



Health Care Consumers' Association of the ACT
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Submission to the Australian Senate Committee Inquiry into the Healthcare Identifiers Bill 2010

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The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA welcomes this opportunity to comment on the Healthcare Identifiers Bill 2010. HCCA is supportive of the issues expressed in the previous submissions of the Consumers Health Forum and the Health Consumer Council of WA.

We have had limited opportunity to seek views from our members or consult with other health consumer organisations on this issue and have drawn heavily on previous discussions with members of the ACT E-health Consumer Reference Group in writing this submission. This issue is of great interest to consumers and we look forward to working with NEHTA to further explore consumer views on the perceived benefits of unique health identifiers and the assurances consumers want in order to have confidence in the system. One of our members commented that ***we need more conversations about the place of identifiers in health delivery.***

HCCA can see the potential for a national system of healthcare identifiers to improve communication within, planning of and research relating to the healthcare system. A national system of health care identifiers will also greatly improve patient safety by reducing the risk of mismatching data, such as test results, with individuals. It will also lay the foundations required for the creation of e-health records in the future. This will be an enormous step forward for many health care consumers. One consumer noted that UHIs are ***an essential step forward towards better coordination and e-management of health, from which we as consumers should benefit in due course.***

Consumers must have confidence and trust in the privacy provisions and understand how their information will be collected and used. Simple, transparent

mechanisms which allow individual health care consumers to control the flow of information about them must be built into the delivery interface of the healthcare identifier system. One consumer commented that the identifier must be ***seen as part of an assurance mechanism.***

To this end HCCA is pleased to note that the UHI system comes under the jurisdiction of the Privacy Commissioner and would like to see provision in the Act to ensure that the privacy provisions are reviewed from time to time to align them with current national privacy standards and frameworks. One consumer commented that *we want assurance that our information will be protected.*

Each person must have the right to choose whether to participate in the service, with participation based on full information. We consider it essential that systems are set up for audits, complaints and evaluation of the service.

We have more questions than answers to aspects of the UHI. It is imperative that consumers are given the opportunity to maintain control over the flow of their health care information every time they interact with the healthcare system. Is it possible that some consumers would opt out and not have an UHI? Or that their identity not be verified so that the health record at a particular service does not link to the UHI? Would the system support those consumers who do not choose to use their UHI in some interactions? We are interested to know the degree of flexibility that can be built in to the user interface to enable consumers to control when their identify is verified using the UHI. It follows that access to Medicare funded services should not be dependent on consumers having an UHI or that they be willing to attach the UHI to an episode of care of health service interaction.

It will be necessary to communicate the purpose of the UHIs clearly and consistently to the public and at the same time inform consumers of their options relating to: participation, privacy protection and complaint and feedback mechanisms. HCCA believes that formal participation by trained and supported consumer representatives at every step in the development of the HI system will help to ensure that consumer needs from the HI system are met.

Thank you for your consideration of the issues we have raised.

Darlene Cox
Executive Director