



**CanNET**

Cancer Service Networks  
National Demonstration Program

Linking regional and metropolitan  
cancer services for better  
cancer outcomes



**Australian Government**

**Cancer Australia**

CanNET  
Cancer Service Networks National Demonstration  
Project

The development of a consumer participation  
strategy for difficult-to-access consumers in the  
NEMICS and Hume RICS geographic areas

Final Report

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Prepared by Health Issues Centre for  
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## EXECUTIVE SUMMARY

CanNET Victoria commissioned Health Issues Centre to undertake a study examining the experiences of “hard to reach” consumers accessing cancer services from the northern metropolitan regions of Melbourne and the Shepparton region.

The project was funded by CanNET Victoria in partnership with the North Eastern Metropolitan Integrated Cancer Services (NEMICS) and Hume Regional Integrated Cancer Service (Hume RICS).

The aim of the project was to:

- To ensure the CanNET Victoria project is well-informed of the experiences, needs and viewpoints of consumers affected by cancer from across the urban (NEMICS) and rural (Hume RICS) areas.
- To identify and consult with consumers from urban, Aboriginal and Torres Strait Islander (ATSI) and non English-speaking backgrounds in the CanNET Victoria region.
- Develop a consumer participation strategy that ensures the effective input and ongoing participation of “hard to reach” consumers in the CanNET Victoria project, including:
  - the Italian community in Shepparton
  - the ATSI community at Rumbalara community in Shepparton
  - the CALD group in the catchment area of the Northern Hospital
  - a group of “hard to reach” urban consumers within this same catchment

This qualitative project was undertaken between November 2008 and March 2009. It comprised of 17 semi-structured interviews and 5 focus groups. A total of 57 consumers were consulted along with five Indigenous health and community workers.

Consumers were recruited from various linguistic, cultural and socio-economic backgrounds including Australian-born English-speaking Turkish, Spanish and Italian people.

Discussions and interview questions focused on people’s experience of cancer, care and treatment received, access to services, information received about care, treatment and services, challenges faced in relation to their cancer journey and quality improvements from a consumer perspective.

This report adds to the findings of a previous project undertaken by Amos et al (Amos A., Hurst S., & Picco L., 2008) who interviewed 128 participants in the NEMICS and Hume RICS catchment but did not capture the voices of culturally diverse consumers.

## Key Findings

This project discovered a number of key findings related to the discussion topics and questions described earlier.

Consumers across all population groups were generally satisfied with the treatment and care they received. All participants commented that most health professionals were accessible and inclusive of them in their treatment and care. Despite this a number of issues emerged that are worth considering from a quality improvement point of view.

This project found that a number of themes emerged in relation to different aspects of their cancer experience as described below:

### Quality of Care

- Some consumers from culturally and linguistically diverse backgrounds believed that participants who accessed the private health system received better quality of care
- Some consumers felt that there was little support post-discharge from the acute system

### Supportive Care

- There was a low uptake of counselling services and support groups by the participants consulted

### Information needs

- Most consumers considered they had not been given information from health professionals about support services but accessed these services through word of mouth or from family and friends
- There was a lack of information for carers, and family members
- Quantity and quality of information varied with tumour type. For instance participants who had experienced breast cancer had access to a plethora of information, however lesser-known cancers were not well resourced in terms of information available
- Language and medical terminology presented a challenge for some consumers from CALD and Indigenous communities
- There was low uptake of interpreters with consumers preferring to use family members
- Translated information is not always the preferred method for some CALD consumers due to low literacy levels in their first languages

### Travel

- Travel and accommodation were the main challenges for rural consumers accessing metropolitan health services
- There was a low uptake of the Victorian Patient Transport Assistance Scheme

### Access to services

- Many rural consumers were unaware of local treatment options
- Many rural consumers felt that there was a lack of services in rural areas

## RECOMMENDATIONS

This report makes a number of recommendations that will assist CanNET Victoria, NEMICS and Hume RICS to ensure that consumers' needs and perspectives are considered in relation to professional development activities that are to be undertaken.

HIC recommends that:

- Staff from CanNET Victoria, Hume RICS and NEMICS have access to professional development in relation to community engagement, consumer participation and community development frameworks
- When managing staff workload consideration is given to the time required to engage and build relationships with Indigenous and CALD communities

This section makes a number of recommendations for CanNET Victoria, NEMICS and Hume RICS in relation to services, programs and policies

HIC recommends that

- The Integrated Cancer Services (ICS) ensure the information obtained through this project is used to develop services that reflect the perspectives and experiences of all those directly affected by cancer.
- NEMICS and Hume RICS maintain contact with consumers and community members consulted during this project and feedback to the participants any outcomes related to their input.
- ICS promote the participation of all consumers in the development of policies and programs.
- There be a central centre providing information and a support network in the Shepparton area that assists people with information and support in relation to all aspects of care but in particular travel and accommodation to metropolitan and rural services.
- The ICS work to improve coordination and communication with and across local, regional and metropolitan services, building on existing multidisciplinary collaborative structures.
- Further investigation is carried out on the needs of newly-arrived and religiously diverse groups.
- The regional ICSs contribute to the reform of the VPTAS system through systemic advocacy and lobbying.
- That ICSs promote the design of tailored strategies that recognise and respect the diversity of local communities, issues and concerns.
- That the ICSs coordinate and are involved in the development of resources that assist consumers to navigate and understand the private and public system.

## 1. INTRODUCTION

This report details the findings from consultations with 57 consumers and 5 Indigenous community workers undertaken by Health Issues Centre (HIC) for CanNET Victoria. It captures the voices and experiences of consumers, carers and community members affected by cancer from the northern metropolitan region of Melbourne and the Hume regional area.

The Cancer Services Network National Demonstration Program (CanNET) is a national program funded by Cancer Australia to improve outcomes and reduce disparities in outcomes for people affected by cancer, by providing high quality, clinically effective and coordinated cancer services across Australia. CanNET Victoria is one of seven demonstration projects funded as part of the national CanNET project.

CanNET involves the Australian, state and territory governments working collaboratively with consumers and health professionals to improve outcomes through better coordination of existing cancer services. Further information on the CanNET program is available at [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au).

In 2004, the Victorian Department of Human Services established eight Integrated Cancer Services (ICS) to support the development of integrated care and defined referral pathways for the populations they serve. The ICS are the platforms through which improvements in cancer service delivery and patient care are being implemented in Victoria.

The CanNET Victoria project is a partnership between NEMICS and Hume RICS. NEMICS includes the following health services: Austin Health; Eastern Health; Mercy Hospital for Women; and Northern Health. Hume RICS includes the health services in the entire North East area of Victoria, encompassing 12 local government areas from Kilmore to Wodonga, Mt Beauty to Cobram.

This report adds to the body of knowledge collected by Amos et al (Amos A. et al., 2008) in a previous project, which consulted 128 consumers affected by cancer living in the Hume and North Eastern Metropolitan area of Victoria. CanNET Victoria decided that the voices of some urban consumers, culturally and linguistically diverse consumers and Indigenous consumers were under represented in the previous report and therefore commissioned HIC to undertake this second phase of the project.

### 1.1 Aims and objectives of this project

#### Aims

- To ensure the CanNET Victoria project is well-informed of the experiences, needs and viewpoints of consumers affected by cancer from across the urban (NEMICS) and rural (Hume RICS) areas.
- To identify and consult with consumers from urban, Aboriginal and Torres Strait Islander (ATSI) and non English-speaking backgrounds in the CanNET Victoria region.

## Objectives

- Develop a consumer participation strategy that ensures the effective input and ongoing participation of “difficult-to-access” consumers in the CanNET Victoria project, including:
  - the Italian community in Shepparton
  - the ATSI community at Rumbalara community in Shepparton
  - the CALD group in the catchment area of the Northern Hospital
  - a group of difficult-to-access urban consumers within this same catchment.
- Ensure the activities undertaken by the CanNET Victoria project reflect the perspectives and experiences of all those directly affected by cancer.
- Ensure that consumers’ needs and perspectives are considered in relation to professional development activities that are to be undertaken in CanNET Victoria.

This report outlines the work of Health Issues Centre to meet part of the first of the objectives, and to inform CanNET Victoria of the second and third objectives to be met.

### 1.2 Report

This report is the final deliverable for the CanNET Victoria Consumer Participation Project.

Findings from a series of focus groups and interviews, conducted by Health Issues Centre, with 57 participants affected by cancer are presented along with recommendations for future engagement with diverse consumers.

The report has several sections. The first section describes the methodology implemented by Health Issues Centre to consult with different population groups.

The next section outlines findings from the consultation process and discusses the experiences of cancer by urban English-speaking consumers in the northern metropolitan area; by rural English-speaking consumers in the Shepparton area; a group of culturally and linguistically diverse (CALD) consumers in the northern region; and a group of CALD consumers in the Shepparton area. The report then explores questions relating to the effective engagement of ATSI consumers based on the consultation with Indigenous workers in the Shepparton area.

The final section of the report synthesises findings from the consultation process. From these findings we have formulated strategies for engagement and recommendations for CanNET Victoria, NEMICS and Hume RICS.

## 2. METHODS

This project used qualitative research methods to identify consumers' experiences of cancer. This method was used because it provides a greater opportunity to gain an understanding of social processes and the reasons for certain attitudes or behaviours. Qualitative methods also facilitate learning, are participatory and improve community engagement (Meredith D. et al., 2008).

Focus groups and semi-structured interviews were conducted with specific population-group configurations including consumers from different geographic regions and CALD backgrounds.

The findings were documented as raw data and later coded for thematic analysis. Open coding was used; a method based on grounded theory. This involves developing coding categories that reflect the content of the data collected rather than the interview questions; that is, data are not slotted into predetermined categories so findings are 'grounded' in the experiential world (Strauss A. & Corbin J., 1998).

Focus groups and interviews were conducted at times that were convenient for participants, either in their homes, during regularly scheduled meetings, or at a public place of their choice. Focus groups were facilitated by the Health Issues Centre project officer. Staff from NEMICS, Hume RICS or CanNET Victoria also attended the focus groups. Interviews were conducted by the Health Issues Centre. Interpreters were offered to consumers from CALD backgrounds; however, the option of an interpreter was not taken up by participants. Where appropriate, participants used community members or bilingual staff as interpreters.

Participants were financially reimbursed for their participation.

### 2.1 Recruitment

Consumers were recruited using a targeted approach through established community groups, associations, and organisations. These groups were contacted using group leaders and community workers.

The project officer also used Health Issues Centre's relationship with health services such as Goulburn Valley Health, Northern Health and Dianella Community Health to assist with recruitment. Support and active promotion of the consultation process was received from Dianella, which sent letters to a range of clients who had been diagnosed with cancer. The letters invited consumers who were interested in participating to contact the project officer directly.

ATSI community workers in the Shepparton area were recruited via Indigenous specific services and workers.

### 2.1 Consultation

Five focus groups were conducted with consumers. Three focus groups were conducted with Spanish-, Turkish-, and Italian-speaking consumers respectively, as well as a focus group with English-speaking consumers from the northern metropolitan region and another with English-speaking consumers from the Shepparton region.

Seventeen individual interviews were conducted with consumers from the northern metropolitan region and one from the Shepparton region.

## **2.3 Focus group and interview questions**

All focus groups were conducted in English except one, which was conducted in Spanish by a Health Issues Centre bilingual project officer.

Participants were asked to comment on their cancer journey in relation to aspects such as:

- experiences of cancer
- treatment and care
- access to services
- challenges
- culture
- language
- information received
- quality improvement.

Not all focus group discussions covered the full range of questions as group dynamics sometimes determined what content was emphasised.

Meetings were held with Indigenous staff from Goulburn Valley Health and Koori Information Resource Centre in Shepparton.

## **2.4 Limitations of project**

The project was conducted between the months of November 2008 and February 2009. This impacted both on the recruitment strategy and the scheduling of interviews and focus groups. The Christmas–New Year holiday period fell in the middle of the consultation period, which meant that most services and groups were closing and not meeting again until February.

CanNET Victoria sought to capture the experience of the Iraqi community in the Shepparton area. Initial consultations with Iraqi community leaders identified that the incidence of cancer in this community was low due to the relatively young age of those arriving in Australia. It was therefore decided—collaboratively with NEMICS and Hume RICS—to consult the rural Italian community instead. This community is a well-established community in the Shepparton area and has an ageing population.

CanNET Victoria's original call for expressions of interest also sought to capture the experiences of Indigenous consumers through the Rumbalara community in Shepparton. Due to the short timeframe, consultation with the Rumbalara Indigenous community was not seen as feasible. Therefore the experiences of Indigenous consumers affected by cancer are not included in this report.

The Health Issues Centre project officer did conduct interviews with two Indigenous liaison officers and three Indigenous community workers in the Shepparton area to collect their experiences of working with Indigenous consumers and suggestions for long term engagement.

This sample is not necessarily representative of all consumers' experiences of cancer across both the urban (NEMICS) and rural (Hume RICS) areas. The report describes a small number of consumers' positive and negative experiences of cancer according to their perspectives.

## 3. FINDINGS

### 3.1 Characteristics of participants

Demographic data was collected about all the participants. This is included in the table below:

**Table 1: Demographics of participants**

<b>Gender</b>	44 women and 13 men were involved in the consultation
<b>Age</b>	The average age of participants was 62 years; the youngest being 44 and the oldest 81
<b>Country of birth</b>	
Australia	15
Turkey	12
Italy	13
Scotland	3
Spain	3
India	2
Cyprus	2
Netherlands	2
Pakistan	1
Indonesia	1
Uruguay	1
Ireland	1
England	1
<b>Years in Australia</b>	Of those born overseas the average number of years in Australia was 30 years
<b>ATSI</b>	None
<b>Language spoken at home</b>	<ul style="list-style-type: none"> <li>English</li> <li>Italian</li> <li>Turkish</li> <li>Spanish</li> </ul>
<b>Experience of Cancer</b>	<ul style="list-style-type: none"> <li>19 participants had directly experienced cancer</li> <li>35 had experienced cancer through family member or friends</li> <li>2 participants identified themselves as carers</li> </ul>
<b>Year of diagnosis of self or family member</b>	<ul style="list-style-type: none"> <li>1978–2008, with the majority of participants diagnosed between 2000 and 2008</li> </ul>
<b>Stage of treatment</b>	<ul style="list-style-type: none"> <li>Most of the participants had completed their treatment. Only a small number were still receiving treatment.</li> </ul>
<b>Location</b>	<ul style="list-style-type: none"> <li>21 participants were from the Hume Rural Region.</li> </ul> <p>The majority of participants, including those consulted in the Shepparton area, received their treatment in a metropolitan health service.</p>
<b>Tumour Types</b>	<ul style="list-style-type: none"> <li>4 participants were diagnosed with a secondary</li> </ul>

	cancer
Breast	12
Bowel	7
Leukaemia	3
Pancreatic	3
Prostate	3
Throat	2
Lip cancer	1
Ovarian	1
Thyroid	1
Non-Hodgkin lymphoma	1
Granular Cell Myoblastoma	1
Macroglobulinemia Waldenstrom	1
Brain	1

## 3.2 Consultation

This section details the findings from the consultations by demographic group, regions and ethnicity.

### 3.2.1 Urban consumers

This section of the report details findings from a group of urban consumers within the northern metropolitan region. This group of participants was mostly Australian-born and all fluent and literate in English. This section also draws comparisons with the previous report by Amos, Hurst and Picco (2008).

#### *Reaction to Diagnoses*

Participants were asked to describe how they felt when they were first informed of a diagnosis of cancer. While most participants were aware of people who had survived cancer, and understood that advances in cancer care have resulted in higher survival rates, they all initially associated their diagnoses of cancer with death:

*When I first found out I had this fear that I was going to lose him, I was worried about what he was going to go through, it's the fear of the unknown.*

Participants also reported feeling shock or disbelief after their diagnosis:

*When you find out you don't think it's real.*

*Because it was so quick I thought this isn't happening to me.*

## **Treatment and care**

The consultations revealed that consumers were generally satisfied with the medical treatment they received, in both the private and public systems.

Some participants commented that doctors were accessible, honest and followed up their questions and concerns:

*I found that the doctors are all great: they don't hold anything back and they don't use big words. He even drew a picture of what he was going to do...He said we will be getting you and your family here to discuss the operation and he has told me that we could ring him anytime and that even the kids could ring him if they were worried.*

*My doctor gave me his number and told me I could ring him any time day or night and I did and he was so nice.*

In both these comments participants were referring to their surgeons.

This supports conclusions from the previous report by Amos et al. (2008:p 32-33) who found that one of the most valued aspects of care was that participants appreciated health professionals making themselves available at any time and that they were honest and responsive.

However, one participant commented that while her surgeon was competent she found his manner patronising:

*My surgeon was probably one of the best breast surgeons in Australia; his manner, however, is typical (of surgeons) it was like "I'm going to fix you dear that's all you need to know dear. You don't need to know the technical side of things.... I'm the physician".*

## **Access to services**

While participants were satisfied with the care and treatment they received in hospital, they were not satisfied with the support received after discharge.

This supports Amos et al.'s conclusions that one of the challenges faced by consumers was the lack of support after treatment (2008, p. 30):

*They offered me one nurse from the hospital but the day I needed her I rang her and she never bothered to come out so I had to ring one of the local doctors to change the dressings.*

*The district nurse could only come once a week and they couldn't get anyone else there one Sunday... His bandages were soaked and they needed to be changed so on the Monday I called Dianella and the nurse from Dianella showed me how to do it and then I did it myself, they were wonderful.*

Only a few people accessed additional non-medical services such as counselling, home help or support groups. Of those who did, participants couldn't remember how they accessed these services or who offered them. Most commented that they thought perhaps a social worker had initially mentioned them or that their doctor had passed on their details to the services.

Consumers who did access additional services reported their main entry point was through friends or family. This supports Amos et al. (2008), who also found that people became “aware of services and assistance via word of mouth or by accident” (p. 25).

Consumers who accessed complementary programs like the Cancer Council’s ‘Look Good Feel Better’ commented that they were crucial in their recovery journey:

*I went to the ‘Look Good Feel Good Program’ for women who are going through cancer; they teach you how to wear a wig, how to wear a bandana, put on make-up; they taught me how to draw on eyebrows.... [Interviewer: How did you find out about it?] Not sure I just heard about it... If cancer support services or hospitals had this sort of stuff it would have helped.*

Other participants sought other complementary treatments, accessing therapies such as naturopathy, meditation, yoga and relaxation:<sup>1</sup>

*They [health professionals] are not supportive of natural therapies for recovery; they would just tell me to go home and rest, and if you mention something alternative they roll their eyes or ignore it or don’t recommend it. They didn’t understand that I had to work.*

People commented that they used massage, meditation and other relaxation therapies to deal with stress and anxiety. Three participants expressed excitement and anticipation about the new cancer Wellness Centre, which is being planned at the Austin in Melbourne. They welcomed this shift away from the existing medical model offered by cancer services.

Interestingly, other participants stated that if they had been offered complementary therapies during or after their treatment they may have used them.

Participants stated there was little support offered to family members; in particular adult children. One woman reported that she wanted to explain things to her 18-year-old daughter but found all the information targeted towards younger children.

Another woman found information for her 13-year-old daughter while she was at the hospital.

*We were worried about our kids... one day when we were at the hospital we saw this brochure in the waiting room for kids whose parents were going through cancer...she looked up the website on the internet and attended a few events... I think she found them helpful but has stopped going because she didn’t know anyone.*

Two participants who identified as carers felt that they would have coped better had they received some assistance. In the case below the carer was offered assistance in the presence of her husband on a number of occasions, but her husband refused.

*Two weeks ago someone from City Mission rang to see if we needed anything and he [my husband] told them that he didn’t need anything... they said they would ring back and they did today but this time I picked up the phone... they are going to come and talk to us.*

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<sup>1</sup> This question was not originally included in the planning. However, as people discussed what challenges they faced and how they overcame them the question was included in later interviews and focus groups.

Again in another case assistance was offered but refused.

*They offered me help with my mother but I didn't accept it because I helped her... me and my husband... we don't want to use something that we don't really need, we prefer to leave it to people that need it.*

One carer felt that they had been left out of discussions about health care and treatment.

*When they ask him things he always says that he is alright – they should ask me – they only see him for five minutes when he has had a shower and dressed. They don't see him when he is in pain or has not slept for days... if they ask me I could give them more information.*

### **Support groups**

Participants were asked if they had accessed support groups. Many said they hadn't for a variety of reasons, which included:

- it wasn't offered
- they didn't believe they needed it
- they felt uncomfortable going to a group with other people they didn't know
- they were reluctant to access support groups because they believed they were going to be confronted by sick or dying people
- they had supportive social networks such as senior citizens' groups, church groups and activity groups
- they used family and friends for support

Participants said they valued the emotional support received from their family and friends. This supports the findings of Amos et al. (2008; p. 34)) who cited family and friends as the most valued aspect of support outside the health system.

*Because I had a wide group of friends and family I didn't feel like I needed any support. Also I had my church and religion.*

One participant commented that she didn't want to access support groups because she didn't want to become part of the "cancer culture".

Only two participants in this consultation accessed counselling services and only one accessed a cancer-specific support group.

### **Challenges**

Participants were asked to identify and describe the challenges they experienced during their cancer care. The findings were similar to those reported by Amos et al. (2008). Challenges reported included, transport and cost of parking, financial impact of cancer, and access to information.

#### **Travel, transport and cost of parking**

Participants stated that they often used public transport because parking was expensive or car parks were full.

*Many times we used public transport because of the parking... The hospital offered us a discount (for parking) but it was always full.*

Another participant commented that sometimes going to hospital for treatment using public transport was tiring and sometimes it “took the whole day” because she had to wait for tram, train and bus connections.

Participants commented that the cost of parking could sometimes add up to \$50 or \$60 per week and that, along with other costs, this added extra burden on people, particularly if they were on a pension.

Several participants also stated that they often needed someone to take them to treatment sessions. They felt this was a burden on family members and friends who often drove them to their appointments. This supports the finding of Amos et al. (2008; p. 21) who reported that travel, and issues associated with it, was one of the major challenges faced by both rural and metropolitan consumers.

### ***Financial impact of cancer***

Consumers stated that they had to pay for radiotherapy but most were able to claim some of the costs back on their insurance cover or through Medicare. Even so participants stated that the initial outlay for treatment set them back financially. Two participants told us that if it hadn't been for their children helping them financially they would have found it difficult to meet treatment costs.

Incidental costs associated with their treatment and the impact that this had on the family was also challenging for some participants.

One participant said:

*We had private health cover but it still set us back at least 10 years financially. At first I used my sick leave, holiday leave and long service leave, then we had to use our savings... we still had bills to pay, school fees and mortgage... my husband would take time off work to help and drive me to appointments.*

Other costs included:

- medication
- bandages and dressings
- loss of income due to illness of the consumer or carer having to leave work
- impact of illness on self-employed consumers.

These findings are also supported by Amos et al. (2008).

A range of challenges were raised relating to treatment were similar to those found by Amos et al. (2008). These included:

- receiving chemotherapy and radiation
- not having choice in treatment
- waiting for treatment in crowded facilities with no privacy
- being treated in Outpatients.

Participants also raised some personal challenges including:

- trying to stay positive
- feeling isolated and depressed at night.

### ***Information received***

This consultation revealed discrepancies in the quantity and quality of information received by consumers and carers. Those consumers who had experience of breast cancer reported having received a plethora of cancer-specific information.

Most participants reported having received reading material, audio-visual material or had accessed information on internet sites specific to breast cancer. Some participants said they preferred receiving material in hard copy because they would often read it in their own time at home or after other members of their family had gone to bed:

*I needed the information... and I needed to come home in my own space and read through it and then put it aside... and then read through it again.*

Participants also identified the need for information that was specific to their cancer. Several consumers who had less common cancers found that they had to find the information themselves. This was also found by Amos et al. (2008).

*We were told that someone from the Cancer Council would contact us but it never happened... we tried to look on the internet for information but it takes too much energy to look for information or services... it seems there is a lot of information for breast cancer but nothing for others... I guess bowel cancer is not as sexy.*

Participants were asked if they had contacted the Cancer Council for information or used the telephone counselling service. Only one of the urban consumers had contacted them and found them helpful:

*If I was uncertain I rang the Cancer Council 13 11 20... I rang them quite a lot... the nurses were fantastic... they got me through.*

Participants who had experience of breast cancer also commented that the breast care nurses were able to assist. One consumer who was previously diagnosed with leukaemia over 20 years ago commented that trying to navigate the system and finding out information at that time was difficult; however, her recent experience of finding a lump on her breast was totally different:

*I recently found a lump in my breast and the doctors were all worried... I wasn't, because when you have been through what I have been through then that's nothing... but all of a sudden this breast care nurse appeared like from nowhere and she was making appointments and getting me this and that.*

Participants also identified family members as a source of information. In particular those participants who had older children said they receive information through their children, who used the internet. However, they were aware that often children filtered the information so as not to worry them:

*As soon as she found out what operation he was going to have my daughter looked it up on the internet... She even googled his surgeon.*

### ***Participation in their own care***

Participants were asked if they felt as if they had participated in decisions regarding their treatment and health care and most stated that their doctors and surgeons had included them. However, this observation was later refined by participants.

Some said that most times, because of the urgency of their situation, there was little time to discuss options with their health care providers; and in most cases, after treatment the only options discussed between them and their health care providers pertained to either chemotherapy or radiotherapy.

One woman commented that she was not given information to prepare her for the side effects of chemotherapy or radiotherapy.

*I have been relatively happy with the medical treatment, although no one told me that chemo would hurt and that radiotherapy would burn your skin.*

Some participants identified their own participation in decision-making as changing over time. They stated that while, initially, they followed their doctors' advice, as they become more confident they began to participate in decisions and to ask questions:

*In the beginning I won't have questioned anything ... They [health professionals] have always held that sort of special thing... so you don't really question them. But I've learnt now I can ... now, the doctor that I am seeing now has made himself open.*

*I go in with my list and they have to answer all my questions first before we continue. Once upon a time the medical professionals were gods and they had halos but they lost their halos a long time ago.*

Despite participants' initial shock and distress about their diagnoses, some said their diagnosis of cancer had had some positive aspects in their lives. One woman said that she was initially embarrassed to speak to her sons about it but that once they found out it had brought them closer together:

*When my sons found out a lot of good things happened, it brought us closer together... we speak about anything... my sons said "Mum you're not to do that we are a family now and we have to support each other". The good thing about getting sick meant that I had to focus my life – I had to focus on the present. Now if an opportunity arises I take it.*

### **Suggested improvements**

This group of participants had a number of suggestions for improvements. These included:

- support services offered at various stages of their cancer treatment and journey
- the need for more services offering public radiotherapy treatment in the northern metropolitan region
- a "one stop shop" cancer facility that encompassed the whole cancer journey from treatment to recovery, including access to information about what services consumers can access
- doctors could be more supportive of complementary therapies and services.

One participant stated:

*Unless services publicise themselves you don't know they exist... If they don't suggest things then you never try it... if there is a semi-professional available that you can talk to, you are likely to strike up a conversation and*

*then ask questions. But if you don't know what is available you don't know what to ask for.*

### **3.2.2 Rural English-speaking**

This project also conducted a focus group and one interview with English-speaking consumers in the Shepparton area.

#### ***Reaction to Diagnoses***

As with other groups, this group also commented that when they were initially told of their diagnoses they were in "shock" and believed that they would die. This was then followed by not knowing what would happen next:

*When they tell you that you have cancer they don't start treatment straight away so you have to wait. And you don't know what's going to happen*

#### ***Treatment and care***

Participants commented that they were satisfied with the level of care they received:

*Oh yes the doctors have been very good.*

All but one participant in this group received treatment in metropolitan hospitals.

*I felt a lump, I had my first scan in Shepparton but I couldn't get back to see the GP as she was sick. I just happened to be travelling down to Melbourne so I rang the Freemasons women's centre and they saw me the same day... the Shepparton clinic sent my x-rays down to Melbourne.*

#### ***Challenges***

When asked about what challenges people faced the most common response related to travel. This supported the report by Amos et al. (Amos A. et al., 2008) as well as that of Mansourian et al, (Mansourian., Bruce N., McBride T., & Romios P., 2008), which found that the biggest challenge for people from rural and regional Victoria was travelling to Melbourne for treatment. The additional issue of finding accommodation was also cited:

#### ***Travel***

*I got treatment here but had to go to Melbourne for radiation and that cost me a bit, you know, with travel and that, I got some back on Medicare for the radiation.*

Travel was often related to the lack of services in rural areas, in particular radiotherapy services.

There was also a common perception among this group that they were receiving better treatment by travelling to Melbourne:

*I found the services in .... very poor, especially Outpatients; the toilets were dirty, and you have to repeat yourself all the time to different people. In Melbourne I feel like you get better treatment but I was in a private hospital.*

When asked about how they dealt with the issue of travel most replied that they had friends or family drive them to Melbourne for the day and then drive back. Others had friends or family in the city with whom they could stay.

None of the participants had applied for the Victorian Patient Transport Assistance Scheme (VPTAS) for the following reasons:

- they were unaware of it
- it was too complex
- they didn't think they would qualify for the VPTAS scheme

### ***Access to services***

The majority of participants in this group did not access support services during or after discharge. This was mainly because they used family members; with one man stating that they didn't need anything because he had his wife who had now become his carer. This was the same for another participant who had now become the carer for her husband. However, one participant had accessed services such as home help and had been offered counselling:

*My doctor was great. He asked me if I needed any help with anything and got me some home help; I also got a package of information from the hospital.*

### ***Information***

In this context information refers to information received about their tumour type, treatment and support services.

Only one participant commented that she had received information through the hospital in the form of an information kit and had also received information via a social worker. Others did not receive any information and seemed confused about their treatment and care. Participants in this group then began to ask detailed questions about treatment and procedures, indicating that they had not understood or been given information about their treatment.

### ***Suggested Improvements***

Participants were asked to comment on what could improve their experience:

- more medical services in the Shepparton area
- more specialised cancer support in the Shepparton area
- information about cancer support groups
- more cancer specialists in the area
- a cancer centre in Shepparton that has information about all types of cancer and information about services that can be accessed.

Italian-speaking consumers in the Shepparton area raised similar issues. This will be discussed in the next section of this report.

### **3.2.3 Spanish group**

The following section documents findings from a focus group and one interview with Spanish-speaking consumers in the northern metropolitan region.

As with the other participants groups, this group was satisfied with the level of care they received in hospital. One participant commented, "From my experience everything was perfect".

One woman who was from Uruguay commented that “compared to my country the Australian system is wonderful... in Uruguay you have to bring everything... your own food, bandages, sometimes even medicine”.

The comments made by this group of participants need to be contextualised, as some were comparing the level of service received in Australia to the services they experienced in their country of birth.

### ***Challenges***

There were issues of note raised in relation to general practitioners (GPs). Some participants reported varied and conflicting care at the beginning of their pathways. This potentially led to a lack of trust in their GP. One participant commented that his GP referred him to two specialists before the cancer was diagnosed; he felt that had his GP referred him to the right specialist in the first place he may have been able to start treatment earlier.

### ***Language services***

Participants were asked if they had used an interpreter. All said no because they felt that their level of English was “good enough”. However most commented they used family members, mostly adult children to explain anything that they didn't understand.

### ***Information***

One participant was able to access information in Spanish from the local library, for her elderly mother who had experienced breast cancer. While she had accessed information for herself in English from the Cancer Council, she had never thought to ask them for information in Spanish and was unaware if it was available.

Other participants in this group seemed to receive most of their information through word of mouth via other community members who had experienced cancer. Discussion revealed a number of strongly held myths and beliefs about cancer, including; that cancer is hereditary, eating over-toasted bread or charcoaled meat causes cancer, eating tomatoes is good to prevent cancer.

The CanNET Victoria project officer who attended the focus group provided written material to this group both in English and in Spanish. Further to our consultation the group leader has contacted CanNET Victoria and requested more information for other members of the group.

### ***Suggested improvements***

Following discussion with the group leader it was suggested that participants would benefit from a language-specific awareness campaign regarding the causes, prevention and treatment of cancer.

## **3.2.4 Italian Group in Shepparton**

This section details the consultation with a group of consumers from the Italian-speaking community in the Shepparton region. While most of the participants in this group were born in Italy they had a high level of English proficiency and had been in Australia for over 30 years. Some had arrived after World War Two as teenagers or young adults. Those who arrived as adults were able to communicate

in English, although most had little formal education. Some were not fluent or literate in modern Italian but spoke a dialect of Italian from their particular regions. There were also a number of community workers and community “leaders” in this group who worked closely with the ageing Italian population in the Shepparton area.

At the beginning of the consultation the group discussion focused on ‘why me’ or ‘why my family’. This followed questions about whether or not cancer was hereditary. This issue also arose in the Spanish group.

### ***Reaction to cancer diagnosis***

As with other groups this group also associated cancer with death:

*The world is finished.*

*The first thing you think it that they are going to die.*

Participants also reported feeling shocked and helpless and that their initial concerns were for their families and children. This was similar to the group of Turkish-speaking consumers who also expressed initial concerns not for themselves but for their children and family members. One participant said:

*The whole family is involved because you think well it's in the family.*

### ***Language services***

Participants were asked if they had been offered an interpreter at any stage during their care and treatment. All commented that they had but most had refused the offer and they chose to use family members or self-assessed their level of understanding as adequate enough to not need an interpreter. For those who only spoke a dialect they felt that an interpreter who spoke modern Italian was not appropriate.

*My dad only speaks Calabrese -Italian dialect- so when he got an interpreter he couldn't understand him.*

*The interpreter didn't understand him and he didn't understand the interpreter.*

*I've been 49 years in Australia. I don't know some Italian words.*

*We understand enough so we no need an interpreter.*

However, what emerged after further investigation was that often adult children were not proficient enough in the parents' first language to interpret medical terms correctly.

Participants did, however, recognise the usefulness of having an interpreter in a health setting as interpreters do not filter information. They recognised that family often did not disclose all the information passed on by the doctor because they either didn't want to upset them or because they weren't able to explain complex terms.

*Interpreters can be useful as they tell you what is happening and don't try to protect you.*

## **Participation**

Most of the decisions about care and treatment seem to be guided by the doctors; the GP at first and then the specialist. This was later guided by family members, usually adult children, who often advocated for their parents.

*The doctor made the decision .... He said "you can have that but you have to say yes" ... then we talked to my daughter and she came to talk to the doctor and then she decide... And when we were at home she said "oh sorry Papa I didn't ask you what you want, I decide for you but I think this is the best for you".*

*You're trying to find out but the doctors don't really explain what they're doing.*

## **Challenges**

Participants identified a number of challenges that were related to navigating the system, access, travel and information.

### **Navigating the health system**

Discussion revealed some misunderstandings about navigating the health system as well as eligibility criteria for support services:

*My sister wasn't eligible for anything; she found it difficult ... financially she was in dire straights.*

*Medicare doesn't cover everything.*

There was also confusion about the private and public systems and the benefits or not of having private cover. One participant stated:

*They have the biggest costs. It cost my uncle \$10,000 and he had private cover; he paid for everything and he had a friend who had the same condition who had public care ... he paid nothing.*

### **Lack of services**

Participants also commented that there weren't enough locally dedicated services; several references were made to the need for local treatment options. This issue was closely related to why participants felt they had to travel to Melbourne.

*For a town like Shepparton with a population of 10,000 people it is sad that we have to go to Melbourne or Bendigo because we don't have those services here.*

In this particular case participants were referring to radiation treatment.

### **Travel**

As with other rural consumers that we spoke to, travel to Melbourne or Bendigo for treatment was one of the biggest challenges for this community:

*Everything is based in Melbourne and that's a big problem... or we can go to Bendigo ... which is half way but there is no public transport... and also people are not used to driving in the city.*

*Some people they don't have the support network to drive them around because people are in full-time employment and that makes it difficult.*

*Sometimes I drive to Melbourne and come back and then I go come back again.*

*My girlfriend was driving her mother to Melbourne and she got to Seymour and called her and said you better go back because we are booked out today... so she started driving back and then they called her again and said ok you can come in now. They [health services] don't realise how far it is.*

There did not seem to be awareness or uptake of travel and accommodation support. One participant stated:

*My sister went down because her son died this year and they were going back and forward everyday, they're in their 80s, and then they were told that you could go to the office at the hospital and you fill in this form and you could claim for petrol and she went and she was told that they don't do it any more.*

### **Information**

As with other groups of consumers consulted, the participants reported that their access to information was ad hoc and scattered. Participants made the following comments:

*Nobody told me about anything that I could get to help me*

*I didn't know that at the GP you can get a pack of information.*

Participants believed that information should be coordinated locally by a language-specific community worker. One participant said:

*A social worker who speaks the language may be more able to explain things.*

*Need a social worker who speaks the language. You can't always have someone who speaks all the dialects but really important to have someone who knows Australian Italian community.*

### **Suggested Improvements**

Participants suggested the need for the development of culturally specific services and a general awareness campaign of what support is available targeting the Italian community. They suggested this could be developed in partnership with the local community.

Participants were enthusiastic with their suggestions of how to improve their local services. There was a general agreement that the system needs to change. One participant said:

*It's not user friendly.*

Another commented:

*There needs to be someone who can intervene to give you the options.*

One suggestion was that “there should be a crisis team like a person to resource people who need it”. Several suggested there should be a social worker who needs to be a part of this team.

Participants also suggested a “one stop shop” for information and support.

One suggestion that seemed to have broad support was for a language-specific support network with information sessions as well as social outings. This network would then become part of the community. However, participants were clear that it needs to be staffed by paid professionals and not left up to volunteers or small ethno-specific services that are already under-resourced.

There was further general agreement that: “there needs to be improvement in transport—if you need to get to the hospital”.

It was also recommended that there should be a cancer resource centre. One participant stated:

*Having that centre in Wodonga was a great source of comfort in the northeast as they didn't have to go to Melbourne... .*

Further support was given for family-centred care with participants commenting that anything planned must include families as well as consumers and carers.

### **3.2.5 Turkish Group in northern metropolitan region**

This section details the consultation with a group of consumers from the Turkish-speaking community in the northern metropolitan region.

#### ***Reaction to diagnoses***

Shock, fear, worry and anxiety are common responses among people who are diagnosed with cancer. The Turkish participants in this group were no exception. Upon hearing they had cancer, they thought about death and suffering. The word ‘cancer’ seems to strike everybody in the same way. One said,

*When I say the word I have to touch wood.*

Consumers were worried about impacts of cancer diagnosis on their family, that their family might be upset by the diagnosis. This was particularly pertinent to female participants who tended to link the impact of diagnosis to their family. They were worried about not being there for their children. Some feared the cancer could be passed on genetically to their children. One woman was told she had cancer when she had her husband and children in the room. When asked if whether having the family with her was helpful, she said:

*No, it was worse. Instead of concentrating on how I was going to survive and what to do next, I was worried about my family and how they coped with the news.*

Another participant did not tell her family about her cancer:

*I did not want to worry my family so I told them that I was pregnant. When I was going in for surgery I said that there was complication with the pregnancy and I had to have an abortion.*

The experiences of the Turkish consumers suggest that the delivery of information about a cancer diagnosis is a significant challenge. One participant said that the doctor told him that he had cancer in such a manner as if informing him that he had flu. Another woman said she did not want to ask as many questions as she wished, because:

*When you are diagnosed with cancer you are panicking. You wanted to ask many questions and if you ask too many questions you are labelled as paranoid.*

Some participants suggested that improvements could be made by facilitating and providing access to information about cancer in a family-centred way and with a consideration to culture. One woman recalled:

*Twenty years ago my husband was diagnosed with lung cancer. The doctor told me because my English was better. I didn't want to tell him but the doctor said if you don't tell him I will call an interpreter and he will tell him. So I had to tell my husband. I will never forget the look in his eyes.*

### **Language services**

Participants in this group said they were offered an interpreter but did not use them because they had family members present or were able to understand. However, upon reflection, participants stated that interpreters are useful, and having a professional interpreter is better than using a family member. One woman who interpreted for her father said that sometimes she was embarrassed to talk about aspects of care with her father and sometimes she did not understand the medical terms.

### **Challenges**

This group identified a number of challenges, including navigating the health system, information and travel.

#### **Navigating the health system**

As with many other cancer patients, waiting for results of tests was a concern for the group. The longer they waited, the more anxious they became. Waiting for treatment was another cause of anxiety. Some consumers were told to wait for months before they could have surgery to treat cancer.

*They treated you three months after you knew you had cancer. You thought you were going to die - during that time. ... I beg the registrar to put me in front [of the waiting list].*

Waiting time was perceived as being related to the consumer's financial status. One man believed that only those who had private health insurance received timely care. Another woman reported that the specialist discussed money with her to determine treatment time, regardless of the diagnosis. She recounted:

*My doctor said, "Do you have private health insurance? If you do you can have an operation straight away. I asked him how much.... He said 15-20 thousand dollars. I said, "I am not going to pay. If I die, I die.*

Several consumers shared their frustrations about waiting and discrimination in treatment. One participant said:

*Why do they ask about you about private insurance? If you need treatment they should just give you treatment. First they tell you that you have cancer then they ask you "do you have health insurance?" and then "do you have money?" He told me if you pay I can get the test done straight away. I showed him my keys and I said "you can have my house, I just want my life". He got me the tests and I didn't have to pay.*

Another consumer said:

*If you don't have private health insurance they don't care, they don't explain what is going to happen; they just do things.*

There was the perception among participants that as public patients they did not have their own doctor or specialist and therefore no opportunity to build trust and rapport with their treating doctor. One man said:

*They put you to sleep and you don't know who will cut you up. ... And when you wake up you don't know whether they tell you the truth or not.*

One participant commented that she would like to see the same doctors. This woman was frustrated as she saw different doctors each time she went for her appointments.

*I had to start telling my story all over again and again each time I go there. I don't like it.*

### **Information**

This group also commented that written information alone is not an effective strategy, it needs to be supported verbally because, "not everyone reads pamphlets." Information in different languages was considered helpful as well as the involvement of ethnic groups and associations in the provision of information.

Information which this group thought was needed included:

- prevention of cancer
- financial assistance
- how to get treatment quickly
- other support available
- where and how to lodge a complaint.

Participants in this group also highlighted access to support services or programs. The majority of participants were unaware of services that were available to them, such as housekeeping and home visits, and this caused frustrations:

*Why don't doctors tell you about services? If you don't ask, nobody helps you but how do you know what questions to ask?*

## **Culture**

The following collection of quotes reveals the extent of participants' perceptions of the impact on culture and health care:

*As a nation we are very emotional people... we experience our emotions in a very strong way – this is the reason why we are misunderstood by some of the other races' professionals – we become excited and we become involved*

*I had trouble because of my culture – because my operation side is my, underside, so they want to have a look you know if I have any infection there. It was a bit hard for me especially if lady nurse come... Australian culture is different you know... they are free, open.*

## **Travel**

Participants were unaware of any transport assistance. Most people used their cars but commented on lack of parking spaces at hospitals and expensive parking fees. Many were driven by their family members to hospital.

Some participants travelled by public transport. One woman said she had to take a bus, a train and a tram to her appointments. That was after her daughter could no longer drive her because she had to work.

## **Suggested improvements**

Participants suggested that more funding should be allocated to public hospitals to improve services for people who do not have private health cover.

Participants also suggested that there needs to be greater awareness of services that can be accessed. However, they did not suggest how this should be coordinated or delivered, but did comment that some of this information should be translated and provided to associations, groups and health services. The group also acknowledged that pamphlets are not always read, so seminars, meetings and information sessions should also be provided. This group suggested that this information should be available at all stages of their cancer journey including prevention, diagnosis, treatment and recovery.

### **3.2.6 Indigenous consultation**

Two Indigenous health workers and three Indigenous community workers were consulted in the Shepparton area regarding the Indigenous community experience of cancer, cancer services and recommendations for engagement.<sup>2</sup>

Anecdotal evidence suggests that cancer is just as widespread in Indigenous communities as in non-Indigenous communities; however, they were aware of little recorded data. One participant commented that "just about everyone knows someone who has been affected by cancer".

Another participant emphasised the prevalence of cancer in Indigenous communities, stating:

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<sup>2</sup> These numbers were not included in the total 57 as they were consulted as community workers and not consumers.

*There is cancer in Indigenous communities but how do you prevent it. People can't afford to eat fresh fruit and vegetables. They have limited access to preventative treatments - what are they supposed to do?*

The consultations revealed that, as in non-Indigenous communities, the word 'cancer' is associated with death. This is further complicated by the fact that mistrust of public health services is still prominent in the Indigenous community. Indigenous consumers of health services are reluctant to engage with mainstream services or health professionals due to mistrust based on historical events and past and present government policies.

Participants also commented that for some Indigenous people hospitals are seen as places to die.

Another area of focus was that Indigenous consumers very rarely participate in their own care and treatment because they fear speaking up or asking questions of health professionals "because they don't want to be seen as stupid". Indigenous community workers, leaders, or Indigenous health professionals were often left to advocate for consumers.

All participants consulted described language barriers experienced by Indigenous consumers. Indigenous consumers found health professionals difficult to understand because of their use of the English language. One participant who was fluent in English said that she herself had asked the pharmacist a number of times to explain a prescription for her son but she still walked away unclear and confused about the medication.

The issue of having to travel to Melbourne or other regional centres like Bendigo for treatment because of the lack of services in the area was seen as the major accessibility challenge. There were concerns about driving into the city, not knowing anyone, accommodation and the expense related to travel. One participant who drove a member of her family into Melbourne for treatment commented that she had never driven in the city before and so was stressed for weeks before about where she was going, where she was going to park as well as dealing with the traffic. She said:

*If you have never driven or been in the city it's quite scary. Then trying to find accommodation for families is hard. We had to ring around ourselves [and] we didn't know how close they were to the hospital or how to get from the accommodation to the hospital. Hospitals should have a list of all that information. We were driving back and forward all the time. Eventually someone told us about VPTAS.*

Two of the participants, while aware of the VPTAS system, commented that it was not appropriate for their Indigenous communities because it requires people to outlay money that they don't have and claim reimbursement later. As well as this, the workers commented that the process was confusing and time-consuming:

*Travel is an issue for people. If they have to go to Melbourne or Bendigo for treatment it may cost money that they don't have. We don't use the VPTAS system much because it's complicated and takes too much time ..... so what's the point?*

Indigenous health workers had their own strategies for dealing with rural Indigenous consumers travelling to Melbourne:

*If we know someone is going to Melbourne for treatment we will call the ALO in the metro hospital or the social worker and tell them so at least they can go and have a name or they know someone is going to meet them. We just don't send them off. Our people are about the "meet and greet".*

When asked if this practice was hospital policy he commented that when working with Indigenous communities you sometimes have to do things differently.

*We know how to work with the community, because we are from here, they trust us and ...[the hospital] leaves us alone and lets us do our job. It's not like a 9 to 5 job, our work never stops. We get called out after-hours. It doesn't stop for us.*

He added:

*You don't need to be from the community to work with Indigenous people but it helps if you are. The community trusts us—we grew up here and we have relationships with people based on respect. We've gone through the same battles as them, even people older than us call us 'Uncle' and 'Aunty. You have to get out amongst the people - be seen - always say "G'day", talk to them find out what's going on. It's not just about going to hospital... what happens when you go home and you have no heating, food or money for medication... people are embarrassed to ask for help but they will ask us because they know we understand.*

From our discussion with Indigenous workers it was clear that any health information targeting Indigenous communities needs to be developed and delivered by the communities themselves. Indigenous workers commented that often mainstream services want to come into the community and "fix things".

*Health professionals speak a different language. Indigenous people need to deliver the message and programs to Indigenous community because we speak the same language.*

*If mainstream organisations want to work with Indigenous communities they have to listen to us, take advice from the community.*

Indigenous consumers engage with health services when they need them and acute health services rarely work in an outreach model. Indigenous workers commented that this medical model of health care or a 9 to 5 model is not appropriate for this group of consumers, who are reluctant to access hospitals or health services due to mistrust issues.

*When people are in hospital they prefer to speak to us. They won't speak to a social worker because they are scared.*

It was suggested that mainstream services work with trusted Indigenous community workers to pass on information.

Another significant comment was that because of entrenched beliefs some community members will refuse health services. Participants were clear that if the community didn't want services then you couldn't force them and that you had to respect their decision.

The concept of partnerships was discussed with workers who commented that partnerships only work if mainstream health organisations provide what they referred to as “real help”, not just words.

Goulburn Valley Hospice was mentioned during the consultation as a service that engaged successfully with the community and managed to develop trust and respect with a number of community members. The concept of culturally relevant health care was supported by the Goulburn Valley Hospice Care Service Coordinator who commented that as a service they just listen and respond to the needs of all patients, including Indigenous patients. She recalled that about three years ago she attended a Palliative Care workshop in the local region and there were some Indigenous community members who attended and presented information about Indigenous community attitudes and customs about death and dying. “As a service we just kept talking and listening to them and we have learnt a lot over the years but we never think we know everything.”

She recalled a story about how one day when they bought a hospital bed to someone’s home the family asked if people had died in that bed:

*We didn't lie to them we said yes although we didn't actually know since it was a hospital bed. So they asked if they could do a smoking ceremony and we said of course. They did and then they were happy, that's all it took. Now we tell people and say to them that they can do a smoking ceremony if they want, why can't other hospitals do that... I guess now people tell others and that's how it works.*

## 4. KEY FINDINGS AND IMPLICATIONS FOR CANCER SERVICES

The findings of this report confirm those of Amos et al. (2008).

This consultation found that consumers across all population groups were generally satisfied with the treatment and care they received. All participants commented that most health professionals were accessible and inclusive of them in their treatment and care. Despite this participants raised a number of issues which are discussed below.

### **Quality of care**

An issue that arose early in two of the focus groups was the perception that quality of care was associated with whether or not participants had private health insurance. Participants believed that consumers who had private health insurance received better quality of care. This came through strongly in the focus group conducted with the Turkish and the Italian communities.

While it did not emerge as a strong theme in other groups, a previous study conducted by Bruce et al. (2008) found that this is a common assumption held by some consumers.

However this report also found that this assumption was not always held by consumers who had experienced both the private and public system. (Bruce N., Romios P., Naksook C., & McBride T., 2008). This finding suggests a lack of broad understanding regarding the Australian health care system. For this reason pathways and service options for consumers regarding public and private care need to be clearly articulated by health care providers to aid decision making and avoid stress and confusion.

### **Supportive care**

#### **Post Discharge Support**

A common theme that emerged was the lack post-discharge support. Once people had been discharged from hospital many participants felt there was little support and communication available. People often turned to their local GP or community health service for assistance. This strategy if coordinated by cancer services can be a legitimate and useful pathway for consumers once they have left the acute system. Engaging and building relationships between cancer services and local services, such as GPs or community health centres can create a legitimate pathway to support people once they have completed treatment as well as for carers and family members.

#### **Counselling Service**

This consultation revealed a low uptake of counselling services. One of the reasons for this was that often consumers were reluctant to discuss the private nature of their illness with someone they didn't know. This finding has implications for the structured model of counselling that is currently offered by health services and cancer services. It appears that counsellors are not always engaged with consumers during their treatment and care and therefore have no prior relationship or rapport. In contrast consumers often develop relationships with nurses or doctors, therefore referral or introduction via a trusted source may encourage better uptake of counselling services or the development of strategies to increase communication

with other team members. Services should also consider a less structured model of counselling, for example informal conversations with people while they are waiting for or receiving treatment.

#### Support Groups

Many of the consumers consulted in this study felt reluctant to access support groups believing that they would be confronted by sick or dying people. This finding has implications for how support groups promote themselves to consumers. Support groups are often made up of a mixture of people at different stages of their cancer journey. A more staged approach to groups, focusing on where different consumers are along the stage of their journey, may better meet the needs of some consumers.

#### Social Networks

Participants commented that they often used social networks for support such as senior clubs, planned activity groups and fitness groups. Building the capacity and knowledge of existing groups may engage consumers who are reluctant to become part of the "cancer culture". These strategies have been used in the youth sector where sport and recreation has been used to engage young people in services and programs to combat anti-social behaviour, bullying, youth suicide and delivering health messages.

#### Complementary Therapies

This consultation revealed that some consumers had used complementary therapies either during or after they had completed their medical treatment. This question was not included in the original set of questions but was added early in the consultation after two consumers raised it in discussions about valued aspects of care. The use of complementary therapies by consumers with cancer is not uncommon however some health professionals are often reluctant to encourage this. A more holistic approach to cancer care within cancer services as well as cancer services working more closely with complimentary services would benefit consumers seeking such an approach. For example, consumers who were aware of the new cancer centre planned at The Austin were hopeful that it would provide a more holistic approach to care and treatment.

### **Information needs**

Access to information for all the participants was an issue. Participants who had experience of breast cancer reported having access to a lot of information. However, access to information for people with other tumour types varied, often depending on how proactive they were at sourcing the information themselves.

This was the same with regard to information about services. Participants who had experience of breast cancer received information along their journey, partly due to the introduction of breast care nurses who were with consumers throughout their treatment. Consumers from other tumour groups only received information at the initial diagnosis or in an ad hoc manner. This finding has implications for how and when services and information are offered to consumers. As the consultations confirmed, consumers who are diagnosed with cancer are often in shock in the initial stages. Therefore too much information at this point may not be appropriate, but information received in a staged approach or even repeated at a later date may be more useful.

Almost all participants across the consultation found that non-medical services and support services were not offered directly to them but they were often accessed via information received from family or friends. This finding has implications for health

services in the way they provide information to consumers once they have been discharged. While strategies such as information packs, brochures and flyers should not be discounted it seems that verbal information passed on by a trusted source is often more influential for consumers. Information and coordination of services through health professionals such as social workers or breast care nurses can assist people to be informed of their options. The model of a local community social worker who can provide support post discharge was one that the Italian community in Shepparton favoured. A number of community workers who were present at the consultation were already providing this type of support informally. These workers had developed trusted relationships with the community and were therefore seen by many as a reliable source of information and support.

#### Information for CALD consumers

Access to information in relation to the CALD consumers focused around the type of information, with translated information not always seen as being beneficial to CALD communities because of low language proficiency of some participants in their first and second language. This finding has implications for the amount of financial resources some services may allocate to translating written information that may not be useful. Communities placed greater value on information that was delivered verbally by a trusted and reliable source. This was often a community social worker or in most cases adult children who had been born in Australia and were fluent in English. While this study did not focus on the issues for second generation immigrant children this group emerged as one who needs appropriate support and information, as they were often the ones assisting their parents in health decisions.

#### Carers

##### Support for Carers

Another theme that emerged was that carers felt that they were left out of discussions about services and support and that they themselves seldom accessed assistance or support. While only two participants identified themselves as carers in this consultation, our observations indicated that family members, spouses, partners, siblings and even children were acting in carer roles. This was particularly evident in the consultations with CALD groups in which carers were not directly referred to but it was implied that carers were often family members. There are implications for organisations which provide support to carers in how they promote themselves and provide support to a group that does not identify themselves as their target group. This will require strategies to assist both consumers and carers to develop an understanding of the carer role and its impact and implications for the consumer, carer and family. This is highlighted by an example in one of the focus groups where the person with the diagnosis was accompanied by his partner, who did not identify herself as a carer however was acting in the carer role.

##### Engagement of Carers

When questions regarding support services were asked the male participant responded for his partner and implied that support wasn't need because she was acting in the same role before his illness and therefore he saw no need for extra support.

Organisations therefore need to be aware of gender issues when trying to engage carers. For example, one of the carers reported that she was only able to access support when she was offered it without her husband being present. This implies that services may need to explore options for supporting carers that encourage and enable deliberative and separate decision-making.

## Model of Care

The current model of care can sometimes exclude family and carers.

- Recognising that cancer impacts on more than just the person with the diagnosis is a shift from current practice but one that may need to be looked at in order to address this gap.
- The women's and justice sectors have successfully done this by seeing domestic violence not only as a women's issue but one that affects the whole family, hence the change in terminology from " domestic violence" to " family violence". This has also been followed by a number of systemic changes in practices and policies.

## Travel

For rural consumers travel and accommodation emerged as the main challenge. Travel and cost of parking in metropolitan hospitals also emerged as an issue for metropolitan consumers who did not have access to a vehicle, relied on family members or found the cost of parking prohibitive.

For rural consumers this issue is linked to a number of secondary issues which include;

- scheduling of appointments
- inability of metropolitan hospitals to refer consumers back to rural services
- the lack of uptake for the Victorian Patient Transport Assistance Scheme (VPTAS) and the lack of, or perceived lack of services in rural areas.

While some of these issues are outside the scope of the ICSs it has implications for the type of partnership models the ICSs develop in the future with sectors such as transport. It also relies on the ICSs ability to feed this information back to the Department of Human Services which is currently reviewing the VPTAS system.

## Access to services

The lack, or perceived lack, of services for rural consumers in the Shepparton area was something that came through strongly from the focus groups and interviews. While suggestions raised by consumers related to increasing services in their area it seems that more emphasis needs to be placed on increasing consumer awareness of existing services. Many consumers were unaware of local treatment options. This is closely linked to metropolitan health services that often do not refer consumers back to local treatment options. A more integrated and collaborative partnership between metropolitan health services and rural services would go some way to address this issue. Increased consumer awareness of what services are available locally would potentially allow consumers to actively participate in decision-making about their care, by exercising the option of being referred back to rural care.

The lack of access to public radiation treatment centres was raised by both metropolitan and rural consumers. Consumers suggested more treatment centres as one solution. *Victoria's Cancer Action Plan 2008-2011* details an initiative to support cancer patients from disadvantaged areas to access radiotherapy treatment as close to their home as possible. Under this initiative, where a public patient requires radiotherapy but there is no local public service, patients will be able to access nearby private services under shared-care arrangements with the local public hospital. While details are still being finalised, the aim of the initiative will be to support disadvantaged public cancer patients from areas such as Western and Northern Melbourne, Frankston and Wodonga to receive their cancer care locally and in a coordinated manner, reducing the need for lengthy travel for these patients to more distant public radiotherapy facilities. (Victorian Government. 2008).

Access to radiotherapy services needs to be explored for Shepparton consumers who even under this initiative will still need to travel to Wodonga, Bendigo or Melbourne for treatment.

### **Engaging specific communities**

The terms “difficult-to-access” or “hard-to-reach” are sometimes used to describe groups such as CALD, Indigenous communities and ‘disenfranchised’ communities. However, this terminology is misleading and can often be problematic as it implies that the problem is with the groups themselves and not the organisation or processes used to engage them. Engaging such groups requires the development of trust between the parties, an outcome that can seldom be achieved quickly. This was evident in our efforts to try and engage Indigenous consumers. This report highlights the need to engage such groups by developing a relationship and maintaining that in the long term, rather than any ‘one off’ approach for specific purposes.

#### Linking in with existing services

Collaborative working partnerships with:

- ethno-specific services
- Indigenous services
- ethnic associations
- community health

can provide cancer services with links to community members and secondary consultations with key staff and group leaders. This is a particularly important strategy for Indigenous communities where Indigenous leaders and workers are used as the link between mainstream services and Indigenous consumers.

#### Needs of community

Engaging such groups also requires services to recognise where some groups are along the spectrum of cancer awareness, care and treatment. The CALD groups who were consulted for this project are well-established communities with an ageing population and therefore at a greater risk of cancer. Their needs will differ compared with newly arrived communities who have a younger population, are less established and report low incidences of cancer. Strategies here need to focus on awareness and prevention of risk factors and screening. While this target group was not consulted in this project we think that further investigation of the needs of new arrivals is necessary.

For both these groups engagement strategies need to take into consideration barriers that are specific to the particular community.

#### Consumer Participation

Participants in this study were asked if they wanted to be kept engaged in CanNET Victoria through newsletters, information and events. Participants were also advised that they could contribute to improvements in quality and services through committees, focus groups and further consultations. All participants except one were interested in participating. The challenge for CanNET Victoria, Hume RICS and NEMICS is how to ensure that participation for these consumers is meaningful and effective. This therefore requires resourcing and support for consumers and the ability of services to be flexible and input consumer perspectives into decision making process at all levels.

## 5. ENGAGEMENT STRATEGIES

This section will suggest a number of strategies that can be used to engage consumers in cancer services. These strategies have been developed from the suggestions made by participants in the focus groups and interviews and in consultation with the Indigenous workers in the Shepparton area.

### English-speaking

- That cancer services collaborate with GPs and community health services to deliver information about cancer prevention, services and support, using a range of strategies including through social network groups
- That support services which work across all tumour types engage with consumers at various stages not just one, e.g. at diagnosis, treatment, discharge and during recovery.
- That cancer services engage with their communities by making themselves visible using a 'one stop shop' approach for cancer information

### CALD

- That cancer services engage with the community through ethno-specific associations, networks and key community contacts
- That cancer services actively promote themselves via ethnic media using a variety of strategies such as newspaper, radio and television
- That cancer services partner with ethno-specific services to gain access to the community
- That cancer services employ language-specific workers to deliver information and engage people to participate
- That cancer services establish and maintain long-term relationships with CALD communities in their catchment areas
- That cancer services develop messages and information that are culturally relevant and appropriate for CALD communities by engaging CALD people in the development of these messages and resources
- That cancer services are aware and respond to any cultural issues affecting their clients

### Rural

- That cancer services collaborate with GPs, community health services and other rural agencies to deliver information about cancer prevention, services and support, using a range of strategies including social network groups. This is especially important in towns that do not have dedicated cancer organisations or information services.

## **Indigenous communities**

- That cancer services work with and build the capacity of Indigenous workers to deliver information about services to the community
- That cancer services have models, policies and frameworks in place to engage Indigenous communities in the development and delivery of Indigenous specific information and services
- That cancer services develop messages and information that are culturally relevant and appropriate for indigenous communities by engaging Indigenous people in the development of these messages and resources
- That cancer services take into account resourcing issues for small Indigenous organisations and communities when developing partnerships
- That cancer services take into consideration a social model of health when working with Indigenous communities
- That cancer services respect local customs and traditions when engaging Indigenous communities
- That cancer services are aware of the barriers to participation and engagement for Indigenous communities
- That cancer service use strategies such as sport, art and music to engage communities
- That Hume RICS engage with the community through Rumbalara and Goulburn Valley Base Hospital Aboriginal Liaison Officers
- That Hume RICS consider creating a paid position for an Indigenous liaison officer

## 6. RECOMMENDATIONS

This report makes a number of recommendations that will assist CanNET Victoria, NEMICS and Hume RICS to ensure that consumers' needs and perspectives are considered in relation to professional development activities that are to be undertaken by CanNET Victoria, NEMICS and Hume RICS

HIC recommends that:

- Staff have access to professional development in relation to community engagement, consumer participation and community development frameworks
- When managing staff workload consideration is given to the time required to engage and build relationships with Indigenous and CALD communities

This section makes a number of recommendations for CanNET Victoria, NEMICS and Hume RICS in relation to services, programs and policies

HIC recommends that:

- Integrated Cancer Services (ICS) ensure the information obtained through this project is used to develop services that reflect the perspectives and experiences of all those directly affected by cancer.
- NEMICS and Hume RICS maintain contact with consumers and community members consulted during this project and feedback to the participants any outcomes related to their input.
- ICS promote the participation of all consumers in the development of policies and programs.
- There be a central cancer centre or support network in the Shepparton area that assists people with information and support in relation to all aspects of care but in particular travel and accommodation to metropolitan and rural services.
- ICS work to improve coordination and communication with and across local, regional and metropolitan services, building on existing multidisciplinary collaborative structures.
- ICS investigate the needs of newly-arrived and religiously diverse groups.
- Regional ICSs contribute to the reform of the VPTAS system through systemic advocacy and lobbying.
- ICSs promote the design of tailored strategies that recognise and respect the diversity of local communities, issues and concerns.
- ICSs coordinate and are involved in the development of resources that assist consumers to navigate and understand the private and public system.

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