cancer voices
australia

Submission to the Senate Standing Committee on Community Affairs.

Topic: Enquiry into the Healthcare Identifiers Bill 2010 and Healthcare Identifiers (Consequential Amendments) Bill 2010

Organisation - Cancer Voices Australia:

Cancer Voices Australia is the national consumer organisation representing Australians affected by cancer. It aims to ensure the voices of people affected by cancer are heard at a national level.

Objectives

- *To promote the fundamental rights of Australians affected by cancer*
- *To effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development, management and evaluation*
- *To promote the value and benefits of consumer participation in the development of national cancer policy and programs*

Introduction

The Senate Human Affairs Committee has set up an open inquiry into the proposed legislation with submissions formally closing on 4 Mar 2010 and hearing in Canberra on 9-10 Mar 2010. This is an extremely short timetable and does not provide organisations with much time to consult and develop a ‘national’ response.

The eHealth process has been in the hands of the bureaucracy, State and Federal for over 15 years with minimal consultation within or about the public sector and virtually none about the private sector.

We are concerned that a last minute flurry to correct this with vendors and some provider associations at the Federal level may resolve some issues, but as yet the jurisdictions through whom the service development is to kick off, have had virtually no contact with the private sector who deliver at least 50% of health services.

Consumer involvement has for all practical purposes been avoided probably because their direct involvement is a long way off, and with the official view of consultation with consumers being singled out by Minister Roxon's recent response to a question:

Q: Juanita Fernando (Privacy Foundation): *We need to hear a consumer voice - and there's no consumer voice.*

A: *Minister:* I think trying to have the public intimately involved with every piece of technical advice that we are getting on how the different pharmacy information and GP information, hospital information will link up is probably beyond the interests of most people. So I don't think that sort of discussion has to be had publicly.

This is a very narrow attitude as it is important for the whole of community wide interests to be represented if the final result is to deliver the practical needs of the patients and their carers. Without this CVA believes that the whole exercise is likely to have limited value.

The extensive time factor before consumers see some positive results, arise in part because of their virtual exclusion from the consultancy process. In any event it is welcome that an eHealth product is moving beyond a bureaucratic committee to committee process.

General Comments on the Proposed Legislation.

The absence of any associated regulations will not assist the Senate committee to know what will eventuate as a final implemented system.

In addition, the Bills are being reviewed and treated in isolation from the larger e-Health agenda. This is of major concern to cancer patients and their families as we seek effective leadership, organisation and governance which were recommended in the 2008 National E- Health Strategy. (Note: CVA attaches a proposed governance structure that has been provided to NEHTA and we believe worthy of consideration and attention.)

This strategy was developed for the Australian Health Ministers Council (AHMC) by Deloittes and subsequently agreed. Furthermore, we are not aware of any full implementation plan, any pilot studies both at the local and national level and further engagement of consumers does show a lack of real commitment to the issue.

Legislation

The UHI legislation does not produce e-health as such but is an initial enabling requirement. The first two stages of the NEHTA strategy which includes the UHI identifiers are primarily focussed on building blocks and the development of service provider products.

As stated above, the Bills are being treated in isolation from the larger e-Health agenda.

CVA has some concerns that the legislation for the HI Service may be passed without a clear recognition of what comes next. CVA understands that a further proposal is being developed by the Department of Health Ageing (to be considered by COAG) for a fuller national E-Health approach whilst this senate Enquiry is being undertaken. CVA believes that discussion on this legislation should be delayed until the wider national framework is fully developed and receives appropriate national consideration including the full engagement of health consumers in this country.

Statement

The issues that we consider are pertinent to cancer patients and their carers

Timing - Consumers are involved in a seemingly complex system without the prospect of seeing the PEHR outcomes for at least 6 years. They may benefit from better system treatment outcomes in the meantime; and Governance - here is no ownership / governance provision as detailed above.

We have commented previously on how patients can expect to be able to gain access to their personal medical record information, the collection of which will hopefully be facilitated by the creation by Medicare of your contracted IHIs, HPI-Os and HPI-Is. Specifically, there is a lack of procedural details.

<u>Authorisation by the Patient</u>

What are the specifics of the procedures necessary between patient and the principal supplier in authorizing secondary members of a care team who may be recommended for inclusion and any restraint on data that may be supplied to them.

This is particularly important as many cancers are now treated in a multi-disciplinary situation.

<u>PKI System on Supplier Security</u>

CVA has expressed doubt about the suitability of the PKI authorization scheme for suppliers and particularly for HPI-I providers employed by an HPI-O organisation.

CVA understands that the detailed checks on the HPI-I may be conducted by the employing organization itself and not by Medicare or whoever is the identifier system controller.

<u>Availability of Medical Record Data to Patients</u>

It seems clear that the first stage of the E-Health system will initially be primarily operated by the jurisdictions, but with connections at the interfaces with their private sector partners. CVA understands from the UHI meeting in Canberra that medical records would be kept by each provider on a distributed network basis.

How will the standard interoperable technology which has been chosen to enable this to be achieved are identified in the legislation.

CVA seeks information on how this distributed network arrangement is planned to work in practice, as it seems to be at variance with the earlier NEHTA recommendations for consumer involvement with the IEHR Plan and seemingly to a degree with the NHHRC – PEHR plan.

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Friday 4th March 2010

Attachment – CVA governance Structure