Consumers Health Forum of Australia

9 September 2011

Ms Christine McDonald
Committee Secretary
Senate Finance and Public Administration Legislation Committee
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Ms McDonald

Further information on informed consent

The Consumers Health Forum of Australia (CHF) provided evidence to the Senate Finance and Public Administration Legislation Committee Inquiry into the *National Health Reform Amendment (Independent Hospital Pricing Authority) Bill 2011* on 7 September 2011. We were asked to provide additional information to the Committee about any work or publications we have completed in relation to the issue of informed consent.

CHF has undertaken a range of work relating to informed consent. Much of this work relates to informed consent for treatment, and the need for consumers to be fully informed about potential risks and benefits, as well as costs (informed financial consent) and other implications. Issues surrounding informed consent for information sharing between health professionals have also been discussed in CHF's work on eHealth. In relation to these forms of informed consent, health consumers have consistently raised issues around the distinction between consent that is informed and consent that is not. Consumers expect to be provided with all the information that could be relevant to their decision, including both short and long-term implications.

In relation to information sharing between agencies, CHF's most relevant work has related to the use of consumer health data for research. A major project conducted in the late 1990s, *Consumers' Health Information for Research Purposes*, considered issues around informed consent for information sharing of both identified and deidentified health information in detail. A summary of findings relating to informed consent is below, and the full project report is available on CHF's website.

Outcomes of the project included a recommendation for nationally consistent standards to govern the use, linkage and disclosure of consumers' personal health information, to address principles including:

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- All groups, organisations and individuals, including governments, health service providers, health administrators, researchers and health insurers, have a responsibility to seek the informed consent of consumers before making use of personal health information.
- When information about the content, storage and use of personal health information is conveyed to consumers, it must be in a language, style and format that are comprehensible to them.
- Consumers must be given the opportunity to participate in decisions about the management and use of personal health information.
- Consumers must have a right of redress where there is evidence that personal health information has been misused.

The report also discussed what constitutes informed consent; for example:

> *When is consent truly informed? This is a contentious issue. There is always a power imbalance between the researcher and the researched based on status, knowledge and expertise, making the negotiation of informed consent a troublesome matter at times. If information about the research or related activity is withheld, any consent that is obtained is obviously not informed. At the same time, if consumers who are keen to see research go ahead on a topic of great concern to them give their consent without examining the implications of the research with due care, that consent is not really informed either. While the old maxim of caveat emptor (let the buyer beware) is relevant here, it should also be an obligation of the researcher/s to ensure to the best of their ability that consumers have weighed up the information put before them.*

CHF considers that the messages around informed consent that emerged from this project are relevant and applicable to the sharing of identifiable consumer health information by new national health reform bodies.

Please do not hesitate to contact me if you would like any more information.

Yours sincerely

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