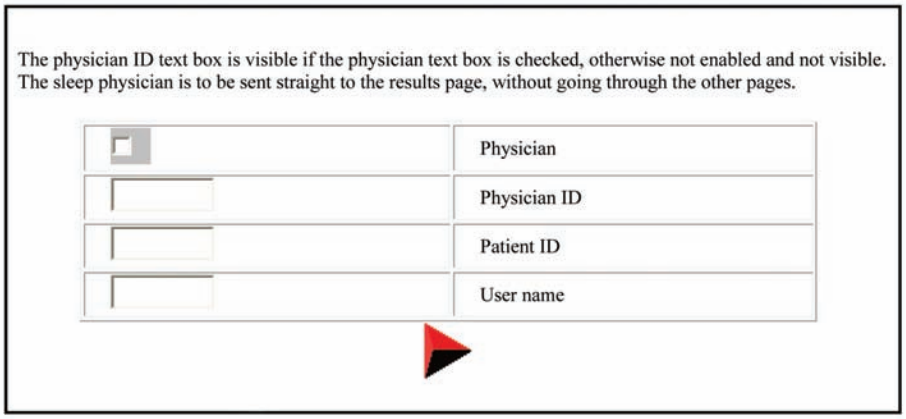
The online sleep diary requirements were developed by using semi- structured interviews with the director of the Sleep Investigation Unit in Prince Charles Hospital, Brisbane, Australia and a review of existing sleep diaries. A requirements document with the specifications of the new system detailed using Unified Modeling Language (UML) with an object oriented approach was produced. Using this document as a template a paper prototype was produced for approval, by the director of the sleep clinic. The suggested changes were then incorporated in a non-functional prototype built in Hypertext Markup Language (HTML) and Javascript. This prototype was placed online and comments requested from the directors of sleep clinic's or sleep researchers, two in Australian, one in New Zealand and one in United Kingdom. The suggested changes were detailed and the online sleep diary sent for coding by an external software development house. The online sleep diary is at this stage currently and will be implemented as a trial in an external server to maintain independence. The first one hundred users to fill in an online diary will be asked to complete a short online questionnaire about the utility of the sleep diary, with those choosing a paper based sleep diary receiving the same questionnaire. These questionnaires will be used as a tool to validate the online sleep diary.

Screen shots of the online sleep diary prototype are used in this section. The entry page of the online sleep diary shown in Figure 1 is a log on page providing the facility to differentiate between physicians and patients and the means to authenticate users through the use of a identification number and user name. Differentiating between physicians and patients is important to customize their interaction with the web site. To facilitate the physician's use of the tool the physician goes directly from log on to the sleep statistic page for the entered patient number. The patient will be taken to the next page of their current sleep diary, so that they may continue to complete their sleep diary. The consent page shown in Figure 2 is required in order that the online sleep diary fulfils the function of a data collection point. Anecdotal evidence suggests that data entry of the data requires a large time commitment from clinic staff to manually compute the data contained in a paper based sleep diary, and is unlikely to be given a priority outside of a specific research project, hence aggregation data is not available. The ease of electronic data collection facilitates the aggregation of data to provide an evidence base of sleep patterns for future research.

Online Sleep Diary

The bed time page shown in Figure 3 requires the user to pick from a drop down box, the time they went to bed, the time they settled for sleep and an estimate of how long it took them to go to sleep. Bootzin (2005) suggests that for good sleep hygiene a minimum amount of time is spent in bed before settling to sleep, no longer than ten

Figure 1. Log on screen



minutes. This is so that bed time is associated with dropping off to sleep quickly. Sleep on-set latency is the amount of time between the person settling for sleep, for example turning of the light and the time when sleep occurred. People with insomnia tend to overestimate sleep latency while people without insomnia tend toward estimating the correct amount of time taken to fall asleep (Smith & Trinder, 2000). Sleep latency is used as an indicator of a sleep disorder. A short sleep latency time indicates a sleep deficit, while a long sleep latency time may indicate insomnia.

The wake time web page is shown in Figure 4; the four values shown there form part of the sleep statistics used by sleep physicians to confirm a diagnosis. The subtraction of the time the user got up from bed from the time they went to bed gives the time available for sleep. To produce a value of the total sleep period the time value of sleep latency, the time finally woken up and the time spent awake through the night is subtracted from the time the user settles to sleep. Total sleep time is the total sleep period less the time spent awake. Total wake time is the addition of wake

Figure 2. Consent page

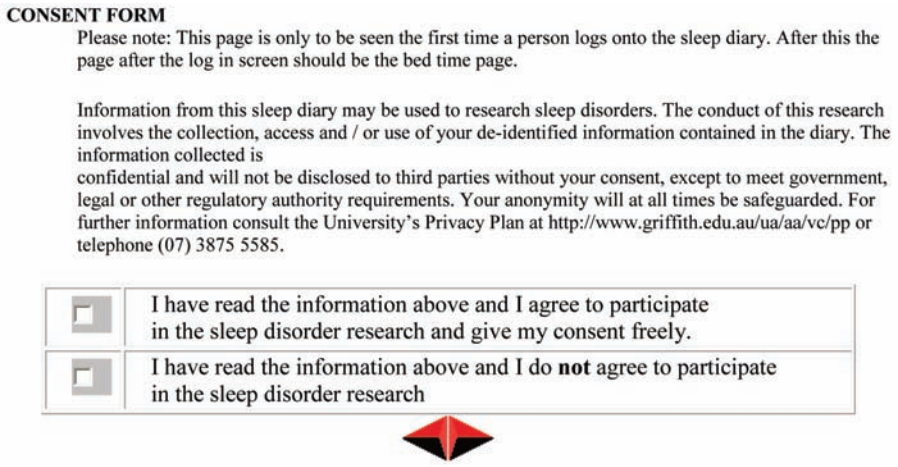
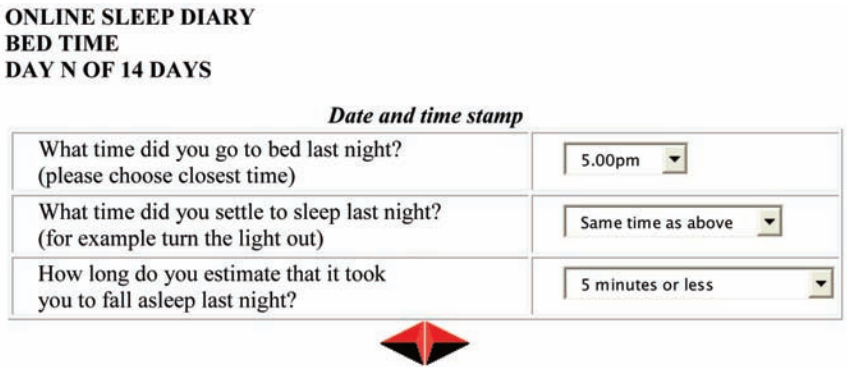


Figure 3. Bed time page



time during the period available for sleep. Sleep efficiency is a percentage measure of the total sleep period divided by the total sleep time.

Figure 5 is the sleep quality page and provides explanations for wakefulness through the night, perhaps some of the symptoms of excessive daytime sleepiness can be attributed to the sleep environment or small children. This allows the physician make suggestions to improve sleep quality. This page also provides an insight opportunity for the user, for example if they are checking woken by light mostly, or thinking about things is keeping them awake. In this case they have an opportunity to ask the sleep physician what they can adjust to change the waking pattern. If choking or suffocating is checked as a reason for waking then a pop-up page asking how long the feeling persisted and whether accompanying feelings such as breathlessness, heartburn or wheezing exists. This information aids the physician in diagnosing the reason for the feeling of choking or suffocating.

Lack of refreshing sleep and excessive daytime sleepiness can manifest itself as a feeling of irritability and apathy, and is an indicator if excessive daytime sleepiness is a problem in the user's life, the sleep quality page is shown in Figure 6. The data contained in this page can be used to demonstrate the importance of compliance with treatment, if the user is reporting waking feeling tired and irritable. This data is also useful for research into the impact of sleep patterns on mood.

Finally, the statistics page shows a graph of the sleep patterns and a summary of sleep measurements such as sleep efficiency, sleep latency and the number of times the user woke after falling asleep. The presentation of the complete set of summary sleep measures in a format which is immediately usable to the physician will facilitate the physician's diagnosis by removing time pressures and hence ensures that the information contained in sleep diary is used efficiently.

This project is to implement an online sleep diary; a sleep diary is used to record sleep patterns usually for fourteen nights. The person notes the parameters of their nights sleep day-by-day building up a picture of sleep habits known as sleep hygiene. A sleep diary is used by a number of health professionals, including psychologists, physicians and sleep specialists and is the primary diagnostic tool for insomnia and an aid to the diagnosis of other sleep disorders. An online sleep diary has a number of benefits, the data contained within the diary is presented in a summarized readily accessible format available in real time, while building a database of sleep patterns.

CONCLUSION

Excessive daytime sleepiness is a problem in many communities, the increasing international awareness of this problem and its associated costs

Figure 4. Getting up time

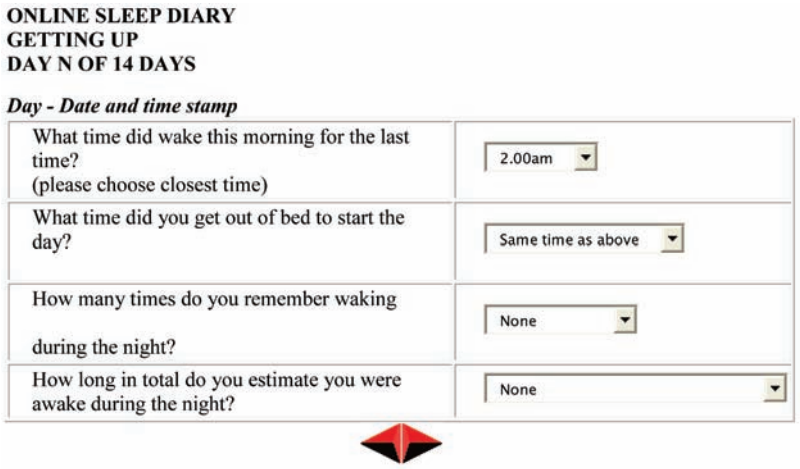
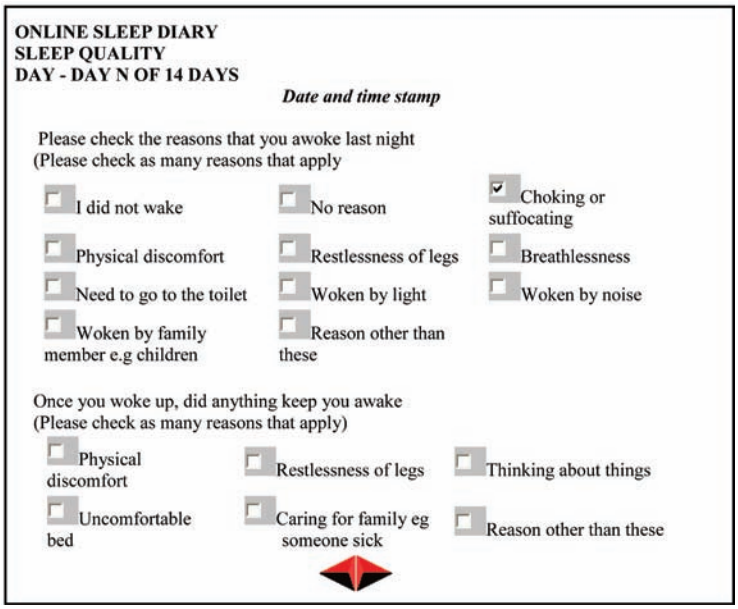


Figure 5. Sleep quality

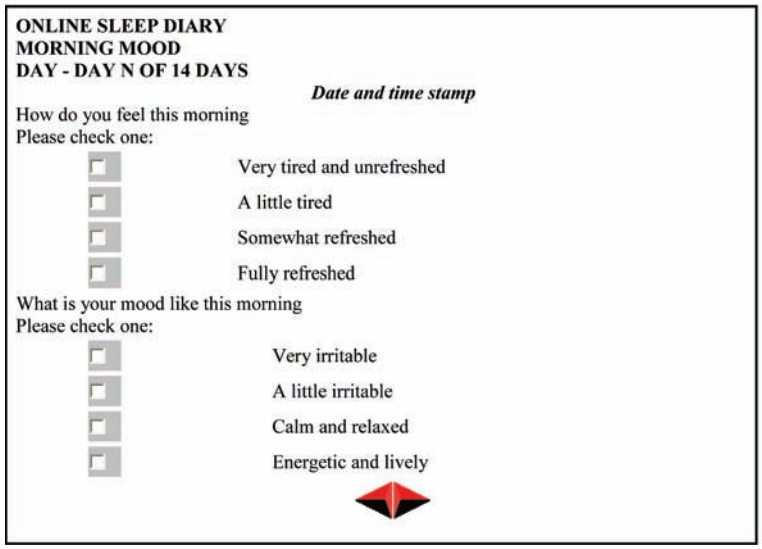


has placed existing health care frameworks under pressure. The development of an online sleep diary provides patients with an avenue to self-monitor sleep patterns and habits in a readily assimilated graphical format to support good health. The online sleep diary will provide a standard, validated tool for patient appraisal in sleep disorder treatment and facilitate the collection and distribution of high quality data to provide support to physicians in patient assessment.

FUTURE RESEARCH DIRECTIONS

As the quality of sleep information is higher if the data is entered on a day-to-day basis the op-

Figure 6. Mood page



portunity exists to develop a version of the online sleep diary which is suitable for use in a mobile computing device, such as a mobile telephone or personal digital assistant. This would give users more channels to access the sleep diary and facilitate day to day entry of data. Movement to an online sleep diary means that the data collected will be in a format facilitating the movement of this information to a future electronic health record. The electronic nature of the information also makes possible the construction of an evidence database. This evidence database can be made available to registered researchers making possible collaborative research projects into sleep patterns and the effect of lifestyle on sleep quality. As the development of the online sleep diary continues there is an opportunity to include more interactivity into the interface. This interactivity may take the form of electronic feedback so that alerts can be used to provide information back to the user, for example that the total time they have made available for sleep is insufficient. Such alerts can then be combined with provided hyperlinks to information web sites to increase a user's knowledge and potentially their ability to self-monitor their condition.

The development of the online sleep diary is part of a bigger project to also develop an online admissions questionnaire and an intelligent decision support system which will provide support for the physician's diagnostic process at the time and place that the decision is being made. The importance of this study is that it does not try to second guess a sleep study but instead makes timely information available to the patient and sleep specialist. The patient gains self knowledge, with increased knowledge and correct health beliefs shown to improve health outcomes (Smith, Lang, Sullivan, & Warren, 2004). For the physician the burden of filling in standard forms is removed from the sleep specialist to the patient freeing consultation time to see more patients. Patient information is available earlier, in an easy to assimilate format with necessary calculations already carried out automatically, meaning that the information is used efficiently.

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KEY TERMS AND DEFINITIONS

Continuous Positive Airway Pressure: (CPAP): used to treat sleep apnea by sending positive airway pressure at a constant, continuous pressure to help keep an open airway, allowing the patient to breathe normally through his/her nose and airway.

Insomnia: May involve, trouble falling asleep, frequent or prolonged nocturnal awakenings, or early morning awakenings with an inability to return to sleep (Morin et al, 1999).

Obstructive Sleep Apnea: A common disorder characterized by the repetitive pharyngal collapse during sleep (Malhotra & White, 2002).

Self-Monitoring: As awareness of symptoms or bodily sensations that is enhanced through periodic measurements, recordings and observations to provide information for improved self-management (Wilde & Garvin, 2007)

Sleepiness: The propensity to doze or fall asleep when intending to remain awake (Johns & Hocking, 1997).

Sleep Hygiene: A list of behaviours, environmental conditions, and other sleep-related factors that can be adjusted as a stand alone treatment or components of multi-modal treatment for patients with insomnia (Stepanski & Wyatt, 2003) and other sleep disorders.

Chapter 22
Doctors Using Patient Feedback to Establish Professional Learning Goals:
Results from a Communication Skill Development Program

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ABSTRACT

There is growing interest in the way that communication between doctors and patients affects important aspects of patient care and health outcomes. However, there is not much research on quantifying the effect of specific training programmes in communication skills for doctors. The aim of this chapter is to describe a research project that addresses this issue by first asking patients to provide feedback to doctors on their interpersonal skills. A set of training objectives is then discussed with individual doctors based on patient feedback. A training programme is subsequently undertaken by doctors, who are re-assessed by patients to determine the effectiveness of the feedback and training. The results indicate significant improvement on re-measurement. The chapter discusses the reasons for this improvement and the implications for providing personalised interpersonal skills training programs that target those skills that have been specifically identified by patients.

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INTRODUCTION

Increasing importance is being placed on the ability of doctors to communicate effectively with patients. For instance, the Accrediting Council for Graduate Medical Education (ACGME, 2007) stipulates that 'Residents must demonstrate interpersonal and communication skills that result in the effective exchange of information and collaboration with patients, their families, and health professionals'. The ACGME (n.d.) also provides an educational resource on advancing education in interpersonal and communication skills, where various methods are introduced and discussed for teaching interpersonal skills, including cinemeducation (the use of video clips using actors (Alexander, 2002)) and invite-listen-summarize (ILS) model role play in small group format (Boyle, Dwinnell & Platt, 2005) to teach and assess patient centred communication.

The growing importance of ensuring effective communication between doctors and patients is documented by Rowland-Morin and Carroll (1990), who provide a comprehensive review of how research in 'bedside manners' during the 1970s has now evolved into an important area of research concerning the content of medical training programs. In addition to this recognition that doctor-patient communication can affect health and clinical outcomes (e.g. Kaplan et al, 1989; Stewart, 1996; Epstein et al, 1993), there is also recognition that good doctor-patient communication can help offset the threat of malpractice suits (Levinson et al, 1997). In other words, there is growing evidence that poor communication skills are correlated with patient dissatisfaction and that clinical outcomes can depend to some extent on doctors' interpersonal skills (Trumble et al, 2006).

BACKGROUND

Training modules in communication and interpersonal skill building are now prevalent in medical education programmes. Such modules typically involve senior colleagues observing student doctor interaction with standard patients and providing feedback to help student doctors improve their interviewing techniques (e.g. Roth et al, 2002). Performance-based training can also be used involving evaluation of clinical performance.

Patient feedback (outcomes-based research using patient questionnaires) has received little attention as a potentially effective educational tool in the training of medical practitioners. Research shows that discussing one's results of patient feedback with a more experienced colleague has a significantly positive impact on future performance (Cope et al, 1986; Blurton and Mazzaferri, 1985; Greco et al, 2001). Whilst there is some evidence that the use of patient feedback can stimulate change for doctors-in-training, there is little evidence that the same can be said of fully qualified and practising doctors as opposed to doctors going through medical education (Greco et al, 1998).

With regard to outcomes-based research, a number of tools have been developed to measure patient experience of interaction with doctors. For instance, Trumble et al (2006) used 10 questions modelled on the 'Art of Medicine Survey' (Webster, 1989):

- How well did the doctor listen to your concerns and questions?
- How respectful was the doctor?
- How well did the doctor understand your problem?
- How accepting was the doctor of you and your problem?
- How well did the doctor explain to you what he or she was doing?

- How well did the doctor use words that are easy to understand?
- How well did the doctor cover what you expected of them?
- Did the doctor spend enough time with you?
- How much confidence do you have in the doctor's ability?
- Overall, how satisfied are you with the service you received from your doctor?

Patients were tested one week prior to an educational workshop for their doctors and again at least three months after the workshop. Trumble et al (2006) showed that while patients were generally satisfied prior to the workshop there was a shift towards complete satisfaction after the workshop. They conclude that the brief educational intervention results in improved performance across the full range of doctors' communication skills. No attempt was made by Trumble et al (2006) however, to identify a specific programme of training based on patient feedback so that key areas for improvement could be targeted.

Issues and Problems

The aim of this chapter was to undertake a more systematic outcomes-based analysis than that presented in Trumble et al (2006). In particular, it is not clear from the earlier work what the effect would be if the pre-workshop questionnaire were analysed and a specific training programme put in place for individual doctors based on the pre-questionnaires. Also, there is little understanding of how the various interpersonal skills and overall satisfaction with a doctor are related. Some interpersonal skills may be more important than others for contributing to patient satisfaction with their interaction with doctors, for instance. If so, it may be important to know about these relationships when constructing personalised training programmes for doctors, as part of either their medical education training or continual professional development.

Patient questionnaires issued prior to training intervention and then after the intervention must take into account immediacy of effect. The question arises as to whether the outcomes of a training intervention are more immediate (within a matter of weeks rather than months, as is the case with Trumble et al, 2006). This may have an impact on future research strategies and methods for outcomes-based patient surveys, as well as for the content and structure of training programmes.

Finally, an outcomes-based analysis using pre-training intervention questionnaires must distinguish between two levels: for the cohort of doctors as a whole, and for individual doctors. For the cohort of doctors as a whole, the level of analysis needs to be focused on all patient responses, irrespective of which doctor they saw. The results of such analysis provide valuable information on whether the training intervention has improved the communication skills of the cohort of doctors as a whole. But another level of analysis concerns individual doctors and whether a personalised training intervention has improved their performance.

We are not aware of any previous work that addresses the level of individual doctor improvement through personalised training interventions. The purpose of giving feedback to individual doctors is to raise awareness of areas of communication that may need enhancing for their training intervention. These can then be re-measured after the training intervention to see if their performance has improved in relation to the cohort of doctors.

In summary, the aim of this chapter is to explore whether devising personalised training interventions based on pre-intervention questionnaires leads to improved post-intervention outcomes, from the perspective of patients, both for individual doctors and for doctors as a whole.

METHOD

In order to carry out this task, we conducted pre and post intervention workshop surveys which

included GPs and hospital doctors (consultants, specialist registrars and SHOs) employed in the South West of England. Doctors undertook the *Doctors Interpersonal Skills Questionnaires* (DISQ) with 20-50 patients prior to the one-day workshop (pre-DISQ), and did the same again six weeks after the workshop (post-DISQ). In the intervening workshop, doctors reflected on their patient survey results from DISQ, their motivations, explored new ways of approach in patient care and involvement, and importantly trained in specific communication skills. Figure 5 in the Appendix provides a specimen patient questionnaire and Figure 6 in the Appendix provides an overview of the skills taught and their link to the DISQ.

The workshop began with doctors reviewing a summary of pre-intervention patient feedback, including specific patient comments and how their results compared to national averages for their specialty group. Upon reflection, doctors were invited to identify a specific questionnaire item that they would most want to improve. They discussed in small groups their goals, the meaning that item had for them and the communication techniques that involved doctors learning and rehearsing the following skills:

- Greeting or welcoming skills
- Collaboratively setting an agenda for the consultation
- Reflective listening
- Explanations (i.e. information which patients understand)
- Eliciting patient concerns and fears;
- Expressing empathy
- Acknowledging emotions and returning to the agenda
- Non-verbal communication
- Collaboratively developing an action plan

Figure 1. Summary of improvement in results between pre-DISQ (Survey 1 – maximum 896 patient responses) and post-DISQ (Survey 2 – maximum 925 patient responses) for the 25 doctors returning sufficient patient responses in both surveys

Group Statistics

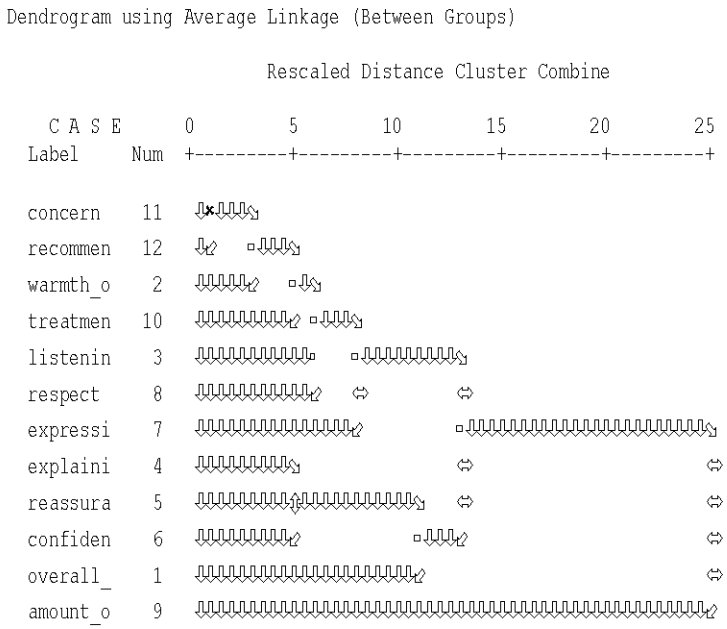
					Std Error
q1	1	889	446	.724	.024
	2	918	458	.667	.022
q2	1	891	446	.728	.024
	2	925	460	.639	.021
q3	1	876	445	.749	.025
	2	921	460	.688	.023
q4	1	879	439	.792	.027
	2	922	454	.700	.023
q5	1	881	436	.782	.026
	2	921	446	.742	.024
q6	1	884	447	.748	.025
	2	915	457	.670	.022
q7	1	883	433	.845	.028
	2	917	454	.707	.023
q8	1	889	454	.687	.023
	2	923	468	.589	.019
q9	1	884	424	.837	.028
	2	916	441	.765	.025
q10	1	877	439	.790	.027
	2	908	450	.727	.024
q11	1	886	435	.804	.027
	2	910	450	.711	.024
q12	1	888	447	.756	.025
	2	910	458	.687	.023

The workshop consisted of short lectures, reflective exercises, small group facilitated discussions and group activities. Videotaped case studies (cinemeducation) and live actors (ILS-type model) allowed participants to rehearse specific skills. The 1059 patients completed the pre-DISQ for 33 doctors. The post-DISQ was completed by 25 doctors from the original sample. Of these doctors, 896 patients completed pre-DISQ forms and 925 patients completed post-DISQ forms. The eight doctors from the original 33 not included in the post-DISQ left employment prior to completion of the study or had insufficient numbers of questionnaires.

ANALYSIS

Two levels of analysis were undertaken. The first level of analysis consisted of checking whether there was a significant difference in patient responses pre-DISQ and post-DISQ. This level of analysis determines whether the educational intervention had any effect at all on the cohort of doctors as a whole. Each of the 12 items was compared across the two patient populations (t-test for equality of means). The second level of analysis consisted of aggregating patient responses for each doctor ('per doctor') on each set of pre-DISQ and post-DISQ questionnaires separately. The method of aggregation was to take the mean response, item by item, across all patient responses on that item

Figure 2. Hierarchical cluster analysis (HCA) of pre-DISQ patient responses aggregated per doctor, using correlation as the distance metric. Correlation strengths have been rescaled so that the strongest relationships occur on the left side of the diagram (items 11, 12 and 2, for instance, are grouped tightly together) and weaker ones to the right (items 4, 5 and 6), followed by a description of how these items form larger clusters (the cluster consisting of items 11, 12 and 2 first merges with item 10 and then items 3 and 8, for instance). The item numbers refer to the 12 questions in the questionnaire (Figure 5 in the Appendix). The dendogram is horizontal with the root of the tree on the extreme right. The table below the dendogram provides the key to interpreting the variable names



Name	Attribute
amount_o	amount_of_time
confiden	confidence_in_ability
explaini	explaining
expressi	expressing_concern
listenin	listening
overall_	overall_satisfaction
reassura	reassurance
recommen	recommendation_to_friends
treatmen	treatment_and_advice
warmth_o	warmth_of_greeting
concern	concern
respect	respect

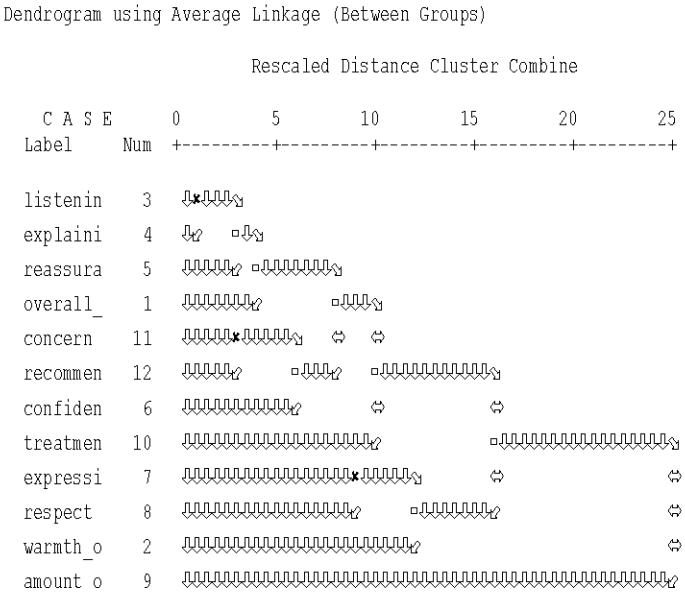
for a doctor. So, for instance, if a doctor had 10 completed patient questionnaires for the 12 DISQ items, the doctor's aggregated item score for item 1 was the mean of the 10 patient responses on item 1, and similarly for the other 11 items.

Each doctor therefore had 24 aggregated scores: 12 pre-DISQ and 12 post-DISQ. Two interpersonal skills indexes (ISIs) were then calculated for each doctor (Greco et al, 2001). The first was an ISI (ISI-1) per doctor based on summing the 12 aggregated pre-DISQ scores and the second (ISI-2) on summing the 12 aggregated post-DISQ scores per doctor. These ISIs are essentially scales formed from the 12 aggregated items through simple summation (rather than using weighted items). SPSS Version 14.0 for Windows was used for all statistical analysis.

Figure 1 provides an overview of the first level of analysis summary statistics across both surveys (pre-DISQ average 35.84 responses per doctor, minimum 9, maximum 56, std. dev. 13.474; post-DISQ 37.00, 9, 86, 16.882) on the 12 questionnaire items pre-DISQ and the 12 questionnaire items post-DISQ, item by item, showing a significant difference between the means of the questionnaire items between the two surveyed patient populations (t-test for equality of means, two-tail significance $p<0.01$ for all 12 items) for those 25 doctors taking part in both pre-DISQ and post-DISQ.

The standard technique for testing the reliability of a questionnaire is Cronbach's α, which is a measurement of the reliability of any psychometric instrument. Values of α over 0.85 are considered strong indicators of questionnaire reliability in terms of the items making up the questionnaire. In our data the overall reliability of the 12 questionnaire items across both surveys was very high (Cronbach α = 0.964, inter-item correlation mean (IICM) of 0.691) with good intra-class correlation (ICC - a measure of respondents' agreement ranging from -1.0 to +1.0) on how the 12 items are to be interpreted and used) of 0.688. Reliability and agreement remained almost identical when the responses were split by survey (pre-DISQ α = 0.964, IICM 0.692, ICC 0.689; post-DISQ α

Figure 3. HCA of post-DISQ patient responses. Item 9 (time given for visit) is still an outlier but there have been subtle shifts in patients' perceptions of their doctor (see main text)



= 0.972, IICM -.683, ICC 0.680), indicating no significant difference between the two surveyed patient populations in terms of interpretation and use of questionnaire items.

To check that there was indeed a significant difference pre-DISQ and post-DISQ at the cohort level of scale analysis rather than an individual item level, a paired-samples T-test was undertaken on ISI-1 and ISI-2. A paired-samples test compares the means of two variables for a single group (in this case, the doctor cohort) and checks for a significant difference. The mean for ISI-1 was 52.77 and the mean for ISI-2 54.36 (25 doctors). The paired-samples t-test showed a significant difference in doctors' ISI-1 and ISI-2 (t=-3.47, two-tailed significance <0.01). On the basis of these results at both levels of analysis, the significant difference (improvement) in the means of the two surveyed patient populations and aggregated scores for doctors pre- and post-DISQ can be attributed to workshop influence.

A deeper analysis was then undertaken to identify the reasons for the improvement. A hierarchical cluster analysis of questionnaire items was run on

Table 1. Summary of change in patient scores for the whole cohort of doctors, with significances

	F	Sig.	t	df	Sig. (2-tailed)	95% Confidence Interval of the Difference	
						Lower	Upper
q1	16.749	.000	-3.584	1805	.000	-.181	-.053
			-3.579	1782.208	.000	-.182	-.053
q2	34.702	.000	-4.596	1814	.000	-.210	-.085
			-4.585	1765.175	.000	-.211	-.084
q3	22.145	.000	-4.248	1795	.000	-.211	-.078
			-4.239	1763.118	.000	-.211	-.077
q4	23.516	.000	-4.290	1799	.000	-.220	-.082
			-4.277	1747.717	.000	-.220	-.082
q5	4.835	.028	-2.952	1800	.003	-.176	-.036
			-2.948	1783.319	.003	-.177	-.035
q6	17.547	.000	-2.920	1797	.004	-.163	-.032
			-2.915	1760.536	.004	-.163	-.032
q7	38.284	.000	-5.795	1798	.000	-.284	-.141
			-5.776	1719.718	.000	-.285	-.140
q8	51.744	.000	-4.608	1810	.000	-.197	-.079
			-4.595	1747.427	.000	-.197	-.079
q9	5.350	.021	-4.545	1798	.000	-.246	-.098
			-4.538	1770.231	.000	-.246	-.098
q10	10.763	.001	-3.066	1783	.002	-.180	-.040
			-3.061	1758.654	.002	-.181	-.040
q11	21.428	.000	-4.228	1794	.000	-.222	-.081
			-4.221	1754.996	.000	-.222	-.081
q12	19.873	.000	-3.279	1796	.001	-.178	-.045
			-3.275	1770.519	.001	-.179	-.045

aggregated patient responses per doctor separately for the two surveys, using inter-item correlation strength as the distance measure for revealing the internal structure among the 12 questionnaire items (Figures 2 and 3). The aggregation consisted of calculating the mean for items per doctor using all patient responses for that doctor.

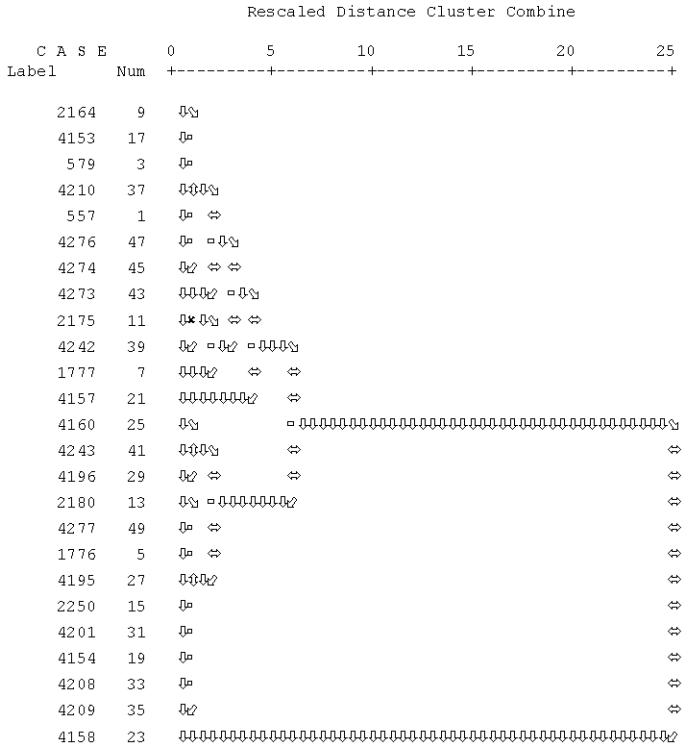
A hierarchical cluster analysis was also undertaken on the aggregated data of individual doctor improvement using cluster analysis per doctor. Squared Euclidean distance was used as the distance measure.

DISCUSSION

For the pre-DISQ patient responses (Figure 2) there is a strong association between doctor concern (item 11), recommendation to friends (item 12) and doctor warmth (item 2). Item 9 (amount of time) is a clear outlier, followed closely by item 1 (overall satisfaction). Confidence in the doctor's ability (item 6) is strongly associated with reassurance (item 5) and explanation (item 4). Post-DISQ (Figure 3), ability to listen (item 3) and explanation (item 4) are now most strongly linked, whereas they were separated pre-DISQ. Overall satisfaction (item 1) is more centrally embedded with ability to listen, explanation and reassurance (items 3, 4 and 5).

From this, we can conclude that the major outcome of the individualised workshop for doctors was to integrate listening and explanation skills much more closely with reassurance and overall doctor satisfaction. Another outcome from the workshop was to relate confidence in the doctor more closely with doctor concern for the patient. Also, whereas doctor consideration of patients' per-

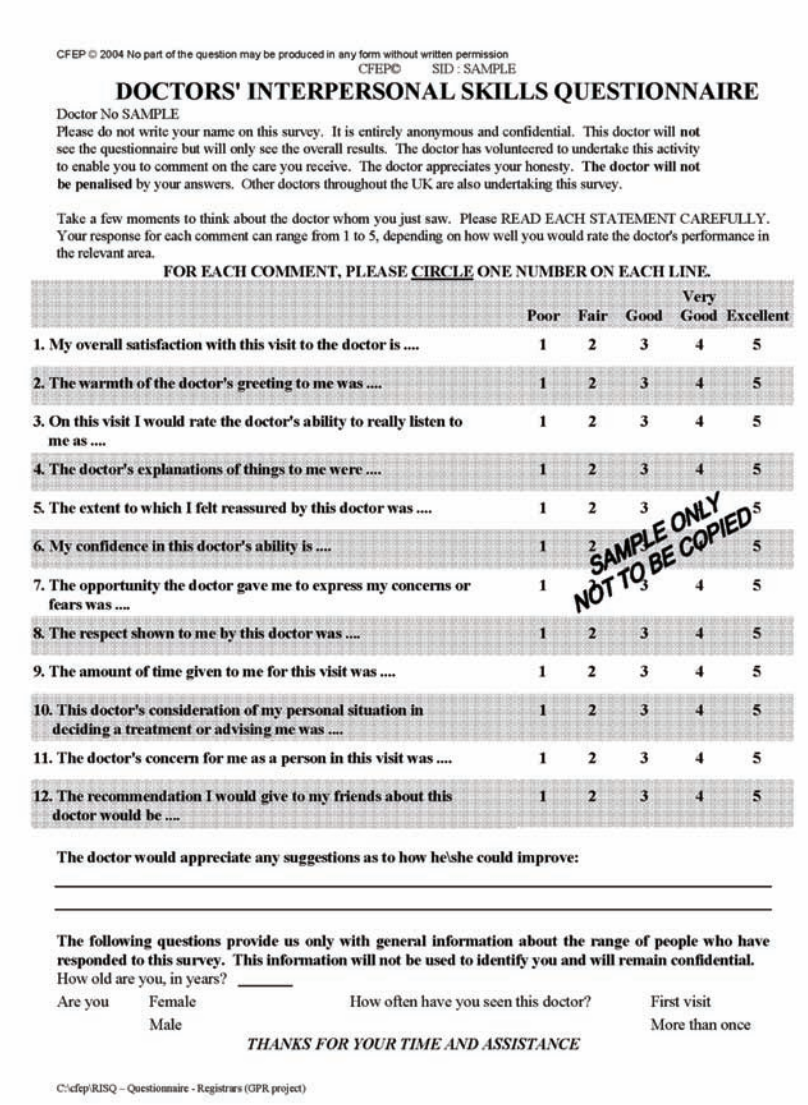
Figure 4. HCA of all 25 doctors using aggregated pre-DISQ patient responses. Doctor 4158 (system case number 23) is a clear outlier with significantly below average performances on every item



sonal situation in deciding treatment (item 10) was embedded within a number of interpersonal skills (warmth of greeting, listening, respect shown) pre-DISQ, after the workshop this item stood outside a number of interpersonal skills, demonstrating that patients appreciated the difference between doctors' communication skills on the one hand and advice on treatment on the other. In other words, patients were more satisfied with advice on treatment, provided that the doctor was an effective communicator who listened, explained, reassured and showed concern for the patient.

Pre-DISQ, one doctor stood out as an outlier (Figure 4). Doctor 4158 was between one and two standard deviations below the mean on one item, between two and three standard deviations below the mean on four items, and more than three standard deviations below the mean on the remaining seven items. However, after the workshop, Doctor 4158 moved to the centre of the population. The

Figure 5.



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CFEP© SID : SAMPLE

DOCTORS' INTERPERSONAL SKILLS QUESTIONNAIRE

Doctor No SAMPLE

Please do not write your name on this survey. It is entirely anonymous and confidential. This doctor will **not** see the questionnaire but will only see the overall results. The doctor has volunteered to undertake this activity to enable you to comment on the care you receive. The doctor appreciates your honesty. **The doctor will not be penalised** by your answers. Other doctors throughout the UK are also undertaking this survey.

Take a few moments to think about the doctor whom you just saw. Please READ EACH STATEMENT CAREFULLY. Your response for each comment can range from 1 to 5, depending on how well you would rate the doctor's performance in the relevant area.

FOR EACH COMMENT, PLEASE CIRCLE ONE NUMBER ON EACH LINE.

	Poor	Fair	Good	Very Good	Excellent
1. My overall satisfaction with this visit to the doctor is	1	2	3	4	5
2. The warmth of the doctor's greeting to me was	1	2	3	4	5
3. On this visit I would rate the doctor's ability to really listen to me as	1	2	3	4	5
4. The doctor's explanations of things to me were	1	2	3	4	5
5. The extent to which I felt reassured by this doctor was	1	2	3		5
6. My confidence in this doctor's ability is	1	2			5
7. The opportunity the doctor gave me to express my concerns or fears was	1		3	4	5
8. The respect shown to me by this doctor was	1	2	3	4	5
9. The amount of time given to me for this visit was	1	2	3	4	5
10. This doctor's consideration of my personal situation in deciding a treatment or advising me was	1	2	3	4	5
11. The doctor's concern for me as a person in this visit was	1	2	3	4	5
12. The recommendation I would give to my friends about this doctor would be	1	2	3	4	5

SAMPLE ONLY NOT TO BE COPIED

The doctor would appreciate any suggestions as to how he\she could improve:

_____

_____

The following questions provide us only with general information about the range of people who have responded to this survey. This information will not be used to identify you and will remain confidential.

How old are you, in years? _____

Are you Female Male

How often have you seen this doctor? First visit More than once

THANKS FOR YOUR TIME AND ASSISTANCE

C:\cfep\RISQ – Questionnaire - Registrars (GPR project)

'worst-performing' doctor is now Doctor 4242, who nevertheless was not more than two standard deviations below the mean on any item (lowest raw average of 3.88 on the original Likert scale, which corresponds to between 'good' and 'very good').

From this we can conclude that the workshop helped doctors improve their performance across the board and, in the case of one doctor, led to much improved patient scores.

CONCLUSION

Figure 3 can be interpreted as providing a 'blueprint' for how individual aspects of communication join with other aspects to provide an overview of why patients are *satisfied* with doctors and have *overall confidence* in them. Figure 3 clearly associates listening with explanation skills, which together provide reassurance and lead to *overall satisfaction* with the doctor. It appears that a doctor who listens carefully and takes time to explain and provide reassurance is also a doctor that patients are *satisfied* with. Similarly, *overall confidence* in a doctor is strongly associated with showing concern for the patient's wellbeing, leading to patients recommending the doctor to others.

Patients' rating of a doctor's treatment and advice (performance based aspects) is associated with *overall satisfaction* and *overall confidence* with the doctor. This may explain earlier results that relate clinical outcomes with doctor com-

Figure 6.

DISQ items and doctor behaviors that can improve patients' report of their experience

DISQ Item	Welcome the patient	Setting the agenda	Discover patient expectations	Listen to the patient's story uninterrupted	Maintain eye contact	Make a personal connection	Mirroring body language	Matching voice and vocabulary	Express empathy	Touch and go	Check patient understanding	Questions	Common Language	Collaborate on a plan	Listen	Explain
Warmth of Greeting	✓				✓	✓										
Listening Skills		✓		✓							✓					
Clarity of Explanation											✓		✓			✓
Reassurance				✓		✓				✓						
Confidence in ability			✓			✓								✓		
Allows expression of concerns/ fears				✓				✓				✓				
Respect shown					✓			✓					✓			
Time given		✓		✓						✓						
Considers personal context			✓	✓										✓		
Concern for patient as person						✓	✓		✓							

munication skills: a doctor's suggested treatment leads to better clinical outcomes if patients have *overall satisfaction* and *overall confidence* in that doctor, where such *satisfaction* is associated with listening and explanation skills and *confidence* with showing concern.

Two interesting aspects of Figure 3 relate to amount of time given to the consultation and the three aspects of allowing patients to express their concern, respect shown by the doctor and warmth of greeting. Amount of time is an outlier in both Figures 2 and 3, indicating that patients did not relate amount of time given to a consultation with communication skills and therefore satisfaction and confidence in a doctor. It appears that patients recognise that quality of time spent with a doctor is more important than quantity of time.

Also the three aspects of allowing patients to express their concern, doctors showing respect to the patient and warmth of greeting by a doctor, according to Figure 3, are not strongly associated, if associated at all, with overall satisfaction and confidence in the doctor. While respect shown by the doctor is associated with allowing patients to express their concern and warmth of greeting, these appear peripheral to the core aspects of overall satisfaction and confidence in the doctor. Again, it appears that patients are making subtle distinctions between the social aspects of a consultation and the caring/treatment aspects of that consultation.

While these interpretations need further investigation with controlled experiments, they nevertheless provide for the first time some guidance on how it may be possible to construct individual training programmes in communication skills. The most important aspects of communication can be hypothesised to be listening, explaining and providing reassurance skills (to increase overall satisfaction with the doctor), followed by showing concern (to increase overall confidence in the doctor). Together, these provide patients with confidence that the suggested treatment will work, leading to better clinical outcomes.

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Chapter 23
TACMIS:
A Total Access Care and Medical Information System

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ABSTRACT

TACMIS is an inclusive solution to the management of health care and medical information and its design is based on a detailed process analysis of patient journeys and the pathways of clinical care of stroke patients as they progress from acute care, through rehabilitation to discharge and independent living, often with a residual disability. The findings are the work of a team based in the Discovery Research Laboratory at Ritsumeikan University in Japan. The clinical analysis was conducted at King's College Hospital in London and in several care institutions for the disabled and the aged in Japan.

INTRODUCTION

Background, Aims and Focus

How can disabled and aged populations gain access to and benefit from information and communications technologies (ICT) through the development of inclusive design systems? This was the fundamental question asked when the program began in May 2000. It was initiated as a cross-national collaborative research and development program of the Centre for Global Education and Research (CGER) at Ritsumeikan University, and is currently being executed at the Discovery Research Laboratory (DRL) established within CGER to incubate projects that link ICT with human, social and environmental needs (Cassim, M., 2004). TACMIS is a project that aims to create exemplars for this form of interlinking in the field of health care. This chapter will focus on the inclusive design aspects of TACMIS.

The TACMIS system is a composite of three integrated subsystems:

- **HIMS:** A Hospital Information Management System, which largely deals with the acute care phase and rehabilitation in a secondary care situation;

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- **SEAHCSS:** A Socio-Economic and Health Care Support System, which extends the findings of HIMS into primary care situations and into the aggregate realm of epidemiology and health care policy; and
- **PEECSS:** A Patient Empowerment and Environmental Control Support System, which extends care into the home environment and supports independent living.

The development work carried out thus far focuses on HIMS and PEECSS, with SEAHCSS seen as likely to evolve as a natural extension through dialogue with stakeholders involved in health care policy formulation. The chapter describes the access technologies used for integrated and inclusive solutions to health informatics issues in general and for dealing with stroke disability in particular. The findings indicate that such solutions will enhance the quality of electronic patient and health records, enabling them to contribute directly to improvements in a patient's individual care. They will also support a more enjoyable level of independent living for stroke victims with a residual disability, who are seen as a microcosm of the wider disabled and aged populations.

TACMIS

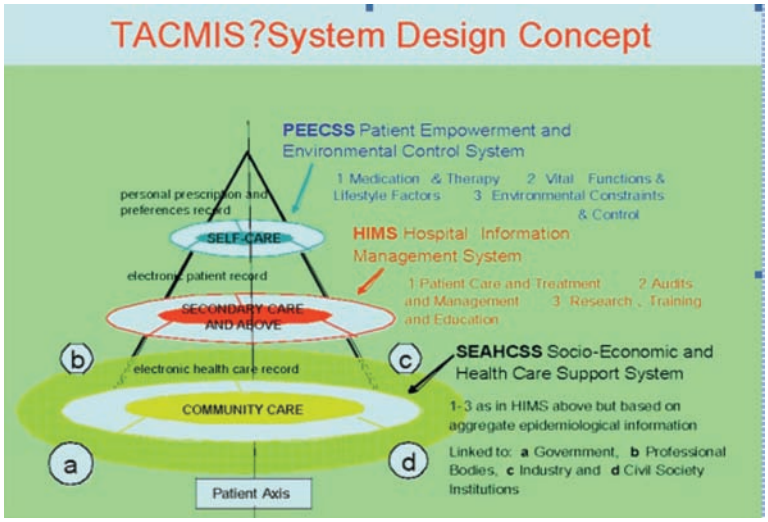
System Design and Key Questions

TACMIS commenced with an analysis of health informatics needs in several care and medical institutions in Japan and of national trends in several selected countries, including the United Kingdom. Based on this, the core technologies to be used in working towards prototype development were clarified, selected after discussions at several rounds of *Technology Seeds Seminars*, held in Japan and the USA. Next, the scope of the project was defined when it was decided to work with stroke patients and their residual disabilities of neurovascular origin, and a case study was designed. This has been conducted as a collaborative exercise between DRL/CGER at Ritsumeikan University, GKT Medical School at King's College London and the Acute Stroke Unit at King's College Hospital. The output of this exercise, the conceptual systems design of an integrated and inclusive health informatics system for the TACMIS prototype, is described below.

As noted above TACMIS is tripartite in composition (Figure 1), comprising of: (1) HIMS: A Hospital Information Management System, which largely deals with the acute care phase and rehabilitation in a secondary care situation; (2) SEAHCSS: A Socio-Economic and Health Care Support System, which extends the findings of HIMS into primary care situations and into the aggregate realm of epidemiology and health care policy; and (3) PEECSS: A Patient Empowerment and Environmental Control Support System, which extends care into the home environment and supports independent living. The three components are integrated into a holistic health informatics record, with the patient/care receiver seen as the integrating element.

In this chapter integration is seen as the process of bringing together critical elements of the system, the information it contains and the stakeholders involved. The purpose of integration is to enhance the performance of the system (in terms of speed, quality, reliability, etc) and to work towards enabling those participants (stakeholders) in the system who are disadvantaged to contribute more effectively. Inclusion, in the case of TACMIS, is seen as the process which makes it possible for the target of health care (the stroke patient) to participate to the fullest extent possible in the care process, in daily living activities (DLA) and in contributing socially and culturally at the highest conceivable level. Access technologies are the means by which this possibility is afforded to the target of care either directly or indirectly. The latter includes technologies that facilitate system integration.

Figure 1. The TACMIS design concept (Source: Cassim, 2004)



Work conducted thus far on TACMIS indicates that information integration is the key to arriving at successful inclusive solutions. This includes the integration of the following three categories:

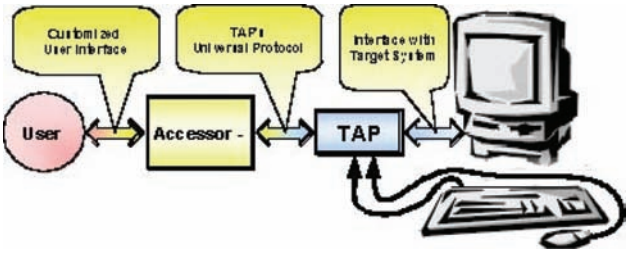
1. Disability needs, lifestyle preferences and health condition information, including links to a referral case record of clinical narratives
2. Environmental constraints information, covering the physical, sensory and cognitive environments
3. Capability assessment information, including a referral case record of individual coping strategies

Understanding the nature of this information and analysis of the modules of information relevant to the design task being addressed would be the starting point for designers involved in TACMIS. The design tasks generated by TACMIS would include systems design, interface design, product design, service design, policy design and the design of a successful business model.

ACCESS TECHNOLOGIES: THE TAP-TAS CORE CONCEPT AND OTHER SELECTED TECHNOLOGIES

Keeping abreast of technological developments is a daunting but necessary condition for TACMIS' design team members. Both the exponential increase in computing power (Moore's Law) and advances in telematic transmission technology make developments in ICT a continual and rapidly moving target. Thus, it was felt that a binding underlying concept was required to prevent the project team from becoming too enamoured by devices, gimmicks and gadgets, many of which might soon become obsolete. The answer came in the form of the integrated system design based on a detailed analysis of the processes involved in stroke patient care, indicated in Figure 2. This became the guide for directing the different work components into a single holistic entity. Under this framework, for selecting access technologies, Neil Scott's concept of a Total Access System (TAS) and its accompanying core device, the Total Access Port (TAP), was inspirational (Scott,

Figure 2. Conceptual diagram of TAP-TAS in the early 1990s (Source: Scott, 2003a)



2003a& b; Figure 2). The beauty of Scott's idea was to separate the accessor, which was often very expensive when it had to be customized for disability, from the target system, which was often very cheap and mass-produced as in the case of PC-type computer systems, through a bridging device, a port which he called the Total Access Port (TAP). He described the integrated entity, comprising of accessor, port and target system, as the Total Access System (TAS).

TAP has been refined and made more intelligent since its debut at the Archimedes Project of the Center for the Study of Language and Information (CSLI) in Stanford University in the early 1990s. Scott now runs the Archimedes Project from the University of Hawaii. The patient 'J.B'. can be seen in Figure 3, using an early wired-version of TAP at CSLI. He is paralyzed from the neck downward and can move only his head on his own volition. He is seen using an expensive laser head-tracker, his customized accessor, with run-of-the-mill personal computers via the little box in front of the screen, the TAP. Figure 4 shows a later version of the now wireless TAP channeling voice commands to operate household appliances. A pre-prototype test bed 2003-version of TAP (i-TAP) developed by Scott (2003a) for DRL in Ritsumeikan University was the inspiration for the PEECSS component of TACMIS. The **i-TAP** concept design is indicated in Figure 5.

The underlying concept of TAP-TAS, however, prevails throughout the thought processes that led to the tri-partite TACMIS model, particularly in the design of accessors to meet:

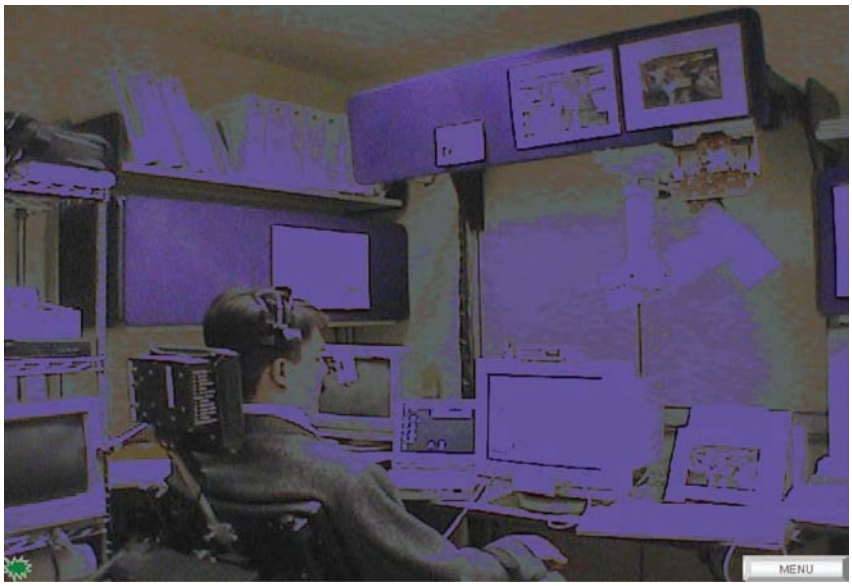
1. The independent living needs of the care receiver in PEECSS
2. The variety of clinical needs of the professionals providing the care in HIMS, and (3) the diverse epidemiological and policy information needs of the larger range of stakeholders in SEAHCSS. The advantage of TAP-TAS is that it is a robust system that can respond to change and incorporate new technologies.

THE BROAD CANVAS OF HEALTH INFORMATICS ISSUES: INTEGRATION AS THE KEY TO INCLUSION AND EMPOWERMENT

An analysis of information needs in several long-term care institutions in Japan and of trends in the use of information and communication technologies (ICT) in care and medical institutions in Japan and the UK led to the identification of the key issues which TACMIS would have to address. They deal with: (1) Health information system design and integration; (2) Easing the burden of information input, retrieval and analysis; (3) Patient empowerment; and (4) Privacy control. They are an invaluable brief for members of the design team and are elaborated upon below:

1. **Health Information System Design and Integration:** In designing an integrated care and medical information system, as a patient journeys through the health care system, a

Figure 3. JB operates PCs with laser head-tracker via TAP (Source: Scott, 2003b)



number of discrete subsystems and several legacy systems have to be taken into account. Integrating this information transforms it into a useful evidence base for capturing epidemiological trends and for charting health care policy. However, the accumulated body of tacit knowledge and judgment born of experience, or the rich narrative base (Figure 6) of medical practice, best represented in the patient-clinician interaction, can get left out of the evidence base. It is important that this semantic aspect, extremely important for clinical interpretation and inference must be included in designing TACMIS, especially when critical decisions that hover over life and death have to be made. The systems

Figure 4. Home appliances controlled by voice commands (Source: Scott, 2003a)

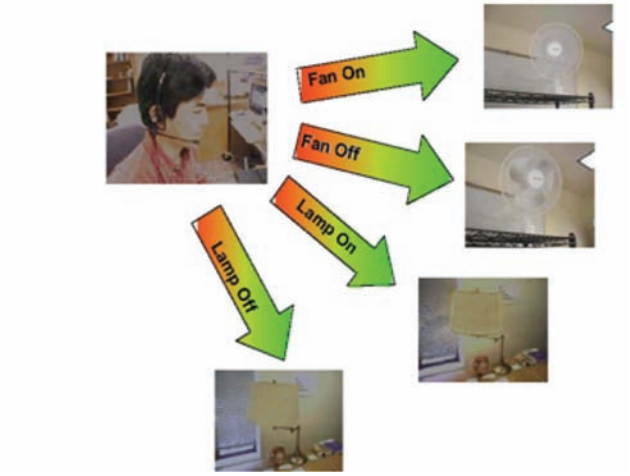
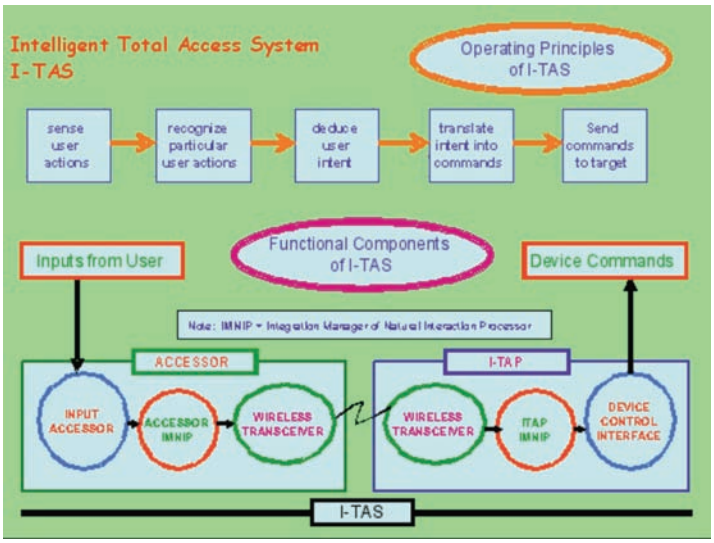


Figure 5. Operating principles and functional components of I-TAP (Source: Scott, 2003a)



design aspects of TACMIS and the system integrating devices/software protocols and the data mining/management software developed will have to address this challenge.

2. **Easing the Burden of Input, Retrieval and Analysis:** This aspect has emerged as important following an analysis of the operational needs of medical and care institutions. Against a background of increasing ICT investment by the health care sector, even in developing countries, we find that such investments are under-utilized. Health care professionals constantly have to adapt to rapidly evolving hardware and software environments. Furthermore, in most ICT systems used, access devices commonly used for data input and retrieval, and the software used for analysis, are not user-friendly to health care professionals and their patients. Easing the burden of engaging with ICT systems is of paramount importance. The accessor design aspects of the research exercise, working in concert with system integrating devices/protocols, will address this challenge;

3. **Patient Empowerment:** The isolation and dependency of the disabled patient or of the aged and infirm are a serious concern. High quality long term residential care at affordable prices is increasingly difficult to provide. Independent living, in familiar environments with social interaction for as long as possible, appears to be the alternative. The same accessors that facilitate patient engagement with the data management system can be used to enhance patient interaction with the surrounding physical and social environment. Patient control of electrical appliances in the home, interactive engagement with navigation aids and information regarding the surrounding environment can assist in enhancing the quality of life for the patient/care receiver, function as an emergency help line and also act as a conduit for the continual transmission of clinical information relating to vital functions. This last is especially important when the patient leaves the closed confines of the hospital or residential care. Knowing patient/care receiver needs in respect to hindering environments, in order to be able to respond

to them, is also crucial. The empowering of patients with information about their health and enabling them to make choices is another important challenge;

4. **Privacy Control:** Given the confidentiality of much of the personal information that has to be managed within the system, a privacy control policy has to be articulated at the outset. The information flowing through the system can be likened to several strands that originate from the different stakeholders involved (Figure 8). These strands intertwine from time to time and it is necessary to have a clear indication of who the custodian of each strand of this information is, and who should be the overriding authority when these strands intertwine. What happens when the target of care is incapable of sound judgment? Whose decisions prevail when the balance between life and death is at stake? Also, to optimize the use of these information strands in clinical decisions, their channeling along the care pathways is likely to be automated. Thus, the system will not be error-free and nodes of human judgment, possibly where the information strands intertwine, will have to be built into the health informatics system. Needless to say, the patient/care receiver's rights in regard to exercising control over this information and the conditions under which it can be overridden need to be defined.

FOCUS ON STROKE DISABILITY: AN ANALYSIS OF PATIENT JOURNEYS AND THE PATHWAYS OF CARE

Stroke was chosen as the focus of analysis for developing the TACMIS prototype because it is a widely prevalent medical condition of sufficient epidemiological impact. Also, stroke care involves information dealing with a range of conditions, from conditions prior to the onset of stroke, at the onset of stroke, in emergency and acute care, in rehabilitation and chronic care, in hospice care and preparation for death where treatment is unsuccessful, or discharge into community care or independent living, usually with a chronic disability, when the patient survives. This patient journey, seen in juxtaposition with the clinical care pathways and other stakeholder involvement in the process of care, was mapped with an analysis of timelines, conditions, treatment/engagement and outcomes. This is indicated conceptually in Figure 7.

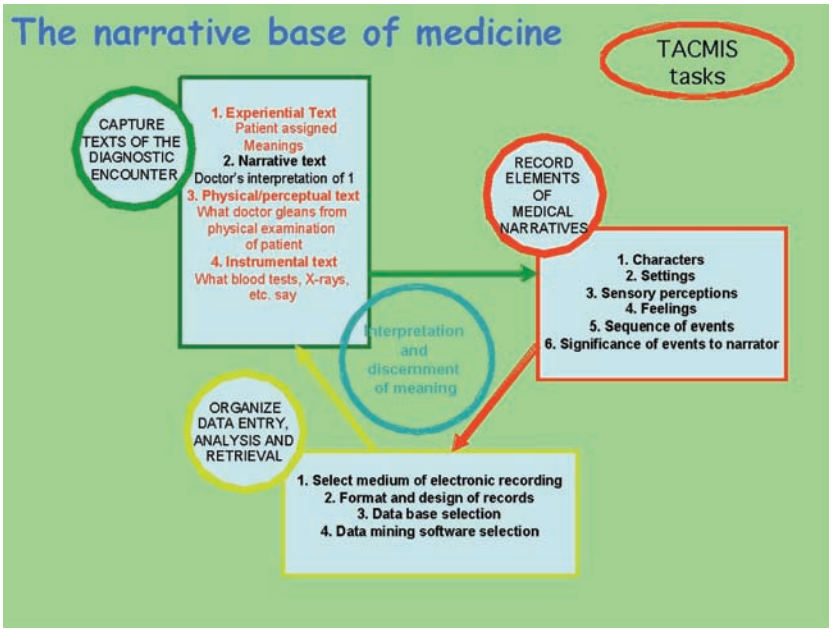
The vascular origins of stroke indicate a strong correlation with lifestyle related factors, including stress, diet, alcohol consumption, physical exercise regimes, etc. Thus information relating to patient history prior to the onset of stroke is of great value in the treatment of stroke in the acute, chronic and community care phases of treatment. Considering that stroke leads to neurological impairment, the principal types of disability that have to be addressed are related to:

- Paralysis
- Sensory disturbances, including pain
- Using/understanding language
- Swallowing difficulties
- Thinking and memory
- Emotional disturbances

Designing a prototype based on an analysis of the residual disability of stroke patients and of stroke care could be quite easily extended to deal with conditions of both disability and ageing, the usual targets of inclusive design. The role of the clinicians dealing with these disabilities is indicated in Figure 8.

The analysis of stroke patient journeys at King's College Hospital (KCH) has indicated two broad domains of patient care which are important after the patient leaves the secondary care institution (KCH) and goes into intermediary care (for rehabilitation, largely), community care or independent living:

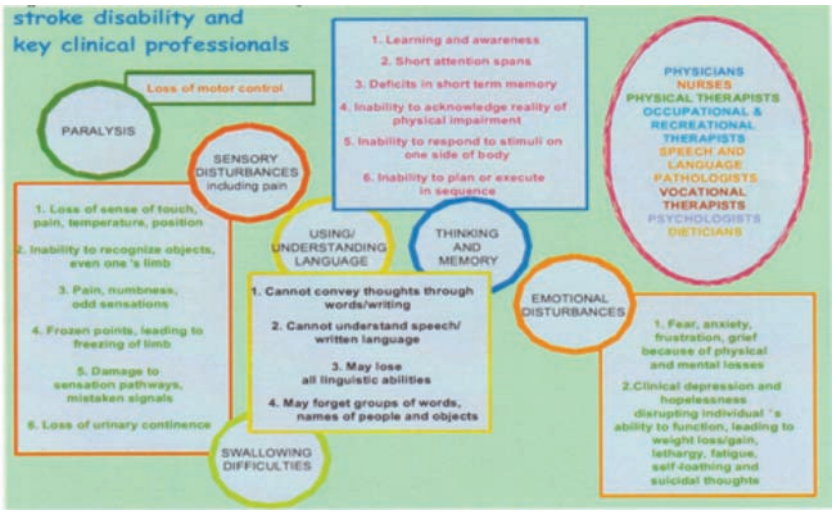
Figure 6. Capturing the narrative base of medicine (Source: Cassim, 2004)



1. **Preventing the recurrence of stroke.** This involves ensuring that the patient follows the medication and treatment regimen in his/her care package as well as the monitoring of key vital functions and lifestyle factors. In the event of recurrence, this information is most valuable to the clinicians in emergency and acute care, as well as those in rehabilitation and chronic care. However, it is precisely this information that falls in the crevice between secondary and primary care and is either not collected or often not shared if collected. Information and communication technologies, particularly ubiquitous devices, micro-engineering electro-mechanical systems (MEMS) incorporating RF transmitters can come to the rescue in this regard, provided the issue of privacy control mentioned earlier can be dealt with;
2. **Supporting independent living.** This involves helping overcome the chronic residual disability that invariably accompanies a discharged stroke patient. Using the TAP-TAS concept, separating the customized user accessor from the mass-market target system, a series of disability aids can be designed. They may range from mobility aids to smart beds, smart rooms and smart homes. Intelligent sensors can monitor the patient condition discreetly and warn the appropriate care/medical service facility when matters take a turn for the worse. An analysis of the environmental barriers around the patient's "home" environment and an understanding of the coping strategies employed by patients are important inputs for designing these aids. Aids to the enjoyment of life should be the aim of the inclusive design exercise. A whole raft of inclusive design products could emerge from this.

Based on the above needs, the Patient Empowerment and Environmental Control Support System (PEECSS) component of TACMIS is seen as a framework for designing products/services which are intended to facilitate self-care, sup-

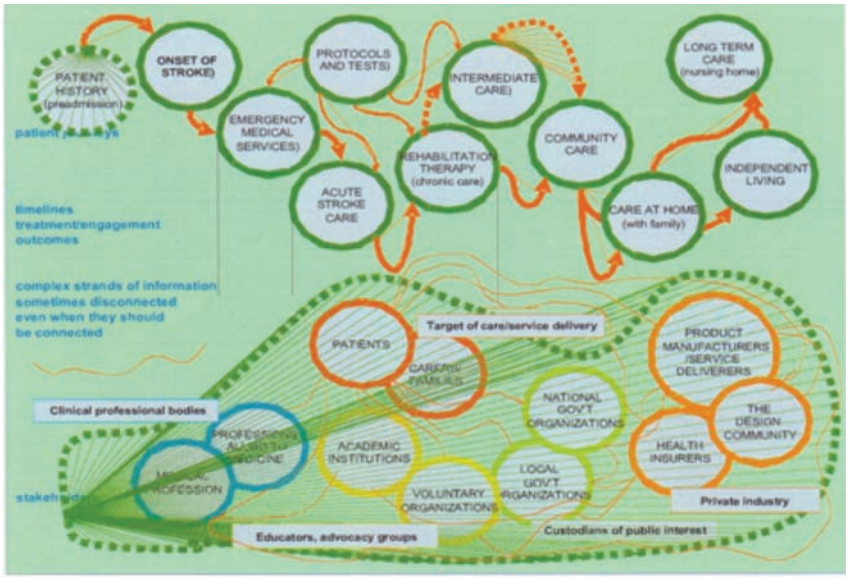
Figure 7. Stroke patient journeys and the stakeholders involved (Source: Cassim, 2005)



port independent living and empower the patient through control over his/her surrounding environment, thereby enriching the patient's quality of life. With the spread of ubiquitous telematic devices, lifestyle information monitoring of populations at risk (or even of the population at large) might well become a common phenomenon, although with caveats for ensuring privacy and confidentiality. As indicated earlier in Figure 1, the three domains considered for product/service design under PEECSS are:

1. Medication and Therapy
2. Vital Functions and Lifestyle Factors
3. Environmental Constraints and Control

Figure 8. Stroke disability and the clinicians involved (Source: Cassim, 2005)



The same three domains will be considered for collating information into a Personal Prescription and Preferences Record (PPPR), which is to be ultimately integrated with the Electronic Patient Record (EPR) at the Hospital Information Management System (HIMS) level and the Electronic Health Care Record (ECHR) at the Socio-Economic and Health Care Support System (SEAHCSS) level of TACMIS. The integrated whole may be termed a Holistic Health Informatics Record (HHIR). The ideal situation would be where inclusive products/services designed for PEECSS also function as information accessors, contributing to the information base of the PPPR.

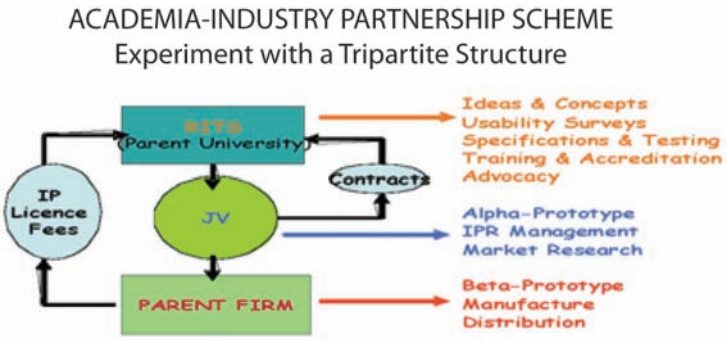
Although the Discovery Research Laboratory was an invaluable focal point in the innovation and developmental stages, and in creating social awareness through its Technology Seeds Seminars, it is important to establish a framework for partnership among industry, academia, government and civil society within which TACMIS can operate in the long term as it moves towards institutionalization and commercialization. Being cross-national in the composition of its team of contributors, the system must also be able to deal with the intellectual property rights (IPR) of the contributing parties. A scheme for this management of technology (MOT) exercise for TACMIS, which could be used for other DAITS exemplars as well, is shown in Figure 9.

CONCLUSION: CONTRIBUTIONS TO INCLUSIVE DESIGN

Observations from the stroke patient study at KCH and efforts to implement the TACMIS conceptual design indicated in Figure 1 provide us with a basis for summing up the work done thus far from an inclusive design perspective. The empirical findings of TACMIS in this regard can be briefly described as follows:

1. Stroke needs are a *microcosm of needs* which have to be addressed in the wider context of the disabled and ageing population (refer Figures 7 and 8)
2. TACMIS sees *information integration* as a prerequisite for social inclusion and personal empowerment and places the patient at the central axis of this process (refer Figure 1)
3. TACMIS aims at creating *electronic records* at the patient level (PEECSS-PPPR), the institutional level (HIMS-EPR) and the societal level (SEAHCSS-EHCR), linked to a series of referral records (which could include legacy systems) that can be integrated into a holistic health informatics record (TACMIS-HHIR, refer Figure 1)
4. The customized *accessors* used in PEECSS, HIMS and SEAHCSS are easy to use tools which reduce the burden of input and enhance the quality of information gathered, but can

Figure 9. Partnerships for commercializing TACMIS outputs (Source: Cassim, 2005)



also be seen as powerful aids to inclusion and empowerment (refer Figures 2, 34, 4 and 5)

5. The TAP-TAS concept enables an inclusive solution at *affordable cost* by freeing the expensive customized accessor from the target system, which could include computers, household appliances, sensor-based monitoring systems and even, perhaps, domestic robots (refer Figures 2, 3, 4 and 5)
6. The neural network based data-mining techniques currently being experimented with to mine information in the narrative base of medicine (NBM, Figure 6) could be used to analyze a variety of *descriptive case information* and *chaotic or nonlinear phenomena*, thereby providing a valuable input for inclusive product and service designers
7. The creative use of a *neutral university-based focal point*, such as Ritsumeikan's DRL, which can attract cross-national collaboration in the early stages of the developmental work, when *social awareness* building is the key, was an important factor
8. As the project (TACMIS) enters the stages of *institutionalization* and *commercialization* of the outputs, a longer term system of public, private and academic partnership is necessary (Figure 9)

Paraphrasing D'Souza, 2004, if knowledge is seen to accumulate as a consequence of an action (or event), then universal design (or inclusive design) may be seen as a knowledge accumulation (and transfer) process which is a consequence of *design action*. While TACMIS can provide a considerable range of empirical evidence which could shape the design brief for inclusive product/service development, it has no overt mechanism for mobilizing the design community. Also, in its current form, TACMIS has no explicit mechanism for recording the design action and its consequences, although this can be easily remedied. As a referral data base appended to TACMIS, perhaps at the SEAHCSS level, it could become a powerful tool for the advocacy of inclusive design solutions and for setting guidelines, specifications and performance standards drawn from exemplary practice.

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Chapter 24
IT Applications for Medical Services in Japan

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ABSTRACT

The Information Technology (IT) application for medical services has developed in line with two major national level factors. One was the "E-Japan Project" which was proposed and implemented to revitalise the Japanese economy by introducing IT to a wide range of industries and sectors of the society and by promoting establishment of so-called IT infrastructure. The other was serious concern over the fast rising healthcare expenses in the country in the face of the coming aging society. First, the major efforts were, therefore, made for productivity improvement and const reduction in the health insurance bill claiming procedure and other related fields. These initiatives were followed by construction of medical information sharing and processing system first, and then developed further for regional collaborations among medical institutions. Other examples of the IT applications in the medical services can be found telemedicine to cope with the serious shortage of medical doctors.

INTRODUCTION

IT applications for the medical services in Japan have been developed, by and large, in line with the government's initiatives in this field. The reasons behind this process are:

1. IT applications, by nature, require so-called IT infrastructure, such as high speed digital communication networks
2. The medical services are principally covered by the national health insurance scheme where digitisation of medical services and payments have been required
3. In the face of aging society in Japan, fast improvements in technology and productivity

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of the industry have become urgent agenda for the government

This chapter introduces an overview of IT applications in the medical field in Japan. Therefore, we need to start our discussion on the brief history of the IT revolution and government initiatives in the IT field in that Country.

THE IT REVOLUTION AND JAPANESE GOVERNMENT INITIATIVES

The 1990s was the beginning of the IT revolution in Japan. The Internet became a household name during this decade, while offices were transformed by the "server-client" environment. The old system, called the "legacy system" before the IT revolution, was made by a large host computer or a mainframe and many terminals which had only limited capability. In principle, all the data processing was undertaken by the host computer. This central control system was not only very expensive but also often suffered from a long processing time. Development of microprocessors and personal computers (PC) changed this in a short period. The server-client environment, a system where most of data processing is undertaken by PCs offered an excellent solution to problems with the legacy system. It was much cheaper and often faster than the legacy system. These made the server-client environment extremely popular not only in big businesses but also among a wide range of smaller firms. In addition, the use of the internet made it possible to acquire, exchange and transmit various information without any physical restriction.

The US government noticed the significance of this historical change, later often referred to as "the IT revolution". Vice President Al Gore was one of the leading figures who championed "the Information Superhighway Plan" in the early 1990s. Many other countries followed the US lead and Japan was not an exception. In the early 1990s, the Japanese economy was in the middle of stagnation after the collapse of the so-called bubble economy. Reinforced by a declining birth rate and an aging population, pessimistic views on Japan's future dominated the entire atmosphere. The newly formed socialist party led coalition government of this time brought "IT (Information Technology)" into the policy discussion and established an "Advanced Information and Telecommunication Society Promotion Headquarters (hereinafter referred to as the Promotion Headquarters)" within the Cabinet. However, this fragile coalition government had a short life of less than two years and could not achieve any noteworthy result.

In July 2000, "IT Strategy Headquarters" was established within the Cabinet under the Mori administration of the LDP (Liberal Democratic Party). Under the IT Strategy Headquarters (hereinafter referred to as the Headquarters) Cabinet Ministers were assigned to be the members and the Prime Minister chaired the IT Strategy Council (hereinafter referred to as the Council). This Council was established with expert members invited from industry and the universities to undertake policy research and discussion at the same time. The Council worked out a "Basic IT Strategy" for the Country and unveiled it on 27 November 2000 (IT Strategy Council, 2000). The Basic IT Strategy emphasised that Japan needed to transform herself to a "knowledge-emergent society" to achieve higher added value in the era of the aging society. Acknowledging the aging society, the report predicted that the Japanese population would start to decline shortly. This population decline would inevitably bring about GDP decrease unless productivity is improved and capital accumulation proceeds. Therefore, the Basic Strategy proposed to "establish a national infrastructure, including legal frameworks and information infrastructures, suitable for a new society where information and knowledge are the sources of added value" (IT Strategy Council, 2000:1).

The first issue that the Council pointed out was that internet usage in Japan was the lowest among major industrial nations. It attributed this to high telecommunication costs and a wide range of legal and regulatory restrictions on the use of communications networks "obsolete laws" (IT Strategy Council, 2000:2). Although the telecommunication market was liberalised in 1985, market competition was still very weak because of many obstacles for new entrants to the market. Based on these observations, the Basic IT Strategy set the following targets:

1. Establishment of an ultra high-speed network infrastructure and competition policies
2. Facilitation of electronic commerce
3. Realisation of an electronic government
4. Nurturing high quality human resources.

In a concurrent plan for an ultra high-speed network infrastructure, the government aimed at the establishment of the world's most advanced internet networks within five years (30-100 Mbps) at affordable rates. To achieve this goal, the government established a basic principle that "the private sector should play a leading role in the establishment of the network infrastructure while the government should establish an environment to allow the private sector to exert its full potential" (IT Strategy Council, 2000:4).In line with this basic principle, the Headquarters outlined roles and concrete actions to be played by the private sector and the government.

The year of 2001 is often referred to as the dawn of broadband communication services in Japan. As shown in Figure 1, the broadband services market grew rapidly from 2001. This rapid growth was initially driven by CATV (Cable Television Networks) and ADSL (Asymmetric Digital Subscriber Line) services (Tanaka et al, 2008). Based on further discussion in the headquarters and the growing broadband service networks, the headquarters unveiled an upgraded version of plan, as "the e-Japan Priority Policy Program 2002" on 18 June 2002 (Figure 2).

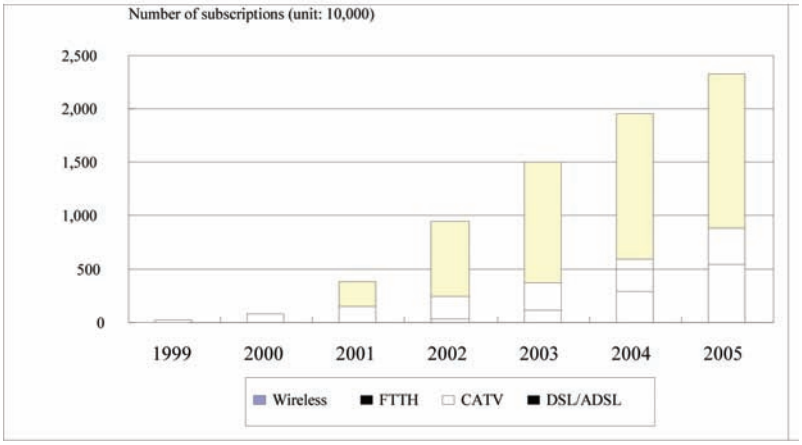
THE NATIONAL HEALTH SERVICE SYSTEM AND MEDICAL EXPENSE CONTROL

The Japanese national health service system has been based on the principle of "health insurance for everyone" since the end of 1961. Indeed, this principle has been the backbone of Japan's health service system. However, fast growing medical expenses coinciding with the fast social transformation to the aging society has seen one of the most acute policy agenda discussions in recent years. Figure 3 shows the recent trend of Japan's medical expenses.

The Japanese health insurance system is made up of sector-specific health insurance schemes such as the civil servants health insurance scheme and the company employees' health insurance scheme. Those employees working for a large corporation usually subscribe to memberships of a health insurance union fund established within the corporation. Medical expenses for their dependents are also covered by the health insurance union. On the other hand those who are self-employed and retirees mainly subscribe to the national health insurance scheme. Those who are 75 years old or older subscribe to the elderly health insurance scheme. With fast growing public bonds outstanding, the government faced the urgent necessity to suppress the growth of budget items (public bonds outstanding exceeded 550 trillion yen in 2008. This amount was equivalent to 105% of GDP).

Among other things, attention was focussed on medical expenses for the elderly in connection with the aging society. Figure 4 shows the medical expenses each year for different age groups. The medical expense per person for younger people (less than 65 years old) was 159

Figure 1. Growth of broadband network services in Japan (source: informatization white paper 2006, Japan information processing development corporation (ed.), BCN, 31 October 2006)



thousand yen for fiscal year 2005. However, the medical expense per person for those who are 65 years old or older was 656 thousand yen for the same period. This means that medical expenses for older people cost 4.1 times more than those for younger people. The share of the population of those who are 65 years old or older was only 10.3% in 1985. However, it steeply increased to 17.3% in 2000 and had doubled to 20.1% by 2005. It is expected to exceed 30% in 2025 according to the National Institute of Population and Social Security Research. This fast social transformation to an aging society will inevitably bring about skyrocketing medical expenditure. This was one of the most serious challenges which the Japanese government recognised in the 1980s and 90s.

There was common sentiment shared by many in Japanese society that fast growing medical expenses would become a heavy burden for the future generation in the country if alternatives were not found. The editorial of a leading Japanese newspaper, Asahi Shimbun on 19 August

Figure 2. Structure of e-Japan priority policy program 2002 (source: The IT strategy headquarters, http://www.kantei.go.jp/foreign/policy/it/0618summary/03_e.html)

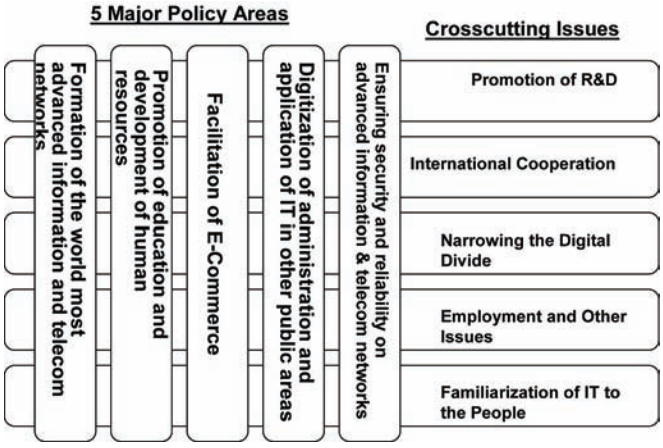
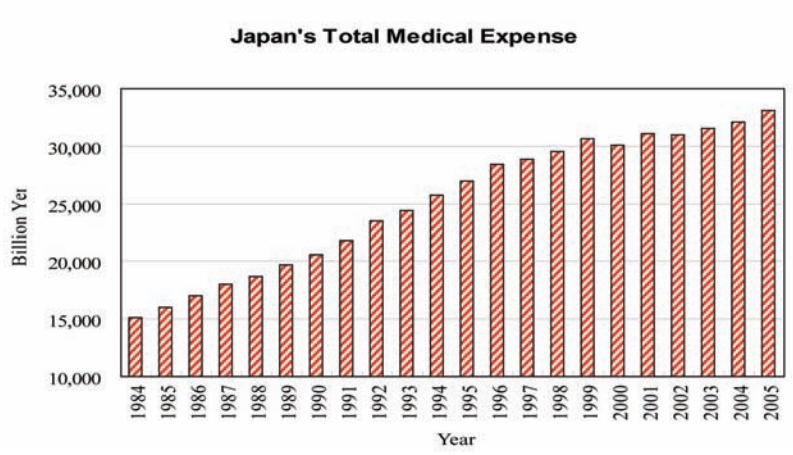


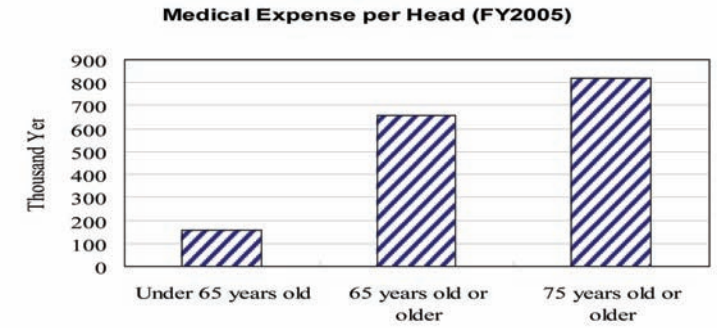
Figure 3. Recent trends in Japan's medical expenses (source: health and welfare statistics in Japan (Kosei Tokei Yoran 2007FY), ministry of health, welfare and labour, Tokyo)



1984, called for "the control of growing medical expenses without worsening of medical service quality". Among other factors, the increasing share of elderly in the society was blamed for the growing medical expenses together with "excessive medicine dispensing and excessive medical testing" (Asahi Shimbun, 19 August 1984). The latter arises because in the framework of the National Health Insurance Scheme medical institutions claim medical expenses for each patient and each treatment from the health insuring institutions. This medical expense claim system was based on the point accumulation method: if an additional medicine was dispensed for a patient, the medical institution treating the patient received additional remuneration.

In parallel to the efforts to strictly control the medical services for the elderly, the government was urged to suppress other costs as well. The editorial in the Asahi Shimbun on 12 August 1986 described the situation that the Ministry of Health and Welfare (later merged with the Labour Ministry to become the Ministry of Health, Labour and Welfare) looked just like a "Health and Welfare Division of the Finance Ministry" by criticizing the ministry's "welfare cutting" (Asahi Shimbun, 12

Figure 4. Medical expense per capita by different age groups (source: health and welfare statistics in Japan (Kosei Tokei Yoran 2007FY), ministry of health, labour and welfare, Tokyo)



August 1986). There was strong resistance by the Japan Medical Association, the politically active and influential medical doctors' union.

The health authority was pressured to find out other possibilities for medical expense control besides medicine dispensing and medical testing expenses control. One of the promising candidates for this purpose was the medical service billing system related administration cost. In the medical service billing system, every medical treatment, medicine dispensing and medical testing have to be recorded and filed by medical institutions to claim medical expenses from the medical insuring institutions such as the Japan Health Insurance Association. The medical insuring institution first examines those claims and makes necessary payment in accordance with the medical point table prescribed by the health authority. This process involves heavy office work as well as time. There came the idea that encouragement of IT into this area would contribute to medical expense control.

E-JAPAN STRATEGY II AND TARGETS IN THE MEDICAL SERVICE SECTOR

IT Strategic Headquarters unveiled its blueprint for the second phase of Japan's national IT strategy as "e-Japan Strategy II" on 2 July 2003. The headquarters outlined the seven important areas to be improved by effective utilization of IT where the private sector takes the leading role with government support. They were 1) medical services, 2) food, 3) life style, 4) small and medium enterprise financing, 5) knowledge, 6) employment and labour, and 7) public services. In the medical service sector, the government set four targets to achieve through the active introduction of IT into this sector (Table 1).

To achieve these goals, the working group in the framework of the E-Japan Project II was established and worked out the conceptual model of the *Online Medical Service Billing System*. The conceptual model consists of four major components. The first is the digitisation of medical service claims at the medical institution. However, simple introduction of IT into medical service claim cannot be effective alone. An integrated digitised administration system of medical institutions has been discussed in the context of BPR (Business Process Reengineering) since the 80s. The components of the integrated digitised administration system are: 1) digitised medical record database (DWH: Data Warehouse); 2) digitised ordering system (digital medical service instruction system where a medical doctor gives necessary instructions to co-medicals such as pharmacists and medical test engineers); and 3) digitised medical service expense claim system. The DWH was understood as an important direction of IT introduction into medical services also from an EBM (Evidence Based Medicine) point of view (Kumamoto, 2008). The idea of the digital medical service claim system was further developed in the Online Medical Service Billing System.

Table 1. Targets in the medical service sector in the e-Japan strategy II

Measure
• By 2005, authentication system is to be established, and the transfer and external saving of electronic medical records by medical institutions is to be approved; • Costly duplications of medical tests, medications, clerical work and etc. are to be reduced; • From FY 2004, the medical service billing process system will be moved online, and by 2010, a 100% online medical billing system will be in place; and • By maximum utilization of IT, the medical services will be made available to remote mountainous areas and isolated islands.

Source: "e-Japan Strategy II", IT Strategic Headquarters, the Government of Japan, 2 July 2003, http://www.kantei.go.jp/foreign/policy/it/0702senryaku_e.pdf, accessed 12 June 2009.

The second component of the new conceptual model is a computerised medical service claim examination and evaluation system. Although many experts have been deployed to do this work, it was the most time consuming part of the original health insurance system. In order to reduce work pressure, the process of simple error checking is made automatic (IT Strategy Headquarters, 2008). The third and fourth components are the supply chain management of medical supply and the medical related financing system respectively (Figure 5). The medical service evaluation committee of the IT Strategic Headquarters, in its FY2007 report on 19 March 2008, outlined the BPR efforts in this framework as in Table 2.

The discussions of the expert committee in the IT Strategic Headquarters were then extended further in a new direction. Patient and medical service data are useful not only for the health insurance billing system, but also for the formation of medical service networks where general practitioners, medical specialists (surgeons, pediatricians, physicians and others) share medical treatment and medicine prescription information for better cooperation. In some cases, patients are treated by multiple medical institutions. Sharing medicine dispensing records through the medical information network can avoid a possible accident due to a bad combination of medicine prescribed by two or three different medical institutions. Figure 6 shows such a conceptual model of a medical information network.

The Health Authority is planning to make medical service claims through the online billing system compulsory from April 2011. However, a large number of small medical institutions are feeling uneasy about the introduction of IT because of additional costs as well as lack of knowledge of IT (CB News, 2009). The current situation is that those medical institutions are promoting medical service claims through four different channels:

1. To prepare handwritten medical claims and submit them
2. To prepare digitized medical service claim forms by using specialised PCs, print them out and to submit them as hardcopy forms
3. To prepare digitized medical service claim forms by using specialised PCs, download them to CD-ROM and/or other memory medium and to submit them as softcopy forms
4. To prepare digitized medical service claim forms by using specialised PCs, and to submit them through information network digitally

However, the authority is planning to make method 4 compulsory. Those independent general practitioners, particularly those who are relatively older medical doctors are pessimistic about this

Figure 5. The conceptual model of online medical service billing system (source: "e-Japan strategy II", IT strategic headquarters, the government of Japan, 2 July 2003, 9p., http://www.kantei.go.jp/foreign/policy/it/0702senryaku_e.pdf)

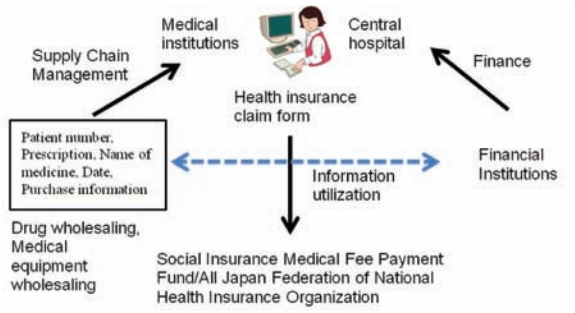


Table 2. BPR on the medical service claim, billing and examination process

BPR Requirements
• Electronic points tables (simple and transparent calculation rules are indispensable for the digitization of the medical services billing system); • BPR on medical service billings process; • BPR on medical service claim examination process; • BPR on revised processes of medical service fee system; and • Necessary measures to achieve the on-line-based medical service billing process.

Source: Medical Service Evaluation Committee, the Report for the FY 2007, IT Strategy Headquarters, 19 March 2008.

plan. The Osaka Medical Practitioners Association issued a protest against this plan on 28 January 2008. It is still not clear though how establishment of the Online Medical Service Billing System will occur under such circumstances.

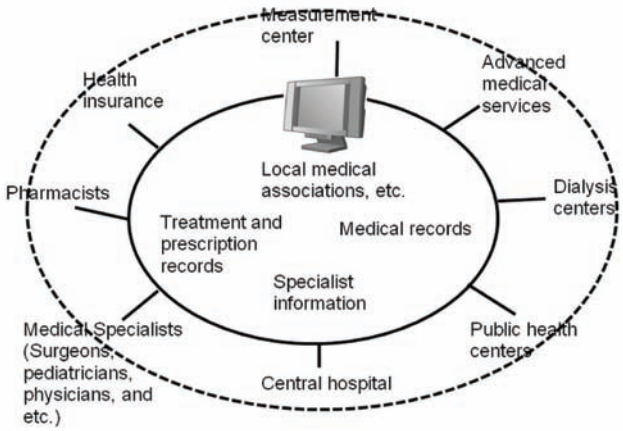
APPLICATIONS OF IT IN THE OTHER MEDICAL SERVICE AREAS

As pointed out by Kumamoto (2008), efforts to apply IT-based methods to medical services in Japan were centred in productivity improvement in administrative and medical claim works in medical institutions in the 80s and the 90s. These were developed further towards information sharing in a medical institution. This has been said to make a clear contrast with European cases where main focus has been set at collaboration supporting functions among medical institutions in a community (Matsuoka, 2008; Takada, 2008). Under the current medical insurance system, there exist a large amount of administrative works, as pointed in earlier parts of this chapter. However, as productivity improvement efforts, particularly in the large sized medical institutions, have achieved certain results, the main focus of IT applications has been changed towards new directions:

1. Safety assurance in medical services
2. Quality improvement of medical services
3. The medical service management system

The medical service management system might be better understood as further efforts for safe and reliable medical services are made. For

Figure 6. Digitised medical information network (Source: "e-Japan strategy II", IT strategic headquarters, 2 July 2003, http://www.kantei.go.jp/foreign/policy/it/0702senryaku_e.pdf)



this purpose, DPC (Diagnosis Procedure Combination), for example, plays an important role in DWH for diagnosis process analysis (Kumamoto, 2008; Fujimori & Matsuda, 2008).

IT applications in medical service recently faced an entirely new and unexpected challenge: a serious shortage of medical doctors. For a long period, the biggest issue for the health authorities has been rapidly rising medical expenses, as pointed out in the previous sections. Besides the aging society, the increasing number of medical doctors was also blamed as a reason for rising medical expenses. It was believed that the increasing number of medical doctors brought about excessive medication and unnecessary duplications of medical tests. In 1982, the Japanese government made a cabinet decision to take a measure to reduce medical school intakes. This was supported by the Medical Doctors Association which was worried about increasing competition among doctors and institutions. This policy measure was reiterated a few times until 2008, when it was cancelled by the Government (Weekly Toyo Keizai, 1 November 2008).

When "the new medical doctors post graduation training programme" was introduced in 2004, the serious shortage and uneven distribution of medical doctors became clear and visible (Table 3). In many local medical institutions, it became impossible to maintain medical services to the community because of shortage of medical doctors. Emergency medical service, obstetric care and pediatrics care were hit the most (Weekly Toyo Keizai, 1 November 2008).

At the same time, the serious shortage of medical experts of highly specialised areas became particularly apparent in many rural regions in Japan. Because of the drastic change in medical doctors' regional assignment system, specialised medical experts tend to concentrate in large cities rather than local medical institutions, as is common in other advanced countries. On the other hand, the demand for the medical experts on chronic sickness such as diabetic complications is rising because of the fast aging society, particularly in the rural regions. Therefore, the gap between demand and supply is inevitably widening. Telemedicine researches had been undertaken by many universities and research institutes. However, they did not attract so much public attention until the serious shortage of medical experts became obvious. Telemedicine is now considered as a practical solution to the current lop-sided distribution of medical doctors (Weekly Toyo Keizai, 1 November 2008).

CONCLUSION

The application of IT to medical services in Japan has been centred on the rising medical expense issues in the face of fast aging society at the national level. Although many researchers in the field aimed at quality improvement of medical services by the application of IT, cost reductions

Table 3. Reduction of medical service due to shortage of medical staff

Medical Service	% Shortage
Internal medicine	34.0
Obsterics	33.4
Pediatrics	21.7
Anesthesiologics	16.4
Otolaryngologics	11.4

Source: Nihon Keizai Shimbun, 6 July 2008, 1.

and labour saving have attracted more attention from the authorities. The quality improvement of medical services has become an important issue in this field quite recently however. The major technological breakthroughs such as the electronic medical record, DWH and other new systems have made substantial improvement of the system a priority. However, it has been pointed out that there remain many issues to be overcome. For instance, many IT systems constructed by the regional medical institutions were designed and built by different suppliers. Those IT companies tend to use their own proprietary systems which are not necessarily compatible with other systems nationwide (Weekly Toyo Keizai, 1 November 2008).

Finally, many have pointed out that the entire Japanese medical care system is now in crisis. The new approaches that will be made possible within a clear and grand design of IT applications in the medical service field are required.

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Index

D

E

F

G

H

I

J

K

L

M

N

O

P

Q

R

S

T

U

V

W