

6 March 2015

National Health Board  
Ministry of Health

## **Shared Electronic Health Records: The Management of Withheld Information in Today's Health Care Environment (A Discussion Document)**

Thank you for the opportunity to comment on the Ministry of Health's discussion document, '*Shared Electronic Health Records: The Management of Withheld Information in Today's Health Care Environment*' (the Discussion Document).

The Discussion Document aims to provide a basis for consultation on how to manage the rights of individuals in relation to personal health information held in Electronic Health Records (EHR) and Shared Care Record systems. Specifically, it addresses ways to facilitate an individual's right to control access to their personal health information, while maintaining access for health care practitioners in order to ensure the continuity of care provided.

I understand that you are currently seeking feedback on the Discussion Document from various key stakeholders before it goes to Cabinet for consideration and that the Discussion Document will not be released for general submissions until later this year. My comments are therefore focussed on the Discussion Document's content, and not on the questions for submission. I would welcome the opportunity to provide substantive submissions once the Discussion Document is released more generally.

### **Background**

As the Health and Disability Commissioner, I am charged with promoting and protecting the rights of health and disability services consumers, as set out in the Code of Health and Disability Services Consumers' Rights (the HDC Code). One of my functions under the Health and Disability Commissioner Act 1994 (the HDC Act) is to make public statements in relation to any matter affecting the rights of health or disability services consumers.

I have made comments, set out below, on those parts of the Discussion Document that I consider may benefit from input from my Office.

### **Comments**

#### *Right 1 of the Code*

At paragraph 6.4, the Discussion Document states:

“The responsibilities for managing health information are reinforced in the HDC Code of Health and Disability Services Consumers' Rights which states that every Consumer has the right to have his or her privacy respected.”

Right 1 of the HDC Code relates to physical privacy, not information privacy. Health information privacy issues are outside my Office's jurisdiction, and are instead dealt with by the Office of the Privacy Commissioner.

### *Capacity*

In Section 13 of the Discussion Document (entitled 'Other Considerations') there is a discussion of health information privacy rights and competence, particularly in regards to children and the intellectually disabled. I have some concerns about the content of this section.

Much of the discussion regarding competence in this section revolves around Right 7 of the Code, which relates to the right to make an informed choice and give informed consent in regards to the provision of health and disability services. The Discussion Document applies the presumption of competence set out in Right 7 to the question of whether a child can deny their parents access to their personal health information, and determine whether information should be withheld from health professionals.

As a matter of law, the rights set out in the HDC Code only apply to the provision of health and disability services. The HDC Code does not provide any rights in respect of personal health information. I suggest you engage with the Office of the Privacy Commissioner in this regard.

The Discussion Document's application of Right 7(4) to a consumer's rights in relation to personal health information is also problematic. Right 7(4) sets out the situations in which care can be provided where a consumer (or their legal representative) is not able to give informed consent themselves. The Discussion Document suggests that Right 7(4) means that:

“...in situations where the Consumer is deemed incompetent by the health practitioner responsible for updating the shared EHR [Electronic Health Record] – and in the absence of a guardian or person with power of attorney for the impaired person – that they may be required to make decisions on behalf of the Consumer as to whether any portion of their shared EHR should be withheld.”

As with Right 7 more generally, Right 7(4) is designed specifically in regards to the process of obtaining informed consent for health care and disability services. It does not apply to obtaining consent for health information processes.

I would also express caution at the wording of paragraph 13.11, which states:

“As with children, the issue of whether a person with an intellectual disability has the right to see their shared EHR and determine who can view it and whether parts of the record should be withheld, again turns on the issue of competence.”

I do not consider this to be an accurate statement of the legal position. A person's information privacy rights do not cease to exist simply because the individual lacks competence. Rather, a lack of competence usually means that the right is exercised on that individual's behalf by a representative. The Discussion Document's wording of the relevant consultation question is perhaps more accurate:

“Given that children and those with intellectual disabilities have the same rights as adults with regard to how their health information is managed...”

#### *Accountability of health practitioners*

At paragraphs 14.7 and 14.8, the Discussion Document addresses whether a health practitioner should be held responsible for any adverse outcomes of their clinical decisions where the patient has withheld relevant information. The Discussion Document concludes that, in such a situation, “they should not be held responsible.”

I consider this statement is too definitive. When issues of accountability come before statutory decision makers such as myself, all the circumstances of the particular case are taken into account. While this will include a consideration of what information was known to a practitioner (as well as what they should have known), this is but one consideration among many. It is therefore difficult to make definitive statements about when a health practitioner will be “held responsible”, without reference to the specific circumstances. I note that, in the context of New Zealand’s medico-legal system, it also isn’t clear what is meant by a practitioner being “held responsible”.

Secondly, I am thoughtful as to whether this is an appropriate issue on which to seek submissions. Ultimately, issues of formal accountability in this area are determined by employers, and by statutory entities such as my Office and the regulatory authorities constituted under the Health Practitioners Competence Assurance Act 2003. I would be surprised if any guidelines developed out of the Discussion Document consultation process make a statement about when a practitioner will be “held responsible” for failures in care.

#### *Withholding information from consumers*

At paragraphs 14.19-14.24, the Discussion Document addresses whether health practitioners should have the ability to “seal” certain information about the consumer, so that the consumer cannot have access to it. The Discussion Document suggests that such information might include a note that a nurse should be in attendance when a doctor sees the consumer, or that a young consumer’s parents are involved in a custody dispute. It also suggests that this could be useful:

“...where the health practitioner has made a provisional cancer diagnosis but does not want to advise the patient of this until further tests have been undertaken and the diagnosis can be confirmed.”

The Discussion Document acknowledges that individuals have the right to view all information pertaining to them, unless the information can be withheld under one of the exceptions set out in the Privacy Act; but suggests that release of the information could be “delayed”. I suggest you seek legal advice on the appropriateness of such an approach. The comment in relation to not keeping a consumer up to date with information about a provisional cancer diagnosis is particularly concerning to me. If a practitioner were to take this approach it could, depending on the circumstances, be regarded as a breach of Rights 6(1)(a), 6(1)(f) and 6(1)(g) of the HDC Code.

#### **Conclusion**

I trust that you find these comments of assistance.

I look forward to providing further comments as part of the wider consultation process.