HealthConnect: making consent and privacy a priority

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Introduction

One of the biggest challenges for consumers and health care providers at the point of care is the limited flow of essential health information associated with current health-record-keeping systems. Health care providers generally keep their own patient records, often in a paper-based format. This means that parts of an individual’s health information may be stored in many different locations and can be difficult to access in times of medical need. Even when information is kept in electronic form, it is often scattered across incompatible databases, which inhibits sharing of the information.

Imagine the scene of a car accident on a major highway, in which the unconscious driver, Jane Smith, has been rescued from her wrecked car and lifted into an ambulance. She is about to be sped to hospital in what should be a smooth passage to safety and care. However, this may not necessarily be Jane’s experience. In her unconscious state, she cannot warn the doctors that she is allergic to some medications and cannot take other drugs because of an underlying medical condition. If such crucial information is inaccessible to treating medical staff, potentially fatal errors may result.

Every year, many Australians become ill or die owing to adverse events during diagnosis or treatment because of circumstances, especially in emergency situations, similar to those described in this hypothetical case. It is anticipated that HealthConnect, a cutting-edge national information technology project now under way, will revolutionise the handling of medical records, while dramatically reducing the risk of adverse treatment due to the inaccessibility of health information. HealthConnect is being developed as a partnership between all Australian governments. It will provide an up to the minute, national, Internet-based register of clinically relevant, summarised patient information which will be available to treating doctors and nurses in any location, at any time, subject to the consumer’s consent.

Personal health information is extremely sensitive, however, and consumers must be confident that their information is valued and used wisely. Accordingly, HealthConnect has spent considerable time ensuring that the community’s right to privacy, as well as its interest in achieving better health, is upheld and protected.

This article outlines work under way at the national level to develop HealthConnect and how some of the key issues relating to consumer consent and privacy are being addressed in consultation with key stakeholders.

HealthConnect research and development

The HealthConnect Project was jointly funded by the Australian, State and Territory governments for two years (July 2001 to June 2003), to investigate the feasibility and potential of a national electronic health record network for Australia. At their November 2002 meeting, Australian Health Ministers agreed to a further two-year phase of design and development work, ahead of national implementation of the scheme.

The fundamental purpose of HealthConnect is to collect, store and exchange personal health information, in order to improve the delivery and quality of health care while enhancing the privacy and respecting the dignity of health care consumers. Under HealthConnect, a person’s health-related information will be collected in a standard electronic format at the point of care, such as at a hospital or a general practitioner’s clinic. This information will take the form of health summaries, rather than the complete notes that a health care provider may choose to record in relation to a consultation. Participation in HealthConnect will be voluntary for both consumers and providers. With the consumer’s consent, these summaries will be retrievable at any time they are needed and exchanged via a secure network among those particular health-care providers authorised by the consumer to access this information.

The HealthConnect Project is being undertaken by the HealthConnect Program Office, located in the Australian Government Department of Health and Ageing. Overall governance of the Project is via a joint Australian, State and Territory Government Board. A Stakeholder Reference Group comprising key consumer and provider group representatives has been established to ensure that a wide range of stakeholder views feed into the project.

Substantial progress has been made to date, and the foundations for possible national implementation are now in place. In particular:

- HealthConnect trials in Tasmania (diabetes focus) and Northern Territory (remote and Indigenous focus) have been operating for over 12 months and are showing positive results with strong stakeholder support.
- A North Queensland trial commenced in December 2003, with other trials due to be launched in Brisbane and in two sites in New South Wales in 2004.
- Substantial progress has been made in developing key building blocks, including a national health privacy framework and data, messaging, storage and security standards.
- The HealthConnect Interim Research Report (www.healthconnect.gov.au/researchrep/irr.html), which includes key findings of the value, technical feasibility, building block requirements, costs and sustainability of HealthConnect, has been published.

The Australian Government has also been developing MediConnect, the proposed electronic medication record, which is designed to improve quality and safety in the management of medications by giving
doctors and pharmacists more complete information about the medicines people are using. MediConnect will now be integrated with HealthConnect and will, in effect, become the medications record for HealthConnect.

Consumer consent

Consumers and providers need to have trust in the way their personal health information is kept secure. Consent is one of the mechanisms by which privacy is ensured. In general, consent refers to the provision by one person of a voluntary agreement to a proposed action by another person. Consent should be voluntary and informed and the individual must have the capacity to provide, understand and communicate his or her consent. It is important that when an individual consents to make available personal information to certain providers he or she is properly informed about what this might entail and to what information the various providers might have access. Individuals must also be aware of the circumstances in which a provider would be able to access their records; for example, whether only when the individual is present with the provider during treatment or care, or whether there may be other situations in which the provider needs to access the record in the absence of the individual.

The scope of HealthConnect therefore requires that careful attention be given to how information about the system will be accessed by health providers, to what information providers will have access and how an individual can maintain control over the overall handling of his or her health record. In the HealthConnect context, consent signifies that the consumer agrees that an entity (eg, a health service provider) can enter new data into HealthConnect, or have access to personal information already held on HealthConnect. Consent is a crucial issue for the e-health agenda. It operationalises privacy, and provides the mechanism by which the collection and exchange of information can occur. The challenge is to devise a means of gaining informed consent that protects consumers’ privacy while remaining workable for providers.

To date, electronic health records systems in Australia and overseas have been built to apply to specific organisations or sectors, such as a hospital, an area health service or to the pharmacy sector. Some systems have been developed to have a wider application (eg, to apply to a group of hospitals or medical centres), but these generally still have clearly defined boundaries or target audiences. The vision for HealthConnect is therefore much broader than most existing electronic health systems and initiatives.

HealthConnect is expected to bring about many benefits, and this derives from its wider access to the information beyond that which individuals have previously experienced. In this context, work on privacy and consent is critical not only to the success of HealthConnect, but to any future e-health initiatives aimed at increasing the flow of information beyond existing organisational boundaries.

Trialing of consent models


The Northern Territory trial is testing a model in which consumer consent is obtained before the inclusion of an event summary on the HealthConnect record and prior to a provider accessing an individual’s HealthConnect record. The Northern Territory is continuing to test this model for the trial extension from June 2003 to June 2004.

In the Tasmanian trial, the consumer gives standing consent at registration. This spells out what types of information providers are permitted to view on the HealthConnect record. Unless the consumer specifically requests otherwise, all event summaries are automatically included in the HealthConnect record.

The NSW trial (EHR*Net) is testing a model in which consent is obtained at the point of registration, with the capacity to exclude particular individuals from accessing records, or the ability to limit access to only a small number of individuals.

In the North Queensland trial, the consent model uses the participating consumer’s initial consent to participate in the trial to allow nominated practices to have access to the HealthConnect record any time for the consumer’s health care and treatment. This model also uses a standing consent at registration for event summaries being added to HealthConnect. However, providers will also be encouraged to seek verbal consent from the consumer prior to the addition of the summary to the HealthConnect record.

The MediConnect Field Test is testing a consent model which provides consumers with more choices than the HealthConnect models. They include choice about emergency access, restricted access to particular parts of the record, and the consumer’s capacity to add or change information to the record, etc. An important part of the Field Test evaluation will be to assess the workability of these choices in daily practice.

Privacy issues

In addition to the consent issues discussed above, there needs to be in place a robust privacy framework ahead of a national implementation of HealthConnect. The HealthConnect Project is developing a multi-layered approach to privacy. This approach is expected to include legislation and policy rules based on the proposed National Health Privacy Code (Draft National Health Privacy Code, <www.health.gov.au/pubs/nhpcode.htm>) being developed by the National Health Privacy Working Group. The proposed Code sets out a single set of health privacy principles that would apply to the collection, use, disclosure and storage of personal health information held in both the public and private sectors across Australia. There will also be a need for a set of rules and possible legislation for HealthConnect that will set out:
• the uses of data, and the related consent mechanisms;
• national security arrangements for HealthConnect which cover the functions of identification/authentication, access-control mechanisms, message protection, monitoring and detection mechanisms and audit/logging processes; and
• organisational practices, including staff training, which ensure appropriate privacy and security standards are maintained by organisations participating in HealthConnect – as well as ensuring the development of an organisational culture which upholds privacy.

A critical part of the work is to ensure that the proposed privacy framework is developed in close consultation with key stakeholders at all stages. In this way, consumers and providers can help shape HealthConnect so that it meets their needs and engenders trust that health information will be safely handled across the network.

Where to next?
Evidence from the HealthConnect Project and international activity in the area of electronic health records indicates that Australia is on the right track with a national approach. As indicated above, the HealthConnect trials and MediConnect Field Test provide the opportunity to test a range of consent models ahead of national implementation. Building on the work on consent undertaken thus far, the HealthConnect Program Office will be developing a consent framework for HealthConnect drawing on the experiences of the trials and Field Test to date.

A consent working group has also been established by the Australian Health Information Council to consider broader e-health consent issues in 2004. Further policy work on privacy arrangements for HealthConnect is also being undertaken over the next 18 months as part of the pre-implementation work for HealthConnect.

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