

QUEENSLAND COUNCIL FOR CIVIL LIBERTIES

HEALTH CARE IDENTIFIERS & PRIVACY REGULATIONS

**Submission to the Primary and Ambulatory Care Division (MDP1)
Department of Health and Ageing**

by Michael Cope, President

Thank You

Thank you for your undated letter seeking a submission from the Council in response to the discussion paper “Health Care Identifiers and Privacy Regulations”.

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 it should not be taken that where no comment is made on an issue raised in the discussion paper that the Council agrees with that proposal. Whilst we think the Law Reform Commission’s position is often inadequate we accept the position of the Australian Law Reform Commission in its recent report as stating a minimum. Accordingly we oppose any reduction in the minimum standard of protection proposed by the Australian Law Reform Commission.

1. Inadequacy of Consultation Process

It is the Council’s view that the issues raised in the discussion paper cannot be properly addressed in the absence of the complete understanding of the proposed ehealth system. It is in the Council’s view impossible, for the reasons we will enunciate later, to make a proper assessment of the issues raised in this paper without the full details of the proposed ehealth system. For that reason we consider the outcome of this consultation process will inevitably be unsatisfactory.

2. The Benefits to be Obtained from a Unique Health Identifier

The discussion paper identifies, particularly at page 16, a number of benefits said to flow from improved health care identification, including a reduction of

preventable errors, increased productivity, more efficient use of resources.¹ As we read the debate on the health system many of these benefits could be said to be the benefits flowing from the development of an ehealth system in general.

The Council certainly accepts that the keeping of medical records should not remain in the 20th century. Like all other record keeping processes in our modern society medical records should move on to an electronic system. However, as has been recognized on many occasions health information is amongst some of the most sensitive of information. The damage that can be done to a person by the release of their health records is significant. Accordingly, in the Council's view we need to proceed cautiously so as not to take steps which may adversely affect the privacy rights of individuals in relation to their health information.

It is in this context that we observe comments such as that by the Australian Health Information Council ("AHIC") in its ehealth Future Directions Briefing Paper delivered to the Australian Health Minister's Advisory Council on 4 October 2007 at page 16:

"AHIC's main message to AHMAC is that it sees this debate about benefits realization and economic value of ehealth as a distracting and mostly futile exercise. The fact is that ehealth will not save money for treasuries.

Ehealth is a key enabler *among others* of raised productivity and efficiency a more effective and efficient workforce and higher quality, safer and more accessible care in multiple locations producing better health outcomes. ...ehealth is simply a tool (and cost) of doing business in 21st century health care."

In her submission to the *Healthconnect Interim Research Report and Draft Systems Architecture (January 2004)* the Privacy Commissioner observed at paragraph 23 that:

"Research published in 2001, for example, disclosed that one in ten respondents to a South Australian survey were not confident that health care providers keep and use information responsibly while US research concluded that over half of US adults...say the shift from paper record keeping systems to computer based systems makes it more difficult to keep personal medical information private and confidential. Such concerns raise the possibility that individuals may refuse to participate."

In fact, the overseas evidence would support the proposition that privacy is critical to the delivery of good health care.

¹ These benefits are by no means uncontroversial, see Terry & Francis: *Ensuring the Privacy and Confidentiality of Electronic Health Records* 2007, University of Illinois Law Review 681 at 692 and following

3. **Decentralised Database**

On 7 July 2009 I wrote to the Minister seeking details of the proposed ehealth system which had been discussed in the media. To date I have received no response to that correspondence. In the circumstances then the Council has only a very limited idea of exactly how the ehealth system will function. However we take it from the comments at pages 20 to 21 of the discussion paper, it is proposed to create some form of centralized database from which apparently patients will be able to choose data to include on an electronic card.

The Council opposes the creation of a centralized database or linking of databases to create in effect a centralized database. A centralized database of this nature is a honey pot for fraudsters and for public servants and other government officials. In our view the creation of some form of centralized database or central networking of existing databases flies in the face of the alleged consumer focus of this system.

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 potential for misuse of a database combined with a unique identifier is well demonstrated 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.”²

4. **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*.³ At page 16 when commenting on various electronic health records in the UK the report said:

² Karen Curtis, Federal Privacy Commissioner, in a speech to the Second International Policing Conference, 3 November 2004

³ March 2009

“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.

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 in the briefing paper referred to above at page 23 where it is said:

“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

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

patient identifier and the creation of large databases of identified patient information.”

Our Canadian colleagues at the British Columbia Civil Liberties Association have pointed to the possibility of making use of the much cheaper open source software system known as “OSCAR”.

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.⁵

5. **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.

6. **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 making reference to the questions as numbered in the paper.

Question 6

The following comments on the secondary uses for which information can be put simply reflect comments which we have made on previous occasions in relation to privacy:

1. The release of identifying data for research purposes should only occur when there is no other way of carrying out the research.
2. The threat to health, life or safety should be imminent.
3. We oppose a general exemption for the protection of the public revenue. Like the Queensland Parliament’s Legal, Constitutional and Administrative Review Committee⁶ the Council is concerned about the breadth of the “protection of the public revenue” exception because of the

⁵ Terry & Francis Op cit pages 721 to 724

⁶ Privacy in Queensland (Report No. 9)

prospects for it to be used for data matching. In our view disclosure should only be made with the certification of the Privacy Commissioner

Question 7

We observe that the office of the Privacy Commissioner in its March 2007 Consultation on the Privacy Blueprint-Unique Health Identifiers at paragraphs 100 to 105 raised questions about the need for the health identifier organization to collect address details. We query whether the issues raised by the office of the Privacy Commissioner have been adequately addressed.

Question 13

It is our view the existing regulations and administrative arrangements need to be audited by the Privacy Commissioner and the Auditor General to ensure that they are adequate.

Question 18

The Council supports a strong anonymity principle. It is our view that it should be couched in similar terms to that contained in the Northern Territory Privacy Principles.

Questions 21 and 22

This raises the very difficult issue of trying to ensure that private providers to government are subject to the same accountability mechanisms that are applied to public service providers. The writer has some familiarity with Commonwealth government contracts of ten years ago which usually included dispute resolution procedure clauses which compel the providers to establish some sort of dispute resolution procedure initially between the contractor and the customer. The Department's attention is drawn once again to the Report of the Senate Committee on *The contracting out of government services* where the Committee cites evidence from Dr Seddon that where contract disputes are settled without going to litigation, the settlement generally favours the contractor.

There are three fundamental problems with contract based dispute resolution procedures the:-

1. Customer is of course not a party to the contract.
2. Amounts involved are usually so small as to make litigation uneconomical.
3. Remedies provided to the government are either potentially unenforceable or of no benefit to the customer.

Contractual remedies usually involve either the termination of the contract or some form of liquidated damages. Termination of the contract is obviously a very harsh remedy which in the writer's experience, the government is reluctant to use because it will disadvantage many people who depend on the service provider. That is especially so in remote areas.

Liquidated damages also cause legal difficulties in that if they are classified by the Courts as a penalty they are unenforceable. Certainly in numerous

judgments the Courts⁷ have given governments latitude when it comes to striking down liquidated damages clauses as penalties. However, assuming that the liquidated damages clause is not a penalty the person that is entitled to the money is the government and not the customer.

Of course, the customers might be said to have the option of taking their business elsewhere. This is hardly an option for persons in isolated communities or where there are costs involved in changing suppliers (be they monetary or otherwise).

No doubt the Senate Committee was correct in its view that citizens making use of private service providers should not have any lesser rights than citizens making use of government service providers.

The Council certainly thinks that a relatively simple and cheap mechanism should be made available. The Privacy Commission is an obvious candidate for this role.

Question 23

We agree that the requirements for dealing with complaints including independent administrative or judicial mechanisms or appropriate sanctions from breaches of the law are vital. We would respectfully suggest that the details of these mechanisms should be contained in this discussion paper. It is entirely impossible for us to comment on any proposals about which we know nothing.

Question 25

The Council accepts the argument of the ALRC report that like the obligation of confidentiality at common law, the Privacy Act should extend to the information of deceased persons. Furthermore, there should, as the Law Reform Commission recommends, be specific procedures to enable relatives and other people in appropriate circumstances to have access to information relating to deceased persons.

The effect of the recommendations of the Law Reform Commission is the principles relating to use and disclosure, access, data quality and data security should apply to the information of deceased persons. We agree with those recommendations.

Question 28

We oppose the proposal to amend collection principle 2.5(c) to allow the collection of sensitive information where “there is a serious threat to an individual’s welfare”. We consider that this is too broad an exception. In fact, as we have stated previously our view is the exception should be stated even more narrowly to be only where it is necessary to prevent or lessen an “imminent” serious threat to life or health of an individual. We are particularly concerned to note that this proposal has not been considered by

⁷ For example, *Clyde Bank Engineering & Ship Building Co Ltd v. Don Jose Ramos Yzquierdo Y Castaneda & Ors* [1905] AC pages 10 – 11 especially

the Law Reform Commission in its recent comprehensive inquiry in relation to these issues.

The concept of a person's individual welfare is far too broad. If the department faces particular issues with homeless persons or mentally ill persons then they should seek a specific public interest determination from the Privacy Commissioner. In that process specific guidelines and rules can be laid down.

Question 30

We oppose the modification to Uniform Privacy Principle 5.1(c) for the same reasons that we opposed the modification to 2.5(c). We agree with the modification to principle 5.1(g) making it a requirement that sensitive information can only be used or disclosed for research if that research cannot be carried out with de-identified information and it is unreasonable or impractical to seek the consent of the person involved.

In relation to the disclosure of information where a person is suspected to be missing or deceased we agree with the position of the Australian Law Reform Commission that it is not desirable to create this further specific exception preferring that an agency or organization make use of the other exceptions which we think would cover most cases. Where the other exceptions do not apply then a specific public interest determination should be sought.

Question 33

The council strenuously opposes the release of personal information for marketing purposes except with the express consent of the person to whom the information relates.

Questions 38 and 39

We support strong restrictions on the use of the identifier. We observe in this regard that the New South Wales Ministerial Advisory Committee in its report on Privacy and Health Information at page 15 made it clear that the use of the identifier should be strictly limited to the ehealth system with a clear prohibition on its use outside that system. We support any regulation consistent with that principle. To the extent that the proposal in the paper for the modification of Uniform Privacy Principle 10 is inconsistent with that proposition, we oppose it.

Questions 40 and 41

We can accept that there should be an exception in relation to the transfer of data outside of the country only where it is necessary to "lessen or prevent an *imminent* serious risk to life, health or safety of the person and the person be immediately advised what information has been released and to whom."

PREPARED ON BEHALF OF THE QUEENSLAND COUNCIL FOR CIVIL
LIBERTIES BY MICHAEL COPE, PRESIDENT

Brisbane, 14 August 2009