QUEENSLAND COUNCIL FOR CIVIL LIBERTIES
G.P.O. Box 2281 Brisbane 4001

The Committee Secretary
Senate Standing Committee on Community Affairs

By Email: **community.affairs@sen.aph.gov.au**

Dear Madam

Health Care Identifiers Bill 2010

Thank you for the opportunity to make a submission to this Committee concerning this Bill and related legislation.

About the Council

The Council is a voluntary organization which seeks the implementation in Queensland and Australia of the Universal Declaration of Human Rights.

Article 12 of the Universal Declaration of Human Rights provides:

> "No one shall be subjected to arbitrary interference with his privacy...Everyone has the right to protection of the law against such interference or attacks."

As a voluntary organization the Council does not have the time or resources to make as detailed a submission as it would like. For this reason a failure to comment on an issue should not be taken as an indication of the Council's position one way or another.

Inadequacy of Consultation Process

It is the Council's view that the issues raised by the legislation cannot be properly addressed in the absence of the complete understanding of the proposed ehealth system.

Decentralised Database

On 7 July 2009 I wrote to the Minister seeking details of the proposed e-health system which had been discussed in the media. The response was not entirely uninformative. In the circumstances then the Council has only a very limited idea of exactly how the ehealth system will function.

The Council opposes the creation of a centralized database or linking of databases to create in effect a centralized database.

We will discuss shortly the type of ehealth system the Council would favour, but even in that system we would have serious concerns about the introduction of a unique identifier because of the function creep possibility. Those possibilities are starkly illustrated by the tax file number:

> "The use of the tax file number provides a recent example of function creep. There is a voluntary quotation principle...by which quoting one's tax file number is guaranteed to be voluntary. When the tax file numbers first came into effect in 1988, for many people, the only penalty for not quoting it was that for some income, for example a dividend stream, you made an interest free loan for less than a year to the tax office of the difference between the top marginal tax rate and the marginal tax rate you paid (this amounted to nothing for high income earners and not much for most others). Through a range of legislative changes since 1988 it is now the case that some Australians are not able to survive without obtaining and quoting their TFN (for example to obtain unemployment benefits and a number of other interactions with government). The function of the tax file number has moved from a purely taxation related function, as it was initially, to the present situation where it is used to cross-match data relating to government assistance of various sorts."[1]

A Push or Federal Model

The Council endorses the comments of the recent report of the Joseph Roundtree Reform Trust Limited entitled, *The Database State.*[2] At page 16 when commenting on various electronic health records in the UK the report said:

> "Putting everything into one pot not only makes privacy compromises more likely (more users have access to a larger set of data) but also precludes careful consideration of context specific information flows. It also becomes less clear who is the "controller" of the data. Given that the whole data protection system hinges on the duties of the controller and that patients mostly trust their doctors, but distrust ministers and officials, any move to make the Secretary of State that data controller rather than a doctor, undermines both legal protection and trust. There is thus a developing consensus among practitioners that for safety, privacy and system engineering reasons we need to go back from the shared record model to the traditional model of provider specific records plus a messaging framework that will enable data to be passed from one provider to another when this is appropriate."

The proposition is well summarized in recommendation No. 4 of that report at page 43:

> "By default sensitive personal information must be kept on local systems and shared only with the subject's consent or for a specific lawful purpose."

The Council's view is that the government should produce an ehealth model which does not focus on pulling or centralizing all the data into one system, but rather in facilitating local health practitioners to place their records in an electronic system in which they can, with the consent of a patient, share that data with other health practitioners when appropriate.

---

[1] Karen Curtis, Federal Privacy Commissioner, in a speech to the Second International Policing Conference, 3 November 2004

[2] March 2009

The Council accepts that entirely personal health records are going to be of limited value as they are unlikely to be viewed as reliable by medical practitioners. In the Council's view the preferred model is a shared model in which practitioners and patients share responsibility for control over electronic records the data being collected in a common format allowing for transfer in consultation with patients and subject to their consent to other physicians or health practitioners.[3]

Professor Ross Anderson of Cambridge wrote in the February 2008 edition of "The Economist" magazine as follows:

> "Patient data held at a GP practice may be vulnerable to a security lapse on the premises but the damage will be limited. You could have security or functionality or scale. You could even have any two of these. But you can't have all three and the government will eventually be forced to admit this. In the meantime billions of pounds are being wasted on gigantic systems projects that usually won't work and that place citizen's privacy and safety at risk when they do."[4]

This approach seemed to garner some support from the Australian Health Information Council which has said[5]:

> "Recent work in the United States demonstrates that rather than investing in, and waiting on, the creation of new integrated systems, sharing and aggregation of data can be achieved by connecting existing health information systems using innovative integration techniques. This method may even make it possible to avoid the need for a unique patient identifier and the creation of large databases of identified patient information."

Summary of Overall Position

The Council opposes the creation of a centralized database or the linking of databases in a fashion which would have the same effect as that. The Council is unequivocally opposed to the introduction of a unique health identifier in the context of a centralized database.

The Council would have concerns about a unique health identifier even in the context of a push model or localized model as we have described it above. However at this stage we have not adopted a final position on that issue. We simply say for the purposes of this submission that if, as we understand the proposal, it is that the government intends to create a centralized database then we are opposed to the introduction of a unique health identifier.

Specific Issues

We turn now to address the specific issues whilst maintaining our general opposition to the introduction of a unique health identifier. We address the specific issues raised by the draft Bills.

---

[3] Terry & Francis: *Ensuring the Privacy and Confidentiality of Electronic Health Records* 2007, University of Illinois Law Review 681at pages 721 to 724

[4] Quoted by Michael Vonn in a talk given to the membership conference of the British Columbia Civil Liberties Association in March 2009 found at www.bccla.org.ca

[5] ehealth Future Directions Briefing Paper delivered to the Australian Health Minister's Advisory Council on 4 October 2007 page 23

Other Submissions

The Council has had the opportunity to review the submission of the office of the Information Commissioner Queensland located on the Committee's website. We endorse the comments contained in that very useful submission.

We also endorse comments of the Victorian Privacy Commissioner in section 3 of her submission.

Clause 24

We wish to make specific comment on clause 24 of the Bill.

We object to the terms of this section. It is a clearly established principle that the use and disclosure of Unique Identifiers needs to be strictly limited

In our view this section needs to be amended to reflect that principle in the following manner:

1. We would oppose the release of the health care number for research purposes except there is no other way of carrying out the research.
2. The threat to individuals' life, health or safety should be imminent.
3. We oppose the use or disclosure of an identifier for "funding, management, planning, monitoring, improvement or evaluation of health services" as being too broad. No justification for this broad power has been provided.
4. We oppose clause 24(1)(b)(ii) on the basis that an exemption allowing the release of the number where there is a serious threat to public health or public safety is far too broad. It grants far too broad a level of discretion particularly when that discretion is to be exercised by an individual health care provider who will of course not be subject to the same restraints and processes that a government department would be subject to.[6]

We trust this is of assistance to you in your deliberations.

Michael Cope
President
For and on behalf the
Queensland Council for Civil Liberties
8 March 2010

---

[6] In saying that we would also oppose the granting of such a broad power to a government department.