

STANDARD FOR

Informed financial consent



Collaborative initiative of Breast Cancer Network Australia, Cancer Council, Canteen and Prostate Cancer Foundation of Australia



Why Australia needs a standard for informed financial consent

Australia has a mixed healthcare system financed by public and private insurance, and direct contribution from patients for services not covered by insurance.

Cancer is often a complex and long-term condition. Treatment may require different doctors from various settings including, hospital, out-patient, community care, and can be delivered across both public and private sectors. These multiple service interactions can create fragmentation in the continuity of care, leading to confusion about who pays for which service, resulting in unexpected out-of-pocket costs. Services are increasingly offered in both the public and private sectors, and patients with private health insurance may have a perception that all services and charges will be covered by their insurer. In addition, patients treated in the 'free' public system may have no understanding of costs they may incur, including, take home medications, dressings, medical equipment and parking.

Higher out-of-pocket costs are reported by patients with private health insurance and patients with a recent cancer diagnosis. Patients commonly cite costs associated with traveling to treatment, and direct costs of treatment as highest sources of out-of-pocket expenses, which can influence their treatment decisions, leading to potentially unsafe or sub-optimal care decisions. The loss of household income due to temporary and permanent changes to employment add to the experience of out-of-pocket expenses and if left unaddressed, can lead to financial hardship. People affected by cancer report borrowing money, accessing superannuation early, selling investments, re-mortgaging assets, increases in their partners' working hours, and credit card limit increases to meet treatment costs and everyday living expenses.

A higher service provider fee is not an indicator of increased clinical benefit or quality of care. There is no standard system to capture and report outcome performance in Australia. Therefore, the ability to benchmark and compare services, and measure improved performance over time is limited. This restricts the patient's ability to assess quality outcomes against the degree of out-of-pocket costs they are comfortable to pay when considering their care options. Other indicators of quality, including participation in multidisciplinary teams, provision of care coordination services and College quality audits could be communicated to patients to help them consider options that are right for them.

Although the benefits and harms associated with different treatment options are discussed with patients, some patients continue to experience unexpected costs after treatment. High out-of-pocket costs and prevalence of hidden expenses indicate that improvements can be made to the upfront transparency of fees and costs associated with treatment options.

Intent of the Standard

This standard for informed financial consent ('the standard') outlines the elements to support informed financial consent as a component of informed consent for medical treatment.

This is in the context of a shared care conversation regarding the risks and benefits of treatment options. The American Society of Clinical Oncology's *Guidance Statement on the Cost of Cancer Care* recommends that 'patient-physician discussions regarding the cost of care are an important component of high-quality care'¹. This standard reflects this component of high-quality care and plays an important role in delivering appropriate information and reducing unexpected out-of-pocket costs.

The goal of the standard is to guide discussions to include cost of care between patients and health care professionals to help make informed decisions.

The standard defines the level of appropriate information that people should expect to be offered. It guides doctors and service providers to deliver information on the financial implications of treatment options, both direct and indirect, ensuring that service charges are understood by the patient prior to undergoing treatment, where possible. The standard also acknowledges the broader practice and health system responsibilities to facilitate the principles. The standard guides doctors and service providers to be transparent about the fees they charge, open to having conversations about costs with patients, and to support patients in obtaining cost information from other doctors or service providers involved in

their care. Practice team members can assist in the provision of information however, the doctor retains ultimate responsibility for facilitating informed financial consent with their patients.

This standard is one component of delivering quality care. Principles outlined in the standard are not meant to be prohibitive or create additional burden on the doctor or service provider however, they represent a quality of care standard to facilitate financial disclosure. It is critical that doctors or service providers drive transparency and communication about service charges and potential out-of-pocket costs with patients to encourage and enable patient participation in an informed discussion regarding their care options.

Australian doctors have both an ethical and professional responsibility to disclose information about treatment costs to support informed financial consent prior to treatment. The standard is focused on informed financial consent facilitated by doctors or service providers in oncology diagnostic and treatment services however it has broader application and can be adopted by other health professionals.

Explanations for the purpose of the standard

Informed financial consent is defined by the Commonwealth Department of Health 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'².

It is an ongoing process and is revisited over time as treatment plans change, ensuring that the patient continues to understand their options and is empowered to make decisions about their care.

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'³.

Shadow billing is the practice of separate invoicing for expenses that are not part of the bills submitted via Medicare or the patient's insurer. These fees may be termed a 'booking' or 'administrative' fee by the doctor or service provider but are excluded from public records of fees paid, which then do not reflect the true cost paid for a service.

FEE SETTING: In Australia doctors set their own service fee. Private service providers often charge a higher fee than that charged to private patients in the public sector. Private service providers set their fees to not only cover the doctor's service, but additionally to fund services within their practice that support the practice to deliver comprehensive care but do not attract Government funding. This includes practice facilities and staff, and members of the clinical support team, such as specialist nurse consultants. This can represent a reasonable charge above the doctor's service. Private health insurance may cover additional expenses after the Medicare reimbursement however, these are individual arrangements such as through Gap Insurance Cover.

AUSTRALIA'S HEALTH SYSTEM: Cancer services are often available as both public and private service

options. Decisions about which doctor or service provider to see are made at the commencement of treatment can be difficult to change later. For patients who begin their journey in the private system, the ability to meet ongoing out-of-pocket costs can become problematic over time as costs accumulate. Patients considering or receiving care in the private system must be advised that some aspects of treatment may not be covered by their health insurance and that they can be supported to switch to public care at any point.

LEVELS OF RESPONSIBILITY: The standard recognises the involvement of various people in the delivery of care to enable the principles outlined to facilitate informed financial consent. This includes:

- **Doctor** the individual treating or providing care to the patient.
- **Health service** represents the practice or place in which a doctor provides a medical service, and the institutional processes or network within which the doctor works, such as in providing administrative services and supportive care.
- **Health system** the broader network of services, both publicly and privately funded, either state and territory or federal, provided to people. This could also include non-government organisations.

MEASURING ACHIEVEMENT: The standard articulates a purpose and corresponding indicator for each principle to assist in the self-assessment and monitoring the implementation of each principle to facilitate informed financial consent.

² DoH. *Out-of-pocket expenses for private medical treatment (Informed Financial Consent)*. 8 March 2017. Comm. of Australia.
³ Currow, D & Aranda, S. *Financial toxicity in clinical care today: a menu without prices*. 20 June 2016. MJA, vol. 204 (11).

PRINCIPLE 1

Transparency of service details

Indicator 1: Service details are transparent



Purpose

To enable patients to be informed upfront about fees and potential out-of-pocket costs and remain informed to reduce unexpected out-of-pocket costs.

KEY TASKS

Doctors participate in the following:

- Public disclosure of average fees charged for each of the most common services billed by doctors;
- Public disclosure of doctor's practice status (public, private or mixed);
- Develop a fee estimate process for treatment that includes all costs associated with all doctors and other service charges involved in the delivery of care;
- Encourage and support patients to contact additional doctors or service providers involved in their care for their exact fee;
- Develop a process to update patients about service fees if treatment plans change. Doctor provides relevant information to the patient and for display their charges to the general public.



Levels of responsibility

- **Doctor** provides relevant information to the patient and for display their charges to the general public.
- **Health service** through practice team can provide information about cost under direct instruction of the doctor, and institutional processes support doctors to understand institutional arrangements and publish institutional level fee structures.
- **System** provides the platform on which to display the information.

PRINCIPLE 2

Referral to independent information

Indicator 2: Patients are referred to independent information



Purpose

To assist patients to access additional resources that support them to understand potential costs, their impact, and options to reduce financial burden.

KEY TASKS

As part of doctor – patient discussions about the risks and benefits of care options and cost, the doctor is required to inform the patient of available resources related to financial costs, such as independent information on care pathways, health system costs and options, provision of access to support services, such as financial counselling, and other patient information resources that are appropriate to their needs, level of understanding and capacity to engage in their healthcare planning.



Levels of responsibility

- **Doctor** is responsible for making the patient aware, referring and informing the patient of resources or information.
- **Health service** provide resources or information on behalf of the doctor and offer supportive care services.
- **System** supports availability and accessibility of information and resources.

PRINCIPLE 3

Doctor – patient communication

Indicator 3: Patients' rights to be informed are respected and upheld



Purpose

To ensure that each patient is provided with appropriate information about expected costs of treatment options for their condition, alongside risks and benefits of treatment, and provided support required to comprehend these options.

KEY TASKS

The patient has the right to ask the doctor about their charges, and expenses for related services, and to be provided with full disclosure of these expenses. The doctor must strongly advise patients to ask about costs, to be active and engaged in decisions about their treatment and care.

The doctor has a responsibility, under the requirement to receive consent, to engage in and/or initiate a conversation about expected costs and ensure the patient has understood their options prior to treatment. This conversation must include the following elements:

- A private doctor discloses where the equivalent procedure and care can be provided in the public system as a no or lower-cost service alternative; All the issues around convenience, cost, expertise and experience must be made clear to and understood by the patient during this discussion
- Disclosure of expected additional services associated with treatment such as diagnostic or anaesthetic services, hospital charges, supportive services such as allied health, and medicines that will incur a fee to the patient;
- Discuss the impact of different treatment options on indirect aspects of cost, including potential time off work due to side effects or intense treatment regimens;
- Provide service information to support patients to check coverage with private health insurance or Medicare Benefits Schedule listings;
- Where feasible, discussion is held at a time, place, and in a manner that supports the patient's right to choose, providing them with sufficient time, information and support to do so.



Levels of responsibility

- **Doctor** leads this conversation and support patients to engage in this conversation
- **Health service** team members can assist to explain fees and answer questions.
- **System** provide resources that may assist doctors to ensure the elements within the principle are met.

PRINCIPLE 4

Transparency of benefit

Indicator 4: Service details are evidence-based and transparent



Purpose

To protect patients from making decisions based on false or unproven claims from an individual doctor that may result in unnecessarily costly care.

KEY TASKS

A doctor commits to not charge a higher service fee based on a claim of better outcomes than another service unless they are able to defend this claim with published evidence which meets health literacy requirements available to the patient.



Levels of responsibility

- **Doctor** cannot charge a higher service fee based on claims of superior outcomes without published evidence to support the claim.
- **Health service** supports transparency of information where doctors do participate in data collection that produces evidence of better outcomes.
- **System** communicate this key message through education activities to patients.

PRINCIPLE 5

Commitment across practice and community

Indicator 5: Patient–decision making is supported across full care requirements.



Purpose

To recognise that addressing financial burden and reducing the experience of unexpected out-of-pocket costs is complex and requires a whole-of-system and community approach to address.

KEY TASKS

A doctor and/or health service commits to:

- Full financial disclosure,
- No shadow billing, including booking fees;
- Inform patients about the Medicare reimbursement, and disclose gap fees;
- Working with other doctors or service providers, and health services, also committed to full financial disclosure;
- Commitment to available reporting and benchmarking processes;
- No upward fee adjustment based on greater capacity to pay.



Levels of responsibility

- **Doctor** commitment to each point listed.
- **Health service** commitment to each point listed and ensure doctors within their practice or institution uphold this commitment.
- **System** makes doctors accountable to these commitments.

Useful resources

For patients

- [Informed Financial Consent patient information](#) – Cancer Council
- [5 questions to ask your doctor or health care provider before you get any test, treatment or procedure](#) – Choosing Wisely
- [Informed Financial Consent resources for doctors and patients](#) – Australian Medical Association
- [What to Expect \(Consumer resources of the Optimal Care Pathways\)](#) – Cancer Council
- [Financial Counselling Australia](#)
- [Commonwealth Ombudsman](#)
- Additional information can be obtained directly from your private health insurer.

For doctors and health services

- [Informed Financial Consent resources for doctors and patients](#) – Australian Medical Association
- [Informed Financial Consent Advisory](#) – Australian Commission on Safety and Quality in Healthcare
- [Optimal Care Pathways for health professionals](#) – Cancer Council
- [Informed Financial Consent patient information and resources](#) – Royal Australasian College of Surgeons
- [Guidelines for Informed Financial Consent](#) – Royal Australian and New Zealand College of Radiologists

Endorsing organisations

This standard for informed financial consent is endorsed by the following organisations.



