

Issues on Health Data Collection

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Abstract

In health care, information about health clients is important so health workers can do their best to ensure that their clients are properly cared for. With the speedy development of the Internet, the health information of patients can be retrieved instantly; otherwise it can take weeks and this long delay can create problems for patients, their families and health centres. However, data collection, particularly with the use of information technology, can cause problems which do not normally occur in the traditional data collection approach. This paper examines the concepts and issues relating to the development of an integrated health record system and identifies problems which are faced by health workers in relation to intercultural communication, privacy and safe data collection in health care.

Keywords: Health data models, data collection, online health, integrated, electronic health records.

Introduction

The Internet has been hailed as a revolutionary superhighway which connects numerous global villages together. It is a unique phenomenon that no one could imagine in the last century. Business institutions, particularly the banking section, have brought their companies to the homes of individual clients. Bill payment, stock exchange, e-tickets, teaching and learning processes can be undertaken via the Internet. The virtual world is increasingly becoming a real world of human interaction. However, this electronic paradigm has not created a big impact on health care. As Laughnan simply illustrates:

If you are a resident of Wisconsin and insert your card in an ATM in San Francisco, the system will immediately recognize you, your bank, and your financial records. But if you find yourself in an emergency room you'll likely need that same card to pay for an extensive series of tests because your medical record is a piece of paper sitting in your hometown doctor's office. (Laughnan 1997)

This paper examines the concept of an integrated electronic health record system and some issues and principles underlying such a system. In the final part of the paper, the discussion will focus on potential problems in implementation of such a system from an intercultural perspective.

Integrated Electronic Health Record Systems

The Internet has permeated many aspects of society. However it is rather slow in building a bridge for health workers, clients and health institutions to interact. The irony is that the United States of America (USA) is the heart of information technology development and according to the Health Information Technology Leadership Panel Final Report, 96 percent of physicians use computers. However,

the same report showed that 49 percent of physicians surveyed do not intend to use electronic health records. (Laughnan 1997)

The USA is the champion of modern information technology with various powerful information networks. However, a national health record network is still in its embryonic development. On 16 June 2005, Mike Leavitt, Secretary of Health and Human Services announced that the US government set an aggressive goal of making electronic health records available to a majority of Americans within ten years. (USDHHS 2005)

The integrated electronic health record system is needed for the following reasons:

- Patients do not always know their health conditions and remember their health treatment history.
- There is a need for health workers to access the same information from a common source so they have adequate information about their patients.
- Testing and related results held at different health centres should be made available via a common e-system.
- An integrated health record system can be of great interest to research, health management and administration.

Mount et.al. (2000) identifies the following additional benefits for the healthcare system:

- Better-informed policy development;
- Improved resource allocation and management;
- Outcomes and cost-benefit analysis of interventions;
- Identification of causes and risk factors of disease;
- More efficient collection of demographic data for management and epidemiological purposes;
- Monitoring of disease outbreaks and adverse reactions; and
- Establishment of registers for diseases, devices and treatments.

In Australia, two initiatives have been developed: *MediConnect* and *HealthConnect*.

MediConnect, previously known as Better Medication Management System (BMMS), is a national electronic framework drawing together information about the medicines people use. *MediConnect's* main aim is to help doctors, pharmacists and hospitals to deal with problems when medicines are not used properly by improving consumer and health care professionals' access to more complete medicines information. The electronic *MediConnect* record will be stored with Health Insurance Commission (HIC) which administers Medicare and other government health programs. With clients' consent, doctors, pharmacists and authorised hospital staff will be able to view and download information to help them to treat clients appropriately as well as to add new medicines information to clients' records. (*MediConnect* 2003)

Before *MediConnect* is made available to all Australians, the system is being tested to ensure that it has the right features for everyone - consumers, doctors, pharmacists and hospitals - and works well. A test was conducted in Launceston, Tasmania and Ballarat, Victoria in March 2003 and concluded on 31 December 2004. Over 3100 consumers, 62 GPs and 100 pharmacists from 37 pharmacies were involved in the Field Tests. During the Field Test, over 110,000 messages were sent between health care providers and *MediConnect*. *MediConnect* Field Test will integrate into *HealthConnect*. (*MediConnect* 2004)

HealthConnect is a network of electronic health records. It is metaphorically seen as the health superhighway for the flow of information across the Australian health sector. It is a partnership between the Federal Government and the states and territories, has undertaken an extensive program of investigation, evaluation and trials to find the best model for the health information network. *HealthConnect* provides the electronic collection, storage and exchange of consumer health information. It aims to provide health professionals, quick and secure access to important and potentially lifesaving medical information. *HealthConnect* trials have been operating in the Northern Territory and Tasmania since 2002. In 2003 another trial commenced in North Queensland, and in 2005 more trials will begin in New South Wales and South Brisbane. (*HealthConnect* 2005a)

MediConnect is a secure electronic system of medication records held by different doctors, pharmacies and hospitals. It is designed to provide doctors and pharmacists with adequate medicine information to improve quality and safety in medication management. The *MediConnect* is integrated with *HealthConnect* and will form the medicine component of *HealthConnect*. (*HealthConnect* 2005b)

Concepts and Principles Underlying a Health Record Network

What are electronic health records? This question was raised by the National Electronic Health Records Taskforce (2000). This is a key question before working on building an integrated health record system or network. The Taskforce favoured the following definition:

An electronic longitudinal collection of personal health information usually based on the individual, entered or accepted by health care providers, which can be distributed over a number of sites or aggregated at a particular source. The information is organised primarily to support continuing, efficient and quality health care. The record is under the control of the consumer and is stored and transmitted securely (National Electronic Health Records Taskforce 2000, p. 21).

This definition includes the following key words which designate the important concepts and principles underlying a health record system: electronic, longitudinal, organised information, control, stored, transmitted and secure.

The term 'information' is used here as it signals the 'content' which is embedded in a record.

The two concepts 'information' and 'data' tend to be used very loosely in daily communication. This is partly due to the fact that they are both used interchangeably in some contexts and not in others. For example, doctors needed to find out a great deal of information about their patients' health conditions and backgrounds so that they could provide adequate care to them. In this context, it is information gathering or data gathering. However, there is a great amount of information about a hospital or a university which may not be treated as data.

The term 'data' is used in research to indicate some sense of control in information collection. The *what* and *how* questions about data collection need to be legitimately explained in order to turn information into data, or vice versa as indicated in the definition above. Thus data may be accepted as solid data by some researchers but can be rejected by others as soft data or merely ordinary piece of information.

In the health area, information about various aspects of health can be obtained. They come from different sources such as news from the media, governments' documents, records of patients, reports, announcements, research publications etc. Information

gathering for health records should take into account the features and principles underlying the development of a health record model. These features and principles to a great extent determine whether information is treated as data or a mixture of fact and fiction. This factor is very important in health care as flimsy information can easily lead to misinformation, mismanagement and fatal results for individuals and institutions.

It is expected that all health care services keep some form of health records of their clients. However, the differences can be in terms of data type, depth of information, terminology, file system, and procedure. The challenge is how to establish an integrated health record system which captures the health records provided by different health care providers.

An integrated health record system is metaphorically like different streams leading into a big river. Thus there should be shared standards governing data collection and management.

One of the biggest issues for health data today is the lack of shared data standards. The lack of shared standards increases paperwork and data collection burdens, and reduces the analytic potential of health data. Without consistent use of data standards, there is little ability to make multiple uses of or link data, limiting the usefulness of Health and Human Services (HHS) data to our public and private data customers and State partners, and vice versa. (HHS - Data Council Committee on Health Data Standard 1997)

In the development of a powerful integrated health record model, these principles can be seen as a number of key 'building blocks' developed to underpin the network. The building blocks are the 'road rules' governing the system:

The following part of the paper will discuss a number of concepts which can be seen as building blocks in an integrated health record system. They include clarity, appropriateness, consistency/standard, security and confidentiality.

Clarity. Validity and reliability are widely used in research to discuss experiment, observation and various kinds of data collection tools such as questionnaire and testing. In health care, information needs to be systematically and adequately checked and recorded so that subjectivity and negligence can be avoided.

According to the Privacy Amendment (Private Sector) Act 2000, an organisation must take reasonable steps to make sure that the personal information it collects uses or discloses is accurate, complete and up-to-date.

Appropriateness: This applies at different levels of data collection and entry. It is important to consider how the data is collected, by whom and for what purpose. For example, data collection by questionnaire may be linguistically and culturally appropriate to the mainstream Australian public but could be inappropriate to some cultural groups. Clinical interview can create tension between health care workers and their interviewees as the cultural gap and social distance of their backgrounds are huge.

Consistency/standard: Coherence and consistency require some uniformity in data collection, storage, and description. This is where the notion of 'standard' applies most.

Standards are intended to facilitate data analysis and they are used to ensure comparability, quality and interoperability regardless of data collecting from different sources. This is accomplished through messaging (or communication) standards used by software vendors and application developers. According to National Committee on Vital and Health Statistics (NCVHS), Health Level Seven (HL7) is a

standard for the electronic exchange of patient record information. (Tracy & Dougherty 2005)

In terms of Internet security, standard also involves technical encoding and decoding for various data exchange. The standard mechanism for communicating over networks is in a secure fashion for delivering structured medical record content. For example, DICOM defines messages for encoding and exchanging medical images, patient registry records, test results, and X12 is a set of standards for exchanging authorisation, referral, and billing records. The communication standards of choice are the internet standards including the base internet protocol for sending packets of information, the Secure Sockets Layer for encrypting transmitted information, Certificates for verifying the identity of the communicant, and Electronic Data Integration (EDI) over the Internet for secure MIME e-mail, etc. (McDonald 1997; Tracy & Dougherty 2002)

The National Minimum Dataset (NMDS) reflects the concern for a unified health record system and it is used widely in New Zealand and Australia. It is important for policy formation, performance monitoring, research and review. The NMDS is a national collection of public and private hospital discharge information, including clinical information, for inpatients and day patients.

The NMDS has been subject to changes so that it can adapt to new situations. In other cases, additional fields have been included and events are reported in more detail than in the past. (NZHIS National Collection – NMDS 2003)

Security and Confidentiality:

The Privacy Amendment (Private Sector) Act 2000 in Australia made the following statements about data security:

- An organisation must take reasonable steps to protect the personal information it holds from misuse and loss and from unauthorised access, modification or disclosure.
- An organisation must take reasonable steps to destroy or permanently de-identify personal information if it is no longer needed for any purpose for which the information may be used or disclosed. (National Privacy Principles - 2000)

Confidentiality is the most important aspect of data collection in health care. For most patients, the appropriate degree of confidentiality will fall between and will be a compromise between privacy and the desire to receive informed help from medical practitioners (Mandl et al. 2001). This is one of the reasons why patients are reluctant to provide personal information about their health to those they do not trust. When medical records are traditionally in hard copy, confidentiality is still at risk due to theft or personal abuse by file keepers. This tends to occur in a limited context and breach of confidentiality can be identified and rectified. However, it is a big concern when data collection, storage and transmission are electronically based. Institutions such as banks, industrial companies, the armed forces place security as the ultimate condition for their survival. In health care, absolute computer security is expected by patients and doctors. There are mainly two broad problems caused by breach of confidentiality: problem caused by users and problem caused by the system.

- Problem caused by users: Health care users include those who are responsible for maintaining records at various destinations at health centres. If they are not conscious of confidentiality issues and are not properly trained to handle health records, problems can arise.
- Problems caused by the system: Traditionally health records are kept in hardcopy and it is very time-consuming to access a particular record, particularly for those who are not specifically assigned to the task. Though the traditional system tends

to be not user-friendly, this negative feature can be 'constructive' in the sense that it is hard for outsiders to infiltrate the system. Nowadays, an e-system is most productive in terms of speedy access and transfer. However it can cause serious problems if it is not securely protected. When an intruder can access the file system, the consequence is far-reaching. The lost data can be transferred to numerous destinations for misuse. This is why consumers should have full control over both the content of their health record and which health care providers can access their record. It can be achieved by the use of passwords, audit trails, review processes etc.

In the "USA, a recent poll showed a near tie between Americans who believed the benefits of HIT would outweigh privacy concerns—and those who believed the privacy risks are simply too high. The HIPAA [Health Insurance Portability and Accountability Act] provisions represent a beginning toward resolving privacy issues, but not the end. With 50 States and 50 sets of State law affecting privacy, there is still ground-level work to be done—and this is work that is crucial to the success of HIT. (Clancy 2005)

In Australia, the Privacy Amendment (Private Sector) Act 2000 was passed to strengthen personal information safeguard. This Amendment Act covers the collection, transfer and use of personal information in the private sector. This has far-reaching implications for health data protection and confidentiality. Ten National Privacy Principles were introduced: collection, use and disclosure, data quality, data security, openness, access and correction, identifiers, anonymity, transborder data flows and sensitive information. ((National Privacy Principles - 2000)

Privacy is one of the key principles governing *MediConnect*. Consumers are able to have control over their personal information, including the ability to 'block' information and decide who can access their medication records, and when, through a consent process. Participation in *MediConnect* is voluntary for all participants - consumers, doctors, pharmacists and hospitals. (*MediConnect* 2004)

It is essential that personal health information is adequately protected within a health record system and there are stringent controls over who has access to what information. The high standard of *HealthConnect* would be compromised unless adequate access controls are provided.

- limit access to authorised users;
- establish governance structures to oversee user authorisation;
- promote strict access rules and safeguards, which provide auditing and monitoring mechanisms to prevent unauthorised access, use or disclosure of data held within *HealthConnect*; and
- govern secondary uses of data. (*HealthConnect* 2005c)

Potential Problems

As discussed previously, it is important to set up an integrated health record system which can provide a central source for health workers and health institutions to access so that health care can be greatly enhanced. However it is not always smooth sailing as there are potential problems.

Clancy points out the following issues relating to creating and implementing a health record system:

- not just availability of information whenever and wherever needed, but information that is secure and private, and guided by the patient's wishes;

- not just evidence-based information for better quality care, but information that's truly accessible and usable—at the point of care;
- not just quality in the patient's care, but quality measurements for the consumer;
- and in the end, a system not imposed by edict or mandate, but adopted and used because it works. (Clancy 2005)

Frequent updating is very important to health records of individuals to keep up with changes. For some, the change can take place in a matter of days or weeks; for others a periodic updating can be sufficient. This is why e-data is very useful in this regard as e-data can be updated quickly and can be systematically integrated into a wide system of distribution. However, updating can be a problem if it is not systematic or undertaken in an ad hoc way. There should be a mechanism to monitor updating of individual health records. In some cases, it is better to have no records than to have inadequate or outdated records.

Cost is also a factor in the development of an electronic health record system. As a whole, a national health record system can be very cost-effective and it saves a great deal of paper, energy, and storage. The costs for purchasing hardware and software can be economical. However it may not be the case with smaller practices. It can cost less for larger practices because the physicians can share some of the bigger expenses, like a server, networking cost etc. (Gunter & Terry 2005; Hawryluk 2004)

Security is considered the most important issue facing the implementation of an electronic integrated health system. Paul et al. (2005), point out the following threats:

- a sniffer, software like a phone tap, monitors network traffic to intercept;
- unauthorised Internet users and unauthorised intranet users intrude the network; and
- spoofing can take place (i.e. someone pretends someone else).

Standardisation

The word 'standard' is used repeatedly in the discussion of an integrated health record system as it helps to enhance uniformity, constancy and interactivity at various levels and stages of implementing the system. However, standardisation can cause problems. For example:

- the standards themselves may cause problems to some stakeholders if they are highly technical.
- A standard undergoes review and revision. This can cause problems when rational statements for a standard are misunderstood by new users.

Apart from problems associated with building an integrated health record system such as standard, consistency, systemic integration, hardware and software, there are moral, legal and ethical problems which need to be addressed.

According to the National Electronic Health Records Taskforce 2000 (NEHRT), the enhanced electronic capacity to collate, share, match and manipulate information generates risks as well as benefits.

Access and ownership

According to the NEHRT (2000), Australian consumers do not have a uniform right to access their medical records. They may have access to those held at public hospitals but not those held in the private sectors. This access problem leads to the issue of ownership. Who 'actually' owns the record? Even with non-electronic records, ownership resides with medical practitioners (or their employees) who have the right to decide whether or not to show a record to a person when requested to.

The issues of access and ownership have many legal implications, particularly when there are disputes among stakeholders.

Privacy: whose privacy?

Privacy and confidentiality are among the most important features of an integrated record system but they also are very culturally determined. Some migrants may not treat personal privacy as seriously as their Western counterparts. From their cultural point of view, there is not a strict boundary between the private domain and the public domain. What is seen as private in a Western culture may not be so in their cultures. This can cause problems in maintaining health privacy in an integrated health system unless it is dealt with in an induction program for migrants.

Accountability: whose accountability?

Accountability is central to the ethics required in operating an integrated record system. Patients provide their personal health information to a system where they feel absolute accountability is adhered to. Ethically, accountability refers to the acceptance of responsibility to certain actions and consequences. An integrated system can be so vast and virtual that accountability is hard to apply. As accountability is socially and culturally constructed, participants in an integrated health record system may bring to their tasks different cultural interpretations of accountability. It is easy to set a standard for hardware security but it is very difficult, if not impossible, to create a solid standard of accountability when participants have different cultural expectations of accountability to the system, health workers, patients and themselves.

Cultural inclusive

In a pluralistic society like Australia, consideration of intercultural issues need to be made as people of different cultural backgrounds bring cultural meanings and expectations to the interpretation of health care issues and implementation of health practices.

According to the NEHRT (2000), there are important implications for a national approach in a multicultural Australia. For example:

- A national approach to electronic health records must be cultural inclusive.
- Indigenous community controlled health services must be the brokers of the implementation of electronic health records in their community.

Kinship

In Asia, as in any other society in which such traditional kinship relationships are emphasised, any individual is acutely aware of his or her obligations and responsibilities to those who have come before as well as those who come after. From birth one is made conscious of the debt owed to one's own parents, which is largely carried out in the form of duty and obedience.

Scollon and Scollon (1995, p.130)

Kinship should be taken into account in examining the relationship among closed and extended family membership. To some extent, the actualisation of kinship in social discourses can be seen in terms of individualism and collectivism. For some their health records are their personal property and it is up to them to decide who can access their personal health information. This may not be the case with those whose values and beliefs are driven by the principle of collectivism. Parents may exert their rights to control the access of their family members and this can cause problems in implementing an integrated health system based on individualistic ideology.

Cultural interference takes place in a system where participants come from different cultural backgrounds. The discussion of just a few concepts and issues above aim at

highlighting the problems which go beyond the general aspect of Internet and system security. It is important to situate the system into a socio-cultural discourse so that we are fully aware of the potential problems in implementing an integrated health record system in an intercultural country like Australia.

Conclusion

The Internet has opened many innovative windows for industry, education and health. It is not only a tool but also a new paradigm for professionals and services to operate in a changing and complex environment. The idea of creating an electronic integrated health record system reflects the recognition of the power and usefulness of the Internet and its significant contribution to health care. While there are many envisaged advantages for having such a system in terms of rapid access to personal health records, consistency, cost-effectiveness, effective management and administration, there are also potential problems which can turn constructiveness into destructiveness. The introduction of an electronic integrated health record system will undoubtedly pose some risks to individuals and organisations. However it is a very worthwhile risk to take.

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