LIBERTY VICTORIA SUBMISSION

Executive Summary

* The lack of a plan for implementation leading to queries both on the ability to successfully carry out the scheme and to consequent privacy outcomes.

* The lack of a focus on individual rights and rights of redress, which is evident both in the design of the scheme and the lack of a design which holds the value of the individual rights and privacy in high regard.

* The lack of guarantees regarding the future linkage of the personal medical data to other government and corporate records, and to the storage of that data within a known regulatory environment with respect to client rights and privacy.

Due to these and other deficiencies Liberty Victoria is opposing the Health Identifier Bill and the Health Identifier (Consequential Amendments) Bill 2010.

The scheme is so flawed that no amendment or set of amendments could create a sound basis for public policy. Suggestions for the most extreme failings are included.

Healthcare Identifiers Bill 2010 and Healthcare Identifiers (Consequential Amendments) Bill 2010

The Victorian Council for Civil Liberties Inc¹—Liberty Victoria— (Liberty) is an independent non-government organization which traces its history back to the first civil liberties body established in Melbourne in 1936. Liberty is committed to the defence and extension of human rights and civil liberties. It seeks to promote Australia's compliance with the rights and freedoms recognised by international law. Liberty has campaigned extensively in the past on issues concerning human rights and freedoms, democratic processes, government accountability, transparency in decision-making and open government.

Privacy and the Individual

The structure of this scheme and the governmental mechanisms used to design and implement the scheme show that privacy and transparency are afterthoughts. The use of COAG processes to drive what is essentially a Federal initiative to harmonise medical records moved the whole design process out of the usual oversight and FOI system. The lack of oversight is plain in the shortcomings that have become so central to the plan as to make it unsafe to implement as proposed.

For a national scheme the right to privacy will vary according to state jurisdiction. Whilst there is an offence to act in a manner against those allowed under the Bill there is no right for the individual to try and enforce their rights. The individual is not the focus of the Bill nor of the privacy provisions, but rather an after thought. By rushing this scheme through ahead of a full national privacy scheme and without a road map for the e-Health Initiative function creep is systemic - planned but unacknowledged.

Privacy where considered is only a public wrong and not a breach of the individuals rights. The Individual is not accorded rights to access and confirm or correct their HI record.

1. An overall Privacy Statement is included that has right of access, right of correction and facilities for redress in both content and for righting privacy breaches

The lack of a full method for anonymising Individuals - excepting certain public figures - is very worrying. Those who live in certain social circumstances, where treatments and diagnosis of conditions have the possibility of social and physical consequences, will not seek treatment if their records do not have a high degree of privacy with strong sanction against misuse. The recent reports that Medicare personnel have been accessing the less personalised Medicare records shows what a temptation socially, monetarily and criminally these records can become.

2. A mechanism to allow individuals to use an identity not associated with their own record and that this be accessible only by Health Professionals in carefully described circumstances.

The Australian Medical Association ² in their submission state that future amendments may deal with electronic privacy concerns. It is not sufficient to plan to patch holes in a poorly built dam. It is better that the dam be designed and constructed on sound principles.

Privacy and Liberty

The lack of firm constraints on the project and a structure built to stop incorrect access and usage is disturbing. The belief that auditing terminals will provide a trail to misuse is a naive view of the hectic pace at Public Hospitals and Clinics.

3. That audit trail be based on an RFID type card provided to all relevant health staff. Access to be monitored by individual user.

The 'honeypot' effect of linking all medical data with current address and the date of birth should not be under estimated. The demand for this data from criminal networks and from those with civil and uncivil procedures in mind requires the very highest of standards.

The second 'honeypot' effect is the legal encroachment from other areas of the executive, who will seek to use the HI as the basis for civil registration. The submission of the Australian Privacy Foundation³ notes the broad similarities between the identity regimes of the last 25 years including but not only the Australia Card, the Access Card and now the Health Identifier.

The treatment of the individuals health data as a public document rather than a personal record that is made available to health professionals is indicative of the poor planning. The lack of provisions requiring accurate, complete and up to date data is disturbing given the claim that this scheme is to over come shortcomings in service delivery and medical misadventure due to ill advised medication. As noted in the Queensland Office of the Information Commissioner ⁴ submission this provision becomes even more worrying given that the provider of IT services could be outsourced by regulation and thereby limit the coverage of the Federal Privacy Act.

4. That the Federal Privacy Act provisions be made the minimum standard for providing any service or storage associated with the scheme

By increasing the risk that certain groups will not access essential health care because of fear that their medical records may be accessed. The increased availability of current treatments and address to spouses and others. The high possibility that data errors will not be caught because the patient cannot check the accuracy of the data the health professional will rely upon.

Liberty includes freedom from harm, and this scheme is not providing the increase in safety that it is proposed to deliver. If the information placed in a system is poor it is GIGO - garbage in, garbage out.

References

- [1] Liberty Victoria see http://libertyvictoria.org/node/9
- [2] Australian Medical Association submission 8 to the Inquiry
- [3] Australian Privacy Foundation see <u>http://www.privacy.org.au/</u>
- [4] Queensland Office of the Information Commissioner submission 13 to the Inquiry