



Consumers Health  
Forum **OF** Australia

ONLINE SURVEY CONSULTATION

**Response to Proposed  
Standard for Informed Financial  
Consent**

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Consumers Health Forum of Australia (2019)  
*Response to Proposed Standard for Informed  
Financial Consent*

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# CONTENTS

## **Contents**

Introduction..... 4

Comments..... 5

    Context Feedback ..... 5

    Principle Feedback..... 6

    General Feedback..... 7

# Introduction

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Consumers Health Forum of Australia (CHF) appreciates the opportunity to provide feedback in response to the proposed Standard for Informed Financial Consent (the Standard), developed by the Cancer Council Australia, Breast Cancer Network Australia, CanTeen and Prostate Cancer Foundation. CHF is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health care consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. At the heart of CHF's policy agenda is patient-centred care.

CHF support the development of a nationally consistent guide or standard for informed financial consent. We believe informed financial consent is a necessary component of informed consent and forms an important part of consumers' decision-making process about proposed treatments. There are many benefits for improving informed financial consent including strengthening the ability of consumers to make informed choices about their health care options. Consultations previously undertaken by CHF only reinforces the importance of developing a nationally consistent standard for informed financial:

- Many consumers report being unsatisfied with their personal experiences of informed financial consent when seeking and / or receiving care; and
- In general consumers reported that information financial consent involved the provision of information about costs of their treatments before they accept it, in the form of written, itemised quote outlining what costs are, and are not, covered.

Today, there continues to be a difference between what doctors and health professionals constitute informed financial consent and what consumers experience.

Our response is informed by our recent position statement on Specialist Fees and Performance Transparency<sup>1</sup> and consumer members of our Safety and Quality Special Interest Group. A total of five consumer members for the special interest group provided feedback.

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<sup>1</sup> Consumers Health Forum & the University of Melbourne 2019, 'Specialist Fees and Performance Transparency – potential for improvement', Position Statement, accessed 7 February 2019, [https://chf.org.au/sites/default/files/190129\\_position\\_statement\\_-\\_specialist\\_fees\\_and\\_performance\\_transparency\\_roundtable.pdf](https://chf.org.au/sites/default/files/190129_position_statement_-_specialist_fees_and_performance_transparency_roundtable.pdf)

<sup>4</sup> Consumers Health Forum of Australia

# Comments

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## *Context Feedback*

**The context/background of the standard is explained in the Executive summary, Explanation, Framing the standard and Why Australia needs a standard for informed financial consent sections, on pages 2 to 5.**

### ***'Explanation' - Feedback***

In this section of the Standard, the Commonwealth Department defines informed financial consent as 'the provision of cost information to patients, including notification of likely out-of-pocket expenses (gaps), by all relevant service providers, preferably in writing, prior to admission to hospital or treatment.' One consumer member felt that the Department's definition of informed financial consent would most likely be challenged by consumers for the following reasons:

- Regarding consent comprising 'the provision of information': consumers would expect the opportunity for two-way communication and then a formal agreement process.
- Regarding 'likely' costs: consumers would expect to be provided with at least a range of costs linked to potential circumstances. If a provider cannot do this, does it mean they cannot predict, and have not talked about, all the possible clinical outcomes?
- Regarding 'preferably' writing': if it can be said, it can and should, in this case, be written down.

Furthermore, one consumer member suggested including the following in this section to put emphasis on the importance of informed consent:

*"Informed consent, including informed financial consent, and the context in which this occurs, is a health right. In 2008, all Ministers agreed that The Australian Charter for Healthcare Rights, has seven rights, one of which is Communication: the right to be informed about services, treatment options and costs in a clear and open way".*

CHF support the addition of this information.

While another consumer member suggested the most valuable information for consumers in this section was "Financial disclosure is defined in the Australian health context as not only how much a procedure will cost but, crucially, whether there are alternatives that offer similar benefits at less or no cost to the patient. The omission of cost information reduces informed financial choice and increases the potential for significant financial and health disadvantage". The consumer highlighted that the effects of which are experienced most by people of lowest socioeconomic status and may lead patients to choose inferior cancer treatment or decline treatment completely.

### ***'Why Australia needs a standard for informed financial consent' – Feedback***

CHF support the inclusion of indirect 'out of pocket expenses' that patients often encounter on top of the direct costs of treatment, such as loss of employment, travel, accommodation. Consumers need to consider these additional costs and genuine informed consent and

informed financial consent would include these considerations as people work through their options.

The Standard is not a consumer facing document but is rather directed towards doctors and health professionals. While this is clearly stated in the Standard, consumer members suggested a nationally consistent guide or standard for informed financial consent for consumers should be developed. Additionally, consumers were surprised and confused to see that this document was not consumer facing, especially given they perceived the target audience of the Cancer Council to be patients, carers and potential donors, not doctors or health professionals.

### ***'Framing the Standard' – Feedback***

One consumer member suggested the most valuable information for consumers in this section was 'it is critical that doctors drive transparency and communication about service charges and costs with patients to encourage and enable patient participation in an informed discussion about their care options'. The consumer suggested improved transparency about treatment options, charges and expected out-of-pocket costs can enable patients to be more engaged in conversations about their options with their doctor.

### ***Principle Feedback***

***The principles outline the quality components of informed financial consent and are outlined on pages 6 to 7 of the Standard.***

#### ***Principle: Transparency of service details***

***This principle guides doctors to disclose their service charges.***

CHF support increased fee transparency and price disclosure. This would raise consumer awareness of 'out of pocket costs' and support people to make more informed decisions about their healthcare. Furthermore, increased fee transparency may increase competition between provider and therefore reduce fees. However, there is potential for data on fees to be used by providers as a collective device, resulting in higher prices overall. Information on fees without context does not help consumers understand what a 'reasonable' cost is for each service or how fees relate to quality. First, we would recommend making the data currently being collected by the Government on doctors' fees public via a website. If consumers find that useful and it does not result in significant adverse effects, then this can be expanded to include additional data on fees supplied by providers.

#### ***Principle: Referral to independent information***

***The principle guides doctors to inform patients of available resources about financial costs.***

While there was no feedback received relating directly to this principle from consumer members, CHF support this action of the Standard and believe it forms an important aspect of informed consent. We believe it is particularly important that information is accessible to consumers in a way that they can understand.

***Principle: Doctor-patient communication***

***The principle outlines the conversation about expected costs as part of healthcare planning.***

There are existing resources, such as the ‘5 questions’ model developed by Choosing Wisely Australia, which could be used to promote informed financial consent and support the implementation of this principle. Another column for the Standard, between ‘action’ and ‘level of responsibility’ could include ‘resources’ that include links to existing resources that may help the doctor or practice implement the voluntary action.

***Principle: Transparency of benefit***

***The principle encourages doctors to avoid claiming a higher fee based on quality outcomes without evidence.***

There is little evidence to support the relationship between cost and quality of care in the Australia health system. Despite considerable work from the Royal Australasian College of Surgeons to make it clear that high fees do not necessarily guarantee quality of treatment, care or outcomes, consumers falsely assume that higher cost services are high quality than lower priced alternatives. This highlights the need for more transparency around quality measure as well as addressing fee variation. CHF support this principle of the Standard, however as this is voluntary, we worry that this will not be widely implemented by doctors and health professionals across Australia.

***Principle: Commitment across practice and community***

***The principle guides doctors to demonstrate their commitment to reducing out-of-pocket costs in their community.***

Increased fee transparency and price disclosure would raise consumer awareness of out of pocket costs and support people to make more informed decisions about their healthcare. Refer to our feedback above for the principle on ‘transparency of service details’.

***General Feedback***

CHF encouraged members of our Safety and Quality Special Interest Group to provide feedback to CHF to help inform our response. Consumer members provided the following general feedback:

- Consumer members felt it was unnecessary for the Cancer Council (or any other organisation) to develop “their own guides [standards] to informed consent or financial consent” and felt there were already good existing examples from reputable bodies that advise practitioners, including the Royal Australian College of General Practitioners (RACGP), Royal Australasian College of Surgeons (RACS) and the Royal Australasian College of Physicians (RACP).
- To avoid duplication, consumers agreed it would be more beneficial for CHF to encourage NGO’s to refer to these existing documents. One consumer felt, at the very least, if NGO’s are creating their own guide [standard], it should be based on the other documents that already exist.
  - One consumer highlighted that the current [RACGP Standards \[5<sup>th</sup> edition\]](#) already requires a practice to do some of what is already being

covered in the Standard and is covered as part of accreditation. For example, Criterion C1.5: Costs Associated with Care Initiated by the Practice.

- Consumers members found it ‘problematic’ that the Cancer Council were developing the Standard when consumers viewed “the Cancer Council as a charity with their audience being patients, carers and potential donators to the charity, that is, **NOT** doctors”. Therefore, having a Standard for informed financial consent that is targeted towards individual doctors and practices seemed puzzling to come from Cancer Council. Consumers suggested it might be better if the document came from, the Oncologists, for example.
- These views represent four of the five consumer members who provided feedback.

CHF strongly believe that informed consent extends beyond demonstrating a person has received a piece of paper. One consumer member said:

*“There is a range of well established, evidence-based programs designed to skill health professionals to ensure people are informed. Some of these positions the health professional as the expert in the conversation while others support an approach closer to shared or supported decision-making. Consumers are entitled to the latter approach”*

The consumer member suggested the UK College of Surgeons, ‘Consent: Supported Decision-Making – a guide to good practice<sup>2</sup>’ provides a useful perspective on provider obligations regarding consent.

From a consumer perspective, the most important question **is how implementation of the Standard may be monitored and used for accreditation, for the benefit of consumers**, which does not seem to be addressed in the Standard. In addition to the development of a nationally consistent standard or guide for informed financial consent, CHF believe the next steps are to:

- Agree on legally enforceable sanctions for the failure to obtain informed financial consent; and
- Clarify legislative issues relation to informed financial consent, specifically in relation to unexpected events and unconscious patients<sup>3</sup>.

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<sup>2</sup> Royal College of Surgeons 2016, ‘Consent: Supported Decision-Making – a good practice guide’, accessed 7 February 2019, <https://www.rcseng.ac.uk/library-and-publications/rcs-publications/docs/consent-good-practice-guide/>