

# CanNET

**Cancer Service Networks  
National Demonstration Program**

Linking regional and metropolitan  
cancer services for better  
cancer outcomes



**Australian Government**

**Cancer Australia**

## **Assessment of Cancer Care Perceptions and Experiences of People Affected by Cancer**

August, 2010



## Executive Summary

### About the Project

Cancer Australia in collaboration with several jurisdictions<sup>1</sup>, commissioned an assessment of cancer care to examine the experiences and perceptions of people directly affected by cancer. This includes both those living with the disease and those who care for them.

The primary objectives of the survey were to:

- Gain a baseline snapshot of the perceptions and experiences that those affected by cancer have with cancer delivery across Australia and what information this baseline snapshot provides about the current strengths and gaps in cancer care delivery from a consumer and carer perspective; and
- Provide information to the cancer care sector to support strategies to strengthen the delivery of cancer care to the Australian community.

In order to achieve these objectives Cancer Australia engaged the services of Campbell Research and Consulting Pty Ltd to undertake the development, delivery, analysis and delivery of the survey.

Cancer Australia also engaged GSB Consulting and Communications to assist in the preparation of the summary report of the survey findings. This summary report reflects the findings of the survey, and where appropriate demonstrates support for those findings from other research activities.

### Questionnaire Framework

In terms of an over-arching structure for the questionnaire, questions related to either experience or perception of cancer care services:

- Experience  
What have people affected by cancer **experienced** in their treatment?
- Perception  
What are the **perceptions** of people affected by cancer relating to the quality of their cancer care?

It should be noted that this survey did not include evaluation of the clinical effect of the patient experience or the clinical appropriateness of treatment.

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<sup>1</sup> Northern Territory, Queensland, Tasmania, South Australia and Western Australia.

## **Strategic Summary of Recommendations**

The report's recommendations are summarised under the following strategic headings:

1. Increase the use and effectiveness of care plans
2. Improve quality of services
3. Improve the comprehensiveness and quality of patient information materials
4. Improve access to care that is supportive by enhancing existing emotional support services to assist the person with the diagnosis of cancer to cope with fear, stress, anxiety, isolation and depression
5. That cross-jurisdictional agreements be developed to allow people living in remote communities to access treatment that is closest to them regardless of state border issues
6. That people providing cancer care receive specific education

Details about these recommendations are discussed further in the next section.

## Summary of Survey Findings

### Objectives of High Quality Cancer Care

The goal of high quality cancer care<sup>2</sup> in the context of this study is to improve access to quality, clinically-effective cancer services throughout Australia, particularly for specific population groups that may currently have poorer cancer outcomes, including Aboriginal and Torres Strait Islander peoples and people living in rural and regional areas.

The objectives that accompany this goal are:

- Fair access to high quality evidence-based, patient centred cancer care for all Australians
- Care that is culturally appropriate and supportive
- Care that encourages self-management and shared decision-making
- Multidisciplinary coordinated shared care provided in a respectful team environment

### Patient Journey and Critical Intervention Points

For the purposes of this report, patient and carer perceptions of service quality will be examined using a framework based on critical intervention points to describe the general cancer journey. However, it is important to note that a person diagnosed with cancer will encounter a range of care and treatment providers and depending on the cancer type their progression through the cancer journey may be longer, tougher and involve more uncertainty. The different effects of cancer types should be considered throughout this generalised patient journey.

#### Critical Intervention Points

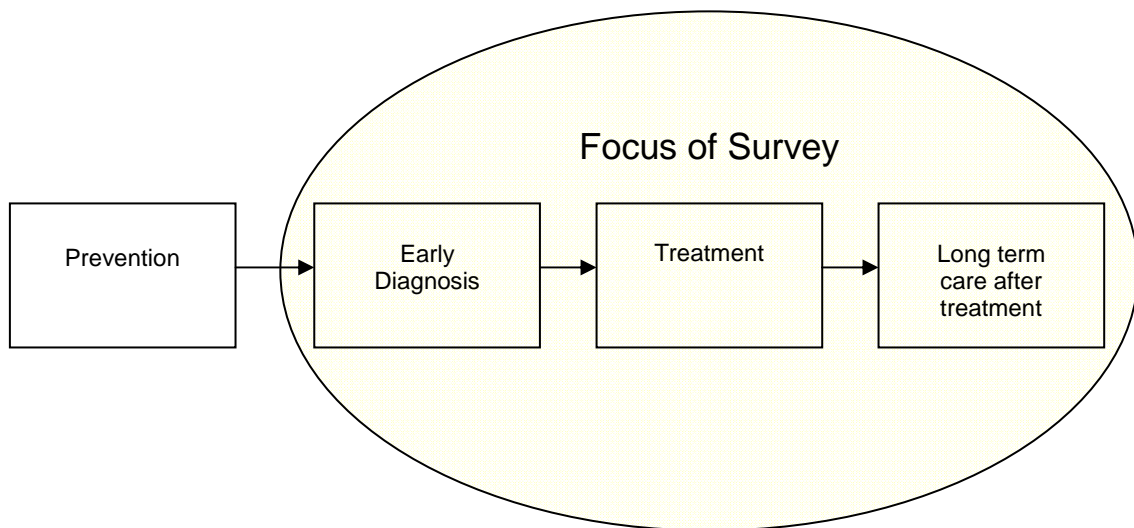
Critical intervention points<sup>3</sup> (see Figure 1) are components of care at each stage in the patient journey that have an effect on either or both the actual or perceived health outcome, quality of life or satisfaction with care.

It is important to note that this report focuses on patient and carer reported experience and perceptions; therefore the effect on each critical intervention point demonstrates the patient or carer's perception of the services and is not a judgement of clinical appropriateness.

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<sup>2</sup> High Quality Care in Cancer is described in detail in the *National Service Improvement Framework for Cancer* (Commonwealth Department of Health and Ageing)

<sup>3</sup> *National Service Improvement Framework for Cancer*



**Figure 1: Critical Intervention Points**

The critical intervention points for the stages of the patient journey that are relevant to cancer care and this evaluation are:

**Early diagnosis**

- That the appropriate diagnostic tests were conducted to facilitate diagnosis
- That there was no significant delay in diagnosis
- That sufficient patient information was provided to allow the person diagnosed with cancer to engage in the decision making process about treatment
- That sufficient psychosocial support was provided

**Treatment**

- That a care plan to facilitate shared care/multidisciplinary care was developed in association with the patient and/or carer
- That there was appropriate communications between patient and primary care clinician and the multidisciplinary team
- That the correct treatment was commenced
- That the time to treatment was not significantly delayed
- That travel to the location of treatment did not cause a barrier or delay in access to treatment
- That sufficient patient information was provided to allow the person having treatment and/or their carer to self manage their condition including side effects to their chosen level
- That sufficient psychosocial support was provided

## **Long Term Care**

- Discharge process and interface for long term return to community care setting
- Sufficient patient information was provided for the patient to rehabilitate and self-manage long term
- Care plan/shared care/multidisciplinary care included long term care, ongoing monitoring, possible long term side effects, long term medication use, consideration of psychosocial support
- Palliative care

## **Findings of the Survey and Recommendations**

**Objective 1: Fair access to timely, high quality, evidence-based, patient centred cancer care for all Australians**

### **Perceptions of care at diagnosis and treatment**

The study included an examination of perceptions from both the patient and the carer. In general both patients and carers reported that the care provided was respectful (83%, 80% respectively), and sensitive (77%, 73%) and the care providers answered questions understandably (82, 79%). Carer ratings were slightly lower across each measure. Similarly, both patients and carers reported that service providers acted in a professional manner (87%, 84%) and provided information about what was happening (83%, 76%). 78% of patients felt the advice they received at the time of diagnosis was either excellent or very good, although 7% thought it was fair or poor. It is worth noting that as a comparison, both patients and carers perceived the management of side effects less positively (68%, 69%).

### **Treatment facilities**

The survey included a measure in relation to perception of treatment facilities finding that patients and carers perceived that room cleanliness was good (84% 77%) and comfort was generally good (75%, 67%), however several of the measures provided results that were relatively poor including:

- Room privacy (64%, 57%)
- Space (58%, 54%)
- Ease of getting from entrance to place of treatment (57%, 48%)
- Facilities for family and carers (54%, 47%)
- Quality of meals (49%, 47%)
- Parking arrangements (34%, 29%)

**Recommendation 1:** Improving quality of services by:

- Increasing the availability of parking facilities at treatment centres
- Improving treatment facilities to allow for more space and privacy
- Providing accessible and meaningful avenues for complaints, and responding to complaints in an effective manner

### Care after treatment

There was a significant deterioration in patient and carer perceptions of care after treatment with patients and carers perceiving their care providers help in managing their future physical wellbeing as relatively low (60%, 36%). The Role Redesign in Primary Care project<sup>4</sup> demonstrated that models of care for some cancer types require long term follow-up to be conducted by non-specialist providers e.g. GPs and that some people, particularly those with no existing relationship with a GP preferred follow-up care and advice from a cancer specialist.

Patients and carers also perceived that they received relatively poor help with their future emotional wellbeing and only around half of respondents thought they received sufficient information to get in touch with other health professionals who may have helped in their care.

### Access to support services

One clear area in which additional focus is necessary is the perception of access to and role of support services. In general, less than half of all respondents felt that support services had helped them however only three in ten people diagnosed with cancer used support services. More people indicated they would have liked to have more access to or information about support services available to them.

### Perceptions of health

In general there was a clear relationship indicating that people who considered their health to be good reported a more positive experience of diagnosis and that people who considered their health to be poor reported a more negative experience of diagnosis. It is likely that the different treatment regimes – including the type of treatment, the likelihood of side effects, the severity of side effects, the likelihood of cure, the duration of treatment and long term surveillance – of different cancer types has an impact on patient and carer perceptions of the quality of care.<sup>5678</sup>

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<sup>4</sup> *Role Redesign in Primary Care* Report for Cancer Australia by GSB Consulting and Communications

<sup>5</sup> *Health-related quality of life in breast cancer patients: a bibliographic review of the literature from 1974 to 2007.* Montazeri A. *J Exp Clin Cancer Res.* 2008.

<sup>6</sup> *Research in Danish cancer rehabilitation: social characteristics and late effects of cancer among participants in the FOCARE research project.* Høybye MT et al. *Acta Oncol.* 2008.

<sup>7</sup> *Exploratory survey of patients' needs and perceptions of psychosocial oncology.* Preyde M et al. *J Psychosoc Oncol.* 2010.

**Recommendation 2:** That patient information includes information about other services available in the patient's area that may assist in providing appropriate services for individual patients or by cancer type.

**Recommendation 3:** That an increased focus be placed on ongoing surveillance and survivorship including:

- Inclusion in the care plan of requirements for ongoing surveillance
- Patient information to contain:
  - a clearer explanation of the expected pathway to survivorship or end of life including ongoing monitoring
  - possible long term side effects, patient knowledge of symptoms and appropriate responses in the event that side effects arise
  - information about which care providers are available, how they can help and how to contact them including referral pathways where required e.g. referral by GP

### Travel to treatment

The survey found that 86% of patients travelled less than two hours to receive treatment, however 8% of people reported that the travel was either difficult or very difficult which may have caused some patients to delay or refuse treatment. The Role Redesign in Primary Care project<sup>9</sup> found that the funding of cancer services on a jurisdictional basis meant that people often had to travel long distances in order to be treated within their residential jurisdiction, when they could have travelled a much shorter distance had they been able to be treated in another jurisdiction. The survey did not examine the clinical effect of delays in treatment. It is important to note that people living in those states with a predominance of remote communities consistently reported greater difficulty in travelling to and accessing cancer care services. Approximately one in seven people required alternative accommodation whilst receiving cancer treatment.

**Recommendation 4:** That cross-jurisdictional agreements be developed to allow people living in remote communities to access treatment that is closest to them regardless of state border issues.

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<sup>8</sup> A 1-year prospective study of individual variation in distress, and illness perceptions, after treatment for breast cancer. Millar K et al. *J Psychosom Res.* 2005.

<sup>9</sup> *Role Redesign in Primary Care* Report for Cancer Australia by GSB Consulting and Communications



## Access to and quality of complaints processes

Although the perception of service quality was generally high across most criteria there were areas in which small numbers of respondents expressed dissatisfaction including:

- The poor manner or situation in which some people affected by cancer were told of their condition
- The lack of information provided to people affected by cancer regarding the diagnosis itself as well as the treatment options and support available
- The general lack of empathy and poor attitude demonstrated by some health professionals towards patients
- The time lapse between various tests, diagnosis and surgery and the perceived levels of overall service

Complaint mechanisms are the primary mechanism for patients and carers to feed into continuous quality improvement processes. The survey examined patient and carers' experience in relation to complaints. Most patients and carers indicated they were happy with the care received by the patient, or the way in which they were treated. However, some respondents to the survey perceived that the person with the diagnosis of cancer had received care that was sub-optimal (13%, 16%).

It is noted that of the people unhappy with care approximately one in four were under 50 years of age, and one in four had a tertiary education. Generally the provision of high quality patient information is likely to result in better health outcomes but also more complaints as a result of greater awareness of what should be available to them and higher expectations. Accordingly, complaints should be seen as an important tool in continuous quality improvement. Of the patients who felt they had a complaint only half actually made a complaint with the remaining half perceiving that there was no opportunity to complain.

Of the patients who felt they had reason to complain, poor communication was the cause in 42%, 28% mentioned the manner of the health professionals, 22% identified waiting times from being told that they required treatment to actually receiving treatment and 15% identified the delay between their arriving for treatment and actually receiving treatment. The treatment causing harm was identified by 20% of patients with a complaint.

**Recommendation 5:** That communication between service providers and the person diagnosed with cancer is improved by providing cancer care providers with specific education about:

- How to sensitively communicate a diagnosis of cancer to patients and their carers
- How to identify a patient or carer in need of support services
- How much and in what form to provide information to patients and carers at the time of diagnosis
- The provision of the right information to the patient and carer at the right time and in the right format.

**Recommendation 6:** That patients and carers information include information about how to make complaints, comments and provide positive feedback in order to enhance continuous service quality improvement.

### **Objective 2: Care that is culturally appropriate and supportive**

It is important in providing cancer care that care be culturally appropriate and supportive. Although this study looked extensively at the support issues, it was considered that the issue of cultural appropriateness was so specialised, and that the participant population for this survey so general, that it would have been inappropriate to include the issue in this survey.

In relation to supportive care the study found that cancer support services could be generally divided into:

- Professional support and cancer care organisations
- Support from other patients or patient support groups
- Patients individual support network e.g. carer, family, friends

The times when patients and carers perceived a need for support services were generally across the entire patient journey including the time of diagnosis, between diagnosis and treatment, during treatment and after treatment. The study found that 49% of patients were told that they could have a family member or friend with them, 44% that they were able to involve their family in the decision making process and 27% were told they could receive emotional support.

Further, the study found that 53% of patients and 35% of carers felt that they had been provided with care that helped emotional wellbeing and less than 50% of all patients and carers received information or were referred to support services. Less than 40% of patients and even fewer carers felt they had received effective services to improve their psychological wellbeing including coping with stress, anger, depression, isolation and uncertainty.

**Recommendation 7:** That increased supportive care be provided by the:

- Inclusion of a psychosocial support (individual or by cancer type) needs assessment across all stages of the patient journey in care plans.
- Inclusion of written information about the role and availability of support services (including peer support) across all stages of the patient journey in patient information provided at the time of diagnosis

**Recommendation 8:** Improve access to care that is culturally appropriate and supportive by enhancing existing emotional support services to assist a person with the diagnosis of cancer to cope with fear, stress, anxiety, isolation and depression by:

- Identifying areas of unmet need in terms of non-urban access, age and cancer type
- Identifying workforce resources that could meet this need with minimal additional training e.g. cancer nurses could identify and refer patients requiring support

### **Assistance with managing effect of treatment on physical appearance**

The survey found that some people being treated for cancer felt that they should have been provided with assistance with the identification and access to devices to overcome the effect of cancer treatment on their physical appearance e.g. wigs for patients experiencing hair loss from chemotherapy.

**Recommendation 9:** Provide assistance with prosthetics and wigs both during and after treatment by:

- Identifying needs for prosthetics based on cancer types
- Develop a funding model, taking into consideration sources currently available and organisations with the capacity to undertake a facilitating role
- Develop and implement an information resource to inform target patients of assistance available in accessing prosthetics and wigs

### **Objective 3: Care that facilitates shared decision-making and self-management**

#### **Patient experience at the time of diagnosis**

Experiences at the time of diagnosis varied widely for those respondents diagnosed with cancer. Over 83% were informed of at least one of the seven items<sup>10</sup> but of the 15% of people diagnosed with cancer who did not receive the information

- 54% were presented with options for treatment
- 50% were involved in the decision-making process
- 40% were told where they could obtain further information
- 23% were given the option *not* to have treatment

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<sup>10</sup> Helped understand what might happen, helped understand need for further treatment, reassured you, helped physical wellbeing, advice about other medical professionals they could go to, helped with prosthetics and wigs, helped emotional wellbeing

The study indicated that, in general, a higher proportion of people diagnosed with prostate and breast cancer were given more extensive advice at the time of diagnosis compared to those with bowel cancer, melanoma and lymphoma.

Where patients and carers were given information, most found it easy to understand (72%, 63%), relevant to their needs (68% 58%) and useful (67%, 60%).

The survey identified that there was also significant variation in the provision of information between cancer types. Of the patients and carers who received no information at the time of diagnosis, 9% had a diagnosis of prostate or breast cancer, 18% had a diagnosis of bowel cancer and lymphoma and 29% had a diagnosis of melanoma.

There is a significant variation in the quality of service and patient information between the various cancer types. Patients with more common cancers or cancers that have received significant focus in the past receive higher quality treatment and information than those with less common cancers.

**Recommendation 10:** It is recommended that the lessons learned from implementing improvements to the models of care and patient information for common cancers by lead organisations and service providers be shared.

In measuring whether the model of care encouraged shared decision-making and self-management the study examined whether the care provider had:

- Let patients and carers know what was happening (83%, 76%)
- Answered questions understandably (82, 79%)
- Informed patients and carers about side effects (77%, 72%)
- Given treatment advice (79%, 73%)
- Given understandable information (76%, 72%)

Although most patients and carers rated the information received at time of diagnosis and treatment highly, they rated the information they received after treatment as relatively poor. Specifically patients and carers reported that fewer than seven out of ten (67%, 62%) were informed by their treatment provider what may happen with their health in the future and the need for further treatment (67%, 62%).

**Recommendation 11:** Special focus should be given to the after treatment period when devising strategies to improve patient information.

**Recommendation 12:** Providers of cancer care should increase the use of care plans to assist patients and their carers to understand what to expect in relation to treatment, side effects and survivorship, and to facilitate communication between the care providers and treatment team.

#### **Objective 4: Multidisciplinary coordinated shared care provided in a respectful team environment**

##### **Shared care in multidisciplinary teams**

In measuring whether the model of care included multidisciplinary, coordinated shared care the study examined patient and carer perceptions of communication between professionals, 77% of patients and carers thought there had been communication with other professionals in relation to their treatment.

**Recommendation 13:** That care plans are developed at the time of diagnosis (or the planning of treatment) that includes all aspects of treatment and all care and treatment providers including who is doing what and when, agreed methods of communication and contact details for key care providers.

##### **The inclusion of carers in the care team**

Carers are a crucial member of the patient's care team and deserve respect and recognition for their important role in assisting the patient to self-manage and spend more time at home and out of hospital. The study indicated that 91% of carers lived with the patient during the treatment period and 94% accompanied the patient during treatment. The provision of appropriate information is fundamental to the successful role of a carer.

The study identified that the provision of information to carers is relatively poor with less than 60% of carers reporting that they had received all of the information they needed to care for the patient, 63% of carers reported receiving information about the nature of the cancer, 54% options for treatment, 51% possible side effects, 40% how to deal with side effects and 43% how to look after the patient's health.

**Recommendation 14:** That the identification and role of the carer be included in the care plan and that carer specific versions of patient information be made available in an appropriate format and timely manner.

##### **After treatment**

Consistent with other findings in the study carers reported a relatively poor level of experience with health care providers after treatment with less than 50% reporting a transfer of medical records (48%) , having a plan made for follow up visits (47%), and being informed about long term side effects (42%).

Even poorer results were identified in relation to being informed about steps needed to be taken by the patient to recover from treatment (35%) how the patient should take their medications (34%), other healthcare providers to aid the patient's recovery (25%) and the availability of emotional and physical support for carers (16% and 15%).

It has been reported in other studies that moving from the treatment period when patients and carers get care and attention to the after treatment period where they get little care and attention is like stepping into a 'black hole' where they don't know what to expect and what to do.

**Recommendation 15:** That care plans and patient and carer information include a greater focus on the after treatment period including ongoing monitoring, potential side effects, symptoms and appropriate responses, long term medication use, survivorship challenges and support systems.

## Summary of Strategic Activities

### General Principles

The study highlighted issues across all cancer types which should be used as a set of guiding principles when considering each of the strategic activities below. These principles are:

- A. Patients are receiving diagnosis, treatment and information from a range of health care professionals. Any strategies to improve services should include the identification of all relevant service providers a patient can be expected to see throughout the patient journey and consideration of how to include all providers in implementation.
- B. There is a significant variation in the perceived quality of service and patient information between the various tumour types. The trend in the findings is for cancers which tend to be treated surgically with less adjuvant therapy, e.g. melanoma and colorectal cancer, to have more positive responses from consumers across the board, whereas cancers with a more prolonged course involving chemotherapy and radiation e.g. lymphoma, produced more mixed responses. Positive responses also segregated around cancers which have had more resources expended on them e.g. breast cancer. It is therefore recommended that the lessons learned from implementing improvements to the models of care and patient information for common cancers by lead organisations and service providers be shared, modified and implemented for use by all service providers and in particular for the less common cancers. Furthermore, attention should be paid to tumours with a more prolonged course involving adjuvant therapy and repeated courses of treatment.
- C. There was a significant drop in perceived quality and information in the periods after courses of therapy. Whilst patients and carers generally reported receiving good information at the time of diagnosis and treatment, they consistently reported receiving less information about what to expect after specific courses of treatment. All strategies to improve patient information should give special focus to the after and between treatment periods.
- D. The data indicated a relationship between patients' self-perception of poor health and their perception of inadequacy of the information and support they received. This can be interpreted in two ways. Firstly that poor information and support may reduce self-rated health. The second (and not necessarily exclusive) reason could be that people whose illness was more severe, or whose treatment course was more prolonged and exposed to side effects, felt let down by the information and support they received. Both suggest extra attention be paid to people in poor health and those whose treatment course is predictably more turbulent.
- E. The data indicated that people with a higher income (and perhaps by proxy, higher levels of education) were more likely to report that the information and support they received was less than they needed. It is possible that higher health literacy, and therefore patient understanding of their condition, leads to greater expectations and what this finding is actually revealing is an across-the-board problem only detected in those

more able or confident to express these views. Consequently the recommendation is not to focus on high income or highly educated consumers when developing patient information but consideration should be given to increasing health literacy and focussing on those with the lowest levels ensuring that the format and media are appropriate.

- F. Care plans and patient information should include consideration of access to appropriate support services including professional, organisational, peer and family support.

### **Strategic Summary of Recommendations**

In response to the findings from the survey, 16 recommendations for strategic activities have been developed to address the issues raised. Many of these recommendations include similar or aligned activities; therefore, GSB have grouped and summarised the 16 recommendations into the following recommended strategic activities.

**1. Increase the use and effectiveness of care plans including** (*response to recommendations 2,3,7,12,13,14,15*):

- (a) Which care providers will be involved across all stages of the patient journey
- (b) What each provider will do and when
- (c) Contact details for each provider and agreed methods of communication
- (d) Ongoing monitoring
- (e) Treatment and after treatment medication regimes
- (f) Potential side effects during and after treatment, symptoms to be alert to and appropriate patient responses if symptoms occur
- (g) Potential medium and long term side effects, symptoms to be alert to and appropriate patient responses if symptoms occur
- (h) Needs assessment of psychosocial support (individual or by cancer type) across all stages of the patient journey and written information about the role and availability of support services (including peer support) across all stages of the patient journey
- (i) Providing to patients and carers a copy of the care plan along with other patient information

**2. Improving quality of services by** (*response to recommendation 1*):

- (a) Increasing the availability of parking facilities at treatment centres
- (b) Improving treatment facilities to allow for more space and privacy
- (c) Providing accessible and meaningful avenues for complaints, and responding to complaints in an effective manner



**3. Improve the comprehensiveness and quality of patient information materials including (response to recommendation 3,7,9,10,11,15):**

- (a) Other services available in their area who may assist in providing appropriate services for individual patients or by cancer type
- (b) Written information about the role and availability of support services (including peer support) across all stages of the patient journey in patient information provided at the time of diagnosis
- (c) The clinical effect of time to treatment
- (d) Post treatment issues including:
  - i. a clearer explanation of the expected pathway to survivorship or end of life including ongoing long term monitoring
  - ii. possible medium to long term side effects, symptoms to be alert to and appropriate patient responses in the event that side effects arise
  - iii. information about which care providers are available, how they can help and how to contact them including referral pathways where required e.g. referral by GP
- (e) How to make complaints, comments and provide positive feedback in order to enhance continuous service quality improvement

**4. Improve access to care that is supportive by enhancing existing emotional support services to assist the person with the diagnosis of cancer to cope with fear, stress, anxiety, isolation and depression by (response to recommendations 8 and 9):**

- (a) Identifying areas of unmet need in terms of non-urban access, age, cancer type
- (b) Identifying workforce resources that could meet this need with minimal additional training e.g. cancer nurses could identify and refer patients requiring support
- (c) Providing assistance with prosthetics and wigs both during and after treatment by
  - i. identifying needs for prosthetics based on cancer types
  - ii. developing a funding model taking into consideration sources currently available and organisations with the capacity to undertake a facilitating role
  - iii. developing and implementing an information resource to inform target patients of assistance available in accessing prosthetics and wigs.

**5. That cross-jurisdictional agreements be developed to allow people living in remote communities to access treatment that is closest to them regardless of state border issues (response to recommendation 4)**

- 6. That people providing cancer care receive specific education about**  
*(response to recommendations 3,6,7) :*
- (a) How to sensitively communicate a diagnosis of cancer to patients and their carers
  - (b) How to identify a patient or carer in need of support services
  - (c) How much and in what form to provide information to patients and carers at the time of diagnosis and the provision of the right information to the patient and carer at the right time and in the right format