



Office of the Information Commissioner
Queensland

Submission by the
Office of the Information Commissioner

THE HEALTHCARE IDENTIFIERS BILL 2010

Queensland Information Commissioner, Julie Kinross
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The Queensland Office of the Information Commissioner (**OIC**) made a submission to the National Minister's Advisory Council in July 2009, regarding the issues canvassed in the *Healthcare identifiers and privacy discussion paper* (**discussion paper**). The Healthcare Identifiers Bill 2010 (**HIB**) was released for comment on 24 February 2010. Some of the issues raised in the OIC's submission have been addressed in the HIB; others have not.

Below are the key issues raised in OIC's earlier submission which were either not addressed, or not addressed fully, in the HIB.

Key issues from the OIC's submission on the discussion paper

1. *AHMAC intends to proceed with introducing health identifiers prior to ensuring adequate privacy protections are in place. The rights of individuals should their personal information be misused, mismanaged, or improperly used or disclosed will not be equal, depending on in which jurisdiction they live*

The HIB makes some attempt to address these concerns by making an offence against the HIB an 'interference with an individual's privacy' under the *Privacy Act 1988* (Cth) (**Privacy Act**), and by giving the Privacy Commissioner the power to investigate complaints even where they concern a State or Territory.

However, the offences under the HIB are limited to use or disclosure which is not authorised under the Act. There are numerous other misuses of personal information, which are reflected in the privacy principles contained in all Australian information privacy legislation. These include improper collection, obligation to ensure accuracy and completeness, and to only use relevant personal information. Additionally, for privacy protection to be meaningful, it must include the right of an individual to make a privacy complaint in relation to all potential mishandling of their personal information.

Under the HIB, privacy protection will not be equal for all Australians. Those who live, or receive healthcare services, in jurisdictions with comprehensive privacy legislation will receive the full gamut of protection for their personal information, compared with the limited protection for individuals who live or receive healthcare elsewhere.

For those jurisdictions where privacy protection is present, individuals will be able to complain about mishandling of their personal information under that legislation. However, individuals living (or receiving healthcare services) in those jurisdictions which **do not** possess privacy legislation will be limited only to the use and disclosure protections in the HIB.

In order to overcome this inequality, in addition to use and disclosure the HIB must also address the privacy principles concerning collection, accuracy and relevance.

2. *Explicit and specific complaint handling powers should be built into the legislation; redress options for individuals should be included in the legislation*

There is a complaint handling provision built into the legislation—an individual can make a complaint to the Privacy Commissioner about breaches of the HIB.

As noted above, in the current iteration of the HIB this is a limited right. Alongside the expansion of the HIB to include all the privacy principles must be a corresponding capacity to make a privacy complaint in relation to all of the privacy principles.

3. *Consumers have a right to receive healthcare anonymously; individuals should be able to receive a healthcare service without their healthcare identifier*

The HIB does not require an individual to supply their healthcare identifier in order to receive a healthcare service; this does not necessarily mean that an individual can receive a healthcare service without involving their healthcare identifier. Under section 14 of the HIB while an individual is not required to provide their healthcare identifier, neither is the individual's consent required for the health care service provider's retrieval of the individual's healthcare identifier. A healthcare service provider is authorised to send identifying information concerning an individual to the Service Operator where 'it is necessary' to retrieve the individual's healthcare identifier from the Service Operator. There is no guidance in the HIB as to the meaning of *necessary*. However, it appears from the purpose and drafting of the legislation, and from the material surrounding it, that the sole qualification for 'necessary' is that an individual has not themselves provided their health care identifier. There is no distinction made between the individual declining to provide their health care identifier and an individual who is, through injury or illness, unable to provide it.

As the individual has no say in the exchange of information between the health care provider and the Service Operator concerning the individual's health care identifier, the provision of anonymous medical services does not seem to be possible, or practicable, under the HIB unless the healthcare service provider decides that they do not need to retrieve the identifier. The question then turns to what are the circumstances that informs the health care provider's obtaining of an individual's health care identifier.

The uses to which a health care provider can put an individual's health care identifier are set out in section 15 of the HIB. These are by any definition so broadly-worded as to encompass any health care interaction. The health care provider can use the identifier for purposes of communicating or managing information as part of:

- the provision of healthcare services to an individual
- the management, funding, monitoring or evaluation of healthcare
- the conduct of health or medical research.

The only mechanism under the HIB in which an individual can be guaranteed to receive health care services anonymously is where that individual does not have a health care identifier. The Minister for Health and Ageing, the Honourable Nicola Roxon MP's media release of 10 December 2009 states that for the majority of Australians a health care identifier will be automatically issued through their existing Medicare card or Department of Veteran Affairs treatment card.

It appears there would be two circumstances where a person can receive health care services without involving their health care identifier. The first is where the individual presents to the health care provider using a pseudonym and that pseudonym has not been previously used and issued with a health care identifier. The second is where a person does not have a Medicare card (for example, they are a tourist) and presents for the first time to a health care provider.

In either circumstance, the Service Operator is authorised under section 6 of the HIB to

assign a health care identifier to an individual. However in order to do so, the health care provider would need to provide identifying information for the individual to the Service Operator.

The proposed arrangement may discourage people from seeking primary health care and health care when it is needed and appears to undermine a fundamental privacy principle concerning the requirement for people to consent to the use of their information.

Accordingly, the HIB should include provisions that require the following:

- The healthcare service provider to seek the consent of the individual to retrieve the identifier where the individual is in a fit state to give it.
 - If the individual is not in a fit state to give consent, the healthcare service provider may retrieve the identifier.
 - If the individual is in a fit state, but refuses consent, a healthcare service provider may only retrieve the identifier where the lack of the identifier would make providing the healthcare service impracticable.
4. *Penalties should extend beyond unauthorised disclosure, to use, access, modification, any other misuse of information and to loss of information.*

Please see the comments at 1 and 2 above.

5. *Individuals must have the right of access to and amendment of personal information linked to their healthcare identifier.*

The Service Operator will receive and must hold identifying information. In the HIB, no obligation is placed on the Service Operator to take reasonable steps to ensure it is accurate, complete, up to date and not misleading, and no provision is made for individuals to access the personal information held by the Service Operator which is linked to their healthcare identifier. Medicare, as the Service Operator, is bound by the Commonwealth Privacy and FOI Acts and these mechanisms can be used for individuals to access and amend this information. If the Service Operator changes to a private sector organisation – and this could be as simple a matter as making a regulation¹ - then there may be no access or amendment rights. Given that the purpose of the HIB is to ensure that a "person who provides or receives healthcare is correctly matched to health information" this seems a significant oversight.

In addition to the issues mentioned above, the HIB must provide for access and amendment of personal information held by the Service Operator.

Additional issues – Healthcare Identifiers Bill 2010

1. Obligations on the Service Operator

There are no obligations placed on the Service Operator with regards to the healthcare identifier and associated identifying information beyond use, disclosure and security. While the Service Operator remains Medicare, the Privacy Act will place obligations on the storage and management of the personal information. Should the Service Operator become an entity which is not subject to the Privacy Act, the entity's only obligations with relation to the information will be in the areas of use and disclosure.

¹ See definition of 'service operator' in section 5 of the HIB.

The HIB should include provisions relating to the collection, relevance, and accuracy of the healthcare identifier and associated identifying information. The importance of public confidence to the success of the new healthcare identifier system cannot be overstated. Not only would including such provisions ensure the full protection of this information, it would also go a long way towards reassuring the public of the system's commitment to proper privacy protections.

The OIC reiterates the importance of public confidence in the healthcare identifiers system, and the fundamental need to ensure the privacy of those who participate in it. It is imperative to 'get privacy right'. While the HIB takes the first steps down that path, it comes up short of complete privacy protection. "If patients lack confidence around privacy protection they may not seek treatment or may withhold information, resulting in harm to themselves or others."