

## POSITION STATEMENT

### **Informed decision making – about cancer treatment options and costs**

#### **ISSUE**

Cancer patients and their advisers would benefit from written information about both clinical and financial aspects of their decisions for treatment, irrespective of whether treatment will be in the public or private sector. This information needs to be provided and discussed before commencement of any treatment.

#### **BACKGROUND**

A cancer diagnosis and consequent need for treatment is a shock to most people, so information provided verbally in this unfamiliar and stressful situation is usually difficult to absorb and retain. Good decision-making needs to be based on accessible, adequate and documented information.

After, or even mid-way through their treatment, patients often express regret that they did not have prior, clear, written information about their treatment options, and/ or options for public or private treatment, and details of all associated costs of especially those related to surgery, radiotherapy, chemotherapy. . As cancer is increasingly treated in the private sector, costs are a vital consideration in decision-making.

#### **PRESENT SITUATION**

##### **1. Informed consent for treatment offered by public & private service providers**

Currently, the information received about a patient's treatment options may not be sufficiently detailed and clearly presented, nor provided sufficiently early to allow adequate consideration time between a consultation and the treatment decision.

##### **2. Informed consent for out of pocket costs (private treatment)**

There are two aspects:

- Some patients are not made aware whether the referral from their GP is to the public or private sector and this can lead to embarrassment, confusion and even "financial toxicity".
- Many cancer patients with private health insurance (PHI) believe that their health fund will fully, or almost fully, cover private cancer treatment; they are unaware of the substantial gaps to be paid (eg for outpatient radiotherapy, anaesthetic services, or new drugs not yet on the Pharmaceutical Benefit Schedule).

#### **RECOMMENDATIONS**

Cancer Voices proposes that we begin discussions about how these issues are best addressed.

We consider that consent forms should be developed, in consultation with consumers, for universal use by providers in both public and private sectors. The forms need to be short, in plain language, and must fully inform patients (and/or carers) before any agreement to proceed can be considered valid. The forms need to cover:

- treatment proposed, including options and multidisciplinary aspects - and whether it will be in the public or private sector;
- cost estimates for all treatment, associated services and out-of-pocket items/services whenever private sector treatment is planned - and advice that "free" public services are available (and where).

While mandating use of such forms may appear difficult, they could be regarded as best practice and offered to all consumers as a matter of course. Specialists, cancer centres and GPs would all need to be made aware of how important these matters are to consumers.