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# **Review of Australian Privacy Law Discussion Paper 72**

**September 2007**

## **Supplementary submission to the Australian Law Reform Commission – Health Services**

**January 2008**

### **DP 72 Part H – Health Services and Research**

Our submission on Chapter 58 – Research - was included in our main submission on ALRC DP72 dated 30 December ('main submission' hereafter).

#### ***Chapter 56 – Regulatory Framework for Health Information***

##### **National Consistency**

The ALRC has provided in Table 56-1 a very helpful listing of the current level of health privacy regulation, both legislative and administrative. However, this level of analysis is not sufficient to determine the real gaps. Mention is made in the text that there are differences at the concept or rules/principles level, but those differences are not comprehensively identified. It would be beneficial to analyse the commonalities to determine where gaps currently exist and determine if the proposed national consistency would be at the least or the highest common level.

The APF submits that any new national standard should represent the highest common standard. Areas of comparison mentioned in DP72 are: coverage, privacy principles, standards, and sector. We submit that other areas of comparison should be complaints handling, compensation, penalties, and consent mechanisms. In these latter respects some of our comments on other parts of DP72 in our main submission are relevant, and we urge the ALRC to take them into account in any further consideration of these issues in a health privacy context.

56.17 mentions research. However, research and researchers are not addressed in the Introduction to the section. Research activities are often an area of contention because the person whose information is involved is not necessarily the direct beneficiary of the use of their information. The Foundation suggests that separate analyses be conducted with regard to, firstly, use of health information for direct health benefit to the individual

and secondly, for health administration, and, thirdly, for research purposes including in academic, public health, or experimental treatment contexts.

The ALRC appears to remain in favour of the recommendation in its earlier joint report with NH&MRC on genetic information for a single set of privacy principles for the handling of all health information. We submit that this approach may not meet the needs of any of the stakeholders, and most importantly, the concerns of the consumers for whom these privacy protections exist in the first place. There is a serious risk that legitimate claims for privacy may be undermined by the claims of administrators and researchers. Those claims should not be given equivalent weight to those of health care of direct benefit to the individual.

While the Foundation generally supports national uniformity of privacy protections, we submit that the same principles should apply to use of personal information in the different contexts of health care, health administration and research ONLY IF the *highest common* standard of protection and of recourse for the consumer are available for all such information uses.

We note that health privacy could be expected to be one area where the generic proposal to agree on a list of specific ‘non-excluded matters’ would be likely to apply (ALRC DP72 Proposal 4-3 – see paragraph 56.39). This would preserve the ability of the States and Territories to set particular standards for the use of health information, and would seem to undermine the movement towards uniform principles.

**Proposal 56-1** *The Privacy Commissioner should consider delegating the power to handle complaints under the Privacy Act in relation to interferences with health information privacy by organisations to state and territory health complaint agencies.*

The Foundation would only support this proposal, to allow the Commissioner to delegate complaints handling to state and territory health complaint agencies, if it incorporated a guarantee of complaint mechanisms and remedies that were no less generous than the default Privacy Act standard (see our submission on Part F of DP72 – specifically on Proposal 45-3).

## **Separate Set of Health Principles**

**Proposal 56-2** *Health information should continue to be regulated under the general provisions of the Privacy Act and the proposed Unified Privacy Principles (UPPs). Amendments to the proposed UPPs that relate specifically to the handling of health information should be promulgated in regulations under the Privacy Act – the Privacy (Health Information) Regulations.*

**Proposal 56-3** *The Office of the Privacy Commissioner should publish a document bringing together the proposed UPPs and the amendments set out in*

*the Privacy (Health Information) Regulations. This document will contain a complete set of the proposed UPPs as they relate to health information.*

**Proposal 56–4** *The Office of the Privacy Commissioner – in consultation with the Department of Health and Ageing and other relevant stakeholders – should develop guidelines on the handling of health information under the Privacy Act and the Privacy (Health Information) Regulations.*

We accept that privacy of health information is a special case, requiring special attention. It is very disappointing that the attempt to address these special needs through the AHMAC Working Group has proved so ineffective – and that after seven years work the draft National Health Privacy Principles (NHPP) have still not been released for public scrutiny.

We support Proposals 56-2 to 56-4 subject to our general reservations about the ‘hierarchy’ of regulation and about Privacy Commissioner guidance, as set out in the Introduction to our main submission.

## **Electronic Health Information Systems**

**Proposal 56–5** *The National Unique Healthcare Identifiers (UHIs) scheme and the National Shared Electronic Records (SEHR) scheme should be established under specific enabling legislation. The legislation should address information privacy issues, such as:*

- (a) the nomination of an agency or organisation with clear responsibility for managing the respective systems, including the personal information contained in the system;*
- (b) the eligibility criteria, rights and requirements for participation in the UHI scheme and the SEHR scheme by health consumers and health service providers, including consent requirements;*
- (c) permitted and prohibited uses and linkages of the personal information held in the systems;*
- (d) permitted and prohibited uses of UHIs and sanctions in relation to misuse; and*
- (e) safeguards in relation to the use of UHIs; for example, that it is not necessary to use a UHI in order to access health services.*

We agree that E-health information systems raise specific challenges which should be addressed in specific authorising legislation.

The Foundation believes that despite a great deal of consultation, both the current legislative underpinnings and the current proposed information design strategies from NEHTA do not adequately support the roll-out of the ubiquitous e-health program that is being proposed. We agree that specific legislation is required to address the increased risks associated with e-health projects of this scale and scope, and in particular any proposed assignment of a Unique Health Identifier to almost all Australians.

We believe Proposal 56-5 is dangerously premature, and implicitly makes pre-judgements about matters that are seriously contentious.

Centralised health information systems, and universal identifiers, pose an unacceptable risk to the privacy of health care data. Moreover, as the many failed attempts show, a monolithic health data system is doomed to failure (both because it involves massive diseconomies of scale and scope and because it excites political opposition from many different quarters). It is in any case unnecessary, because only portions of a person's notional health care data ever need to be consolidated, and only on specific occasions, for specific purposes.

We note that the drive for centralisation appears to come mainly not from health care professionals, but from administrators, researchers and other interests more interested in efficiency and social control than in respecting the privacy of patients.

The approach that is appropriate for both functional and privacy reasons is a federated model of separate systems, only linked in specific circumstances and subject to strict safeguards.

The Foundation urges that the ALRC not reach any conclusions, and not make any recommendations, that pre-suppose that centralised data schemes or a universal identifier are even desirable, let alone inevitable.

The Foundation further submits that the ALRC should expressly recognise that strong arguments exist against those approaches and in favour of federation among large numbers of independent databases, and should frame its conclusions and recommendations in order to reflect the unsettled nature of health care data architectures.

## ***Chapter 57 - The Privacy Act and Health Information***

### **Definitions**

**Proposal 57-1** *The definition of 'health information' in the Privacy Act should be amended to make express reference to information or an opinion about the physical, mental or psychological health or disability of an individual.*

**Proposal 57-2** *The Privacy Act should be amended to define a 'health service' as:*

- (a) *an activity performed in relation to an individual that is intended or claimed (expressly or otherwise) by the individual or the service provider to:*
- (i) *assess, record, maintain or improve the individual's health;*
  - (ii) *diagnose the individual's illness, injury or disability; or*
  - (iii) *treat the individual's illness, injury or disability or suspected illness, injury or disability; or*

- (b) *a disability service, palliative care service or aged care service; or*
- (c) *the dispensing on prescription of a drug or medicinal preparation by a pharmacist.*

**Embedded proposal (in 57.26):** *ALRC proposes to keep the verb ‘record’ in definition of providing a ‘health service’.*

We support Proposals 57-1 and 57-2.

## **Application to agencies and organisations**

**Embedded proposal:** Removal of SBO exemption and employee records exemption will ensure appropriate protection of health information in public and private sectors (para 57.38-40).

We support the application of the proposed Regulations to both agencies and organisations, with minimal exemptions – see our comments on Part E of DP72 in our main submission.

We question whether sufficient attention has been given to the application of the proposed Regulations to organisations which, while not ‘health service providers’ are routinely and necessarily handling health information – such as employers and insurers.

## **Provision of Health Services and Consent**

We refer to our comments on Chapter 16 of DP72 in our main submission. We believe that the default presumption for collection, use and disclosure of health information should be express and informed consent, with strong justification being required for *any* exceptions.

## **Content of Privacy (Health Information) Regulations**

**Proposal 57–3** *The Privacy (Health Information) Regulations should provide that a health service provider may collect health information from a health consumer, or a person responsible for the health consumer, about third parties without consent when:*

- (a) *the collection of third party’s information into a health consumer’s social, family or medical history is necessary to enable health service providers to provide a health service directly to the consumer; and*
- (b) *the third party’s information is relevant to the family, social or medical history of that consumer.*

**Question 57–1** *Should the proposed Privacy (Health Information) Regulations provide that health information may be collected without consent where it is*

*necessary to provide a health service to the individual and the individual would reasonably expect the agency or organisation to collect the information for that purpose?*

We support Proposal 57-3, to incorporate the relevant existing public interest determinations<sup>1</sup> in the Regulations, and we also support the addition of further exception to the requirement for consent to cover collection within the reasonable expectation of the individual concerned.

**Embedded proposal (in 57.110-116):** *Refers to the ALRC's proposal in Chapter 18 of DP 72, in relation to proposed UPP 2, that health and other sensitive info can be collected where "required or specifically authorised by law" – to replace NPPs 10.1(b) and 10.2 and reduce inconsistency between them. NPP 10.2(b)(ii), re 'professional rules', should be removed.*

We support the proposed 'by law' exception from UPP 2 in relation to health information – see our main submission on Proposal 18-2.

**Proposal 57–4** *The provisions of National Privacy Principles 2 dealing with the disclosure of health information in the health services context to a person responsible for an individual should be moved to the Privacy (Health Information) Regulations. The proposed regulation should:*

- (a) be expressed to apply to both agencies and organisations;*
- (b) provide that an agency or organisation that provides a health service to an individual may disclose health information about the individual to a person who is responsible for the individual if the individual is 'incapable of giving consent' to the disclosure and all the other circumstances currently set out in NPP 2.4 are met;*
- (c) include a definition of a person 'responsible' for an individual amended to incorporate the term 'authorised representative'; and*
- (d) refer to 'de factor partner' rather than 'de facto spouse'.*

We support Proposal 57-4

**Proposal 57–5** National Privacy Principle 2.1(ea) on the use and disclosure of genetic information should be moved to the *Privacy (Health Information) Regulations* and amended to apply to both agencies and organisations. Any use or disclosure under the proposed regulation should be in accordance with binding rules issues by the Privacy Commissioner.

We support Proposal 57-5

**Proposal 57–6** *The Privacy (Health Information) Regulations should provide that, if an organisation denies an individual access to his or her own health*

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<sup>1</sup> Now PIDs 10 and 10a, issued by the Privacy Commissioner in December 2007 to replace PIDs 9 and 9a.

*information on the ground that providing access would be reasonably likely to pose a serious threat to the life or health of any individual, the:*

- (a) organisation must advise the individual that he or she may nominate a registered medical practitioner to be given access to the health information;*
- (b) individual may nominate a registered medical practitioner and request that the organisation provide access to the information to the nominated medical practitioner;*
- (c) organisation must provide access to the health information to the nominated medical practitioner; and*
- (d) nominated medical practitioner may assess the grounds for denying access to the health information and may provide the individual with sufficient access to the information to meet the individual's needs if he or she is satisfied that to do so would not be likely to pose a serious threat to the life or health of any individual.*

**Embedded question (in 57.177):** *“ALRC interested in receiving feedback on whether an organisation should have the opportunity to object to the individual's choice of nominated medical practitioner.”*

We support Proposal 57-6, consistent with our support for a more general ‘intermediary access’ provision in UPP 9 – see our main submission on Proposal 26-2. We suggest that the intermediary should need to be mutually agreed (as in UPP 9.3), with the Privacy Commissioner being empowered to nominate an intermediary in event of disagreement.

**Proposal 57-7** *The Privacy (Health Information ) Regulations should provide that where a health service practice of business is sold, amalgamated or closed down and a health service provider will not be providing health service in the new practice or business, or the provider dies, the provider, or the legal representative of the provider, must take all reasonable and appropriate steps to:*

- (a) make individual users of the health service aware of the sale, amalgamation or closure of the health service or the death of the health service provider; and*
- (b) inform them about proposed arrangements for the transfer or storage of individuals' health information.*

We support Proposal 57-7.

**Proposal 57-8** *The Privacy (Health Information) Regulations should provide that if an individual:*

- (a) requests that a health service provider, or the health service provider's legal representative, make the individual's health information available to another health service provider; or*
- (b) authorises a health service provider to request that another health service provider transfers the individual's health information to the requesting health service provider;*

*the health service provider must transfer the individual's health information as requested. The health information may be provided in summary form.*

We support Proposal 57-8.

**Proposal 57-9** *The Privacy (Health Information) Regulations should make express provision for the collection, use and disclosure of health information without consent where necessary for the funding, management, planning, monitoring, improvement or evaluation of a health service where:*

- (a) the purpose cannot be achieved by the collection, use or disclosure of information that does not identify the individual;*
- (b) it is impracticable for the agency or organisation to seek the individual's consent before the collection, use or disclosure; and*
- (c) the collection, use or disclosure is conducted in accordance with rules issued by the Privacy Commissioner.*

We support Proposal 57-9 which would set a high threshold for exceptions to the default 'consent' requirement for health administration purposes. As noted earlier, it is all too easy for agencies and organisations to assert a need for collection, use and disclosure of personal information on grounds of administrative convenience or efficiency. Particularly in the case of health information, it needs to be established that the use of personally identifiable information is necessary and that seeking consent is impracticable – not merely inconvenient or expensive. We assume that the reference in (c) is to *binding* rules.

**Embedded proposal (in 57.229):** *No special provision for use of information for training purposes without consent – not the same public interest balance in favour of this.*

We agree that there is no need for a special exception for the use of health information for training purposes.

**Proposal 57-10** *The Privacy Act should be amended to empower the Privacy Commissioner to issue rules in relation to the handling of personal information for the funding, management, planning, monitoring, improvement or evaluation of a health service.*

We support Proposal 57-10 on the understanding that these would be *binding* rules (see our main submission on Proposal 44-2 and our general comments on OPC Guidance in the Introduction to our main submission).

## Other matters

**Embedded proposal:** At several points ALRC refers to (and supports) the Office of the Privacy Commissioner (OPC) developing further guidance on the use and disclosure of health info (57.43, 57.54, 57.144, 57.204).

We refer to our general reservations about OPC guidance in the Introduction to our main submission.

Finally, we note that there have been recent examples in the media involving release and publication of health information about celebrities (e.g. sports drug testing and treatment) and politicians (health and medical history). The ALRC could usefully 'test' the application of the proposed regime for health information privacy against such scenarios, and address the issue of whether there should be a public interest exception for such disclosures and uses and how would they relate to the more limited proposed exemption for journalism (Proposals 38-1 to 38-5).