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The Secretary
House of Representatives Standing Committee
on Legal and Constitutional Affairs
Parliament House
Canberra ACT 2600

By Facsimile 02 6277 4773 6 pages

12 May 2000

Dear Sir,

Inquiry into Privacy Amendment - (Private Sector) Bill 2000

A discussion paper has recently been sent by the Consumer Health Forum of Australia to its member organisations of which the Wollongong Health Consumer Advisory Group is one. That paper asked for a response on the use of Information Technology and a central data base which would store details of current medication prescriptions for identified persons. Such a scheme has many advantages to avoid inconsistent and dangerously conflicting medications; it may even discourage doctor shopping; but it also raises issues of confidentiality and privacy.

To explain our credentials, here is a brief statement on the Wollongong Health Consumers' Advisory Group: Our group is one of six health consumer groups in the Illawarra, established with the support of the Illawarra Area Health Service in 1994/95, to raise consumer issues with the Illawarra Area Health Service, and with any agency, and with government. The groups meet monthly for free discussion on matters of health with community health staff, hospital staff and general practitioners. The groups are open to members of the community. A good relationship has developed between members of the groups and health service providers in the Illawarra.

The Wollongong Health Consumers Advisory Group discussed the matter if information technology and the medication data base on 21 March 2000, and since it has relevance to privacy issues, I quote part of the minute [somewhat edited]:

> To avoid conflicting or excessive medication, the database is to be accessible by doctors, hospitals and pharmacist. A case was given by a member who had to coordinate his own medication given by five providers when there is no single database. Members expressed the need for limited access and security so that access was entirely for the benefit of the consumer, and the database could not be

accessed by commercial interests or for unethical purposes. Furthermore, this agreement by members is limited to 'prescribing and medication management' and is not an agreement on any centralised database on patients' medical records generally. WHCAG favours the use of information technology in prescribing and managing medication with the limitations and precautions stated above, and overseen by an independent privacy watchdog.

At that meeting, one alert member knew of the Government's proposal to amend the ***Privacy Act*** 1988. Since then, as secretary of the group, and after seeing a notice of the proposal in the press, I have obtained the ***Privacy Amendment (Private Sector) Bill 2000*** from your office; but since tonight is the last opportunity to make a submission, our group has not had the opportunity to study the amendments against the ***Act***.

After learning today that tonight is the closing date, this response is as much as we can give. You must fit our non-legal opinions and comments into your deliberations.

A better medication management system for Australia through Information Technology and a central data base.

We take this matter first because of its obvious implications on privacy as one example against which the value of privacy legislation can be judged, and because it represents the views of a community group.

Who will have access to the records?

- The patient.
- The patient's GP (the patient might have been doctor shopping).
- The patient's dentist (who expects patients to list any current medication).
- The patient's private psychiatrist would be included in the term ***doctor***. Who else should be included in the term ***doctor***? What professions have been left out and so distort the record? Dermatologists? Nutritionists? Alternative medicine?
- The carer. The carer's role is not always recognised by practitioners who assume that some magic will care for a person after discharge from hospital. The patient may not be competent to manage medication; the carer must be competent and must be informed.
- The community pharmacist (an 'outreach' pharmacist attached to Community Health who checks on medication of discharged patients, particularly valuable for elderly NESB patients and families).
- There are other players in the field: The emergency ward when a patient has turned up without identification; the out-of-hours visiting medical service; the ambulance service (allergies).

The Privacy Act 1988

We note that in Part VII of the Act, **privacy advisory committee** s.82(7)(b):

> [of the appointed members] at least one shall be appointed to represent the general community interest relating to social welfare.

But those over the age of 65 are not eligible.

It is a strange constraint in an era of anti-discrimination and the view that the elderly have something to contribute; particularly the elderly who are carers for spouses and for the many who care for a person with a disability in their homes.

The Privacy Amendment (Private Sector) Bill 2000

A perusal of this ***Bill***, and of other information, raises some serious concerns for consumers of health services.

a pre-election commitment by the Government to extend privacy regulation to the private sector has been weakened. A reason given is compliance cost; a reason which panders to any private industry that has a responsibility to shareholders or to self; in any event to a responsibility far removed from any benefit or protection of the individual consumer of heath services

It is now not clear how privacy provisions apply to a private contractor (or subcontractor, or sub-subcontractor) under contract to a government department such as NSW Health or any other. This at a time when contracting to the private sector for services traditionally provided by government has become the flavour of the day. What are the rights of the individual caught up in the terms of any contract? What rights of redress and what control would he or she have over private information and its security?

We also understand that services or contractors can be excluded from the provisions of the ***Act*** (amended as proposed) by ***regulation*** rather than by legislation. It becomes easy for the Minister to make dramatic changes to compliance, not merely to one contractor, but to a whole class of contractors or industry (self or shareholders' interest), without any reference to Parliament. An eventual review by Parliament will do nothing to correct the situation; indeed it cannot be corrected.

We also understand that the process of privacy compliance will be largely by self-regulation which, even if supervised by the Privacy Commissioner, will go largely unchallenged unless the conditions for compliance are strictly laid down and are uniform, unambiguous, and enforceable. For the benefit of the person whose information (liken it to intellectual property) is at stake; security can only be achieved by uniform, unambiguous, and enforceable legislation; not by legislation made variable by ***regulation***.

The individual already has no right of access to his or her medical records when these re held by a private practitioner. The ***Bill*** does nothing to remove that barrier; on the contrary, the ***National Principles*** allow for all sorts of reasons (which will not be overseen by an outsider) to withhold information.

3 Objects [p.2]

(b)(iii) recognises important human rights and social interests that compete with privacy including the general desirability of a free flow of information (through the media and otherwise) and the right of business to achieve its objectives efficiently.

This rings alarm bells in the mind of anyone who wishes to protect the privacy of his or her medical records and any other information (medical or not) which finds its way into those records. That should not become the subject of a free flow of information; and business must not be given the right of access to such information "to achieve its objectives efficiently" if such information can - however small the risk - identify the individual. There are businesses, whose business it is "to achieve its objects efficiently", that will search for information for the benefit of its shareholders, and to the detriment of the individual. The insurance business and its shareholders should not be the beneficiaries.

If the confidential medical (or other) information identifies and alleges some criminal activity or intent, perhaps to defraud, then it is not the business of anyone other than the law to have access to the information; and then only with strict observance of legal authority.

11 Subsection 6(1) [p.5]

contracted service provider*:** This covers (a) ***contractors and (b) ***subcontractors***. Knowing of the interpretation of legislation which is not always precise, and the use made of any lack of precision by guilty parties, does ***subcontractor*** cover also the next and more remote person, the ***sub-subcontractor*** and beyond. What legal loopholes will the ***Bill*** open for abuse?

27 Subsection 6(1) [p.10]

When considering this, you might have in front of you the ***Mental Health Act*** 1990 (NSW) s.11.

Where is ***health information*** defined? Whereas a condition such as a diagnosed or a suspected disorder as seen by a health professional is ***health information*** recorded by that professional, is a condition that might be suspected by, or known to, an insurance company ***health information***; and is the company that holds the information bound by privacy principles?

32 Subsection 6(1) [P.11]

Does this answer my concerns on **11 Subsection 6(1)**?

6A Breach of a National Privacy Principle (and similar later) [p.12, 13]

(2)(b): This is part of an 'and'-'and' section; but the application and meaning of ***inconsistent*** cannot be judged without the ***Act***. In the time allowed, we have had no chance to peruse it.

13A Interferences with privacy by organisations [p.28, 29]

(1)(b)(ii): We question "***not*** bound"

16B Personal information in records [p.32]

(1) We question (without having had the opportunity to look thoroughly at the ***Act***): "or a generally available publication."

16C Application of National Privacy Principles [p.33]

(3) Why do Principles 2 and 6 apply "only in relation to personal sensitive information collected ***after*** the commencement of this section."

What is the logic? Does it protects the individual?

16D Delayed application of National Privacy Principles to small business [p.33]

Since ***small business*** may include health practitioners, the same comments apply here as to the previous section.

95A Guidelines for National Privacy Principles about health information [63]

Uncertainty whether confidentiality by way of non-identification is adequately covered under any section of the ***Act*** and any ***guidelines*** which permit disclosure of information for any purpose, statistics, public interest, etc. Far more important, however, is the converse: the force of the ***Act*** to ensure that the identity of individuals is protected.

(3)&(5) ***Public interest test***

A person carrying an infectious disease will be identified by medical practitioners to other health providers on the basis of ***the need to know***. That person may, under very limited public interest considerations, be identified publicly.

Schedule 3 - National Privacy Principles [p.66]

1 Collection [p.66, 67]

1.3 We question "***from*** the individual": What if the information is obtained from another party?

1.4 That seems to leave the door wide open. Why not turn the onus on the collector to prove that to collect information from the individual is not reasonably possible. The collector must also prove that the information obtained from another is accurate, up-to-date, and has been legally obtained according to the ***National Principles***; if that cannot be shown, the information should be declared of no value, and not collected; or if collected, it should be destroyed.

2 Use and disclosure [p.67]

2.1(b) Are there any substitute consent provisions (eg ***Guardianship Act*** 1987 (NSW) for people unable to give consent? Yes! later in 2.4.

2.1(c) Whether information is sensitive or not is not always clear and needs judgement. The knowledge that I overindulge in something or other may, if given to another or made public, destroy my reputation and cause me immeasurable harm.

2.1(c)(i) Very loose and open to abuse. There is no line of defence. The agency seeking the information goes ahead without the intervention of a third party. The onus of proof that seeking consent is impracticable should be on the collector. What are the penalties if information has been obtained improperly?

2.1(c)(ii) Triple negatives and incomprehensible.

2.1(c)(iii) Also triple negatives. If translated, this means that the onus is on me to ensure that I do not receive something that I do not want. Granted that this is probably the situation now, it does not mean that it should be so.

[p.68]

2.1(d) Where are the provisions for non-identification?

2.1(d)(i) Similar to 2.1(c)(i); also 10.3(c).

2.4(b) Yet some psychiatrists will still hide behind the ***Mental Health Act*** 1990 (NSW), and will not speak with, consult, or give information to, the carer.

10 Sensitive information [p.75]

10.1(a) Presumably substitute consent provisions apply.

We commend this submission to you for your consideration.

Yours sincerely,

Peter Hutten
Secretary