



***Submission to the Senate Community Affairs Committee on the
Healthcare Identifiers Bill 2010***

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Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF welcomes the opportunity to provide comment to the Senate Community Affairs Committee on the *Healthcare Identifiers Bill 2010*. eHealth is an area of considerable interest to CHF's membership and stakeholders, and CHF provided a submission on the Australian Health Ministers' Advisory Council (AHMAC) paper *Healthcare Identifiers and Privacy: Discussion paper on proposal for legislative support* (August 2009) and to the Department of Health and Ageing on the *Exposure Draft Healthcare Identifiers Bill 2010* (December 2009).

While we welcome the opportunity to respond, we must note the extremely short timeframe allowed for responses, particularly in the context of major health reform announcements during the consultation period. Issues around eHealth, including the Healthcare Identifiers, are complex and often contentious, and the very brief timeframe for responses has precluded detailed consultation with consumers on the issues to be considered during the inquiry. We are also concerned that the tight reporting timeframe for the Committee will prevent detailed consideration of the issues.

CHF would welcome the opportunity to provide evidence to the Committee in order to expand on the issues raised in our brief submission. We would be available to provide evidence on the dates identified for hearings.

This submission reviews each of the issues identified for the Committee to consider during the inquiry:

- Privacy safeguards in the Bill
- Operation of the Healthcare Identifier Service, including access to the Identifier
- Relationship to national e-health agenda and electronic health records.

Privacy safeguards in the Bill

CHF considers that the privacy safeguards in the Bill are sufficient to protect consumers' privacy.

The strong provisions relating to the service operator's duty of confidentiality are welcome, as is the clarity around the purposes for which the healthcare identifier and identifying information about a consumer can be used. CHF also welcomes the strong provisions relating to the unauthorised use or disclosure of healthcare identifiers.

The independent regulation by the Privacy Commissioner of how healthcare identifiers are handled, including handling complaints against the service operator and private sector healthcare providers, is welcomed by CHF. In its submission on the Exposure Draft legislation, CHF called for the annual reports by the Privacy Commissioner to be publicly available, and we are pleased to note in the Explanatory Memorandum to the Bill that these reports will be publicly available, as is general practice with annual reports prepared by Commonwealth agencies.

The amendments to the Privacy Act 1988 to incorporate definitions and offences relating to healthcare identifiers are also welcomed.

Operation of the Healthcare Identifier Service, including access to the Identifier

In its submission to the Exposure Draft of the Bill, CHF called for additional provisions relating to the operation of the Healthcare Identifier Service to specify that the service operator is authorised to disclose an individual's healthcare identifier and other information held by the service operator to that individual. CHF is pleased that an explicit statement has been included in this Bill to ensure that individuals and persons responsible for the individual have a clear understanding of their right to access information held by the service operator, and to provide an appropriate framework for the service operator to make such disclosures.

In its submission on the Exposure Draft legislation, CHF called for the annual reports by the service operator to be publicly available, and we are pleased to note in the Explanatory Memorandum to the Bill that these reports will be publicly available, as is general practice with annual reports prepared by Commonwealth agencies.

In relation to the Healthcare Provider Directory to be established and maintained by the service operator, CHF reiterates its argument from earlier submissions that this Directory should be linked to or incorporated into the NRAS public register.

CHF would also like to reiterate the point made in our submission on the Exposure Draft legislation that emphasises the importance of consumer involvement in the governance structures for the healthcare identifiers service. Consumers should be involved in the independent regulation of the service and in the design and implementation of the information security framework for the service, and should also be consulted about any possible future expansion of the healthcare identifiers service, as they will be the users, beneficiaries, and ultimately the funders of the new healthcare identifiers service.

Relationship to national e-health agenda and electronic health records

It is clear from comments received from consumer representatives that there is still a lack of understanding for some people around the distinction between the healthcare identifiers and a full personal electronic health record. CHF considers that a key message that must be conveyed to healthcare consumers, outlined in the Explanatory Memorandum to the legislation, is:

The inclusion of healthcare identifiers in a health records system or a patient's file will not change how and when healthcare providers share information about individuals, but will provide a much more reliable way of referencing information, particularly in electronic communications and information management systems. Patients will continue to be involved in decisions about how health information is handled by their healthcare team.

CHF notes the statement in the Explanatory Memorandum that 'a public awareness program on the HI Service will provide information to consumers via a range of methods'. This is essential to ensure that consumers recognise the distinction between healthcare identifiers and a complete electronic health record, and to inform consumers that extensive work must still be undertaken before electronic health records will be a reality.

Conclusion

CHF welcomes the opportunity to provide comment to the Senate Community Affairs Committee on the *Healthcare Identifiers Bill 2010*, in spite of the short period for submissions. This submission has considered the three areas identified for the Committee's consideration during the inquiry:

- Privacy safeguards in the Bill
- Operation of the Healthcare Identifier Service, including access to the Identifier
- Relationship to national e-health agenda and electronic health records.

CHF is generally supportive of the legislation, and is pleased to note that some recommendations provided in our submission on the Exposure Draft legislation have been reflected in this version of the Bill.

CHF looks forward to continuing to provide input throughout the implementation of the healthcare providers service.



The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.