

## Inclusion of health information in the Bill

### Introduction

- 6.1 The Bill includes privacy protection for personal health information in the private sector within its coverage and hence the National Privacy Principles apply to health information.<sup>1</sup>
- 6.2 The inclusion of health information has proven to be the most contentious aspect of the Bill. The Committee has received a large number of submissions focussed solely on the issue of the coverage of health information. These submissions have generally concentrated on two issues: firstly, whether health information should be covered by the Bill at all and, secondly, the more specific issue of individuals' access to their own health information.
- 6.3 The Committee has received a large number of detailed submissions canvassing other issues, such as the use of health information for research purposes, and it has taken careful note of the evidence on these matters. However the Committee has also noted that the issues of both the privacy of health information in general, and patient access to health information, in particular, have received significant attention over recent years. The Committee particularly notes the report of the Privacy Commissioner to the Attorney-General in December 1999 – *The Application of the National Principles for the Fair Handling of Personal Information to Personal Health Information* – and the Report of the Senate Community Affairs References Committee on *Access to Medical Records* (June 1997). It would not be productive for the Committee to traverse ground that has already been extensively canvassed.

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<sup>1</sup> The definition of 'health information' is included in paragraph 7.1 of the following chapter. Also see Item 16 of Schedule 1 of the Bill which amends subsection 6(1) of the *Privacy Act 1988*.

- 6.4 Given the short time frame for the inquiry, the Committee has decided to focus on the two principal issues raised in the submissions:
- whether health information should remain part of the Bill or not; and
  - whether the regime established by the Bill concerning individual access to health information is satisfactory. This issue is canvassed in the following chapter.

## Background to the inclusion of health information

- 6.5 In his Second Reading Speech on the introduction of the Bill, the Attorney-General, the Hon Daryl Williams AM QC MP, stated that:

The government recognises that Australians consider their personal health information to be particularly sensitive and that they expect that it will be handled fairly and appropriately by all those who come into contact with it. Following consultation with health stakeholders, it was agreed that the national privacy principles be modified to accommodate the particular sensitivities surrounding the collection, use and disclosure of personal health information.<sup>2</sup>

- 6.6 In its *Information Paper on the Introduction of the Privacy Amendment (Private Sector) Bill 2000* the Government further described the background to the inclusion of health information in the Bill.

In May 1999, the Attorney-General asked the Privacy Commissioner to conduct public consultation on how the National Principles for the Fair Handling of Personal Information could be applied to personal health information in a sensible and workable way. The Privacy Commissioner's report on those consultations was of great assistance in developing the relevant provisions.<sup>3</sup>

## Support for inclusion of health information in the Bill

- 6.7 The Privacy Commissioner 'strongly supports' the inclusion of health information in the Bill.<sup>4</sup> He stated that the:

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2 Second Reading Speech, 12 April 2000, House of Representatives, *Hansard*, p.15076.

3 Attorney-General's *Information Paper, Exhibit 31*, p.3.

4 Privacy Commissioner, *Submissions*, p.S390.

... health sector is a significant part of the Australian economy and personal health information is also held in a variety of other contexts, for example in insurance, superannuation and employment. ... A different approach to the protection of personal health information would make the objective of a nationally consistent framework difficult to achieve.<sup>5</sup>

6.8 In addition, the Department of Health and Aged Care submitted that 'overall' it:

...is strongly supportive of both the intentions of the Bill in providing adequate coverage to health information and the specific modifications that have been made to the National Principles incorporated in the Bill to accommodate the special needs of the health sector.<sup>6</sup>

6.9 The Bill, will 'for the first time' it said:

...extend general privacy protection to the private sector and set minimum benchmark standards for the appropriate handling of personal information in the private sector – this is particularly important within the context of the rapidly expanding "information economy".<sup>7</sup>

6.10 The Department further submitted that the Bill is:

...both sensible and workable and that it strikes an appropriate balance between the rights of the individual with respect to privacy and other public interests, such as research and the compilation and statistical analysis of health information.<sup>8</sup>

## **Opposition to the inclusion of health information**

6.11 A considerable number of submissions urged the Committee to recommend that health information be removed from the Bill.

6.12 Those advocating this view have generally argued that the Bill does not provide appropriate rights to privacy in respect of health information and access to health records. Three principal reasons have been advanced in support of this view:

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5 Ibid, p.S390.

6 Department of Health and Aged Care, *Submissions*, p.S404.

7 Ibid, p.S404.

8 Ibid, p.S404.

- that the health sector is so different from other sectors that the attempt to incorporate it within the general framework of the Bill is misguided;
- that the regime established by the Bill will lead to the creation of inconsistent standards governing privacy rights in the public and private sectors; and
- that the access rights contained in the Bill enabling individuals to access their own health information are totally inadequate.<sup>9</sup>

## The health sector is unique

### 6.13 The Health Issues Centre commented:

The attempts made to modify the National Privacy Principles to accommodate health concerns regarding for example, access, disclosure of records and use of identifiers, has served only to reinforce the view that the framework is inappropriate for the health sector.<sup>10</sup>

### 6.14 The Public Interest Advocacy Centre argued that health information is different from personal information in other industries. One reason for this is the sensitive nature of health information. It argued that if people lose confidence in the ability of the health system to protect personal information they will be reluctant to divulge information that may be relevant and this could have serious consequences.<sup>11</sup>

### 6.15 The Breast Cancer Action Group Victoria and the Breast Cancer Network Australia in their joint submission to the Committee stated:

This current legislation does not meet the needs of individual patients within the health system ...[the] health system has some unique characteristics which would require the removal of health records from this bill to be dealt with in separate legislation.<sup>12</sup>

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9 See Breast Cancer Action Group Victoria and Breast Cancer Network Australia, *Transcripts*, p.313; Wollongong Health Consumers Advisory Group, *Submissions*, p.S231; Health Consumers Council, *Submissions*, p.S234; Mental Health Council of Australia, *Submissions*, p.S368.

10 Health Issues Centre, *Submissions*, p.S349.

11 Public Interest Advocacy Centre, *Submissions*, pp.S412-413.

12 Breast Cancer Network, *Transcript*, p.315. The ACT Council of Social Service has 'real concern about the adequacy of the protection created by the amendments and this relates to the privacy protection of health records and personal health information', *Submissions*, p.S202. See also Health Care Consumers Association ACT, *Submissions*, p.S81, Australian Consumers Association, *Submissions*, pp.S85-86; Australian Plaintiff Lawyers Association, *Submissions*, p.S219; People with Disabilities, *Submissions*, p.S418; Australian Council of Social Service, *Submissions*, p.S34; Fiona Tito, *Submissions*, p.S31; Rebecca Coghlan, *Submissions*, pp.S28-29.

- 6.16 The ACT Community and Health Services Complaints Commissioner agreed with this argument and suggested the Bill:
- ...will not lead to effective privacy protection in the health industry. Nor will [it] lead to consistency....The Bill aims to apply consistent privacy provisions across all industries with minor modifications, consistent with National Privacy Principles, introduced by means of voluntary industry codes. Because of the nature of the health industry this will not occur.<sup>13</sup>
- 6.17 The Commissioner suggests that the health industry is so different because it comprises hundreds of thousands of health service organisations of different types and scores of professions, occupations and specialties. Health services are also mostly local, not national. Hence no single organisation would be able to prepare a 'code which would be accepted voluntarily by even a significant minority of the industry.' The Commissioner contrasts this with other industries, such as banking, where there are few national organisations and which could hence easily create a specific code to govern their industry.<sup>14</sup>
- 6.18 Several organisations, such as the Health Care Consumers Association ACT, expressed their particular concern that a Bill incorporating privacy protection in relation to health information held by the private sector is being introduced at a time when health care reforms such as the development of electronic health records and possibly unique patient identifiers are being actively developed.<sup>15</sup> The Committee notes, however, that these developments as well as others, such as the foreshadowed electronic linkage of medical and pharmaceutical records, makes the issue of privacy protection for health information more urgent.
- 6.19 Many of the organisations that argued that health information should not be included in the Bill were not persuaded by the argument that it was better to proceed with the Bill than potentially remain without any privacy regime for health information in the private sector. For example, the Health Issues Centre rejected the 'suggestion that the inadequacies in the Bill can simply be remedied at a later date.'<sup>16</sup> The Centre was concerned about 'giving the impression we have done something when really we have not.'<sup>17</sup> This would give 'a false sense of assurance.'<sup>18</sup> The inevitable

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

14 Ibid, *Submissions*, p.S243.

15 Health Care Consumers Association ACT, *Submissions*, p.S81. See also Australian Consumers Association, *Submissions*, pp.S85-86; Health Consumers Council, *Submissions*, p.S235; and Public Interest Advocacy Centre, *Submissions*, p.S413 and *Transcripts*, p.151.

16 Health Issues Centre, *Transcripts*, p.303.

17 Ibid, *Transcripts*, p.304.

18 Ibid, *Transcripts*, p.304.

delay in developing any alternatives was, the Health Issues Centre argued, better than ‘bad legislation.’<sup>19</sup> The Centre argued that the drive for electronic management of health information would sustain the momentum towards a more acceptable outcome.<sup>20</sup> The Public Interest Advocacy Centre also thought the application of the Bill to health information was significantly flawed and proceeding with the Bill would result in these flawed provisions becoming permanent.<sup>21</sup>

- 6.20 It was clear from the evidence presented to the Committee that there is no consensus at this time within the health sector on the best approach to be adopted in relation to the privacy and access issues relating to health information in the private sector. The choice whether to proceed with the Bill in its current form or to delay it indefinitely is such an important issue from the consumers’ perspective that the Committee would need to be satisfied there was a significant measure of agreement within the health sector on these issues before recommending that the provisions relating to health information be removed from the Bill.

### **Differing standards in the public and private health sectors**

- 6.21 The second major concern of those advocating that the health provisions be removed from the Bill was that it would entrench a lesser standard of privacy protection in the private sector than that currently applicable in the public sector. Some of the issues cited as being covered by public sector legislation that would not be covered by the Bill include access by patients to their health records being subject to fewer exceptions under public sector legislation, enforcement of privacy rights being stronger in the public sector (for example criminal sanctions in the Medical and Pharmaceutical Benefits Schemes), and that there are provisions in public sector legislation relating to data matching, data linkage and how long identified data may be retained.<sup>22</sup>
- 6.22 The ACT Community and Health Services Complaints Commissioner noted that the health industry consists of a variety of government, private-for-profit and private non-profit organisations. Health service customers commonly use a mixture of services from each sector and often use a combination of service types simultaneously, for example a private GP, a private specialist and a public hospital. He stated that, in consequence:

... the health industry, unlike most others, requires a privacy regime which remains consistent when people move between

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19 Ibid, *Transcripts*, p.305.

20 Ibid, *Transcripts*, p.306.

21 Public Interest Advocacy Centre, *Transcripts*, p.156.

22 Health Issues Centre, *Transcripts*, pp.307-308.

public and private services, as happens tens of thousands of times each day....A vast amount of personal information is collected by health service agencies. An equally enormous amount of information flows between health service providers within and between different organisations. ...The flow of personal health information between service providers is essential for the safe and effective treatment of patients. An effective privacy regime for the health industry must be based on an understanding of this. It must allow for the efficient flow of information but must also include provisions which ensure that consumers have control of that flow, in terms of what information may be shared by whom.<sup>23</sup>

- 6.23 The potential problems for health consumers of inconsistent regimes were most clearly illustrated by the evidence of the Breast Cancer Action Group Victoria and the Breast Cancer Network Australia which outlined the potential scenario facing individual patients using both public and private sector health services in treating serious illness. The Network stated that one of their 'core problems'<sup>24</sup> with the coverage of health information by the Bill was the distinction between the public and private sectors 'that you would have different sets of rules relating to the public and private sectors'.<sup>25</sup> They went on to say that:

... making an arbitrary distinction between public and private health sector areas, and having different privacy requirements for those two areas, is inappropriate for meeting the needs of consumers.<sup>26</sup>

- 6.24 The Network noted that in the area of breast cancer, treatment teams consisting of practitioners from both the public and private sectors will be involved and patients will move between both sectors frequently and indeed could be in both sectors simultaneously in the course of treatment.<sup>27</sup> They stated that from the perspective of individual patients the proposed distinction between privacy protection in the public and private sectors is 'unrealistic'.<sup>28</sup> In their view, privacy 'must surely relate to the unique and sensitive nature of the medical record, not to the business arrangements of the practitioners.'<sup>29</sup> They pointed out that 'the

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

24 Breast Cancer Network, *Transcripts*, p.321.

25 Ibid, *Transcripts*, p.321.

26 Ibid, *Transcripts*, p.313.

27 Ibid, *Transcripts*, p.314.

28 Ibid, *Transcripts*, pp.314-315.

29 Ibid, *Transcripts*, pp.314-315.

last thing on [the patient's mind] is whether the practitioner is operating in the public or private sector.'<sup>30</sup>

## Suggested alternatives

- 6.25 Those advocating the removal of the health provisions from the Bill generally urge the enactment of 'effective information privacy legislation that is specific to the health sector and covers both the public and private sectors.'<sup>31</sup> An alternative proposal is the possibility of an enforceable code developed by the Privacy Commissioner under the current Bill<sup>32</sup> although some, such as the Health Issues Centre, did not have confidence that the principles that the Privacy Commissioner would be operating on would be strong enough to give them confidence that the resulting Code would be strong enough.<sup>33</sup>
- 6.26 The ACT Community and Health Services Complaints Commissioner favoured the development of a single compulsory privacy code that would be a disallowable instrument.<sup>34</sup> The Commissioner stated that this would be one way of addressing the problems created by the Bill, for example, that some of the assumptions in the Bill 'are not suitable for the health industry because they allow the passing on of information outside the therapeutic relationship.'<sup>35</sup> He recommended an amendment to the Bill to 'provide the Privacy Commissioner with the authority to develop a [compulsory] code in association with the bodies responsible for the regulation of the health industry.'<sup>36</sup>

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30 Ibid, *Transcripts*, p.315. The Australian Consumers' Association also cited the importance of consistent rules across the public and private sectors, *Submissions*, p.S85. See also Public Interest Advocacy Centre, *Submissions*, p.S413. The Health Consumers Council also stated that 'what is proposed for the private sector by way of regulation falls far short of even the limited privacy regime currently applicable in the private sector.', *Submissions*, p.S234. See also Australian Consumers' Association, *Transcripts*, p.118; Public Interest Advocacy Centre, *Transcripts*, pp.158-160.

31 Health Issues Centre, *Transcripts*, p.303. The Privacy Foundation also supports the enactment of specific legislation relating to health privacy on the basis that health is unique in involving competing interests such as the medical profession, insurers, private and public hospitals and patients. *Transcripts*, p.107.

32 See for example the Health Issues Centre, *Transcripts*, p.303.

33 Health Issues Centre, *Transcripts*, p.306.

34 ACT Community and Health Services Complaints Commissioner, *Submissions*, p.S242 and *Transcripts* p.67.

35 Ibid, *Submissions*, p.S244.

36 Ibid, *Submissions*, p.S247.



- 6.27 The Commissioner stated that ‘the only alternative would appear to be separate legislation for the health industry.’<sup>37</sup> The Commissioner did not advocate taking health information out of the Bill. He thought that
- ...would really slow things down. On the other hand if the Bill progresses as it is, it would also limit opportunities to do something better. That is why my proposal was really what I would see as a relatively minor amendment to the Bill, which means that the code for the health industry is a compulsory code.<sup>38</sup>
- 6.28 The Breast Cancer Action Group Victoria and the Breast Cancer Network Australia advocated a separate act ‘which can deal comprehensively with the complex issues in a way which empowers consumers to work with medical professionals to ensure that records are accessible when needed, are accurate and comprehensive and that the privacy of records is absolutely protected.’<sup>39</sup>

## Should health information remain part of the Bill

- 6.29 The Committee has considered the evidence on this matter very carefully. It is fully cognisant of the strength of feeling on the issue. It is clear that a large number of people have concerns about the wisdom of including health provisions in the Bill in their current form.
- 6.30 It is also clear to the Committee that privacy issues in the health context are complex. The Committee is of the view that there is merit in the argument that there are significant differences between the health industry and many of the other industries that will be covered by the Bill. The health industry is more localised, it has few national organisations in the private sector and it is made up of many specialties, professions and occupations. It impacts upon all Australians at some stage.
- 6.31 The Committee accepts the proposition that most Australians would regard their personal health information as among the most sensitive, indeed intimate, information concerning them. They expect it to receive the highest possible level of privacy protection. It is also clear that many people expect to be able to access their personal health information. Whether or not they choose, or feel the need to do so, is a different matter.

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37 Ibid, *Submissions*, p.S247.

38 ACT Community and Health Services Complaints Commissioner, *Transcripts*, p.64.

39 Breast Cancer Network, *Submissions*, p.S241.

- 6.32 These factors make the idea of separate legislation or a separate compulsory and enforceable code attractive. However, the Committee is not persuaded of the wisdom of this course at this time.
- 6.33 The evidence disclosed that the areas of disagreement between health service providers and consumers on issues such as access to health records are large and fundamental. The Committee has no reason to believe on the basis of the evidence before it that a consensus leading to the development of a separate legislative or regulatory code governing health services in the private sector would be reached in the near future. The Committee is of the view that health information should remain part of the Bill.
- 6.34 The Committee has formed this view in the interests of the protection of consumers in the private health sector. The retention of the provisions would ensure that health consumers in the private sector would receive the benefit of those privacy provisions contained in the Bill. Despite the doubts expressed about the adequacy of the privacy protection provided by the Bill in the context of health, it would provide an interim acceptable level of privacy and access rights throughout Australia. The ACT is, at present, the only jurisdiction with legislation applying privacy and access rights to health information held within the private sector.<sup>40</sup>
- 6.35 However, while the Committee is of the view that health information should remain part of the Bill, the Committee is concerned about the resulting plethora of principles that will then apply to both the public and private health sectors if the health provisions in the Bill retain their present form.
- 6.36 The evidence has clearly demonstrated the extent to which the public and private sectors intermingle and the experience of patients is a wide ranging and often simultaneous use of the two sectors. In the light of this the Committee is particularly concerned that the privacy principles applicable to the two sectors be harmonised as much as possible and the principles applicable to the public sector be applied in the private sector. The Committee's views as to how this could be achieved in the context of access to health records is discussed in the next chapter.
- 6.37 The Committee is of the view that it will take some time to develop a comprehensive set of privacy policies covering both the public and private health sectors. There will also be the important task of explaining the obligations of doctors and other health professionals to comply with the privacy principles and provide patient access so that the objectives of the legislation are achieved in practice.

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40 The *Health Records (Privacy and Access) Act 1997 (ACT)* is discussed in paragraphs 7.26-7.32 in the following chapter.

- 6.38 On balance, proceeding with the Bill at this time will at least commence that process of change and set some minimum standards for the private sector.
- 6.39 However the arguments of those concerned about the limitations of the Bill have considerable merit and there will be serious problems because of the nature of the health sector. If different rules apply within a State run hospital to those applying to a doctor or pharmacist there will be inevitable problems with transfer of records and information.
- 6.40 The rules in the legislation should therefore be explicitly recognised as interim and the Government should establish processes to resolve a consensus view for the health sector in the review proposed to take place in two years.

#### **Recommendation 14**

**The Committee recommends that the Government encourage all relevant parties to reach an agreed position on the major issues raised in the evidence to this inquiry, such as the harmonisation of privacy principles applicable to the public and private sectors, as a matter of urgency.**

#### **Recommendation 15**

**In the meantime the Committee recommends that health information be included in the Bill subject to its comments in Chapter 7.**

