ASSESSING CANCER PATIENTS’ EXPERIENCES OF CARE: FINDINGS FROM FOCUS GROUP CONSULTATIONS WITH CONSUMERS AND HEALTH PROFESSIONALS

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October 2011
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INTRODUCTION

The Victorian Cancer Action Plan (VCAP) has prioritised the need to create better experiences for cancer patients and their carers. To this end, the Patient Management Frameworks have orientated the health system to the delivery of patient-centred care—an orientation that views the patient as active participants in their care with their values, beliefs and preferences informing the delivery of care. Quality cancer care includes the delivery of both anti-cancer therapy and supportive care to patients and their families and the Victorian Department of Health’s ‘Clinical excellence in cancer care’ blueprint states that quality care is care that meets the needs of the consumer3.

The Cancer Strategy and Development (CSD) section of the Victorian Department of Health is investigating the possibility of conducting a consumer experience survey to help evaluate a range of VCAP priorities. The CSD intends for the cancer consumer survey to inform progress of policy implementation in the areas of: i) Multidisciplinary care, ii) Care coordination, iii) Supportive care and iv) Reducing variation.

Working within the VCAP, it is intended that the CSD survey will approach the care experience from a patient centred viewpoint. The ‘Clinical Excellence in Cancer Care’ blueprint sees patient centred care as involving several key components including: respecting consumers’ values, preferences and needs; providing co-ordinated and integrated care across system boundaries and providing the information, communication and education that meet consumer’s needs. In addition the blueprint highlights the importance of communication between consumers and their health care providers in determining consumers’ quality of care assessments. Communication difficulties highlighted by consumers include: perceptions of lack of honesty in the communication, over use of jargon or medical/technical terms, attitude of staff and perceived power imbalance. The blueprint identifies 39 key elements of cancer care quality grouped into the six areas of: consumer focus (5 elements), safety (4 elements), effectiveness (3 elements), appropriateness (17 elements), access (3 elements) and continuity and care coordination (7 elements). While all elements are concerned with improving the quality of care received by consumers, some elements concern health system procedures (eg in response to adverse events) while others may be considered to have more direct relevance to how consumers experience their care. The elements that have direct consumer relevance and of relevance to the consumers’ experiences of care are shown in Box 1.

The CSD has contracted the Cancer Council Victoria to conduct a series of projects to investigate the type of survey that may be used to assess cancer patients’ experiences of care from diagnosis to end of first-line treatment/follow-up. The first part of this work involved a literature to identify existing surveys in the academic and health services area that aimed to measure experiences of care for cancer patients. This work reviewed 15 survey tools in the academic literature and 6 tools used by population based health services to assess cancer patients’ experiences of care. The identified tools were assessed according to their ability to be used with all cancer patients and to assess care experiences from diagnosis through to end of treatment/follow-up. The review identified two survey tools that were in current use
and that covered most of the different areas of care and were able to be used for all cancer patients.

The next phase of the project was to examine the adequacy of these two surveys in capturing the aspects of care Victorian cancer patients and health professionals deemed important and to assess preferences for each of the two different surveys. This phase of the project involved consultations with consumers and health professionals via focus groups and interviews. Consultations with health professionals also discussed methods of feeding back the results of the survey to health services, including who should receive the report, level for reporting results, timing of receiving the feedback report and frequency of conducting the survey.

In this report the findings from these consultations are reported and recommendations regarding the issues that need to be addressed in a patient experience survey and preferred style of questionnaire made. In addition findings regarding health professionals preferred method of feeding back survey results are presented along with recommendations for this component of the study.
Box 1: Elements of clinical dimension of cancer care quality that specifically relate to consumer involvement in care or experience of care

1. **Consumer focus**
   - Strategies are developed for developing and enabling cancer consumers’ rights and building them into decisions for treatment.
   - Strategies are developed that enable consumers to access relevant information during all steps of their care.
   - Consumers are provided with a record of the care they receive.
   - Consumers are informed of the multidisciplinary team process and recommendations and participate in informed decision making regarding their treatment.
   - Relevant supportive care is offered to consumers at all phases of their care.

2. ** Appropriateness**
   - All consumers with cancer have access to multidisciplinary care that aligns with best practice guidelines and takes into account their individual circumstances and needs.
   - Consumers are referred to an appropriate clinician when a different type of expertise is indicated.
   - All consumers are regularly assessed for degree of pain and appropriate pain relief is prescribed.
   - Supportive care needs are assessed as close to diagnosis as possible and at regular intervals throughout the diagnostic, treatment and follow-up phases of care.
   - Relationships, which include appropriate referral pathways, are identified and developed with community and other services that can offer supportive care.
   - All consumers have access to appropriate rehabilitation and palliative care services as needed.

3. **Continuity and care coordination**
   - A process is developed for effective communication between service providers.
   - The involvement of GPs at all relevant stages of care is encouraged and facilitated.
   - Systems are established that ensure efficient and effective processes for treatment, care and delivery; for example, appointment scheduling, availability of investigations for appointments and meetings, communication processes, treatment protocols, referral protocols.
   - Treatment and discharge planning considers all the consumers’ and carers’ ongoing needs and planned treatment, and ensures communication with the GP and clinicians who will provide the next phase of treatment.
   - Timely communication of relevant information occurs between service providers. This information may include diagnosis, interventions and management plan, contact details of the primary health professional, discharge medications, advice relayed to the patient, relevant referrals and follow-up plan.
   - Consumers receive written individualised information about their ongoing care.

### METHOD

#### Participants

Three types of participants were recruited for the focus groups consultations: consumers (people with cancer), health professionals (nurses, quality managers, allied health professionals) and representatives of consumer advocacy groups. It was intended to consult with health professionals and consumers in each of the Regional Integrated Cancer Services (RICS) and in metropolitan Melbourne.

The table below provides a breakdown of participants.

**Table 1: Number of participants participating in the focus groups in Melbourne and Regional Integrated Cancer Services.**

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<thead>
<tr>
<th>Location</th>
<th>Type of group</th>
<th>Number of attendees</th>
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<tbody>
<tr>
<td>Melbourne</td>
<td>Consumers</td>
<td>26</td>
</tr>
<tr>
<td>Melbourne</td>
<td>Health Professionals</td>
<td>46</td>
</tr>
<tr>
<td>Melbourne</td>
<td>Advocacy groups</td>
<td>4</td>
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<tr>
<td>RICS*</td>
<td>Consumers</td>
<td>18</td>
</tr>
<tr>
<td>RICS</td>
<td>Health Professionals</td>
<td>50</td>
</tr>
<tr>
<td><strong>Total</strong></td>
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<td><strong>144</strong></td>
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*Excludes number of participants consulted as part of a day long workshop

#### Recruitment

**Consumers:** Consumers from metropolitan areas were recruited through a flyer distributed to members of the advocacy groups: Cancer Voices, Prostate Cancer Foundation and the Breast Cancer Network Australia. Consumer volunteers at several large metropolitan hospitals that treat cancer were also sent flyers for the focus groups. Consumers participating in a research study conducted by the Cancer Council Victoria were also sent flyers regarding the focus groups. The flyers provided a brief description of the aim of the project and asked for volunteers interested in participating in a focus group discussion to determine the issues that need to be addressed in a patient experience of care survey and provide feedback on several example questionnaires.

Consumers in regional areas were recruited through the relevant RICS through their consumer representative groups. Members of these groups were sent the same flyer as used in Melbourne and interested consumers volunteered through the RICS or by contacting the Cancer Council directly.

In one regional area, discussions with consumers occurred as part of a consumer forum. In this area, the discussion groups were part of an hour-long workshop that occurred as part of the forum.
Health Professionals: Health professionals in Melbourne were recruited through the three Metropolitan Integrated Cancer Services (MICS). A flyer providing a brief description of the project’s aim and asking for volunteers interested in participating in a focus group discussion was circulated to health professionals through the MICS’ networks. Volunteers responded to the researchers who arranged a date and time for the group. Two metropolitan hospitals arranged for health professional focus groups at these hospitals. Volunteers for these groups responded to the individual arranging the group at these locations.

Health professionals in regional areas were recruited through the relevant Regional Integrated Care Services.

In one regional area, discussions with health professionals occurred as part of two day Living with Cancer training program. In this area, participants were divided into two groups and an hour long discussion took place.

Advocacy Groups: Five consumer advocacy groups were approached about participation in the study. Specifically, advocacy groups were asked for a representative to participate in a focus group to discuss the care issues they consider important for their consumers and to give feedback on the different questionnaires. Representatives from two advocacy groups participated in the focus group and another representative participated in a phone interview.

Materials

Prior to participating in the focus group, participants were sent a brief outline of the project (Appendix 1), a copy of the Patient Survey 1 (Appendix 2), Patient Survey 2 (Appendix 3) and the Additional questions sheet (Appendix 4). Participants were asked to review the questionnaires and told that the focus groups will discuss the good and bad aspects of the questionnaires.

Procedure

The focus groups were conducted on a weekday and lasted approximately two hours. First, the group was welcomed and the group moderator asked their permission to tape the discussion using a small digital voice recorder, which was placed in the middle of the room. Participants were provided with a brief background explanation of the project and the rules of how the group would run.

In all groups, the focus group moderator began the discussion by eliciting participants’ thoughts about the issues consumers consider important health system interactions during their cancer care. Participants are asked to think about the issues that may influence consumers’ judgements of their care as either good or bad. Participants were then asked for comments on the different questionnaires sent to them, and asked for their preference for either Patient Survey 1 or Patient Survey 2. The surveys differ in their question style and in the topics covered. Patient Survey 1 was drawn from the Cancer Council Victoria’s Prospect Survey (see Appendix 2). Patient Survey 2 was based on the 2010 UK’s National Health Service (NHS) National Cancer Patients Experiences survey (Appendix 3). In Patient Survey 1 the care experience is structured around stages of the treatment trajectory and included specific sections on: diagnosis, treatment planning, each of the different treatment
modalities (surgery, chemotherapy, radiotherapy), having treatment, finishing treatment and continuity of care. Patient Survey 2 structures care experiences assessments around hospital interactions and sections included: diagnosis, diagnostic tests, clinical nurse specialist, operations, hospital doctors, ward nurses, hospital care, outpatient care, outpatient appointments and support at home. The focus groups discussed different items in the two surveys and participants were asked which items should or should not be in a survey about cancer patients’ experiences of care. In addition to these two surveys, patients and health professionals were sent an “Additional Questions” page. This page contained a set of questions assessing access to supportive care services and symptom management that were not included in the other two surveys. This set of questions was adapted from the experience of care surveys used in the Australian state of New South Wales, and the Canadian province of Ontario.

Health professionals also discussed methods of feeding back the findings of the survey. This discussion assessed who the reports should go to, the level of reporting required for the data to be useful, acceptable time period for reporting results and frequency of conducting the survey.

With participants’ permission, focus groups and interviews were tape recorded.

Data analysis

Focus group discussions were transcribed and main themes and ideas emerging from the discussions identified.
RESULTS

The findings from the focus groups are presented in three sections. The first section presents the main themes regarding the aspects of care that consumers and health professionals thought influence consumers’ assessments of the quality of care. The second section reports the main themes arising from discussions of the different survey tools. The third section reports the main themes and ideas arising from health professionals’ discussions regarding feeding back the findings for the results to health services.

Section 1: Aspects of care that influence consumers' care experiences

Many different aspects of care were raised in this discussion. The main themes and ideas discussed are presented below.

Access to services

Most health professional groups raised access to care as an area of importance to consumers and carers. While both metropolitan and regional health professionals raised this issue, regional health professionals identified a greater number of problems in this area. The issues identified in both regional and metropolitan areas included: access to specialists, access to treatment services particularly radiotherapy services in regional areas, access to allied health professionals before and after treatment, access to supportive care services and access to interpreters. Metropolitan health professionals also discussed the issue of waiting times and parking in relation to access to services.

“I think also access to their appointments so access meaning the timeliness from perhaps diagnosis to referral…. but also access to the facility so can you park, how do you get there, do you get to clinic and wait five hours, because if you’re waiting for five hours your ability in essence to absorb what you need to absorb can be hindered by being worked up by the wait time. Can they sit in the waiting room for five hours in pain, all those level of comfort things as well” Melbourne health professional.

“Access…..patients in regional or rural areas were often disadvantaged getting the care that they need …..to get the work ups done that they need to get somewhere, even to surgery” Regional health professional.

“In rural areas, its access to services and having to travel.” Advocacy Group.

“…Which flows on back to access because you talk about the border folk. Trying to get a district nurse to someone over in [rural town A] is an absolutely circus. [Rural town B] says, no it’s [rural town C’s] job and [rural town C] says, no, we go through somebody else. ……there’s only a private one [specific clinic] up in [regional town E]. That’s no use to public patients, so you know, access I think is a huge thing really and causes all the issues of transport, accommodation……” Regional health professional.
As indicated in the last quote, related to the issue of access was the issue of distance and the need for long distance travel to attend appointments and treatments. Regional health professionals often commented that the need to travel for treatment was often associated with financial stress due to the cost of transport, possibly accommodation and the need to take time off work.

“*The distance travelling to where they have to have their treatments.*

**Q1: So what things are involved with travelling?**

Well, it can be financial, plus alone and time factor.

“Well, it can be financial, plus alone and time factor. *Some of these people are coming from [regional town F], but some people come from [rural town G, rural town H]. Rural town H to [rural town F] is nearly a three-hour drive .... and it’s another three-hour drive to Melbourne. It’s a huge issue for them. Or if you can’t see the oncologist locally, you have to go to Melbourne to have half your treatment and then come back when there’s a spot, and that might be catching the 6 o’clock train to Melbourne and then booking in, having a treatment and then, you know, a fairly quick one and then reversing the whole thing.*” Regional health professionals’ exchange.

Health professionals in regional areas also talked about the stress consumers feel if they have to drive to an area they not very familiar with, with driving to Melbourne seen as very stressful. Health professionals also commented that asking people who weren’t well to make a long drive to a treatment centre was not ideal.

“A lot of our patients from our region because they don’t go to Ballarat for a start. So it causes stress just to actually have to go physically out of their region, aside from having to go to Melbourne, which is even the bigger stress. …… And if you look at the demographics, I mean particularly the older patients that don’t like driving long distance and potentially who aren’t healthy enough to drive long distance, to be asking them to drive a long distance to Melbourne or a long distance to Ballarat is actually not suitable....” Regional health professional.

While consumer groups acknowledged access to treatment services as an issue (especially among rural/regional patients), in general, consumers spoke about access in terms of the actual problems they encounter: eg, waiting times, choice of doctor and treatment location, costs of services, travel and accommodation issues. These issues are discussed separately below.

**Co-ordination of care**

Health professionals talked of the importance of care co-ordination for patient experiences, suggesting that patients’ negative care experiences were often due to the lack of care co-ordination. Care co-ordination involved a number of different aspects and included: ensuring that treatment appointments/follow-up appointments are made, ensuring medical record information is passed on to different services and is available when it should be, linking patients to supportive care services, providing patients with an overview of their care pathway and providing patients with information. Health professionals talked about some services or tumour streams within services having care co-ordinator or nurse co-ordinator positions, others talked about breast care nurses being an example of a care co-ordinator role. Care co-
Assessing Cancer Patients’ Experiences of Care: Findings from Focus Group Consultations with Consumers and Health Professionals

ordinators were also seen as a point of contact for patients and as providing “an anchor” for them.

“…ask the patient what would have helped and what we’ve found with cancer care co-ordination is that they’ve gone, ‘thank God we’ve got an anchor’. …….. They’re now coming and they come back and they ask you, ‘Do you know where I could find this information?’ and that seems to be what you need, is this core person or core group that can just answer the variety of questions…” Regional health professional.

“…..the idea of nurse co-ordinators or in the literature they talk about navigators, it’s that sort of role. Having somebody that can help the patient navigate. So the idea of breast care nurses or brain tumour support officers, so having something like that for all the tumour streams.” Melbourne health professional.

“….I think of things that patients have said to me, because this is all about patients’ experiences. Patients will often say to me ‘It’s so good to be able to come to you because I can ask you all the questions I don’t want to bother the doctor with or I feel the doctor hasn’t got time to answer.’” Melbourne Health Professional

However some health professionals were concerned if this co-ordinator role fell onto one person and they spoke of burnout issues for many of the early breast care nurses because they were making themselves too available to their patients. Health professionals discussed how treatment is meant to be delivered through a team and suggested it would be better to think about how the treatment team works to deliver co-ordinated care.

When this issue was raised with consumers they talked about breast care nurses and saw breast care nurses as providing this co-ordination role. Many women who had had breast cancer and had had a breast care nurse talked about how that position provided them with information and support. Women discussed how they had follow-up appointments with their breast care nurse soon after their diagnosis and this offered them the opportunity to ask questions and receive information they missed at their diagnosis appointment. Consumers with other cancers talked about the breast care nurse being there for women with breast cancer and thought it would be good if this sort of role was available for other tumour streams.

“…But I was looked after all the time by two breast care nurses who were, I mean I just felt so reassured all the time and knew that if there was a problem I could always go to them and they were, I mean they were just wonderful.” Melbourne consumer.

“…There should be a specialist nurse for the guys with prostate cancer; all the certain cancers should have a specialised nurse.” Melbourne consumer.

The discussion around care co-ordination and breast care nurses raised the issue of the number of different doctors, nurses and allied health professionals patients interact with and the confusion this can generate for patients and their families. Health professionals thought that due to the number of doctors patients interact with, there may be confusion regarding who has overall charge of their care.
“…Well who is the right one? You have a resident, you have a registrar, you have a consultant. Each time they come into the ward it may be a different consultant or a different registrar. So across episodes of care as an inpatient, again it’s who do I speak to.

That occurs in outpatients as well. Every time you come to outpatients you may actually see a different doctor every single time…” Melbourne health professionals’ exchange.

Some health professionals also talked about the number of nurses that patients have contact with in both wards and outpatient services. Health professionals commented that the lack of consistency in the medical staff patients interact with could harm their trust and confidence in the medical team.

Some consumers also raised the issue of having many different doctors and nurses looking after them and while they understood the teaching role of hospitals and consultants, there was concern when important information was being told to them by doctors they had never meet before.

“….maybe your head surgeon or your head doctor, there’s obviously a team of people around him and at different times people will just pop open…and it’s like 7.00 and they’ve just woken you up. ‘Hi I’m such and such’ and blah, blah, blah and you’re like ‘who? what? I’ve never seen you before and apparently you were in the operating theatre and now you’re telling me what?’ You don’t meet all those peripheral people at the start but then they’re quite often the ones who are delivering important pieces of news or check-ups to you and that needs to be…it would be nice if at some point you could meet them so they didn’t seem like some random person that has picked up my file today and is telling me this is how your operation went.” Melbourne consumer.

Some health professionals also talked about the need for patients to receive an overall plan of their care and how this could include issues regarding what needs to happen before different treatments starts, expected time periods before treatment starts, what happens during treatment, how long side effects of treatment might last and when people might expect to return to work/usual activities. These comments arose from discussions regarding the issues people raised with their breast care nurse, as well as specific needs health professionals identified.

“I probably have at least two emails a day, probably numerous phone calls a day, just from patients about what’s my next step, where am I going? You said there’d be some appointments they haven’t arrived in the mail yet, what’s happening? That sort of thing….“ Melbourne health professional.

“…..perhaps it is a piece of paper that’s filled out at that initial consultation by the doctor…..to say expect to have [treatment X] approximately August 2011, planning [for treatment Y] September 2011, commence approximately…;” Melbourne health professional.

“….if they knew you have this, then it’s two months before you do that, and then it’s usually another six weeks until the treatment starts, and these are the reasons why; if it was written down….something like that would probably help…..“
“[A timeline] … A visual would be good. Because usually when they’re diagnosed everything is like bang, bang, bang, right at the beginning, and then there’s this gap of nothing, and I think that that’s time of twiddling their thumbs going ‘oh what’s going on?’ sort of thing.” Melbourne health professionals’ exchange.

Scheduling

Appointments: All metropolitan and regional health professional groups commented that scheduling appointments was less than optimal and caused problems for patients. One of the main issues raised in this area was scheduling appointment times and dates without considering the distance the consumer had to travel to get to the appointment or what other appointments the consumer was having that day or the day after. While this issue was particularly important among regional health professionals, metropolitan health professionals also considered it an issue if people had to travel from outer Melbourne to inner Melbourne or when they had several appointments at different locations on the same day. Appointments that were discussed in these conversations were: doctor appointments, tests/scans and treatment appointments. Regional health professionals discussed how patients, particularly rural/regional patients, can find the need to come back for appointments or further tests distressing.

“I think regional patients tend to be the most distressed in terms of having to then come back for another test. So they may have travelled four hours to see the doctor and then they’re told ‘oh sorry, you have to come back a week later to have another scan or test…those patients end up being the most distressed because they have to come back in.” Regional health professional.

When discussing scheduling of appointments health professionals talked about co-ordinated care and the developments in their services to help with this. Several health professionals talked about the use of multidisciplinary teams for certain tumour streams (eg breast, head and neck, haematology) and how this is used to assist patients in seeing all their specialists and allied health professionals at the one session.

However other health professionals talked about how the medical system still operates in “silos”. They discussed the lack of adequate communication systems between services and across systems (eg public and private) as limiting the ability to deliver co-ordinated care for patients.

Consumers also raised the issue of scheduling appointments both in order to reduce waiting times at appointments and as a way to reduce the need for multiple trips back to the same or different clinics. Consumers discussed how burdened they felt by having to go to different centres for treatments or tests. There was a sense that going to a treatment centres where they were unknown and the centre was unfamiliar added to the burden of treatment.

“I found a big thing also was not being able to go to the same place for everything. Feeling really down, you have to have…I have my chemo and radiation at one hospital but if I had to have a MRI, I had to go to there [another place] and then they decided they’d follow that up so I had to go to there [another place] and I thought I think I’ve sat in every waiting room in every hospital in Melbourne.
Whereas the one stop shop would have been ideal which I know they’re trying to get that …” Melbourne consumer.

However consumers and health professionals discussed how sometimes trying to get all the appointments done on one day may not be ideal either. Consumers talked about the stress of going from one appointment to another when there was distance to travel or if the appointments were not scheduled appropriately. This latter issue arose when appointments were scheduled to closely together or when they were scheduled at the beginning and end of the day. Health professionals commented about this as well, especially if the patient then had to return to a regional area on public transport. Both health professionals and consumers thought that this resulted in a long, tiring day for the patient.

Others talked about how scheduling appointments didn’t seem to take into account the actual needs of the patients both in terms of the volume of patients being seen and the type of appointment needed. Consumers talked about how the length of appointment needed to reflect the stage of treatment (eg diagnosis and treatment planning needed longer appointments than follow-ups) yet it seemed to them that many appointment schedules in public hospitals didn’t reflect these differences. Many considered that this situation contributed to the waiting times people experience.

Health professionals also raised the issue of different times needed for different appointment types and spoke about how they were attempting to address this by scheduling only the same type of appointments (eg follow-up or diagnosis/treatment planning) in one session.

**Provision of test results/diagnosis information:** In addition to scheduling appointments, some consumers also discussed the timing of when people received their diagnosis or test results. Consumers spoke of people being given a diagnosis or bad news regarding test results on Friday afternoons or late in the day. Consumers were concerned that receiving this information at these times meant there was little or no opportunity for people to access any support services and that people were left in a state of distress and uncertainty for several days.

**Allied Health referrals/access**

Health professionals’ discussions regarding referrals to allied health and supportive care services suggested that access to these services was better in some areas of care than others and was also better for some tumour streams than others. It seems that access to allied health depends on how these positions are funded within the hospitals. Some health professionals indicated that patients could not be referred to allied health professionals from surgical outpatient departments, but were able to be referred to these services from inpatients, radiotherapy and chemotherapy services. Health professionals indicated that this situation can lead patients coming into radiotherapy or chemotherapy requesting to see allied health professionals. Health professionals also indicated that once these treatments had finished, follow-up by allied health professionals was a grey area as officially this was not funded.

“Can't see physio prior to it [surgery] to ensure that they're kind of got good mobility prior to their surgery for example because there is no allied health provided from outpatients”. Regional health professional.
“….our experience in radiotherapy, what was always very interesting was that patients would come saying I know you have a social worker, I know you [have a] dietician and they’re actually told that these services are available in radiotherapy. Whereas in outpatient departments there’s no funding for allied health at this point in time…..

“……a bit of a grey area of who follows them up after their treatment is actually finished because again officially they were not funded, we weren’t being funded for caring for those patients.” Melbourne health professionals’ exchange.

Another issue raised concerned continuity of care from the allied health professionals. Health professionals indicated that access to certain health professionals might be by ward or by oncology department. This meant that patients might see a particular dietician when they were an inpatient and then see another dietician once they move to chemotherapy or radiotherapy.

“….each allied health discipline might work differently. So the dieticians work by unit so if a patient has come in for surgery they’ll see the dietician. If they come back for chemo at day onc, they’ll see the day onc dietician. If they then go to radiotherapy, they’ll see the radiotherapy dietician. So it’s a separate person for each area, whereas physios see patients by ward. So if they’re always admitted to Ward 9, they’ll always see the same physio, so it’s a bit different for each discipline ……” Melbourne health professional.

Some health professionals indicated that their allied health services were not designated to cancer but rather serviced the entire hospital. They considered that this meant that allied health didn’t get to specialise in oncology care and that this lack of specialisation could be detrimental to the care cancer patients receive.

While consumers did not comment about the funding arrangements for allied health referral, some did comment about lack of access to these services prior to surgery, while others commented that these services were only offered when they arrived at radiotherapy. Males with prostate cancer and prostate cancer advocates talked about the benefit of being taught pelvic floor exercises by a physiotherapist before having surgery and how access to physiotherapists for this was not possible in the public system at this time. A consumer commented that she accessed a physiotherapist through the radiotherapy department because she couldn’t lift her arm enough for radiotherapy to be delivered. This woman had been asking her surgeon if she should see a physiotherapist and was told it wasn’t necessary. This woman was disappointed in this situation both because the information she was getting from her surgeon was incorrect (she did need physiotherapy) and because it meant her radiotherapy was delayed. She ended up thinking that access to allied health at the hospital was random.

Health professionals at another site talked of similar situations regarding women with breast cancer needing physiotherapy before radiotherapy commencing. However in this centre physiotherapy was not available through radiotherapy department necessitating women to access radiotherapy services privately. This centre indicated they had excellent access to other allied health professionals for instant speech pathology and dieticians but not physiotherapy.

Other health professionals also talked about consumers having to access allied health services in the community either by having their GP refer them or by the
treatment centre referring patients back to the community health centre. Waiting times to access these services was raised as an issue.

Health professionals from regional areas discussed the situation where people treated in Melbourne often had no access to allied health services in their local area. This was partly due to the lack of co-ordinated care, with Melbourne services not referring people back to their local treatment centres. Regional health professionals also talked about the long waiting times people can have in accessing allied health services in regional areas.

Health professionals especially from Melbourne raised the issue of access to interpreters and how inadequate this could be. Health professionals talked about how the interpreters were generally designated to the whole hospital and so the interpreter needs of oncology patients were competing with the interpreter needs of other patients. This issue is discussed further below.

Communication

All groups raised communication issues. Health professionals raised issues of communication between the medical team and the patients, between health professionals, between treatment departments and between hospitals. Consumers raised issues around communication between themselves and health professionals, and between themselves and administration/reception staff.

Communication issues for consumers covered a number of issues including: feeling that health professionals were talking down to them, health professionals not answering questions honestly; health professionals not hearing or respecting what they say to them and health professionals providing different opinions and receiving conflicting information.

Many consumers spoke of how they generally felt “rushed” when they saw their doctor. This perception often arose from sitting in a waiting room full of people, as well as the doctor appearing busy and in a rush. This feeling often restricted the conversations or questions patients felt they could ask of doctors, with one patient commenting:

“… they’re [Doctors] just “any questions?, no?” and that’s it, out of the door and sometimes when you’re in there you have all these questions you want to ask but once you go in there it’s like oh! And then you go out and you thought oh I should have asked that.” Melbourne consumer.

To help address this, some consumers spoke about developing a question list for when they see the doctor

“He’d sort of run in and run out so write down your questions while you’re lying in the bed, you’ve got 24 hours before his next visit, write them down and don’t let him out beforehand. So I found that was the way of communication.” Melbourne consumer.

Others spoke about how they asked their “dumb” questions to nurses. Often these “dumb” questions regarded practical issues around treatment, managing side effects etc but sometimes they also allowed patients to clarify the nature of their cancer and
their treatments. Consumers commented that the nurses “had more time to answer their dumb questions” and that you have a lot of “dumb” questions.

Some health professionals also talked about how patients asked certain questions of nurses and other questions of doctors. Health professionals also felt there was a distinction in the type of questions patients asked the nurses compared to those asked of the doctors.

“…specifically there is a difference between the information that consumers feel that they can get from nurses, from allied health workers, from the institution and that great and precious information that they get during their 10 minutes with the oncologist” Regional health professional.

While most health professionals thought that most patients were well informed about their treatment and illness, there was recognition that some patients’ understanding of the information given to them was poor. Health professionals also had experiences where they were present when patients were given specific information only to be told by the patient later that they hadn’t received this information. There may be several possible reasons for this discrepancy including: information being told to patients when they are in shock or at a point of information overload; failure to check that the consumer understood the information provided and the possibility that for some consumers information needs to be repeated several times before it is understood. Consumers also commented that due to the shock they experienced at diagnosis they didn’t take in what was said to them and that they needed a follow-up appointment to go through the information again.

While many consumers spoke about having good communication with their specialist and other members of the health team, some commented about the dismissive or condescending style of health professionals when they talked to them. Often when one consumer bought this up, others in the group could identify with this experience even though it may not have been a common occurrence. Those consumers that raised this issue often talked about an experience where the health professional was dismissive of what the patient was telling them, with the consequence that the patient suffered the side effect they were warning the health professional about.

“…..after I’d had my first mastectomy they had the drainage bottles and they changed the drainage bottles and one of them when they changed them there was nothing come out and I said to the nurse there’s nothing come out the drainage bottle, previously there had been lots and they said oh no, no, it’s okay and a few hours later there’s still nothing coming out and then they had a change of shift and I said there’s still nothing coming out and then that night I came down with a really bad fever and I ended up with a very, very serious infection and the nurses had completely ignored my six hours saying there’s something not right here, they said no, no, no, it’s okay and then I ended up being on IV antibiotics for about eight weeks afterwards.” Melbourne consumer.

or as demonstrated by this conversation between some Melbourne consumers:

“……and I went to the nuclear medicine, and I said to this man, ‘what are you injecting me with?’ And he said ‘you don’t need to know about that dear’. And I said ‘excuse me, but you will not inject me with anything that I don’t know what it is…..”
“Sometimes they say stupid things.”

“It’s paternalistic, is that the word?”

“It’s an entire set of attitudes, and it’s an old fashioned patriarchal role of medicine.” Melbourne consumers’ exchange.

In addition consumers often spoke of the difficulty of getting results of tests told to them or getting copies of results. Health professionals talked about how there has been a shift towards consumers wanting their health information with many consumers now keeping records of their test results and care.

“But most patients these days you find wander around with a file under their arm anyway of their own things.”

“Especially breast cancer.”

“They have a plastic satchel or a…”

“And an iPad.” Melbourne health professionals’ exchange.

Repeating medical histories: Both patients and health professionals raised the issue of consumers “repeating their medical history” to different health professionals. This was often a consequence of seeing different registrars at each appointment. As one consumer said

“you see a different doctor every time, when I was going for radiation at [Hospital], every week I saw a different doctor, normally registrars, which is fine, I support that, but it was a different one every week and it was like ‘are you serious, I have to go through the same thing again, can you just read my file’. Because it’s so draining…..” Melbourne consumer.

Health professionals also thought this was a major concern for patients and while they try to assure patients that doctors work as a team and that all doctors they meet will be aware of their medical needs, they reported that these reassurances were undermined when patients see a medical oncologist who has “no idea about what is going on with that patient and is just reading the history in front of the patient” Health professionals thought this also undermined the relationship consumers could develop with their doctors and health care team.

“….for people to feel confident that actually they’ve been heard ….if the same questions [keep] being asked it doesn’t seem like there’s communication within the team” Melbourne health professional.

Again health professionals talked about strategies hospitals were doing to rectify this situation but they acknowledged it is still likely to happen particularly at follow-up clinics.

Conflicting information: A few consumers also raised the issue of receiving conflicting advice or information from health professionals and how this can undermine the confidence they have in the information their medical team provides. They also felt confused regarding whose advice they should follow. However some consumers differentiated between receiving conflicting information and being given
different opinions regarding possible treatments especially when there was no clear best treatment. A consumer talked about this latter situation where he asked about

“….hormone therapy’, because I’d known two people who’d had hormone therapy as well, and he [urologist] said ‘no’… So when I went to [another doctor] he said ‘I think you should have hormone therapy in addition, get back to the specialist and ask him’. … So I rang him again and asked him and he said ‘no, no hormone therapy’. When I went back to [doctor] and told him …… So there are two leading people in their fields who were diametrically opposed [in] views.” Melbourne Consumer.

While acknowledging that the advice he was receiving from the doctors was conflicting, the consumer was aware that in this situation it wasn’t that there was a right and wrong option, and that the specialists were expressing different opinions on the best treatment for him. This consumer thought that consumers needed to be aware that sometimes there isn’t one “right” or “wrong” treatment but rather there are different options and that consumers needed to be involved in determining the option that best suited them.

Administration and ancillary staff communication: Health professionals and consumers also talked about the importance of the interactions patients have with administration and ancillary staff at hospitals and doctors’ rooms. Both groups acknowledged that this interaction can set the tone of the patient’s experience of care at that treatment centre for the day and sometimes for a longer period.

“I would say sometimes just unnecessary grumpiness by people maybe on reception … these people [patients] don’t want to be there waiting for a CT scan, they don’t particularly want to be waiting for a bone scan but sometimes…… it’s not like something they’ve chosen to do, and coming up to the desk and having someone that is really short with them or really irritated just does not help the whole experience…… It’s amazing how through that whole experience of being treated for cancer, things like that stay in their memory” Melbourne health professional.

“…..and rude receptionists…. When you’re struggling and not coping and you get confronted with a rude receptionist ……” Regional consumer.

Communication between services/doctors: Health professionals also raised poor communication between health services as an issue affecting consumers’ experiences of care. While there were many examples of the poor communication one issue that seemed to demonstrate the impact of this on patient care was when test results or medical histories were not available when patients attended appointments. Health professionals suggested that this often led to situations where patients were constantly repeating their history as discussed above or having repeat tests which could have an impact on when treatment started.

Consumers discussed how technology could be used to help the transfer of information to different departments or doctors. They discussed an electronic medical record which could be available to the relevant medical team so all doctors knew what tests had been done, what the results were etc.
Consumer participation in treatment decisions

Health professionals raised the issue of consumer choice as an area of importance. Health professionals talked about consumer choice in where they are treated, what treatment they have and to a degree who treats them. In regional areas, health professionals raised the issue of consumers’ treatment choices being influenced by their reluctance (due to either financial or practical issues) to travel long distances for radiotherapy. Metropolitan health professionals talked of how poor information or poor understanding of what chemotherapy and radiotherapy are like, coupled with little or no understanding of the services that can be accessed to support people through these treatments, can influence patients' treatment decisions.

Regional health professionals also talked about Melbourne clinicians' reluctance to refer patients back to their local services - including radiotherapy and chemotherapy services. While some health professionals commented that this might be due to limited knowledge of the services available, some also commented that the reluctance was due in part to concern regarding the quality of the service.

Regional health professionals spoke about the need to consult with consumers regarding where they wanted to go for treatment before making the referral as the presence of family members in an area might make a treatment centre further away preferable to a more local treatment centre.

“…also you can’t assume that everyone in the country, its simpler for them to be treated in the country …they might have family in Melbourne that are quite close to where they want treatment .....” Regional health professional.

Consumers also spoke about the issue of choice in their treatment. Consumers spoke about choice in terms of the specialist treating them, treatment received, where they were treated and using the public or private system.

While some consumers spoke of how the specialist they saw and consequently where they were treated was a consequence of their GP’s referral patterns, others spoke of making an active decision regarding where they were treated and who treated them. While this letter scenario seemed generally more common among Melbourne consumers than regional consumers, some regional consumers also spoke of their decision to go to Melbourne for treatment or to return to the local radiotherapy service. At one extreme in this process, a Melbourne consumer spoke about how he

“… interviewed oncologists. I mean .... I’m a professional and I thought well people come and check me out if they want to engage me, why wouldn’t I do it for an oncologist, which is about my life, why wouldn’t I do that. But they were really annoyed that I was wasting their time and they were way above all that. In fact, I went through five to get to the one that I stayed with ...” Melbourne consumer.

“….the choice of St Vincent’s, Peter Mac…to make a valid choice.

Q3: Did you have to go and seek out that information or were you…?

“Yeah I did. There was a bit given to me at the initial…you don’t have to come here but these are your options. So yeah, we did some scouting on the internet and then made the choice based on a number of factors and Peter Mac has the
private and the public and everything in the one spot and I’m still getting the quality. So it wasn’t just one individual, it was a combination [of factors]...” Melbourne consumer.

In contrast were comments from people who thought they weren’t given a choice of specialist or where to have treatment but who commented that as they were well they weren’t complaining.

“Q4: So did you feel like you had a choice as to where you went to?
No.

Q5: Is that something that you think is important?
We are not complaining about it.

No, I’m not complaining. I’m still above ground, I’m not complaining. You trust your doctor.” Regional consumers’ exchange.

The difference in attitude between the consumers might reflect differences in age, with younger patients wanting to take a greater role in determining their care and having a greater expectation of this happening. However it may also reflect the importance of the outcomes of treatment on satisfaction with care and treatment decisions.

Rural consumers talked about how if they were seeing a Metropolitan specialist they had to advocate to return to their local area for some treatment.

“...and the choice is very important because my surgeon was in Melbourne and she didn’t really know much about the oncology unit at [regional hospital] ....... and I actually made the choice against her wishes to come here, but she did say to me “I’d be very interested to get your feedback” and I did provide her with feedback and she said to me that she had no qualms about sending anybody else here [regional hospital] now. But it is really important to be able to make these choices...” Regional consumer.

While many consumers expressed a desire to participate in treatment decisions, not all consumers thought this was a good development in care. Consumers expressing these latter concerns commented that they were concerned about the pressure that this expectation placed on consumers; others discussed situations where patients were choosing not to have specific treatments to avoid the potential of negative side effects (eg chemotherapy). These consumers expressed concern about the consequences of choice for some consumers.

However most consumers wanted a role in treatment decisions and discussed how it gave them a sense of empowerment. Consumers also discussed how their clinician provided them with information regarding the recommended course of treatment.

“I think the sense of empowerment for the patient is really important and so I know with my surgeon she did give me choices but she also always made it very clear what she thought was the right way to go.” Melbourne consumer.

Consumers who wanted to be involved in their treatment decisions also talked about difficulties of doing this due to the number of treatment options and lack of someone to help them work through the decision process.
“….there’s many treatment options, …..and… you go to a surgeon, he tells you about surgery; you go to a radiological oncologist he tells you about that. You seem to have to work it out at each step of the way, there wasn’t really a support process in my case….there are so many treatment options......... and there is confusion out there…….” Melbourne consumer

“The thing that struck me was I was given four treatment options, so they did the right thing, they went through…..four options. But how was I meant to make that decision? ……. I get the whole empowerment model and it’s great that I chose my treatment plan and I felt better for it – I get all of that side of it, but at the same time I still would have liked someone to sit and talk to.” Melbourne consumer.

Consumers agreed that patient involvement in treatment decisions should be to the extent consumers’ wanted.

Other issues that influenced consumer involvement in treatment decisions was feeling “rushed” to make a decision regarding treatment. While there was recognition that some people did just want to start treatment as soon as possible, consumers also considered that this approach did not allow them to make a considered decision about their treatment. Indeed some consumers commented that the sense that things needed to be done quickly helped to make them feel like they didn’t have a choice regarding treatment.

“Yeah, I was given 24 hours, and I do feel like sometimes you don’t get a choice. … Because you’ve got to recognise that different cancers have different treatment plans, for breast and prostate, we have a little bit of time, but I had 24 hours.” Melbourne consumer.

“The surgeon said ‘I can book you in for the next week or two’. And I said ‘hold on a minute, I just want to have a think about it’. Melbourne consumer.

“……… I was shoved at high speed through early breast cancer treatment, which was just ridiculous. It’s not necessary.” Melbourne consumer.

Consumers raised the issue of being treated in the private or public system and discussed how they chose to go into one system or the other. As might be expected having private health insurance influenced whether people considered the private health system. Some consumers didn’t feel that they were given a choice about which system they went into, but rather felt that they were swept into the private system. This is likely to follow from being referred to a private specialist as consumers talked about this happening while they were in the daze of just being diagnosed.

“…..once I had entered into the mainstream of the private sector I didn’t know there were choices. I just kind of got railroaded into that, it’s not that it was bad, but never at any point did anyone stop and say, well actually they’re here, but these are the other choices that you have.”

“Yes, I agree…….” Melbourne consumers’ exchange.

Others spoke about how they seemed to have to fight to remain in the public system as it seemed that many of their health professionals wanted to direct them to the private system.
“I was treated in a public system, but you go and have a mammogram and somehow you end up in the private system paying for a mammogram, and I never, ever understood that. ….. But quite often, they knew I didn’t have private health insurance, and somehow no one ever explained that to me, that somehow I’d be in the private system. So we felt like we always had to campaign to stick in the public system, I don’t know, we couldn’t work it out.” Melbourne consumer.

Waiting times

All health professional groups, consumer groups and advocacy group representatives raised the issue of waiting times as something that frustrated patients. The areas where waiting times were discussed included: the waiting time for an appointment with specialists, waiting times to have tests/scans, waiting times for treatment to start, waiting times at appointments and waiting time for results.

Appointment waiting times: This was the most commonly discussed ‘waiting time’ issue among consumers. While all groups raised this issue, there was also a feeling that some waiting is to be expected in the public system. Consumers indicated that they are used to waiting for other services including the GP so they expect some waiting at hospitals especially in the public system.

“The most I have waited is probably an hour and a half, but it’s free so I don’t care, I’m going to wait.” Regional consumer.

However, while consumers were accepting of a certain amount of waiting in the public hospital system, there was also agreement that at a certain point the waiting become too long and was no longer acceptable. Consumers talked about waiting for three or four hours for some appointments and that this was not acceptable. Consumers spoke about the consequences of these long waits including becoming tired, hungry, thirsty and irritable. In addition patients talked about car parking and waiting times and how long waiting times increased anxiety about the need to move the car or getting a ticket. Despite consumers commenting that they understand that emergencies happen and that doctors are called away or have to see patients with a higher health priority, they also agreed that long waits can led to patients feeling frustrated. A comment from a health professional suggests that long waiting times can heighten patients’ anxiety that they have been forgotten or have “dropped off” the system. A consumer also suggested that if they are waiting to receive test results, a long wait increases the anxiety associated with this.

Consumers talked about strategies they used to get through the waiting including bringing a book and talking to other patients. Others talked about how staff communicating reasons for the wait could help to reduce frustrations associated with waiting. Other consumers mentioned that this communication didn’t happen frequently enough.

Consumers discussed how technology could be used to reduce the need for patients to sit in waiting rooms waiting for their appointments. Consumers spoke of sending SMS’s or using a system which “buzzed” people when their appointment was coming up (eg within the next 20 minutes).

Waiting for tests/treatments: The other waiting area highlighted by consumers was the waiting time for tests in the public system. Consumers felt there was an
inconsistency in being told they needed to have a particular test or scan as part of their treatment but then finding out there was long delay in having this test done in the public system. There was a sense of being let down by the system.

“And I needed to have a brain MRI and at [Hospital Name] it was a three month wait to have a brain MRI, .... that wasn’t reasonable, so we went private, and paid. So I do think again, if they say it’s something you need as part of your treatment, and you are concerned, obviously they wanted to check I didn’t have secondaries in my brain, three months is just not a reasonable amount of time to have someone sitting there worrying that they’ve got brain mets.” Melbourne consumer.

Health professionals also raised the issue of delays in getting a test or a scan and how this can delay access to other oncology services or in starting treatments. As indicated above under “care co-ordination” health professionals thought there was a need for patients to have an overall understanding of the process of the treatment including what needs to happen before the treatment can start and likely delays in starting the treatment. Health professionals thought this might help reduce some of the disappointment patients experience when treatment doesn’t start because they need to have a test or scan first.

**Waiting time for oncologists/specialists referrals:** Regional health professionals mentioned the delay that can happen if people are referred to the local oncologist or specialist. Some health professionals estimated that consumers could wait as long as 3 months to see an oncologist in their local area. There was a belief that the length of this delay often meant patients opted to be referred to a Melbourne oncologist. While consumers did not specifically speak of the delay in getting an appointment with a cancer specialist, they did talk about the fears they had if treatment was delayed. Consumers generally indicated that they thought the sooner they could be treated the better.

**Printed Information resources**

While consumers and health professionals recognised the need for information and the benefit of having information about treatment and services, health professionals and some consumers also talked of patients being overloaded with information. Health professionals talked of consumers getting “show bags” of information. Consumers and health professionals talked about how information provision needs to about providing people with the information they need when they need it rather than simply providing people with the complete suite of resources they may need somewhere along their treatment path. Some health professionals talked about how someone should talk patients through the information they receive highlighting what information is in the resource rather than simply handing brochures to patients.

“and I just wonder whether you are misguided and believe that you are informing the patient, when you’re giving a show bag full of information and booklets and it’s bad enough after a consultation where you’ve been given your diagnosis of cancer, let alone ‘here you are, here’s a show bag full of goodies, go away and read it, and if you’ve got any questions come back to us.” Melbourne health professional.

“Everyone is quite different, I’ve got some friends who they wouldn’t even be able to tell you what chemo drugs they had, whereas I can tell you exactly what they
are and how they were derived, I love information. But my team were quite good at saying ‘the next step is chemo, so this is what you need to know, here’s your book from the Cancer Council, read that, get your head around chemo, and we won’t talk about radio until you have to start radio’. So that information, my team were quite good at doing that, which helps you, because you can only get your head around so much at a time.” Melbourne consumer.

However, while there was a sense from both consumers and health professionals that patients were provided with a lot of information, consumers also highlighted some deficits in the provision of information. These included information about the impact of treatment on fertility and IVF options, information about long and short-term side effects of different treatments and information on how to manage some side-effects of treatments.

Financial Impact of cancer treatment

Health professionals, consumers and advocacy groups raised the issue of costs associated with different aspects of care as an issue that is important to consumers.

Regional health professionals raised the issue of costs when discussing transport and travel to treatment centres. The costs associated with this included transport costs (petrol, public transport costs), accommodation costs, forgoing wages if they need to take time off work and costs associated with childcare. The Victorian Patient Transport Assistance Scheme (VPTAS) was raised often and the health professionals talked about the importance of patients finding out about the scheme and how many consumers didn’t seem to know about it. Health professionals also discussed the limitations of the scheme including the distance that needed to be travelled before the scheme could be accessed and how patients living just within this distance had difficulty understanding why they couldn’t access this funding scheme.

Consumers’ discussions regarding costs related to those associated with treatment and medicine and largely focused on private system costs. Consumers were often surprised and shocked at the amount of out-of-pocket expenses they encountered when they went privately. Consumers also talked about the lack of information provided to them about the costs of different tests or treatments prior to them agreeing to have the tests. Several consumers gave examples of how they went from a public clinic to a private centre to have a test done and were only informed of the costs of the test when they were asked to pay the fee upfront, just prior to having the test. Consumers talked about how this situation was distressing and embarrassing for them.
Parking

While the health professionals generally indicated that parking or the lack of parking was an issue for consumers, only a few consumer groups directly raised this issue. Health professionals acknowledged that parking was a problem in some locations. There was awareness that patients became stressed if they parked on the street and their appointment was late and that part of the problem with parking on the street were concerns regarding getting a parking ticket.

“….I know if patients are parking in the street, and if we keep them waiting for any reason….. I know that parking can create a lot of anxiety and stress, because there’s financial implications for patients if they do get tickets, and then for them to say ‘look I need to go out and put money in the meter and then come back’, can be a stress.” Melbourne health professional.

Other issues with parking concerned the actual fees charged,

“With parking yes, because we’ve only got limited parking and like you said if the patients need to park in the street or park at St Johns, it costs considerably more than in the street even.” Regional health professional.

When consumers talked about parking they raised the issue of costs, the stress of finding a parking spot and concerns about whether they will return to their car before they receive a parking ticket. Part of the issue with parking fees for consumers seemed to stem from the belief that they are a means of raising revenue.

“And trying to find a spot and not knowing if you’ve got long enough when you are in that spot.” Melbourne consumer.

“I think there should be free parking… it shouldn’t be about the money” Melbourne consumer. .” Melbourne consumer.

Emergency Department treatment

While both health professionals and consumers raised issues regarding experiences in Emergency Departments, the issues were slightly different for both groups. For consumers the issue with Emergency Departments was the inadequate response from Emergency Department staff to their health problems. Consumers considered that Emergency Department staff generally had a poor understanding of both the reason for their presentation and the potential negative consequences of sitting in an emergency waiting room for many hours with a weakened immune system.

“..everyone I know that’s had cancer treatment has ended up at some stage in emergency……. but if you are going through chemotherapy and you have no immune system, the thought of sitting among 20 people in emergency who are coughing and who have got skin rashes……I went three times to emergency during chemotherapy, and one time we were there for eight hours…… but to be in emergency for eight hours when you are so fatigued and so sick. I couldn’t cope.” Melbourne consumer.
“...[in the emergency department]...I waited and waited and waited and in the meantime I was vomiting my guts out being dehydrated and I knew I was dehydrated and I couldn’t drink, every time I'd take a mouthful it would come up and I was getting weaker and weaker and I said to my husband I don’t know what’s going to happen, I can’t stand it anymore.” Melbourne consumer.

These consumers spoke of being given a card to show the Emergency Department and also being told to ring the oncology ward if they had bad reactions to the drugs. Consumers appreciated this. Both these consumers called the oncology ward when they had had a bad reaction and the nurses told them to go to the Emergency Department. While one consumer said that the nurses indicated they would phone the Emergency Department to let them know they were coming, she indicated that it didn’t seem to influence how she was treated in Emergency. Both consumers felt let down by their Emergency Department experiences.

Some health professionals also raised the issue of emergency departments. They talked about patients being given a card to explain the chemotherapy they are having which they could show staff in emergency departments if needed and how this can be empowering. Others talked about how poor communication between different treatment departments/hospitals, doctors and GPs can delay an Emergency Department’s response to a patient because they don’t know what chemotherapy drugs the person is on.

“..I’ve been involved in a couple of times, I won’t name hospitals or whatever, but a hospital down in Melbourne, somebody presents in ED, really, really unwell, they’ve got no idea what chemo they’ve had or nothing, the GP doesn’t know, we’re trying to get through to the hospital. It’s a big issue..” Regional health professional.

Some advocacy groups also raised the issue of emergency department care. They saw the need to inform patients of what signs or symptoms means they should go to an Emergency Department and spoke about the need to provide patients with the information they would need to tell the Emergency Department staff. This advocacy group thought the chemotherapy card given to patients describing their chemotherapy was helpful for both consumers and Emergency Department Staff.

Issues raised by health professionals

**Consumers from Cultural and Linguistically Diverse Backgrounds:** Health professionals, especially those from Melbourne, talked about the issues people from cultural and linguistically diverse groups (CALD) faced when they have a cancer diagnosis. Regional health professionals also raised the issue of cancer care experiences for people from Aboriginal and Torres Strait Islander Backgrounds. The issues ranged from having different understandings of health and illness, a lack or low levels of understanding of anatomy, language problems, cultural differences/barriers and difficulty in accessing interpreters. Adding to the difficulty of accessing interpreters was the issue of different cultural approaches to cancer and treatment.

“...it’s not only the language barrier but also cultural barriers as well. Do they want to say something about their cancer in front of family or family in front of patient.
"It’s how much they want to know or they want their family to know." Melbourne health professional.

“….but you might only have 2-3 Greek interpreters for the entire hospital in any one day, so those people are just run off their feet…..it’s very hard for them also to allocate their time because [a] family meeting may take longer than what they’ve got in their diary for and there’s somebody in outpatients waiting for an interpreter who gets cross because there’s no interpreter.” Melbourne health professional.

Health professionals discussed the difficulty of providing CALD consumers with information partly because written resources may not have been translated into their language, but also because they may not be able to read their own language. There was also difficulty of aligning western medicine’s need to talk to the patient about their disease and its treatment to obtain they consent for treatment and using a hospital translator rather than a family member, with cultural or family needs of not talking about the cancer with the patient and working with a family member rather than the patient regarding treatment.

Health professionals also talked about issues relating to use of traditional medicines and the difficulties people from CALD backgrounds have in first talking to their medical team about these medicines and second understanding that they may not be able to combine both traditional and western medicines. While there was recognition that an increasing number of English speaking people are using alternative/traditional medicines and that combining traditional and western medicines can also be an issue for them, health professionals recognised that language barriers and cultural differences can make explaining why traditional medicines are not recommend more difficult for people from CALD backgrounds.

“…and the other one is some of the cultural things which you would get in pharmacy is them wanting to use some of their traditional medicines, trying to fit them in with….” Melbourne health professional.

**Unnecessary repeating of tests:** Several health professional groups raised the issue of repeating tests and spoke about how this often annoys and confuses consumers. While both metropolitan and regional health professionals raised this issue, regional health professionals tended to discuss this topic slightly more often. Regional health professionals discussed how repeat testing often occurred when patients went to Melbourne for treatment and there was a feeling that some of the re-testing was done because the Melbourne health professionals didn’t trust the testing done in regional areas. Health professionals talked about how this retesting was often a waste of resources. They also talked about how it can create distress for the patients and can add to their financial distress as well.

“If I was a patient [it] would drive me crazy the amount of repeat tests people have…..” Regional health professional.

“….sometimes I think it is [a] bit because the information is not shared. Sometimes it might be as simple as they’ve had CAT scan without contrast and it should have been with contrast so it’s about knowledge of what happens up here. Sometimes I think it’s a bit of ego on the part of some hospitals……” Regional health professional.
Non-oncology ward bed: Several health professional groups discussed potential problems when oncology in-patients were not on oncology wards. The problems stemmed from the staff on these wards not having oncology care experience, with health professionals commenting that this helps to reduce patients’ confidence in their medical care team.

“…when they don’t get to the oncology ward. So they go to a separate ward. There’s no beds, the oncology ward is full and they get put on another ward…… And that experience is uncomfortable because those nurses don’t know how to treat that and look after that person……”

“And it’s very frequent that nurses on different wards don’t know how to access ports and all that adds to the trauma and I’ve had so many comments …… they feel very insecure, very vulnerable, even though there’s qualified nurses. Oncology is a very specialised field…..” Melbourne health professional.

Privacy: Lack of privacy particularly for allied health consultations was raised by a number of health professionals. Health professionals talked of a lack of dedicated office space in outpatient departments for allied health professionals particularly psychologists/social workers and consequently these professionals often meet with people in public waiting areas. Regional health professionals discussed how this could restrict the issues patients raised. Lack of privacy was also raised for inpatient consultations with health professionals mentioning how drawing a curtain may provide privacy for physical examinations or physical care, but it did not work well for language based consultations, eg social work/counselling/psychology sessions.

Physical environment: Only a few health professionals raised the issue of the pleasantness of the treatment environment for consumers. These health professionals felt that creating an environment that was pleasant for patients, especially in chemotherapy and radiotherapy wards was important.

Issues raised by consumers

Peer support programs: In most consumer groups, participants talked about the benefit of talking to someone who had been through the experience of having their cancer. They spoke of the benefit of talking to people about different treatment options and hearing them talk about their treatment experiences and how this can help make treatment decisions. They spoke of the benefit of hearing practical advice from people who had been through it and how peers provide them with tips to get through the different treatments and negotiating the hospital/medical system.

“…but even then a lot of people you can see them, they seem as though they do look lost in it and they do look confused. And it’s almost like they need a mentor with them to liaise with the system, that’s the way I would put it.” Regional consumer.

I’m in a support group, the Leukaemia Foundation and there’s a girl ahead of me who has had a transplant and she goes to the same hospital and … she goes get off at the next tram stop, go in that entry, go to that blood pathology. ….. So I’ve learned a lot more off a person ahead of me, all those tricks…” Regional consumer.
“...the other patients you go on a journey with tell you more than anyone....”
Melbourne consumer.

Some consumers also spoke of how they felt the health care team did not promote peer support programs adequately. These consumers were generally heavily involved in support groups and their experience was that clinicians were reluctant to promote support groups to patients.

Complaints: Some consumers also talked about the importance of knowing they can make a complaint and how this can do this. Although only a few participant raised this issue, when it was raised other consumers generally agreed that it was an important issue.

Discussion and Recommendations

The Victorian Department of Health has identified the consumer experience as important in assessing the quality of care. The issues raised by consumers and health professionals regarding the aspects of care that influence consumers’ experiences reflect the key elements of cancer care quality as identified in the Department of Health’s ‘Clinical Excellence in Cancer Care’ blueprint. They also reflect most of the eight principles of patient centred care identified by the Picker Institute (ref) and shown in Box 2.

Key areas in both the Health Department’s blueprint and in the Picker Institute’s principles are: i) access to care and ii) continuity and care co-ordination (see Box 1 and Box 2). Both health professionals and consumers deemed access to care and co-ordination of care important. Breakdowns in the provision of co-ordinated care and limitations in accessing care were factors that consumers’ thought influenced their judgements of whether care was good or bad. Consumers spoke about the breast care nurse as an example of a care co-ordinator and discussed how this role provided an identifiable point for information provision. Those consumers who had had a breast care nurse generally spoke highly of them and the importance of their role in their care, while those who did not have breast cancer spoke about the need for a similar role to be developed for other tumour streams. Both consumers and health professionals identified access to supportive care services like physiotherapists, psychologists and dieticians as important. Comments from some consumers suggested that sometimes access to these services seemed at “random”. Other issues relating to access concerned waiting times to have tests or to see oncologists in the public system, availability of services in local area and referral to these local services, access to information about financial costs of treatments and tests and access to information on financial supports.

Communication and provision of information was also identified as issues for both consumers and health professionals. While consumers spoke of the communication issues between the health care team and themselves, health professionals also talked about communication of information between services and health professionals. Consumers’ thought their experience of repeating their medical history to different health professionals demonstrated this lack of communication between health services and health professionals. Information provision is a key principle of the Picker Institute’s patient focused care. Consumers and health professionals spoke of information overload for many patients and this has lead consumers and health professionals to place a greater emphasis on the provision of timely and appropriate information.
Box 2: The PICKER Institute’s eight principles of patient centred care

| 1. | Respect for patients’ values, preferences and expressed needs |
| 2. | Co-ordination and integration of care |
| 3. | Information, communication and education |
| 4. | Physical comfort |
| 5. | Emotional support and alleviation of fear and anxiety |
| 6. | Involvement of family and friends |
| 7. | Transition and continuity |
| 8. | Access to care |

Both the Health Department and the Picker Institute recognise the importance of valuing and respecting patients’ preferences, needs and rights. The Health Department sees that enabling consumers to participate in their treatment decisions is an element of quality cancer care. Both consumers and health professionals spoke of the need to include patients in treatment decisions and to provide them with information to allow them to participate in these decisions. Involvement in decisions could relate to what treatment to have, who to be treated by, where to be treated and scheduling of treatment. Consumers spoke about the need for health professionals to respect and value their wishes to be treated locally. While in general consumers spoke positively about being involved in treatment decisions, some consumers thought this placed an unrealistic burden on them and most indicated that patients should participate in their treatment decisions at the level they were happy with. Other consumers commented that if they were to participate in decisions having the information necessary to make that decision, having someone that they can work through the information and having the time to make a decision were important.

To capture the experiences of care in areas considered important by consumers and health professionals’ surveys need to assess the following experiences:

- Continuity and co-ordination of care: including communication between health services, doctors, a care plan, access to a role that is similar to a (supportive) care co-ordinator.
- Scheduling: including scheduling doctors and treatment appointments.
- Waiting times: including waiting time for tests/scans, for appointments, for treatments to start.
- Communication experiences: including openness of communication, experience of being talked down to, being heard by medical staff and repeating medical history to medical team.
- Costs associated with care: including being informed of costs, being informed of financial support, timing of receiving information about costs
- Being involved in treatment decisions: including where to be treated and what system to be treated in.
- Access to care and support services.
- Provision of information that is timely and appropriate.
Section 2: Response to Questionnaires

Survey procedures and methodology

Timing of survey in relation to treatment: The discussion of the survey and even the issues affecting patients’ perceptions of their care raised the question of when the surveys would be completed by patients. There were comments among both health professionals and consumers that the issue of when patients would be asked to complete the survey would influence their responses, as well as the length of the survey that needed to be completed. Health professionals commented that if consumers were asked to complete the survey soon after treatment, experiences of the treatment and outcomes from the treatment might have an influence on their responses. While some health professionals suggested completing the survey 12 months after treatment, other health professionals thought that this timing may reduce consumers’ recall of events. Some health professionals thought it would be good to get patients to participate in the study prospectively, asking patients to complete the appropriate section of the survey soon after having each of the different treatments. Other health professionals thought it would be appropriate to ask patients undergoing the different treatments to complete a survey only about that specific treatment. While these issues were raised, in general there was no consensus as to the best time for patients to complete the survey.

Health professionals’ comments suggested that many assumed that patients would be asked to complete the survey when they were at the treatment centre. Staff were concerned that this would take staff resources and that patients were unlikely to complete it because they were sick or anxious. Health professionals were informed that it was intended to send the questionnaire to consumers to complete at home.

Consumers also asked when people would be asked to complete the survey. Consumers commented that it would be most relevant to recently diagnosed patients rather than patients many years post diagnosis. Consumers commented that treatment was constantly changing and that experiences of care delivered five or so years ago would not be relevant to treatment now. Consumers thought that the survey would need to ask how long ago consumers had had their treatment and raised the possibility of only asking those patients who had been treated in the past 12 to 24 months to answer questions about their care experiences.

Timing of survey in relation to other surveys: Health professionals were also concerned that this new survey would add to the number of surveys consumers are being asked to complete and they were particularly concerned about any overlap with the Victorian Patient Satisfaction Monitor (VPSM). Concerns included overlap in questions asked and potential overlap in patients surveyed. When deciding when to run the survey consideration needs to be given to when the VPSM is in the field and ensure that cancer patients are only approached about completing one survey.

Method of completing the survey: Both consumers and health professionals also asked if an online version of the survey would be available. Both groups believed there would be a large number of patients who would be interested in completing the survey online and they thought this would help to tailor the questions to the treatments received. Consumers commented about doing the census online recently and how this seemed to simplify filling in the form.
Including people from Culturally and Linguistically Diverse (CALD) backgrounds: Health professionals and some consumers asked whether the survey was to be completed by people from a CALD background. Health professionals in Melbourne were adamant that this population group needed to be included in the survey both because their experiences were very important to assess but also because they make up a large proportion of the client base for metropolitan hospitals. Excluding this group would mean the survey did not reflect the experiences of a large groups of patients attending many metropolitan treatment centres.

Including people having treatment in the private system: Both health professionals and consumers asked whether the survey would include people treated in the private system. Both groups commented that as many patients can have care in both systems it would be appropriate to include private hospital patients. Patients also commented that as private patients make up a significant proportion of all cancer patients it would be important to include patients treated in the private system. There was also interest from consumers to examine differences in the care experiences of people treated in the public and private system.

Collecting background/demographic questions: As the surveys presented to consumers and health professionals had no questions assessing cancer type and time since diagnosis, both consumers and health professionals commented on this omission from the surveys and indicated that it was important to know this information. Patient Survey 1 included some demographic questions. Both consumers and health professionals thought that only the relevant demographic information should be collected. (eg age, gender, education or some indicator of socio economic status to get an understanding of who is completing the survey).

Overall perceptions of the surveys

In their current format, neither Patient Survey 1 nor Patient Survey 2 was endorsed unconditionally for use in the state-wide survey by either consumers or health professionals. Consumers and health professionals liked some aspects of both surveys but they also disliked aspects of both surveys. Consumers and health professionals generally recommended combining items from the two surveys into a new survey.

However, health professionals and consumers differed in the aspects of the surveys they liked. While not unanimous, health professionals generally preferred the style of questions in Patient Survey 2. In contrast, although again not unanimous, consumers preferred Patient Survey 1. Health professionals generally thought that both questionnaires were long and commented that patients would be reluctant to complete such long surveys. While some consumers also commented that the surveys were long, in general consumers were less concerned about the length of the survey.

One health professional did not like either survey. This health professional suggested that orienting the survey around unmet needs or the items in the distress thermometer might provide more information about the extent of supportive care needs screening in treatment centres and the extent of referral when needs are identified. Other health professionals commented that it would be useful if the survey could be used to assess prevalence of unmet need screening. However others noted that this may be too difficult as screening mechanisms may not be uniform across
treatment centres and consumers may not recognise that assessment of unmet needs has occurred.

Health professionals had strong opinions regarding the style of the two surveys and preferred the style of Patient Survey 2 to that of Patient Survey 1. Positive attributes of Patient Survey 2 included: using simple language, being easy to read, having direct questions, having response options that were appropriate to the questions and allowed for a “not sure” response, using tick box response options, larger font size, and using simple headings. Health professionals commented that these factors would make the survey more appealing to patients and could increase the likelihood that they would complete it.

Health professionals’ comments on Patient Survey 2

“Survey 2 is much easier to read, it’s more friendly on the eye. It’s a better one.”

“The headings are really easy and you know exactly, okay now I’m dealing with the doctor, now I’m dealing with the nurse…”

“Yeah, true. Even if you want to take the size of the lettering, it looks…it’s pretty straightforward.”

“To me it’s easier to read. When you’re looking at all different demographics and all different age groups and things like that, I think it’s…”

“So that was one of the strengths of survey two because most of the questions that were those types of one’s had ‘I don’t know can’t say’ or ‘don’t know can’t remember.’”

Many health professionals also expressed strong negative opinions on the style of Patient Survey 1. Health professionals didn’t like the survey’s use of the words “module” and “section” and having sections that contained long lists of items. Health professionals also didn’t like circling numbers to indicate their responses. Patient Survey 1 was also seen as being too wordy and needing a relatively high reading age which health professionals thought would reduce the likelihood of some consumers completing it. Additionally, some health professionals thought many of the items in the survey were leading and because it used words like “quality” or “adequate” or “within a reasonable time” they thought that some items were to open for interpretation.

However while health professionals expressed a preference for the style or format of Patient Survey 2, there was acknowledgement that Patient Survey 1 was better at assessing the supportive care aspects of care and that Patient Survey 1 would collect useful information.
Health professionals’ comments on Patient Survey 1

Negative comments

“I didn’t like, in the survey where it’s got A, B, C, D, I just found that really confusing down the side, I don’t know that you’d need that there when you’ve got like the 1, 2, 3, across. I just though do they want me to circle A, B, C or D, or..?

“Survey one seems to be quite wordy.”

“I thought in terms of literacy and simple English, this was a little bit hard to follow. You have to really read the questions and it would be easy to miss what you’re actually trying to.”

“I found at a quick glance, the Survey 1 quite wordy, very wordy. And if I had to fill this out I’d think ‘oh that’s all too hard’, and not even do it probably.”

“With the sections and modules.”

Positive comments

“It did ask great questions, the first one [Patient Survey 1] asked great questions, I agree on that one, but a lot of people get overwhelmed by a full page of text like that..”

“…the fact that it’s under the different modalities as well, if we were going to use this for service improvement it gives you a much better idea of were there’s gaps in the system.”

“And I like the finishing treatment stiff too [in Patient Survey 1] because you know that’s always identified isn’t it hen someone actually finishes their cancer treatment and then there’s nothing and the isolation that they feel.”

While many consumers liked the style of Patient Survey 1, some expressed a preference for the type of response options used in Patient Survey 2. Consumers generally thought that the content of Patient Survey 1 was very relevant to the aim of the survey and covered issues of importance. Similar to the concerns of health professionals some consumers thought that Patient Survey 1 was too wordy and some but not the majority of consumers liked the response options used in Patient Survey 2.

Consumers’ comments on surveys

“I just think the questions [in Patient Survey 2] have the answers more targeted to the question, which made more sense to me.”

“It [Patient Survey 2] gave you more choices.”

“I liked the more choices, except that in most of them I’m saying ‘doesn’t apply, doesn’t apply, doesn’t apply’.”
“I like Patient Survey 1 because it’s quick…”

“It [Patient Survey 1] seems to be a bit more in depth and they’re asking for more personal questions. Some of these questions are really quite on the ball….. Q: And what about the response options? I thought they were fine. But this to me is more in depth, and this is what really should be in the survey…”

“I found that I could relate to the style of this one. [Q: Survey 1?] It was good, it was giving you that degree of something. Yes definitely, yes I think so, no or no definitely not. So it’s sort of like grading the degree of how well these things were handled. So I think in that regard, that was good.

Including more opportunities for consumers to provide comments: Health professionals and consumers thought that providing opportunities for comments throughout the survey would give a greater understanding of consumers’ experiences of care. Both consumers and health professionals thought the survey would benefit if there were opportunities to comment at the end of each section of the survey (eg after a section on diagnosis) rather than just at the end of the survey. Both groups thought this might encourage comments from consumers and they would provide comments relevant to that part of their treatment experience.

Organisation of questions in surveys

Health professionals discussed how Patient Survey 2 was focused on the hospital experience and in particular the inpatient experience. Health professionals commented that as cancer patients in Victoria mainly receive their care as outpatients or as day patients, the emphasis on inpatient experiences is not appropriate. However despite this view some health professionals did like the flow of questions in Patient Survey 2 indicating that the sequence of questions mapped easily onto patients’ treatment trajectories.

“I like the way there’s a clear flow of events in Survey 2. So the headings are really clear and to me, I know that I have a health background, it’s a clear pathway and I think that sort of orders your thinking a bit. I kind of like that.” Melbourne health professional.

However, consumers commented that structuring the questionnaire around treatments, as Patient Survey 1 does, made sense to them. Some consumers commented that the organisation of Patient Survey 2 didn’t seem to map onto their experiences of care well.

“I think the thing that I found with survey 2 was that the process because you sort of go through a process was not the process that I think we have in Victoria so it was a bit hard to sort of, it doesn’t seem to fit with what normally happens rather than the questions per se or the options…..” Melbourne consumer.

“For me I like the fact that it’s in sections of whether you’ve had surgery, chemo, and therapy and so you can report it back in that way.” Melbourne consumer
When asked, health professionals indicated that the structure of Patient Survey 1 would work and be understandable to consumers. Some consumers and health professionals questioned whether it was appropriate to have separate sections headed “Treatment planning” and “Having treatment”. Both consumers and health professionals thought it would be better to have the items in these sections within each of the sections about the different treatment modalities as their responses could be different for each treatment. Some consumers commented that the instructions in Patient Survey 1 regarding completing the different modules in the Critical Cancer Care Events section were confusing and that they needed to be read several times to make sense of them. Consumers suggested that this could be made easier by having the questions about the experiences of care for the different treatment modalities next to the questions about having the different treatments. Patients thought that this structure would mean that people who didn’t have the treatment could then skip to the next set of question.

Content of surveys

Consumers and health professionals discussed questions or sections of the surveys that they liked or disliked. As indicated above, in general consumers and health professionals wanted the content of the two surveys to be combined into one survey. Health professionals and consumers felt that there were not enough items dealing with outpatient care in Patient Survey 2. Some health professionals thought that the survey should focus on the supportive care elements of care as they felt this was an area that was not adequately assessed. Many health professionals discussed the introduction of supportive care screening in their services and suggested that tying the content of the survey to this screening would be beneficial.

Much of the discussion focused on the questions or sections in Patient Survey 2 and discussion aimed to determine whether questions in these sections should be included in the state-wide survey. Comments on several specific areas of the survey are presented below. There was generally less conversation about specific items in Patient Survey 1. In the main this was because many items contained in the Critical Cancer Care Events section of the survey were thought to be appropriate.

Clinical Nurse Specialist: As both health professionals and consumers discussed care co-ordinators and breast care nurses when discussing issues that create better care experiences, groups were asked for their opinion on the questions in Patient Survey 2 under the heading “clinical nurse specialist”. Participants were asked whether questions like those in this section should be included in the statewide survey. In general both consumers and health professionals thought it would be good to include similar sorts of questions. Health professionals indicated that “clinical nurse specialist” wasn’t a term that was used consistently across treatment centres in Victoria and suggested that if these sort of questions were to be included it would be better to describe the role and then ask if patients thought there was anyone in their treatment team that played this role. While health professionals and consumers thought that it would be interesting to include a question to assess who this person was, some health professionals thought people would just say a “nurse” because “they see everyone as a nurse”.

While there was general interest in asking these sorts of questions there was also a counter view in health professional groups that having one person in this role was unrealistic and not best practice. Many health professionals commented that the
health care team should be delivering the aspects of care asked about in this section of Patient Survey 2.

Some health professionals recommended assessing who patients thought was in charge of their overall care, as consumers often commented to them that they were not sure who was doing this.

While consumers and health professionals recommended asking the questions in this section of Patient Survey 2, they also wanted some wording changes. For instance for question 23, they suggested to drop the word “important”, some health professionals also thought question 24 could be phrased to assess whether they had enough time to address their concerns.

**Ward nurses and hospital doctors:** There were mixed opinions about including questions regarding ward nurses and hospital doctors. Some health professionals thought the questions in these sections were phrased a bit negatively and they suggested having more neutral questions. Health professionals questioned the value of having questions about ward nurses and hospital doctors given that much of the health care cancer patients receive is delivered through outpatients. Some health professionals suggested that the questions about nurses could be included for all treatment modalities: chemotherapy, radiotherapy and surgical. Other health professionals suggested it might be more appropriate to ask about patients’ confidence in the clinical and communication skill levels of the staff.

“I think something along the lines of...did you feel that the nurse had the skills to look after you and then you’d be looking at skill mix and cancer being a speciality.”

“Something around the clinical skill level, but also the interpersonal skills.”

Regional health professionals’ exchange

When discussing the issue of nursing staff and doctors, health professionals commented that it would be of interest to know whether the patient was in an oncology ward or whether they were in a more general ward. Health professionals were interested to know whether there was a difference in perceived skill levels of staff depending on whether they were in a specialist oncology ward.

Consumers were in favour of having questions about the nursing care they received. Consumers generally felt very positively about their nurses and they thought this might provide an opportunity for them to praise their nurses.

**Communication between patient and medical team:** Patient Survey 2 contained several questions assessing communication between patients and members of the medical team. As consumers often raised this issue in their discussion of regarding positive and negative aspects of care, consumers were asked for their thoughts on these questions. While consumers thought some of the questions were interesting, they also thought that they didn’t quite address their issues regarding communication. For instance, several consumers liked the question assessing whether they felt like they were “treated as a set of cancer symptoms rather than a whole person”. These consumers felt that this captured their experiences of not being treated as a person.

Consumers were asked whether questions assessing being treated with respect and dignity and having questions answered by doctors and nurses adequately captured their concerns about patient/medical staff communication. In general consumers did
not think that these questions were adequate as they failed to capture their comments about being treated paternalistically or feeling that they were treated condescendingly.

“It’s even more than that, it’s the condescension that ‘you won’t understand, I’ve got the knowledge and you haven’t’. Is that what you..?”

“You don’t need to know.” Melbourne consumers’ exchange.

Consumers thought that questions about medical staff answering their questions freely and openly were important.

“Did people provide freely information.”

Q6: To answer your questions directly

“Provide freely, and provide enough time.

“And particularly the response, did they respond to your questions adequately and with courtesy. ……….

“……I think you’ve got to ask ‘were your questions answered’....

“To your satisfaction. When you asked them. …” Melbourne consumers’ exchange

Where treated, public/private system and travel: Consumers and health professionals commented that as patients often swap between the public and private system the survey needed to assess where treatment was delivered. Questions in Patient Survey 1 asked patients for the name or postcode of their treatment centres and whether they were treated as a public or private patient. Consumers and health professionals thought that gathering this information was important. They also thought that as some treatment centres share a postcode it would be important to ask for the name of the hospital along with the postcode.

Consumers and health professionals were interested in gathering information about distance travelled to attend treatment and for appointments with oncologists. Health professionals were interested in including questions regarding costs involved with travel and access to financial support if available.

Costs associated with medical care: Patient Survey 2 included a question on whether hospital staff gave information about how to get financial help or benefits and one about access to free prescription. Health professionals and patients indicated that the latter question wasn’t appropriate for Australia and that the question needed to be dropped. However these questions stimulated a discussion about the costs involved in having treatment especially costs associated with the private system and whether consumers were informed about costs before deciding on where to be treated. Health professionals and consumers considered that asking questions about these issues appropriate. Consumers also suggested that questions could assess whether costs of treatment were involved in deciding which treatment to have.

“That mightn’t be a bad question in there…… understanding did you know that there may have been costs or were there costs…”
“Or were you advised how to ascertain how to get the costs or something like that. It’s about being informed.” Melbourne health professionals’ exchange.

**Participating in treatment decisions:** Patient Survey 2 includes questions assessing patients’ involvement in treatment decisions. While consumers and health professionals generally thought questions about this issue were appropriate and that the items in Patient Survey 2 covered some good issues, others thought that the section could be expanded to include decisions regarding where to have treatment along with questions assessing factors influencing treatment decisions. While most consumers, health professionals and advocacy groups thought a question regarding patient involvement in decision making was important, they commented that involvement should be at a level the patient wanted. A small number of health professionals thought the wording of the question in Patient Survey 2 was “outdated” as it didn’t reflect practice of talking about treatment options and asking patients to consider treatment in terms of what is right for them based on their circumstances.

**Provision of information:** While there were several questions in both Patient Survey 1 and Patient Survey 2 that assessed provision of information, both consumers and health professionals seemed to consider that these questions were too blunt in that they didn’t assess whether the information was timely and appropriate. Both consumers and health professionals considered this aspect of information provision was important.

**Waiting times:** While Patient Survey 1 includes questions about the length of time patients had to wait before starting chemotherapy, radiotherapy or having surgery, it does not ask about waiting times at appointments, for tests/scans or for receiving results. Patient Survey 2 includes one question assessing waiting times at outpatient appointments with doctors. Both health professionals and consumers thought the survey should include questions on waiting times for appointments, tests, and test results. Regarding the waiting time questions in Patient Survey 1, while health professionals liked these questions, they also commented that it was important that patients understood that this did not include the time involved while having tests or needing to put on weight or to finish other treatments. Radiotherapy health professionals discussed that generally there is a delay of about 2 weeks between the treatment planning meeting (simulation) and starting treatment, as this is the time needed to develop the treatment plan. These health professionals suggested that delays longer than 2 weeks would normally be due to waiting times for the service.

The waiting time question in Patient Survey 2 had seven response options with a “don’t know/can’t remember” option as well. The response options provided 4 options for the first hour and then a “1 to 2 hours” and “more than 2 hours” response. Consumers and health professionals thought the number of response options within the first hour were too many and could be reduced to 2 (within half and hour, 30-60 minutes).

No questionnaire addressed the issue of waiting time to have tests/scans and waiting times for test results. As these were issues that were important for consumers’ experiences of care, items addressing these issues would be recommended for the state-wide survey.

**Radiotherapy:** Health professionals working in radiotherapy indicated that some items in the radiotherapy section of Patient Survey 1 were not appropriate because people having radiotherapy attended the service every day and this has implications...
on the type of interactions they have with their health care providers. As one radiotherapy department health professional commented:

“….radiotherapy there’s not likely to be an issue, till they’ve had about their say three weeks of treatment, so you’re not going to bombard them with a question every day, as to how they’re feeling, you would start to question more closely when you expect to see side effects. So for instance here we monitor, nursing wise we monitor weekly, so we would see a patient once a week. The doctors, let’s say head and neck, they would monitor weekly, they have a one week review, and then the RTs are doing a general ‘how are you going’, but they’re certainly not saying ‘have you got any pain or how’s your skin going’, because probably they’d all start reporting a skin reaction that wasn’t even there.”

In addition, radiotherapy staff commented that the items assessing whether they had one doctor overseeing their different treatments, would be difficult for patients to answer, as they are likely to see registrars as well as the consultant. They thought that this question was not needed.

Order of items in Patient Survey 1: Several health professionals thought that the order of some items in the different sections of the modules was not appropriate and suggested some reordering of items. Health professionals suggested that questions assessing understanding of why the treatment was necessary should go ahead of questions assessing receiving information about where they would be having treatment. In addition health professionals thought that questions about understanding how to take their medications and the reasons for taking medications in Module 8 headed “Finishing treatment” should be included in Module 3 headed “Treatment planning”. These health professionals thought issues regarding medication were most relevant to treatment and commented that patients needed to know about medications to counter side effects when they are taking the medications.

“In Section 2 Module 3, I think in there, there should be something about the medications, because it’s way down in Module 8 that they’re actually asked if they get information about their medications and that, where here you are talking about the information that the doctor gave, there’s nothing about medications there, but it’s just sort of in the finishing cancer treatment…” Regional health professional.

Wording

While there were specific questions in both questionnaires that consumers and health professionals liked and recommended including in the state-wide survey, they also commented that the wording used in the survey or in particular questions was not quite right and suggested some changes. As mentioned above health professionals didn’t like the use of the terms “module” and “sections” in Patient Survey 1. Many health professionals and some consumers commented that many questions in both surveys were negatively worded or focused. This comment was often made in relation to questions about interactions with the health care team. Health professionals and consumers recommended using more neutral language. Some health professionals also commented that some of the response options used in the two surveys implied an inadequacy in the delivery of care, as they didn’t have a balance of how frequently good and bad aspects of care happened. This is demonstrated in these comments from health professionals:
“It seems like they’re all full of negative connotations, like there is nothing about the positive aspects of their treating team.”

“That’s what I meant by loaded, particularly in that question, you’ve got the choice of yes often, yes sometimes or no and obviously you hope the people put no and that would be an indication, but it actually doesn’t give them an opportunity to say I was always included.” Melbourne health professionals’ exchange.

Health professionals also commented that because of the wording of some questions, they were open to interpretation and that interpretations could differ substantially between patients. These comments were about the use of words like “good quality”, “enough information”. Health professionals considered that the use of these words weakened the value of these questions because their meaning is not quantified and is likely to vary across individuals. However other health professionals thought these sorts of questions were assessing satisfaction and thought there should be more satisfaction type items in the survey.

“The type of language that they use in the additional questions, particularly down the bottom where they say ‘did you get enough information about the possible changes in your relationship’, well what is enough and we all perceive that differently…” Melbourne health professional.

“…within a reasonable time of being told that I had cancer……it’s open to interpretation. I received good quality care. What’s good? ……. But just to not have it so open and to not be leading and it sort of happens in various parts in that one [Patient Survey 1].” Melbourne health professional.

Pain and nausea side effect questions: Patient Survey 1 includes a number of items in the radiotherapy and chemotherapy modules that ask about the management of pain and nausea. Health professionals asked why only these two side effects were addressed and indicated that there were many more that could be assessed including: diarrhoea, constipation, fatigue, bleeding and febrile neutropenia. Health professionals indicated that these side effects were as important as pain and nausea. It was suggested to ask about side effects in general and ask if they were well managed or to provide a list of the main side effects and ask which if any patients experienced and then assess how well it was managed.

“I think that would be better than to leave it as symptoms, or give them options to tick what’s more problematic for them maybe, and then were they controlled well.” Regional health professional.

Additional questions

Both consumers and health professionals liked most of the items in the “Additional Questions” sheet and thought that it would be appropriate to include these questions in the state-wide survey. The first two questions on this sheet concerned pain and its management and again health professionals commented that there were other side effects that could be assessed here. Consumers commented that for questions regarding symptoms, the wording needed to be altered to make it clear that they were as a result of the cancer. In addition, for questions regarding the provision of information, the wording of the question needed to make it clear it was information provided by their health professional or treatment centre.
While there was general interest in including most of the items in this section, there was some concern about the wording of the items. Consumers did not want the items to upset people if services were not offered to them when they were wanted. As indicated above some health professionals had concerns about using the term “enough information” for some of these items. Health professionals thought the item about changes in relationships could be dropped but generally liked the other items. Younger consumers thought a question about receiving fertility information could be included.

One of the questions in this section asked whether consumers wanted but did not receive information about a number of different supportive care services. Both consumers and health professionals liked this question and recommended including something similar in the state-wide survey. Health professionals commented that the list of services might be able to map onto those assessed in the supportive care screening tool being implemented in hospitals. Both consumers and health professionals thought the list of services could be extended to include: volunteer services at the hospital, pharmacy advice, drug and medication information, financial planning services and support groups. In addition, both consumers and health professionals commented that the counselling option should be divided in two to allow psychology and social work services to be assessed separately. Both groups also thought that physiotherapist should be used instead of physical therapist. Consumers and health professionals also suggested changing the way this question was phrased as both groups thought it important to first determine if people wanted information about each of the services and only if they did to ask if they received information about the service from their health care team.

“….it would be nice to have a question about do they have access to pharmacy or get appropriate drug or medication counselling on their discharge or about their therapy from the pharmacists…… so a few questions around that I think would be good. Dieticians have got a big role in lots of tumours and I think that might be part of it. Physio maybe for certain people. So maybe a broad questions about did you come into contact with any of these other health professionals…….” Melbourne health professional.

Included in the “Additional questions” were questions assessing the use of complementary and alternative medicines (CAMs) and feeling comfortable talking to medical staff about CAMs. Both consumers and health professionals liked these questions and recommended that at least the question on talking to health care team about CAMs being included in the survey.

Areas of care not assessed by the surveys

In addition to the areas of care consumers and health professionals thought were missing from Patient Survey 1 and Patients Survey 2 discussed above, several other areas of care were also thought to be missing.

Care co-ordination: While acknowledging that Patient Survey 1 did include some questions on care co-ordination, health professionals generally thought that neither survey adequately addressed this issue.
Scheduling: Scheduling of appointments and treatments to reflect patient needs was also thought to be absent from the two surveys. While this area could be part of care co-ordination, there was a general feeling from health professionals that some items around this issue should be included in the survey.

Travel issues: Consumers and health professionals also thought the issues of distance travelled and access to financial support for travel were absent from the surveys and they commented that this area should be addressed.

Treatments not assessed: Health professionals and consumers (particularly men with prostate cancer), commented that neither survey asked about having hormone therapy. Health professionals questioned whether hormone therapy would be included in the chemotherapy questions, while men with prostate cancer indicated that as this can be the only treatment some men have, a survey that did not include this treatment would not reflect their treatment experiences. Health professionals and consumers thought that some questions about hormone therapy should be included in the survey.

The advocacy groups also indicated that Patient Survey 1 also didn’t cover stem cell transplant treatments. While they thought that the chemotherapy section of this questionnaire could be expanded to include the high dose chemotherapy that stem cell transplant involves, the absence of this treatment was noted.

Other advocacy groups also noted that the survey didn’t ask about access to, or having reconstruction surgery that may be needed after some treatments for cancer.

Repeating tests and histories: The issue of retesting and repeating the patient story to different clinicians is not addressed in either survey.

Acknowledging the shock at diagnosis: Several patients expressed a desire for the questionnaire to address the issue of whether health professionals acknowledged that patients go into shock at hearing their diagnosis and any information relayed at that time was often not attended to. These patients expressed an interest in having questions assessing whether there were follow-up appointments with medical staff to go through information with them again.

Survivorship: In addition, consumers suggested including questions on receiving information about staying well after treatment and survivorship issues in the state-wide questionnaire.

Access to interpreter services: As part of the discussion around the need to have the questionnaire available to people who speak a language other than English, was the recognition that it would be appropriate to include questions around access to interpreter services in questionnaires for people from a CALD background.

Response from administration staff at treatment centres: As consumers and health professionals both commented on the importance of the attitudes and communication styles of administration staff at treatment centres, both groups considered that it would be appropriate to ask a question about consumers interactions with these staff members.

Emergency Department experiences: Neither survey asked questions regarding patients’ experiences in Emergency Departments. As several consumers raised the
issue of inadequate care in these departments, it may be appropriate to include a question regarding consumers’ experiences in Emergency Departments.

**Video-conferencing availability:** Finally a health professionals group from regional Victoria recommended including a question to assess whether patients from rural areas of Victoria were offered video conferencing facilities for follow-up appointments with doctors as an alternative to travelling some distance to see the doctor.

**Discussion and Recommendations**

Many of the issues consumers and health professionals raised as important factors in determining patients' experiences of care were absent from the two surveys. Issues that were absent include: continuity of care, access to appropriate local services, involvement in decisions regarding where to be treated, waiting times for tests/scans and for oncologists referral appointments, scheduling appointments to take into account patients’ needs, Emergency Department experiences, receiving timely and appropriate information, receiving timely information about costs associated with treatment, issues to do with privacy for supportive care consultations, and access to parking and costs. To fully reflect consumer experiences, the state-wide survey should attempt to address these areas of care.

Based on issues raised during the focus group, the following recommendations are made regarding the state-wide survey.

During the focus groups both health professionals and consumers commented on the discrepancy of them believing that the surveys they viewed were too long and their suggestions that other questions could be included. Both groups acknowledged that it would not be likely to accommodate all suggestions and they thought that it was important for those putting the survey together, along with the Health Department, to determine the areas and questions thought most important.

The recommendations below represent all comments and should be seen as a starting point for the development of the state-wide survey. The recommendations are classified into three groups: “strongly recommend” and “recommend” and “recommend if possible”. The classifications reflect the importance consumers and health professionals seemed to give to the issue or the frequency with which the issue was raised.

It is recommended that questions developed from the recommendations below are examined to determine their alignment with best practice recommendations or departmental policies. Where possible questions used in the state-wide survey should align with best practice recommendations or policies.
Survey format

Strongly recommend

- Merge styles of Patient Survey 1 and Patient Survey 2. As most consumers liked the format and questions of Patient Survey 1, use this survey as a basis for the state-wide survey.
- Organise questions around treatment modality rather than type of hospital admission.
- Place questions regarding whether consumers had each of the different treatments and questions regarding the experience of care during those treatments, together.
- Use simple headings to inform consumers what area of care questions in the section addresses.
- Include a space for “comments” at the end of each section of the survey.
- Ensure wording of the questions is simple and clear and that the reading age for the survey is relatively low (e.g., Year 7 or 8).
- Avoid the use of words like Module and Sections in the survey.
- As much as possible ensure that questions do not include wording that is open to interpretation such as “good quality” “in a reasonable time” etc, unless the item is intended as a “satisfaction” type question.
- Ensure wording of items doesn’t seem either negatively or positively biased.
- Include a mix of response options and include options that allow consumers to indicate that the item doesn’t apply to them, or they are not sure.
- Ensure that the range of response options for questions is spread evenly from positive to negative.
- Use tick boxes rather than circling to indicate a response.
- Ensure the font used is a size that is readable for older consumers.

Content of survey

Strongly recommend

- Combine the content of Patient Survey 1, Patient Survey 2 and the Additional Questions page.
- Use Patient Survey 1 questions for each treatment modality as basis for questions. Extend treatment modalities assessed to include hormone therapy treatment and stem cell therapy/high dose chemotherapy.
- Include questions to assess where consumers had their different treatments ask for name of treatment centre, postcode and whether treated as a private or public patient.
• Include questions regarding support services from “Addition Questions” pages. Ensure that questions ask about information received from the hospital/treatment centre.

• Include a question based on Question 11 of the “Additional Questions” page. Revisions to this question are needed however and these include: extending/modifying list of support services to include: pharmacy information, social worker, psychology, dental services, physiotherapist, volunteer services, fertility services etc. Revising question to assess whether consumers were aware they could access these services and for those that needed the services, whether they were referred and ease of accessing service.

• Include question on access to interpreter if needed.

• Include a set of questions assessing whether there was a health professional or team of health professionals that patients considered their contact point for questions and supportive care information. Base this set of questions on those in Patient Survey 2 under the heading “Clinical Nurse Specialist.”

• Extend questions on co-ordination of care from Patient Survey 1 and include items around communication of results between doctors/treatment centres, receiving information about treatment plans, co-ordination of tests and treatments etc.

• Include questions assessing whether scheduling of appointments was consumer focused.

• Include questions assessing cancer diagnosis and diagnosis date.

• Include questions assessing how and when consumers were told their diagnosis, that is: face to face or phone, and ask level of satisfaction with this method.

• Include questions regarding treatment decisions and involvement in treatment decisions based on questions in Patient Survey 2

• Include questions on communication between patient and health professionals to assess perceived honesty/openness of communication; being talked down to, being listened too, perceived availability of doctors to ask questions.

• Include questions on need to repeat history to doctors and confidence in doctors’ knowledge of patient.

• Include set of questions assessing information provision and whether this was timely and appropriate.

• Include a question assessing whether clinicians acknowledge shock patient goes into when hearing diagnosis and offers to repeat information provided to them at a subsequent appointment.

• Assess provision of information about fertility issues for younger people.

• Include questions regarding whether consumers received information on costs of treatment/tests and timeliness of this information.

• Include questions around distance travelled to treatment centre and assess how consumers travelled to treatment centre and access to financial support if available.
• If consumer travelled a long distance to treatment, include questions on accommodation and ask who arranged accommodation.

• Include questions assessing experience of waiting: to get an appointment with oncologist, for tests, for treatment and at appointments. Where applicable, ensure response options match either Department recommendations for waiting times or work practices (e.g., time period needed to develop treatment plans for radiotherapy).

• Revise questions in Radiotherapy section to reflect practice: patients attend for radiotherapy 5 days a week, so questions need to reflect that level of interaction between patients and health professionals, e.g., monitoring of symptoms not likely to occur “at most visits” but instead would happen weekly or after 3 weeks as this is when most side-effects start to present.

• Re-order some items in Patient Survey 1’s Critical Cancer Care Event section. Move items about understanding reasons for taking medications and how to take medications into treatment modality sections. Move items about understanding reasons for having the different treatments to before knowing where to go for these treatments.

• Include questions on experience at Emergency Departments.

Recommend

• If possible align support services asked about with issues or problems assessed in supportive care screening tool used in many hospitals.

• Include questions assessing involvement in decisions regarding where to receive treatment, including questions on being treated in public or private system.

• Include a question asking if treatment decisions influenced by: travel requirements, costs, time needed off work, etc.

• Include a question assessing choice of doctors.

• Include some questions about ward nurses and doctors from Patient Survey 2 into the different treatment modality questions.

• Include a question assessing whether doctors sought patient permission if they were bringing students on rounds with them.

• Include questions around confidence in skills and knowledge nurses and other health professionals.

• Include questions regarding ease of access to medical information, e.g., test results.

• Include questions regarding whether consumers had enough privacy when seeing allied health professionals such as psychologist, social workers, etc.

• Include a question regarding communication with administration staff.
Recommend if possible

- Include question on knowledge regarding how to make a complaint.
- Include question regarding whether inpatient bed was in “oncology ward.”
- Include questions assessing survivorship information provision.
- Include questions regarding perceived ease of discussing complementary and alternative medicines with health care team.
- Assess comfort of treatment environment.
- Include questions around access to allied health services before treatment.
- For rural patients, include question regarding use of video conferencing for at least some follow-up appointments.
- Include questions regarding parking, adequacy and costs.

Section 3: Feeding back survey findings to health professionals

Health professionals discussed issues concerning feeding back data from the survey to treatment centres. It was stated to health professionals that survey data was intended to be useful to health services, feeding into quality improvement programs. Health professionals discussed: who the results should be reported to; the level of reporting required, whether some form of benchmarking within the report was of use, turnaround time to receive the survey results if they are to be seen as being of relevance and how frequently the survey should be conducted. Results for each of these areas are presented below.

Who results should be reported to

Health professionals suggested there were many groups that should receive a copy of the survey’s findings including: management of the relevant Integrative Cancer Services; hospital/treatment centre management; management of cancer services at each treatment centre, quality improvement staff and department staff at the different treatment centres. Health professionals considered it important to report the results to all groups and they commented that reporting to department staff was important if changes were to be made.

“Some of the questions are very, like ‘at ward level were you given enough information on discharge. But if that doesn’t come down to the ward then …’”

“No one is going to action it.”

“No one is going to do anything.”

“And that’s a really easy piece of data that the unit could see okay so 50 percent of people said …. [we need to review that]….” Melbourne health professionals exchange

There was concern that simply reporting data back to senior management might result in no or limited action. Health professionals talked about the need to ensure
that the findings resulted in some operational plan for improvement. There were comments that this might make it more likely that the survey’s findings would be attended to and that some response would be made.

Health professionals also commented that the release of the data could be promoted to staff through conferences and relevant newsletters and indicated that this might increase the likelihood of staff becoming aware of the data and seeing it as useful.

Level of reporting

Health professionals suggested several levels of reporting for the data. They suggested reporting at a state level, at an ICS level, at the health services level, the hospital and if possible the department level within the hospital (eg chemotherapy ward). Health professionals realised that whether results could be presented at the ward or department level depended on having a sufficient number of patients from that unit in the survey. They recognised that sufficient numbers were needed to ensure both confidentiality of the people responding and reliability of findings. However in general health professionals thought that this level of reporting would be very useful and would increase the likelihood of the data being used by staff.

“You just really need to be able to break it down to units that are functional in order to get their attention. So we’ve just actually had a break down to CSU unit [of VPSM results] which is probably workable here. When we went down to ward unit, which would be better, the numbers are too small…… But that’s what we’d like to do. If there’s been a change and you can actually identify to a particular ward and then go and talk to them and say what’s happened, has there been a change of staff, you know what I mean So I think to break down a smaller unit and functional units.” Melbourne health professional.

Regional health professionals commented that due to the size of the area covered by their ICS and the different types of health services in their region, presenting data at the health service level is essential if the data is to be useful.

“But the main issue with this is that [Regional ICS] is one unit, and the variation in care in the [Regional ICS] region is enormous, so you really have to break it down to health service.” Regional health professional.

Health professionals were asked whether results needed to be reported at the tumour stream level as well as at the treatment centre or ward level. There was a general feeling that reporting by tumour stream would be useful as it would enable health professionals and managers to see whether care experiences differed between tumour streams. However there was recognition that some tumours had low numbers and it may not be possible to get a sufficient number of respondents from these tumour streams to enable data to be reported for them.

“So I think tumour streams make sense to me. You’ve got a lot of variation and I’ve seen some of those reports, big variations in your tumour streams. So it makes sense then to go back to a tumour stream who are doing well and say look, you’re doing well and they can compare.” Melbourne health professional.
“...I think the people with the power, let’s say, the tumour streams, otherwise if it’s average out across everybody, which it’s probably valuable to do as well, ...... then no one’s any the wiser....” Melbourne health professional.

“We can pinpoint things that they’re doing well and transfer them into other tumour streams that aren’t doing so well.” Melbourne health professional.

Health professionals were asked whether the results needed to be broken down by tumour stream within the health services. While many health professionals supported this idea, they also realised that it may not be possible due to small numbers. Health professionals identified several problems that might arise when doing this sort of breakdown if the numbers are small including: results being influenced by extreme responses of one or two people, possibility of being able to identify the respondent and increasing the likelihood that comments about health professionals can be directly related to staff. In recognition of these issues, health professionals suggested having the results broken down by tumour stream at the smallest level that would not breach confidentiality and would produce reliable results.

Several groups of health professionals suggested supplying the ICS or the Health service with a data cube of the data from their surveys so they could interrogate the data themselves. Health professionals commented that if data was supplied to the ICS or health service, it would be important to have a mechanism in place to prevent analyses being conducted when numbers were small would be needed. Health professionals commented that for the Victorian Patient Satisfaction Monitoring (VPSM) survey there is a mechanism for preventing presentation of results when there are fewer than 10 people in the analyses. Health professionals recommended drawing on the experiences and methods of supplying VPSM data to health services for this project.

Benchmarking

In general there was agreement that some sort of benchmarking or comparator for their health service results would be useful. Health professionals thought that comparators could be the state average, the average for the ICS and other treatment centres. However regarding the last two comparators, health professionals strongly believed that this would only be useful if the treatment centres or ICS used as the comparator were similar to the treatment centre being reported on. Health professionals considered it inappropriate to compare regional treatment centres or regional ICS to metropolitan treatment centres or metropolitan ICS and health professionals from metropolitan treatment centres considered it inappropriate to compare smaller treatment centres to large tertiary and specialist cancer hospitals. Some health professionals suggested that the hospital categories used in the VPSM reports could be used for this study. In the VPSM reports hospitals categorised as “A” group hospitals are compared to other “A” group hospitals, while those categorised as “C” hospitals are compared to other “C” hospitals.

Some health professionals thought that it could be important to discuss factors that could influence results. These factors included annual patient numbers, proportion of patients from CALD backgrounds and staffing resources (eg numbers of nurses, allied health etc).
“Regional with regional, metro with metro. It would be interesting to have a look at it and there might be good reasons for the differences.” Regional health professional.

“You’d have to look at the amount of resources that everyone has got across health services.

“They’re different, very different.

“You might have one social worker for 10,000 cancer patients whereas another hospital might have three and a half for the same amount. And that’s just because I’ve been in social work and I know what social work is like. So yeah your resources you’re spread out to do the best you can....” Melbourne health professionals’ exchange.

While there was general agreement that benchmarking the data from the survey would be useful and informative there was also a concern for the data to not be used as a performance measure. Health professionals were interested in the data as a quality improvement tool, but did not think it would be appropriate to use it as a performance measure.

“As long as it’s not used as a performance measure.” Regional health professional.

Health professionals also thought it would be useful to compare results for the health service over time to determine whether the experiences of their consumers were improving.

Reporting and frequency of surveys

Health professionals were asked for their thoughts on the acceptable “turnaround time” for receiving a report on the survey’s findings from when patients completed the survey. Health professionals commented that ideally the shorter the turnaround time the better, as it was easy to dismiss 12- to 18-month-old data as not relevant to current practice. Health professionals did understand that processing data and formulating a report would take time, but thought that receiving reports within 4-6 months of the survey being completed would be ideal. When questioned as to what sort of turnaround time would make it less likely that the data would be useful and of interest, health professionals generally thought that receiving the report 12 months after the survey was completed was too long.

“A year is too long, way too long, six months max, I’d say four to six months, you’d want to know.”

“That’s probably the minimum return.”

“I know but in terms of wanting to get thing improved, you don’t want to be using old, old data.” Melbourne Health professionals’ exchange

Health professionals were also asked for their thoughts on the frequency of the survey. Health professionals’ views on this ranged from every year to every three years.

Health professionals were asked to think about the frequency of the surveys if the survey tool was to be used as a means of generating quality improvement interventions and assessing whether these had made a difference to patients’ experiences of care. There were still differences in health professionals’ opinions on
the ideal frequency of the survey, with some suggesting a year, some suggesting two years and a few still suggesting 3 years.

“At least every 12 months to make it valuable data.” Melbourne health professional.

“I think at least two. Time to work out what you need to change and make sure you implement it and the patients have the effect of the change. I don’t know what but I wouldn’t [say] less than two years….

Q7: From when you get the results?
“We might change your practice after the get the results. So again just picking a number really.”

“I think that’s fair. Two to even three I would say….” Melbourne Health professionals’ exchange.”

Discussion and recommendations

While there were differences in the opinions of health professionals regarding how useful the survey data will be for them, there was a consistent belief that if it was to be useful the results of the survey had to reach both the management of oncology services within hospitals and treatment centres as well as the ward staff. There was a strong view that if the results did not reach the ward staff, practice changes were unlikely. However health professionals also saw the need to have management endorse the results and promote quality improvement initiatives in response to the survey findings. To this end health professionals believed the data needed to be reported back to: State government, ICS management, Management of the Hospital/Health Service, management of oncology services within the hospital/health service and ward/department staff.

Recommendations

- Reports of the study’s findings need to be provided to ICS management, hospital/health service management, management of oncology services at each hospital/health service and departmental staff.

- Promoting the study’s findings and availability of hospital specific reports to staff via newsletters, conferences and emails is recommended as this will make it more likely for staff to attend to the report’s findings.

The level of reporting of results reflected who the data should be reported too. Health professionals thought there would be advantages to reporting the data at a state level, the ICS level, the hospital/health service level and if possible at the ward/department level. Health professionals also thought that the data should be reported by tumour stream and that tumour stream reporting should happen at the smallest reporting unit possible.
Recommendations

- Findings from the survey need to be reported as several different levels including: the state level, the ICS level, the hospital/treatment centre level and if possible the department/ward level.

- Findings from the survey also need to be reported by tumour stream. Results should be presented for tumour streams as a state level, an ICS level and a hospital/treatment centre (if numbers allow).

Providing some sort of benchmarking or comparator for comparing results obtained for the treatment centre was recommended. However health professionals had a strong opinion that the health service used as a benchmark needed to be similar to the treatment centre in terms of location (metropolitan or rural/regional), size, teaching hospital or not and patient population.

Recommendation

- Benchmarking results against a similar organisation (eg category A hospitals or other metropolitan ICS) is recommended.

There was general agreement that receiving a report on the survey findings within 6 months of the survey being conducted would be optimal. There was also agreement that the results of the survey would be less useful if the turnaround time was 12 months or longer.

Recommendation

- Ideally the results need to be provided to health services within 6 months of the survey being conducted. While it might be acceptable to extend this turnaround time to 8 months, a turnaround time of 12 months or more is not acceptable.

There was no consensus on the ideal frequency for conducting the survey. Health professionals expressed a range of views about this issue including every 12 months, every 2 years and every 3 years. Conducting the survey every 2 to 3 years would be acceptable to most health professionals.

Recommendation

- Conduct the survey every 2 or 3 years.
REFERENCES


APPENDIX 1: BRIEF OUTLINE OF PROJECT
Project Background

The Cancer Strategy and Development section understands the benefits of measuring patient experience of cancer services across Victoria. The policy document *Clinical excellence in cancer care* (2007), Department of Human Services (DHS), describes a model for safety and quality in Victorian cancer services. A variety of measures are suggested to monitor safety and quality, the policy acknowledges that surveying of consumers, carers and community members informs service improvement.

*Victoria’s Cancer Action Plan (VCAP) 2008-2011* outlines priority areas for improvement, providing strategies and targets. The VCAP notes Action Area 4: Priority 1 is to ‘create better experiences for cancer patients and carers’. Undertaking a consumer experience survey will help evaluate a range of VCAP priorities. A survey will inform progress of policy implementation for the cancer reform priorities of:

- Multidisciplinary care
- Care coordination
- Supportive care
- Reducing variation

In Australia, there has been some development of cancer patient satisfaction and experience tools over recent years. Commencing in 2007, the Cancer Institute NSW initiated a three year state-wide cancer patient satisfaction survey. In 2008, the Cancer Council Victoria established the PROSPECT research program as a collaborative initiative between the CCV’s Cancer Epidemiology Centre and the Centre for Behavioural Research in Cancer (CBRC). PROSPECT (Patient Responses: an Ongoing Survey of People Experiencing Cancer Treatment) was designed as a platform for continuous monitoring of the experiences of Victorians who receive cancer treatment and care. As part of this pilot project researchers at the CCV developed a survey tool that consisted of questions assessing delays in diagnosis and treatment, quality of life, anxiety and depression, unmet supportive care needs, impact on work, experiences of care and demographic information. In 2009, Cancer Australia piloted a consumer and carer survey tool in most states excluding NSW and Victoria.

Project Overview

The overall aim of the Victorian Cancer Patient Experience Survey Tool project is to assist Victorian cancer services to improve the quality of cancer care delivery and outcomes through the collection and reporting of adult patient experience. This project will promote a quality improvement culture that acknowledges the importance of the patient experience and promotes patient-centred care. The project includes the engagement of the CBRC to refine the PROSPECT patient experience measurement tool for state-wide use in both the public and private sector. The project will include the investigation of the published and gray literature, broad cancer clinician consultation, the development of an efficient and sustainable patient selection criterion, and consideration of a quality reporting framework to lead to service improvement.

The project will deliver the following:

- Literature review report
- Consultation with cancer clinicians across the state
- Proposed patient survey tool
- Proposed patient selection criterion
- Proposed quality reporting framework
Critical points in the care experience

The Victorian Department of Health’s management frameworks for cancer care have identified nine critical points in the cancer disease trajectory. These are:

1. At community level, recognition of potential cancer signs or symptoms or abnormal result from a screening test
2. Initial consultation with a GP
3. Referral to, and diagnosis by, appropriate clinical specialist
4. Determination of treatment program
5. Implementation of treatment
6. Follow up program
7. Recognition of disease recurrence and determination of treatment program
8. Implementation of treatment for recurrence

Initially the statewide survey of cancer patients will focus on care received at critical points 3 to 6. It is recognised that supportive care is an important component of care at all care points.

The focus group discussions will focus on care points 3 to 6.
APPENDIX 2: PATIENT SURVEY 1
Patient Survey 1
SECTION 1: EXPERIENCE OF TREATMENT

The questions below are about your experiences of cancer treatment. They ask about the length of time that you had to wait until accessing different types of care for cancer and where you received your treatment. Please give as accurate an answer as you can.

*Please circle your answer.*

When cancer is suspected, most people are referred to see a specialist doctor.

1. **How long was it between when you were referred to a specialist doctor and your first appointment with the specialist?**
   - 3 days or less .........................................................1
   - More than 3 days, but within a week .............................2
   - More than a week, but within 2 weeks ..........................3
   - More than 2 weeks, but within 4 weeks ..........................4
   - More than a month ..................................................5

   If the length of time was more than a week, was this due to:
   - Personal decision to wait .........................................1
   - Specialist waiting times ...........................................2

Sometimes people will have several tests before a diagnosis of cancer is given. Screening tests (e.g. mammograms, PSA tests), X rays or ultrasounds are used to show whether a person might have cancer. A sample of tissue (a biopsy for a solid cancer, or a blood test or bone marrow biopsy for blood cancers) is usually needed to show that a person definitely has cancer.

2. **Who gave you the result of the test that showed that you definitely had cancer?**
   - GP .............................................................................1
   - Surgeon ........................................................................2
   - Medical oncologist .....................................................3
   - Radiation oncologist ..................................................4
   - Haematologist ..............................................................5
   - Other (please specify) ________________________________

Surgery to treat cancer usually involves an operation to remove some or all of the cancer. If you have had more than one surgery to treat cancer, please think about the first surgical treatment that you had when answering the questions.

3. **Did you have surgery to treat cancer?**
   - Yes .............................................................................1
   - No .............................................................................2

   → **PLEASE GO TO QUESTION 7**

4. **Did you have surgical treatment in a:**
   - Public hospital or public clinic ....................................1
   - Private hospital or private clinic .................................2
   - Not sure ........................................................................3
5. Where did you have your surgical treatment? (please indicate name of town/suburb or postcode of town/suburb where hospital is located)

Town/Suburb______________ OR Postcode_____________

Sometimes other treatments or tests need to be completed before a person is ready to be booked in for surgery.

6. Once you were ready to be booked in for surgery, how long did you wait until you actually had surgery?
   3 days or less..............................................1
   More than 3 days, but within a week......................2
   More than a week, but within 2 weeks ..................3
   More than 2 weeks, but within 4 weeks ............4
   More than a month .......................................5

   If the length of time was more than a week, was this due to:
   Personal decision to wait....................................1
   Surgery waiting times .......................................2

Radiotherapy is the use of radiation to destroy cancer cells in the body, to slow the growth of cancer, or to reduce the symptoms of cancer. External radiotherapy is given using a machine that directs radiation onto the body. Internal radiotherapy (brachytherapy) involves temporarily putting thin tubes, seeds or rods containing radioactive material inside the body.

7. Did you have radiotherapy treatment for cancer?
   Yes..............................................................................1
   No .............................................................................2 → PLEASE GO TO QUESTION 12

8. Did you have radiotherapy treatment in a:
   Public hospital......................................................1
   Private hospital .....................................................2
   Not sure ......................................................................3

9. Where did you have your radiotherapy? (please indicate name of town/suburb or postcode of town/suburb where hospital is located)

Town/Suburb______________ OR Postcode____________________

10. Did you have to arrange different accommodation while receiving radiotherapy? For example, this might have been at the home of a friend or relative or in a hotel or hostel
    Yes.....................................................................1
    No .....................................................................2

Sometimes other treatments or tests need to be completed before a person is ready to start radiotherapy.
11. Once you were ready to start radiotherapy, how long did you wait until having your first radiotherapy treatment?

- 3 days or less .......................................................... 1
- More than 3 days, but within a week ............................ 2
- More than a week, but within 2 weeks ....................... 3
- More than 2 weeks, but within 4 weeks ....................... 4
- More than a month .................................................... 5

If the length of time was more than a week, was this due to:

- Personal decision to wait ........................................... 1
- Radiotherapy treatment waiting times ......................... 2

Chemotherapy is the use of drugs, which aim to destroy cancer cells in the body, or to stop them from multiplying and spreading. It can be given through a drip that goes into a needle in your vein, through an injection, as a tablet that you swallow, or as cream that’s put on surface of the skin.

12. Did you have chemotherapy treatment for cancer?

- Yes ............................................................................ 1
- No ............................................................................ 2  ➔ PLEASE GO TO QUESTION 17

13. Did you have chemotherapy treatment in a:

- A public hospital ...................................................... 1
- A private hospital ...................................................... 2
- Somewhere else .......................................................... 3  ➔ Please specify ________________
- Not sure ..................................................................... 4

14. Where did you have your chemotherapy? (please indicate the name of the town/suburb or the postcode of the place where you had chemotherapy)?

   Town/Suburb ___________ OR Postcode _________________

15. Did you have to arrange different accommodation while receiving chemotherapy? For example, this might have been at the home of a friend or relative or in a hotel or hostel

- Yes ............................................................................. 1
- No ............................................................................. 2

Sometimes other treatments or tests need to be completed before a person is ready to start chemotherapy treatment.

16. Once you were ready to start chemotherapy, how long did you wait until your first chemotherapy treatment?

- 3 days or less .......................................................... 1
- More than 3 days, but within a week ............................ 2
- More than a week, but within 2 weeks ....................... 3
- More than 2 weeks, but within 4 weeks ....................... 4
- More than a month .................................................... 5

If the length of time was more than a week, was this due to:

- Personal decision to wait ........................................... 1
- Chemotherapy treatment waiting times ......................... 2
17. Have you finished treatment?
   Yes .................................................................1
   No .....................................................................2

   If you have not finished treatment, are you currently having:
   Chemotherapy ....................................................1
   Radiotherapy .......................................................2
   Immunotherapy ....................................................3
   Targeted therapy ................................................4
   Hormone therapy .................................................5
   Other (please specify) ______________________________
SECTION 2: CRITICAL CANCER CARE EVENTS

We are interested in getting an accurate picture of the care that you received from the treatment centre(s) involved in your cancer care. Each module asks about a particular phase of your cancer care, so please think about that time when giving your answer. For example, question h in Module 1 asks whether you were given written information about cancer. You have four choices for your answer:

“Yes, definitely” if you are definitely sure you were given written information,
“Yes, I think so” if you are unsure but think you probably were given written information
“No, I don't think so” if you are unsure but think you probably weren’t given written information,
“No, definitely not” if you are definitely sure that you weren’t given written information.

Please tell us whether or not the following things happened as part of your care. Please circle your answer.

Questions in Module 1 are about the doctor who gave you the results of the test that showed that you definitely had cancer. For many people this test would have been a biopsy.

<table>
<thead>
<tr>
<th>Module 1: When you were told you had cancer</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>When my doctor told me that I had cancer:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. It was at a face-to-face appointment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. I was told before the appointment that I could have a friend or family member with me if I wanted to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. I clearly understood the explanation my doctor had given me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>When I was told that I had cancer my doctor:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Encouraged me to ask any questions that I had.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. Showed that he / she understood how I was feeling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Encouraged me to talk about how I was feeling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. Asked if I wanted to be given information on the likely outcome of treatment at that appointment or later.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Within a reasonable time of being told that I had cancer:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. I was given written information about cancer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. I was given a sheet with suggestions about questions that I might like to ask at my next appointment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. I was told how I could get further information about cancer e.g. websites, booklets, cancer helpline.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall, when I was diagnosed with cancer:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>k. I received good quality care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Please read the instructions above Module 2 to Module 8 carefully. Some modules may not apply to you because you did not receive treatment or you did not receive the treatment mentioned or you have not finished treatment. If a module does not apply to you please skip to the next module to see if that module applies to you. Module 9 should be completed by everyone.

Please note, treatment for cancer may be different for each individual and depends on the type of cancer you have. Treatment options may include: surgery, chemotherapy, radiotherapy or hormone therapy. A person with cancer may undergo only one treatment, for example surgery or a combination, for example surgery and chemotherapy.

If you have not undergone any treatment for cancer, please answer all questions in Module 2 and Module 9 only. If you have had treatment (eg surgery, chemotherapy etc), please go to Module 3.

Questions in Module 2 are for people who have not had any treatment but who are being observed or monitored. For example, regular tests or check ups to monitor your condition.

### Module 2: Observation/Monitoring

<table>
<thead>
<tr>
<th>The doctor(s) involved in planning my cancer treatment/management</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Told me why treatment was not recommended.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Asked me how much information I wanted.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. Encouraged me to ask any questions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. Gave me information about support services (e.g. the cancer helpline, support groups or other services).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. Told me that counselling services were available if I wanted them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Throughout the monitoring of my cancer</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>f. I was told how often I would need to have tests and check-ups to monitor my condition.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. I was told what the follow-up tests involved.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. A doctor asked my permission to discuss my case with other health professionals (i.e. a multidisciplinary team).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. One doctor is responsible for overseeing my care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. I was able to talk to a health professional about any concerns or fears I had.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>k. I was able to ask any questions that I had.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>l. Overall I feel that my cancer is being well managed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Questions in Module 3 ask about care given to you by a health professional when treatment (e.g., surgery, radiotherapy, chemotherapy, etc.) was being planned. This means any professional involved in your cancer care, for example, doctors, nurses, radiation therapists, social workers, physiotherapists, psychologists, etc.

### Module 3: Planning Cancer Treatment / Management

<table>
<thead>
<tr>
<th>The doctor(s) involved in planning my cancer treatment/management:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Gave me information about the advantages and disadvantages of different treatment options.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Gave me information on the possible short-term side effects of treatment(s) (e.g., nausea, pain, fatigue).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. Gave me information on the possible long-term side effects of treatment(s) (e.g., reduced fertility, lymphodeama).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. Asked my permission to discuss my case with other health professionals (i.e., a multidisciplinary team).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>When my cancer treatment was being planned a health professional:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>e. Asked me how much information I wanted.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Encouraged me to be involved with planning my treatment</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. Encouraged me to ask any questions about treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>h. Gave me information about support services (e.g., the cancer helpline, support groups, or other services).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. Told me that counselling services were available if I wanted them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. Told me about additional services (e.g., nutritional advice, occupational therapy, physiotherapy, support groups) that I could access during my cancer care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>k. Checked if I had concerns about practical issues such as childcare, finances, or transport to and from the hospital.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>l. Made me feel comfortable to ask any questions I had.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>m. Checked that I understood the information provided to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>n. The health professionals involved in my care helped me to make a treatment decision that I was comfortable with.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Questions in Module 4 are about surgery that you had as part of your cancer treatment. This does not include biopsies. If you have had more than one surgery to treat cancer, please think about the first surgical treatment that you had when answering the questions.

**If you have had surgery, please answer all questions in Module 4. If you did not have surgery, go to Module 5.**

### Module 4: Surgery

<table>
<thead>
<tr>
<th>Before having surgery for cancer I was given information about:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Where to go in the hospital for surgery.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Why the surgery was necessary.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. How to prepare for surgery (e.g., if changes to other medications were needed).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. What would happen during surgery.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. How I would feel after surgery.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. How to manage any feelings of anxiety or stress before surgery (e.g. relaxation exercises).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. What I could do after surgery to manage any pain or discomfort.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Throughout my surgery planning and follow up:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>h. One surgeon was responsible for overseeing my surgical care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. I was able to talk to a health professional about any concerns or fears I had about surgery.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. I was given information about what I could do to manage any physical side effects at home.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>k. I was able to ask any questions that I had.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>l. Any pain I had was well managed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>If you did not experience any pain, please check this box and go to question m.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>m. A health professional checked that I understood the information provided to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>n. I felt as well prepared as possible for surgery.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
**If you have had or are currently having chemotherapy, please answer all questions in Module 5. If you did not have chemotherapy, go to Module 6.**

<table>
<thead>
<tr>
<th>Module 5: Chemotherapy</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don't think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Before starting chemotherapy for the first time I was given information about:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Where to go in the hospital for chemotherapy treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Why the chemotherapy was necessary.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. How to prepare for chemotherapy (e.g., if changes to other medications were needed).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. How the treatment would be given (e.g. through a needle/ drip or a tablet that you swallow).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. What having chemotherapy would feel like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. How I would feel after chemotherapy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. How to manage any feelings of anxiety or stress before having chemotherapy for the first time (e.g. relaxation exercises).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Throughout my chemotherapy treatment and follow up:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. One doctor was responsible for overseeing my chemotherapy treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>i. I was able to talk to a health professional about any concerns or fears I had about chemotherapy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>j. I was given information about what I could do to manage any physical side effects at home.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>k. I was able to ask any questions that I had.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>l. Any pain I had was well managed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>If you did not experience any pain, please check this box and go to question m.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>m. Any nausea I had was well managed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>If you did not experience any nausea, please check this box and go to question o.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n. A health professional checked that I understood the information provided to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Overall:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>o. I felt as well prepared as possible for starting chemotherapy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
**IF YOU HAVE HAD OR ARE CURRENTLY HAVING RADIOTHERAPY, PLEASE ANSWER ALL QUESTIONS IN MODULE 6. IF YOU DID NOT HAVE RADIOTHERAPY, GO TO MODULE 7.**

## Module 6: Radiotherapy

<table>
<thead>
<tr>
<th>Before starting radiotherapy for the first time I was given information about:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Where to go in the hospital for radiotherapy treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Why the radiotherapy was necessary.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. How to prepare for radiotherapy (e.g., if changes to other medications were needed).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. What would happen when the treatment was given (e.g., how I would be positioned during treatment; being in a room by myself as the treatment was given).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. What having radiotherapy would feel like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. How I would feel after radiotherapy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. How to manage any feelings of anxiety or stress before having radiotherapy for the first time (e.g., relaxation exercises).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

| Throughout my radiotherapy treatment and follow-up:                                                                                                                                                                                                 |   |   |   |   |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|   |   |   |   |
| h. One doctor was responsible for overseeing my radiotherapy treatment.                                                                                                                                                                                             | 1   | 2   | 3   | 4   |
| i. I was able to talk to a health professional about any concerns or fears I might have about radiotherapy.                                                                                                                                                      | 1   | 2   | 3   | 4   |
| j. I was given information about what I could do to manage any physical side effects at home.                                                                                                                                                                      | 1   | 2   | 3   | 4   |
| k. I was able to ask any questions that I had.                                                                                                                                                                                                                   | 1   | 2   | 3   | 4   |
| l. Any pain I had was well managed                                                                                                                                                                                                                               | 1   | 2   | 3   | 4   |
| If you did not experience any pain, please check this box and go to question m.                                                                                                                                                                                     |     |     |     |     |
| m. A health professional checked that I understood the information provided to me.                                                                                                                                                                                | 1   | 2   | 3   | 4   |

| Overall:                                                                                                                                                                                                                                                        |   |   |   |   |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|   |   |   |   |
| n. I felt as well prepared as possible for starting radiotherapy.                                                                                                                                                                                                  | 1   | 2   | 3   | 4   |
**ModuleName:** 7  
**Module Title:** Having Treatment for Cancer

<table>
<thead>
<tr>
<th><strong>When I was having treatment for cancer:</strong></th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. On most visits to the hospital a health professional asked if I had any side effects or symptoms.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b. Side effects of treatment that I experienced were well managed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c. The hospital staff asked if my family needed more information or support (i.e. help with practical or emotional issues).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d. I was regularly asked how I was dealing with the emotional side of cancer treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e. On most visits to the hospital, a health professional asked if I had any pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. I was regularly asked if I needed referral to other services (e.g. counselling, nutritional advice, physiotherapist).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>g. I had access to all the additional services I would have liked (e.g. counselling, nutritional advice, physiotherapist).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**If you did not experience any pain at any time during your treatment phase, please check this box [ ] and go to question i.**

**If you had pain at any time during your treatment please answer the next question:**

| h. My pain was well managed. | 1 | 2 | 3 | 4 |

**Overall:**

| i. Problems I had during treatment were managed well. | 1 | 2 | 3 | 4 |
**Module 8**

**Finishing Cancer Treatment**

<table>
<thead>
<tr>
<th>Towards the end of cancer treatment I was given:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. A written plan that included information about my cancer treatments and recommended follow-up.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Towards the end of cancer treatment I was given information about:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>b. Which follow up tests I might need.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. When I would need to have follow-up tests.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. The purpose for taking each of my medications.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. How to take each of my medications, including how much I should take and when.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. How to manage any ongoing symptoms or side effects.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Which new symptoms might mean that cancer has come back.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h. What I could do to stay as healthy as possible in the future (e.g. information about exercise, diet, stopping smoking).</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. How people commonly feel emotionally after finishing treatment.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. Where I could get extra support if I needed it.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall, toward the end of cancer treatment:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>k. I knew where I could get help for any problems related to cancer that might come up over the next few months.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Module 9**

**Continuity of Care**

<table>
<thead>
<tr>
<th>From when I was diagnosed until now:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I prefer to see the same doctor(s) throughout my treatment and follow-up.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The treatment centres involved in my care:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>b. There has been a health professional that I could contact if I had any questions about my care.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. My GP has been kept well informed about my cancer care.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. The health professionals involved in my care appeared well informed about my cancer care.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If more than one treatment centre was involved in your care, please answer the following questions:</th>
<th>Yes, definitely</th>
<th>Yes, I think so</th>
<th>No, I don’t think so</th>
<th>No, definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>e. Were well informed about the care I received from other hospitals or health services.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Co-ordinated my appointments to suit my needs.</td>
<td>1 2 3 4</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SECTION 3: BACKGROUND

This section asks for some background information about you and your cancer treatment. These questions help us get an idea of who is participating in the study. Please circle your answer.

1. **What is the highest level of education that you have completed?**
   - Primary school..........................................................1
   - Secondary school..........................................................2
   - Certificate or Diploma.....................................................3
   - University Degree.........................................................4

2. **What is your current marital status?**
   - Married ........................................................................1
   - De facto or living with a partner .........................................2
   - Separated or divorced .....................................................3
   - Widowed ..........................................................................4
   - Single or Never married ...................................................5
   - In a relationship but not living with partner .......................6

3. **What is the name of the town/suburb or postcode of the town/suburb where you currently live?**
   - Town/Suburb______________________________ OR: Postcode__________________________

4. **Where were you living when you received your treatments for cancer?**
   - Same address as listed in Question 3.............................1
   - A different address: Town/Suburb__________________________ OR: Postcode__________________________

5. **Who is currently living at home with you?** *(Please circle as many as applicable)*
   - I live alone ........................................................................1
   - My partner .........................................................................2
   - My children or partner’s children .....................................3
   - My grandchildren or partner’s grandchildren .................4
   - My parents or in-laws .....................................................5
   - Other family members .....................................................6
   - Friends ..............................................................................7
   - Housemates ......................................................................8
6. Are any languages other than English spoken at home?
   Italian..........................................................1
   Greek...........................................................2
   Cantonese......................................................3
   Arabic (including Lebanese)...............................4
   Vietnamese.....................................................5
   Mandarin.......................................................6
   Other (please specify) ________________________________

7. What is your current work situation?
   Full-time employment .......................................1
   Part-time employment ......................................2
   Casual employment .........................................3
   Household duties.............................................4
   Retired or aged pensioner ..................................5
   Disabled pensioner ..........................................6
   Unemployed ....................................................7
   Student ...........................................................8
   Other..................................................................9
   If other, please specify: ______________________________

8. Before your cancer diagnosis what was your main work situation?
   Full-time employment .......................................1
   Part-time employment ......................................2
   Casual employment .........................................3
   Household duties.............................................4
   Retired or aged pensioner ..................................5
   Disabled pensioner ..........................................6
   Unemployed ....................................................7
   Student ...........................................................8
   Other..................................................................9
   If other, please specify: ______________________________

9. What is or was your main occupation?
   __________________________________________________
   __________________________________________________
   __________________________________________________

10. What is your current gross family income each week (that is, before tax)?
    Less than $300 per week ....................................1
    Between $300-$599 per week..............................2
    Between $600-$999 per week.............................3
    Between $1000-$1299 per week.........................4
    Between $1300-$1599 per week.........................5
    Between $1600-$1999 per week.........................6
    Between $2000-$2499 per week.........................7
    More than $2500 per week..............................8
11. Do you currently have private health insurance?  
   Yes .................................................................................................................. 1 
   No .................................................................................................................. 2 
   Not sure ......................................................................................................... 3 

12. Do you currently have any health problems other than cancer? *Please circle as many as applicable*)  
   Heart disease ............................................................................................... 1 
   Arthritis ........................................................................................................ 2 
   Diabetes ....................................................................................................... 3 
   Asthma .......................................................................................................... 4 
   Depression .................................................................................................... 5 
   Anxiety ......................................................................................................... 6 
   Chronic pain ................................................................................................. 7 
   Other ............................................................................................................ 8 

   If you circled ‘Other’, please describe:  
   ________________________________________________________________________  
   ________________________________________________________________________  
   ________________________________________________________________________
APPENDIX 3: PATIENT SURVEY 2
Patient Survey 2
SEEING YOUR GP

These questions are about what happened before you went into hospital about cancer.

1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?
   - [ ] None - I did not see my GP before going to hospital  ➔ Go to Q6
   - [ ] I saw my GP once
   - [ ] I saw my GP twice
   - [ ] I saw my GP 3 or 4 times
   - [ ] I saw my GP 5 or more times
   - [ ] Don’t know / Can’t say

2. After your GP first told you that you would need to see a hospital doctor, how long did you have to wait before your first appointment with a hospital doctor?
   - [ ] I was seen the same day or next day
   - [ ] I was seen after 2-14 days
   - [ ] I was seen in 3 to 4 weeks
   - [ ] Waited 1 to 4 months
   - [ ] Waited more than 4 months
   - [ ] I did not see my GP before going into hospital
   - [ ] I chose to have a later appointment than the one I was offered
   - [ ] Don’t know / Can’t remember

3. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?
   - [ ] I was seen as soon as I thought was necessary
   - [ ] I should have been seen a bit sooner
   - [ ] I should have been seen a lot sooner

4. How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?
   - [ ] Less than 3 months
   - [ ] 3-6 months
   - [ ] 6-12 months
   - [ ] More than 12 months
   - [ ] Don’t know / Can’t remember

5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?
   - [ ] My health got worse
   - [ ] My health got better
   - [ ] My health stayed about the same

DIAGNOSTIC TESTS

6. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?
   - [ ] Yes  ➔ Go to Q7
   - [ ] No  ➔ Go to Q11

Thinking about the LAST time you had a diagnostic test for your cancer at one of the hospitals named in the covering letter ....

7. Beforehand, did a member of staff explain the purpose of the test(s)?
   - [ ] Yes, completely
   - [ ] Yes, to some extent
   - [ ] No, but I would have liked an explanation
   - [ ] I did not need an explanation
   - [ ] Don’t know / Can’t remember
Still thinking about the LAST time you had a diagnostic test for your cancer at one of the hospitals named in the covering letter....

8. Beforehand, did a member of staff explain what would be done during the test procedure(s)?
   1. Yes, completely
   2. Yes, to some extent
   3. No, but I would have liked an explanation
   4. I did not need an explanation
   5. Don’t know / Can’t remember

9. Beforehand, were you given written information about your test(s)??
   1. Yes, and it was easy to understand
   2. Yes, but it was difficult to understand
   3. No, but I would have liked written information about the test(s)
   4. I did not need written information
   5. Don’t know / Can’t remember

10. Were the results of the test(s) explained in a way you could understand?
    1. Yes, completely
    2. Yes, to some extent
    3. No, but I would have liked an explanation
    4. I did not need an explanation
    5. Don’t know / Can’t remember

FINDING OUT WHAT WAS WRONG WITH YOU

11. Who first told you that you had cancer?
    1. A hospital doctor
    2. A hospital nurse
    3. A GP (family doctor)
    4. Another health professional
    5. A friend or relative
    6. Nobody – I worked it out for myself

12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?
    1. Yes
    2. No
    3. It was not necessary
    4. I was told by phone or letter
    5. Don’t know / Can’t remember

13. How do you feel about the way you were told you had cancer?
    1. It was done sensitively
    2. It should have been done a bit more sensitively
    3. It should have been done a lot more sensitively

14. Did you understand the explanation of what was wrong with you?
    1. Yes, I completely understood it
    2. Yes, I understood some of it
    3. No, I did not understand it
    4. Can’t remember
15. When you were told you had cancer, were you given written information about the type of cancer you had?

1. Yes, and it was easy to understand
2. Yes, but it was difficult to understand
3. No, I was not given written information about the type of cancer I had
4. I did not need written information
5. Don’t know / Can’t remember

18. Before you started your treatment, were you given written information about the side effects of treatment(s)?

1. Yes, and it was easy to understand
2. Yes, but it was difficult to understand
3. No, I was not given written information about side effects
4. Don’t know / Can’t remember

19. Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?

1. Yes, definitely
2. Yes, to some extent
3. No, but I would like to have been more involved
4. Only one type of treatment was suitable for me

DECIDING THE BEST TREATMENT FOR YOU

16. Before your cancer treatment started, were you given a choice of different types of treatment?

1. Yes
2. No, but I would have liked a choice
3. I was not given a choice because only one type of treatment was suitable for me
4. Not sure / Can’t remember

17. Were the possible side effects of treatment(s) explained in a way you could understand?

1. Yes, definitely
2. Yes, to some extent
3. No, side effects were not explained
4. I did not need an explanation
5. Not sure / Can’t remember

CLINICAL NURSE SPECIALIST

A Clinical Nurse Specialist is a specialist cancer nurse who makes sure you get the right care and gives you help and advice on coping with cancer.

20. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

1. Yes ➔ Go to Q21
2. No ➔ Go to Q25
3. Don’t know / Not sure ➔ Go to Q25

21. How easy is it for you to contact your Clinical Nurse Specialist?

1. Easy
2. Sometimes easy, sometimes difficult
3. Difficult
4. I have not tried to contact her/him
22. The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?

1. Yes, definitely
2. Yes, to some extent
3. No

23. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

1. All or most of the time
2. Some of the time
3. Rarely or never
4. I do not ask any questions

24. The last time you saw or spoke to your Clinical Nurse Specialist, do you feel that the time you spent with them was too long, too short or about right?

1. Too short
2. About right
3. Too long

26. Did hospital staff give you information about how to get financial help or benefits?

1. Yes
2. No, but I would have liked information
3. It was not necessary
4. Don't know / Can't remember

27. Did hospital staff tell you that you could get free prescriptions?

1. Yes
2. No, but I would have liked information
3. It was not necessary
4. Don't know / Can't remember

28. During the last 12 months, have you had an operation (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?

1. Yes  ➔ Go to Q29
2. No  ➔ Go to Q33

Thinking about the LAST time you went into one of the hospitals named in the covering letter for an operation for your cancer...

29. The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?

1. No
2. Yes, it was changed once
3. Yes, it was changed 2 or 3 times
4. Yes, it was changed 4 times or more
Still thinking about the LAST time you went into one of the hospitals named in the covering letter for an operation for your cancer...

30. Before you had your operation, did a member of staff explain what would be done during the operation?

1. Yes, completely
2. Yes, to some extent
3. No, but I would have liked an explanation
4. I did not need an explanation
5. Don’t know / Can’t remember

31. Beforehand, were you given written information about your operation?

1. Yes, and it was easy to understand
2. Yes, but it was difficult to understand
3. No, I was not given written information about my operation
4. Don’t know / Can’t remember

32. After the operation, did a member of staff explain how it had gone in a way you could understand?

1. Yes, completely
2. Yes, to some extent
3. No, but I would have liked an explanation
4. I did not need an explanation

HOSPITAL DOCTORS

33. During the last 12 months, have you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter?

1. Yes ➔ Go to Q34
2. No ➔ Go to Q53

Thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

34. When you had important questions to ask a doctor, how often did you get answers that you could understand?

1. All or most of the time
2. Some of the time
3. Rarely or never
4. I did not ask any questions

35. Did you have confidence and trust in the doctors treating you?

1. In all of them
2. In some of them
3. In none of them

36. Do you think the doctors treating you knew enough about how to treat your cancer?

1. Yes, definitely
2. Yes, to some extent
3. No
4. Don’t know / Not sure

37. Did doctors talk in front of you as if you weren’t there?

1. Yes, often
2. Yes, sometimes
3. No
38. If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
   □ Yes, definitely
   □ Yes, to some extent
   □ No
   □ No family or friends were involved
   □ My family did not want or need information
   □ I did not want my family or friends to talk to a doctor

42. In your opinion, were there enough nurses on duty to care for you in hospital?
   □ There were always or nearly always enough on duty
   □ There were sometimes enough on duty
   □ There were rarely or never enough on duty

WARD NURSES

Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

39. When you had important questions to ask a ward nurse, how often did you get answers you could understand?
   □ All or most of the time
   □ Some of the time
   □ Rarely or never
   □ I did not ask any questions

40. Did you have confidence and trust in the ward nurses treating you?
   □ In all of them
   □ In some of them
   □ In none of them

41. Did ward nurses talk in front of you as if you weren’t there?
   □ Yes, often
   □ Yes, sometimes
   □ No

43. While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?
   □ Often
   □ Sometimes
   □ Only once
   □ Never

44. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?
   □ Often
   □ Sometimes
   □ Only once
   □ Never

45. Were you given enough privacy when discussing your condition or treatment?
   □ Yes, always
   □ Yes, sometimes
   □ No
Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

46. Were you given enough privacy when being examined or treated?
   - [ ] Yes, always
   - [ ] Yes, sometimes
   - [ ] No

47. Do you think the hospital staff did everything they could to help control your pain?
   - [ ] All of the time
   - [ ] Some of the time
   - [ ] Not at all
   - [ ] I did not have any pain

48. Were you treated with respect and dignity by the doctors and nurses and other hospital staff?
   - [ ] Always
   - [ ] Most of the time
   - [ ] Some of the time
   - [ ] Never

50. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
   - [ ] Yes
   - [ ] No
   - [ ] Don't know / Can't remember

51. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?
   - [ ] Yes, definitely
   - [ ] Yes, to some extent
   - [ ] No
   - [ ] No family or friends were involved
   - [ ] My family or friends did not want or need information
   - [ ] I did not want my family or friends to be given information

ARRANGING HOME SUPPORT

Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

52. After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?
   - [ ] Yes, definitely
   - [ ] Yes, to some extent
   - [ ] No
   - [ ] I did not need help from health or social services
   - [ ] Don't know / Can't remember

INFORMATION GIVEN TO YOU BEFORE YOU LEFT HOSPITAL

Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

49. Were you given clear written information about what you should or should not do after leaving hospital?
   - [ ] Yes
   - [ ] No
   - [ ] Can’t remember
HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

53. During the last 12 months, have you had radiotherapy at one of the hospitals named in the covering letter?
1. □ Yes  ➔ Go to Q54
2. □ No  ➔ Go to Q55

54. Did hospital staff do everything possible to control the side effects of radiotherapy?
1. □ Yes, definitely
2. □ Yes, to some extent
3. □ No, they could have done more
4. □ I have not had any side effects from radiotherapy

55. During the last 12 months, have you had chemotherapy at one of the hospitals named in the covering letter?
1. □ Yes  ➔ Go to Q56
2. □ No  ➔ Go to Q57

56. Did hospital staff do everything possible to control the side effects of chemotherapy?
1. □ Yes, definitely
2. □ Yes, to some extent
3. □ No, they could have done more
4. □ I have not had side effects from chemotherapy

57. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?
1. □ Yes, definitely
2. □ Yes, to some extent
3. □ No, they could have done more
4. □ I did not have any pain

58. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?
1. □ Yes, definitely
2. □ Yes, to some extent
3. □ No, I would have liked more support
4. □ I did not need emotional support from staff

OUTPATIENTS APPOINTMENTS WITH DOCTORS

59. In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?
1. □ Yes  ➔ Go to Q60
2. □ No  ➔ Go to Q63

60. The last time you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?
1. □ Seen on time, or early
2. □ Waited up to 5 minutes
3. □ Waited 6 - 15 minutes
4. □ Waited 16 - 30 minutes
5. □ Waited 31 - 60 minutes
6. □ Waited 1 to 2 hours
7. □ Waited more than 2 hours
8. □ Don’t know / Can’t remember
61. The last time you had an outpatients appointment with a cancer doctor, was the time you spent with them too long, too short or about right?
1. Too short
2. About right
3. Too long

62. The last time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?
1. Yes
2. No
3. Don't know / Can't remember

65. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?
1. Yes, always
2. Yes, most of the time
3. Yes, some of the time
4. No, never
5. Don't know

66. How much information were you given about your condition and treatment?
1. Not enough
2. The right amount
3. Too much

67. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your care over the last year, did you feel like that?
1. Yes, often
2. Yes, sometimes
3. No

63. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?
1. Yes
2. No
3. Don't know / Can't remember

64. Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?
1. Yes, definitely
2. Yes, to some extent
3. No, they could have done more
4. My general practice was not involved
APPENDIX 4: ADDITIONAL QUESTIONS SHEET
ADDITIONAL QUESTIONS

1. In the past 6 months, if you had pain, was it usually severe, moderate, or mild?

- [ ] Severe
- [ ] Moderate
- [ ] Mild
- [ ] Didn’t have pain in the past 6 months

2. Do you think the staff did everything they could to control your pain or discomfort?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Didn’t have pain

3. Did you get enough information about possible changes in your physical appearance?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

4. Did you get enough information about possible changes in your emotions?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

5. Did you get enough information about your nutritional needs?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

6. Did you get enough information about possible impact on your capacity to work or do activities?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

7. Did you get enough information about possible changes in your energy level?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

8. Were you offered counselling or support relating to issues such as concerns about cancer or coping?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

9. Did you get enough information about possible changes in your relationship with your partner?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply

10. Did you get enough information about possible changes in your sexual activity?

- [ ] Never
- [ ] Sometimes
- [ ] Usually
- [ ] Always
- [ ] Doesn’t apply
11. Did you want but NOT receive information about any of the following services?

- Counselling
- Spiritual support
- Dietician
- Speech therapist
- Occupational therapist
- Physical therapist
- Support groups
- Palliative care
- Dental practitioner
- Cancer helpline
- Other

12. Did you feel comfortable talking with staff about complementary or alternative therapies?

- Never
- Sometimes
- Usually
- Always
- Doesn’t apply

13. Have you been using complementary or alternative therapies for cancer over the last 6 months?

- Yes
- No
- Not sure

14. Did you use any traditional treatment or remedies for your cancer not prescribed by your doctor?

- Yes
- No
- Not sure