Moving Goal Posts[1]

Andy Hyde, MSc, MBCS[2]

Abstract

Technology is like a moving goal post. Before a new technological concept is properly established so the concept changes. This is the case in Electronic Patient and Health Records. The basic concept launched over 10 years ago of a patient record located within a health care institution electronically instead of on paper, although only partially realised, is now an old concept. The new concept will be one of patient information ownership and Web based electronic patients records. Patient ownership implies that the patient has a personal storage for their health information, a smart card or a Web based EHR for example. A patient not only owns his or her own information but can make it available to a care provider as needed. An exciting addition to the concept that is now in the research phase is that of Medical Net Instruments (MNI), a development in the Telemedicine field. Here is the possibility for a patient to be connected to monitoring equipment such as ECG, blood pressure, temperature etc. at home and feed the Web based EHR with information. This is a major step to reducing the cost of the health care system. The combination of home based patient care and Web based patient information really gives the patient the chance to be in control and move many of the services out of the traditional health care environment.

Introduction

Electronic health records (EHR)have now been under development for over a decade and use has, in the last few years, just started to accelerate. However, no sooner have they started to be recognised as a functional tool for managing aspects of health care, so the concept is beginning to change.

There is one major driver for these changes and that is a global overloading of the health care system. This is predicted to become worse as the population becomes older. A solution needs to be found before the whole system breaks down. One solution is to spread the care system out across the different levels of the health service and connect it together with information and communication technology (ICT). The EHR is a major enabler for this as is the concept of telemedicine.

With these new technologies, health care can eventually be moved outside the traditional boundaries of the health service and into patients' homes. It is here that a real saving will be made. There will be a need for a massive re-organisation of traditional health provision for this to happen, but many governments are beginning to realise that there is no alternative if costs are to come down.

Towards eHealth

The change towards Web based heath or eHealth is being catalysed by the development of a multitude of medical and health based Web portals. Web portal development growth was initially in the USA, but is rapidly spreading to the rest of

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[2] The author is Senior Project Manager at MedIT, Oslo, Norway. andy.hyde@medit.no

the world. Patients, relatives of patients and the general health conscious consumer are able to find information about almost any illness, rare disease or aspect of healthy living much of which was until recently the carefully guarded domain of the medical profession. Their defence of this was that the public would not understand, and this may be true, but the public appears to want to know. Much of the available information is un-censored and of poor quality but this does not deter the innocent information surfer. The previously closed domain of the god-like doctor is slowly being opened. This is an expression that the public wants to take more control of their own health, at least in the area of knowledge. A simple development in communication between the patient and the health service that is provided by some Web portal sites is e-mail exchange with general practitioners. Even renewing of prescriptions and other simple services are becoming available. All of this means that the patient is or will be visiting the doctor less.

These changes have a parallel in banking. The bank was once in control of your money. If you wanted to invest your money you went to the bank to talk to an expert. If you wanted cash, you went to the cashier and if you wanted a loan you talked to the bank manager. Now cash point machines have replaced the cashiers, bank loans can be handled by your Internet bank and a greater percentage of people know how to invest their money without asking the bank, thanks to open information. Again this is an increase in knowledge that was previously the domain of specialists and there appears to be no reason why the heath care domain will not show the same development patterns.

Patient Owned Health Information

Such developments in the domain of health and medicine are fuelling the next debate and inevitable change, which is one of patient ownership of their own medical and health information. This is reflected in the aims of TEHRE as opposed to TEPR (Towards an Electronic Patient Record). The Health Record is more that just medical information gained as a patient in the health service. The record is a life long diary of information that maybe of use if one is unfortunate to become a patient in the future.

To create such a health record requires that you have a place to collect the information and a format in which to store it that is accessible to the health service when required. Having a place to store information that is accessible to the masses immediately points to an Internet based solution. An ever growing percent of the population of most developed countries have access to the Internet. Just as with electronic banking, we trust (or many do and the number is increasing) that we transfer information over the Internet and expect that it will be safe and stored as if we had visited the bank ourselves. Security of access to information from the Web and the transfer of information over the Web are developed to a high enough level such that no serious breaches of security have so far been reported in the regular computer or tabloid media (to the best of my knowledge). Security breaches from *inside* the companies storing information have been reported and this is clearly an area of concern. So the Internet should be a place where we can start to store our health information, but there is still the question of making it available in a usable format.

Standards!

Standards! Are there really such things and are they usable? In the health care domain there are many. Three will be mentioned here and this is because they all claim to be

interoperable in some way and because they cover the aspects of storage and communication of health information necessary for a distributed model. Health Level 7 (HL7) is the first. This is the American messaging standard for integrating proprietary information technology (IT) systems in health care. This is now making a breakthrough in Europe. HL7 is for passing mainly text based information between systems. Digital Imaging COmmunication in Medicine (DICOM) is a standard for image storage and sharing. DICOM and HL7 have a number of elements in common by design. The third is a new developing standard called CEN/TC251 (www.centc251.org), which again claims interoperability with HL7. Part of the CEN/TC251 standard is a description of HISA (Health Information Systems Architecture) and is a standard for a "middle layer" between services and existing standards and an underlying database. It also includes standard terminology, a pre-requisite for any usable standard. All of the afore mentioned standards are also being XML-enabled. XML (extensible markup language) will be a major part of information exchange on the Web. It appears that standards are becoming open, consensus based and interoperable. These are three ingredients which may allow a broad acceptance where more closed standards have failed.

Telemedicine

With a place to store information and a format in which to store it, Internet based, patient owned health information is beginning to be more than just a future development. These changes are accompanied by changes in medical device technology and so called telemedicine. Telemedicine is a field often associated with the transfer of medical images from one doctor to another for a second opinion, often also called teleradiology. But telemedicine has advanced far beyond this and is now providing a new opportunity for moving some basic hospital and general practitioner (G.P.) services out nearer to the patient. Much effort is now being put into the "home care" concept. This is the movement of medical monitoring into the home and connecting it to health care establishments by telecommunications. In order to enable this, medical instrumentation needs to become more portable and Web enabled. The term Medical Net Instruments (MNI) has been coined to describe this new technology.

> An MNI is an intelligent, miniature medical biosensor with wireless communication allowing connection of the device to a communications network where monitoring and other medical services are provided.

The development of MNIs is part of the European Union's 5th Framework program of projects, specifically TelemediCare (www.telemedicare.net). The aim of the project is to develop miniaturised sensors for vital signs monitoring that will transmit the medical information over a network such as the Internet to a server running a HISA based storage system. Health care professionals can monitor the information and send messages to or contact the patient by phone if required. The system will automatically generate alarms if needed, based on the information received, which will be available locally and at the monitoring site. The patient will have access to and control of the information and will control the access given to others. Such technologies will be available as early as 2001.

A New Health Care Scenario

The combination of patient ownership, Internet storage, standards, new medical technology and a push by governments provides a extremely strong case for change. The future for many health care services will then be more like the following scenario. A member of the public, interested in their health, will visit a local pharmacy or other supplier and buy or rent the appropriate Medical Net Instruments. A Public Key for controlling access, identification and encryption based on the Public Key Infrastructure (PKI) system will be assigned if not already available. The MNI is wireless enabled to connect to a communications network via, for example a 3rd generation cell phone (UMTS), which is online to the Internet permanently. Once a month, the health conscious consumer will connect the MNIs and record information directly into his or her health record. At some point after this time the person may become a patient in the health service. At this point he or she will give access to the information to a doctor by granting permission to view it. This can be done using the PKI system. The doctor may be given access to allow a specialist to view the information and add conclusions. Further, more advanced MNI equipment may be provided by the consulting doctor for more advanced analysis. Artificial Intelligence based analysis will also be available, enabling high quality, full time, expert analysis. If the patient is not happy with the service received, he or she can revoke access and seek another opinion. All this and more will be available sooner rather than later changing the electronic patient record before it is really established in its current form.