



Consumers
Health Forum
of Australia

12 April 2012

Senate Finance and Public Administration Committees
PO Box 6100
Parliament House
CANBERRA ACT 2601

Dear Sir/Madam,

National Health Reform Amendment (Administrator and National Health Funding Body) Bill 2012

The Consumers Health Forum of Australia (CHF) welcomes the opportunity to provide input on the *National Health Reform Amendment (Administrator and National Health Funding Body) Bill 2012* (the Bill), which was referred to the Finance and Public Administration Legislation Committee for inquiry and report.

CHF is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF's feedback on the Bill focuses on the protection of a health consumer's right to privacy and confidentiality, in particular, as it relates to the notion of informed consent. This is an issue of great significance to our members and stakeholders, and one which has been reinforced through years of consumer consultation, including our recent consultations on the Personally Controlled Electronic Health Record (PCEHR) system.

Our specific concern with this Bill relates to those aspects covering the disclosure, publication or dissemination of information about a consumer that takes place with his or her consent. This includes:

Section 277: Disclosure with consent

An official of the Funding Body may disclose protected Funding Body information that relates to the affairs of a person if:

- a) The person has consented to the disclosure; and*
- b) The disclosure is in accordance with that consent.*

It also includes:

Section 279: Protection of patient confidentiality

Protection of confidentiality

2) In the performance of the person or body's functions, the person or body must not publish or disseminate information that is likely to enable the identification of a particular patient.

3) Subsection (2) does not apply if the publication or dissemination of the information takes place with the consent of:

a) if the patient is aged at least 18 years – the patient; or

b) if the patient has died but is survived by a person (the surviving partner) who was:

i) his or her partner immediately before he or she died; and

ii) living with him or her immediately before he or she died;

the surviving partner; or

c) in any other case – an individual who, under the regulations, is authorised to give consent to the publication or dissemination of the information.

It is CHF's view that these aspects of the Bill must be strengthened to clearly outline that the consent that is sought must be *informed* consent, which would include providing the consumer with all the information that could be relevant to their decision, including both short and long-term implications. We believe this could be reflected in the Bill, either through the term 'consent' being replaced by 'informed consent' in the body of the legislation, or through the inclusion of a definition of 'consent' indicating that this refers to informed consent.

We note we have drawn attention to this same concern in our comments on the legislation relating to the establishment of the Australian Commission on Safety and Quality in Health Care as a permanent body, and the establishment of the National Health Performance Authority and the Independent Hospital Pricing Authority.

We appreciate the opportunity to provide input to the Inquiry. If you would like to discuss these comments in more detail, please contact CHF Policy and Project Officer, Ms Dewi-Inala Zulkefli.

Yours sincerely,

Carol Bennett
CHIEF EXECUTIVE OFFICER