

## Patient access to medical records

7.1 National Privacy Principle 6 (NPP 6) establishes the general rule that an organisation is required on request to provide an individual with access to personal information held about him or her. This rule applies both in relation to personal information generally and to health information which is defined as:

**health information** means:

- (a) information or an opinion about:
  - (i) the health or disability (at any time) of an individual; or
  - (ii) an individual's expressed wishes about the future provision of health services to him or her; or
  - (iii) a health service provided, or to be provided, to an individual;

that is also personal information; or

- (b) other personal information collected to provide, or in providing, a health service; or
- (c) other personal information about an individual collected in connection with the donation, or intended donation, by the individual of his or her body parts, organs or body substances.<sup>1</sup>

7.2 However, NPP 6 also contains a number of exceptions to the general right of access. NPP 6.1(b), for example, relates specifically to health information and provides that access to information may be denied to the extent that:

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<sup>1</sup> See Item 16 of Schedule 1 of the Bill which amends subsection 6(1) of the *Privacy Act 1988*.

(b) in the case of health information – providing access would pose a serious threat to the life or health of any individual.

- 7.3 Other exceptions are of a more general nature and apply to personal information as a whole. For example, NPP 6.1(d) allows access to information to be denied if the request for access is ‘frivolous or vexatious.’
- 7.4 The text of NPP 6 is attached at Appendix D.

## Reasons for access

- 7.5 It was suggested in evidence that, subject to limited exceptions, patients should have a general right of access to their own personal health information.<sup>2</sup> It was further suggested that the exercise of this right would be of benefit to both patients and doctors. For example, one benefit of providing patients with access to their records is that it allows them to gain a better understanding of their condition and treatment.<sup>3</sup> Granting the opportunity to ensure that records of the importance of health records are accurate can also produce the important benefit of increasing confidence in the integrity of the health system.<sup>4</sup>
- 7.6 In addition, the Breast Cancer Action Group Victoria and the Breast Cancer Network Australia, in their joint submission to the Committee, noted that:
- The right of patients to access their medical records has been a constant refrain from many quarters over the last decade. The philosophical, moral and, in some countries, the legal imperatives have been well documented. Yet, what has possibly not been so well enunciated is the overwhelming evidence which supports the notion that patient access to their clinical record ultimately improves the quality of medical record keeping and thus ensures a better health outcome.<sup>5</sup>
- 7.7 The Australian Council of Social Service, from a different perspective stated that:

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2 Consumers Health Information for Research Purposes (CHIRP) Principles – quoted by the Australian Council of Social Service, *Submissions*, p.S33; Consumers’ Health Forum of Australia, *Submissions*, p.S276.

3 Public Interest Advocacy Centre, *Submissions*, p.S415.

4 Ibid.

5 Breast Cancer Action Group Victoria/Breast Cancer Network Australia, *Submissions*, p.S240.

...there is much anecdotal evidence that people who are affected by poverty and other groups...suffer discrimination in receiving health care. This can sometimes lead to comments being recorded on their health records which influence the course of their treatment and the nature and thoroughness of the care provided to them. Where such information is recorded on a record, accurately or inaccurately, it is crucial that the person to whom it relates can have the opportunity to access their record, and where necessary, seek its correction.<sup>6</sup>

7.8 The Australian Medical Association (AMA), on the other hand, recognises only the importance of communication between doctor and patient and the right of the patient to be informed about their health care.<sup>7</sup> The AMA's 1997 *Guidelines for Doctors on Providing Patient Access to Medical Records* provide that:

1. Patients have a right to be informed of all factual information contained in the medical record relating to their care, but do not have an absolute right to access medical records.<sup>8</sup>

7.9 This fundamental conflict as to the extent of patients' rights is reflected in a number of submissions that argue that the health industry has been reluctant to allow health consumers access to their medical records.<sup>9</sup>

7.10 The Committee does note, however, that the Committee of Presidents of Medical Colleges expressed its support for aspects of NPP 6.<sup>10</sup>

## Criticisms of the access provisions

7.11 The access provisions in the Bill have been criticised by advocates on both sides of the argument as to whether access to records should be granted. Those who advocate patient access have argued that the Bill:

- provides too many exceptions to the access principle;
- is inconsistent with the access currently available for health records held in the public sector; and
- does not represent best practice.

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6 Australian Council of Social Service, *Submissions*, p.S32.

7 Australian Medical Association, *Exhibit 22*.

8 Ibid.

9 Enduring Solutions, *Submissions*, p.S30; Health Consumers' Council, *Submissions*, p.S235; PIAC, *Submissions*, p.S415; People With Disabilities, *Submissions*, p.S418.

10 Committee of Presidents of Medical Colleges, *Exhibit 37*.

- 7.12 Those who advocate a more restricted form of access argue that the Bill:
- provides for access to too much information; and
  - may interfere with doctors' copyright in medical records.

## Exceptions to access

7.13 The range of possible exceptions to the provision of access to information was criticised by a number of witnesses. Health Consumer Perspectives argued that the Bill provided ample opportunity for a medical specialist to hide behind the exceptions in order to justify refusing access to records.<sup>11</sup> This view was shared by People With Disabilities (NSW)<sup>12</sup> and the Health Consumers' Council.<sup>13</sup>

7.14 The possibility of misuse of the exceptions in NPP 6 was also considered by a number of witnesses. Enduring Solutions Pty Ltd stated that:

Experience of consumers thus far indicate that broad exemptions of the kinds included in draft Principle 6 could be misused if they were available in relation to personal health information.<sup>14</sup>

The Australian Council of Social Service made the same comment.<sup>15</sup>

7.15 The Australian Plaintiff Lawyers Association argued that the range of exceptions available will mean that access to personal information in the health context will be denied more often than it is granted.<sup>16</sup> The Breast Cancer Action Group Victoria and the Breast Cancer Network Australia also endorsed this view, noting that:

...history would seem to indicate that the more exemptions listed, the greater the chance that this will be interpreted as favouring refusal of access.<sup>17</sup>

7.16 A further concern expressed by witnesses was that the exceptions in NPP 6 contained a number of matters that were irrelevant in the health context. The Health Issues Centre submitted that the extension of NPP 6 to health records was inappropriate because 'only some of the grounds on which access can be refused specifically relate to health.'<sup>18</sup> The Public Interest

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11 Health Consumer Perspectives, *Submissions*, p.S28.

12 People With Disabilities (NSW), *Submissions*, p.S418.

13 Health Consumers' Council, *Submissions*, p.S234.

14 Enduring Solutions Pty Ltd, *Submissions*, p.S31.

15 Australian Council of Social Service, *Submissions*, p.S33.

16 Australian Plaintiff Lawyers Association, *Submissions*, p.S220.

17 Breast Cancer Action Group Victoria/Breast Cancer Network Australia, *Submissions*, p.S240.

18 Health Issues Centre, *Submissions*, p.S357.

Advocacy Centre (PIAC) argued that by including the exceptions the Bill ignored:

...the reasons for providing consumers with access to their personal health records. A major proven benefit of providing consumers with access to their personal health records is that it assists them to better understand their condition and treatment... The sort of considerations set out in clause 6(d) – (j) should never be a relevant consideration in the context of improving the communication between health consumers and their providers.<sup>19</sup>

7.17 In oral evidence, PIAC went on to say that:

The primary motivation in health is to improve communication between the doctor and patient. The exemptions that should legitimately apply should really only be those that would interfere with the privacy of other people or where there is a risk of imminent harm. We believe it is not relevant and not an appropriate exemption that a police investigation is going on, whereas the bill would say that that is a relevant and applicable exemption.<sup>20</sup>

7.18 The Australian Consumers' Association argued that a number of the exceptions to the access principle should be amended or removed in relation to health information.<sup>21</sup> The amendments suggested by the Association included deleting or adequately defining terms such as 'unreasonable', 'frivolous' and 'vexatious' to ensure that consistency in interpretation is maintained.<sup>22</sup> It was recommended that other exceptions such as NPP 6.1(i), (j), (k) and 6.2 should be removed altogether as far as health records are concerned.<sup>23</sup> The dangers of retaining the exceptions in their entirety was illustrated by pointing out that:

A number of the exceptions, Section 6.1(f) in particular, embody a power asymmetry between the consumer and the organisation. In the particular case of section 6.1(f), providing access would reveal the intentions of an organisation in relation to negotiations with the individual in such a way as to prejudice those negotiations. Some providers [could use this clause] to hide information from consumers who, providers believe, wish to complain.<sup>24</sup>

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19 Public Interest Advocacy Centre, *Submissions*, p.S415.

20 Public Interest Advocacy Centre, *Transcript*, pp.151-152.

21 Australian Consumers' Association, *Submissions*, pp.S92-93.

22 Ibid.

23 Australian Consumers' Association, *Submissions*, p.S93.

24 Ibid.

7.19 In oral evidence, the Australian Consumers' Association described the right of access to health records under the Bill as being:

...undermined by a range of exemptions that can be used to deny access to health records. When you tie this range of exemptions to the fact that, under a self-regulation scheme, the person making the decision about whether or not to get access to those records may be the person who compiled the records in the first place, you have got a fairly weak protection there for consumers.<sup>25</sup>

### **Inconsistency with public sector**

7.20 The Australian Plaintiff Lawyers Association suggested in its submission that 'those treated in the public hospital system have almost full rights to access records under the Freedom of Information legislation.'<sup>26</sup> The Consumers' Health Forum of Australia pointed out that freedom of information (FOI) legislation in each state has for the last ten years provided patients with a right to access medical records held about them in the public health system.<sup>27</sup> The Forum went on to note that the only reasons that access to a health record can be refused under FOI legislation is if access would:

...be detrimental to the consumer's "physical or mental health" or would endanger others, or

...would "involve unreasonable disclosure of information concerning the personal affairs of any person" or may place the community at risk.<sup>28</sup>

7.21 Further, if access to medical records under FOI legislation is denied because of the apprehension of harm to an individual, the records can be provided to a medical practitioner of the applicant's choice.<sup>29</sup>

7.22 The Bill, on the other hand, provides 12 possible exceptions for denying access to a record. The Health Issues Centre argued that this means that on passage of the Bill the rights of private patients will be dramatically weaker than those whose records are kept in the public sector:<sup>30</sup>

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25 Australian Consumers' Advocacy Centre, *Transcript*, p.115.

26 Australian Plaintiff Lawyers Association, *Submissions*, p.S219.

27 Consumers' Health Forum of Australia, *Submissions*, p.S279.

28 Consumers' Health Forum of Australia, *Submissions*, p.S279.

29 Public Interest Advocacy Centre, *Submissions*, p.S415.

30 Health Issues Centre, *Submissions*, p.S357.

This leaves a private patient in a hospital bed with less rights of access to their records than the public patient in the bed next to them!<sup>31</sup>

7.23 The Public Interest Advocacy Centre argued that the range of exceptions is unacceptable because:

...it would in fact introduce a standard in the private health sector that is quite different from the public sector. Under freedom of information people have a right of access to personal health records held by the public sector, except where it is going to interfere with the rights of others or where there is...imminent harm likely. So we would say that the standard that applies under FOI is really the standard that should apply in the private health sector. This is not what this bill would achieve; it would actually provide a much wider range of exemption.<sup>32</sup>

7.24 In addition, in the ACT the *Health Records (Privacy and Access) Act 1997* provides a right of access to patient records in both the public and the private sectors. The exceptions to that right of access are similar to those in FOI legislation.<sup>33</sup> This legislation is discussed further below.

7.25 An example of the importance of consistency between the public and private health sectors in terms of access to records was illustrated for the Committee by the evidence of the Breast Cancer Action Group Victoria and the Breast Cancer Network Australia.<sup>34</sup>

## Best practice

7.26 It was submitted to the Committee that the Bill did not represent best practice in terms of patient access to medical records. The Bill does not, for example, deal with situations where patients wish to have their health records transferred to another doctor when changing doctors or after the closure of a practice. It was suggested to the Committee that these issues need to be taken into account as they are in the ACT *Health Records (Privacy and Access) Act 1997*.<sup>35</sup>

7.27 It was further submitted that the ACT *Health Records (Privacy and Access) Act 1997* is overall a better model than that proposed in the Bill. That Act

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31 Health Issues Centre, *Submissions*, p.S357.

32 Public Interest Advocacy Centre, *Transcript*, p.152.

33 Consumers' Health Forum, *Submissions*, pp.S279-280.

34 Breast Cancer Action Group Victoria/Breast Cancer Network Australia, *Submissions*, p.S239. This issue was discussed in some detail in the previous chapter.

35 ACT Community and Health Services Complaints Commissioner, *Submissions*, pp.S245-246.

provides that an individual has a right of access to his or her medical records unless:

- the provision of the information would constitute a significant risk to the life or health of any person;
- the provision of the information would contravene a law of the Commonwealth, the Territory or an order of a court of competent jurisdiction; or
- the record is subject to an obligation of confidentiality.<sup>36</sup>

7.28 The Australian Council of Social Service said in its submission that it believed that the ACT legislation ‘more fully meets the needs of consumers in that it provides only limited exclusions to access.’<sup>37</sup> The Health Care Consumers Association of the ACT advised that it was generally pleased with the outcomes achieved under the ACT Act.<sup>38</sup> The Public Interest Advocacy Centre submitted that:

The ACT legislation is widely regarded as model legislation to protect privacy across the private and public health sectors and it has proven workable, even by its strongest critics. The Federal Parliament should be using the ACT legislation as a model for nationally consistent standards in health...<sup>39</sup>

7.29 The ACT Community and Health Services Complaints Commissioner advised the Committee that:

The Health Records Act is based on two simple assumptions: a patient and the treating team should have access to all the information in a patient’s health record, unless there is a very good reason why not; and no-one else should have access to information in a patient’s record unless there is a very good reason why.<sup>40</sup>

7.30 The Commissioner further advised the Committee that the ACT legislation was originally enacted by way of a trial. It was intended that if the legislation proved to be of value in practice it would be proposed as a model for nationally consistent legislation through either State or Commonwealth enactments.<sup>41</sup>

7.31 Not all witnesses agreed with the overwhelmingly positive assessments of the ACT legislation above. Ms Meredith Carter of the Health Issues

36 *Health Records (Privacy and Access) Act 1997* (ACT) – sections 14, 15 and 17.

37 Australian Council of Social Service, *Submissions*, p.S34.

38 Health Care Consumers Association of the ACT, *Submissions*, p.S80.

39 Public Interest Advocacy Centre, *Submissions*, p.S414.

40 ACT Community and Health Services Complaints Commissioner, *Submissions*, p.S243.

41 ACT Community and Health Services Complaints Commissioner, *Submissions*, p.S242.



Centre, for example, gave evidence that she was of the view that the legislation was 'base level legislation, but certainly better than [the Bill] in terms of health.'<sup>42</sup> The Health Issues Centre also argued that best practice would mean that the standards applying in relation to personal information held under the Medical Benefits Scheme and the Pharmaceutical Benefits Scheme should be adopted as standards for the protection of health information in the private sector.<sup>43</sup>

- 7.32 The Australian Medical Association expressed an even less enthusiastic view of the ACT scheme. The Association suggested that rather than providing a patient with rights to access their medical records to improve the patient-doctor relationship, the ACT legislation had been used to obtain access to records for the purposes of pursuing legal proceedings against doctors.<sup>44</sup> However, when asked to provide evidence for this assertion, the AMA informed the Committee that its comments were based on anecdotal information only.<sup>45</sup> The AMA stated that it was '...in the process of gathering...' further information. At the time of writing this report, the Committee had received no further evidence about the matter.

## Too much access

- 7.33 The Australian Medical Association took a different view of the access provisions. It argued in its submission that access to:
- working notes, aides memoire and communications between treating doctors which do not represent considered therapeutic opinion;
  - information prepared for legal proceedings; and
  - information prepared for and owned by third parties
- should be excluded from the Bill as they would, in effect, provide too much or inappropriate information to patients.<sup>47</sup>
- 7.34 The AMA sought to draw a distinction between working notes and the considered therapeutic opinion of medical practitioners. The former would amount only to objective information about the patient, while the latter could include notes, aides memoire and initial opinions about the patient. It appears that a corollary of this distinction is that the AMA:

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42 Health Issues Centre, *Transcript*, p.304.

43 Health Issues Centre, *Transcript*, p.303.

44 Australian Medical Association, *Transcript*, p.89.

45 *Ibid.*

46 *Ibid.*

47 Australian Medical Association, *Submissions*, p.S269.

Has no difficulty about patients having access to the information contained in their records, as distinct from their records... The AMA has never had any difficulty with patients having access to their health information.<sup>48</sup>

- 7.35 Information prepared in relation to legal proceedings, the AMA argued, should not be available to patients under the Bill because individuals should not be able to use the National Privacy Principles to override the discovery and access procedures that are established under court rules.<sup>49</sup>
- 7.36 The AMA also argued that reports containing health information written by doctors for third parties for legal and insurance purposes should not be made available to patients. In some cases the doctor writing the report is not in a direct therapeutic relationship with the individual, but is rather in a contractual relationship with the organisation requesting the report.<sup>50</sup>
- 7.37 Dr Ron Morstyn, a clinical psychiatrist and psychotherapist, criticised the Bill on the basis that the granting of access to medical records on the terms described in the Bill would 'render psychotherapeutic practice impossible.'<sup>51</sup> Dr Morstyn suggested that psychiatrists would feel constrained as to the information they could record on a patient's file if there was a possibility that the patient could access that information:
- ...treating practitioners need to have a space to work through their own honest hypotheses and private subjective opinions without having to censor or commit these to memory in order to be able to consider how best to treat and relate to their patients.<sup>52</sup>

## Copyright issues

- 7.38 The AMA also opposed the provisions allowing access to health information contained in medical records on the basis that they would abrogate the doctor's copyright in the records. The Association submitted that:

The High Court in *Breen v Williams* based its decision that there was no patient access to medical records in part on the grounds that copyright attaches to the notes made by medical practitioners in the course of their professional practice.<sup>53</sup>

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48 Australian Medical Association, *Transcript*, p.86.

49 Australian Medical Association, *Submissions*, p.S269.

50 Australian Medical Association, *Submissions*, p.S267.

51 Dr Ron Morstyn, *Submissions*, p.S447.

52 Dr Ron Morstyn, *Submissions*, p.S449.

53 Australian Medical Association, *Submissions*, p.S266.

- 7.39 The AMA questioned whether the Bill overrode the rights of the copyright owner.

...[U]nder the Copyright Act, authors are given certain rights and one of the rights is the right of keeping the work exclusive. National privacy principle 6.1 states that – and I will keep it in the medical context – the organisation holding the information must provide the individual with access. National privacy principle 6.1 is then coming into direct conflict with the right of exclusivity... The point we are raising is: is this sufficient in law to override the rights that are granted in the Copyright Act...<sup>54</sup>

- 7.40 The Committee notes that the Department of Health and Aged Care suggested that the interaction of the Bill and doctors' copyright is an issue that may need clarification.<sup>55</sup> However, the Committee also notes the evidence of the Attorney-General's Department that the Bill:

...is not changing the fact that the ownership of those records will still reside with the organisation that holds them, be it a private medical practitioner or a larger organisation... This is acknowledging that there are different interests at play here and that the person whose information is contained in those records also has an interest in what is in them.<sup>56</sup>

## Conclusions

- 7.41 The Committee accepts that there should be a general right of patients to obtain access to their medical records. The Committee accepts the evidence provided to it that such a right to access would assist in the development of better doctor/patient relationships and an improved ability amongst patients to understand their own health status and treatment.
- 7.42 The Committee does not agree that a useful distinction can be drawn between working notes and considered therapeutic opinion in relation to health records. Health records will necessarily consist of objective factual material and the subjective opinions of the treating doctor. Both types of information concern the intimate health details of the patient and are relevant to an understanding of his or her health status and treatment. The Committee has not been provided with any evidence to suggest that there would be any benefit in denying patients access to both the objective

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54 Australian Medical Association, *Transcript*, p.84.

55 Department of Health and Aged Care, *Submissions*, p.S405.

56 Attorney-General's Department, *Transcript*, p.18.

and subjective components of their health records. Nor is it readily apparent why some parts of the medical profession are unwilling to do so.

- 7.43 The Committee is concerned that the access principle in the Bill contains such a large number of exceptions that have the potential to operate to deny individuals access to their health records. The Committee does not comment on the appropriateness of the exceptions to personal information generally. However, it is concerned that, in the context of health information, the range of exceptions may be too broad.
- 7.44 The arguments advanced to the Committee that the access regime is in fact too accommodating were not convincing. The Committee does not propose that normal rules of confidentiality be displaced but, where a health record contains health information about an individual, the Committee believes that the individual has a prima facie right to access that record. The Committee does not believe that a right of access to medical records will interfere with the discovery or subpoena processes set out in court rules or that the rights of third parties will be unduly affected.
- 7.45 Nor is the Committee willing to accept that the copyright interests of doctors in their notes should override the basic right of the patient to access his or her health information. It is acknowledged that the right of access does have an effect on the copyright interest held by the doctor. However, the Committee notes that the High Court in *Breen v Williams*<sup>57</sup> observed that the choice as to whether a patient has the right to know what is in their health records is a matter 'appropriately for the legislature rather than a court.'<sup>58</sup> Clearly the introduction of a statutory right of access is a policy decision to be made by Parliament. The Committee does not accept that the decision in *Breen v Williams* can be used as a smokescreen to obscure Parliament's consideration of that policy decision.
- 7.46 That the Bill proposes an access regime different from that generally in place in relation to public sector health records is of concern to the Committee. As was pointed out by a number of witnesses, many patients will interact with both the public and private health sectors in the course of a single health event. It would seem unnecessarily complicated to grant different rights of access in relation to information held in the public and private sectors. The Committee is of the view, therefore, that rights of access to medical records in the public and private sectors should be harmonised.

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57 *Breen v Williams* (1996) 186 CLR 71.

58 *Breen v Williams* (1996) 186 CLR 71 per Dawson and Toohey JJ at 99; similar comments were made by Gaudron and McHugh JJ at 114-115.

- 7.47 The Committee's proposal will allow access to medical records in the private sector to be on equivalent terms to the access that is currently available in the public sector (and the private sector in the ACT). By minimising the differences between rights of access, consumers will be able to more easily understand the extent of their rights, and health service providers will be able to more easily understand their obligations.
- 7.48 The Committee does not foresee any difficulties in integrating the public sector access standards for health records into the National Privacy Principles and anticipates that relevant privacy codes will be able to incorporate the standards with little difficulty.

### **Recommendation 16**

**The Committee recommends that the basis for this harmonisation be the access standards set out in the *ACT Health Records (Privacy and Access) Act 1997*. That is, a patient should have a right of access to his or her medical records unless:**

- **the provision of the information would constitute a significant risk to the life or health of any person;**
- **the provision of the information would contravene a law of the Commonwealth, State or Territory or an order of a court of competent jurisdiction; or**
- **the record is subject to an obligation of confidentiality.**

