



## WHOSE HEALTH RECORDS?

*Attitudes to consumer access  
to their health records  
and the need for law reform*

**Amanda Cornwall**  
**Public Interest Advocacy Centre**

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### Rights at present

The health care sector has seen a significant change in attitudes to consumers over the past ten years, with greater professional accountability and consumer autonomy. Part of the change has been the development of a movement for consumer rights, which includes calls for consumers to have a right of access to their health records.

The calls for consumers to have a right to access their health records have been supported by numerous public inquiries in Australia and more recently, governments have promised law reform.

Health service consumers in the UK, New Zealand, Canada and the USA all have a right of access to their medical records.

Health service consumers in Australia have had a right of access to their health records in the public sector for many years under Freedom of Information and government policies. Consumers in the private sector have a right to test results, x-rays and similar reports, but not to the notes and records kept by doctors, hospitals and other health professionals in the private sector. In NSW, special regulations on private hospitals, nursing homes and day procedure centres have provided consumers with a right of access to 'clinical records' since 1990.

Therefore, consumers rights to access their health records depends on where they live, and whether they are receiving services in the private or public health sector.

Despite the long existence of rights of access to records in the public sector, there is a low level of awareness of the rights among consumers and health service providers.

There is evidence that health service providers refuse access to records or give incorrect information about consumers rights. Health complaints commissions report that they have a role in dealing with complaints about 'reasonable' access to records, but there is little agreement on what it means.

The best chance for national law reform is through amendments to the *Privacy Act* (Clth) proposed by the Commonwealth Attorney General, extending privacy protections to the private sector. Rights protected under the *Privacy Act* include rights to access and correct errors in personal records.

### Attitudes to access?

Consumers want access to records for variety of reasons, including:

- to gain control of their treatment and their lives;
- to better understand their condition and treatment, or that of their loved ones;
- to check the accuracy of the records.

Case studies in Chapter 3 illustrate consumers' reasons for seeking access to records.

The number of requests for health records by consumers is relatively small, even in the public health system, probably because they do not regard it as a right. The reasons for consumers seeking access to their records suggests that even if all consumers had a right of access to their health records, the number of requests would remain limited.

Health service providers increasingly accept that consumers should have access to their records, but are divided on how and when this should occur.

### Merits of access

There is evidence of the benefits of health consumers having access to their records in relation to:

- improving communication between health service providers and consumers;
- improving accuracy and quality of records;
- improving the efficiency and reducing the time required in treating consumers; and
- helping consumers to make more informed decisions.

The benefits of consumer access to records are demonstrated for psychiatric records as well as physical health records.

There is no conclusive evidence of the claimed disadvantages of consumers having access to their health records, such as increased litigation, harm to the consumer and lower

quality records. While consumers can experience anxiety and anger when they see their health records, the studies show that overall consumers and providers report the experience is positive. Special care in supervising access, and providing counselling support is needed in some situations, but this is not a justification for refusing access.

## Recommendations

### A right of access to health records

- 1 National law reform should be introduced to ensure consumers of private health care services have the same rights of access to their personal health records as those in the public health sector.
- 2 'Health records' should include all personally identifying information prepared in connection with health services provided to consumers.
- 3 Health service consumers should have a right to an outline of information about them held by health providers or health institutions so they can decide which information they wish to request and will know if only part of it is provided to them.
- 4 Consumers' right of access to records should apply to all records and information held by health service providers and health institutions, insurance companies and others who hold such information. The right should apply to all records held by a health provider or institution, including records created by another agency or person.

### The form of access

- 5 Consumers should have a right to access their health records in the form they request, unless it would:
  - impair efficient administration;
  - be contrary to any legal duty of the provider; or
  - prejudice interests protected in exceptions to the right.If the record is not provided in the form requested, the record holder must provide reasons.
- 6 Consumers should have a right to an explanation of their health record by an appropriately qualified person, if they request it,

and if the records are not intelligible without explanation.

### 7 Time limits

A request for records should be required to be responded to within 21 days. A response to a request for an amendment should also be required within 21 days. Provision should be made for reasonable extensions of time where the request for records is large or consultation with others is necessary.

### Rights of relatives and loved ones

- 8 People who are relatives or have a significant personal relationship with a consumer should have a right of access to information relating to the current care of the consumer if:
  - the consumer does not object; or
  - is not competent to object; or
  - it is impractical for them to be given the opportunity to object.

Significant personal relationship should be defined. The criteria set out in the *Guardianship Act* (NSW) provides a model.

- 9 Consumers' legally recognised representatives should have a right of access to the consumer's health records after their death, unless the consumer has made it known that they do not want such access granted. Consumers should be asked their views on who can access their records as part of routine record keeping.
- 10 Children and young people who are legally capable of consenting to medical treatment should have a right of access to their records and be able to refuse access to the records by others, including parents and guardians.

### Charges for access

- 11 No charge should be allowed for consumers seeking access to their health records, except:
  - (a) to cover the reasonable cost of copying and posting the record;
  - (b) if there is more than one request per year from a consumer for records from a private sector agency; or
  - (c) copies of x-rays, CAT scans and video recordings are involved.

A maximum charge should be set to ensure consumers on low incomes are not disadvantaged.

### Exemptions to the right of access

- 12 Consumers access to their health records should be facilitated by allowing parts of a record containing exempt information to be withheld, rather than exempting the whole record. If this occurs consumers must be informed and given reasons.
- 13 Consumers should be able to be refused access to parts of their health records if disclosure of information would breach a duty of confidentiality to another person, express or reasonably implied. The views of the individual whose confidential communication is at risk should be consulted, where practical.
- The holder of a health record should not act on information in the record without taking steps to ensure the information is accurate, up to date and complete.
- 14 Consumers should be able to be refused access to the whole or part of their personal health records if the holder of the record reasonably believes disclosure would endanger the life or physical safety of someone.

### Amending errors in the record

- 15 Consumers should have a right to seek amendments to their health records if the information is incomplete, incorrect, out of date or misleading. The right should not depend on whether the consumer has a right of access to the record.

Where the holder of a health record refuses to make the requested amendment, the consumer should have a right to reasons for the refusal, to appeal against the refusal, and to be told of the right to appeal. A note setting out the consumer's views should be attached to the record if the amendment is not made.

Consumers should also have a right to be told they can seek amendments and how to go about it.

### Appeals

- 16 Decisions to refuse consumers access to their health records should be subject to review by the Privacy Commissioner and State/Territory health complaint commissions.

### Retrospectivity

- 17 Consumers should have a right of access to all health records created after commencement of legislation providing consumers with a right of access, and access to all factual information,

including test results, in records created prior to the commencement of the legislation.

### Privacy and management of health records

- 18 The privacy of health consumers' personal information should be protected by extension of the *Privacy Act* to the private sector, backed by a Health Information Privacy Code of Conduct.

Public consultation is needed on appropriate exceptions to individual rights to privacy necessary to protect public health and the public interest.

- 19 The content, management, retention and disposal of health records needs to be reviewed for the purpose of establishing nationally uniform minimum provisions.

### A model for law reform

- 20 A package of legislation is needed to provide health service consumers with a legal right of access to their health records. It should incorporate a separate *Access to Health Records Act*, providing the right of access, amendments to the *Privacy Act* extending the Information Privacy Principles to the private sector, and an enforceable health information privacy code of conduct for the health sector.
- 21 The law reform package should be introduced by the Commonwealth government to achieve national uniformity. It should also amend the provisions of the *National Health Act* which require information to be kept confidential.
- 22 The Privacy Commissioner and State and Territory health complaints commissions should be able to investigate and conciliate complaints about consumer access to health records. This should be reinforced by agency agreements with the Privacy Commissioner.
- 23 The Privacy Commissioner should have power to investigate and conciliate complaints, and to seek enforceable assurances against repetition of breaches of a health privacy code, the *Privacy Act* and the *Access to Health Records Act*. Where a breach is found to have occurred, the Federal Court should be able to award compensation, issue restraint orders and impose penalties for serious breaches of privacy obligations.

### Implementing the rights

- 24 The Commonwealth government should impose a legal obligation on holders of personal health information to inform consumers of their rights to information.

To implement the reforms the Commonwealth should promote professional and community understanding of consumers' rights of access to their health records by using a range of appropriate measures, such as:

- approving and promoting the draft *Australian Health Consumers Charter* as a basis for community and professional education;
- encouraging the NHMRC to re-release its *Guideline for Medical Practitioners on Providing Information to Patients*; and
- encouraging professional and health industry associations to make their members aware of consumer rights of access to their records.

### Abbreviations

ACA – Australian Consumers Association  
ACON – AIDS Council of NSW  
ALRC – Australian Law Reform Commission  
AMA – Australian Medical Association  
ANHECA – Australian Nursing Homes and Extended Care Association  
ARC – Administrative Review Council  
CHA – Consumers Health Advocacy (Qld)  
CHF – Consumers Health Forum  
CWA – Country Women's Association (NSW)  
DPI – Disabled People International (Tas)  
FOI – Freedom of Information  
HCC (WA) – Health Consumers Council (WA)  
HIC – Health Issues Centre  
HIMAA – Health Information Managers Association of Australia  
HIMA (NSW) – Health Information Managers Association (NSW)  
NCW – National Council of Women (NSW)  
RACGP – Royal Australian College of General Practitioners

### Terminology

*Carer* – people who identify as providing care and support to relatives, significant others or friends, for no financial reward whether on a part time, periodic or full-time basis.

*Provider* – any person, organisation or institution providing health care services.

*Consumer* – people who receive health care service, incorporating patients, clients and residents of nursing homes and similar care facilities.

*Common law* – The body of law which evolves through decisions of the courts, as distinct from laws made by the Parliament in the form of statutes.

*Personally identifying information* – a term used in the privacy context to describe any information, or combination of information, about a person which would allow someone to identify them. It could be anything from a name to a combination of information, such as a rare condition combined with race and geographic location.

*We must see moves towards a legal duty to provide greater information to patients in the context of wider social developments which affect society and the law. All professions, including judges, are now more accountable.* Justice Michael Kirby, 1993<sup>1</sup>

## 1.1 Why access to records has become important

There has been a move away from the traditional paternalism of the medical profession since the 1970s to greater consumer autonomy. As part of seeking to achieve more of a partnership between consumers and providers, consumer advocates have sought greater rights of information for consumers. An integral part of the campaign for greater consumer autonomy has been a call for consumers to have the right to access their health records. The campaign challenges the traditional notion that consumers are merely the subject of records, maintained for the exclusive use of health providers, insurers, researchers, educators and regulators.

Health consumer advocates have found support for their calls for reform in a series of public inquiries into the health care industry and Freedom of Information over the past few years.<sup>2</sup> They have also seen health service consumers gain a right of access to their records in Canada, New Zealand, the UK and the USA.

However, in seeking to pursue the right to access their records, consumer advocates faced problems resulting from the uncertainty of the law in Australia. After a right of access to records was gained in the public health sector under Freedom of Information laws (FOI), attention was turned to the private health sector. A test case in 1994, *Breen and Williams*, which concerned a consumer's right of access to her plastic surgeon's notes, became the focus of the campaign. When the New South Wales Court of Appeal decided that consumers have no right of access to doctors' records, consumer groups called for law reform through Parliament.<sup>3</sup> Governments in turn said they had to wait until the decision of the High Court as the case had been appealed. The High Court affirmed the Court of Appeal's decision in September this year.<sup>4</sup>

## 1.2 PIAC's Whose health records? project

Public Interest Advocacy Centre (PIAC), a legal and policy centre located in Sydney, has a longstanding interest in the rights of health service consumer. It has campaigned for consumers to have a right to access their health records for many years (see Appendix 1). PIAC applied to intervene in the Breen case as a friend of the court to present public interest arguments on behalf of Consumers' Health Forum and Health Issues Centre. With its accumulated expertise, PIAC decided in 1996 that it was time to develop the policies which would provide a basis for law reform.

The *Whose health records?* project has a number of complimentary aims:

- to encourage a more balanced public debate on consumer access to health records;
- to develop consumer opinion on the key policy issues arising from providing consumers with a right to access their health records;
- to consider the policies of health providers and the law in comparable countries; and
- to develop a model for law reform for State, Territory and Commonwealth Governments.

An issues paper entitled *Whose medical records?* was released by PIAC in May 1996. It set out key policy questions and provided information on consumer rights to their health records in Australia (with an emphasis on NSW), New Zealand, England and the USA. The initial mailout of 500 copies grew to over 2,000 in response to demand from consumer and provider groups.

Information about the project was distributed through many community and industry newsletters and magazines. An edited version of the paper was published in *Health Issues Journal* in June and a fully referenced version was published in the *Health Law Bulletin*, August 1996.<sup>5</sup>

Responses to the issues paper were received from a wide variety of interest groups and individuals. (See Appendix 2)

The consultation process was primarily based in New South Wales (NSW) due to funding constraints. However, Health Issues Centre and state-based health consumer groups – the Chronic Illness Alliance in Victoria, the Consumers Health Advocacy in Queensland and the Health Consumers Council in Western Australia, enthusiastically embraced the project and helped to provide a nationwide perspective on the issues. PIAC also participated in a national workshop organised by Consumers' Health Forum (CHF) on the use of personal health information for research in June 1996.

We encouraged people to let us know their views through a variety of mediums – telephone, e-mail, written submissions, small meetings and three workshops. The main workshop occurred in Sydney in June, attended by representatives of NSW and national health consumer groups. The Chronic Illness Alliance organised a smaller workshop in Melbourne in July. (See Appendix 3)

Many organisations representing health providers and administrators were invited to make submissions, including those representing doctors, nurses, hospitals, Area Health Boards in NSW, social workers, health information managers, health complaints bodies, as well as unregistered health providers such as chiropractors and natural therapists. While governments were not specifically asked for responses, the issues paper was sent to a number of government agencies for information.

The Centre for Health Law, Ethics and Policy at Newcastle University organised a workshop with health professionals and educators in Newcastle in July, providing practical perspectives on the issues and enlightened ethical ideas. (See Appendix 3)

### 1.3 Moves for change by consumers

Public calls for consumer access to their health records were made in Australia as early as 1986, by the Australian Consumers Association and Public Interest Advocacy Centre.

In 1990 the CHF produced a report on health consumer rights in conjunction with PIAC, titled *Legal Recognition and Protection of the Rights of Health Consumers*. It explored the law on access to records in detail. In 1991 CHF produced *For Whose Eyes Only?* which includes recommendations for legally enforceable health consumer rights and a 'charter of rights'. It also recommended detailed codes of practice on consumer access to, and amendment of, health records. CHF developed the proposal for a charter of health consumer rights further in *Consumer Health Rights – a summary of your health rights and responsibilities in 1992*.

The Health Issues Centre in Melbourne supported a legal right for consumers to their health records in *Healthy Participation: Achieving Greater Public Participation and Accountability in the Health Care System in 1993*.<sup>6</sup> The report also proposed a charter of health consumer rights to reinforce the right to access. In the same year they produced a report titled *The Power of Information* which examined the extent of legal and non-legal processes which enable consumers to have access to, and to ensure the privacy of, their medical records. It includes results of a survey of public health services on how they respond to, or facilitate, consumer requests for access to their records.

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The draft Health Consumers' Charter developed by PIAC for the Australian Consumers' Council during 1994 and 1995, deals with access to and the privacy of health records. The Charter, a statement of consumer expectations of the health sector, says consumers should have the right to:

- ... take part in the recording and keeping of information about your personal health care, which means:
- being given access to all recorded information relating to your health care and condition, other than information about third parties who have not given their reasonable consent;
- being given an explanation of the contents and meaning of any recorded information if you request it;
- being given appropriate support or advocacy at the time that information is provided, if appropriate;

- being able to seek amendments or additions to all information relating to your health care and condition; and
- having your comments attached to any records or files.

The draft Charter is currently being considered by the Commonwealth Minister for Health and Family Services, Dr Michael Wooldridge.

#### 1.4 Public inquiries into health records

A number of public inquiries in Australia have called for law reform to provide consumers with a right to access their health records and to protect the privacy of personal information in health records.

The issue was raised as early as 1987 by the NSW Privacy Committee. In a report to the NSW Department of Health they stated it was 'Privacy Committee policy that every person should be able to know of the existence of and the content of data which relates to himself'.<sup>7</sup>

Major research on the management of medical records and consumer access to them, was conducted by the *Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease* in 1993 and 1994 (*Inquiry into CJD*).<sup>8</sup> The inquiry arose following the death of four women from Creutzfeldt-Jakob Disease after being treated with pituitary-derived hormones. The Australian Human Pituitary Hormone Program provided the treatment for infertility and growth hormone deficiency.

The inquiry report documents the significant problems encountered by participants in the hormone program when they sought to obtain their medical records, which were often 20-30 years old. Problems encountered included: records lost when doctors had died or gone overseas or hospitals had closed; records split between different facilities; and records taken for use in medical education. The report also criticised the Commonwealth Department of Health for refusing to provide access to records they held, insisting that such information could only be made available through a medical practitioner.<sup>9</sup>

The report recommended a uniform approach by Australian governments on consumer

access to, and the disposal of, medical records. It said a uniform, Australia-wide law should create legally enforceable consumer rights regarding access and disposal of records held by private hospitals, private medical practitioners and public hospitals.<sup>10</sup> These recommendations have not been implemented.

Another call for national law reform to provide people with a right of access to their health records was made in the final report of the *Review of Professional Indemnity Arrangements for Health Care Professionals (Professional Indemnity Review)* in December 1995.<sup>11</sup>

In its Interim Report the review proposed developing legislative options for consumer access to records in consultation with the Australian Medical Association, medical defence funds, other health care professions and consumers as a short-term measure.<sup>12</sup> However, the AMA released a new guideline on patient access to medical records in October 1993, which effectively left the issue of access to the discretion of individual practitioners.

The final report of the *Professional Indemnity Review* recommended that the Commonwealth Government ensure consumers access to their medical records via legislation.<sup>13</sup>

Health consumer access to their medical records was also discussed in the review of the *Freedom of Information Act 1982 (Clth)(FOI Act)* by the Australian Law Reform Commission (ALRC) and the Administrative Review Council (ARC) in 1994 and 1995. FOI provides people with a right to access documents held by the government or its agencies, including documents which originated in the private sector but which are held by government. The review considered, among other things, whether the Commonwealth *FOI Act* should be extended to the private sector.

An issues paper issued by the ALRC and the ARC in 1994 noted that people were increasingly seeking access to medical records using Commonwealth, State and Territory FOI laws.<sup>14</sup> In a discussion paper issued in May 1995, the ALRC and the ARC supported health service consumers being given a right of access to their health records.<sup>15</sup> They proposed that rights to access and correct personal

health records should be seen as a privacy issue. The final report of the FOI review noted that a number of submissions claimed there was an urgent need for legislation to enable consumers to gain access to their health and medical records in the private sector. They urged 'a national regime to be implemented quickly', providing access by extending the *Privacy Act*.<sup>16</sup>

The Privacy Commissioner has supported calls for consumers to have a right of access to their health records in the context of broader protections of privacy in the health sector. The Commissioner's office funded research into consumer access to medical records in 1995, focussing on the issues for people with disabilities.<sup>17</sup> The NSW Privacy Committee also support these reforms.

### 1.5 Promises for reform

The former Commonwealth Government and the A.C.T. Government promised law reform to give consumers a right of access to their records in 1995, but waited for the High Court decision in *Breen and Williams*.

The best chance for reform came within a week of the High Court decision in the *Breen case* when the Commonwealth Attorney General issued a discussion paper *Privacy Protection in the Private Sector*. The discussion paper proposes extending the Privacy Act to the private sector, along the lines of the recommendations of the ALRC and ARC. When launching the paper the Commonwealth Attorney General, Mr Daryl Williams, said his government would give special attention to consumers access to medical records when considering extensions to the *Privacy Act*.<sup>18</sup>

### 1.6 Rights of consumers in other countries

In England the law is influenced by article 8 of the European Convention on Protection of Human Rights and Fundamental Freedoms 1950, which deals with the right to respect for private family life. The European Court of Human Rights decided in 1989 that the refusal to allow access to certain health records by a doctor was in breach of this right.<sup>19</sup>

In *R and Mid Glamorgan Family Health Services* the English Court of Appeal considered the issue in a somewhat ambiguous

way.<sup>20</sup> In this case the doctor did not provide the consumer with access to the records, offering instead to provide the records to an independent medical adviser who might judge whether the information was likely to cause harm to the consumer or anyone else.<sup>21</sup> The Court of Appeal upheld the original decision that there had been no breach of article 8. The consumer's application for access to his medical records was dismissed.

As a result of the ambiguity of the decision, the UK government introduced the *Access to Health Records Act 1990* which commenced in November 1991. The right of access to records covers a wide range of health providers. It provides exceptions to the right if access would harm the consumer or would breach the privacy of others.

In New Zealand health service consumers gained a right of access to their records under amendments to the *Privacy Act* and the *Health Information Privacy Code*. Refusal to provide reasonable access to records or to make corrections to personal health records can be the subject of complaint to the Privacy Commissioner.

In the United States of America state governments started introducing laws providing consumers with access to parts of their medical records in the 1980s. By 1995, 50 States had a law on the subject, some covering only hospital records or doctors' records and some specifically excluding mental health records. In 1995 the US Senate passed the *Medical Records Confidentiality Act* which provides a right for consumers across the USA to access and seek amendments to their medical records.

In Canada the Supreme Court decided in *McInerney and McDonald* in 1992 that a patient is entitled to reasonable access to see and copy their doctor's records.<sup>22</sup> The court said non-disclosure is only allowed if there is real potential for harm to the consumer or someone else. They based the decision on the doctor's duty to advise the consumer about information in the records concerning their health. They said the duty extends to granting 'access to the information the doctor uses in administering treatment.'<sup>23</sup>

Health consumers in Canada, New Zealand, the UK, and the USA have gained a legally recognised right to access their medical and health records over the past five years. In Australia, consumers' rights to their health records depends on where they live, which part of the record they want and whether they are using a private or public health service.

### 2.1 What are health records?

Health and medical records are made up of a range of different pieces of information. A typical General Practitioner's records will include consultation notes, medical history, test results, correspondence between providers, observations and opinions about the consumer and details of treatment. Hospital records would include similar information as well as admission forms, consent forms (if applicable), medication sheets, progress notes, nursing care notes, x-rays and pathology reports. Specialists records may include, pathology reports, CAT scans and test results on video. In psychiatric hospitals the record is likely to include detailed family history, clinical assessments and prognosis, observations about the consumer's personality and details of treatment.<sup>24</sup>

For the purpose of this report, health records also means the records kept by all other health service providers, including dentists, counsellors, therapists, people providing traditional health services, chiropractors, or osteopaths.

### 2.2 Changes to the doctor-patient relationship

Decisions in a number of cases in Australia over the past ten years have made medical professions more accountable and led to greater recognition of consumer rights. For example, in *Rogers and Whitaker* in 1992, the High Court recognised a doctor's obligation to provide a consumer with sufficient and appropriate information to allow them to give informed consent to treatment.<sup>25</sup> The court also said the question of whether a doctor has provided adequate information to a consumer to satisfy the duty of care owed to the consumer, can be reviewed by the courts. It is not just a matter for professional medical bodies.

The trend is also reflected in recent policy documents and guidelines. The National Health and Medical Research Council produced a *Guideline for Medical Practitioners on Providing Information to Patients* in 1993 to assist doctors in obtaining informed consent to treatment from consumers. It addresses the discomfort of doctors with the changes, saying it is not appropriate to withhold information because the consumer might be disconcerted or dismayed, or because the doctor finds giving particular information an unpalatable task.<sup>26</sup>

Consumers rights to privacy have also been recognised by the courts in relatively recent times, overturning the traditional notion that doctors could do as they wished with the records. Information acquired about consumers as part of receiving health services must be kept confidential.<sup>27</sup> They have a concomitant right to have the information made available to them by the health provider if the future treatment or well-being of the patient may be prejudiced by its absence.<sup>28</sup>

Consumers gained a right of access to the medical and dental records held by public health services and government agencies under FOI between 1982 and 1994. The law on access to health records in the private sector was uncertain until earlier this year.

### 2.3 Rights in the private health sector

The High Court decision in *Breen and Williams* in September 1996 clarified the rights of consumers of private health services. The case involved a claim by Mrs Breen, who sought a copy of records held by her plastic surgeon for the purpose of legal action against Dow Corning, the manufacturer of silicone breast implants. The records consisted mainly of hand-written notes.<sup>29</sup> Mrs Breen conceded that the doctor legally owned the records and this was not questioned in the case.

In 1994 the NSW Court of Appeal decided by a majority of 2/1 that a health consumer has no right to access health records held by their doctor.<sup>30</sup> On appeal, all of the six High Court judges who heard the case affirmed the Court of Appeal's decision.<sup>31</sup> They said notes prepared by doctors as part of care and treatment of consumers are the same as the notes prepared by any other professional, and consumers have no legal right of access to them. Reports prepared by services such as pathology laboratories and radiologists are different. They are prepared for the consumer and are the property of the consumer once they have paid for them.<sup>32</sup>

The High Court said the doctor-patient relationship is based in contract and negligence, which imposes on the doctor a legal duty of reasonable care and skill in providing advice and treatment. It is the doctor's obligation to judge what a consumer needs to know, which may involve showing them the records, but that is for the doctor to decide.

The court rejected the Canadian case of *McInerny and McDonald*, which held that there is a fiduciary (or trust) relationship between doctor and patient which imposes an obligation to provide access.<sup>33</sup> They said the Canadian decision does not reflect the law on fiduciary duty in Australia. When the case was heard by the NSW Court of Appeal, President Kirby (as he was then) supported the idea that doctors owe a fiduciary duty to patients and the duty includes a duty to release the medical records.<sup>34</sup>

Consumers in private hospitals, nursing homes and day procedure centres in NSW have similar rights to access and amend their health records as those available to consumers in public health services under FOI. This includes private psychiatric hospitals. The practical use of the rights have been fairly limited, due to a lack of awareness of the rights by hospital staff and consumers. A number of submissions reported incidents of nursing home and private hospital staff providing consumers with misleading or incorrect information about their rights.<sup>35</sup> The NSW Privacy Committee reported a

hospital that had wrongly told a consumer they needed to justify a request for the records. Another common claim is that the regulations provide only a right to see the records, not to copy them. This effectively prevents people seeking independent advice in interpreting them. New regulations this year have clarified this issue, specifying separate rights to access records, to a copy of the records or specific parts of the record, as well as a right to an explanation.<sup>36</sup>

Health complaints commissions in most States and Territories – except South Australia (SA) and the Northern Territory (NT) – cover the public and private health sectors. They operate under statutory guidelines which encourage 'reasonable' access to information in health records, except where prohibited by law or where the information is in personal notes of the health service provider.<sup>37</sup> However, there is no consensus on what constitutes 'reasonable access'. The Victorian Health Complaints Commissioner reports that in private hospitals the decision is usually left to the treating doctor.<sup>38</sup>

## 2.4 Rights in the public health sector

Consumers have rights of access to their medical records held by government agencies and health services under FOI laws and government policies.<sup>39</sup> FOI covers public health services such as public hospitals, community health centres and publicly funded psychiatric services. A right of access to records under FOI does not mean a consumer owns the personal health records about them.

Under FOI laws people can be refused access to their personal health records on two main grounds. Access can be refused if the government agency is of the opinion that it would be detrimental to the consumer's 'physical or mental health' or would endanger others.<sup>40</sup> This view may be formed by consulting with the practitioner who prepared the record. If access is refused on this ground in NSW, the record is provided to a registered medical practitioner nominated by the consumer. Access can also be refused if giving access would 'involve unreasonable disclosure of information concerning the personal affairs

of any person' or may place the community at risk.<sup>41</sup> The relevant government agency must take steps to obtain the views of the person concerned as part of their decision about whether access should be given.

Amendments to factual errors in personal health records can be sought under FOI laws.<sup>42</sup> People can also appeal against a decision to refuse access to records and a refusal to amend the record.<sup>43</sup>

The right of consumers to access personal health information in the public sector was reinforced nationally under the 1993 *Medicare Agreement*. It required all States and Territories to develop a *Public Patients' Hospital Charter*, which would set out what public hospital patients can expect from hospital services. The model charter, developed by the Commonwealth and States and Territories after nationwide public consultations, includes a right for consumers to access information in their personal health records.<sup>44</sup> It says 'you should have reasonable access to information in your medical records, except information which is expressly prohibited by law from being disclosed or information contained in personal notes by a person giving health care'.

The right was translated in a variety of ways by the State and Territory Governments when they produced their versions of the charter. In NSW the charter was published as *Commitment to Service*, which provides a right for consumers to have access to their medical records. In the *Northern Territory Public Patients' Hospital Charter* the consumer only has the right to access information in the medical records, 'unless the doctor believes the information would be damaging to their health or the outcome of their treatment.'<sup>45</sup> In Victoria *Putting Patients First*, simply says there are rights to some records under FOI, and access to records under FOI 'may not be immediate and may involve some charges'.

The difference in approach in NSW reflects the policy of the NSW Health Department since 1982, which supports access to records, without the formality or expense of an FOI application. The policy is restated most recently in the NSW Health *Information*

*Privacy Code of Conduct*. It says that NSW Health supports the 'right of a client/patient to see and obtain copies of information held about him or her by a health care facility'.<sup>46</sup> Access can be refused on the grounds set out under FOI in NSW. Some individual public health facilities have developed their own policies and practices on consumer access to records, to inform consumers of their rights and facilitate access.<sup>47</sup>

Despite the charters and the long-term existence of the rights of access in States such as NSW and Victoria, many submissions reported a lack of knowledge of consumer rights in the public health system.<sup>48</sup> A survey of health providers in public health services in Victoria in 1993 revealed that only seven services out of 56 agencies informed consumers that they could have access to their records. Only 24 provided information about rights if requested.<sup>49</sup> A review of NSW Health policies on consumer access to records in 1988 found that most hospitals made it extremely difficult for consumers to obtain access to their records. It said individual hospitals had developed their own ways of dealing with requests, with some keeping consumer rights a secret, while others simply refused consumers access to their records.<sup>50</sup> In Victoria, most requests for records are under FOI, which is – as the submission from of the Health Services Commissioner put it – 'time wasting and frustrating and gives the impression that bureaucrats are not people oriented.'

The Commonwealth Department of Health has also been criticised for a policy of refusing consumers access to their records on the basis of claimed obligations of confidentiality. The Department argues that it is bound by the confidentiality exception under FOI and section 135A of the *National Health Act*, which requires staff to keep information obtained as part of their work confidential. The *Inquiry into CJD* called for an amendment to the Act and a review of the Department's policy on access to records.<sup>51</sup>

## 2.5 Psychiatric records

People have a right to psychiatric records held by public health services under FOI and in NSW consumers have a right of access to records held by private psychiatric hospitals.<sup>52</sup> This is consistent with the principles in the *Disability Discrimination Act 1992* (Clth) which prohibits discrimination on the grounds of disability, including mental illness.

People who are to be admitted as involuntary or forensic patients in NSW and Victoria have the case reviewed by a board or magistrate. As a part of the process the consumer should be given the opportunity to read the Medical Report of the hospital and peruse the clinical file.<sup>53</sup>

However, gaining access to psychiatric or mental health records appears to be more difficult than gaining access to other records. A workshop with consumers of mental health services organised by NSW Health in 1996, found that people seeking mental health records are frequently forced to go through FOI. The result is a more onerous and costly process, which effectively discourages people disabled by a psychiatric condition to pursue their application for records.<sup>54</sup>

A review of the content of 80 psychiatric records available to consumers under FOI in Victoria found many carelessly written comments, many potentially distressing comments, and a high level of jargon and illegibility.<sup>55</sup> All this indicates that records are prepared without consumer access in mind.

## 2.6 Records in nursing homes

Residents of nursing homes and hostels have special rights under Commonwealth laws and some State laws.<sup>56</sup>

A right of access to personal and medical records is provided under Commonwealth laws which require proprietors of nursing homes and hostels to enter into an agreement with each resident. The agreement incorporates a *Charter of Residents Rights and Responsibilities* which states a resident's right to have access to all their documents and records – including personal and medical

records – to the extent that such access is not limited by legislation.<sup>57</sup> The right of access to the records is backed up by requirements in the *Outcomes Standards* for nursing homes which require residents to be consulted in preparation of and review of their care plan.<sup>58</sup>

## 2.7 Part of legal action or complaint

Medical records can be subpoenaed as part of legal action either against the creator of the records or some related party, such as the manufacturer of a faulty medical device. For example, in the *Breen and Williams case*, Mrs Breen could have subpoenaed the records of her plastic surgeon, which most of the High Court judges pointed out.

This can often work to compromise consumers' privacy if records about them are being sought for the purpose of legal proceedings to which they are not a party. The issue was addressed in a discussion paper by NSW Attorney General's Department, *Protecting Confidential Communications from Disclosure in Court Proceedings* issued in June 1996.

# 3

## Why do people want access?

*If patients have access to their files they will be better informed, less confused and frightened. They will take more responsibility for their own health care and consequently should be better satisfied with the results. As a general rule, the doctor should not be able to withhold any information which might affect the patient's decision to accept or refuse treatment.* Australian Consumers Association, 1986.

### 3.1 The role of health records

Consumers having access to their medical records goes to the heart of the consumer-provider relationship. Doctors, in particular, have been able to maintain authority and a certain mystique with consumers being the passive recipient of health services. Records have been maintained traditionally as a tool for:

- health care professionals to record and communicate information
- managers of health services to monitor quality of care;
- insurers to monitor services;
- health researchers; and
- health educators.

They have not, until relatively recently, been considered useful as a potential tool for communication with consumers.

### 3.2 Do consumers want access?

Submissions to PIAC from consumer groups indicated that they believe asking to see or copy their health records is likely to put at risk the relationship with their health provider. A number of consumer groups said they would be reluctant to ask for records, especially in rural areas where the choice of doctors is limited.<sup>59</sup>

A number of submissions pointed out that consumer access to records should not be seen in isolation, but as part of keeping consumers well informed about their health care.<sup>60</sup>

A number of surveys on consumer attitudes to access to records have been conducted by consumer advocacy groups. A consultation by the CHF on computerisation of health records in 1990 showed that consumers saw the trend as an opportunity to obtain print outs of their records, which they welcomed. A survey of the members of Consumers Health Advocacy (Queensland) conducted last year found 96% wanted a right of access to their medical records.<sup>61</sup>

In Western Australia the Health Consumers Council developed a policy on consumer access to records after consulting with its members.

They say 'access to medical and health records by consumers is essential ... for the consumer to be active and informed participants in their own health care'.

The Country Women's Association, on the other hand, said they are only interested in consumers having records such as test results and x-rays, not doctors' notes.

People in nursing homes and psychiatric institutions were singled out in many submissions as the most vulnerable health service consumers. Access to their health records by such consumers or by their nominated representatives was identified as important to protect these people from poor standards of care.<sup>62</sup> As the Australian Consumers Association noted, the alarm bells would have gone off much earlier about experimental deep sleep therapy at Chelmsford hospital if people had access to their records.<sup>63</sup>

### 3.3 Why do people ask for access?

The issues paper asked people to tell us why they had sought access to their health records. The responses from consumers and information managers in the public hospital system indicate that people are reluctant to ask for records. Where people do ask for access to their records it is likely to be when communication and trust has broken down. The people most likely to be seeking their records are people who are heavy users of the health system. They are therefore more reliant on their health service providers and are also likely to be more vulnerable and on a low or fixed income.

• **Improving consumers' sense of control**

The right to access health records can give consumers a sense of control over their treatment and their lives. This is particularly so for people with chronic illnesses and long term disabilities. As AIDS Council of NSW pointed out, access to records empowers communities affected by HIV and allows them to be partners with health care service providers in decisions relating to treatment and care.

Disabled People International (Tasmania)(DPI) emphasised the power of health providers over disabled people in determining access to pensions and similar entitlements as well as appropriate devices. We received complaints during the course of the project from people with disabilities who believed providers had been reluctant to give them copies of records, required for the purpose of establishing entitlement to benefits.

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*Joanne's scooter*

*Joanne is unable to walk and needs a wheelchair to get around. She is active in her community in Townsville. She is an independent person and wanted an electric wheelchair so that she could get about and do more things on her own.*

*When her request for a wheelchair was knocked back by the hospital which provides her treatment she suspected it was because her specialist believed it would not be good for her. She sought access to her records at the hospital through another health worker who was caring for her.*

*After obtaining the records she wrote to the occupational therapist refuting the opinions of the specialist and referred to the views of others in her health care team who supported her having an electric scooter.*

*She did not ask the specialist for the records because she did not want to damage the existing relationship. He was one of only two specialists in town and Joanne did not want to have to deal with the conflict she anticipated would follow a request for the records.*

*Joanne got her scooter and has enjoyed better quality of life as a result.*

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• **Prejudicial comments**

Some consumers told us they had experienced detriment because of derogatory statements about them in their health records or in their children's records. Personal and pejorative comments by a doctor in one case were regarded as the reason for other doctors providing incorrect diagnoses.<sup>64</sup> Another consumer reported being described in a hospital record as a middle-aged social worker, when she had described herself as a 38 year old social planner. She found the error stigmatising.<sup>65</sup>

The ACON said their members tend to seek access to their records to find out how their case is being presented to others.

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*Jane's story*

*Jane is a person living with HIV in Dubbo. She was seeking a place on the compassionate access program for Sequinavir, a protease inhibitor which is not yet available through Medicare in Australia. Sequinavir, taken in combination with another class of HIV drugs, markedly reduces sickness and prolongs lives, compared to previous HIV treatment regimes.*

*Jane's condition made her easily eligible for compassionate access to Sequinavir. Her doctor told her that he had entered her in the lottery for access, but after several weeks of missing out Jane began to worry that her application in the lottery did not properly describe her condition.*

*After several months had passed Jane sought access to her health record, but was denied. Jane felt progressively frustrated by her lack of knowledge about the process of her application for Sequinavir.*

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- **Concerns about accuracy**

A number of submissions said consumers sought to see their medical records, or those of their relatives or significant others, because of concerns about inaccurate information in the records.<sup>66</sup>

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*Ron's story*

*Ron's wife, Helen went to hospital to have a benign tumour removed. She was attended by community care nurses on a daily basis when she returned home, as Ron is older and not able to attend to her needs.*

*After a week or so, Ron realises from the way the nurses have been treating him and Helen that they must think Helen's tumor was malignant and is dying. When he questions them about what is in their records they treat him as if he is 'in denial' of his wife's fate. It takes another two weeks of dealings with the hospital before Ron is able to establish that the nurse's records are incorrect.*

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- **Continuity of care**

A number of people told us about the benefits of having their records for the purpose of providing information to other health service providers. For example, two women told us about having their records while receiving obstetric and related services in England. They kept the records maintained by three or four different health service providers and felt reassured by being able to read what each of them had said.<sup>67</sup>

Others talked about the importance of having copies of pathology tests and x-rays when they moved cities or changed doctors. Consumers with chronic conditions often need to go to a series of providers before they find one who knows how to diagnose or treat them. Having a copy of referral letters and test results minimises the stress for the consumers and avoids unnecessary duplication of services. Access to records can frequently become a problem when complications arise from people changing doctors.<sup>68</sup>

However, overall consumers were ambivalent about having the responsibility of keeping all their health records, and health providers were divided on the issue.<sup>69</sup>

- **Compensation claims**

Public hospitals and private health service providers routinely dispatch medical reports for the purpose of people obtaining compensation for injury. These may be for work related injury, for victims of assault or a similar purpose. A medical report, rather than a copy of the original record, is usually prepared for these purposes. NSW Health charge \$175 for medical reports.

A number of consumers complained to us during the course of the project about being refused access to records, and instead being charged relatively large fees for medical reports where compensation claims are involved. For example, one consumer told us of a medical centre in Sydney which charged \$250 for a report on a single consultation during which a man was treated for injuries sustained during an assault. The consumer, who wanted a copy of the record or a medical report for the purpose of claiming compensation, was therefore faced with paying disproportionately large fees. Although the cost of the medical report would be reimbursed if the claim was successful, the up front cost presented a barrier to the consumer making the claim.

- **When someone goes to hospital or dies**

According to hospital information managers we spoke to, people commonly request information from public hospitals when a loved one has died in a hospital or other health care institution. They want records of the last hours before the death so that they can better understand what happened. In these circumstances people frequently want to take the record to a GP or other health provider they know for an explanation, rather than talking to someone at the hospital.<sup>70</sup>

Submissions to PIAC also raised the importance of consumers and their carers having access to hospital and nursing home records to monitor their care.<sup>71</sup>

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#### *Arthur's story*

*Arthur is 64 years old and has been admitted to a hospital in New South Wales following a stroke. He does not appear to fully regain consciousness afterwards. He is diagnosed as suffering from dementia by the hospital. His relatives are alarmed at Arthur's condition and question the diagnosis. They try to get access to the medical records but are refused initially, on the basis that Arthur has not consented to them having access.*

*With the help of an independent advocacy service they eventually obtain the record which reveals heavy sedation. Soon after the sedating medication is phased out and Arthur's condition starts to improve considerably.*

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- **Compiling a family medical history**

People are increasingly seeking copies of public health records for the purpose of compiling a family medical history. Sometimes this may involve quite sensitive information on genealogy and the risks of developing certain diseases or conditions. In such cases special care is taken to counsel applicants.<sup>72</sup>

- **Making a complaint or taking legal action**

Pursuit of a complaint, is regarded as a common reason for people seeking access to public hospital records, although this is anecdotal because people do not need to give reasons for requests.<sup>73</sup> According to health complaints commissions and the NSW Privacy Committee access to records is frequently an issue as part of a complaint against health care providers. Consumers often become distressed when they find out during a dispute with a provider that they have no enforceable right of access to records.<sup>74</sup>

### **3.4 How often are people seeking access?**

The number of requests for medical records is not recorded in the public health system in Australia, nor are the number of requests recorded in England or New Zealand.

However, anecdotal estimates indicate that the number of requests remains relatively small. The health information manager at a major Sydney hospital estimated the number of requests for records from consumers to be about 50-60 per month for medical records (720 per year) and 6 per month for dental records.<sup>75</sup>

The New Zealand Privacy Commissioner's office estimate, based on their experience and a small survey of GPs during 1994, is that,

... many GPs practices would not receive an access request at all during the year and others would be unlikely to get more than three. As knowledge of the new rights increases it is to be expected that more people will seek access .... if you were to approach practitioners themselves at random I would be confident you would strike many who have not had to handle a single request in three years since the Act came into force. Others you would find had always had an attitude of openness towards their clients and are delighted to make access available.

Health complaints commissions also report a low level of complaints about access to records. They say this is because people do not regard access to records as a right, and express frustration about lack of information generally as a treatment or communication problem. However, both the NSW Health Care Complaints Commissioner and the Victorian Health Services Commissioner report an increase in complaints about access to medical records. The number of complaints to the NSW Health Complaints Unit on access to records went from 28 in 1990-91 to 46 in 1993-94. Complaints about access to medical records to its successor, the HCCC remained high in 1994-95, making up 43% of the total of 60 complaints about consumers' rights.<sup>76</sup> The Victorian Health Services Commissioner received 40 complaints about lack of access to records in 1995/96, out of a total of 200 complaints about consumers' rights. The Health Services Review Council in Victoria received 26 complaints on the subject in 1988.<sup>77</sup>

The NSW Privacy Committee also reported that a significant proportion of inquiries to the Committee relate to consumer access to medical records. The majority are dealt with by advising people of their rights. They told us that many doctors appear willing to keep their patients informed about the contents of their records.

### 3.5 Professional and industry attitudes

Organisations representing doctors, general practitioners, private hospitals, nursing homes, and social workers all accept that consumer access to their records could improve communication. Their views vary, however, on how and when access should be given.

The reluctance of the medical profession to support consumers having a right of access to all medical records is reflected in the policy of the Australian Medical Association (AMA) developed in 1993. The AMA's guideline says 'the patient has a right to *be informed* (emphasis added) of all relevant factual information contained in the medical record, but all deductive opinion ... remains the intellectual property of the doctor...' or institution maintaining the record. They say that where the record contains reports by others, such as specialists, the material should only be released at the discretion of the person who prepared the information.<sup>78</sup>

However, the AMA has endorsed discussions with the Commonwealth Government on legislation that would allow consumers access to medical records. They believe any access to the record should not include the doctor's notes and should remain largely at the discretion of the doctor. In their submission to PIAC the AMA said:

Co-operative access allows the sharing of information with the patient. It allows the doctor to release information in a sensitive manner with regard for the overall health and welfare of the patient. It allows a doctor to explain the information recorded and why it is recorded. This is often more valuable than just the bare information. It also allows the doctor to protect the confidences of third parties who have provided information relating to the patient.<sup>79</sup>

The AMA's position contrasts with the policy of their American counterpart, the American Medical Association which says '...on request of the patient a physician should provide a copy or a summary of the record to the patient or to another physician...'<sup>80</sup> It also contrasts with the policy of the Royal Australian College of General Practitioners (RACGP), which provides that 'patients should be permitted to have access to their medical record upon request...except...where access is likely to cause serious harm or distress...'<sup>81</sup> The Doctors Reform Society policy also says consumers should have access to their records in the private and public sectors.<sup>82</sup>

The insurers of the medical profession are divided in their views on the benefits of consumers having access to their records. United Medical Defence told us 'in the interests of ensuring a good doctor/patient relationship an open rapport between the two should be encouraged and this includes access to health records...' In contrast, the Medical Defence Association of Victoria told PIAC 'if a patient ... requires information from medical records, this should be provided by the doctor in the form of a medical report.'<sup>83</sup>

The NSW Nurses Association supports consumers being able to access and copy their health records, although they have no formal policy on the issue.<sup>84</sup> The Australian Nursing Homes and Extended Care Association (NSW) said consumers already have access to information in their medical records in the aged care industry. They pointed out however, that in many situations consumers need information about their care rather than just access to their records. An opportunity to discuss their concerns about their care and to have the records interpreted is therefore imperative, along with counselling, if appropriate.<sup>85</sup>

Both the Australian Hospitals Association (AHA) and the Australian Private Hospitals Association (APHA) supported consumer access to records during consultations on the draft *Australian Health Consumers Charter* in 1995. The AHA view was that access to records should be allowed, with qualifications. They said, the important concept to emphasise is 'participate'.<sup>86</sup> The APHA said private hospitals already have a process for involving and informing consumers in the development of medical records. Most would not have a problem with the provisions of the draft Health Consumers Charter dealing with access to records.<sup>87</sup>

The Australian Psychological Society Code of Professional Conduct does not deal with the issue of consumer access to records, although it covers privacy and confidentiality in some details.<sup>88</sup>

The Australian Association of Social Workers Code of Ethics says social workers 'will afford clients reasonable access to official social work records concerning them. When providing clients access to records, due care must be taken to protect the confidences of others.'<sup>89</sup>

## 4 The merits of consumer access to records

*There is research evidence supporting the benefits of consumers having access to their records, including lessening consumer anxiety, improving compliance with medical advice and improving the quality of the records. A survey of doctors attitudes, however, showed little awareness of the benefits. PIAC, 1996*

### The arguments in favour and against access<sup>90</sup>

#### Arguments in favour

Consumers will be:

- more involved and informed about their health care;
- more attentive to their health care and more likely to comply with instructions for medication and treatments;
- more in control of their health care and their lives, and less anxious about their condition;
- in a better position to give informed consent to treatment;
- better able to ensure continuity and co-ordination of care by different health services and when people move or change doctors;
- able to facilitate a more open and equal relationship with the health care service provider; and
- able to improve the quality of the record by ensuring the information in the record is accurate and relevant.

#### Arguments against

- Consumers will not understand the records and will take offence.
- The records belong to the health providers and are prepared and maintained for their purposes, not for the purpose of communicating with consumers.
- The quality of records will suffer because providers will hesitate to record mere speculations and 'would be forced to sacrifice directness and clarity for diplomacy'.<sup>91</sup>
- Consumers anxiety will be increased or consumers will be harmed by showing them the records.
- Consumers will see information given by other people which might put that person at risk.
- Consumers may misuse the records to their own detriment.
- The doctor-patient relationship will be harmed.
- Consumers having access to records will increase litigation.

The arguments in favour and against consumer access to their medical records are well known. This chapter reviews the evidence about the arguments gathered from the submissions during PIAC's consultations and Australian and overseas studies.

### 4.1 Improving communication and understanding

Overwhelmingly the message from consumers in the workshops was that consumer-provider communication would be improved if people read what went into health records at the time the record is made.<sup>92</sup> The view is backed by research on consumer access to their records in the USA.

Six studies in the USA demonstrated better consumer education through the use of their medical records. In three of the studies more than two thirds of consumers said they could better understand their problems.<sup>93</sup> Two other studies tested consumers knowledge of their health problem and treatment after having access to their records. They both found consumers knowledge was significantly better after reading their medical records and a treatment protocol.<sup>94</sup>

One of the most positive outcomes of consumer access to health records is improved communication. One study concluded that the most significant effect was that the responsibilities of the doctor and consumer were clearly defined. Another study found that communication channels opened up, and consumers with access to their records were more assertive and directed the flow of communication. While spending the same amount of time with the doctor, the consumers with access to their records elicited twice as many factual statements from the doctor.<sup>95</sup> A study of rehabilitation consumers found that they used their records as a reference to explain their illness to family. The study also found that references in the record to emotional and sexual problems facilitated discussion of these issues.

A significant gap between what doctors think consumers know and what consumers actually know influences their views on whether access to records would be helpful.<sup>96</sup> A particular problem area is consumers lack of knowledge of their medication. This is being addressed by the *Quality Use of Medicines* campaign. Principles on privacy in the use of medication data recently released by the Australian Pharmaceutical Council state, among other things:

Medication data is factual data relating to the consumer, therefore ultimate ownership and control of such information should remain with the consumer. This does not imply that all medication data records should be consumer held. Medication data records identifying a prescriber or dispenser can also be held and controlled by the prescriber or dispenser.<sup>97</sup>

#### 4.2 Consumer anxiety

A number of consumer submissions said consumers have found that seeing their health records was a soul destroying experience, and access therefore needs to be handled sensitively.<sup>98</sup> The AMA and the RACGP said they are concerned that access to records could cause consumers anxiety and this would justify not allowing access.

Concerns about consumer anxiety are backed by research. A US study in 1979 showed that some consumers felt more pessimistic after seeing their record, felt staff had made untrue statements about them, and feared for the confidentiality of the record. Half of those surveyed were generally upset.<sup>99</sup>

However, while research shows that consumers experience anxiety when they see their records, particularly psychiatric records, consumers regard the experience as beneficial. A study of people admitted to psychiatric units who had seen their records showed that while 41% experienced anger or anxiety, they all considered the experience useful, as it provided an opportunity to discuss their feelings. Two thirds of the consumers felt better as a result of seeing their record.<sup>100</sup> Another study of psychiatric patients reported patients felt more involved in treatment after access, although half were upset by what they read.<sup>101</sup> A study of consumers at a US health

care centre showed that access to the record can serve to allay hidden fears.<sup>102</sup> At Given Health Care Centre in Burlington, USA, consumers were provided with access to their records routinely over a period of 15 years. A survey of the Centre's consumers found 97 out of 100 felt less worried about their health after reviewing their records.<sup>103</sup>

#### 4.3 Quality of records

Some health providers argue that consumer access to their health records will result in lower quality records because frankness and clarity would be sacrificed for diplomacy.<sup>104</sup> Consumers on the other hand, argue that if they are given access to their records they can help to ensure the record is accurate and free from derogatory statements. The major issues therefore are the extent to which medical records contain inaccurate information, or derogatory comments, and whether consumer access actually leads to inadequate record keeping.

Taking the last issue first, information will be presented differently in a health record that is available to the consumer than one that is not, but that does not justify the omission of clinical information. Health information managers in public hospitals told us that in their experience, consumer access to records does not mean anything clinically important needs to be omitted. To the contrary, it is a matter of ensuring completeness and distinguishing speculation from conclusions.<sup>105</sup> They said inadequate documentation and unintelligible records continues to be a problem. They also said that health providers in the public sector do not understand how to maintain a health record in a manner appropriate for disclosure to consumers.

Some US studies show that medical staff have tampered with records in anticipation of consumers being given access to records, but the changes were not made to factual material. Language was changed so that prognosis was stated in a less discouraging way ('tumor' instead of 'cancer') and psychiatric labels were avoided.<sup>106</sup> Overall, however, US studies have found that staff in medical facilities believe records are more accurate as a result of consumers having access to them.<sup>107</sup>

A high level of factual inaccuracy in health records identified through consumer access, has been shown in a number of US studies.<sup>108</sup> Three studies showed around 50% of consumers who had access to their medical records made corrections of fact. This view is supported by the anecdotal information obtained during PIAC's consultations. A Newcastle general practitioner who started showing people their record, while trialing the use of computers in prescribing practices, said he found that people frequently commented on the record and corrected errors.<sup>109</sup> One consumer reported she had been described as diabetic in a hospital record, with a hospitalisable blood sugar level because someone else's pathology results were on her file.<sup>110</sup>

We were told that derogatory and offensive comments occur quite frequently in health records in the public health system, despite consumer rights of access. People who work in the public health system and consumers told us they had seen such comments, but health information managers believe they are less frequent these days with training in the public sector on record keeping.<sup>111</sup> Derogatory and offensive comments have been found to occur frequently in psychiatric records. An Australian study of records in Victorian public psychiatric services found many potentially distressing comments. A US study found a substantial proportion of psychiatric records contain offensive statements, and a UK study considered a third of entries were alarming or worrying.<sup>112</sup>

The issue of derogatory or offensive statements in records has been taken up by the private medical profession. The Entry Standards of the RACGP say for example, that derogatory or prejudicial comments about consumers are unacceptable.<sup>113</sup>

#### **4.4 Quality of care and risks to health**

A link between access to records and enhancements or risks to consumers health has not been established by research so far. On examining a number of studies Bergen concluded in 1988 that the question of whether access to records can cause harm remained unanswered. In the same year Westbrook concluded that the fear of most health professionals regarding the harmful

effects of access to records are unjustified, and that one of the benefits is positive effects on consumer health.<sup>114</sup>

On another level, openness can also be a measure of quality. A 1994 study of nursing homes showed a direct relationship between the level of openness with Commonwealth nursing home Standards Monitoring Inspectors and compliance with the standards. It concluded that lack of openness was the hallmark of poor quality facilities, while openness was a characteristic of a high quality facility. Open flow of information also became a resource for regulators to help facilities improve their quality of care.<sup>115</sup>

#### **4.5 Costs and time**

A commonly held view in the private health sector is that consumers having access to records will increase the time in consultations and increase record-keeping requirements.<sup>116</sup> The AMA submission suggested providing access would cost a general practitioner \$10,000 a year, assuming one request per day and allowing 15 minutes of professional time for each request.

Such views seem to be based on the assumption that access to records will not occur as a part of the normal consultation and fail to recognise the potential benefits of consumer access to records. A US study in 1985 showed that staff in an in-patient psychiatric unit felt that record-sharing saved time because there was no second-guessing what consumers had been told. Use of the record as a communication tool has been shown to result in much better consumer understanding, without extra time having to be spent with the doctor.<sup>117</sup> Better consumer understanding of their condition and treatment has also been shown to result in less follow-up visits.<sup>118</sup>

#### 4.6 Compromising the privacy of others

Health professionals and consumer groups expressed a high level of concern about the potential for exposure of confidential information about other people if consumers have access to their records. However, it is important to clarify whose privacy should be protected.

Information about health providers involved in a consumer's care should not be protected from disclosure, unless it is of a personal nature.

Information about other consumers mentioned in the record should clearly be kept private. ACON pointed out that medical records can contain information about other consumers and information about them – such as their HIV status – should not be revealed. This information can simply be excised or blacked out from the copy of the record provided to the consumer, with an explanation of why it has been withheld. It is not a reason to refuse access to the whole record.

Records can also contain personal information about another person, such as information provided by carers or family members about their preparedness to care for the consumer. The submissions to PIAC supported such information being kept confidential if the person tells the provider the information is confidential, or if confidentiality is implied in the circumstances. However, it is not a reason for refusing the whole record.<sup>119</sup>

The more difficult issue is information provided by other people (third parties) about the consumer, where the third party does not want the consumer to know what they have said about them. General practitioners and mental health services rely heavily on information provided by family members who would not want the consumer to know what has been said. On the other hand, consumers should not be the unknowing victims of gossip and should have some rights to know and comment on information about them. FOI laws deal with the problem by disallowing disclosure if it would 'involve unreasonable disclosure of information concerning the personal affairs of another person'. However, this has tended to operate in practice to

protect the person who is the source of the information, rather than the consumer. Balancing these potentially competing rights is discussed in chapter 5.

#### 4.7 Increased litigation

Health service providers' fear of increased litigation and consumer abuse of health records do not stand up to scrutiny. A number of studies indicate that access to records does not increase litigation or it may be associated with reduced litigation.<sup>120</sup> As health providers can only be sued for negligent care, access to records itself could hardly be the basis for litigation. At present the only way to obtain access to records is as an adjunct to the litigation process. If people can have access to their records without recourse to litigation, people will less often have a need to litigate.

#### 4.8 Psychiatric records

A study on psychiatric records in Australian public hospitals in 1994 revealed a high level of carelessly written and potentially distressing comments. It cited other studies which found consumers of psychiatric services commonly experience anxiety when they see their record, but that this was outweighed by the substantial benefits – benefits acknowledged by staff and consumers.<sup>121</sup>

A US study of consumers with access to their psychiatric records in a surgical hospital setting provides a warning. All the consumers in the study had a psychiatric consultation after being hospitalised for a medical or surgical diagnosis. The consumers were classified as having 'compelling emotional needs that surfaced in the medical setting' and often had an adversarial quality to their interaction with staff. The study found any harm resulting from access to records was of a psychological or emotional nature, except one consumer whose emotional reaction jeopardised his cardiac status.<sup>122</sup> The study is cited as justification for laws on consumer access to records providing doctors with the discretion to refuse access to records where it would cause harm to the consumer.

The concluding comments of the authors of the Australian study offer a guide to future practice in psychiatric care.

What is most apparent from the studies is that access should be carefully supervised by a professional who understands the patient's clinical details. With adequate supervision, access need not be delayed except in the most disturbed patient.

#### **4.9 Conclusions**

A survey of Australian doctors in 1988 revealed that they did not recognise the benefits of consumer access to their records. It showed almost unanimous disapproval of consumer access to records, rejecting the notion that access will lessen consumer anxiety, help consumers make more informed decisions or improve the quality of the record.<sup>123</sup> In light of the evidence, one hopes that these views have changed in the last 10 years.

The evidence of the benefits of consumers having access to their health records, and the lack of evidence to substantiate the arguments against access, point to an inevitable conclusion. Consumer access to health records, with appropriate qualifications, should be implemented through legislative reform.

##### **Recommendation 1:**

**National law reform should be introduced to ensure consumers of private health care services have the same rights of access to their personal health records as those in the public health sector.**

### 5.1 Access to which records?

#### Defining the record

Most submissions said the primary purpose of consumers having access to their health records is to improve communication and assist in ensuring informed consent to treatment.<sup>124</sup> Others saw consumer access primarily as a privacy issue, facilitating more accurate records and consumer consent to use of the personal information for other purposes, such as research.<sup>125</sup> If these are the primary purposes of consumers having access to their health records, then the right to access should cover all personal information about the consumer.

Most consumer groups said all health records should be covered by a right of access. The rights to should be consumer focussed, avoiding frustrating technicalities. The AMA believes a doctor's working notes should be excluded. This position is not acceptable if the objectives of improved communication and privacy are to be achieved.

Should rights to access be limited only to records prepared in relation to the advice and treatment of the consumer? The AMA and the Medical Defence Association of Victoria took this view, so that medical reports prepared for insurers and employers are excluded. The issue was not raised by any consumer groups. However, consumer rights to access their records in the UK and New Zealand are not restricted in such a way.<sup>126</sup> Of course, information prepared for the purpose of litigation would be exempted from a right of access as it would be the subject of client legal privilege.

The AMA and the Medical Defence Association of Victoria also believe doctors should only be obliged to provide information prepared by them. They say information such as specialists' letters or reports from pathology laboratories and radiologists should only be obtained from the original source. This is out of step with overseas laws and is not supported by Australian health consumer groups. It also appears to be out of step with the law, which recognises consumers as owners of medical reports such as pathology reports and x-rays.<sup>127</sup>

The definition of health information or health record also needs to be sufficiently precise to exclude information which is not personal to the consumer but arise from providers' services. An example provided by the NSW Privacy Committee is records of prescriptions which doctors are required to maintain.

The definition of 'health information' in the New Zealand *Health Information Privacy Code* includes information about an individual's medical history, any disabilities, any services or tests they have or are currently receiving, information from them on donation of body parts or substances, and any information collected during, or incidental to, the provision of health care or disability services.<sup>128</sup>

In the UK manual 'health records' available to consumers include personally identifying information prepared in connection with care of a consumer.<sup>129</sup> 'Personally identifying information' is any information, or combination of information, about a person which would allow someone to identify them. Electronic records in relation to people who are alive are available in the UK under the *Data Protection Act 1984*.

#### Recommendation 2:

**'Health records' should include all personally identifying information prepared in connection with health services provided to consumers.**

#### Access to an outline

A number of submissions and the Sydney workshop said consumers should have a right to know what information is available in their records. This allows people to choose which information they want and to know what information is not being provided to them, for whatever reason. In the UK, unlike New Zealand, people are not told what is in the health record or what should be on the record.

The *Privacy Act* and the *Australian Standard on Personal Privacy Protection on Health Care Information Systems* require organisations to keep a databank register. The register provides an outline of the data collections maintained and the type of information in each collection. This was suggested as a model for informing consumers about what information about them is available.<sup>130</sup>

### **Recommendation 3:**

**Consumers should have a right to an outline of information about them held by health providers or health institutions so they can decide which information they wish to request and will know if only part of it is provided to them.**

#### **Records of which health service providers?**

The workshops and submissions gave strong support for the right of access to records to cover all health service providers, whether registered or unregistered. They also supported the right applying to anyone who holds health records, such as insurance companies or hospitals or educational institutions. This is consistent with the access to records laws in the UK, New Zealand and the USA.

The New Zealand code covers information held by registered health professionals, and health agencies including health services, educational institutions, statutory agencies and health insurance companies.<sup>131</sup>

The UK law covers medical practitioners, dentists, opticians, chemists, nurses, midwives and health visitors, as well as registered professionals such as chiropodists, dietitians, occupational therapists, physiotherapists, psychotherapists and speech, art or music therapists and scientists.<sup>132</sup> This definition does not go as far as the New Zealand code as it specifies health professionals but not institutions, such as educational institutions, health insurance companies or statutory agencies.

The US law uses the term 'health information trustee' which includes any health care provider, health care plan, health oversight agency, public health authority, and other entities that create, receive, or use health information as well as others who obtain such information under specific sections of the Act.<sup>133</sup>

In all Australian States and Territories, except NT and SA, health complaints commissions cover the private and public health sector. The definition of health service providers under the *Health Complaints Act 1993* (NSW) is broad and offers an appropriate model. It includes medical, hospital, nursing, dental, psychiatric, pharmaceutical, ambulance, community health, health education, related

welfare services, and other services such as radiographers, dietitians, chiropractors, optometrists and services provided in other health care fields.<sup>134</sup>

### **Recommendation 4:**

**Consumers' right of access to records should apply to all records and information held by health service providers and health institutions, insurance companies and others who hold such information. The right should apply to all records held by a health provider or institution, including records created by another agency or person.**

## **5.2 What should a right to access mean?**

### **Access in what form?**

Records are increasingly kept in a variety of forms, and a number of submissions said the right of access to records needs to take this into account. FOI laws already provide for consumer access to records held in whatever form, whether electronic, paper (including staff diaries), audio, video or other.<sup>135</sup>

Discussions in the workshops indicate that consumers are interested in seeing their records at the time of the consultation with the service provider. They are then able to effectively participate in accurate record-keeping.<sup>136</sup> However, experience in the public health system shows that people most frequently want copies of their records.<sup>137</sup> A right to a copy of records is therefore important.

A right to a copy of the records is consistent with the rights to access to health records under FOI, and health privacy codes in NSW and the NT and under hospitals and nursing homes regulations in NSW.<sup>138</sup>

Alternatively, consumers may only want a summary report or to view a video. A law providing a right of access needs to be flexible to accommodate the form in which the consumer wants access to their records. The laws in the USA, the UK and New Zealand provide consumers a right of access in the form they request it. This is consistent with the proposal in the Attorney General's discussion paper on *Privacy Protection in the Private Sector* which says personal information would be required to be provided in the form requested by the applicant, unless:

- it would unreasonably interfere with the operations of the record holder;
- be detrimental to the preservation of the document;
- would otherwise not be appropriate; or
- would be contrary to a legal duty of the record holder (such as copyright).

It proposes that where information is not provided in the form requested the applicant must be given reasons.<sup>139</sup>

A right of access to records in any form requested by the consumer should be qualified to accommodate forms of access that would be: particularly expensive, (such as x-rays and CAT scans); impractical to provide; contrary to a legal obligation of the record holder; or breach confidentiality obligations. Each of these potential problems are covered in the New Zealand code.

#### **Recommendation 5:**

**Consumers should have a right to access their health records in the form they request, unless it would:**

- **impair efficient administration;**
- **be contrary to any legal duty of the provider; or**
- **prejudice interests protected in exceptions to the right.**

**If the record is not provided in the form requested, the record holder must provide reasons.**

#### **Right to an explanation?**

The need for access to records to be provided as part of a discussion with the health provider about the consumers' care and treatment was emphasised in many submissions. Health records contain technical terms and abbreviations which consumers will not necessarily understand. There will also be information which may cause distress if not explained. However, while an explanation or guidance from a health professional may be important, people do not always want it from the health care provider from whom they are seeking the record.

Most health service providers told PIAC that an explanation by the health provider who made the record or an appropriately qualified person should be a condition of consumer access to their records.<sup>140</sup> Most consumer

groups, the health complaints commissions and three of the NSW Area Health Services said an explanation should be provided if the consumer requests it. The explanation should be of the whole record, not just technical terms. However, they rejected an explanation being a condition of access because it would be impractical in many circumstances, could be very expensive and may be an unreasonable barrier to access.<sup>141</sup> A number of consumer groups supported an obligation on providers to give an explanation of the record in terms that are appropriate to the consumer's circumstances.<sup>142</sup>

Making an explanation a condition of access may unreasonably restrict a consumers' access. Experience in the public sector shows that such a requirement can result in a provider effectively preventing or delaying access because they are not available to give the explanation. In a situation where access is sought as part of a complaint, or where the relationship between provider and consumer no longer exists, the condition will be of no benefit.

In NSW existing policies in the public sector and regulations for private hospitals and nursing homes both favour assistance in interpreting the records but do not require it. The NSW *Information Privacy Code* says viewing of health records is preferred to copying, and supervision of access by a health care provider or health information manager is required.<sup>143</sup> The hospitals and nursing homes regulations say consumers and their representatives must be given assistance in interpreting the records if they request it.<sup>144</sup>

In the UK an explanation must be given of terms in a health record which are 'not intelligible without explanation'.<sup>145</sup> In New Zealand the health provider is expected to give access to the records in the form requested and this may include an explanation.<sup>146</sup>

The need for consumers to have independent support, counselling or interpreters in some circumstances was raised by some submissions to PIAC, discussed in chapter 3. DPI said consumer advocates can play a vital role in minimising the trauma for the consumer seeing their health records and making the experience an ultimately helpful one. Northern Territory Health asked who should

be responsible for arranging and paying for interpreters if this is necessary. While these aspects of consumers access are important and should be provided for in practice, the financial implications make it inappropriate to provide for them in legislation.

#### **Recommendation 6:**

**Consumers should have a right to an explanation of their health record by an appropriately qualified person, if they request it, and if the records are not intelligible without an explanation.**

#### **Timely responses to requests**

Timely responses to requests for records are essential if the right is to be effective.

Consumers at the Sydney workshop said time limits are needed to avoid the potential for consumers to be frustrated and worn down by delays.

Time limits of between 21 days and 20 working days are provided under FOI in NSW.<sup>147</sup> In Victoria the time limit under FOI is 45 days. The Attorney General's discussion paper on *Privacy protection in the private sector* proposes a time limit of 14 days to acknowledge receipt of a request and 30 days to make a decision. It provides for extensions of time where the request is large or consultation with others is needed.<sup>148</sup>

Consumer groups at the Sydney workshop said that anything more than a month for responses to requests for records is too long.

#### **Recommendation 7:**

**A request for records should be required to be responded to within 21 days. A response to a request for an amendment should also be required within 21 days. Provision should be made for reasonable extensions of time where the request for records is large or consultation with others is necessary.**

#### **Rights of carers**

Sometimes carers of health consumers will want access to health records on behalf of the consumer. In situations where the consumer is not capable of giving consent to medical treatment the law is clear on who has the rights on behalf of the consumer.<sup>149</sup> However, there are situations where consumers still have the legal capacity to make decisions, but are not in a position to effectively advocate for themselves within the health system.

The law requires a written authorisation from the consumer before information in records can be disclosed to others, because the privacy of the health consumer is protected by law.

The need to protect the privacy of consumers was reinforced in most submissions and was emphasised strongly in the Sydney workshop.

Some submissions said flexibility is needed in implementing this requirement in relation to family and friends who are caring for a health consumer. In the Melbourne workshop, for example, the Epilepsy Foundation representatives argued that carers should have some special rights of access because they are actively involved in the consumer's care. In nursing homes in NSW lack of consent from the consumer is commonly given as a reason for refusing carers access to the record, where it is not practical for the consumer to give such consent.<sup>150</sup> On the other hand, other consumer groups said the rights and role of carers should be defined by the consumer where possible. They suggested the process of obtaining consumers' views should be facilitated by procedures or standard form questions in hospitals and other health services.<sup>151</sup>

A related question is the definition of 'next of kin', who are often given information about a dependent consumer. ACON's experience is that if health service providers are left to decide who should be treated as next of kin, relatives are given preference over gay partners or friends who are actively involved in the consumer's life.

The UK *Access to Medical Records Act* requires consent from the consumer before disclosure to others. Flexibility in the application of this law is built into procedures in public health services by the *Patients Charter*. It says 'if you agree, you can expect your relatives and friends to be kept up to date with the progress of your treatment'.

Both the New Zealand code and the US law provide for records to be provided to consumer's representatives, which are given a broad definition. In New Zealand a representative is defined as a person appearing to be lawfully acting on the consumer's behalf or in the consumer's interests if the consumer is unable to give consent or exercise their rights. The US *Medical Records Act* allows

disclosure of health information to next of kin and any person who has a significant personal relationship with the consumer without the consumers' consent if:

- the consumer has been notified of his or her right to object and has not done so; or
- the consumer is not competent to be notified of the right to object; or
- if exigent circumstances exist to make it impractical to notify the consumer of the right to object; and
- the information relates to care currently being provided.<sup>152</sup>

ACON opposes such provisions because they do not define 'significant personal relationship,' leaving the decisions to the health provider, which creates uncertainty. They prefer the criteria for appointment of a substitute decision-maker in the *Guardianship Act 1987* (NSW), which provides a model for dealing with competing claims about the relationship with the consumer.

Given the support for consumer representatives having at least a right to records about care currently being provided, PIAC supports the US model, with the addition of a definition of 'significant personal relationship'.

#### **Recommendation 8:**

**People who are relatives or have a significant personal relationship with a consumer should have a right of access to information relating to the current care of the consumer if:**

- **the consumer does not object; or**
- **is not competent to object; or**
- **it is impractical for them to be given the opportunity to object.**

**Significant personal relationship should be defined. The criteria set out in the Guardianship Act (NSW) provides a model.**

#### **Rights of deceased**

When a relative or loved one dies people often want access to the health record about their care at the time. While legally recognised 'next of kin' will often have such a right, some consumers were concerned about protecting their privacy.

The Sydney workshop and ACON took the view that people's privacy should be able to be protected posthumously. Next of kin, however

defined, should not have an unqualified right of access to their health records. They suggested people should be asked their wishes about who should have access to their records when they die as a part of routine procedures in hospitals and other facilities.

Under the NSW *Health Information Privacy Code of Practice* next of kin – which includes same sex partners shown on the record, may be granted access to health records of a deceased person.<sup>153</sup> In private nursing homes, day procedure centres and hospitals in NSW the executor or administrator of the consumer's estate has the same rights as the consumer to access the health records.<sup>154</sup>

In New Zealand, only the consumer's legally recognised personal representative has a right of access to the records.<sup>155</sup> In the UK, the consumer's personal representative and anyone 'who may have a claim arising out of the consumer's death' has a right of access to the records. However, access will be denied if the consumer has had a note made on the record that they do not want access granted.<sup>156</sup>

#### **Recommendation 9:**

**Consumers' legally recognised representatives should have a right of access to the consumer's health records after their death, unless the consumer has made it known that they do not want such access granted. Consumers should be asked their views on who can access their records as part of routine record keeping.**

#### **Rights of children**

The rights of children and young people in relation to medical treatment was the subject of comment in almost all of the submissions.

Young people in NSW are legally capable of giving consent to medical treatment at the age of 14 years. However, the NSW *Information Privacy Code* says that where the consumer is between 14 and 16 years of age, the consent of the parent or guardian should be sought unless the consumer indicates strong objection to this. For consumers less than 14 years of age, the consent of the parent or guardian is needed for access. Consumers over the age of 16 years are considered legally capable of deciding access for themselves. Special provision is made for situations where a parent or guardian 'against whom action in relation to child abuse may result,' requests

access to a child's health records. In such cases, the treating health care provider may refuse access to the parent or guardian if it could be prejudicial to the physical or mental health of the child.<sup>157</sup>

In the UK children can have access to their health record if they are capable of understanding it. This effectively links the right of access to the child's capacity to consent to medical treatment. Parents or guardians of a child can only be granted access if the child has consented or the holder of the record is satisfied that:

- the child is incapable of understanding the nature of the application; and
- giving access would be in the child's best interests.<sup>158</sup>

In New Zealand children under 16 may have the ability to request their records under the Privacy Act and code. Access might be refused in such a case if disclosure would be contrary to the child's interests.<sup>159</sup>

Given the range of views we received and the complexities of the law, PIAC's view is simply that a right to access privacy of health records should follow a legal right to consent to medical treatment.

#### **Recommendations 10:**

**Children and young people who are legally capable of consenting to medical treatment should have a right of access to their records and be able to refuse access to the records by others, including parents and guardians.**

### **5.3 Costs of providing access**

The arguments about the expected costs of providing access to records were briefly discussed in chapter 3 and section 4.5. As a number of submissions pointed out, if access to records is provided as part of the consultation there would be minimal additional cost.<sup>160</sup>

Substantial costs could be incurred by health providers where requests are made some time after care or treatment and where there are a large number of records to be found. The costs will also depend on whether the records are stored electronically or manually.

On the other hand, the people who are most likely to be seeking old records will be people with a long-term condition, who are often on

a low or fixed income. Even a nominal fee could be a disincentive for such people to obtain their records.

All of the Area Health Boards who made submissions commented that access to records under FOI has imposed considerable costs on the public health system. They expressed concern about increased use of FOI to obtain health records for legal proceedings. The charge for FOI requests in NSW is \$30 per request, or \$15.00 for health card holders, plus 25c per page.<sup>161</sup> A medical report from NSW Health costs \$175. Most Area Health Boards supported consumers being charged photocopying costs, and one supported a fee of up to \$100 per application.

The AMA, ANHECA and HIMAA submissions said consumers should pay the full administrative and other costs of having access to their records. The RACGP indicated concerns about an unreasonable cost burden falling on general practitioners as a result of consumer access to records, but they did not have a clear position. The Medical Defence Union said consumers should be provided with a medical report in appropriate circumstances for which a charge should be made. If providing access to the record is appropriate, the consumer should not be charged.

As the New Zealand Privacy Commissioner's office points out,

The costs tend to be heavier where there are long and detailed files. That will usually be the case where a person has had a very great many dealings with the health service and records have been built up. A prime example is mental health cases where a request for access to the file may require giving access to documentation spanning that person's lifetime and running to many hundreds of pages, several files and various types of documentation. However, the mental health services in New Zealand are almost entirely run in the public sector and therefore the Privacy Act has not changed the position...

Some in the private sector may have found it inconvenient to provide people with access and will have found the costs of doing so a nuisance. However, in future, as they come to grips with the *Privacy Act* requirements they can build the very modest cost into their overheads.<sup>162</sup>

In the UK no fee is allowed to be charged for giving access to health records unless copies are made, in which case the fee must be no more than the actual cost of copying and posting the record. An application fee of up to ten pounds is also allowed.<sup>163</sup> In New Zealand a charge is prohibited for assisting a person making a request, for the processing of the request, for making the information available, or for making a correction or attaching notes. Charges can be imposed if there is more than one request within 12 months for records from private sector agencies and where copies of x-rays, CAT scans and video recordings are involved.<sup>164</sup> In the USA the holder of the information can seek reimbursement for the cost of inspection and copying the records.<sup>165</sup>

The Attorney General's discussion paper on *Privacy protection in the private sector* provides for 'reasonable fees' to be charged, linked to the cost of compiling the request.

Health consumer groups and health complaints commissions said either no fee should be charged, or only photocopying and postage costs. Most said that a fee would be a significant disincentive for consumers of health services who are most disadvantaged and therefore most in need of their records.<sup>166</sup>

**Recommendation 11:**

**No charge should be allowed for consumers seeking access to their health records, except:**

- (a) to cover the reasonable cost of copying and posting the record;**
- (b) if there is more than one request per year from a consumer for records from a private sector agency; or**
- (c) copies of x-rays, CAT scans and video recordings are involved.**

**A maximum charge should be set to ensure consumers on low incomes are not disadvantaged.**

## 5.4 Exceptions

### Right to reasons

In this section we discuss the appropriate exceptions to a consumer's right of access to their health records. An important preliminary principle is that exceptions should not be applied in a way that effectively prevents consumers having access to the whole record, when only part of the record is subject to an exception. This is acknowledged in the

Attorney General's discussion paper, *Privacy protection in the private sector*. It proposes that deletion of exempt information from a copy of the record should be done to facilitate access 'where practicable'. If this occurs, it says consumers must be notified that information had been withheld and be given reasons for the information being withheld.

**Recommendation 12:**

**Consumers access to their health records should be facilitated by allowing parts of a record containing exempt information to be withheld, rather than exempting the whole record. If this occurs consumers must be informed and given reasons.**

### Protecting information about others

In section 4.6 we discussed the various types of information about other people that might be found in health records and how it should be protected. We concluded that:

- information about health providers should not be regarded as confidential unless it is personal to the health provider;
- information about other people should be kept confidential and
- information provided by other people which is relevant to the consumer – but not about them – should be kept confidential if it was provided in confidence, whether express or implied. An example is information provided by a relative caring for the consumer about how much time and effort they can offer for the consumer's care.

The area of greatest difficulty is information provided by other people about the consumer, where they do not want the consumer to know what they have said about them. In these situations there may be competing rights – the consumer's right to know what a health provider has been told about them and the rights of people to provide information on a confidential basis.

An example is information provided by relatives about a consumer's drug or alcohol consumption. Such information is important for treatment, but it may not be appropriate to divulge that information to the consumer.<sup>167</sup> Another example is information provided about allegations of child abuse by parents or guardians.

FOI laws deal with the problem by disallowing disclosure if it would 'involve unreasonable

disclosure of information concerning the personal affairs of another person'. In deciding if the disclosure is unreasonable the government agency must take steps to obtain the views of the person concerned as part of their decision about whether access should be given.<sup>168</sup> However, this has been interpreted very narrowly by government agencies in practice, so that people are refused access to records more frequently than they should be. The recent review of the Commonwealth FOI Act recommended an amendment to clarify the interface between FOI and privacy and to make provision for recognition of a 'special relationship' between the applicant and the third party. It also recommended that guidelines be developed by the FOI Commissioner and the Privacy Commissioner on interpretation of the relevant section of the Act.<sup>169</sup>

*The Inquiry into Pituitary Derived Hormones in Australia and Creutzfeldt Jakob Disease* said the Department of Health (Clth) had interpreted the FOI law much more restrictively than is necessary. It recommended an amendment to the confidentiality provision of the National Health Act and a review of the Department's policy on access to records.<sup>170</sup>

Most of the submissions and discussions at the workshops recognised the need to protect some confidential communications with health care providers. However, consumers were wary because protection of third parties has often been used as an excuse to deny access to consumers. Health providers and the NSW Privacy Committee tended to favour strong protection of information provided by third parties on a confidential basis.<sup>171</sup> The FOI model, which requires people to be consulted about disclosure, was favoured by public health agencies and the health complaint commissioners, with emphasis on the consumer's primary right of access to the record.<sup>172</sup>

The dangers of relying on untested information provided by third parties on a confidential basis were pointed out in some submissions. Particular concern was expressed where the information involves allegations of criminal behaviour, such as child abuse. The Health Issues Centre pointed out that the information privacy principles in the *Privacy*

*Act* dictate that record holders should check the accuracy of information before using it.<sup>173</sup> Holders of health records should be required to comply with this rule.

The same principles apply in the UK, New Zealand and the USA, with other protections to balance consumers' rights with the right of third parties to confidentiality. In New Zealand access to health records can be refused if disclosure would breach an implied promise that the information was given in confidence, or it would involve unwarranted disclosure of the personal affairs of another person. In arriving at these views the New Zealand code contemplates consultation with the third party 'where practicable'.<sup>174</sup> In the UK, health records can be withheld if they contain information about or provided by an individual who could be identified from the information.<sup>175</sup> In the USA access to part of a record can be refused if disclosure could identify a confidential source of information.<sup>176</sup>

#### **Recommendation 13:**

**Consumers should be able to be refused access to parts of their health records if disclosure of information would breach a duty of confidentiality to another person, express or reasonably implied. The views of the individual whose confidential communication is at risk should be consulted, where practical.**

**The holder of a health record should not act on information in the record without taking steps to ensure the information is accurate, up to date and complete.**

#### **When access will harm the consumer**

In chapter 3 and 4 we discussed concerns about the potential for access to health records to cause distress or harm to consumers or cause harm to someone else. There are a range of views on the extent to which this should be a reason for refusing consumers access to their health records.

Submissions from consumer groups and the Sydney and Melbourne workshops either opposed an exception based on apprehended harm to the consumer or supported only a narrow exception covering situations where there is serious risk of harm. A number of submissions from consumers and health complaints commissions, said potential distress should be addressed by providing

counselling or other support. They said such an exception is too easily prone to allowing health providers to deny access where they want to avoid the discomfort of providing people with their records.<sup>177</sup> It also encourages discriminatory attitudes in the mental health sector.<sup>178</sup>

The AMA policy is that consumers having access to their records might not be in their best interests, and it would be dangerous to provide medical records to psychiatric patients.<sup>179</sup> The RACGP policy, in contrast, says access can be refused 'in the unlikely event of disclosure causing serious harm' to the consumer.

Under Australian FOI laws, and legislation in the UK and New Zealand, health providers have some discretion to refuse access to records where it would cause harm or distress.<sup>180</sup> Similar provisions exist in regulations governing private hospitals, day procedure centres and nursing homes in NSW.<sup>181</sup> The exception is known as 'therapeutic privilege'.

In the UK, information can be withheld if the holder of the record believes disclosure would 'cause serious harm to the physical or mental health' of the consumer.<sup>182</sup> In New Zealand the test is similar to the NSW FOI exception – if disclosure 'would be likely to prejudice the physical or mental health of the individual'.<sup>183</sup> In the USA access can only be refused where disclosure would endanger life or the physical safety of someone.<sup>184</sup> The trend therefore appears to be a narrowing of therapeutic privilege, which PIAC believes should be reflected in Australian law.

**Recommendation 14:**

**Consumers may be refused access to the whole or part of their personal health records if the holder of the record believes disclosure would endanger the life or physical safety of someone.**

## 5.5 Right to amend the record

Errors, misunderstandings and derogatory or inappropriate comments can occur in health records, as discussed in chapters 3 and 4.

FOI laws and State Health privacy codes already provide a right for consumers to request amendments to public health records and to have a note added to the record if the amendment is refused. Under those provisions amendments can be sought if the record containing information concerning their personal affairs, is incomplete, incorrect, out of date or misleading.<sup>185</sup> The agency can refuse to amend the record if they are satisfied that the record is in fact correct or the application to amend is incorrect. A person who has applied for an amendment which was refused can appeal the decision and must be informed of that right. If the amendment is not made the consumer can require a note to be added to the record setting out their claims. Similar provisions are included in regulations governing private hospitals, nursing homes and day care centres in NSW, although there is no right of appeal.<sup>186</sup>

In the UK, USA and New Zealand health service consumers can apply for corrections to all their health records. If the consumer is not satisfied with corrections made by the record holder, they have a right of appeal and must be informed of that right in New Zealand and the USA. If the amendment is not made, they can make a note in the record about the issues they believe are inaccurate.<sup>187</sup>

The views in the submissions on this issue were mixed, reflecting concerns about the extent to which amendments will alter the record. Some expressed concern at the potential for tamper with records. They said amendments should not amount to any deletions, just the opportunity for consumers to have their views added to the record.<sup>188</sup> Others said consumer notes as an addendum is no substitute for expunging or removing parts of the record which are wrong or inappropriate.<sup>189</sup> Not surprisingly, public health agencies supported a right of amendment along the lines of the rights under FOI.<sup>190</sup> The majority of submissions favoured consumers having a right to amend health records in the private health sector in the same way that they are able to in the public sector.

Whether amendment by deletion should be allowed under Commonwealth FOI was discussed by the ALRC/ARC review of FOI. After considering a range of submissions, the review concluded that Commonwealth FOI allows a document to be amended by deleting information. They said,

Deletion is merely one way in which a document may be altered to make the information complete, correct, up to date, relevant and not misleading.

However, they considered that the circumstances in which deletion is the only practicable option will be rare and recommended guidelines on when it might be appropriate to do so.<sup>191</sup>

Consumers also supported a right of amendment independent of a right of access to the record. The right to seek an amendment to records under NSW FOI laws and in the UK depends on access having been granted. The New Zealand code allows for amendments to be sought regardless of whether access is granted.<sup>192</sup>

Consumers emphasised the need for the law to impose an obligation on providers to tell people about their right to amend their records. Such rights are provided in the public sector in Australia under FOI and across the health sector in New Zealand and the USA. A number of consumer submissions said there should be clear written procedures for consumer to understand what a right to amend means and how to go about it.<sup>193</sup>

**Recommendation 15:**

**Consumers should have a right to seek amendments to their health records if the information is incomplete, incorrect, out of date or misleading. The right should not depend on whether the consumer has a right of access to the record.**

**Where the holder of a health record refuses to make the requested amendment, the consumer should have a right to reasons for the refusal, to appeal against the refusal, and to be told of the right to appeal. A note setting out the consumer's views should be attached to the record if the amendment is not made.**

**Consumers should also have a right to be told they can seek amendments and how to go about it.**

## 5.6 Appeals

Few submissions had any comment on the question of a right of review or appeal. We assumed this was because it is widely accepted.

There is a right of appeal if access to personal health records is refused in the public health system, or 'clinical records' are refused in private hospitals in NSW.<sup>194</sup>

In the UK, review of a decision to refuse access is available through complaints to the Health Service Commissioner (or Ombudsman), but this process was only established last year. Alternatively people can make an application to a court requiring compliance with the *Access to Health Records Act*.<sup>195</sup> In New Zealand, the consumer can have a decision reviewed by making a complaint to the Privacy Commissioner.<sup>196</sup>

The reasons for refusal of access must be given and substantiated in New Zealand, under FOI laws in Australia and in the USA. Consumers must also be informed of the right to seek a review of the decision. Reviews of refusals are considered with the advice of health professionals.<sup>197</sup>

On the question of which agency is the most appropriate for such appeals, the submissions to PIAC supported health complaints commissions or the Privacy Commissioner. The Department of Health and Family Services or their State counter-parts are regarded as having an interest in health services and lack the required independence.<sup>198</sup>

**Recommendation 16:**

**The decisions to refuse consumers access to their health records should be subject to review by the Privacy Commissioner and State/Territory health complaints commissions.**

## 5.7 Retrospectivity

Consumers and health complaints commissions said overwhelmingly that all health records should be accessible, regardless of when they were made. The law should therefore be retrospective. They believe that records made some time ago are exactly the ones that are important to them. The Health Services Commission (Vic) said records are not likely to change much after a law providing access comes into effect. It was also argued that segmented records are potentially misleading and not much use.<sup>199</sup>

Health service providers unanimously said a law providing consumers a right of access to health records should only apply to records made after the law comes into effect. They argued that no-one should be judged by their conduct during a time when the law was different. Some providers said only current records, made within the last year or so, are of any clinical use. They are, of course, of great importance for the purpose of complaints and legal action.<sup>200</sup>

The UK law does not apply to records made before the *Access to Medical Records Act 1990*. However, it allows access to health records made before the Act came into effect if they are necessary to understand records made after the Act came into effect. This means that if current records do not make sense without those made before 1991, the consumer can have access to them.<sup>201</sup>

In New Zealand access to records is allowed for all health records, whether made before or after the health privacy code came into effect.<sup>202</sup>

The *Professional Indemnity Review* final report recommended that consumers should have,

... access as a right to all records created after commencement of the legislation and access to matters of fact, including test results, for records created prior to the commencement of the legislation.<sup>203</sup>

This appears to offer a reasonable compromise. It provides consumers with factual information they need from old records, while protecting providers from the embarrassing effects of retrospectivity.

### **Recommendation 17:**

**Consumers should have a right of access to all health records created after commencement of legislation providing consumers with a right of access, and access to all factual information, including test results, in records created prior to the commencement of the legislation.**

*Privacy concerns can no longer be met solely by relying on individual practitioners.* NSW Privacy Committee, 1996

Records management and privacy issues were the subject of comment in almost all submissions to PIAC and were a primary issue of discussion in the consumer workshops. Recent developments and comments made in submissions to PIAC are reviewed below.

### 6.1 Privacy

A survey conducted for the Privacy Commissioner in 1994 showed that over 70% of people ranked the confidentiality of personal information as very important and nearly 80% thought computers make it easier for information to fall into the wrong hands.<sup>204</sup>

Developments in information technology open up many opportunities for information to be shared and linked. This raises concerns about mass surveillance and the use of information without knowledge or consent. Personal health information can already be used for teaching, research, management and quality control by a health service provider and more recently, to authenticate the provision of services to health insurers. Technological advances will multiply the possibilities.<sup>205</sup>

The development of smart card technology as a method for storing health information could be open to abuse and lead to a loss of control over the information by consumers, according to the Privacy Commissioner.<sup>206</sup> The increasing use of health registers, many of them mandatory – such as the Immunisation Register for children and the Cancer Registers also poses potential threats to privacy. There are also particular problems arising from the enormous amount of personal information collected by government agencies, which if combined would pose a serious threat to personal privacy.

In the words of the NSW Privacy Committee, 'privacy concerns can no longer be met solely by relying on individual practitioners' duty of confidentiality.' Active measures are needed.

Pressure to improve the protection of privacy in the health industry has resulted in a number of standards and guidelines over past few years. All of the policies support consumers having access to their medical records. They include:

- The Australian Standard on *Personal privacy protection in health care information systems* 1995 which guides health services in dealing with personal health information;<sup>207</sup>
- The *Information Privacy Code of Practice*, NSW Health, May 1996, which consolidates a number of government policies on acceptable practices and procedures when dealing with personal information;
- The *Information Privacy Code of Conduct*, NT Health, final draft April 1996, which also provides a guide for health care workers and the public on acceptable standards when dealing with personal information;
- The *Code of Practice for Computerised Medical Records*, Royal Australian College of General Practitioners, 1993, which provides guidance for GPs on maintaining computerised records;
- A *Discussion paper on privacy issues relating to use of medication data to promote quality use of medicines*, Australian Pharmaceuticals Advisory Council, 1996.

The Victorian government has also sought advice on practices or policies on the protection of personal information held by government from a newly established Data Protection Advisory Council.<sup>208</sup>

Consumer groups have welcomed the development of these codes and guidelines, but they express ongoing concern about the ability of third parties to access personal health records. Legal protection of the privacy of personal information is needed.<sup>209</sup>

The area of greatest concern to consumers, expressed in the submissions is the use of personal health information for research purposes without consumer consent or knowledge.<sup>210</sup> A workshop to develop consumer views on this issue conducted by CHF in July 1996 recommended a number of core principles. They include consumers giving informed consent to uses of personal health information and having access to their own personal health records. The NSW Privacy Committee supports this view, on the grounds that consumers can only give informed consent to others wanting to use their personal health information if they know what is in their records.

A number of public inquiries have called for protection of privacy to be implemented by law. The House of Representatives Standing Committee on Legal and Constitutional Affairs reviewed protection of confidential personal and commercial information held by the Commonwealth in an inquiry in 1994. In its report, the committee recommended consistent protection of privacy in the private and public sectors by extending the Information Privacy Principles of the *Privacy Act* to the private sector.<sup>211</sup>

The ALRC and the ARC supported health service consumers being given a right of access to their records during their review of the FOI in 1994 and 1995.<sup>212</sup> They proposed that the right to access and correct their health records should be seen as a privacy issue. The ALRC and ARC proposed an extension of the *Privacy Act* to the private sector, with codes of conduct to be developed by the Privacy Commissioner for specific industries. They said personal information held by the private health sector is particularly sensitive and urged 'a national regime to be implemented quickly'. They said all of the 11 information privacy principles recognised under the *Privacy Act* should be covered by a code of conduct for the health sector. The final report of the FOI review said a number of submissions claimed an urgent need for legislation to enable patients to gain access to their health and medical records in the private sector. They maintained the view that access to medical records could be dealt with under the privacy regime.<sup>213</sup>

Australia has certain international obligations on privacy which warrant legal protection, as the ALRC and the ARC pointed out in their review of the FOI Act. Australia is a party to the International Covenant on Civil and Political Rights (ICCPR) which prohibits arbitrary or unlawful interference with a person's privacy in article 17. Australia is a member of the OECD which in 1980 issued *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*, which set minimum standards for the protection of privacy and individual liberties.<sup>214</sup> Over 20 countries around the world have introduced laws to protect the privacy of personal information consistent with the OECD guidelines.

Most recently, the Commonwealth Government's law and justice policy promises that a Coalition government will work with industry and State and Territory Governments to provide a co-regulatory approach to privacy within the private sector, comparable with international practice. A discussion paper released by the Attorney General in September proposes a structure for doing so, along the lines proposed by the ALRC and ARC review of FOI.

An accepted exception to consumers right to privacy is where information must be released 'where the health of others is at risk'. The release of the revised AMA Code of Ethics earlier this year produced a wave of protest by consumer groups. They were concerned that the AMA Code leaves the judgement as to public health risk entirely to the discretion of the treating doctor, with no guidelines or steps to ensure disclosure is only made in appropriate circumstances.

One of the risks of allowing disclosure is that people suffering conditions that pose a public health risk will avoid seeking medical advice or not inform health providers of their condition, in turn creating a greater health risk. Clearly public health considerations need to be balanced against personal rights to privacy, but a public debate is needed on how that balance should be achieved.

### **Recommendation 18:**

**The privacy of health consumers' personal information should be protected by extension of the Privacy Act to the private sector, backed by an enforceable Health Information Privacy Code of Conduct.**

**Public consultation is needed on appropriate exceptions to individual rights to privacy necessary to protect public health and the public interest.**

## **6.2 Management**

The way that health records are managed, disposed of, and how long they are retained for, are integral to consumers' ability to access their records. A number of submissions disputed the statement in PIAC's issues paper to the effect that there is no uniform policy or regulation in Australia governing management and disposal of medical records lists of government circulars on the subject.<sup>215</sup> However, other submissions reinforced our view that State government policies and legislation, such as Statutes of Limitations in each State, are far from uniform and often inadequate.

Consumers and health service providers are not certain about how long records should be kept, or what should be done with records when a doctor dies, a practice is sold, or a hospital is closed. The NSW Health Care Complaints Commissioner told that she stores a large volume of health records which have been found on premises previously occupied by medical practitioners. A consumer told us she had to search through the back garage of her doctor's home to find her medical records.

There is also considerable division among health service providers and consumers on how long records should be kept. Privacy principles require personal records to be kept only for as long as necessary for the purpose for which they were prepared. Consumer groups during the Sydney and CHF workshops indicated a desire to have records kept for at least 30 years, especially childhood treatment records. The NSW Health *Privacy Code* provides a general requirement that health records be retained for 8 years, with some exceptions. The Doctors Reform Society policy is retention for a period of 30 years. The NSW Health Care Complaints Commission

has recently adopted a policy of retaining complaint records for eight years, with periods of up to 30 years for serious, substantiated complaints.<sup>216</sup>

The *Report of the Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt Jakob Disease* in 1994 criticised the difficulties for consumers caused by inconsistent retention practices. It recommended a uniform national law on disposal of medical records so they can be tracked by consumers.<sup>217</sup>

The quality and content of health records is also the subject of a number of policies and regulations and professional guidelines. For example, regulations on nursing homes, day care centres and private hospitals in NSW require 'clinical records' to be kept by the facility and stipulate what the records must contain. The RACGP's Entry Standards also deal in some detail with the quality and content of records.

A report on *The care and management of people with a mental illness residing in boarding houses* by the Health Care Complaints Commissioner found that health records in boarding houses were either inadequate or grossly inadequate. They found that clear records were needed to chart the progress of a consumer's illness and to document drugs and treatments tried.

Proposed regulations under the *Medical Practice Act 1992* (NSW), based on guidelines developed by the NSW Medical Board, would cover the creation, content, storage and disposal of medical records.<sup>218</sup> The proposal has received mixed reaction, with some saying it will unnecessarily complicate matters, while others support the reform. The HCCC report on boarding houses, for example, recommended that a regulation be made under the *Medical Practice Act* specifying standards for the content of medical records.<sup>219</sup>

Another approach to regulating management of health records is under the privacy regime. The New Zealand *Health Information Privacy Code* for example, regulates the collection, storage and security of health records, but it does not regulate the content of health records.

The substantial cost of storing health records in public hospitals according to one respondent is so enormously wasteful to justify having consumers made responsible for keeping their records.<sup>220</sup> Some health services in Australia have introduced the practice of giving consumers their medical records to see whether this should become more common practice. The final report of the *Review of Professional Indemnity Arrangements of Health Care Professionals* recommended that the Commonwealth Department of Health investigate as a matter of urgency, the option of patient-held records.<sup>221</sup> However, submissions to PIAC on the benefits and disbenefits of patient-held records were inconclusive.

It is beyond the scope of this project to review the appropriate reforms needed in health record management. We can only conclude that it is a subject in great need of further work.

**Recommendation 19:**

**The content, management, retention and disposal of health records needs to be reviewed for the purpose of establishing nationally uniform minimum provisions.**

## 7.1 Features of a law on access to records

### Objectives

The major objectives of law reform should be:

- to provide consumers access with a right of access and to amend their records;
- to provide a legal framework for protecting the privacy of personal health information kept in health records;
- to provide the rights to access and privacy nationally;
- to provide an accessible forum for review of decisions by record holders on consumer access to records;
- to provide a legally enforceable right of access.

### A privacy regime or a separate Act?

The two major options proposed for law reform are a special Act of Parliament providing the terms on which consumers can access their health records, or an extended *Privacy Act 1988* (Clth).

Access to records containing personal information and a right to amend errors in the record are two of the 11 privacy principles recognised internationally and incorporated in section 14 of the *Privacy Act*. The benefit of providing a regime for access to records within an extended *Privacy Act* is that the complementary aims of proper management of records and consumer access are dealt with together. This option was supported by the ALRC/ARC report on Freedom of Information (discussed above), and is also supported by the NSW Privacy Committee. It reflects the approach taken in New Zealand and the USA.

The Commonwealth Attorney General's discussion paper on *Privacy Protection in the Private Sector* proposes extending the *Privacy Act* to the private sector. It proposes that this be done by extending the statutory Information Privacy Principles (IPP) in the *Privacy Act* to personal information held by the private sector. The discussion paper proposes the development of codes of practice for particular sectors, based on the IPPs, prescribing how the IPPs are to be applied or complied with in the sector. While the codes may modify application of the IPPs, they cannot limit or restrict a person's right to have access to, and seek correction of, personal information.<sup>222</sup>

However, the primary argument for providing consumers with access to their health records is to improve communication with the health provider. The privacy context is therefore not the most appropriate context in which to achieve this policy aim. The option of a stand-alone Act providing rights of access was supported by the *CJD report*, the *Professional Indemnity Review*, the Health Issues Centre in *Healthy Participation* and by PIAC in submissions to the ALRC/ARC review of FOI. It reflects the approach taken in the UK, which has a separate *Access to Medical Records Act 1990* (UK).

The best results are likely to be achieved by a combination of these approaches a stand-alone Act and amendments to the *Privacy Act*. Clarification of the law on consumers rights to access and amend their records is needed not only in the Privacy law context, but also to assist State and Territory health complaints commissions in dealing with complaints about access. In light of the *Breen and Williams* decision, which so unequivocally stated that consumers have no right of access to doctors' notes, a code of practice under an amended *Privacy Act* may not be adequate. An explicit legislative provision would probably be necessary to clarify the legal rights of consumers.

### Recommendation 20:

**A package of legislation is needed to provide health service consumers with a legal right of access to their health records. It should incorporate a separate Access to Health Records Act providing the right of access, amendments to the Privacy Act extending the Information Privacy Principles to the private sector, and an enforceable health information privacy code of conduct for the health sector.**

### National or State?

A national approach to law reform is needed to effectively provide consumers with access to their records and to protect the privacy of personal health information. The most effective way to achieve a national result is Commonwealth legislation. This view has

been supported by all the major health sector inquiries, the FOI review the *In Confidence report* and the Commonwealth Attorney General's discussion paper on *Privacy Protection* in the Private Sector.

Some submissions to PIAC suggested reforms by individual State and Territory Acts, but overall this option was not favoured in submissions. It would be difficult to achieve national uniformity through co-operative State and Territory legislation, particularly given the lack of economic or political imperative on the issue. This is illustrated by the attempt at uniformity in State and Territory based health consumer complaints commissioners and public patients hospital charters required under the *Medicare Agreement*. There are now four models for health complaints commissions and few of the health consumer charters have the same name, let alone the same content.<sup>223</sup>

A potential obstacle to Commonwealth legislation is the limit of Commonwealth Government power under the Constitution. The most relevant Commonwealth power is the 'external affairs' power, which allows the Commonwealth to make laws which give effect to an international agreement.<sup>224</sup> However, under this power the law must conform to the substance of the agreement, it cannot generally deal with the subject of the agreement. Given the obligations of Australia under the International Covenant on Civil and Political Rights and the OECD *Guidelines on the Protection of Privacy*, the Commonwealth Government appears to have a sound basis for legislating.<sup>225</sup> The external affairs power could also be backed up by other powers under the constitution, including the corporations power, and the insurance power. The Executive Government's power on public education could be used to implement a strategy to protect the rights created under the reforms.<sup>226</sup>

Another policy objective of any law reform would be to override relevant provisions of State, Territory, and Commonwealth FOI laws to give consumers consistent rights of access to health records held by governments. The law should also amend the *National Health Act* to

resolve the current conflict between rights to access information under FOI and the obligations of confidentiality in section 135A of the *National Health Act*.<sup>227</sup>

**Recommendation 21:**

**The law reform package should be introduced by the Commonwealth government to achieve national uniformity. It should also amend the provisions of the National Health Act which require information to be kept confidential.**

## 7.2 Complaints and enforcement

### Complaints

One of the benefits of access-to-records legislation and a right of access under a health privacy code, would be the clarity it would provide for State and Territory health complaints commissions. They have a statutory role in dealing with complaints about providers 'unreasonably' withholding records, but there is still no clarity on what it means.<sup>228</sup> As access to health records is frequently linked to complaints about health service providers, this change is important. It would provide an effective mechanism to review decisions by providers to refuse access.

However, the statutory health complaints commissions in each State and Territory do not have powers to make determinations or enforce legislation. They can only conciliate complaints. It would be necessary to ensure that breaches of the *Privacy Act* or health privacy code are enforceable.

The Attorney General's proposal for the Privacy Commissioner to investigate and conciliate complaints about breaches of privacy protections in the private sector offers an important complement to the work of health complaints commissions. A coherent and consumer-focussed complaints structure could be facilitated by agency agreements between the Privacy Commissioner and health complaints commissions.

**Recommendation 22:**

**The Privacy Commissioner and State and Territory health complaints commissions should be able to investigate and conciliate complaints about consumer access to health records. This should be reinforced by agency agreements with the Privacy Commissioner.**

## Enforcement

Without effective enforceability the law would have limited credibility and would cause confusion and frustration for both providers and consumers. The New Zealand code is not enforceable and, according to the Privacy Commissioner, this has been the cause of frustration for consumers.<sup>229</sup> In the UK the only mechanism for enforcement of the rights of access is to take legal action, which is not particularly practical for most people. A complaints service was established by the National Health Service only last year.<sup>230</sup>

It is also important to find an appropriate and credible enforcement agency which provides an alternative to court proceedings. When asked which agency they would prefer to be responsible for enforcement of the law, all submissions said it should not be the Department of Health and Family Services. It is not regarded as independent and its policy of refusing to provide access to records has been the subject of criticism.<sup>231</sup> The Commonwealth Privacy Commissioner was regarded as an appropriate enforcement agency in many submissions. It seems logical to have access to records enforced by an agency such as the Privacy Commissioner which is both independent of the health industry and understands privacy and records management within it.

The Commonwealth Attorney General's discussion paper proposes a complaint handling and conciliation role for the Privacy Commissioner in dealing with breaches of an extended *Privacy Act*. It says the complainant can commence Federal Court proceedings to in relation to the complaint if:

- the Privacy Commissioner is unable to secure settlement or assurances against repetition of the breach; or
- where the matter raises questions of public concern; or
- is not suitable for settlement.<sup>232</sup>

These powers reflect the role of the Commissioner in hearing complaints and the Privacy Commissioner's lack of power to make enforceable determinations. The requirement for a complaint to go to the Federal Court to enforce breaches is unfortunate, as it makes enforcement more expensive and therefore less accessible. However, this is a limitation on the

power of all the Human Rights Commissioners which needs to be addressed generally.

The Attorney General's discussion paper also proposes that the Federal Court have the power to award compensation and restraint orders where a complaint is made out. The Sydney workshop supported these measures but also supported penalties being imposed for breaches of privacy obligations. The Attorney General's discussion paper only proposes civil penalties where there has been unauthorised disclosure of information for profit, or information has been obtained under false pretences.

### Recommendation 23:

**The Privacy Commissioner should have power to investigate and conciliate complaints, and to seek enforceable assurances against repetition of breaches of a health privacy code, the Privacy Act and the proposed Access to Medical Records Act. Where a breach is found to have occurred the Federal Court should be able to award compensation, issue restraint orders and impose penalties for serious breaches of privacy obligations.**

## 7.3 Implementing the right of access

The lack of awareness of consumer rights by both consumers and providers needs to be addressed. There is a very low level of awareness of the NHMRC guidelines according to a survey conducted for the NHMRC last year. The recent review of the NSW Health Commitment to Service revealed a very low level of awareness of the CTS among public health service providers. The low level of awareness of consumer rights to access their records in the public health sector was discussed in chapter 2.

The National Health Service in the UK and the Privacy Commissioner in New Zealand told PIAC that they had made little effort in training professionals and much more needs to be done.

The Interim Report of the *Professional Indemnity Review* recommended that accreditation standards include consideration of consumer access to records or consumer rights standards.<sup>233</sup> This would be an effective way to make professionals aware of the rights, and to keep the issue under constant review

and attention. The importance of periodic review is recognised by Northern Territory Health in the implementation of their Health Privacy Code, which is to be reviewed and updated regularly.

The draft *Australian Health Consumers Charter* could play a crucial role in the education of consumers and the health professions on consumer's rights. Compliance with the rights in the charter could be used to evaluate the quality of health care services.

Special programs would be needed to ensure that Aboriginal people and people of non-English speaking background are specially targeted to ensure they are aware of their rights.<sup>234</sup>

The US *Medical Records Confidentiality Act 1995* makes the 'information trustees' legally responsible for providing clear and conspicuous written notice to individuals of their rights to access health information and a description of the trustees' information practices with respect to protected health information.<sup>235</sup> This conforms with good practice under FOI and general principles of natural justice.

**Recommendation 24:**

**The Commonwealth Government should consider imposing a legal obligation on holders of personal health information to inform consumers of their rights to information. To implement the law reform, the Commonwealth should promote professional and community understanding of consumers' rights of access to their health records by using a range of appropriate measures, such as:**

- **approving and promoting the draft Australian Health Consumers' Charter as a basis for community and professional education;**
- **encouraging the NHMRC to re-release its Guideline for Medical Practitioners on Providing Information to Patients; and**
- **encouraging professional and health industry associations to make their members aware of consumer rights of access to their records.**

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- 23 *supra*, 424, La Forest J
- 24 *The Power of Information*, *op cit*, p3 and the definition of 'clinical record' in *Private Hospitals Regulation 1996* (NSW), *op cit*.
- 25 (1992) 174 CLR 479 at 487.
- 26 NHMRC *Guideline for Medical Practitioners on Providing Information to Patients*, Commonwealth of Australia, 1993, p7.
- 27 *Breen and Williams*, High Court, unreported, per Brennan CJ, Dawson, Toohey and Gummow JJ, citing W. and Edgell [1990] Ch 359 at 389. Also see *Australian Health and Medical Reporter*, CCH.
- 28 *Breen and Williams*, High Court, unreported, Brennan CJ, p2
- 29 Mrs Breen had rejected offers by the doctor to prepare a medical report based on his notes, and alternatively to provide the notes on condition that Mrs Breen sign an undertaking not to take legal action against him.
- 30 *Breen and Williams* 1994 35 NSWLR 522.
- 31 *Breen and Williams*, High Court, unreported, 6 September 1996.

- 32 *Breen and Williams*, High Court, op cit, Dawson and Toohey JJ; *Australian Health and Medical Reporter*, CCH, para 27-860.
- 33 (1992) 93 DLR (4th) 415.
- 34 *Breen and Williams* 1994 35 NSWLR 522.
- 35 NSW Privacy Committee submission; comments from The Accommodation Rights Service, the Health Care Complaints Commission (NSW) and NSW Health, Legal branch.
- 36 *Private Hospitals Regulation 1996* (NSW), schedule 1, *Day Procedures Centres Regulation 1996* (NSW), schedule 1, and the *Nursing Homes Regulation, 1996* (NSW), schedule 1. The 1996 regulations supersede 1990 regulations of the same title.
- 37 For example, *Health Care Complaints Commission Act 1993* (NSW) s7 (which only refers to professional conduct); *Health Services (Conciliation and Review) Act 1987* (Vic) s16; *Health Services Act 1995* (WA) s4. Equivalent Acts in Queensland, the ACT and Tasmania provide for a code of health rights and responsibilities to be developed as the basis for complaints, which are in turn to be based on certain principles including reasonable access to information. In South Australia health complaints can only be made about the public health sector, to the State Ombudsman. In the Northern Territory a health complaints body is yet to be established.
- 38 Annual Report, Health Services Commission (VIC), 1991.
- 39 For example, *Freedom of Information Act 1982* (Clth) ss11, 41; *Freedom of Information Act 1989* (NSW) ss16, 31; and *Freedom of Information Act 1982* (Vic) ss13, 33.
- 40 *FOI Act 1989* (NSW) s31(4); *FOI Act* (Vic), s16.
- 41 For example confidential communications are protected under *Freedom of Information Act 1982* (Clth) s41 and *Freedom of Information Act 1989* (NSW) s31 (2) and schedule 1, clause 6; *Freedom of Information Act 1982* (Vic), s31.
- 42 For example, *FOI Act* (NSW) ss39- 46.
- 43 In NSW appeals go to the Ombudsman or the District Court. In Victoria the appeal is to the Administrative Appeals Tribunal.
- 44 *Medicare Agreement 1992-97* and draft *Public Patients' Hospital Charter*, Commonwealth Government, 1993.
- 45 This reflects the Northern Territory *Administrative Instructions on Confidentiality of Patients' Records* which were superseded by the *Public Sector Employment and Management Act 1993* (NT); NT Health submission.
- 46 The code incorporates previous policies, including *Patient Matters*, which deals with consumer rights to access records.
- 47 An example is Western Sydney Area Health Service policy, *Accessing Medical Records* (draft June 1996), which sets out consumer rights to their records and where and how they can get them.
- 48 For example, the NSW and Victorian health complaints commissioners expressed this view and the NSW Privacy Committee's submission pointed to the lack of over-all monitoring of the operation of FOI laws in a way that would provide evaluation of how consistently access to records is provided.
- 49 *The Power of Information*, Health Issues Centre, 1993, p19.
- 50 *Patient access to medical information, Part 1: a review of the issues*, Westbrook, AMR Journal 18(1) March 1988. p11.
- 51 Allars report, op cit, pp703-704.
- 52 *Private Hospitals Regulation 1996*, (NSW) schedule 2. Under the regulation private psychiatric hospitals in NSW are required to keep as part of the clinical record: a clear statement of reasons for admission, a treatment plan, a record of each evaluation and a discharge plan.
- 53 See discussion of the *Mental Health Act 1986* (Vic) and *Mental Health Act 1990* (NSW), Montague, supra, p17-19.
- 54 The workshop was organised as part of the review of the NSW Health *Commitment to Service*. Its results will be published in the NSW *Commitment to Service Evaluation* report in late 1996.

- 55 S Bloch, C Riddell and T Sleep, *Can patients read their psychiatric records?* The Medical Journal of Australia, 161 December 1994, p665. He also cites a study of 100 patients in the UK, which concluded that one third of comments were alarming or worrying: Sergeant, *Should patients be granted access to their hospital records*, Lancet, 1986; 2: 1322.
- 56 For a discussion of the laws in South Australia, Victoria and New South Wales see *Australian Health and Medical Reporter*, CCH, 28-855
- 57 Agreement between Residents and Proprietors of Approved Nursing Homes, clause 10.6, from *Your guide to residents rights in nursing homes*, second edition, Dept of Human Services and Health, 1994.
- 58 Outcomes Standards, Government Gazette, September 1992, under the *National Health Act 1953* (Clth).
- 59 Walgett Aboriginal Health Service, Medical Consumers Association (NSW), Disabled People International (Tas) and Sydney workshop.
- 60 For example, submissions from Roy Harvey and Australian Nursing Homes and Extended Care Association.
- 61 The results of the survey not published at time of writing.
- 62 Health Consumers Council (WA); Medical Consumers Association (NSW); Maternity Coalition; and The Accommodation Rights Service and Mental Health Co-ordinating Council at the Sydney workshop.
- 63 Lioba Rist, ACA, 1994.
- 64 For example, Kathy Kendall, *Medical records that make you sick*, Health Issues Journal, 42, March 1995.
- 65 Janne Graham, Consumers Health Forum, *Report of the national health information forum*, November 1994, p44.
- 66 ACON; Walgett Aboriginal Medical Service; CHF workshop, Melbourne.
- 67 Melbourne workshop; meeting with Illawarra consumer representatives.
- 68 NSW Privacy Committee and NSW Health Care Complaints Commissioner and inquiries to PIAC.
- 69 Sydney, Melbourne and Newcastle workshops. Tim Smyth, Chief Executive Officer of Hunter Area Health Board said the cost of maintaining health records in the public health system is wasteful and the funds could be put to better use if consumers kept their records. Also submission from NSW Nurses' Association.
- 70 Mrs Sandra Morgan, Manager Clinical Information Department, John Hunter Hospital; Kate Lachlan, Health Information Manager, Westmead Hospital (personal communications)
- 71 Health Consumers Council (WA); Irene Shaw, Maternity Coalition; The Accommodation Rights Service, Sydney workshop.
- 72 Mrs Sandra Morgan, Manager Clinical Information Department, John Hunter Hospital.
- 73 Mrs Sandra Morgan, Manager Clinical Information Department, John Hunter Hospital; Kate Lachlan, Health Information manager, Westmead Hospital; and Michael O'Rourke, Director Health Services Development, South East Sydney Area Health Board (personal communications).
- 74 Privacy Committee NSW; Health Care Complaints Commissioner NSW.
- 75 Kate Lachlan, Health Information Manager, Westmead Hospital, personal communication, 27 June 1996.
- 76 *HCCC annual report 1994-95*, table (iv) and (ix), p12-13 and p42.
- 77 Submission from Victorian Health Services Commission and *Patient Access to Medical Records*, A discussion paper, Health Services Review Council, 1989.
- 78 AMA, *Guideline on access to medical records*, endorsed by AMA Federal Council, October 1993.
- 79 AMA submission.
- 80 American Medical Association, Policy on patient records, 1984.
- 81 RACGP, *Interim Code of Practice for Computerised Medical Records in General Practice*, Feb 1996, section 5.

- 82 Doctors Reform Society, *Confidentiality and Access to Records policy*.
- 83 Submissions from United Medical Defence and the Medical Defence Association of Victoria
- 84 NSW Nurses Association submission.
- 85 ANHECA submission.
- 86 Australian Hospitals Association, Dianne Horvath, President, and Prue Power, Deputy Director, Ageing Agendas, *Report of Consultations on the draft Australian Health Consumers' Charter*, October 1995, supra, p62-63 and p73-75 .
- 87 George Neale, Director Finance and Administration, Australian Private Hospitals Association, Ageing Agendas, op cit, p68.
- 88 *Australian Psychological Society Code of Professional Conduct*.
- 89 *Australian Association of Social Workers Code of Ethics*, July 1989, clause 4.4.
- 90 J Westbrook, *Patient access to medical information, Part 1: a review of the issues*, AMR Journal, March 1988, 18(1), 11; Linda Bergen, *Patient access to medical records: review of the literature*, AMR Journal, September 1988, 18(3), 102; Meg Montague, *Consumer access to medical records, a discussion paper*, Privacy Commissioner and Office of the Public Advocate (Vic), May 1995; D Johnson and S Wolf, *Medical Records – getting yours*, Public Citizen, July 1995; and Health Issues Centre, *The Power of Information*, 1993, p3-4; AMA submission; Health Information Managers Association submission; and Edson Pike, *Patient access to medical records*, speech to Medico-Legal conference, Sydney, July 1996.
- 91 D Johnson and S Wolfe, *Medical Records – getting yours*, Public Citizen, July 1995, 28.
- 92 Melbourne and Sydney workshops and meeting with Illawarra consumer representatives.
- 93 L Bergen, *Patient access to medical records: a review of the literature*, AMR Journal, 18(3), September 1988, p102, at 103.
- 94 L Bergen, supra, p103, citing Greenfield (1985) and Bronson (1986). Bronson studied a group of chronically ill elderly patients and found that while knowledge generally improved, knowledge of medication was not improved.
- 95 L Bergen, supra, p103, citing (1972) and Greenfield (1985) respectively.
- 96 J Westbrook, *Patient access to medical information, Part 1: a review of the issues*, AMR Journal, 18(1), March 1988, p11.
- 97 Australian Pharmaceutical Advisory Council, *Discussion paper on Privacy issues relating to use of medication data to promote quality use of medicines*, August 1996, p14.
- 98 DPI (Tas) and Medical Consumers Association (NSW).
- 99 Bergen, op cit, p105.
- 100 Parrott J, Strathdee G, Brown P., *Patient access to Psychiatric records: the patient's view*, J R Soc.Med.1988; 81:520-22; S Bloch. C Riddell and T Sleep, *Can patients safely see their psychiatric records?*, The Medical Journal of Australia, Vol. 161 5/19 December 1994, p665.
- 101 S Bloch, supra, referring to Stein, Am.J. Psychiatry 1979, op cit.
- 102 L Bergen, supra, p104, citing Golodetz (1976) in which two consumers revealed that they had cancer were resolved when the record was provided; and Stevens (1977).
- 103 J Westbrook, op cit at p12.
- 104 AMA submission and discussions with RACGP.
- 105 Mrs Sandra Morgan, Manager Clinical Information Department, John Hunter Hospital; Kate Lachlan, Health Information Manager, Westmead Hospital; and Michael O'Rourke, Director Health Services Development, South East Sydney Area Health Board (personal communications).
- 106 Bergen, op cit, p104.
- 107 Westbrook, op cit.
- 108 Westbrook, op cit at p21 cites a US study in which 50% of consumers made some addition or correction on a point of fact in their record (Mother Jones, 1984); Bergen, op cit, p104, cites two studies in which a similar level of corrections were made.

- 109 Dr Sprogis, Newcastle workshop.
- 110 Janne Graham, CHF workshop, Melbourne.
- 111 Mrs Sandra Morgan, Manager Clinical Information Department, John Hunter Hospital; Kate Lachlan, Health Information manager, Westmead Hospital; and Elizabeth Catham, Manager, Outpatients Department, Royal Women's Hospital, Melbourne (personal communications); and Katherine Kendall, *Health records that make you sick*, op cit.
- 112 Bloch et al, op cit, at 665-666, citing Crichton, Douzenis and Leggatt et al, *Are psychiatric case-notes offensive?* Psych. Bull. 1992 (16) 675-677 and Sergeant, *The Lancet*, 1986 (2) 1322-1325.
- 113 *Entry Standards for General Practitioners*, RACGP, 1996, criterion 1.4.4, p25.
- 114 Bergen, op cit; Westbrook op cit.
- 115 D Rickwood and J Braithwaite, *Why openness with health inspectors pays*, Australian Journal of Public Health, 1994, 18(2), p165.
- 116 ANHECA and AMA submissions and discussions with RACGP.
- 117 Bergen, supra citing three US studies.
- 118 Westbrook, op cit, p13.
- 119 Health Services Commissioner (Vic); NSW Privacy Committee; Epilepsy Foundation and Melbourne workshop; Sydney workshop.
- 120 See discussion in Tito, *Professional Indemnity Review – Interim Report*, Commonwealth Department of Human Services and Health, February 1994, p159-160; L Bergen, *Review of the literature*, op cit, p104.
- 121 Bloch et al, op cit and see discussion in s4.2.
- 122 Bergen, op cit, citing Altman (1988)
- 123 J Westbrook and M Nugent, *Patient access to medical information, Part 2: a survey of medical practitioners views*, AMR Journal, June 1988, 18(2), 52, at 57. The sample included 107 medical practitioners, with specialities which included surgeons, physicians, anaesthetics, rehabilitation medicine, general practice, and interns.
- 124 For example, ANHECA, Guardianship Board NSW, Health Services Commissioner (Vic), Health Care Complaints Commissioner (NSW) and the Sydney and Melbourne workshops.
- 125 Health Information Management Association of Australia and the NSW Privacy Committee submissions.
- 126 Personal communication, Privacy Commissioner's office, New Zealand, October 1996. Consumers in the UK have a right to see, and limited rights to correct errors, in medical reports prepared for insurance companies and employers under the *Access to Medical Reports Act 1988*.
- 127 See *Breen and Williams*, High Court, unreported; *Australian Health and Medical reporter*, op cit.
- 128 Part 1, s3.
- 129 *Access to Health Records Act 1990*, (UK) section 1 defines 'health record' as information: (a) made by or on behalf of a health professional in connection with the care of a person relating to their physical or mental health and; (b) which could identify them.
- 130 Tina Magennis, lecturer, University of Sydney.
- 131 Part 1, s4, definition of 'health agency'. The powers of State and Territory health complaint commissions are discussed in section 2.3.
- 132 *Access to Health Records Act 1990* (UK), s2.
- 133 *Medical Records Confidentiality Act 1995* (USA); J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, Health Information Management Vol 26, no.1 1996, p33.
- 134 *Health Care Complaints Act 1993* NSW, s4.
- 135 NSW Privacy Committee, Area Health Boards submissions, HIMAA submission.
- 136 Sydney and Melbourne workshops and Newcastle workshop.
- 137 See discussion in chapter 3 on reasons for access.
- 138 The NSW *Information Privacy Code of Practice* defines 'health record' as 'a documented account of a client/patient's health, illness and treatment during each visit or stay at a health care facility, whether in hard copy or electronic form.'<sup>138</sup> The Northern Territory draft *Information privacy code of conduct*, April 1996, p3 has a similar definition, but it specifically recognises 'verbal' as well as paper based or electronic forms. *Private Hospitals Regulations 1996* NSW, op cit.

- 139 Commonwealth Attorney General's discussion paper, *Privacy protection in the private sector*, September 1996, p 18-19.
- 140 Submissions from United Medical Defence, AMA, ANHECA, North Sydney Area Health Service. The RACGP's view are taken from Ageing Agendas, *Report of the consultations on the draft Australian Health Consumers Charter*, October 1995 (for the Australian Consumers' Council), p50.
- 141 Health Services Commission (Vic); HCCC (NSW); Health Issues Centre; South East Area Health Service; Western Sydney Area Health Service; Central Area Health Service; Jennifer Hughes, Central West Health Service; Northern Territory Health; Alex Walker (WA); ACON; Breast Implant Support Group.
- 142 National Council of Women; Walgett Aboriginal Health Service Inc; Maternity Coalition; Health Consumers Council (WA); Southern Shoalhaven Health Watch.
- 143 clause 7.4.1.2
- 144 Private Hospitals, Nursing Homes and Day Procedure Centre regulations 1996 (NSW), op cit.
- 145 *Access to Health Records Act* (UK) s3(3)
- 146 *Privacy Act* (NZ) s42(2) and commentary, supra.
- 147 FOI Act (NSW) s24 – 21 days; *Privacy Act* (NZ) s40 – 20 working days; and *Access to Health Records Act* (UK) section 4(3) – 21 days.
- 148 op cit, p18.
- 149 See the Guardianship Acts in each State and Territory and individual powers of attorney deleting legal responsibility.
- 150 Comment from The Accommodation Rights Service at the Sydney workshop.
- 151 Sydney workshop and the National Council of Women (NSW) submission.
- 152 Section 205(a) *Medical Records Confidentiality Act*, 1995 (USA); J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, Health Information Management Vol 26, no.1 1996, p33.
- 153 *Information Privacy Code*, s7.3 on Informed Consent.
- 154 *Nursing Homes Regulations 1996* (NSW), op cit, schedule 1.
- 155 *Health Information Privacy Code* (NZ), Part 2, rule 6.
- 156 *Access to Health Records Act* (UK) s3(1) (f) and s4(3).
- 157 7.3.2 and 7.3.3.
- 158 *Access to Health Records Act 1990* (UK) s4(1) and (2).
- 159 *Health Information Privacy Code 1994 with commentary*, Privacy Commissioner (NZ), 1994, p25-26; *Health Information Privacy Code*, rule 6 and *Privacy Act* (NZ) s29(1).
- 160 See references in chapter 5; United Medical Defence (who said a charge should be made only where a medical report is prepared); Sydney workshop; Tina Magennis, University of Sydney.
- 161 NSW Ombudsman, *Annual Report 1994-95*.
- 162 Letter to PIAC from Blair Stewart, Manager Codes and Legislation, Privacy Commissioner, Te Mana Matapono Matatpu, 29 August 1996.
- 163 *Access to Health Records Act 1990* (UK), s3(4)
- 164 *Health Information Privacy Code* (NZ) clause 9.
- 165 S101(a) *Medical Records Confidentiality Act*, 1995; J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, Health Information Management Vol 26, no.1 1996, p33.
- 166 Walgett Aboriginal Health Service; Maternity Coalition; Medical Consumers Association; Southern Shoalhaven Health Watch; AIDs Council of NSW; Health Services Commission (Vic).
- 167 Ageing Agendas, op cit, Dr Kirsten Black and Dr Nick Lintzeris, of the Doctors Reform Society at p49 and the RACGP at p50.
- 168 For example, *Freedom of Information Act 1982* (Clth) s41 and *Freedom of Information Act 1989* (NSW) s31(2) and schedule 1, clause 6.
- 169 *Open Government: a review of the Federal Freedom of Information Act*, supra, pp125 – 130, recommendations 59, 60 and 61 concerning amendment to s41.
- 170 Allars report, supra, p703-704.

- 171 Submissions from AMA; RACGP; Australian Hospitals Association, Dianne Horvath, Ageing Agendas, op cit, p62-63.
- 172 Health Services Commissioner (Vic); Health Complaints Commissioner (NSW); SE Sydney Area Health Board.
- 173 Privacy Act, principle 8 and discussion of the principles in the Attorney General's discussion paper on privacy.
- 174 *Health Information Privacy Code*, rule 6; *Privacy Act (NZ)* Parts IV and V, especially section 29(1).
- 175 *Access to Health Records Act (UK)* s5.
- 176 Section 101(c) *Medical Records Confidentiality Act 1995 (USA)*; J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, Health Information Management Vol 26, no.1 1996, p33.
- 177 National Council of Women (NSW); ACON; Medical Consumers Association (NSW); Maternity Coalition; Health Consumers Council (WA); Southern Shoalhaven Health Watch; Health Services Commissioner (Vic); Health Care Complaints Commissioner (NSW).
- 178 Australian National Association for Mental Health, public statement, May 1996; Alex Walker, Health Consumers Council (WA).
- 179 Australian Medical Association, *Guidelines on Patients' Access to Records Concerning their Medical Treatment*, 1993.
- 180 In NSW FOI allows refusal of access if disclosure 'may have an adverse effect on the physical or mental health' of the consumer. If access is refused on this basis, the record is provided to a registered medical practitioner nominated by the consumer (FOI Act 1989 (NSW) s31(4)). In Victoria under FOI, consumers can be refused access to the record where it risks causing harm to others.
- 181 Access to 'clinical records' can be refused if the medical practitioner in charge of a consumer's care advises that the request should be refused and the hospital is satisfied that access would 'be prejudicial to the patient's physical or mental health'; see *Private Hospitals, Nursing Homes and Day Procedure Centre Regulations*, NSW (1996), op cit.
- 182 *Access to Health Records Act (UK)* s5.
- 183 *Privacy Act (NZ)* s29(1); *Health Information Privacy Code (NZ)* rule 6.
- 184 *Medical Records Confidentiality Act, 1995 (USA)*; J. Mair, op cit.
- 185 Right of access to personal health records, s31(4) and right to apply for amendment, ss39 - 46.
- 186 *Private Hospitals Regulation 1996 (NSW)*, schedule 1, et al, op cit.
- 187 *Health Privacy Code 1993 (New Zealand)* part 2, clause 8, rule 7; *Access to health Records Act (1990) (UK)* s6; s102, *Medical Records Confidentiality Act 1995 (USA)*; J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, Health Information Management Vol 26, no.1 1996, p33 at p34.
- 188 The Australian Nursing Homes and Extended Care Association; the Health Complaints Commission (NSW); NSW Nurses' Association; and AMA submissions.
- 189 Health Services Commissioner (Vic); Roy Harvey; Lyn Brown, Illawarra Area patient advocate.
- 190 Northern Territory Health; Central Sydney Area Health Board; and South East Sydney Area Health.
- 191 *Open government*, ALRC/ARC, op cit, at p161-163.
- 192 *Health Information Privacy Code (NZ)*, rules 6 and 7.
- 193 National Council of Women (NSW); Shoalhaven North Consumers Action Group; and Christine Lyall, HCC (WA).
- 194 FOI Act (NSW) Part 5; *Nursing Homes, Day Procedure Centres and Private Hospitals regulations 1996 (NSW)* op cit.
- 195 *Code of Practice on Openness in the National Health Service*, Open Government Taskforce (UK), April 1995.
- 196 *Privacy Act (NZ)* s22F(4).

- 197 *Privacy Act* (NZ) Part IV; *FOI Act* (NSW) Part 5; *Nursing Homes, Day Procedure Centres and Private Hospitals regulations 1996* (NSW) *op cit*; *Medical Records Confidentiality Act 1995* (USA); J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, *Health Information Management* Vol 26, no.1 1996, p33.
- 198 See chapter 7 for a discussion of implementation.
- 199 Health Consumers Council (WA); Walgett Aboriginal Health Service; ACON; Illawarra health consumer groups; Health Issues Centre.
- 200 AMA; RACGP; ANHECA; Medical Defence Association of Victoria; Graham Issacs, Vic; Jennifer Hughes, Health information manager, Central West Health Service, NSW.
- 201 The Act came into effect on 1 November 1991. See NHS Executive (1991) *Access to Health Records Act 1990: a guide for the NHS*.
- 202 *Privacy Act 1993* (NZ).
- 203 F. Tito, *Professional Indemnity Review, Final Report*, December 1995, recommendation 44.
- 204 K O'Connor, *Smart Cards, Privacy Issues*, 1995, citing Roy Morgan Research, Summary Report – Privacy Act Survey 1994, p51.
- 205 Medibank Private offered doctors to agree to providing access to records as are necessary to authenticate the service claimed; see discussion by K O'Connor, *Privacy, Health Care and IT – Issues and Challenges for the late 90's*, paper prepared for Health Informatics Association Annual Conference (NSW), February 1996.
- 206 K O'Connor, *Smart cards: implications for privacy*, 1996.
- 207 AS 4400, 1995.
- 208 Data Protection Advisory Council Proposal, and Terms of Reference, 1996.
- 209 Submissions from Health Consumers Council (WA); AIDs Council NSW; National Council Of Women (NSW); Health Issues Centre; Consumer Health Forum; Walgett Aboriginal Health Service; Country Women's Association (NSW); Maternity Coalition and the Sydney workshops.
- 210 Submissions from Health Consumers Council (WA); Walgett Aboriginal Health Service; Shoalhaven North Consumers Action Group; Maternity Coalition; Consumer Health Forum.
- 211 *In Confidence: Protection of confidential personal and commercial information held by the Commonwealth*, Senate Legal and Constitutional Affairs Committee, 1995.
- 212 Australian Law Reform Commission and Administrative Review Council, *Freedom of Information*, Discussion paper no.59, May 1995.
- 213 *Open government: a review of the Federal Freedom of Information Act 1982*, ALRC report no.77 and ARC report no.40, 31 December 1995, p207
- 214 *Open government: op cit*, p204 – 206.
- 215 Examples of NSW government policies include the NSW Health *Information Privacy Code of Practice (1996)*, *Patient Matters Manual, Health Records and Information Manual for Community Health Facilities, Disposal of Health Records* (Circular no.89/13), *Disposal of Obstetric Medical Records*. There are also regulations dealing with retention of records under the *Nursing Homes Act 1988* (NSW), the *Private Hospitals and Day Procedure Centres Act 1988*, the *Adoption Act 1990* (NSW) and Statute of Limitations Acts.
- 216 HCCC, *Retention of complaint records*, January 1996.
- 217 Allars, *Report of the Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt Jakob Disease*, *supra*, at p702- 703.
- 218 Medical Records Consortium, University of NSW, *Medical records project for the NSW Medical Board, Final Report and Recommendations*, November 1995.
- 219 HCCC, *The care and management of people with a mental illness residing in boarding houses, who require treatment with psychotropic medication*, May 1996, pp40-43.
- 220 Newcastle workshop; Tim Smyth, Chief Executive, Hunter Area Health Board.
- 221 *Professional Indemnity Review*, final report, *supra*, recommendation 45, p101.
- 222 Attorney General's Department, discussion paper, *op cit*, pp13-14.

- 223 See discussion in Chapter 2.
- 224 Section 51(29) of the Australian Constitution.  
See J McMillan, *Commonwealth Constitutional Power over Health*, CHF, 1992, p39-40.
- 225 These agreements are discussed in chapter 6.
- 226 Ss51(20) and (14). See McMillan, *supra*, p75-76.
- 227 As recommended in the Allars report on *Creutzfeldt Jacob Disease*, *supra*.
- 228 See discussion in s2 on rights in the private health sector.
- 229 Privacy Commissioner, New Zealand, *Annual Report*, 1994
- 230 Letter to PIAC from National Health Service (UK)
- 231 Allars report, and comments from TARS and others at Sydney workshop
- 232 Discussion paper, *op cit*, pp14, 26-28.
- 233 *Professional Indemnity Review – Interim report*, *op cit*, recommendation 23.
- 234 Walgett Aboriginal Health Service submission and discussion with Transcultural Mental Health Centre, Sydney.
- 235 Section 103 Medical Records Confidentiality Act, 1995; J Mair, *Access and confidentiality of medical records: a legislative response in the United States*, Health Information Management 26/1 1996, p33.

Public Interest Advocacy Centre is an independent, non profit legal and policy centre located in Sydney. It was the first, and remains the only, broadly based public interest legal centre in Australia.

PIAC was established in July 1982 as an initiative of the Law Foundation of New South Wales to carry on policy-orientated litigation and test cases which would transcend the interests of individual litigants and promote the interests of members of the community at large, with particular reference to disadvantaged groups.

PIAC receives funding from the Law Foundation of NSW, the Commonwealth/State Community Legal Centres funding program and the NSW Legal Aid Commission. It also seeks grants for specific projects and provides policy services on a consultancy basis.

Over the past ten years, PIAC's work has developed in line with its charter of promoting the public interest and enhancing the quality of public policy-making through analysing and seeking reform of laws, policies and practices which are unjust or deficient. PIAC consults regularly with a broad spectrum of groups and individuals in the implementation of its objects and the determination of its priorities. It is therefore well placed to interpret and give definition to "the public interest" and devise appropriate methods for its advancement.

PIAC invokes a multi-disciplinary approach to its work, which combines legal action, research, policy analysis and campaigning. PIAC's cases and projects have focused on three broad areas: consumer protection; professional regulation and maintenance of standards; government policies, services and accountability. To sustain its utility and maximise its effectiveness, PIAC adopted a strategy confining its main activities to portfolio areas which offered prospects of short to medium-term impact for the benefit of significant numbers of people. In recent years, these portfolios have included:

- health products and services;
- access to justice;
- public utilities reforms and competition policy.

PIAC has a long history of involvement in public interest matters relating to health care services and products. Some notable past and current projects include:

- developing a draft *Health Consumers' Charter* for the Australian Consumers' Council during 1994 and 1995.
- developing a protocol for information-giving to breast implant recipients by health care practitioners entitled *Breast Implant Booklet* for the Department of Human Services and Health (1995) and *Common Interests, Best practice to information and complaints about breast implants*, in 1995.
- participating in the Commonwealth's Review of Professional Indemnity Arrangements for Health Care Professionals.
- developing a proposal for a consumer advocacy network in NSW, in conjunction with consumer and non-government welfare organizations.
- intervention before the Supreme Court of NSW and the NSW Court of Appeal as a friend of the court in proceedings initiated by Mrs Breen who had been denied access to her medical records held by her plastic surgeon in 1993 and 1994. PIAC, in conjunction with the Health Issues Centre and the Consumers' Health Forum, intervened to inform the court of legal and policy developments, both internationally and within Australia regarding patient access to medical records held by private practitioners.
- advocating, with a number of community groups, for reforms to the Health Complaints Unit in NSW. The changes were implemented in the NSW *Health Care Complaints Act 1993* (NSW) and PIAC has participated in the consumer advisory committee of the NSW Health Care Complaints Commission since 1994.
- representing people at risk of Creutzfeldt-Jakob disease.
- preparing an issues paper on legislative principles for 'community right to know' about chemicals.
- representing relatives at a coronial inquiry into a hospital deaths.

- a consultancy to the Consumers' Health Forum of Australia to review the regulation of health professionals, facilities and administration, and the extent to which consumer health rights such as informed consent, access to medical records, confidentiality and complaints are recognised and protected by law, culminating in the publication of *Legal Recognition and Protection of the Rights of Health Consumers* (1990);
- representation of the Canberra Women's Health Centre in proceedings before the Human Rights and Equal Opportunity Commission initiated by Alex Proudfoot who alleged that services provided by the Centre contravened the *Sex Discrimination Act (Cth) 1984*;
- intervention before the Federal Court as a friend of the court in proceedings initiated by Mt Isa Mines against Worksafe Australia. PIAC's intervention was in support of a proposed new national lead standard which effectively sought to reduce workplace lead levels, thus allowing women to work in an area previously denied them and making it safe for both women and men to work in areas where lead is used, without risk to their reproductive organs;
- assistance to Australian women to pursue claims of compensation in US courts for injuries caused by the Dalkon Shield contraceptive device;
- the release of *Defective Health Products: Your Legal Rights* (1989), a booklet on the legal rights of consumers injured or damaged by defective health products;
- representation of clients before the NSW Royal Commission investigating "deep sleep therapy" at Chelmsford Private Hospital (Sydney).

**Written Submissions**

1. AIDS Council of New South Wales, Sydney, NSW
2. Australian Consumers Association, Sydney, NSW
3. Australian Medical Association, Canberra, ACT
4. Australian Nursing Homes and Extended Care Association (NSW), Surry Hills, NSW.
5. Breast Implant Resource Service, Bonnyrigg, NSW
6. Breast Implant Support Group, Coffs Harbour, NSW
7. Central Sydney Area Health Service, Camperdown, NSW
8. Rebecca Coghlan, WA
9. Country Women's Association (NSW), Potts Point, NSW
10. Doctors Reform Society, NSW
11. Professor Fred Ehrlich, University of NSW, Division of Extended Care, Kogarah, NSW
12. Guardianship Board, NSW (President, Nick O'Neil)
13. Roy Harvey, University of Wollongong, NSW
14. Health Consumers Council (WA) Inc, Perth, Western Australia
15. Health Information Management Association of Australia, NSW
16. Health Services Commissioner, Melbourne, Victoria
17. Jennifer Hughes, Medical Records Manager, Central West Health Service, NSW
18. Hunter Area Health Service, New Lambton, NSW
19. Glen Innes, and R Stevens, Riding, NSW
20. Graham Isaacs, Mt Eliza Plastic Surgery Centre, Victoria
21. Martin Jarman, Regional Director, North West Regional Administration, Burnie, Tasmania.
22. Christine Lyall, WA
23. Tina Magennis, Lecturer, Faculty of Health Sciences, School of Health Information Management, University of Sydney, NSW
24. Maternity Coalition, Brighton, Victoria
25. Medical Consumers Association of NSW, Balgowlah, NSW
26. National Childrens and Youth Law Centre, Sydney, NSW
27. National Council of Women (NSW)
28. National Health Service, UK
29. Northern Sydney Area Health Service, St Leonards, NSW
30. NSW Health Information Management Association, Parramatta, NSW
31. Privacy Commissioner, Human Rights and Equal Opportunity Commission
32. NSW Nurses' Association, NSW
33. NSW Privacy Committee, NSW
34. Privacy Commission, New Zealand
35. Shoalhaven North Health Consumers Action Group, Nowra, NSW
36. Dr David Smith, South Lakes Medical Group, Newcastle, NSW
37. Southern Shoalhaven Healthwatch, Ulladulla, NSW
38. Territory Health Service, Casurina, Northern Territory
39. The Medical Defence Association of Victoria, Melbourne, Victoria
40. United Medical Defence, Sydney, NSW
41. Walgett Aboriginal Medical Service, Co-operative Ltd, Walgett, NSW
42. Alex Walker, Deputy Chair HCC (WA)

**Oral submissions, interviews and information**

1. Consumers Health Advocacy, Brisbane, Queensland
2. Fiona Nichols and departmental officers, Department of Health and Family Services, Aged and Community Care Branch, Sydney, NSW
3. Disabled People International (Tasmania) – Christopher Newell
4. Tony Pun, Health Sub-committee, Ethnic Communities Council (NSW)
5. Health Care Complaints Commissioner (NSW), Merrilyn Walton, and Gayle Furness (Deputy Commissioner) and Bruce Greetham
6. Ken Patterson, Commissioner for Health Complaints, Canberra, ACT
7. Health Issues Centre, Melbourne, Victoria

8. Illawarra health consumers; Lyn Brown, Consumer Advocate for Illawarra Area Health region; Sally Willington, Association for Improvements in Maternity Services; Julia Hatten and Peter Hatten.
9. Kathy Kendall, Queensland
10. NSW Health, Legal Branch, North Sydney, NSW
11. NSW Health, Quality Assurance branch, North Sydney, NSW
12. South East Sydney Area Health Service
13. Father Des Dwyer, St James Ethics Centre, Sydney, NSW
14. Western Sydney Area Health Service, NSW
15. State Ombudsman, Adelaide, South Australia
16. Royal Australian College of General Practitioners, Forrest Lodge, NSW
17. Australian Traditional Medicine Society, NSW
18. Elizabeth Catham, Manager Out-patients Dept, Royal Women's Hospital, Melbourne
19. NSW Health, FOI Unit
20. Tony Wade, National Association for Mental Health, Brisbane, Queensland

**Sydney workshop, 20 June 1996**

Andrew Allan  
*Medical Consumers Association (NSW)*

Clare Barbato  
*Department for Women, NSW*

Ros Bragg  
*New South Wales Council for Social Services*

Lena Bruselid  
*Policy Officer, Council of the Ageing*

Ian Cooper  
*People with Disabilities of NSW*

Sandra De Marchi  
*NSW Users & AIDS Association*

Kate Fielden  
*The Accommodation Rights Service*

Irene Hancock  
*Association for Child and Adolescent Health*

Joseph Harrison  
*Disability Council of NSW*

Bruce Hutton  
*Combined Pensioners and Superannuants Association of New South Wales*

Joan Kersey  
*Older Women's Network*

Di Lane  
*Project officer, Older Women's Network*

Don Mackay  
*Hastings Hospital, Port Macquarie Action Group*

Leonie Manns  
*Mental Health Coordinating Council (NSW)*

Alice Monk  
*National Council of Women (NSW)*

Jan Monson  
*Older Women's Network*

Timothy Moore  
*Australian Federation of AIDS Organisations*

Patricia Murphy  
*Chronic Fatigue Syndrome support group*

Ann Rauch  
*Community Health Association NSW*

John Rothwell  
*State Council, NCOSS*

Glenda Sleight  
*Alzheimers Association*

Kate Turner  
*Women's Electoral Lobby*

Larry Wellings  
*People Living with HIV/AIDS*

**Melbourne workshop, 14 June 1996**

Workshop convened by Christine Walker,  
*Chronic Illness Alliance*

Margot Boyle  
*Epilepsy Foundation of Victoria*

Shannon Bracken  
*Health Issues Centre Committee of Management*

Meredith Carter  
*Health Issues Centre*

Frank Fisher  
*Monash University*

Chris Hobson  
*Victorian Association for Hospice & Palliative Care*

Beverley Lewis  
*HIC Committee of Management*

Sue Lockwood  
*Breast Cancer Action Group*

Bebe Loff  
*HIC Committee of Management*

Elizabeth Newman  
*National Council of Women of Victoria*

Russell Pollard  
*Epilepsy Foundation of Victoria*

Monica Walters  
*Chronic Illness Alliance*

**Newcastle workshop, 19 July, 1996**

Jo Cooper  
*Acting Director, Centre for Health Law Ethics & Policy, University of Newcastle*

Professor Neil Rees  
*Dean of Law, University of Newcastle*

Mrs Carol Abela  
*Lecturer in Law, University of Newcastle*

Ms Bridget Maxwell  
*Centre for Health Law, Ethics & Policy*

Ms Angela Baker  
*Part-time tutor, Lawyer, Medical student*

Mr Andrew Hooper  
*Part-time tutor, Lawyer, Medical student*

Dr Tim Smyth  
*Chief Executive Officer, Hunter Area Health  
Service*

Mrs Sandra Morgan  
*Manager, Clinical Information Department,  
John Hunter Hospital*

Dr Arn Sprogis  
*Hunter Urban Division of General Practice Ltd,  
King Street, Newcastle*

Dr Malcom Ireland  
*Discipline of General Practice, University of  
Newcastle*

Mr Ron Powe  
*Solicitor, Thomas Laycock, Solicitors, Newcastle*

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