

Submission relating to Healthcare Identifiers Bill 2010

I am a consultant health statistician. My company has an interest in management of clinical data registries.

This submission is to express my concern about an aspect of the Healthcare Identifiers Bill 2010.

The issue is that a 'user' of an Individual Healthcare Identifier (IHI) who is not a 'healthcare provider' would not be authorised to disclose IHIs to any other entity, other than a healthcare provider. This would impact on the ability of an Australian clinical data registry, using IHIs provided with proper authority by a 'healthcare provider', to pass those IHIs to another entity for data linkage – for instance, to link clinical registry data with the Australian Institute of Health and Welfare's National Death Index. Such data linkages are important for accurate ascertainment of long term outcomes (death) and for avoidance of duplicate data collection. As most, if not all, national clinical registries are managed by organisations that are not 'healthcare providers', this is a serious constraint on plans for conducting health research through clinical registries in an e-Health environment.

The expectation amongst clinical data registry managers has been that the availability of IHIs would improve the quality of properly approved data linkage, which currently relies on less accurate probabilistic methods. Operating Principles for Australian Clinical Quality Registries, currently being evaluated by the Australian Commission on Safety and Quality in Health Care, encapsulate such an expectation, supported by architecture developed by the National E-Health Transition Authority. The requirement for Health Research Ethics Committee approval would ensure that additional privacy issues do not arise from extended provisions that would permit 'disclosure' by clinical registries to other entities for purposes consistent with 'health research'. In fact, it could be argued that ensuring higher quality individual data in registries is consistent with privacy principles relating to accuracy of information. I therefore propose such an extension to the Healthcare Identifiers Bill 2010.

I believe that my proposal is consistent with e-Health objectives for health research. I am confident also that my concerns about the exposure draft would be shared by other Australian clinical data registry managers.

I would be happy to provide additional information if required.

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