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Development of a National Electronic Health Record

Introduction

> In November 1999, the National Health Information Management Advisory Council (NHIMAC) released *"Health Online: A Health Information Action Plan for Australia"*. One of the key recommendations in *Health Online* is the development of a national framework for the use of electronic health records.[1]

The Health Ministers established The National Electronic Health Records Taskforce to develop a national framework for a possible system of electronic health records in Australia. The Taskforce developed an Issues Paper "A National Approach to Electronic Health Records for Australia" and invited comment and feedback. As part of the consultative process, a series of public information sessions was organised for most states.

This Policy Issues Paper will be submitted to the Taskforce as a formal response to their Issues Paper.

CONTEXT: privacy and access to general practice medical records.

The Commonwealth *Privacy Act* does not cover GPs working in private practice, but the recently introduced *Privacy Amendment (Private Sector) Bill* will cover general practice records.

Common law means that at present, GPs are deemed to own patient records that have been collected as part of their professional work in their private practice. Patients do not have the right to access them. However, the AMA, as a professional organisation for doctors, and the RACGP, as the organisation that sets standards for general practice, both have positions/codes relating to patient records. Some aspects of these, particularly the question of patient access to records, are summarised below.

A bill introduced in Federal Parliament in early April, *The Privacy Amendment (Private Sector) Bill* will change the current situation, when it is passed. The legislation is based on the National Principles for the Fair Handling of Personal Information (developed by the Office of the Privacy Commissioner, January 1999) and covers the private sector. In the current climate of advanced technology and communication, it aims to protect privacy while allowing business to collect data necessary for its effective functioning. It sets some standards about passing on personal information on to third parties without consent generally and also covers personal health information. It is planned that it will take effect from 1 July 2001. An information sheet released by the Attorney-General's Department on 12th April says:

> *For the first time, all Australians will be able to access their own medical records held by private doctors unless providing access would pose a serious threat to the life or health of any individual. The Privacy Commissioner, in consultation with health consumers and professionals, will set guidelines for access to such information.*[2]

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[1] Letter of invitation from the National Electronic Health Records Taskforce, 22 March 2000, *Submission to the National Electronic Health Records Taskforce*, Commonwealth Department of Health and Aged Care.

[2] Attorney-General's Department, 12th April 2000, *Privacy and Health Information* fact sheet www.law.gov.au/privacy/Healthfact.html

The legislation will also cover private practitioners passing health information onto third parties. An individual's health information may be disclosed for research purposes, providing a number of conditions are met. These include disclosure adhering to new guidelines to be approved by the Privacy Commissioner (drawn up by the NHMRC) under Section 95A of the *Privacy Act (1988)*. [3]

Australian Medical Association (AMA)

> *Patients have a right to be informed of all factual information contained in the medical record relating to their care but do not have an absolute right to access medical records.*[4]

Although the AMA recognises the patient's right to be informed about their health care, the organisation interprets this as factual information; not for example, opinions contained in reports by specialists. Access to this type of information is at the discretion of the doctor. The guidelines suggest no obligation on the part of the doctor to provide a health summary, although she/he should inform the patient of "factual information." The guidelines state explicitly that documents created by doctors in private practice belong to the doctor.

Royal Australian College of General Practitioners (RACGP)

The RACGP's *Code of Practice for the Management of Health Information in General Practice*[5] suggests that medical records should not contain offensive or irrelevant comments. Gaining consent is the guiding principle for providing information to others. "Patients should have access to the information contained in the medical record… in most cases, patients' access to information can be provided by way of any accurate and up-to-date summary containing all relevant material." Access by patients is not an absolute right under this code, but although it is acknowledged that there are cases where access to the record may result in physical or mental harm to the patient and access may therefore be refused, the code suggests that the GP should weigh the harm that would be caused by providing access against the harm of refusing it.

Information Management Strategy Group (IMSG)

This group was funded by the DH&AC, and produced a guide for reference by general practices and general practice organisations, such as Divisions of General Practice.

> *Personal health information should not be collected, maintained or disclosed to third parties without the patient's consent. Ideally the patient's consent to disclosure should be in writing and identify details such as the extent of disclosure agreed to and the doctor to whom it is addressed.* (p.15)

> *Personal health information should only be used for the purpose for which it was gathered unless de-identified or patient consent to the alternative use is obtained.* (p.17)

In this guide, the perspective of divisions as local organisations is apparent when it is noted that simply de-identifying the data may not adequately protect privacy - eg. where a patient in a small

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[3] Further information (written in clear, accessible language) about the bill, the National Principles, and the provisions that apply to health is available at the Privacy Commission's website, www.privacy.gov.au; News; Frequently Asked Questions. Useful information is also on the Attorney-General's website (address above).

[4] AMA, 1997, G*uidelines for doctors on providing patient access to medical records*, www.ama.com.au, Position Statements, accessed 14/4/00.

[5] RACGP, June 1998, *Code of Practice for the Management of Health Information in General Practice*. Melbourne: RACGP.

community has a rare condition, or where there is a small number of GPs within a postcode boundary. The solution to this problem is not clear.

The guide recommends that any patient should be able to obtain access to personal information held on a database. Again there is a proviso that if giving the information is "reasonably expected to result in harm to the patient," it should not be provided. However the guide suggests that in this case the patient may elect disclosure to a nominated medical practitioner who may uphold or override the withholding of information. (p.17)

NATIONAL ELECTRONIC HEALTH RECORD PROPOSAL

General issues

The National Health Electronic Health Records Taskforce's *Issues Paper: A National Approach to Electronic Health Records for Australia* (March 2000) raises a number of important questions to be considered, which relate to settings more broad than general practice. These include:

Potential for better care & consumer concerns

The development of a national system of electronic health records has the potential to enhance patient care. It may have benefits for providers and for patients. It may enable better informed decision-making by clinicians, which should also benefit patients. A system that enables information to be shared effectively has potential for better communication and coordination between providers. For patients, a comprehensive health record might remove the need to remember their entire health history retrospectively, each and every time they have contact with a new health provider, and to repeat the same information. Balanced with this must be careful consideration of issues of privacy and consumer control and access, for several reasons. One of these is that there must be public confidence in the health system, for it to operate effectively. If patients do not have confidence in the system, they will not freely disclose all necessary information to providers, and this can ultimately harm not only the health of the individual, but public health overall. Additionally, some hold the view that patients should know what is contained in a record of their own health care. Although there is some disagreement about this among medical providers (the AMA and the RACGP positions on the issue, for instance, are quite different), it is worth remembering that divisions of general practice were established as a partnership between government, general practice and the community, in order to improve the quality of general practice, and thereby to improve health. This means that divisions have some interest in ensuring that needs of consumers are addressed adequately.

Accountability

The taskforce's public consultation meeting in Melbourne (10th April 2000) made clear that the type of record under consideration is one that consumers would choose to participate in; not one that would be forced upon them. It is not certain whether consent would be for each encounter, or for a group of encounters. An unspecified number and type of health providers would contribute to the record. Given the number of providers participating, there are concerns about accountability: tracing who is responsible for what, in terms of care, diagnosis, communication etc. This may be further complicated by an opt-in system (where consumers are not simply assumed to consent, but must actually give informed consent to each event being recorded on an electronic health record (EHR)). If consumers choose <u>not</u> to participate, their health record may be incomplete and the question arises of who assumes responsibility for the fact that information is missing. Admittedly, incomplete health records are common at present, but the difference might be the assumptions that operate if an EHR is assumed to be complete, but is not. Clear solutions to all these problems would need to be developed, if a national EHR system was to work.

Health record of individual or family?

The *Issues Paper's* definition of the health record (p.11) states that records could be based on individuals or families. Discussion at the public consultation meeting suggested that the primary reason for considering family-based records would be to enable research that may take account of genetic factors. However, another practical reason for the documenting family relationships in general practice and other health records is to note the social situation of the patient or consumer. (In fact, some community health services working under this principle, have in the past organised their records on the basis of households to further the aim of integrating social and medical models of health.) There are dangers in assuming that the social and biological meanings of the family are synonymous, particularly in the current social climate of blended families and assisted reproductive technologies.[6] Family-based EHRs would therefore be useless for research involving genetics, without further investigation of each individual family unit, calling into question the purpose of basing a record on the family rather than the individual.

There may also be concerns about young people's need to access health services independently of their families. GPs have expressed concern that confidentiality issues (the perceived sharing of information between parents and doctors) and the need to procure the family Medicare card have acted as structural barriers to adolescents using health services.[7] Presumably, this effect would be increased if health records themselves were also shared.

Which providers to include?

The taskforce's *Issues Paper* asks which health providers should be included in a national EHR system. (p.21) While concern amongst GPs tends to focus on better coordinating hospital records and general practice records, we need to consider which other providers would need to contribute to a record to make it comprehensive enough to improve patient care.

Balanced with the question of the types of providers to include, is the question of consumer privacy and of the need to ensure that consumers have confidence in the way the records are kept. Lack of consumer confidence in the system will prevent it working effectively. While the central issue *should* be protocols and procedures no matter how many people have access to the record[8], in practice the number of people who have access to a record can increase the risk of privacy being undermined. A recent case of an HIC employee being found to browse through the records of women who had IVF treatments, and Asian women, highlights the potential problem.[9]

Purpose of the EHR

The *Issues Paper* defines objectives and purposes for the EHR system that can broadly be grouped into two sets. The first relates to the enhancement of individual patient care; the second relates to enhancement of patient care through broader public health activity, including research and population health programs. While it is important to clearly define the purpose and subsequently define the technical system to achieve it, discussion at the public consultation indicated that it is likely that a different system might be needed for each of these purposes. For instance, an efficient electronic

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[6] This is particularly relevant at a time when just under half of all households comprise couples with children; nearly 15% are one-parent families (1996 Census Data); and one third of all people marrying have been married previously (ABS *Marriages and Divorces, Australia, 1998* released 24th August 1998).

[7] Veit, Sanci, Coffey, Young and Bowes, 1996, "Barriers to effective primary health care for adolescents," *Medical Journal of Australia*, Vol. 165, No. 3, 5 August 1996, 131-133.

[8] It has been estimated that in any one standard episode of hospital care, between 40 and 160 people may have legitimate cause to access an individual patient's record. (Research cited in M. Carter, 1998, "Health on line" in joint issue of *Health Issues* Issue 57 and *Alternative Law Journal* Vol. 23, No. 6, p.267.)

[9] Meredith Carter on ABC Radio National, *Background Briefing* program, "Digital Doctors Meet Wall Street," 2nd April 2000. Transcript available at www.abc.net.au/rn/talks/bbing/stories/s116711.htm

health information system that provides a great deal of information to practitioners about an individual patient, cannot be easily interrogated about conditions occurring across the patient population.[10] Ideally, it would be preferable to set up a national system to meet both needs, but if one system can fulfil only one set of needs, we may need to prioritise between the two different aims of the system. Clearly the technicalities need to be further investigated, but if this is the case, it is likely that divisions of general practice would favour prioritising the system to better inform decision making for their GPs at the time of individual patient care, rather than the one to better inform health care at the population level.

Issues for general practice

A number of the issues described above are particularly pertinent to general practice. These include some of the potential advantages in a national system for electronic health records:

- Potential to better inform decision making
- Knowledge of what treatments other GPs and other health providers have previously provided, or are currently providing
- Knowledge of results of referrals, tests etc.
- Potential for increased consumer control and/or participation in records about their health.

While some doctors do not recognise that consumer access to records has any benefits, it has also been argued that access to records can lessen consumer anxiety, help consumers make more informed decisions and improve the quality of the record. From the general practice perspective, a major concern is medico-legal issues. But it is worth noting the possibility that failure to allow access in the absence of legal proceedings may provoke rather than prevent legal action, which then becomes necessary simply to access the record.[11] Access to the information may remove the need to take legal action. The Medical Defence Union supports the practice of obtaining the records and subjecting them to expert advice on the standard of professional care before litigation commences.[12]

Practitioner as custodian of data

The *Issues Paper* suggests that a practitioner would be custodian, rather then owner, of health records. This represents a significant change from the current situation where, in private practice, the practitioner owns the patient records. However, as described above, a bill introduced in Federal Parliament last week will change that situation in any case, if passed, as consumers will have the right to access their own medical record.

Record-keeping practices

There is some concern about the way the type of system used to store information can have implications for what type of information is recorded. For example, in general practice, doctors may be less likely to record some of the "notes to themselves" that they currently use without intending the patient to see them. This type of note may in fact help the quality of their work, but they may be reluctant to continue to note things in this way in a permanent, unalterable record. This issue is not peculiar to health, but common to the conversion from paper-based information management systems to electronic ones in all sorts of industries. It is an issue with any electronic system, including the

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[10] The example given was of the system at Peter MacCallum Institute.

[11] Amanda Cornwall, “Can you keep a secret?”, 1998, joint issue of *Health Issues* Issue 57 and *Alternative Law Journal* Vol. 23, No. 6 (269-272) p. 271.

[12] H Aders, 1998, "Should Doctors Let Patients See Their Own Files?" *Journal of the MDU,* April 5, cited in Amanda Cornwall, "Can you keep a secret?"

current practice-based electronic patient records system, so is not applicable only to a national EHR system. However, it may be worth considering protocols for recording information, so that quality is not lost while consumer access increases.

Issues for divisions

Data storage role

The *Issues Paper* raises the possibility of different agencies acting as storage points for data, depending on the type of system that is developed (p.15). One possibility canvassed at the public consultation meeting was using divisions of general practice as storage points. This raises a number of issues for divisions:

- the question of resources and capability to carry out the work
- whether storing data in this way would be a sensible use of divisions' possible position as "a trusted third party" or whether acting in this capacity would undermine that position, associating divisions in the minds of GPs (and possibly consumers, who generally know little of divisions) with a surveillance role.
- currently, the divisions aim to encourage GPs to keep their own records, recall systems etc., rather than relying on outside agencies, which is markedly different to the approach in acting as a storage point.
- how relevant storing this sort of data is to the aims and objectives of divisions, as they stand. It might be argued that a national EHR system is relevant to population health, and therefore relevant to divisions. However, if the primary purpose of the system turns out to be related to individual patient health care, rather than care at the public health, or population health, level, there would be no clear reason to involve divisions as the storage point for data. Given its resource-intensive nature, this storage role would be unlikely to greatly further the aims of the Divisions' Program ("to improve health outcomes for patients by encouraging GPs to work together and link with other health professionals to upgrade the quality of health services delivery at the local level"[13])

Other roles: representation and support

Other major issues for divisions are their role as representative of, and advocate for, general practice (so they can help to convey the position of general practice as a whole, to the National Taskforce) and their practical role in providing education and support in implementing any new national electronic health record system at the practice level. They may need additional resources to carry out this role - or at least a continuation of the current specific IT/IM funding.

Further planning and development

It is important that the taskforce take into account the work that is already being done by other organisations, including the work of the General Practice Computing Group (GPCG). The GPCG Electronic Health Record Architecture Project[14] aims to test the Good Electronic Health Record (GEHR) architecture as a possible standard for electronic health records (EHRs) in Australian general practice. It is important that the taskforce use the GPCG work to ensure that general practice issues are given adequate consideration.

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[13] Department of Health & Aged Care, May 1999, *Divisions of General Practice Implementation Guide for Outcomes Based Funding*, p.4

[14] GEHR , 2000, *GPCG Electronic Health Record Architecture Project*, Summary, http://www.gehr.org/gpcg/ProjectOutline.htm, accessed 20/4/00.

When considering the type of structure for a new system, it is also important for stakeholders to be aware that centralised information systems, (some containing identified data and some containing de-identified data) do already exist eg. for notifiable diseases and childhood immunisation. It may be unrealistic for one system to fulfil all these needs; but the potential for duplication if all the systems co-exist is enormous. The relationships between the different systems will need to be clarified.

Conclusion

It is important that the development of a national EHR is driven by a clearly defined purpose for the system. Of course there may be technical limitations to any system, but it is important not to allow the technical issues, the record architecture, building blocks, data storage mechanisms etc. to dictate the ultimate uses of the record. The system should be designed to meet the purpose; the purpose must not be tailored to the system.

At all points of designing the system, it is essential to consider the likely implications for health practice. From a general practice perspective, these include the implications for the patient consultation as well as practice management issues. We need to consider what practice needs must be met to allow the system to function: what systems and infrastructure must be put in place. This involves allowing for the particular circumstances of different practice settings - for example, reduced access to reliable and cost effective telecommunications infrastructure in rural areas may be a barrier. This may have implications for the type of EHR system that is required.

Divisions of general practice need to contribute to the discussion, and remain involved in the development of a national EHR system, as they are well placed to identify practice implications. They also need to assess the potential data storage role. They may decide they welcome acting as "trusted third party" for storing health record data, as they are local organisations rather than government departments, with GP members whose interests they represent. However, there may be significant risks in adopting this role. Quite apart from the resource and capability issues, GP members may come to lose trust in an organisation that is perceived to be an arm of government, storing patient data in a pseudo-departmental way. Similarly, consumers may be unlikely to trust divisions to carry out this role, as they do not generally see divisions of general practice as *their* organisations.[15]

Given the complexity of the issues raised by an electronic health system, including the array of consumer concerns that must be addressed if there is to be public confidence in the system - without which it will not work - it may be necessary to take more time to explore the issues and identify solutions.

The extremely short timelines for response to the National Taskforce on Electronic Health Records has meant that divisions of general practice have not been adequately consulted. (Presumably this may also apply to other stakeholders.) While we appreciate the need to report to the Health Ministers mid-year, the taskforce's report should raise the fact that fuller consultation with all those who would be using it should take place if the system is to be workable.

[15] Anecdotal evidence of divisions acquiring identified patient data on unimmunised children, suggests a high level of concern by those members of the public contacted by divisions, as well as a lack of awareness of divisions of general practice.

References for further information on privacy and access to medical records

ABC Radio National, "Digital Doctors Meet Wall Street," *Background Briefing* program, 2nd April 2000. Transcript available at www.abc.net.au/rn/talks/bbing/stories/s116711.htm

AMA, 1997, *Guidelines for doctors on providing patient access to medical records,* www.ama.com.au, Position Statements.

Attorney-General's Department, 12th April 2000, *Privacy and Health Information* fact sheet www.law.gov.au/privacy/Healthfact.html. Other relevant information, including *Draft Provisions Relating to Health Information in the 'Privacy Amendment (Private Sector) Bill'* is available through the web-site.

Meredith Carter, 1998, "Health on line," in joint issue of *Health Issues* Issue 57 and *Alternative Law Journal* Vol. 23, No. 6 Vol. 23, No. 6. (265-268).

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NHMRC, March 2000, *Guidelines Under Section 95 of the Privacy Act 1988.* (available via www.health.gov.au/nhmrc/).

Office of the Privacy Commissioner, January 1999, *National Principles for the Fair Handling of Personal Information* (revised edition) Human Rights and Equal Opportunity Commission. These are also available through the office's web site, along with a range of information including *Frequently Asked Questions* about the privacy sector scheme, at www.privacy.gov.au

RACGP, June 1998, *Code of Practice for the Management of Health Information in General Practice.* Melbourne: RACGP.

Victorian Office of the Public Advocate and the Office of the Privacy Commissioner, November 1995, *Consumer access to medical records, a* discussion paper arising from *Private lives? An initial investigation of privacy and disability issues* written and researched by Meg Montague.

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