

## Point of view

# Current privacy law governing the Australian health sector: implications for research and 'audit'

Respect for privacy of the individual is an essential value of a democratic society although privacy as a fundamental legal right remains largely unrecognised in Australia today. For example, there is no constitutional right to privacy in Australia, which means that there is no convenient plinth from which privacy laws can be created.<sup>1</sup> Nor is a general right to privacy recognised by the common law,<sup>2</sup> although recently, the high court has shown a greater appreciation for the protection of privacy by contemplating the development of a common law tort of invasion of privacy.<sup>3</sup>

Nevertheless, Australian legislation at the federal and state and territory levels provides some protection of privacy of personal information with the *Privacy Act 1988* and the *Privacy Amendment (Private Sector) Act 2000* (Cth). The latter extended the *Privacy Act* to incorporate the private sector on a national basis.<sup>4</sup> While some private sector organisations are exempt, all health service providers in the private sector are subject to the new provisions, which commenced on 21 December 2001.<sup>5</sup>

The legislation allows for the development of codes by organisations subject to the approval of the federal privacy commissioner. Section 95 of the *Privacy Act* allows the National Health and Medical Research Council (NHMRC), with the approval of the privacy commissioner, to issue guidelines for the protection of privacy in the conduct of medical research within the public sector.

The guidelines establish a process by which a human research ethics committee (HREC) may approve medical research proposals that involve the use and disclosure of personal information held by Commonwealth agencies without consent from the individual concerned.<sup>6</sup> Section 95A of the *Privacy Act* also allows the commissioner to approve guidelines issued by the NHMRC that establish a process by which HRECs may approve proposals that involve the collection, use or disclosure of health information held by private sector organisations without consent from the individual concerned.<sup>7</sup>

## Ethics of Privacy

The concept of privacy is derived from the notion that individuals have a part of their lives from which they should be able to exclude any intrusion.<sup>8,9</sup> In a practical sense, privacy is largely a cultural construct, the appreciation of which differs according to background and environmental factors.<sup>10</sup> At a primary level, an invasion of one's privacy may be characterised by others destroying one's enjoyment of situations of physical solitude or intimacy. At another level, the concept of privacy concerns the dispersion of private information about persons.<sup>11</sup> The final level of privacy is the concept of autonomy with respect to making private decisions.<sup>12</sup> All three facets of the concept of privacy play a role within the medical profession.

Central to the concept of privacy is the issue of consent. Thus giving up one's privacy may be achieved through granting others access to ourselves and what we consider private. A person's privacy (or lack thereof) ought not to be confused with a person's sense of privacy.<sup>13</sup> For example, a patient may, unbeknownst to him or her, have lost some measure of privacy when someone discovers a medical history or chart and discloses its contents to others. We grant other access to ourselves through implicit as well as explicit consent. In voluntary admission to a hospital, a patient gives both explicit and implicit consent to limited losses of privacy, but importantly, the patient's decision to enter the hospital does not grant or imply unlimited access.<sup>14</sup>

## Do doctors have less sensitivity for privacy than confidentiality?

For two thousand years the Hippocratic oath embodied the highest aspirations of the physician.<sup>15</sup> It sets out two sets of duties: 1) duties to the patient and 2) duties to the profession.<sup>16</sup>

*"... what I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about..."*

This aspect of the Hippocratic oath seems to have been embraced quite literally, resulting in the rule of confidentiality being rigorously upheld within the medical community. There are two philosophical arguments in favour of preserving confidentiality. One is a utilitarian argument whose conclusion is that without such confidentiality the physician-patient relationship would be seriously impaired. Patients are encouraged to fully disclose to ensure that in return better medical advice will be given. The second argument stems from the notion that a right to a sphere of privacy is a basic human right.<sup>17</sup>

Notwithstanding a recognition of privacy within the doctor-patient relationship, the course of practice throughout history reveals that there seems to be an unwarranted emphasis on confidentiality at the expense of privacy. With such a strong emphasis on confidentiality within the doctor-patient relationship, it is somewhat surprising to find that patient's privacy appears not to be equally respected. For example, in teaching hospitals medical students have conducted vaginal examinations in an operating room on an anaesthetised patient without the patient's knowledge or prior consent. Photographs and videos are sometimes taken for educational purposes in circumstances (e.g. during a surgical operation) where the patient is still identifiable. It is common practice for patients to be presented before a gathering of medical professionals to discuss unusual clinical features. Lists are often made to inform doctors (not involved in the direct treatment of the patient), medical trainees and students of the identity and location of 'interesting patients' with an implicit assumption that the reading of patients' case notes without consent of the patient is acceptable. Finally, it is not an uncommon practice for medical professionals to collect and use "personal" information (including body tissue) without the patient's consent.

Why is it then, that doctors behave in a way that is inconsistent with respect for patients' privacy in a professional service in which expectations would anticipate the highest respect for privacy?

Doctors are used to very personal contact with intimate invasion of personal space. Almost no part of a human is inaccessible to a doctor; the psyche to psychiatrists, the surface to dermatologists: where a fibreoptic light cannot penetrate, a scalpel will provide revelation. Dealing with suffering, dying, preventing and curing must make privacy considerations seem somewhat insignificant. Perhaps, over time, medical practitioners become desensitised to seeing and hearing the most personal aspects of people's lives. Yet, it was not until the introduction of privacy legislation, that there has been a shift of focus toward privacy rather than just confidentiality. What was once common practice and conventional is suddenly being reassessed. The convention that doctor's provide all information about patients when referring to each other has been questioned with the introduction of the privacy legislation. For example, a general practitioner may have no particular need to inform a surgeon of a patient's history of sexual or domestic abuse or prior illicit drug taking unless by the consent of the patient.

Doctors have been surprised that these common clinical and educational activities could be argued as being unlawful let alone inconsistent with good ethical standards. The defence of common practice with regard to medical research, clinical audit, and quality improve-

ment has been particularly vigorous with responses from researchers and the learned colleges all arguing that there should be exceptions to the general rule of consent being required to access personal information.<sup>18</sup> In defence of the status quo (almost uncontrolled access to personal information) it has been argued that there would be dangers of decreased standards, increased hazards for patients, and certainly failure to achieve important medical advances.<sup>18</sup> However, there is little or no evidence to support this argument. If asked, patients are generally cooperative, helpful and willing to collaborate in research or improvement programmes. In 1996, the Minnesota legislature passed a Medical Data Privacy Act requiring patient authorisation for the use of medical records and research. A study of 15,997 patients reporting authorisation for access to medical records showed only 3.6% refused authorisation with the highest rate being in women presenting for pregnancy care.<sup>19</sup>

## Medical Research and Privacy

### *The Public Sector*

Information privacy principles (IPPs) set out in section 14 of the *Privacy Act* govern the conduct of Commonwealth agencies in the way those agencies collect, use, store and disclose personal information.<sup>20</sup>

The main requirement of the IPPs is that personal information may only be used and disclosed when consent of the individual is obtained. However, personal information may be used or disclosed without consent for the purpose of medical research, by following the procedures set out in guidelines authorised under section 95 of the *Privacy Act*. Section 95 of the Act allows the NHMRC, with the approval of the federal privacy commissioner to issue guidelines for the protection of privacy in the conduct of medical research. It is a condition of approval of the section 95 guidelines that the commissioner must be satisfied that the public interest in the promotion of medical research outweighs, to a substantial degree, the public interest in privacy.<sup>21</sup> Therefore, section 95 of the Act provides a process which acknowledges that in some circumstances the right to privacy must be weighed against justifiable interests that may benefit society as a whole.

Section 95 restricts the guidelines to medical research only, where medical research includes epidemiology. The section creates a process by which human research ethics committees (HREC) may approve medical research proposals that involve the use or disclosure of personal information held by Commonwealth agencies without consent from the individual concerned. In approving a proposal the HREC must decide that the public interest in the research outweighs, to a substantial degree, the public interest in privacy.<sup>22</sup>

*The Private Sector*

Schedule 3 of the amended *Privacy Act* sets out ten national privacy principles (NPPs) to govern the conduct of private sector organisations not previously covered by the original act in the way those organisations collect, use, store and disclose personal information.<sup>23</sup> The NPPs have stricter requirements than their IPP counterparts in the handling of sensitive information. HREC's may have to review research proposals that involve the handling of personal or sensitive information that is not health information. In these cases they must ensure that the proposed research is conducted in accordance with the NPPs. In most circumstances the NPPs require that organisations obtain informed consent where possible for the collection, use or disclosure of personal health information for research, statistical and health service management activities. The NPPs do however recognise that there are instances where it may be 'impracticable' to obtain consent from the individual.<sup>23</sup>

The section 95A guidelines establish a process by which the HRECs may approve proposals that involve the collection, use or disclosure of health information held by private sector organisations without consent from the individual concerned where:

- The collection, use or disclosure is necessary for the purpose of research, statistical or health service management activities; and
- It is determined that it is impracticable to obtain consent; and
- It is determined that de-identified data will not achieve this intended purpose of the activity; and
- It is determined that the public interest in the research, statistical or health service management activity substantially outweighs the public interest in the level of privacy protection afforded by the NPPs.<sup>24</sup>

Obviously if collecting health information is a directly related purpose and doesn't require obtaining consent then the reason for collection does not need to be put before the ethics committee. It is important to note that in the actual NPPs, the collection of health information where it is impracticable to seek consent from the individual's involved, is also authorised under NPP 10.3(d)(i) - as required by law; and NPP 10.3(d)(ii) in accordance with rules established by competent health or medical bodies that deal with obligations of professional confidentiality which bind the organisation.

**Practical problems with the privacy principles and related guidelines***Competent health or medical bodies*

Principle 10.3(d)(ii) allows an organisation to collect

health information without consent if the information is collected "in accordance with rules established by competent health or medical bodies that dealt with obligations of professional confidentiality which bind the organisation". In this regard, the issue of insensitivity of medical professionals to privacy has been previously discussed.

The professional colleges are increasingly requiring advanced trainees in medicine, surgery, psychiatry, anaesthesia to undertake research projects (e.g. 'audits') as part of their formal training programme. The colleges' positions on issues such as privacy are entirely determined by their members without the moderation of other persons much more attuned to and sensitive to the issues of privacy. One has only to consider the scandals in the history of medical research<sup>25-29</sup> and more recently the revelations of retained body parts<sup>30</sup> and tissues in anatomical collections and research tissue banks to understand that determinations of ethical conduct should perhaps not be self-regulatory.

*Consent*

There are circumstances where to obtain consent is difficult when conducting medical research using medical records where the individuals are not contactable. The term 'impracticable' is defined in the guidelines to ordinarily mean more than simply the incurring of some expense or effort in seeking consent.<sup>31</sup> An example is given that it may be impracticable to seek consent where the organisation is unable to locate the individual, despite making reasonable efforts. However, it is frequently claimed by researchers that it is impracticable to contact patients when in fact it is mostly inconvenient.

*Definition - research/audit/quality improvement*

Interestingly, the definition of 'directly related purpose' in the section 95A guidelines has altered from previous drafts. While previously in the August 2001 draft a directly related purpose was seen to include 'monitoring, evaluating or auditing the provision of a particular product or service the organisation has or is providing to the individual'. The focus on this appears to be on the improvement of the health service being provided as a commodity. The final version of the guidelines have made a small change in the wording with an enormous practical impact. The meaning of directly related purpose now includes 'an organisation's quality assurance or clinical audit activities, where they evaluate and seek to improve the delivery of a particular treatment or service'.

The impact this change might have on the approval of medical research is far reaching. With the broadening of the definition of 'directly related purpose' to include 'audits', researchers wishing to conduct research with-

out the consent of patients have been labeling their research as "audits", thus bringing them within the scope of a directly related purpose, the effect of which is that approval is not required by the HREC and consent need not be obtained.

This has been an increasing problem. The term "audit" is difficult to define, the boundaries of its scope are impossible to specify. There is no debate against the notion that patients are entitled to determine who is entitled to have access to the information contained in their medical records and the purposes for which it can be used. The problem lies in the semantics of the purpose, that is, whether it is collected for "research" purposes or for an "audit". The distinction between research and audit is central to whether or not quality assurance activities require review by ethics committees.<sup>32</sup>

There is a common view amongst health care providers, that research involving access to medical records is permissible but requires ethics committees review and that use of personal information contained in case notes of medical records requires informed consent from the subjects involved.<sup>33-36</sup> This common view also suggests that informed consent for access to medical records is not required under specific 'controlled' conditions such as if it would be impracticable to obtain consent; there is a minimal risk to the individual's concerned; the rights of the subject (confidentiality and anonymity) are preserved; vital information is provided after the study and the research is of sufficient importance to outweigh patient privacy. It is also understood that it is often very difficult to distinguish between research and audit activity, which is highlighted by the fact that no international or national code, statute or report includes satisfactory definitions of research, audit, quality assurance or quality improvement, which adequately permit the distinction between these activities.

Notwithstanding the blurred distinctions between the research activities, there is a consistent view that projects undertaken for the purpose of audit, quality assurance or quality improvement do not require review by an ethics committee.<sup>37-39</sup> Recent developments of privacy legislation in Australia have propelled interest in this debate, with particular emphasis on the rights of an individual to be protected against the use and disclosure of personal identifiable health information on the one hand and the need of medicine to perform audit and quality assurance activities on the other. While ethics committees have a significant role in protecting research participants by approving research or not, there is an obvious problem in consistency in deciding what is research and what is labelled an "audit" but is actually research. Furthermore, there is the issue of HRECs

making differing decisions in relation to the weighing process of public good versus private harm.<sup>40</sup>

#### *Bias and distress*

Included in the justifications for not wishing to seek consent of the patients for access to their health records are considerations of avoiding distress and diminishing scientific validity by introducing bias.<sup>41,42</sup>

Certainly a HREC could be expected to give reasoned, considered assessment of likely distress because its composition includes at least a layman, a laywoman, a minister of religion and a lawyer. Also its decisions are reached by consensus, not by majority vote, which ensures that the medical and scientific members who are very necessary to this committee cannot unduly influence this aspect of decision making.<sup>43</sup> Medical or scientific paternalistic actions justified in the name of non-maleficence have been repeatedly challenged in the courts in the context of informed consent.<sup>44-47</sup> However, when it comes to claims of introducing bias as a justification for ensuring one hundred percent compliance with sampling, this may be more problematic for non-scientific persons.

#### *De-identified data*

The NPPs and the relevant guidelines do not apply to de-identified data. The problem is that the distinction between identified and de-identified data is sometimes misunderstood. A hospital that wishes to know attendance figures, categories of illness, and other demographic information can easily interrogate its data system to get numerical and statistical data. This is obviously de-identified at both source and at disclosure. Medical researchers almost never present identified data on disclosure but almost all information gathering and collection occurs from inspection of case notes or departmental databases where the identity of patients is almost always apparent. In these circumstances it may be that only certain information is sought but access to unrelated, highly sensitive information is unavoidable. However, it is virtually impossible to de-identify case notes and investigatory records to any significant extent. Reference to patients' identity is ubiquitous in case note records.

#### *Weighing the public interest*

Prior to consideration of whether public interest in the proposed activity (health research, collection, compilation or analysis of data) substantially outweighs or does not substantially outweigh the public interest in the protection of privacy, an HREC must assess whether it has "sufficient information, expertise and understanding of privacy issues either amongst members of the HREC or otherwise available to it, to make a decision that takes proper account of privacy matters".<sup>48</sup>

Unfortunately there are no further instructions as to how an HREC is to appropriately assess its capacity to judge proposals. The composition of the HREC by itself alone does not necessarily ensure that an appropriate level of sensitivity or weight is accorded to the value of privacy.

The issue of 'substantially outweigh' introduces some interesting conceptual problems. To assess a balance one must accord some value to privacy. For example, privacy could be expressed as a measurement on a linear analogue scale of ethical considerations, where zero represents no value accorded privacy and ten represents very high value. Let us say that privacy is given a value of six. It would mean that a research project might have to achieve a score of eight or nine to substantially outweigh interest in the protection of privacy. On the other hand, suppose the HREC's quantification of the value of privacy is a score of two. Then presumably a score of three, i.e. fifty percent greater than the score accorded privacy, is significantly greater than, and therefore substantially outweighs, the public interest in the protection of privacy, although a weighting of three out of ten for the worth of a research project is in itself quite low. The point has already been made concerning the relative insensitivity of hospital researchers of privacy issues. Even though consensus is required in decision making by a HREC, the influence of the member(s) "with knowledge of and current experience in the areas of research that are regularly considered by the HREC"<sup>49</sup> may persuade the committee to give undue weight, in comparison to privacy, to the merits of the research proposal.

### Community attitudes

How much do Australians value privacy? The attempted introduction of the Australia card by the federal government in 1986 showed Australians were unable to be persuaded by the merits of such a scheme when faced with the fears associated with loss of privacy.<sup>50</sup> Almost twenty years later Australians' attitude to privacy have not changed and sensitivities toward privacy are actually likely to have increased with the rapid development of information technology and the introduction of privacy-protecting legislation, guidelines and codes. Even though the Australian community regards health service providers, including doctors and hospitals, as highly trustworthy (40%) or somewhat trustworthy (44%), nine out of ten Australians regard it important to know who has access to and how their personal information may be used.<sup>51</sup> Sixty one percent of the sample of 1500 telephone interviewees thought that an individual's permission should be sought before using their unidentified (de-identified) health information for research purposes.<sup>51</sup> Only 33% thought permission wasn't necessary. Interestingly, fifty percent of those with tertiary education or with incomes greater

than \$60,000 per annum still thought that an individual's permission should be sought.<sup>51</sup> When asked whether health professionals should be able to discuss the medical details of an individual, in order to treat them better and in a way which identified them without the patients consent, only half agreed.

### Conclusion

Doctors' attitudes to privacy appear not to reflect those prevalent in the community. The practice of medicine is so personally intrusive as to cause desensitisation to privacy issues. Confidentiality is traditionally well understood and has a longer history of codified rules of conduct and legislative support.<sup>52</sup> Medical researchers are probably also more likely to overemphasise the positive outcomes of medical research, audits and quality improvement in comparison to their valuation of privacy. Claims of bias in sampling and the desire for methodological accuracy can easily be overstated to support a 'scientific' argument for full participation of the sample to achieve access to personal information by appealing to an HREC for approval without the consent of the individuals involved. Although research has shown that only a small percentage (3.2%, 3.6%) of patients declined authorisation for medical record access when asked,<sup>53,54</sup> it is clear that people wish to be asked. Probably, even high authorisation rates would be achieved if specific consent was sought.

While the NHMRC guidelines at first sight appear comprehensive and protective of privacy, they introduce a bureaucratic maze where the reward is obtaining approval for research without obtaining consent. The key words are 'necessary', 'impact on' (improved health outcomes, decreased morbidity and mortality), 'impracticable' and 'bias'<sup>55</sup> (decreasing scientific accuracy which might make a project unethical). It will be interesting to view the annual reports of Australian health ethics committees (AHEC) to the privacy commissioner providing details of applications made under the guidelines.<sup>56</sup> Unfortunately this information will not provide a realistic view of the actual occurrence of access to personal medical records as the bulk is likely classified (and more recently re-classified) to fit the rubric of 'audit' and 'quality improvement'.

One wonders whether the response of health professionals will be positive of promoting respect for privacy. Given the flaws in the legislation, it is imperative that the medical profession and researchers adopt and endorse respect for privacy as a virtue. Failure to understand and promote privacy as a right, may lead to an opportunity lost to reestablish trust in a profession that has lost a degree of public confidence following well publicised scandals in health research, abuses of power relationships and violations of privacy with regard to retention of body parts without consent.

M. D. and D. A. VEDIG  
*Blackwood*  
*SOUTH AUSTRALIA 5051*

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