

*Our Ref: S9968
15 May 2000*

*Ms Catherine Cornish
Acting Secretary
House of Representatives
Standing Committee on Legal and Constitutional Affairs
Parliament House
Canberra ACT 2600*

Dear Ms Cornish

Privacy Amendment (Private Sector) Bill 2000

I have pleasure in enclosing the Consumers' Health Forum's submission on the Privacy Amendment (Private Sector) Bill 2000. I apologise for the delay in providing a submission to the Committee.

CHF is pleased that the Government has recognised the importance of both privacy of health information and consumers' access to their own health records. However, the Forum is concerned that this Bill does not meet consumers' expectations in these and other areas.

Overall, we consider that better legislation would result if health information were removed from coverage under the Bill and new legislation introduced to cover this most sensitive personal information. Alternatively, health information could be covered by an enforceable code directly supervised by the Privacy Commissioner. In any case, it is imperative to ensure that weaker Commonwealth legislation does not override existing and future State and Territory legislation which may provide stronger protection for consumers.

In addition to these broad issues, CHF's submission also comments on specific issues of concern to health consumers and offers some suggestions for amendments which would strengthen the Bill in these areas.

Thank you for the opportunity to comment on this Bill.

Yours sincerely

Matthew Blackmore
EXECUTIVE DIRECTOR

Consumers' Health Forum Submission

Prepared for the House of Representatives Standing Committee on Legal and Constitutional Affairs

Privacy Amendment (Private Sector) Bill 2000

Summary of CHF position

Preferred position

- Health information should be removed from coverage under the proposed legislation and new legislation should be prepared which would cover privacy and access in both the public and private health sectors.
- Alternatively, health information should be covered by an enforceable code directly supervised by the Privacy Commissioner. Any such code should provide consumers with at least as much protection as the *ACT Health Records (Privacy and Access) Act 1997*.
- As an absolute minimum, the Bill should expressly state that it is not intended to override State and Territory legislation which provides stronger consumer protection.

Position on specific issues of concern

Collection, use and disclosure of health information (Principles 2 and 10)

- Collection, use and disclosure of personal health information for research purposes, where obtaining consumer consent is impracticable, should be allowed only under guidelines developed by the NHMRC and approved by the Privacy Commissioner (subject to Parliamentary disallowance). Consumer input should be required in developing these guidelines. This would require the deletion of section 10.3(d)(ii) and strengthening of s95A to require consumer input and Parliamentary disallowance.
- Disclosure to administrators and insurers should be notified to the consumer and should only be provided to the extent necessary (eg insurers should not be provided with complete health records when they only require a part of the record relating to a specific illness or injury). With respect to law enforcement, the provisions should only apply to health information where a court order has been obtained.

Access to health records and correction of errors (Principle 6)

- In relation to health information, restrictions on consumer access to their own information should be limited only to the same extent as under the *ACT Health Records (Privacy and Access) Act 1997*.
- A provision should be inserted requiring corrections to be advised to third parties to whom the information has previously been disclosed. In the case of researchers, this could be restricted to those who have accessed the record in the previous 12 months, reducing compliance costs and accepting the reality that the incorrect information is already likely to have been used or de-identified in such a way as to make correction difficult.

- Some allowance should be explicitly made for incorrect information in a record to be either deleted from the record or removed from the record which is in use and held separately.

Enforceability and sanctions

- It should be made clear in the legislation that all codes and guidelines developed under the legislation have the force of law. Adequate sanctions must be imposed for breaches of the legislation, codes and guidelines. Consumers must have the right to take civil action if they suffer as a result of an organisation breaching its obligations under the Act or relevant code.

Consumer consultation on code development and approval

- The Privacy Commissioner should be required to ensure that consumers are involved throughout the process of developing draft codes. In addition, the Privacy Commissioner should be explicitly required to seek public comment on the draft as presented to him/her for approval, including seeking the views of relevant consumer organisations.

Introduction

The Consumers' Health Forum (CHF) is a national consumer organisation that represents consumers on health care issues. It provides a balance to the views of governments, service providers, insurers and other health professionals. Over the last twelve years CHF has been active in contributing to consumer oriented policy in many areas, including health financing, chronic pain management, mental health, rational prescribing of medicines and consumer rights. CHF has a strong history of consultation with its members on issues of privacy and access in relation to health records. In March 2000, CHF published a position paper commenting on the Key Provisions of the draft *Privacy Amendment (Private Sector) Bill* released by the Attorney-General in December 1999.

The *Privacy Amendment (Private Sector) Bill 2000* (hereafter referred to as 'the Bill') extends the *Privacy Act 1988*, which currently determines the way in which Commonwealth Government agencies must handle all personal information, to cover the private sector as well.

CHF has some significant concerns about the effect of this Bill on consumers' rights to privacy in their health records and their ability to access their own records and seek corrections where necessary. This submission provides an overall comment on the Bill and discusses some specific changes CHF believes would enhance the legislation in protecting health consumers' interests.

Overall comment on the Bill

CHF understands that the Commonwealth Government's approach of including health information in this broad Bill, rather than introducing separate legislation for the health sector which would then cover both public and private sector health care providers, is unique. Unfortunately for health consumers, the result is that the rules applied to private sector health care providers under the Bill differ from those applying to providers in the public sector. If enacted, therefore, the Bill would simply add to a patchwork of laws and codes covering privacy in the health sector, making it even more difficult for consumers to understand their rights in respect of privacy and access to their health records.

In any case, CHF considers that the Bill overall fails to meet consumer expectations on the important issues of privacy and access in the health sector (see the detailed analysis below). The consumer protections in the Bill are substantially weaker than those under legislation relating to health information in other jurisdictions (for example, the ACT *Health Records (Privacy and Access) Act 1997*). It is therefore of considerable concern that this Bill, if enacted, may in fact override the stronger protection for consumers in some State and Territory legislation.

CHF's preferred position: Health information should be removed from coverage under the proposed legislation and new legislation should be prepared which would cover privacy and access in both the public and private health sectors.

Such legislation could be based on the ACT approach, taking into account the points made below. This would allow a rethink of the Commonwealth's approach to privacy and access to information in the health sector, with the aim of moving towards a consistent national approach on these important issues.

A further advantage of a move to separate legislation for the health sector is that it would significantly reduce the complexity of the current Bill. The proposal is in line with that of other privacy advocates, who appear to be united in their view that health information should be treated separately.

Alternatively: health information should be covered by an enforceable code directly supervised by the Privacy Commissioner. Any such code should provide consumers with at least as much protection as the ACT Health Records (Privacy and Access) Act 1997.

As an absolute minimum: the Bill should expressly state that it is not intended to override State and Territory legislation which provides stronger consumer protection.

Specific issues of concern

As it stands, the Bill raises a number of specific issues which are of serious concern to CHF members. The main issues are:

- collection, use and disclosure of information (specifically Principles 2 and 10);
- access to and ability to correct information (Principle 6);
- enforceability and sanctions; and
- consumer consultation on code development and approval.

This section discusses the changes CHF believes would enhance the Bill in respect of these particular concerns. The CHF position is largely based on the findings of the Consumers' Health Information for Research Purposes project (CHIRP).¹ This was a two-year research and consultation project that developed a set of policy principles about the use and disclosure of consumers' personal health information, particularly in relation to information used for research. CHF drew on these principles in developing its submission to the Federal Privacy Commissioner (Privacy Commissioner) on the application of the *National Principles for the Fair Handling of Personal Information* to private health information in 1999.

The CHIRP Principles are:

1. Consumers should have a right of access to their own personal health information.

2. The Commonwealth Government should introduce national privacy legislation that promotes consumers' right of access.
3. The processes of collecting, using and linking personal health information should be overt and open to consumer scrutiny.
4. All groups, organisations and individuals, including governments, health service providers, health administrators, researchers and health insurers, have a responsibility to seek the informed consent of consumers before making use of personal health information.
5. When information about the content, storage and use of personal health information is conveyed to consumers, it should be in a language and a format that they comprehend.
6. The linkage of personal health information should only be undertaken for purposes that are intended to result in either a short or long-term health benefit to the community or to individual consumers.
7. Consumers should be given the opportunity to participate in decisions about the management and use of personal health information.
8. Research partnerships between consumers and researchers should be promoted.
9. The promotion of positive health outcomes for health consumers should be a fundamental principle of all health research and data collection activities.
10. Consumers should have a right of redress where there is evidence that personal health information has been misused.
11. Wherever possible, consumers should be informed of the outcomes of research that used their personal health information.

It should be noted that the CHIRP principles were developed in relation to a specific use of health information and are therefore not a complete list of consumers' views about how their personal health information should be treated. For example, the CHIRP principles do not address the requirement for information held in a record to be accurate, although this is obviously of the utmost importance.

Collection, use and disclosure of information

The use and disclosure of health information held by Commonwealth agencies is subject to fairly tight control. This Bill would not impose the same degree of control over information held in the private sector. Of particular concern are provisions which allow personal health information to be used or disclosed for the purposes of investigating suspected unlawful activity or seriously improper conduct, and those relating to the use or disclosure of health information for research for 'community welfare purposes'. There is also some concern that the provisions would allow for health information to be inappropriately passed on to administrators and insurance companies.

The most complex issue for consumers is the release of information for health and medical research. Currently, medical information held by Commonwealth Government agencies can be released for use in research under one of two main regimes:

- Information relating to claims made under Medicare or the Pharmaceutical Benefits Scheme can only be released in line with guidelines developed by the Privacy Commissioner, any changes to which are subject to disallowance by Parliament.

- Other information can be released under guidelines developed by the National Health and Medical Research Council (NHMRC) and approved by the Privacy Commissioner. The Privacy Commissioner may only approve these guidelines if he/she is satisfied that the public interest in the promotion of the research to which the guidelines relate outweighs to a substantial degree the public interest in adhering to the Information Privacy Principles (which would otherwise make release of the information unlawful).

By contrast, the Bill would allow the release of personal health information from private sector record holders if it is collected 'in accordance with rules established by competent health or medical bodies that deal with obligations of professional confidentiality which bind the organisation' [10.3(d)(ii)]. There is no further definition of who these competent bodies may be.

What consumers have said in the past

During the CHIRP project, consumers consistently emphasised the importance of seeking individual, informed consent to the use and disclosure of their information wherever possible. At the same time, they have acknowledged the need for high quality research and noted that there are sometimes limits on the ability of researchers to obtain consent from consumers for the use of their health information. Where it is practically impossible to seek consent for the use of health information, consumers considered it important that people whose information is used are notified of its use. Consumers further considered that people whose information is used in research should be informed of the outcomes of that research wherever possible.

Arguments for retaining the current draft provisions

Many researchers would argue that bodies that are responsible for dealing with obligations of professional confidentiality are best placed to develop guidelines on how and why organisations can use and disclose personal health information. If there is a requirement for development of guidelines by the NHMRC, this may slow the process considerably, delaying research that could prove to be very important to the community. Further, past experience appears to suggest that researchers generally behave responsibly with the data they collect.

Arguments for tightening the provision

The Bill does not require any independent evaluation of the 'rules' developed by bodies responsible for dealing with obligations of professional confidentiality. This means that there is no requirement for:

- consumer input into the development of rules
- notifying consumers that their information has been used for research
- informing consumers of the outcomes of research where possible, or
- the inclusion of a complaints mechanism if consumers think that their information has been abused.

The possibility of abuse of this system may result in a significant loss of consumer confidence in the confidentiality of the information provided to health professionals. This may result in an unwillingness to provide relevant information or, indeed, to seek access to necessary medical services at all. This is particularly relevant in areas where stigma or discrimination is a problem (eg. Hepatitis C, HIV/AIDS, mental illness).

There is currently little or no way for consumers to complain about the use (or misuse) of their health information, even where they are aware of its use (which is often not the case). This substantially weakens researchers' arguments that they have a good record in the use of information.

CHF position: Collection, use and disclosure of personal health information for research purposes, where obtaining consumer consent is impracticable, should be allowed only under guidelines developed by the NHMRC and approved by the Privacy Commissioner (subject to Parliamentary disallowance). Consumer input should be required in developing these guidelines. This would require the deletion of section 10.3(d)(ii) and strengthening of s95A to require consumer input and Parliamentary disallowance.

Disclosure to administrators and insurers should be notified to the consumer and should only be provided to the extent necessary (eg insurers should not be provided with complete health records when they only require a part of the record relating to a specific illness or injury). With respect to law enforcement, the provisions should only apply to health information where a court order has been obtained.

Consumer access to their own health records

Current access rights

Currently, Australian consumers have no right of access to their personal health records in the private sector, except in the ACT and in private hospitals in NSW. Rights of access in the public sector and in the ACT are outlined below.

For the past ten years, consumers have had a right of access to their records held in the public sector under freedom of information (FOI) legislation. The only reasons that access can be refused under FOI are:

- 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, or
- if giving access would 'involve unreasonable disclosure of information concerning the personal affairs of any person' or may place the community at risk.

In the former case, agencies may form this view by consulting with the practitioner who prepared the record. In NSW, if access is refused on this basis, the record must be provided to a medical practitioner of the consumer's choice to assess whether access should be provided.

If access is refused on the basis of disclosure of information about a third party, the relevant agency must take steps to obtain the views of the person concerned about whether access should be given.

People with health records held in either the public or private sectors in the ACT have a right of access under the *Health Records (Privacy and Access) Act 1997*, which contains similar provisions to the FOI Act. Under the ACT Act, the only exceptions to providing access are:

- where providing access would contravene a court order or a law of the Territory or Commonwealth;
- where the record keeper reasonably believes access would pose a significant risk to the life or the physical, mental or emotional health of the consumer or any other person; or

- where the record is subject to confidentiality restrictions.

Similarly to FOI, where a record holder denies access because of a risk to the consumer there are additional provisions allowing the consumer to nominate a health service provider to whom access must be given by the record holder. If the nominated provider believes that no harm will come to the consumer then that provider can give the consumer access to the record.

Access rights under the proposed Bill

The proposed Bill would theoretically give a right of access to health records held in the private sector. However, in contrast to the ACT legislation, there are a large number of exceptions in the Bill that are not relevant in the health context, but under which consumers' access to their own health information can be refused. For example, record keepers can refuse access if 'providing access would reveal the intentions of the organisation [holding the information] in relation to negotiations with the individual in such a way as to prejudice those negotiations'. This is obviously irrelevant in the health context, but widens the range of excuses from which record keepers can choose in order to justify refusing access.

The existence of this large number of such exceptions in the Bill implies that provisions for consumer access to their health records would remain considerably weaker in the private sector than in the public sector. In this context it is relevant to note that an Australian Law Reform Commission submission² concluded in February 1997 that the (far fewer) exceptions under the FOI Act have been interpreted in a manner which favours refusal of access, and recommended that the Commonwealth FOI Act be amended to strengthen the right of access.

What consumers have said in the past

The principles developed during the CHIRP project clearly show that consumers consider a right of access to their own health information to be very important. Access rights are considered to be crucial in ensuring that the information held about a consumer is correct — three US studies found that around half of all medical records contained factual errors.³ It has also been shown that access to health information can improve health outcomes by empowering the consumer and providing greater certainty and understanding of their condition.⁴

Arguments for retaining the current draft provisions

CHF understands that the AMA considers that the current draft allows consumers too great a right of access to their medical records. Many medical practitioners are concerned that allowing some consumers open access to their records is likely to do more harm than good in terms of increasing the stress on consumers, particularly when there is a possibility that the information will be poorly understood or misinterpreted.

There is also concern in the medical profession that allowing more open access will encourage 'fishing trips' by lawyers looking for grounds for litigation. This and other considerations may lead to practitioners being less open in their written assessments.

Arguments for revising the provisions

As noted above, the general finding with respect to consumer access to their own health records is that it leads to better health outcomes. The available evidence would suggest that the possibility of harm to consumers is generally remote where access is offered in a user-friendly

way.⁵ If health records are likely to be difficult to understand, either because they are complex or because the consumer lacks the skills to understand them, access can and should be provided in a supported way, either through discussion with the practitioner or by providing access to a third party who can understand and explain the information held in the record.

Although there may be some validity in doctors believing that open access will encourage lawyers to 'trawl through' medical records looking for grounds to sue, the available evidence suggests that a great deal of medical litigation could actually be avoided if consumers had better access to their own records. At present, the only way that people outside the ACT or NSW private hospital system can get access to their medical records from the private sector is by starting litigation (requiring the records to be released under discovery). Cornwall (1996) concluded that: 'If people can have access to their records without recourse to litigation, people will less often have a need to litigate' (p. 25).

CHF position: In relation to health information, restrictions on consumer access to their own information should be limited only to the same extent as under the ACT Health Records (Privacy and Access) Act 1997.

Correction of records

As with access provisions, provisions in the draft Bill for correction of health records are largely the same as provisions applying to other information. These do not require that corrections be advised to third parties to whom the data has been disclosed. Neither do they allow for the deletion of information from records, although the Attorney-General's Department has informally advised that the correction principles could be interpreted by the Privacy Commissioner to include deletion.

Arguments for retaining the current draft provisions

Requiring all corrections to be notified to all organisations or individuals to whom the record has been disclosed could prove very costly for businesses. There is no such requirement in the ACT Act.

There is some argument that a complete historical record should be maintained, rather than deleting a part of a record that is found to be inaccurate. If the legislation specifies that part of a record can be deleted, there is a possibility that this would be abused, leading to records being incomplete if information is removed because it is no longer accurate, rather than because it was incorrect at the time of entry.

Arguments for changing the current draft provisions

Obviously, advising third parties of corrections to records that have been disclosed to them is critical where information is being shared for treatment purposes. Not advising researchers of corrections may also compromise research results. It is our understanding that the European Union Data Directive requires advice of corrections to be provided to third parties to whom the data has been disclosed.

Incorrect information remaining on a health record, even where it has been corrected, can lead to stigma and possible discrimination. It is therefore very important that incorrect information in this situation can be removed from the record. The ACT Act expressly forbids record keepers from deleting any part of the record, except where this is done as part of an archival destruction program. However, it does allow for any information that cannot be corrected satisfactorily to be

removed from the record that is in use by the treating team and held on a separate record with very restricted access. This type of provision may be a sensible addition to the Commonwealth legislation.

CHF position: A provision should be inserted requiring corrections to be advised to third parties to whom the information has previously been disclosed. In the case of researchers, this could be restricted to those who have accessed the record in the previous 12 months, reducing compliance costs and accepting the reality that the incorrect information is already likely to have been used or de-identified in such a way as to make correction difficult.

Some allowance should be explicitly made for incorrect information in a record to be either deleted from the record or removed from the record which is in use and held separately.

Enforceability and sanctions

Roger Clarke, a prominent privacy advocate, in his submission to the Attorney General, concluded that '[t]he material made available to date does not make clear how, or even whether, corporate behaviour will be subject to effective oversight, sanctions and enforcement'. As he points out, without these mechanisms in place, 'the legislation would be worse than useless, because it would provide the appearance of action, yet it could and would be ignored by companies, because there would be no scope for legal retribution'.

While the Bill provides some further detail about how the privacy principles and codes will be enforced, it does not appear to offer consumers the ability to seek compensation in a civil action if the Act or relevant code is breached.

What consumers have said in the past

In submissions to the Privacy Commissioner regarding application of the *National Principles for the Fair Handling of Personal Information* to personal health information, the CHF, Health Consumers' Council of WA and the Health Issues Centre highlighted the need for codes and guidelines covering the use and disclosure of health information to be enforceable, with clear sanctions imposed for breaches.

Arguments for strengthening the current draft provisions

Given the poor record of the medical profession (and relevant agencies) in genuinely complying with privacy legislation in the public sector, it is very unlikely that legislation covering the private sector will have any impact at all on corporate behaviour if it is not accompanied by effective enforcement measures. It is important that certainty is provided for both consumers and the health sector by ensuring that their rights and responsibilities, and the results of not meeting those responsibilities, are clear from the outset. Further, the sanctions that are imposed under this legislation need to be meaningful in the context of private practice.

CHF position: It should be made clear in the legislation that all codes and guidelines developed under the legislation have the force of law. Adequate sanctions must be imposed for breaches of the legislation, codes and guidelines. Consumers must have the right to take civil action if they suffer as a result of an organisation breaching its obligations under the Act or relevant code.

Consumer consultation on code development and approval

The Bill does not require industries or sectors to involve consumer representatives in the development of draft codes for approval by the Privacy Commissioner, or indeed to undertake any kind of public consultation during the drafting process. While the Privacy Commissioner is required to be satisfied 'that members of the public have been given an adequate opportunity to comment on the draft of the code' before approval, this could mean consultation is very low level, only at the end of the process, and with the onus on consumer organisations to take the initiative.

What consumers have said in the past

Consumer groups have consistently argued for consumer involvement in the development of codes and guidelines related to the collection, use and disclosure of personal health information.

Arguments for retaining the current draft provisions

The requirement that the Privacy Commissioner be satisfied that there has been adequate opportunity for public comment should protect the interests of consumers in the approval of codes. Requiring consumer input at every step of the process would slow down the development of codes.

Arguments for strengthening the current draft provisions

If consumers are not fully involved in the process of developing codes, one of two things is likely to occur:

- The Privacy Commissioner, under considerable pressure to approve codes, will be satisfied with a short timeframe for public comment at the end of the drafting process. This may result in codes being approved which do not have the support of consumers, leading to a loss of confidence in the ability and willingness of practitioners to protect consumer privacy. In the health sector, this may have tragic results if consumers choose not to access the health services they require due to privacy concerns (for example, people with HIV/AIDS or Hepatitis C).
- The development of codes without consumer input may result in codes being presented to the Privacy Commissioner that consumers find totally unacceptable and which are therefore rejected by the Privacy Commissioner. Organisations would then have to go 'back to the drawing board', but again with no requirement for consumer involvement. This process could result in very lengthy delays in the development of codes in some sectors — an outcome that the health sector cannot afford, given the inadequacies of the principles contained in the legislation to protect health consumers.

CHF position: The Privacy Commissioner should be required to ensure that consumers are involved throughout the process of developing draft codes. In addition, the Privacy Commissioner should be explicitly required to seek public comment on the draft as presented to him/her for approval, including seeking the views of relevant consumer organisations.

Consumers' Health Forum

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15 May 2000

¹ CHF 1998, *Toward the Best Use of Personal Health Information – A Consumer Perspective*.

² Australian Law Reform Commission 1997, *Submission to the Senate Community Affairs Reference Committee on Access to Medical Records*, Submission 26, 24 February.

³ Cornwall, A (Public Interest Advocacy Centre) 1996, *Whose Health Records? Attitudes to consumer access to their health records and the need for law reform*, p. 24. Cornwall quotes the following US studies: Westbrook, J 1988, 'Patient access to medical information, Part 1: a review of the issues', *AMT Journal*, Vol. 18, No. 1, March 1988; and Bergen, L 1988, 'Patient access to medical records: a review of the literature', *AMR Journal*, Vol. 18, No. 3, September 1988.

⁴ For example, Temoshok, L, Heller, BW and Sagabiel, W, 'The relationship of psychosocial factors to prognostic indicators in cutaneous malignant melanoma', *Journal of Psychological Research*, Vol. 29, pp. 139-153.

⁵ A number of other references and a more comprehensive discussion of this issue can be found in Cornwall 1996, pp. 23-25.