

13 August 2009

Ms Rosemary Huxtable
Acting Deputy Secretary
Primary and Ambulatory Care Division
Department of Health and Ageing
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Dear Ms Huxtable

Healthcare identifiers and privacy: Discussion paper on proposals for legislative support

The Public Interest Advocacy Centre (PIAC) is an independent, non-profit law and policy organisation that works for a fair, just and democratic society, empowering citizens, consumers and communities by taking strategic action on public interest issues.

PIAC identifies public interest issues and, where possible and appropriate, works co-operatively with other organisations to advocate for individuals and groups affected.

PIAC is responding to the *Healthcare identifiers and privacy* discussion paper by outlining particular and immediate concerns about the content of the discussion paper and the policy processes referred to in the paper.

PIAC's concerns about the policy process are:

- That there has been a failure to release completed Privacy Impact Statements (PIAs) commissioned by the National e-health Transition Authority (NEHTA). Without the PIAs, PIAC and other organisations and individuals cannot appropriately respond to the contents of the discussion paper.
- That the proposed national legislative framework for health privacy could be deferred until after the 'Health Identifier Service' is in place (governance issues).
- The status of Part B of the Discussion Paper.

PIAC does have other major concerns arising from the content of the discussion paper. These concerns are summarised below:

- The proposal allows for use or disclosure of sensitive information, including health information, when there is 'threat to an individual's welfare'. PIAC considers that such a broad and vague exception to accepted privacy principles has the potential to totally undermine consumer confidence in the maintenance of confidentiality in e-health and other health records.
- Under the proposals, an individual will not be able to get Medicare benefits without using a verified IHI.

These concerns are addressed in further detail below.

Privacy Impact Statements

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The Privacy Commissioner and the Australian Government have previously been very clear on the benefits and importance of PIAs in assessing government proposals that have potential impacts on individuals' privacy:

The over-arching benefit of a PIA is that it allows agencies to identify and analyse privacy impacts during a project's design phase, which in turn assists agencies to determine the appropriate management of any negative privacy impacts and thereby avoid costly or embarrassing privacy mistakes. Dealing with privacy impacts can be challenging for agencies.¹

The Privacy Commissioner in August 2008 said in commenting on the importance of PIAs in ensuring privacy protection and encouraging community confidence in individual electronic health records, said that PIAs 'will be critical to identifying the scope of enabling legislation and privacy protections that need to be built into the operating system'.²

NEHTA has also been very clear in its commitment to independent assessment of privacy issues through PIAs:

NEHTA is committed to the internal and external (independent) privacy impact assessment (PIA) of the HPI, IHI and Shared EHR initiatives. A PIA is a process designed to identify and address the privacy issues of a particular initiative. It is a risk management tool, focused on ensuring that an initiative complies with privacy legislation and meets broader community expectations in relation to privacy. This is particularly important in a national context where multiple privacy regimes apply – all of which broadly cover the same issues but with sufficient differences and breadth of coverage to significantly increase the complexity of privacy risk assessment and management.

Therefore, the PIA process will be an important tool for assessing whether additional legislative support will be required to deliver the HPI, IHI and Shared EHR building blocks. Independent preliminary PIAs of the HPI, IHI and Shared EHR have been commissioned by NEHTA to:

- identify key risks to privacy which need to be addressed by each initiative; and
- recommend how privacy should be further considered in the detailed design phases of the IHI, HPI and shared EHR initiatives.³

PIAC agrees that PIAs are a vital tool to assess privacy impacts of government programs and proposals and to ensure that community expectations in relation to privacy are met.

A Preliminary PIA was undertaken by NEHTA in early 2006. It appears not to be publicly available. PIAC notes the recent reference in *The Australian* to a PIA conducted by Galexia in 2006.⁴ PIAC understands that further PIAs were commissioned by NEHTA on UHIs in early 2008 and on IHIs in January 2009. As far as PIAC is able to ascertain, none of these have been made publicly available. The failure to make PIAs available publicly is inconsistent with the purpose of meeting community expectations in relation to privacy and with the approach recommended by the Privacy Commissioner.

PIAC requests that all Privacy Impact Statements relevant to the Discussion Paper be immediately made public to enable a more fully informed community discussion and consultation process.

Governance Issues

PIAC notes and supports the recommendations of the Privacy Commissioner in her August 2008 Report,

¹ Office of the Privacy Commissioner, *Australian Government Privacy Assessment Guide* (2006) 5.

² Office of the Privacy Commissioner, *Consultation on the Privacy Blueprint for the Individual Electronic Health Records* (2008) 5.

³ National e-health Transition Authority, *NEHTA's Approach to Privacy Version 1.0* (2006) [7] <www.nehta.gov.au/component/.../88-nehtas-approach-to-privacy-v10> at 13 August 2009.

⁴ Karen Dearne, 'Secret report reveals e-health ID findings', *The Australian*, 4 August 2009.

PIAC particularly supports the recommendation that: 'It is essential that a national IEHR system be accompanied by specific enabling legislation'.

The Privacy Commissioner stated that this legislation could usefully provide for:

- identification of an entity with clear responsibility for management of the IEHR and the health information held in it
- authorised and permitted information flows
- prohibitions on specific uses and disclosures of IEHRs to avoid function creep
- provisions for managing secondary uses
- specific sanctions and remedies for privacy breaches
- transparent and accountable governance mechanisms
- requirements for unique health identifiers in the IEHR
- minimum terms and conditions for participation in the IEHR and
- uniform complaint-handling mechanisms.

PIAC supports this proposition and maintains that the above list represents minimum requirements to establish a consumer-focused e-health system.

PIAC also endorses the Privacy Commissioner's support for the use of sensitivity labels as a feature of a national e-health system, outlined in the same paper⁶, and strongly supports the principle, also supported by the Privacy Commissioner, that there must be individual control of personal health information held as part of an e-health system. PIAC also advocates that any e-health system must be 'opt-in', rather than 'opt-out'. All these important safeguards must be entrenched in legislation as part of the governance of e-health in Australia.

NEHTA also recognises the crucial importance of governance issues

While not a privacy principle in its own right, the governance arrangements developed for the UHI Service are both an essential component of the UHI Service and a means of ensuring ongoing engagement with the privacy tenets developed by NEHTA for national e-health infrastructure involving the collection and handling of personal (including health) information. Development of a suitable e-health governance model is a key dependency for privacy compliance and will be critical in establishing the legal connections (and therefore risk allocation) between not only the Data Sources and the UHI Organisation but also between the users of the personal information and the UHI Organisation. Governance issues will require analysis of policy issues and also of legal structures.⁷

PIAC is concerned by the proposal in the discussion paper that legislation about healthcare identifiers will proceed before a new national privacy framework is in place. PIAC is particularly concerned with this proposal because it seems to run counter to the Privacy Commissioner's persuasive arguments about the need for specific legislative and governance regimes for e-health.

PIAC recognises the complexity of existing legislative protection of information privacy in Australia. However, given that there does not seem to be either political or community opposition to the principle of electronic health records, it would seem possible, through the COAG processes for the states and territories to either refer power in this area or agree to uniform legislation.

⁵ Office of the Privacy Commissioner, above n 2, 4.

⁶ Privacy Commissioner, above n 2, 11.

⁷ National e-health Transition Authority, *Privacy Blueprint – Unique Healthcare Identifiers Version 1.0* (2006) [20] <www.nehta.gov.au/.../148-privacy-blueprint-unique-healthcare-identifiers-v10> at 13 August 2009.

Alternatively, although PIAC accepts that there are strong arguments that a national e-health system will improve patient safety, there are stronger arguments that unless there is consumer confidence in the system, then patient safety will be not strengthened but threatened. If consumers are not confident in the confidentiality and security aspects of any e-health regime, they will not participate, or worse not disclose vital information or simply not tell the truth to protect their privacy. Therefore, PIAC submits, if implementation of e-health strategies has to be deferred until a new comprehensive national privacy framework is in place, as well as specific provisions for e-health, then this is preferable to rushing into an e-health scheme without the appropriate governance mechanisms in place.

Status of Part B (Proposed changes to Unified Privacy Principles)

PIAC raises questions above about the status of the proposed changes to the Unified Privacy Principles (UPPs) in Part B.

It is not clear whether what is proposed in Part B is the Government's response to the Australian Law Reform Commission (ALRC) Report of its review of privacy law in Australia, or whether it is a submission from one part of Government to another part of Government about the ALRC report. It is very unclear who will be making the final decision regarding the UPPs in relation to health information. PIAC is also concerned to get a clarification from your office about what is meant by the discussion paper at page 3 when it refers to 'the clear role for Health Ministers on overseeing health information requirements, an appropriate balance in health privacy regulation and privacy protections...'?

PIAC does not object to the participation by Health Ministers in discussions about health information and the UPPs. What would concern PIAC however would be if the outcomes of extensive consultation processes put in place by the Government in responding to the ALRC report, which extensively dealt with and considered issues of health information privacy, were abandoned and set aside to the detriment of privacy protections for health consumers.

PIAC does not necessarily oppose every change suggested in Part B, but nevertheless submits that the processes that lead to all law reform should be open and transparent. PIAC has previously praised the Government on its willingness to seek input from stakeholders prior to developing legislation in response to the ALRC report.⁸ However, it remains unclear how the proposals in part B of the paper fit in with the Government's previous open approach on this question. In particular, it remains unclear how the propositions in Part B are linked with the recommendations on healthcare identifiers in Part A.

Is it the Government's position that the proposed changes to the UPPs set out in Part B alone provide sufficient protection for consumers regarding privacy and security in a future e-health system? If so, then PIAC would strongly disagree for the reasons stated above.

PIAC certainly has no objection to the proposition in Part B that specific health privacy provisions be included in the UPPs and not in subordinate legislation. PIAC, in its submission regarding the proposed UPPs earlier in 2009, clearly stated that its position was that 'there should be no scope for regulatory provisions that derogate from the UPPs'.⁹

PIAC also submitted that 'for clarity and accessibility purposes any ... derogations [from the UPPs] should be required to be included in the Privacy Act immediately following the UPPs and clearly identified as an exception to the UPPs'.¹⁰

Collection, use or disclosure of sensitive information

PIAC has great concern about Proposals 25 and 29.

⁸ Robin Banks, *Unified Privacy Principles – the right way ahead* (2009) 3.

⁹ Ibid.

¹⁰ Ibid, 2.

This is very broad and would allow the virtually unfettered collection and use and disclosure of health information to another health professional/ organisation without the consent of the patient. One could ask, 'when would a health professional (or anyone else) openly seek to use or disclose health information unless he or she thought it in the interests of the patient's welfare?'

PIAC in its submission on the UPPs expressed concern with the proposed absence of the requirement of imminence of threat from UPP 2.5(c):

As drafted, UPP 2.5(c) may allow an agency to collect sensitive information about a person without their consent on the basis that this information might be necessary to prevent a serious threat to their life or health at some time in the future. The requirement that a threat be imminent as well as serious indicates that there must be some degree of urgency and, as a result of that urgency, limited access to other mechanisms available to prevent the threat eventuating.

In PIAC's view, the requirement of imminence operates as an important safeguard. If the exception can be triggered simply when a threat is 'serious' it could be used to justify collection of sensitive information without consent on the basis that the information could prevent some future serious harm.

Given this position, PIAC is greatly alarmed that Proposals 25 and 29 could lead to a further erosion of the principles that underpin UPPs 2.5 and 5.

PIAC is particularly concerned that the argument for Proposal 25 is somehow based on the need to protect disadvantaged groups; and the homeless are cited here as examples.

PIAC strongly submits that it is members of disadvantaged groups, such as the homeless, who are the most vulnerable in our society, and therefore more in need of protection of their personal information. PIAC cannot see any justification to allow sensitive information, including health information, to be used and/or disclosed in situations where the individual is able to exercise express and informed consent. Only in imminent life-threatening situations, can it be said that otherwise competent individuals may be unable to exercise express and informed consent within the timeframe available. Even if the individual does not have the mental or physical capacity to provide that consent, only when there is there an imminent life-threatening situation can it be argued that substitute decision-making mechanisms cannot be exercised or put in place within the time available.

Society has moved away from the situation where we accept that in every situation, 'doctor [or any other health professional] knows best'. PIAC strongly advocates that for e-health to work, the consumer must be able to trust that their health records remain confidential and that they are in control of who accesses their confidential health information.

The Government, including statements by the Prime Minister, has always maintained that consumers will have control in what will be held in Australian e-health records. The disadvantaged and vulnerable in society are more likely than others to be distrustful of consenting to their health information being stored electronically. If their confidential records can be disclosed without their express and informed consent, simply on the basis that someone arbitrarily decides that it is in the interests of their welfare to do so, then there will be potentially no confidence, and therefore little participation, in e-health systems from these vulnerable groups.

It is highly likely that all consumers will react to such a proposition in the same way. Giving health professionals and health organisations the power to disclose information simply on the basis of their subjective belief that it is in the welfare of the patient, without seeking express and informed consent to disclose that information, has the potential to totally undermine any government attempt to gain public confidence in e-health systems, which greatly increase the access of health professionals and health providers to person health records.

Access to Medicare Benefits

It was confirmed in recent public consultations in Sydney and Melbourne that unless the unique health care identifier can be married to a name on an individual Medicare card, the individual will not be entitled to claim under Medicare or to be bulk billed for the service.

The discussion paper states (at page 35) that individuals can continue to exercise anonymity and pseudonymity but this was clarified at the consultations to be subject to the caveat above.

In other words, the options of pseudonymity and anonymity can only be exercised by those who can afford to pay for their healthcare and forego their rights to universal health care under Medicare. This does not represent choice or patient control in any way.

Although what is suggested in the Discussion Paper may not change the way Medicare currently operates, it does beg the question why this position was not made clear in the Discussion Paper. If the Government is serious about maintaining the anonymity and pseudonymity principles, a future system that intermeshes e-health with the universal Medicare Scheme, then provision should be made so that the people the Discussion Paper rightly describes as 'vulnerable individuals (such as victims of domestic violence etc)' can still access universal health care without making themselves even more vulnerable. [national id card]

Conclusion

Part A of the Discussion Paper asks questions and seeks feedback about the specifics of the scheme proposed that would have been addressed by the PIAs prepared by NEHTA but that have, for undisclosed reasons, not been publicly released.

PIAC urgently requests a response indicating when those PIAs will be made publicly available and that the time for public response to the Discussion Paper be extended to allow consumer and community groups to digest the findings of the PIAs and then provide informed responses to the very considerable changes in the way health care operates in Australia that are proposed in the discussion paper.

Yours sincerely



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