

## Electronic Health Records: An International Perspective

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*Development of electronically linked patient records or Electronic Health Record schemes (EHRs) is a priority for governments in many countries, including Australia, as part of a vision for future health care services using call centres, web-based patient information and telehealth. This article discusses the privacy framework needed for EHRs and the role of Privacy Commissioners. It reviews nationally significant EHR schemes in Canada, England, Germany, France and Ireland and the privacy frameworks they operate within.*

EHRs offer health care providers access to a more complete medical history of a patient, with the patient's consent. They are generally used in conjunction with 'decision support' software systems for health professionals, providing medical information such as clinical guidelines and checks, such as adverse drug reactions. EHRs therefore promise to improve the quality of health care services, promote a more integrated approach to care and offer consumers an opportunity to better manage their own health care.

EHRs have been designed to perform a number of different functions. Current EHR schemes are primarily for financial purposes, such as processing claims for health insurance and government health benefits. More ambitious EHR projects are planned in Australia, Canada and Europe to provide a comprehensive lifetime patient record across the health system. They provide summary information about a patient drawn from detailed medical files held by clinics, doctors or hospitals.

According to opinion surveys, Australians generally embrace the benefits of EHRs, but only if the confidentiality and security of their medical record is protected. People also want to control how their personal health information is used. For example, most people expect to be asked before doctors or hospitals share information with others who are treating them or pass on information for research purposes. There are also concerns about the security of personal information transmitted over the Internet (Wendy Bloom & Associates 2000; Office of Federal Privacy Commissioner 2001a).

### EHR Projects

#### *Australia*

The major national EHR initiative planned in Australia is *HealthConnect*, an Internet based network providing for the collection, storage and exchange of summary patient information. A separate but related initiative is the Better Medication Management System (BMMS). It will provide a complete patient medication record, linking information about a patient's medication held by doctors, pharmacists and hospitals. It will be administered by the Health Insurance Commission. Pilot implementation of *HealthConnect* and the BMMS will commence in 2003, with some early fast track pilots of *HealthConnect* in late 2002. They are initiatives of the federal government, supported by state and territory health ministers (*HealthConnect Newsletter 2002*).

There are also EHR schemes being developed at state and regional levels. For instance, the NSW government has announced a statewide EHR, called *NSW EHR\*Net*. It will provide web-enabled access to a lifetime summary record of patient information held by the NSW public health system. (NSW Health 2002) Another example is a pilot program at the Alfred Hospital in Melbourne where admission and discharge information is electronically shared between the hospital and 20 general practice surgeries (Minister for Health and Ageing 2001).

Participation in all of these schemes will be voluntary for consumers. *HealthConnect* and the BMMS will be voluntary for health care providers too.

## *Canada*

A number of nationally significant EHR schemes are being developed and piloted in Canada, with implementation expected in 2003 and 2004 including:

1. The British Columbia *PharmaNet* system, introduced in 1995, provides online, real-time processing of a range of entitlements and benefits for British Columbian residents. *PharmaNet* provides pharmacists with a province-wide patient medication history, comprehensive drug information and automatic checks such as drug interactions. It has been available in hospital emergency rooms for some years and there are plans to extend it to doctors in the future.
2. *PharmaNet* is a lead project of HealthNet/British Columbia, established in 1993 to enable secure sharing of patient information across the province with online health records as part of the vision.
3. The Pharmaceutical Information Network (PIN) in Alberta will cover medicines information held by doctors, hospitals and pharmacists. Trials were completed in 2002. PIN is part of Alberta's *Wellnet* scheme, which aims to provide an umbrella for provincial and regional initiatives to build an integrated health information network.
4. The ePhysician Project in Ontario is developing a secure intranet for general practitioners who have agreed to be part of Primary Care Networks to access each other's patient records, with the patient's consent. It is part of Smart Systems for Health (SSH), an initiative of the Ontario Ministry of Health and Long Term Care, that provides the infrastructure for secure communication of patient information among health care providers across the province. Other SSH initiatives include a Drug Benefits Network (like British Columbia's *PharmaNet* and Alberta *Wellnet*) (Office of Health and the Information Highway 2001a; Information & Privacy Commissioner 2002).

The Canadian government has promoted a collaborative approach to EHR development so that provincial schemes learn from each other and to promote interoperability. A pan-Canadian Health Infostructure Plan was released by Canadian Health Ministers in 2001. Canada Health established the Office of Health and the Information Highway (OHIH) to provide project leadership and funding for government health infostructure programs. OHIH invested \$80 million in a two year Partnership Program to support national implementation of information and communications technologies in health care delivery. Canada Health Infoway Inc was established to foster development of communication technologies in health. It is creating a National Registry of EHR initiatives (Office of Health and the Information Highway 2001a).

## *Europe*

Plans for EHRs in Europe are well advanced with different models emerging in different countries. The European Union (EU) is promoting interoperability of national EHR schemes through a range of projects and EU forums (Schug 2001).

1. The National Health Service in the United Kingdom has conducted extensive pilot programs of EHRs and patient held electronic records over the past two years. An Electronic Patient Record (EPR), electronic prescribing and a patient held record are promised across all health services by 2005. The EPR will provide support for clinical and administrative tasks and track clinical pathways according to patients' conditions (Department of Health 2001; NHS Information Authority 2002).
2. The Department of Health in Germany is planning to introduce a revised health insurance card that will provide German residents with an electronic health smart card to process health insurance claims and provide electronic prescriptions, with the option of also storing other clinical information (Schug 2001).
3. The SESAM Vitale system in France has operated nationally since 1998 to provide secure electronic processing of insurance claims for all the population. It is comprised

of a consumer held smart card (Vitale card), a card for health professionals and a social health network that provides information to health professionals. The smart cards restrict access to the system, ensuring that patients records can only be accessed when the consumer is present. The social health network uses Intranet technology for secure mail exchange, an index of all registered users, electronic address book, transmission of health care forms, medical news, databases, some medical education information, sanitary alerts and diagnostic and prescription advice. There are plans to expand the system in the coming years using a web-based network and will include some patient information such as prescription drugs, immunisation, blood type (Schug 2001).

4. Phased introduction of electronic patient records are proposed in Ireland as part of a yet to be released National Health Information Strategy (Department of Health & Children 2001).

### **Privacy Framework**

The privacy framework gives people control of personal information that is collected about them and assurances that it will be kept confidential and secure. It requires that personal information cannot generally be shared with others unless the person gives consent. Health information is in a category of 'sensitive' information to which special protections apply. EHRs, which facilitate sharing of personal information over a wide network of people potentially conflict with privacy principles in a number of ways.

Privacy principles need to be embedded in the operational design of EHRs and everyone using EHRs must have a common understanding of their privacy obligations. A coherent legal framework to appropriately protect the privacy and confidentiality of personal health records is therefore an essential building block for EHRs.

#### *Australia*

In Australia the patchwork of privacy laws and policies of state, territory and federal governments undermines that goal. Private sector health care providers have been covered by the federal Privacy Act since December 2001, while state and territory hospital and health services are covered by state laws or policies introduced since 1998 (Office of Federal Privacy Commissioner 2001b).

The Federal Privacy Commissioner claims that projects such as *HealthConnect* are threatened by constitutional challenges to sort out inconsistencies between federal and state laws. A national Health Privacy Code has been promised for some years to provide a common standard for all governments to adopt (Woodhead 2002). Progress is being hampered at least partly because the federal government insists on using the federal Privacy Act as the basis for the Code.

The *HealthConnect* and BMMS proposals appear to see privacy as something that can be addressed through special privacy requirements in the laws that establish the schemes. Operational functions, such as consent processes, security arrangements, processes for patients to control how information is shared and patient access to information are not recognised as part of a privacy framework. The Federal Privacy Commissioner has recommended that information about privacy, consent and patient access to records be included in the *Business Architecture of HealthConnect* (Office of Federal Privacy Commissioner 2002).

The attempt to include special privacy requirements for the BMMS in a draft BMMS Bill in 2001 created more confusion rather than clarity. It would have meant that people using the BMMS would need to know when the general privacy law applied and when the BMMS obligations applied (Department of Health & Ageing 2001).

#### *Canada*

In Canada, the regulation of privacy in the health sector is at least as fragmented as in Australia, but progress is being made to develop a national consensus. Each province and

territory has privacy laws covering public agencies, but many of these, like Ontario, do not cover health service providers such as hospitals. None of the provinces, except Quebec has privacy laws covering the private sector. The Canadian government provided an incentive for provinces to introduce privacy and data protection laws for the private sector with the Personal Information Protection and Electronic Documents Act 2001. Initially the law applies only to private enterprises that come under federal jurisdiction. In January 2004, the law will also apply in any province that does not enact 'substantially similar' legislation (Privacy Commissioner of Canada 2001).

The Canadian Standards Association (CSA) has aided a national approach through the development of a *Model Code for Privacy Implementation*. It sets out 10 practices for fair information handling. The Model Code has been adopted in Ontario's Privacy of Personal Information Act 2002 (Privacy Commissioner of Canada 2001).

Canadian Health Ministers have agreed to a harmonised privacy framework in the health sector. The Advisory Committee on Health Infrastructure, serviced by the OHIH, established a working group on privacy in 2000. A nationally harmonised approach to the protection of personal health information has been drafted and the working group is developing a set of guidelines or principles based on the CSA model code (Office of Health and the Information Highway 2001b).

To assist this work Canada Health Infoway is conducting a review of the privacy issues for EHR, identifying the priority issues for implementation of EHR for provincial and territorial governments.

OHIH has promoted understanding of privacy as part of EHR technology by commissioning a *Privacy Technology Review* in 2001. It surveyed and assessed commercial privacy technology available now and in the near future, and recommended the best way forward (Office of Health & the Information Highway 2001b).

### *Europe*

France, Germany, England and Ireland have had data protection laws of some sort for up to 25 years, although their jurisdiction has been limited to the public sector, until recently. The laws varied widely until common privacy and data protection requirements were developed by the European Union (EU) under the EC *Data Protection Directive*. The Directive establishes common elements of privacy and data protection laws that must be adopted by member states. France, Germany, Ireland and England have fully implemented the Directive in 2001 and 2002 (Information Commissioner 2002; Schug 2001; Data Protection Commissioner 2001).

The EU Working Party on Data Protection, made up of the European data protection and information commissioners, is established by the Directive. The Working Group discusses issues of common interest, develops common positions on the application of the Data Protection Directive and emerging new directives on privacy. Members of the working party are currently considering the European Directive on *Personal Data and Electronic Communications*, passed by the European Parliament in July 2002. It addresses privacy issues concerning digital technologies in public communication networks and electronic communication services via the Internet (Schug 2001; Data Protection Commissioner 2001).

Compatibility of health information systems and policies on privacy and health information have been promoted in the EU at a number of other levels (Schug 2001).

### **Role of Privacy Commissioners**

Privacy and Information Commissioners in Canada and Europe have had an important role in providing independent, expert advice on the privacy and security aspects of EHRs. Yet their counterparts in Australia, so far, have had a very limited role in EHRs.

Privacy Commissioners and privacy laws in Australia have a very low profile. A survey conducted by Roy Morgan for the Office of the Federal Privacy Commissioner in 2001

found that just over two in five people were aware that federal privacy laws existed. Only 5% of people said they would report misuse of their personal information to a Privacy Commissioner. A quarter of people said they did not know where to report breaches and of the remaining respondents, most said they would report it to the Ombudsman, the organisation complained of or consumer affairs agencies (Office of Federal Privacy Commissioner 2001a).

### *Audits and Assessments*

Data Protection Commissioners in Canada and Europe use a range of measures to promote compliance and awareness of privacy laws in the health sector. The Data Processing and Liberties Commission in France and the Information and Privacy Commissioner (IPC) in British Columbia conduct regular audits of agencies, notifying the agency beforehand so the audit is carried out with a high degree of cooperation. The Data Protection Commissioner in Ireland has given notice that he plans to carry out random privacy audits on a sector basis (Data Protection Commissioner 2001).

Privacy Impact Assessment (PIA) has been developed in Canada as a tool for agencies to gauge whether new technologies, information systems and proposed programs or policies meet basic privacy requirements. Smart Systems for Health in Ontario conducted a PIA before commencing the ePhysician pilot implementation project this year (Information and Privacy Commissioner 2002).

Surveys have also been used. In British Columbia, for example, the IPC conducted a survey in 2001 of organisations administering health registers, such as cancer registries. It found none were complying with privacy obligations and none had conducted a PIA (compulsory in British Columbia for public sector agencies). In France, the Data Processing and Liberties Commission reviewed health websites to see if they complied with privacy requirements and identified many problems, especially about people being informed of their privacy rights.

### *Development of EHR Schemes*

IPCs in Canada and Europe are actively involved in the development of EHRs and the associated public debate. The Data Processing and Liberties Commission works closely with Caisse Nationale l'Assurance Maladi, the largest national insurer, which is responsible for the SESAM Vitale project. The Commission's opinions on the legal framework for SESAM Vitale are tabled in Parliament. Its opinions on EHR projects, such as a recent trial of a proposed system using the Internet to connect general practitioners and hospitals, are an essential element in public policy debate (Commission Nationale de l'informatique et des Libertés 2001; Commission Nationale de l'informatique et des Libertés 1998).

Smart Systems for Health in Ontario worked closely with the IPC in developing the ePhysician project. The IPC was requested to conduct a Privacy Review of a pilot implementation project following embarrassing allegations about the project in the media (Information & Privacy Commissioner 2002).

### *Access to Information*

Privacy Commissioners in Canada and Europe are acutely aware of the importance of striking a balance between protecting personal privacy and the public interest in freedom of speech. The Privacy and Data Protection Commissioners in British Columbia, Ontario, England and Ireland are responsible for administering both privacy laws and 'access to information' or Freedom of Information laws. Even where those roles are not combined, such as in France, the Data Protection Commissioners see themselves as agents for government transparency, not government censor (Information and Privacy Commissioner 2002; Information Commissioner 2002; Commission Nationale de l'informatique et des Libertés 2001).

In the context of EHRs this is important because governments will seek access to personal health information for a range of purposes and, on the other hand, use privacy

arguments to prevent publication of embarrassing information. Australian governments should consider combining the privacy protection function of Privacy Commissioners with the 'access to information' function of the Parliamentary Ombudsman.

## Conclusion

Australia could learn much from developments in Canada and Europe. Australian Health Ministers need to do more to promote a national framework on the privacy requirements of the health sector and EHRs in particular. A discussion among stakeholders about the privacy and security requirements of EHRs in Australia is long overdue. The structures adopted by the European Commission and Canadian Health Ministers offer some effective models. A national review of the privacy issues for EHRs, along the lines of the work of OHIH and Canada Health Infoway, would assist the debate.

Australian Health Ministers recently considered a recommendation for a new national body to bring together all uses of information in health and strategies to advance the use of new technologies. The proposed body, called the Australian Council on Health Information, would advise Ministers. It would be supported by an Infrastructure Unit to coordinate the national health infrastructure framework. Although privacy and security are recognised as one of three major components of health infrastructure, there is no work and no funding proposed in that area (Australian Health Minister Advisory Council 2002).

Privacy Commissioners need to have an active and public role in promoting awareness and debate about the privacy and security aspects of EHR schemes in Australia.

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*Please note that some of the information used in this article has been drawn from interviews conducted by the author for Churchill Fellowship research.*

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