


Position on the Health Records & Information Privacy Bill

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Privacy NSW

Position Paper

The Privacy Commissioner's position on the Health Records & Information Privacy Bill 2002

14 June 2002

Preliminary comments

I welcome the introduction of this progressive legislation and I congratulate the Minister for Health on its development. I trust that it will be passed by Parliament without undue delay so that the challenging implementation program can be commenced expeditiously.

I note that the Bill has arisen from the Recommendations contained in the December 2000 report of the Ministerial Advisory Committee on Privacy and Health Information, titled 'Panacea or Placebo' (the MAC Report).

The Ministerial Advisory Committee had as its Terms of Reference the need to provide:

"effective strategies to ensure NSW Health and its partners in health services delivery ensure personal health information is collected, stored and used in accordance with NSW and Commonwealth privacy principles".

The legislation is also designed to facilitate the Government Action Plan for Health, with respect to the introduction of unique patient identifiers and electronic health records.

These are both proposals which have my support. However I am of course concerned that the introduction of both legislation and policy in this area must ensure the most stringent protection of the privacy of health information possible.

I am happy to report that my Office has had extensive consultation with officers of NSW Health during the drafting of this Bill. I note that my Office was consulted on eight consecutive drafts of the Bill.

Developing a workable complaints process was a key part of our discussions, and I am pleased with the results. In particular, effective compliance and audit mechanisms have been provided for in the Bill. I am confident that the complaints and compliance model developed in the Bill is workable, and effectively balances the individual's right to seek redress for breaches

of the HPPs, against the need for health service providers to be confident in the manner in which complaint investigation and other compliance reviews will be handled by this Office.

Areas of concern

Small business exemption

I believe that the Bill should not include the exemption for 'small business operators' (which imposes a \$3M turnover threshold test) - see the definition of "private sector person" in s.4 of the Bill. This test has been lifted from the Commonwealth *Privacy Act*, and it is, I believe, too high a threshold.

Many of the complaints received by this Office relate to medical and health records - and often these complaints relate not to health service providers, but other private sector organisations such as insurance companies, pharmaceutical companies, or the complainant's employer. While most insurance and pharmaceutical companies will be regulated by virtue of the \$3M threshold, smaller employers will not. Perhaps not surprisingly, it is my general impression that "big" businesses tend to actually have better practice in terms of privacy protection and the confidentiality of records than "small" businesses do.

If the Bill is not amended to delete the 'small business' exemption, there will be no protection for the privacy of health information held by businesses with a turnover of less than \$3M, either in the Commonwealth or NSW privacy legislation. This will include health information relating to both customers and staff.

I should also note that in practice, the \$3M turnover threshold in the Commonwealth *Privacy Act* is causing uncertainty for complainants and difficulties for this Office. I can only guess that it also causes delays in the handling of complaints by the Office of the Federal Privacy Commissioner, since investigations are required into whether the respondent is over the \$3M threshold before any other steps can be taken. My Office continues to accept complaints about breaches of privacy not covered by the Federal *Privacy Act*, but we are no position to make assessments about whether an organisation meets the \$3M threshold.

I note that the 'small business' exemption currently used in NSW with respect to discrimination generally under the *Anti-Discrimination Act 1977* is only with respect to employers with five or fewer employees. This is a much clearer and more precise test than a \$3M turnover test, and is also much simpler to determine very quickly, by any party.

In my view the Health Records & Information Privacy Bill ought to be amended to either adopt a clearer 'small business' definition as per the test in the *Anti-Discrimination Act*, or be deleted altogether.

Employment records

I disagree in principle with the exclusion (from the definition of 'personal information') in s.5(m) and (n) for "employee records" (with respect to the private sector) and "information or an opinion about an individual's suitability for appointment or employment as a public sector official" (with respect to the public sector).

While I note that this is consistent with current NSW and Federal laws (that is, the PPIP Act excludes "information or an opinion about an individual's suitability for appointment or employment as a public sector official"; the Federal *Privacy Act* excludes "employee records"), I note that no issue of Constitutional inconsistency is raised should the HRIP Bill not include these exemptions. As I understand it, the rationale behind these two exemptions is so as not to introduce an "unreasonable impost on business".

I do not find this a persuasive argument in favour of a scheme which fails to protect health information held by employers, given the very sensitive nature of health information and its possible misuse in the employment context.

This failure to protect particularly vulnerable people is a great disappointment to me. All

employers should be obliged to treat health information they hold about an employee (such as the nature of a disability, their history of illnesses and other reasons for sick leave) in accordance with the HPPs. A failure to do so may in any event render the employer liable to allegations of disability discrimination under s.49D of the *Anti-Discrimination Act 1977*.

The very first judgment from the Administrative Decisions Tribunal under the PPIP Act turned on the scope of the exclusion provided to "information or an opinion about an individual's suitability for appointment or employment as a public sector official". In *Y v Director General, Department of Education & Training* [2001] NSWADT 149, President Kevin O'Connor found that such information need not be limited to selection, promotion, disciplinary or involuntary retirement processes [para 34]. It could include management reviews of work practices, work arrangements, and performance [para 35].

This judgment highlighted the very wide scope of the current exemption under the PPIP Act, and my belief that the exemption is inappropriate extends now to the HRIP Bill as well as the PPIP Act.

HPP 10 (use) and HPP 11 (disclosure)

HPP 10(1)(b) and HPP 11(1)(b) allow health information to be used / disclosed if

"the secondary purpose is directly related to the primary purpose and the individual would reasonably expect the organisation to use/disclose the information for the secondary purpose".

I believe that this test requires a third element, being "and there is no reason to believe that the individual would object", or at least "and the individual has not expressly objected".

HPP 15 (health records linkage system)

I am concerned that HPP 15 does not allow for retrospective application. That is, my understanding is that HPP 15 will only apply to attempts made after the legislation's commencement date to include health information on a health records linkage system.

I would ideally like to see instead a mechanism whereby any *existing* health records linkage systems could be brought into compliance with HPP 15. For example, the Bill could allow organisations until a set date (such as commencement date) to ensure that they have express consent from their clients, or otherwise withdraw their clients from the system.

An alternative and compromise position would be a mechanism which provides that on the date of the first visit (from existing patients) after the legislation's commencement date, the patient must have the system explained to them, and will only remain on an existing system if they expressly consent.

Also in relation to HPP 15, I am concerned that the definition of "health records linkage system" relates only to linkages "held by different organisations". "Organisation" is defined to mean "a public sector agency or a private sector person". A "private sector person" includes "a body corporate".

My concern is therefore with the possibility of vertical integration of different health services within the one "body corporate". If different health services are all part of the one "organisation" (eg. the one body corporate) then they will be effectively exempt from HPP 15.

I also note that the regulation-making power in s.75(2)(e) allows "related bodies corporate" to be prescribed as one organisation for this purpose. I would oppose any move to allow different organisations which are related bodies corporate to be exempt from compliance with HPP15, by reason purely of their inter-relationship.

Genetic information

Section 6(d) defines certain types of genetic information as "health information". Genetic information which is predictive or diagnostic in nature will hence be included in the definition of "health information".

Furthermore it is my understanding that DNA information collected on behalf of an employer or an insurer will be collected in the context of providing a health service (ie. the service being provided by the doctor or pathologist), and hence *will* be caught by the above definition, and therefore will be regulated by the HRIP Act.

However it is my understanding that under this provision, genetic information which is not predictive or diagnostic, but is information about *identity*, is *not* "health information". This latter group will include information generated or collected in the course of forensic tests on crime scenes and criminal suspects, paternity tests, and tests for the purposes of identifying missing persons.

The effect of this is that genetic information which is information about *identity* (rather than about *health*) will remain covered by the PPIP Act's definition of "personal information", and therefore any use of such information by the public sector is in theory regulated by the PPIP Act. For example, DNA collected by police from victims, relatives of missing people, criminal suspects and prisoners is already covered by the PPIP Act (at least in relation to the administrative functions of the police), except where exempted because other more specific legislation covers it.

However private sector use of DNA for *identity* information - such as paternity tests - will not be regulated by either the PPIP Act or the HRIP Bill. This is an emerging area which requires regulation of its privacy-invasive practices.

There are very significant issues which arise in relation to identity testing (especially paternity testing) by unregulated or unscrupulous commercial operators in the private sector. The social consequences for children, families and the community generally can be devastating. I am strongly of the view that genetic samples held, collected or used for identification purposes should be expressly covered, in this legislation at the very least, in relation to purposes other than law enforcement.

Application of the FOI Act

Section 22 of the HRIP Bill effectively replicates s.20(5) of the PPIP Act. This section is extremely ambiguous as to how exactly the access and correction provisions of the PPIP Act relate to the Freedom of Information Act.

The Attorney General had approved cognate amendments to s.20(5) of the PPIP Act as part of the package of the HRIP Bill, but I am concerned that Parliamentary Counsel was unable to resolve the ambiguity satisfactorily, and hence no amendment is proposed at this stage. I believe that s.22 of the HRIP Bill will cause just as much confusion for public sector agencies as s.20(5) of the PPIP Act does now.

I hope that the Attorney General's Department and NSW Health can continue to work together to determine an appropriate amendment in the near future.

Conclusion

I am pleased that my Office has been extensively consulted on the development of this Bill. I do however maintain my concerns about:

- the lack of adequate protection afforded employees in both the public and private sector,
- the lack of adequate protection afforded employees and customers of businesses with less than a \$3M turnover,
- the adequacy of HPP 10 and HP 11 with respect to the 'direct relationship' test,
- the need for some retrospective application of HPP 15 to bring existing systems into compliance with the requirement for express consent, and

· the need to include DNA data used for identification purposes within the provisions of the legislation.

Nevertheless I reiterate my strong support for passage of the Bill in this current parliamentary session. Steps need to be taken now to prepare for things such as the introduction of a NSW system of electronic health records.

I would be remiss if I did not draw the attention of the Parliament to the fact that Privacy NSW remains significantly under-funded to discharge the full range of the responsibilities which will be imposed on this Office by this legislation. I trust this issue will be addressed by the Government if it is serious about making this legislation work.

Chris Puplick
PRIVACY COMMISSIONER

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