Understanding care experiences of people with cancer

Findings from pilot study 2

Technical paper

Health
and Human
Services

To receive this publication in an accessible format phone 9096 2136, using the National Relay Service 13 36 77 if required, or email **cancerplanning@dhhs.vic.gov.au**

Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne.

Where the term ‘Aboriginal’ is used it refers to both Aboriginal and Torres Strait Islander people. Indigenous is retained when it is part of the title of a report, program or quotation.

Available at **www.health.vic.gov.au/cancer**

1. Acknowledgments

The research team at the Centre for Behavioural Research in Cancer, Cancer Council Victoria would like to acknowledge the advice and cooperation of the following people and organisations in this study:

Advisory Committee members:

- Ms Mary Anne Silvers (Chair)
- Ms Melissa Shand
- Ms Anne Kay
- Ms Katherine Fox
- Ms Melinda Williams
- Ms Cathy Fraser.

Cancer Strategy and Development, Department of Health and Human Services, Victoria:

- Ms Spiri Galetakis, Program Manager, Integrated Cancer Services
- Ms Kathryn Whitfield, Assistant Director, Cancer Strategy and Development
- Professor Robert Thomas, Chief Cancer Advisor.

Thanks to those people and organisations who made the survey possible:

- all patients taking the time to complete the survey
- staff of participating hospitals for assisting in the survey's conduct
- Ms Sorayia Noorani for research assistant work on the project.

Prepared by: Victoria White and Susana Huang, Centre for Behavioural Research in Cancer, Cancer Council Victoria

Prepared for and funded by: Cancer Strategy and Development, Victorian Department of Health and Human Services

Contents

Tables

Main messages

This report presents findings from a second pilot study of a patient experience survey. A total of 1160 patients (57% response rate) treated for cancer at six health services (three metropolitan and three regional) completed a self-administered survey assessing their cancer care experiences. Patients were recruited through the patient lists at two health services (one metropolitan and one regional) and through a central database of all Victorian hospital admitted episodes of care at four health services. One regional health service that delivered chemotherapy used a module version of the survey that collected information only on patient characteristics and chemotherapy experiences. Sixty-eight per cent of respondents were aged 60 years or over, 45 per cent were male and 42 per cent had been diagnosed 12 or fewer months earlier. Approximately 81 per cent of respondents described their health at the time of the survey as good to excellent.

1.1. Findings regarding care experiences

Excluding the health service using only the chemotherapy module from the survey, 48 per cent of respondents had all of their treatment at the health service they were recruited through. Common treatments were surgery (71%), chemotherapy (60%) and radiotherapy (60%). Two per cent of patients did not have any treatment.

Comparison of results from pilot study 2 and the initial pilot study conducted in 2013 found that Victorian cancer patients' care experiences were similar over the two study periods.

Overall, the findings show that:

- the majority of patients were very satisfied with their care for surgery (77%), radiotherapy (88%) and chemotherapy (84%)
- the vast majority of patients indicated they were always treated with respect and dignity during their surgical (90%), radiotherapy (98%) and chemotherapy (98%) care.

> *'…the care I have received at the [hospital] relating to my problem, has been exceptional. Every person I have dealt with has been positively professional and very caring.' (colorectal cancer patient, metropolitan hospital)*

Restricting results to patients receiving all of their treatment at one of the pilot study health services provides further insight into patients' care experiences:

- Sixty-seven per cent of patients rated the way their doctors and other health professionals worked together as excellent, with an additional 25 per cent rating this as very good.

  > *'There was nothing I could possibly complain about. All appointments were full of the information that I required regarding the journey ahead. All medical staff were comforting and caring and I never felt alone or scared about what was going to happen to me. They would have to be the most uplifting people you could deal with in such circumstances.' (breast cancer patient, metropolitan hospital)*

- Information provision was reported as very good:
  - Over 75 per cent of patients indicated that that they received information about different treatments including possible side effects and how to manage these.
  - The majority of patients reported active discussion of the information provided and felt they could ask questions of those providing their care.

  - More than 65 per cent of patients reported being informed about follow-up tests needed, frequency of tests or check-ups, how to stay healthy and how to manage any side effects or symptoms at the end of treatment.

- The majority of patients reported commencing radiation treatment (87%) and chemotherapy (83%) within four weeks of being ready to start. Of patients having surgery, 73 per cent had surgery within four weeks of being ready.
- On treatment days, 66 per cent of those having radiation treatment reported waiting less than 15 minutes at their appointments, while 46 per cent of chemotherapy patients were seen within this timeframe.

The pilot study results also highlight a number of opportunities for improvements in care and service delivery across health services, including in the following domains:

- Surgical care and emergency department care
  - 19 per cent of patients experiencing side effects after surgery did not think these were managed well.
  - Approximately 43 per cent of those needing assistance in hospital reported instances when staff did not respond within a reasonable time.
  - 17 per cent rated arrangements for services at home as inadequate to their needs.
  - 35 per cent of patients had attended an emergency department for care since their cancer diagnosis (including 15% attending more than once). Of these patients, 16 per cent thought their condition was not well managed, and 18 per cent did not feel confident that emergency department staff had the skills needed to care for them.

  'I was not ready to come home so soon after surgery, I felt very weak. I suffered terrible constipation after operation (b/c of pain killers). I wish I had been warned of this and given something to treat it.' (thyroid cancer patient, metropolitan hospital)

  'Pain meds were not managed properly, they were understaffed – it was a disgrace, I could not wait to get out of that ward.'(brain cancer patient, metropolitan hospital)

- Communication and supportive care
  - 19 per cent of patients indicated they had received conflicting information from health professionals at least once.
  - 14 per cent felt that on at least one occasion hospital staff were not fully informed about their care.
  - More patients reported receiving information about short-term (78%) rather than long-term (60%) side effects.
  - Just over 40 per cent of patients who thought that fertility preservation was relevant to them did not receive information on this.
  - 16 per cent of patients experiencing pain while in hospital for cancer treatment thought that staff did not do everything possible to help manage this pain.
  - While over 50 per cent of patients did not need health professionals' help or assistance in managing their medical and recovery issues, 13 per cent would have liked help finding support groups, and 11 per cent would have liked a help accessing financial support programs.
  - The 43 per cent of patients reporting they had access to a clinical nurse specialist, and the 30 per cent indicating they had access to a healthcare team member, had more positive experiences in relation to information provision, coping, help with issues like travel and follow-up scheduling than the 27 per cent of patients with no named health professional contact.

  - 35 per cent of patients indicated that a member of the healthcare team discussed with them the possibility of taking part in clinical trials, and 21 per cent of patients indicated that this discussion did not take place but they would have liked it to.

> *‘I would have frozen my eggs. I wanted to have a child.’ (lymphoma patient, metropolitan hospital)*

1.2. Findings regarding survey methodology

This pilot study included an embedded randomised trial which examined the impact of the survey request coming from the patients’ treating hospital or the Victorian Department of Health and Human Services on survey responses. The randomised trial found:

- The letterhead on the invitation letter did not influence response rates to the survey request. An overall response rate of 57 per cent was achieved in both conditions.
- The letterhead on the invitation letter did not influence patients’ responses to survey items.

The response rate achieved for the second pilot study (57%) was higher than that achieved in the first pilot study (45%). Using two reminders and not conducting the study over summer is likely to have improved the response rate for pilot study 2.

At two health services, treatment specific patient lists were used to identify patients for the survey. Comparing the profile of patients responding to the survey from these two health services to that found for participants from the other health services shows that:

- Recruiting patients through treatment specific patient lists can alter the profile of patients completing the survey in terms of both the type of cancers patients have and where patients have other treatments.

One regional health service used a modular version of the survey that collected only information about chemotherapy treatment and patient characteristics. Findings suggest that:

- using a modular version of the survey may improve response rates slightly but not significantly so
- responses to questions in the module version of the survey are similar to those in the larger survey.

This pilot survey was undertaken as part of a project to develop a valid and appropriate survey tool and method to capture data on cancer patients’ experience of care. The project confirms that the method is feasible. Survey results for individual health services participating in the pilot study will be provided to them to inform local service improvement activities.

2. Executive summary

The Cancer Strategy and Development section of the Victorian Department of Health and Human Services commissioned a series of studies to develop and pilot test a survey and methodology to assess Victorian cancer patients' experiences of medical care.

This report describes findings from a second pilot study (pilot study 2) which incorporated methodology and survey changes recommended from findings of pilot study 1. It details findings from an embedded randomised trial to examine the influence of the organisation sending out the survey on survey responses; differences in the profile of patients recruited into the study through treatment specific patient lists or through a hospital-wide data base of inpatient episodes of care; as well as providing information on the care experiences of patients completing the survey.

2.1. Method

Six health services participated in the pilot study. Three were located in metropolitan Melbourne and three in regional Victoria. All health services ran chemotherapy units and radiotherapy centres were located at three (two metropolitan and one regional) services.

Patients eligible for the survey had attended one of health services as an inpatient or outpatient for treatment associated with cancer within the previous 20 months. Two pathways for identifying eligible patients were adopted. Following procedures used in pilot study 1, the Victorian Admitted Episodes Database (VAED) was utilised to identify eligible patients from four health services, with the list of selected patients returned to health service staff who arranged for the survey to be mailed to selected patients. At two health services (one metropolitan and one regional), patients were identified from the patient database associated with a specific treatment centre, and staff at that centre conducted the mailout. Health services using this second procedure were a large metropolitan radiotherapy centre and a regional chemotherapy centre.

To examine the impact of using the health service to invite patients to complete the survey on their responses, at each health service patients were randomly assigned to one of two conditions: condition 1): survey invitation from the health service, or condition 2): survey invitation from the Victorian Department of Health and Human Services.

A total of 2045 surveys were mailed to patients, and 1160 completed surveys were returned, with an overall response rate of 57 per cent achieved. This response rate was higher than the response rate achieved in pilot study 1 (45%).

2.2. Key findings

2.2.1. Influence of approach organisation on survey responses

The overall response rate did not differ between the two conditions, with a response rate of 57 per cent achieved in both. In general, there was little difference in the response rates achieved in the two conditions within the individual health services. Additionally, the distribution of responses on individual survey questions did not differ between the two conditions.

2.2.2. Impact of recruiting patients through centre patient lists on patient profile

Compared to the profile of patients recruited from health services using the VAED, patients recruited from health services using a treatment-specific patient list were more likely to have breast or prostate cancer.

2.2.3. Overall care pathways

Most patients (98%) had treatment, with 42 per cent treated by only one treatment modality, 37 per cent treated by two, and 20 per cent treated by three modalities. The majority of patients had surgery (71%), chemotherapy (70%) and radiotherapy (60%).

2.2.4. Diagnosis and treatment planning

Similar to findings from pilot study 1, most commonly patients were told their diagnosis by a surgeon (35%) followed by their GP (19%). Patients were more likely to receive information about short-term (78%) than long-term (60%) side effects of treatment.

2.2.5. Surgical care

Seventy-one per cent of patients had surgery and 56 per cent had surgery at a pilot study health service. Most patients having surgery received enough information about what would happen after surgery (80%), and potential side effects from surgery (76%).

Nineteen per cent of patients experiencing side effects after surgery did not think their side effects were well managed. Of patients needing assistance while in hospital, 43 per cent thought there were instances when staff did not respond to their need for help within a reasonable time.

Seventeen per cent of patients believing they needed services after discharge reported that arrangements regarding services were not adequate.

2.2.6. Radiotherapy

Three health services participating in the study delivered radiotherapy (two metropolitan and one regional). Most patients were very positive about their radiotherapy care.

Eighty-seven per cent of patients having radiotherapy at a pilot study health service had this treatment within four weeks of being ready for it. Sixty-six per cent of patients treated at a pilot study health service, generally had treatment within 15 minutes of their appointment time.

Nearly all patients received information regarding how to prepare for treatment (91%), what would happen during treatment (94%) and how to manage any side effects from treatment (87%). Most patients (89%) indicated that health professionals regularly checked if they had any side effects from treatment.

Car parking caused the most dissatisfaction, with only 31 per cent of patients indicating they were very satisfied with car parking facilities at their health service.

2.2.7. Chemotherapy

Chemotherapy was delivered at all participating health services. Seventy-eight per cent of patients having chemotherapy had this treatment at a pilot study health service.

Among patients having chemotherapy at a pilot study health service, 57 per cent waited less than two weeks to commence treatment.

Information provision regarding chemotherapy was excellent. Nearly all patients received enough information about how treatment would be given (95%) and how long treatment would last (94%). Additionally, 93 per cent received enough information about the possibility of going to an emergency department.

There were areas for improvement, with 16 per cent not receiving or wanting more information about how they would feel at the end of their chemotherapy, 10 per cent not receiving or wanting more information about side effects they might experience and 11 per cent not receiving or wanting more information about how to manage side effects at home.

Only 38 per cent of respondents who needed car parking were very satisfied with facilities.

2.2.8. Emergency department experiences

Among all patients, 35 per cent had attended an emergency department since their cancer diagnosis, with 15 per cent attending an emergency department more than once. Sixty-seven per cent of patients were admitted to hospital as a result of their emergency department consultation.

Sixteen per cent of patients did not think their condition was well managed while in the emergency department, and 18 per cent were not confident that all or most of the staff at had the skills needed to look after them.

2.2.9. Follow-up care

While between 66 per cent and 78 per cent of patients received information about follow-up tests needed, the frequency of tests or check-ups and how to stay healthy, between 46 per cent and 54 per cent received information about how patients might feel after treatment, how to get extra support and which new symptoms might need investigation.

For patients where this was relevant, 22 per cent did not think their appointment scheduling took into account their travel times or other commitments. In addition, 16 per cent did not think their appointments and tests were coordinated.

2.2.10. Overall care

Most patients reported that health professionals involved in their care worked well together (93% rated this as very good/excellent), and that results of tests were available when needed (88%). The most commonly reported negative communication events concerned receiving conflicting information from health professionals (19%) and health professionals not being fully informed about patients' treatment or progress (14%).

2.2.11. Information provision

The majority of patients indicated they did not need health professionals' help or assistance in managing their medical and recovery issues. Issues the most people wanted assistance with were: finding support groups (13%); access to a psychologist (11%); information about the Cancer Helpline (12%); and accessing financial support programs (11%).

2.2.12. Impact of a health professional contact

Among patients having all their treatment at pilot study health services, 76 per cent indicated there was a health professional they could contact for help or advice throughout their treatment. This did not differ between health services. Forty-three per cent of patients treated at pilot study health services were given the name of a clinical nurse specialist who was in charge of their care, which was related to the health service attended. Patients reporting that they had a health professional contact (either clinical nurse specialist or healthcare team member) were more likely to receive information about allied health services and supportive care services and were more likely to be satisfied with their surgical and radiotherapy care than patients not having this contact person.

2.2.13. Experience of patients having surgical care in the private and public systems

Using data from pilot study 1 and pilot study 2, the experiences of patients having surgery in the public and private health systems were examined. While in general, a greater proportion of patients treated in the private system reported being very satisfied with the care they received, the only statistically significant difference related to perceptions of health professionals working together, with a greater proportion of patients treated in the private system rating this as excellent compared to patients in the public system ($p < 0.05$). Provision of information about the surgery was generally similar in the two systems, although slightly more private patients reported receiving this information than public patients.

2.2.14. Satisfaction with treatment

The majority of patients were very satisfied with their care for surgery (77%), radiotherapy (88%) and chemotherapy (84%). The vast majority of patients indicated they were always treated with respect and dignity during their surgical (90%), radiotherapy (98%) and chemotherapy (98%) care.

2.2.15. Comparison of care experiences between pilot study 1 and pilot study 2

Pilot study 1 in this program of work was conducted in 2012–13, and assessed the care experiences of patients attending one metropolitan health service and two regional health services. While findings from the two studies were generally very similar, there were some differences. With regards to surgery, fewer patients in pilot study 2 reported that arrangements for services they needed after surgery, were made (62%), compared with pilot study 1 (80%). In the area of radiotherapy, a greater proportion of patients in pilot study 2 reported that health professionals checked if they needed help or assistance with diet or physical movement (82%) than in pilot study 1 (72%). Fewer patients in pilot study 2 were very satisfied with car parking facilities at their radiotherapy centre (31%) than patients in pilot study 1 (47%). There were few differences in chemotherapy, emergency department, follow-up and overall care between pilot study 1 and pilot study 2.

3. Recommendations

The initial pilot study demonstrated that people receiving cancer treatment and care in Victorian public hospitals are willing to complete a survey regarding their care experiences. This second pilot study has highlighted several methodological issues that need to be considered in future studies of patients, as well as several issues relating to the survey tool. In addition, findings from the pilot survey regarding patient care experiences have also suggested some areas of care that health services may learn from.

3.1. Survey methodology and survey tool recommendations

3.1.1. Conduct of survey

Recommendation 1: Conduct the study in a time period that does not include major holiday periods (for example, Christmas/Easter, major school holidays). The response rate achieved for pilot study 2 was higher than that achieved for pilot study 1. Unlike pilot study 1, pilot study 2 was not conducted over the Christmas / summer holiday period. Findings from pilot study 2 confirm the recommendation that future studies should be conducted outside major holiday periods.

Recommendation 2: Two reminders should be included in the planned approach to potential survey respondents. As recommended in pilot study 1, two reminders were used for the conduct of the study. Including the second reminder to respondents increased the gross return rate for the study by 12 per cent. Future studies should include two reminder mailouts. Following the strategy used for this study, the reminder system could involve a first reminder consisting of only a letter sent to patients approximately 2 weeks after the first approach, with the second reminder involving a letter and survey sent approximately 4-5 weeks after the first mailout. Approach letters need to inform patients that reminders will be sent if no response is received.

Recommendation 3: Patients' vital status needs to be confirmed before the first approach and also prior to the second reminder.

Recommendation 4: Pilot study 2 examined the impact of the survey invitation coming from patients' health service or the Victorian Department of Health and Human Services (DHHS). The study found no difference in overall response rates between the two invitation letter conditions. While at three health services the hospital approach produced slightly higher response rates, at two health services the department letter produced a higher response. There was no difference in responses to survey items between the two conditions. Findings suggest that future studies could use either the department letterhead or the health service's letterhead to invite patients into the study.

Recommendation 5: Identify a strategy to ensure patients who attend multiple health services are approached only once for the survey. Pilot study 2 used the VAED to identify eligible patients for the survey from four health services. A number of patients completing the survey indicated they attended two of health services participating in the pilot study for their cancer care. Identifying a strategy that could avoid approaching these patients twice would be appropriate. A possible strategy would be to use a linked data set between the VAED and the Victorian Cancer Registry (VCR). This linked data set would enable patients to be uniquely identified and approached only once about completing the survey.

Recommendation 6: If a VAED-VCR linked data set can be used to identify patients, explore the possibility of using the VCR to conduct the mailout to patients. If the department is used as the organisation inviting patients to complete the survey, the need for health service participation in the mailout may be reduced. If a linked VAED-VCR data set is used to identify patients for the study, it may be possible to use patient contact information from the VCR for the mailout. Because the VCR has access to the death register, using the VCR may aid in undertaking death checks before surveys are mailed out.

Recommendation 7: Using treatment specific (for example, chemotherapy, radiotherapy) patient lists to identify patients for the survey is possible, and results in a larger number of patients reporting on their care experiences for these treatment modalities. However, the profile of patients attending treatment specific centres may differ from the profile of cancer patients in general. In addition, many of the patients attending these centres may have their other cancer treatments at other health services, including private hospitals. Thus, using treatment-specific patient lists may not provide an adequate avenue for assessing the care experiences of patients having other cancer treatments at that health service. If treatment specific patient lists are used to identify patients for the survey, explore the utility of using only a modular version of the survey tool.

Recommendation 8: A treatment-specific module version of the survey can be used and may result in a slightly higher response rate. However, using only a specific treatment module means information on the patient’s treatment paths or follow-up will not be captured.

Recommendation 9: To ensure sufficient numbers of patients report on treatment experiences at the index health service, pilot study 2 increased the number of patients identified at each hospital for the survey. This resulted in larger number of patients having specific treatments at each health service. However, it also necessitated approaching patients who were diagnosed 20 months previously. To assess chemotherapy and radiotherapy care, it may be more appropriate to use treatment-specific patient lists to identify patients and use survey modules.

3.1.2. Survey tool

Recommendation 10: For 13 items, 90 per cent or more respondents gave the same response. Review these items and determine whether they can be removed from the survey.

Recommendation 11: Turning treatment sections of the survey into stand-alone modules is possible. Develop a suite of survey modules allowing health services to select the modules they want to use.

Recommendation 12: Develop an online manual on how to administer the survey with guidelines for individual modules. Explore the possibility of providing statewide norms for item responses allowing health services to benchmark against these norms. In future iterations on the manual and survey, explore the possibility of providing hospital peer group norms for comparison (for example, Category A hospitals).

3.1.3. Future surveys

Recommendation 13: Benchmarking hospitals against their own results will provide information regarding care improvements. It is recommended to repeat the survey at regular intervals, which may relate to the development cycles of the cancer action plan (every four years). Because there was little change in survey responses between pilot study 1 (2012–13) and pilot study 2 (2015), an appropriate survey frequency should be determined.

Recommendation 14: Pilot study 2 included several metropolitan and regional health services of a similar category (for example, Category A), allowing appropriate comparisons of results between health services**.** In conducting future studies, include several hospitals within the same category (for example, Category A) to enable appropriate comparisons between health services.

Recommendation 15: Pilot study 2 was conducted in English and required patients to be able to read and write English. There is still a need to test the survey with people from a non-English speaking background. Translate survey into several languages commonly spoken in Victoria and test the survey with these groups. Include use of translated surveys in next iteration of the survey. Use data from the VAED to identify the key languages of cancer patients in Victoria to assist with identifying appropriate languages for translation.

3.2. Patient care experiences

Findings from pilot study 2 were similar to those of pilot study 1. Therefore, recommendations from pilot study 1 are still relevant, and include:

3.2.1. Diagnosis and treatment planning

Recommendation 1: Provide GPs with resources and skills regarding delivering cancer diagnosis information to patients.

3.2.2. Side effect management/management in emergency departments

Recommendation 2: Investigate the side effects patients thought were not managed well in different care areas (for example, surgery, radiotherapy) and develop strategies to address these.

Recommendation 3: Provide emergency department staff with greater information regarding the management of cancer patients attending emergency department.

3.2.3. Information provision

Recommendation 4: Ensure there is a member of the patient's healthcare team that can act as a contact person for the patient. Provide the patient with the contact details of this healthcare team member and ensure patients are aware they can contact them if they have any questions or need any information.

Recommendation 5: Investigate ways to provide patients with more information about side effects of treatment and management of side effects.

Recommendation 6: Investigate ways of ensuring patients receive information about supportive care programs and financial programs.

Recommendation 7: Investigate ways to ensure that patients who are concerned about their fertility are provided with information about fertility preservation and the possible impact of treatment on fertility.

3.2.4. Car parking

Recommendation 8: Ensure patients are informed about car parking arrangements they can access when receiving chemotherapy and radiotherapy treatments.

4. Background

This study forms part of a series of studies to develop and pilot test a survey tool to assess consumers' experiences of their cancer care which were commissioned by the Cancer Strategy and Development section of the Victorian Department of Health and Human Services. The study follows on from work undertaken to develop a survey tool[1] and an initial pilot study (pilot study 1) to test the survey method and survey tool.

Pilot study 1 surveyed patients attending three public health services that delivered all cancer treatment modalities. As well as providing information on the care experiences of Victorian cancer patients, the study aimed to examine the usefulness of the survey tool and assess the feasibility of the method used to approach patients about completing the survey. The findings from pilot study 1 led to several recommendations regarding the study's methodology and survey items.

Recommendations for the study's methodology were: 1) include two reminders in the approach; 2) not conducting the survey over the summer holiday period; and 3) examining whether sending the invitation letter from the patient's treating health service influenced response rates to the survey and survey responses.

Recommendations for the survey items included: 1) revising items that may have been misunderstood by patients; 2) removing items endorsed by over 90 per cent of respondents and assessing the location of follow-up care; 3) removing the section on hormonal treatments; and 4) including items assessing supportive care in all treatment sections.

In addition, it was recommended to turn the treatment sections of the survey into stand-alone modules that may be used by health services or others to assess these care areas.

In response, a second pilot study was conducted to test the revised questionnaire and to examine whether response rates and item responses are influenced by the organisation sending out the survey. Pilot study 2 also examined the usefulness of using a module of the survey to assess experiences of care for patients receiving chemotherapy. Additionally, the study examined the impact on the profile of patients completing the survey if patients were identified using the patient list of specific treatment centres or if they were identified using the Victorian Admitted Episodes Database (VAED) – a database recording all admitted episodes of care at all Victorian hospitals. This report details findings from pilot study 2.

4.1. Health services in the second pilot study

Six public health services participated in the study. Three health services were located in metropolitan Melbourne and three were in regional Victoria. All health services ran chemotherapy units, and radiotherapy centres were located at three (two metropolitan and one regional) health services. One metropolitan health service delivered cancer care at two campuses.

Public hospitals in Victoria are grouped into four types (tertiary, major, other metropolitan and regional) and eight categories (A1, A2, B, C, D, E, M and Z) based on their size, location and the services offered.

Of the three metropolitan health services participating in this study, two were classified as Tertiary Category A1 hospitals (referred to as MH1-A1; MH2-A1), with the other classified as Major Category

---

[1] http://docs.health.vic.gov.au/docs/doc/B48B2C77A3CA4216CA25797B007F1D2E/$FILE/literature_review.pdf and http://docs.health.vic.gov.au/docs/doc/9D1B7577228A1DEECA257996007D1B92/$FILE/FINAL%20Focus%20groups%20report%2030.1.2012.pdf

A2 (MH3-A2). Health service MH2-A1 is spread across several campuses. Both the chemotherapy day unit and radiotherapy unit are located at one campus. This campus is classified as ‘other metro’ Category B (referred to as MH2-OMB). Surgery can be delivered at two campuses, including at MH2-OMB. The other campus delivering cancer surgery is classified as ‘tertiary’ Category A1 (referred to as MH2-TA1). For this health service, when experiences of surgery are compared across each participating health services, experiences of patients attending each campus (MH2-TA1 and MH2-OMB) are reported. For this health service, inpatient chemotherapy is delivered at the MH2-TA1. For reporting ease, these patients are included with MH2-OMB chemotherapy patients. When data from all patients recruited through MH2-A1 are reported, the health service is referred to as MH2-A1.

Two of the three regional health services were Regional Category B hospitals (RH1-B, RH2-B), with the third health service classified as Sub-Regional Category B (RH3-SB).

The different category of health services participating in the study means caution needs to be taken when comparing experiences of care between health services. However, because there are a number of different behaviours and services that should occur regardless of where a patient is treated (for example, being treated with respect and dignity, provision of information about treatment and possible side effects), some comparisons may be appropriate. In this report we present data on the care experiences of patients treated by surgery, radiotherapy and chemotherapy at the pilot study health services for those items that should occur regardless of where the treatment occurred.

5. Method

5.1. Patients selected to take part

Patients eligible for the survey had attended one of the health services as either an inpatient or outpatient for treatment associated with cancer within the previous 20 months.

Two pathways for identifying eligible patients were adopted. Following the procedures used in the first pilot study, the VAED was utilised to identify eligible patients from four health services (MH2-A1, MH3-A2, RH1-B and RH2-B). The VAED contains information about every admitted episode of care in a public hospital in Victoria. The inclusion criteria for the survey were:

- diagnosis of invasive cancer with an ICD code C00 to C96 (exclude C44, C76, C77, C78, C79, C80) or in situ breast cancer (ICD code D05)
- aged 18 and over
- treated for cancer at one of the participating health services
- a cancer episode of care at participating health service between I July 2013 and 3 March 2015
- English speaking.

Staff at the Department of Health and Human Services undertook sampling of patients. The selected patient lists were supplied to the appropriate health service and patient contact details (name and address) were merged with the sample list using hospital identifiers.

Staff at the participating health services conducted a death check using hospital data to remove any patients known to have died.

At one metropolitan health service (MH1-A1) and one regional service (RH3-SB), the patient list associated with receiving a specific cancer treatment was used to identify eligible patients. At MH1-A1, the specific cancer treatment was radiotherapy, while at RH2-SB the cancer treatment was chemotherapy. While patients attending the radiotherapy centre were mailed the complete survey, the survey used at the chemotherapy centre focused only on the experience of chemotherapy.

5.2. Survey approach

Surveys were posted to the selected cancer patients from each participating health service. Two reminders were sent to non-responders. A reply-paid envelope was included for return of surveys to an organisation separate from the health service (Cancer Council Victoria). Patients were supplied with the contact numbers of staff at the health service, the department, and Cancer Council Victoria (CCV), if they had any questions or concerns about the survey.

5.2.1. Impact of approach organisation on survey response

To examine the impact of the health service sending the survey request on response rates and survey responses, a randomised two-arm trial was embedded into the study. As part of the trial, patients were randomly assigned to one of two conditions: Condition 1) survey request from the health service; or Condition 2) survey request from the Victorian Department of Health and Human Services. In Condition 1, the invitation letter was printed on the letterhead of the health service the patient attended with the department's logo included on the letter's bottom right-hand side. The invitation letter was signed by a representative from the cancer services department of the health service and the Chief Cancer Advisor for Victoria. In Condition 2, the invitation letter was from the department, with the letter placed on the department's letterhead with the Chief Cancer Advisor the sole signatory. The letter's text, and the number of reminders sent, was the same in both conditions.

5.3. Overall response rate

A total of 2045 surveys were mailed to patients attending the six participating health services, and 1160 completed questionnaires were returned, giving a response rate of 57 per cent. One hundred and sixty blank questionnaires were returned. Thirty-six patients contacted the CCV to inform them that they would not complete the survey. In addition, 28 patients were identified as having died after the survey was initially sent and family members of 14 patients contacted the CCV to inform them that the patient had died. Another 15 people contacted the CCV to indicate that they did not have cancer. After excluding patients who had died or did not have cancer from the survey numbers, the response rate increased to 58 per cent.

5.4. Impact of letterhead on response rate

Table 1 shows the overall response rate and response rate at each health service for the two letterhead conditions.

Table 1 Response rates for each letterhead condition by study site

Condition	Total number	MH1-A1	MH2-A1	MH3-A2	RH1-B	RH2-B	RH3-SB	Total
Condition 1: Health service letterhead	Total number of surveys sent out	260	308	135	165	100	56	1024
	Total number completed returned	151	177	64	91	63	37	583
	Response rate: completed returns	58.1%	57.5%	47.4%	55.2%	63.0%	66.1%	56.9%
Condition 2: Victorian Department of Health and Human Services letterhead	Total number of surveys sent out	259	305	135	165	102	55	1021
	Total number completed returned	155	155	75	97	60	35	577
	Response rate: completed returns	59.8%	50.8%	55.6%	58.8%	58.8%	63.6%	56.5%

The overall response rate did not differ between the two conditions. Within the individual health services, there was generally little difference in response rates between the two conditions. The largest difference (9%) was found at MH3-A2, where a 56 per cent response rate was found when the invitation was from the department compared to a 47 per cent response rate when the invitation letter was from the health service. However, this difference was not statistically significant at $p < 0.05$ (difference 10% 95% CI: -2% to 22%). In both conditions there was a slightly higher response rate at the site using the shorter survey (Condition 1: 66%; Condition 2: 64%). While this may suggest that a shorter survey could increase response rates, it is noted that the response rate at another regional site that used a longer survey was only three per cent lower.

The distribution of responses on individual items between the two conditions was compared using chi-squared tests. In the main there was little difference in the distribution of responses, with the vast majority of comparisons showing no significant difference. Indeed, the distribution of responses differed significantly for only four items. However, because responses on over 100 items were compared, it is expected that a small number of items would differ by chance.

5.5. Who responded to the survey?

Ninety-one per cent of surveys were completed by patients (n = 936). When someone other than the patient completed the survey, they were asked to respond to the survey in light of the patient's experiences. All responses to the survey are included in this report, and for convenience all participants are referred to as patients.

The tables below describe characteristics of patients responding to the full survey including sex (Table 2), age (Table 3), cancer type (Table 4), time since diagnosis (Table 5) and self-reported general health (Table 6). To examine whether the profile of patients recruited through treatment-specific patient lists differed from those identified through the VAED, demographic information is presented for patients recruited through site-specific patient lists.

Table 2 Sex distribution for all patients, and those recruited through treatment-specific patient lists and the VAED

Gender	Total (n = 1127) %	MH1-A1 (n = 300) %	RH3-SB (n = 67) %	VAED health services (n = 760) %
Males	45.4	45.3	35.8	46.3
Females	54.6	54.7	64.2	53.7

Table 3 Age distribution for all respondents, and those recruited through treatment-specific patient lists and the VAED

Age	Total (n = 1122) %	MH1-A1 (n = 300) %	RH3-SB (n = 67) %	VAED health services (n = 755) %
< 49 years	12.0	16.3	10.4	10.5
50–59 years	19.5	16.0	19.4	20.9
60–69 years	33.6	37.3	29.9	32.5
70–79 years	25.3	23.3	32.8	25.4
80–90 years	9.5	7.0	7.5	10.7

The age and sex profile of patients identified through the VAED or treatment-specific patient lists were fairly similar, although slightly more females than males completed the survey at RH3-SB.

Table 4 shows that overall 25 per cent of respondents had breast cancer. Because breast cancer accounts for 14 per cent of all new cancers diagnosed in Victoria (Victorian Cancer Registry 2015), breast cancer is over-represented in the study sample. A greater proportion of patients at MH1-A1 had breast and prostate cancer. Recruiting through the patient list of the radiotherapy clinic is likely to have increased the number of prostate and breast cancer patients in the study.

Table 4 Type of cancers for all respondents, those recruited through treatment-specific patient lists and the VAED

Main cancer types	Total (n = 1074) %	MH1-A1 (n = 293) %	RH3-SB (n = 59) %	VAED health services (n = 722) %
Breast	25.4	36.5	35.6	20.9
Lymphomas	15.2	4.1	10.2	17.7
Bowel	8.0	7.8	11.9	8.0
Prostate	7.2	17.1	11.9	3.2
Multiple myeloma	6.4	1.7	5.1	8.3
Lung cancer/ mesothelioma	5.9	3.8	7.3	7.1
Bladder	4.8	0.0	3.4	6.8
Brain cancer/CNS	4.2	8.5	0.0	2.5
Throat/mouth/trachea	3.7	8.5	0.0	0.0
Leukaemia	3.4	4.8	3.4	3.4
Uterus/ovarian	2.9	0.0	1.7	4.0
Kidney	2.5	0.3	1.7	3.3
Thyroid	1.7	0.0	0.0	2.4
Stomach	1.4	0.7	0.0	1.7
Oesophageal	0.8	0.7	0.0	0.8
Skin	0.5	0.7	0.0	0.4
Other cancers	6.6	4.4	8.5	6.3

Table 5 Time since diagnosis for all respondents and those recruited through treatment-specific patient lists and the VAED

Time since diagnosis	Total (n = 1117) %	MH1-A1 (n = 296) %	RH3-SB (n = 70) %	VAED health services (n = 751) %
Within previous 12 months	42	42	31	44
12 to 24 months ago	39	50	34	35
More than 24 months ago	19	8	34	22

Table 6 Self-reported ratings of current health for all respondents, and those recruited through treatment-specific patient lists and the VAED

Self-reported rating	Total (n = 1108) %	MH1-A1(n = 295) %	RH3-SB (n = 67) %	VAED health services (n = 746) %
Excellent	14	22	13	11
Very good	33	38	28	31
Good	34	26	33	37
Fair	16	10	18	18
Poor	4	3	8	4

As Table 5 shows, 42 per cent of all patients were diagnosed within the 12 months prior to undertaking the survey, while 19 per cent were diagnosed more than two years previously. Patients recruited through RH3-SB were less likely to be diagnosed within the previous two years.

The majority of participants rated their health as very good (33%) or good (34%) (Table 6). A greater proportion of participants recruited through MH1-A1 rated their health as excellent or very good than compared to patients recruited through the VAED or RH3-SB.

5.6. Reporting of results

Within the body of this report results are presented in several ways. For questions assessing the process of diagnosis and treatment planning, data are reported for all participants surveyed combined.

While generally, for questions assessing specific treatment modalities (surgery, chemotherapy and radiotherapy) responses are combined across health services, for some questions the responses of patients treated at each health service are shown separately. As indicated above for patients attending MH2-A1, cancer treatment can be delivered at two campuses. When presenting results for surgery, patients from this health service are grouped according to the campus where they had their surgery and responses for both campuses are shown. Responses for patients from MH2-A1 having radiotherapy or chemotherapy are reported as occurring at MH2-OMB.

The revised survey asked patients to provide the location of their follow-up care. Patients provided numerous locations for this care, including clinician's private rooms and medical clinics. In the current report responses for items assessing follow-up care are presented for patients who received all their treatment at one of participating health services.

A similar approach was taken for questions assessing information provision. Patients receiving all their treatment at one of participating health services were identified, and data regarding information provision is reported for this group of patients.

6. Results

Responses to all survey items are shown in Appendix A.

6.1. Care pathways

Twenty-one patients did not have treatment for their cancer. Of these patients, three had prostate cancer, seven had a haematological cancer (including multiple myeloma and lymphoma), two had lung cancer, with the remaining indicating a mix of other cancers (including cancers of the kidney, bladder and uterus).

Of patients having treatment, 42 per cent (n = 1122) were treated with only one treatment modality, 37 per cent were treated with two treatment modalities, 20 per cent received three treatment modalities. Most patients had surgery (71%) or chemotherapy (70%) and 60% had radiotherapy (Table 7).

Table 7 Numbers and per cent of patients receiving each treatment modality

Patients	Surgery	Chemotherapy	Radiotherapy	Hormonal therapy	No treatment
Number	721	690	586	213	21
Per cent of all patients	71%	70%	60%	19%	2%
Number of cases having treatment at a participating health service	402	539	475	N/A	N/A
Per cent of all patients having treatment at participating health services	56%	78%	81%	N/A	N/A

Excluding patients from RH3-SB, 521 patients (48%) had all their treatment at the health service they were recruited through. This number is lower than found in pilot study 1, due to recruiting patients through a radiotherapy unit (MH1-A1). Excluding MH1-A1 from analyses, 60 per cent of patients had all their treatment at the health service they were recruited through.

After excluding 155 patients with missing data, 27 per cent of patients indicated that one doctor was in charge of their cancer care, with another 28 per cent indicating two doctors were in charge (Table 8).

Table 8 Number of doctors in charge of patients' care and the specialty of doctors in charge of care

n = 1005[1], multiple responses allowed

Category	Overall	Among those with different numbers of doctors in charge of care, per cent of patients reporting each type of doctor in charge of their care					
Number of doctors	(%)	Surgeon (%)	Haematologist (%)	Medical oncologist (%)	Radiation oncologist (%)	GP (%)	Other (%)
One doctor	27	27	31	18	15	4	6
Two doctors	28	51	24	40	28	46	11
Three doctors	25	79	14	76%	58	60	13
Four or more doctors	20	92	24	92	88	95	15

[1] 155 patients not indicating a doctor in charge of their care excluded from analyses.

Surgeons play a key role in cancer care. Of the 73 per cent of patients indicating that more than one doctor was in charge of their cancer care, more than half indicated that a surgeon was part of their care team. For patients indicating that only one doctor was in charge of their care, 31 per cent indicated this was their haematologist, and 27 per cent reported it was their surgeon (Table 8).

6.2. Diagnosis process

Thirty-five per cent of patients received their cancer diagnosis from a surgeon, while 19 per cent were told by their GP. More regional patients received their diagnosis from their GP (Table 9).

Table 9 Who informed patients of their cancer diagnosis

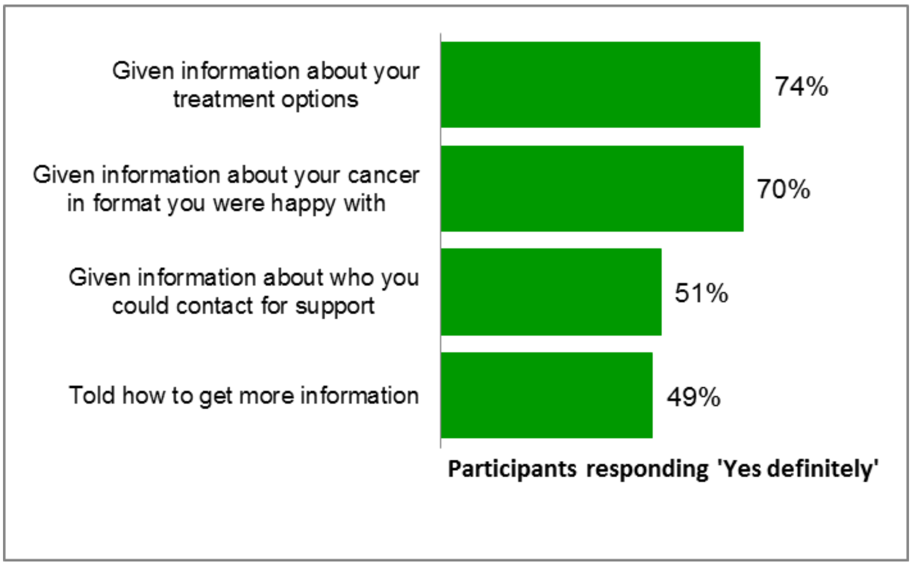
Informed by	**Metropolitan (%)**	**Regional (%)**	**Total (%)**
GP	17	24	19
Surgeon	34	40	35
Medical oncologist	15	19	16
Hospital doctor	13	5	11
Haematologist	9	3	8

When asked if they understood the doctor's explanation of what was wrong with them, 65 per cent of patients said 'yes completely' and 26 per cent indicated 'most of it'. Seven per cent of patients indicated they only understood some of the explanation.

While 74 per cent of patients definitely received information about their treatment options at diagnosis, only 49 per cent definitely received information regarding how to get more information, and 51 per cent definitely received information about who to contact to get more support (Figure 1).

> *'For most people this will be one of the hardest moments in their life. Please use a trained and knowledgeable person to give the diagnosis, with wide options for consultations and choices.' (leukaemia patient, metropolitan hospital)*

Figure 1 Percentage of patients indicating 'yes definitely' to receiving different information when told of their cancer diagnosis



There was an association between the type of doctor telling the patient their diagnosis and information provision. Table 10 shows that patients indicating their surgeon told them their cancer diagnosis were more likely to indicate that they understood the explanation of what was wrong with them (73%) ($p < 0.01$), were given information about their cancer in a format they were happy with (77%) ($p < 0.01$) and were given information about their different treatment options (80%) ($p < 0.01$), than were patients told their cancer diagnosis by a GP.

Table 10 Percentage of patients indicating 'yes definitely' to receiving information when told of their cancer diagnosis by type of doctor informing them of their cancer diagnosis

'yes definitely'	**Surgeon (n = 525) %**	**Medical oncologist (n = 232) %**	**GP (n = 304) %**	**Hospital doctor (n = 192) %**
Understood the doctor's explanation of what was wrong	73	63	60	57
Doctor encouraged you to ask questions	78	78	66	76
Were given information about your cancer in a format you were happy with	77	75	60	65
Were given information about treatment options	80	79	65	67
Were told how to get more information	45	58	49	42
Were given information about who you could contact for support	49	52	51	44

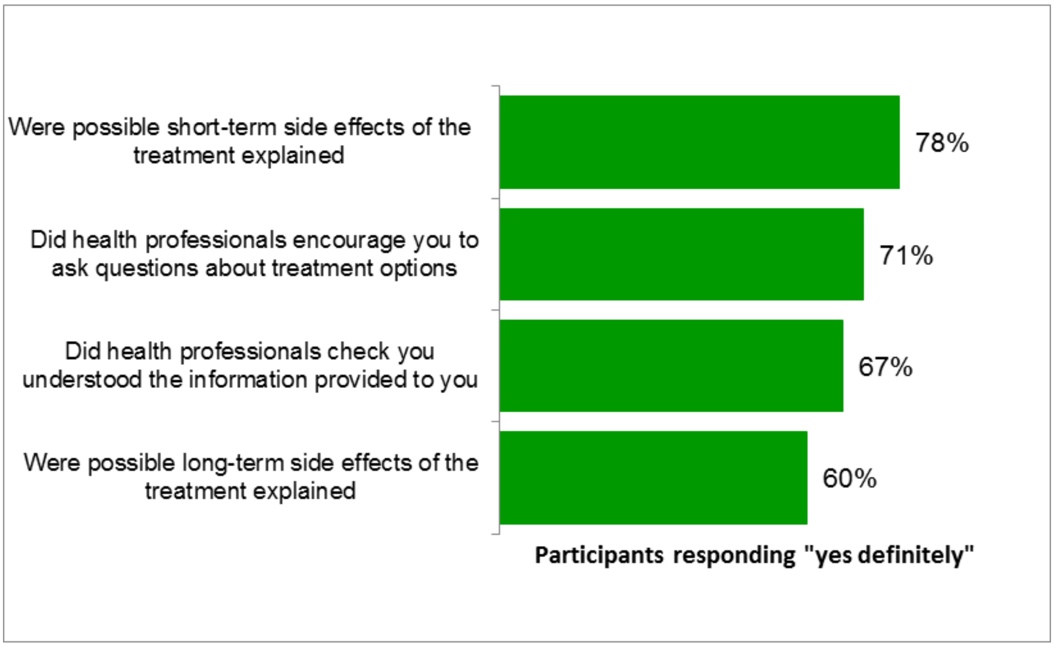
> *'[Surgeon] explained to me all the options and to decide what treatment I want to do. She also explained the side effects of surgery.' (colorectal cancer patient, metropolitan hospital)*
>
> *Recovery – I was not advised on how long it would take to recover from my treatment.' (breast cancer patient, regional hospital)*

6.3. Deciding on treatment

After excluding 10 per cent of patients indicating only one treatment was available to them or they were too ill or did not want to be involved in treatment decisions, 78 per cent of patients indicated they were involved in treatment decisions to the extent they wanted.

More patients received information about short-term side effects (for example, nausea, pain, fatigue) (78%) than long-term side effects (for example, reduced fertility, lymphoedema) (60%) (Figure 2).

Figure 2 Per cent of patients indicating ‘yes definitely’ to receiving information about side effects and that health professionals checked this information was understood



6.4. Surgery

This section describes the care experiences of patients having surgery for cancer. Data from five of the six health services participating in the study are reported here. The sixth health service is not included as information on surgical experiences was not collected. The experiences of patients recruited through the radiotherapy centre located at MH1-A1 are reported if the patient had surgery for their cancer at that health service. Only 25 per cent of these patients had surgery at MH1-A1. This contrasts with the pattern of results found when the VAED was used to identify patients where between 76 per cent and 87 per cent of patients from MH2-A1 and MH3-A2 had surgery at these health services. Of MH1-A1 patients having surgery, 61 per cent had their surgery in the private system.

Overall, 71 per cent of patients had surgery for their cancer. Fifty-six per cent of patients having surgery had their surgery at one of the participating health services. Thirty-nine patients from the two participating regional health services had surgery at a metropolitan hospital.

Seven hundred and twenty-one patients completed the surgery section of the survey. Of these, 52 per cent had their surgery within the previous 12 months while 37 per cent had surgery 12 to 24 months previously. Thirty-seven per cent of patients having surgery indicated that the choice of hospital for their surgery was a joint decision with their doctor, 21 per cent indicated that the doctor made the decision alone and eight per cent reported they made the decision alone.

> *‘Everyone that was involved in my surgery was amazing. My surgeon, the assistant surgeon, nurses and everyone in the theatre that attended to me made me so relaxed. I did not feel nervous or worried in any way. I was so grateful for all the care I was given. Thumbs up, well done.’ (lung cancer patient, metropolitan hospital)*

6.4.1. Length of wait for surgery

Approximately 73 per cent of patients having surgery at one of the pilot study health services reported having surgery within four weeks of being ready for it. Approximately 56 per cent of patients who had surgery at another health service had surgery within two weeks of being ready for it, compared to 30 per cent of patients having surgery at a pilot study health service.

Responses of patients having surgery at the pilot study health services are detailed below.

6.4.2. Information provided

Of the patients having surgery at a pilot study health service (n = 402), the vast majority (91%) were provided with information regarding how to prepare for surgery. Approximately 84 per cent of patients indicated they received enough information about what would happen next (for example, follow-up arrangements, further treatment and so on), 80 per cent were given enough information about what it would be like after surgery, and 76 per cent received enough information about how to manage any side effects from surgery. Eighty-eight per cent of patients thought that health professionals explained things in a way they could understand most of the time. There were no significant differences between pilot study health services.

6.4.3. Health professional assistance

Among patients who experienced side effects after surgery, nearly one in five (19%) thought that that staff did not manage their side effects well. In addition, among patients who had a need for help while in hospital, approximately 43 per cent thought there were times when staff did not respond to their need for help within a reasonable time (Figure 3). Responses to these two questions did not differ between pilot study health services.

Fifty-two per cent of patients having surgery at a pilot study health service experienced pain after their surgery. Of these patients, 16 per cent did not think staff did all they could to help manage this pain.

> *'…post-surgery care from the nurses was appalling! Pain meds were not managed properly, they were understaffed – it was a disgrace, I could not wait to get out of that ward.' (brain cancer patient, metropolitan hospital)*

> *'I was not ready to come home so soon after surgery, I felt very weak. I suffered terrible constipation after operation (b/c of pain killers). I wish I had been warned of this and given 'something to treat it. I couldn't talk and my throat as sore. I could only the next day sip clear soup and it was terrible, undrinkable.' (thyroid cancer patient, metropolitan hospital)*

Figure 3 Proportion of patients indicating that surgery side effects were well managed and that they were able to get a staff member to help within a reasonable time by health service

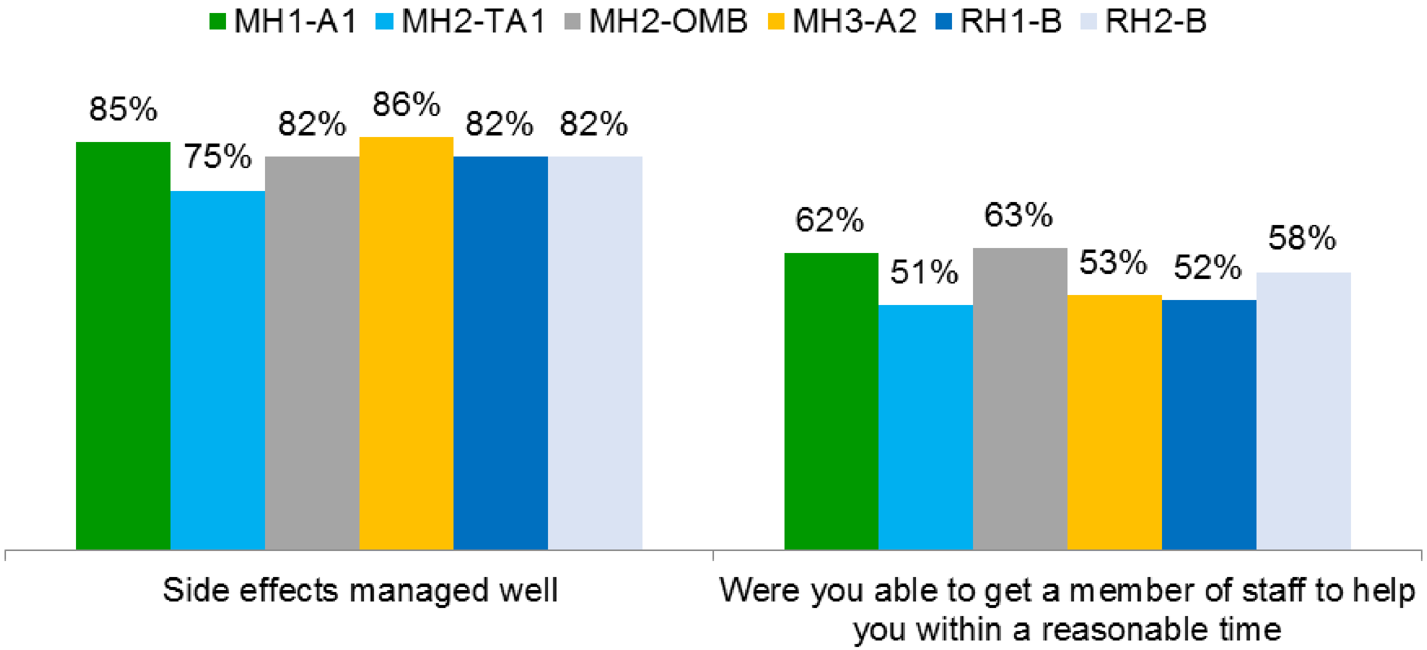
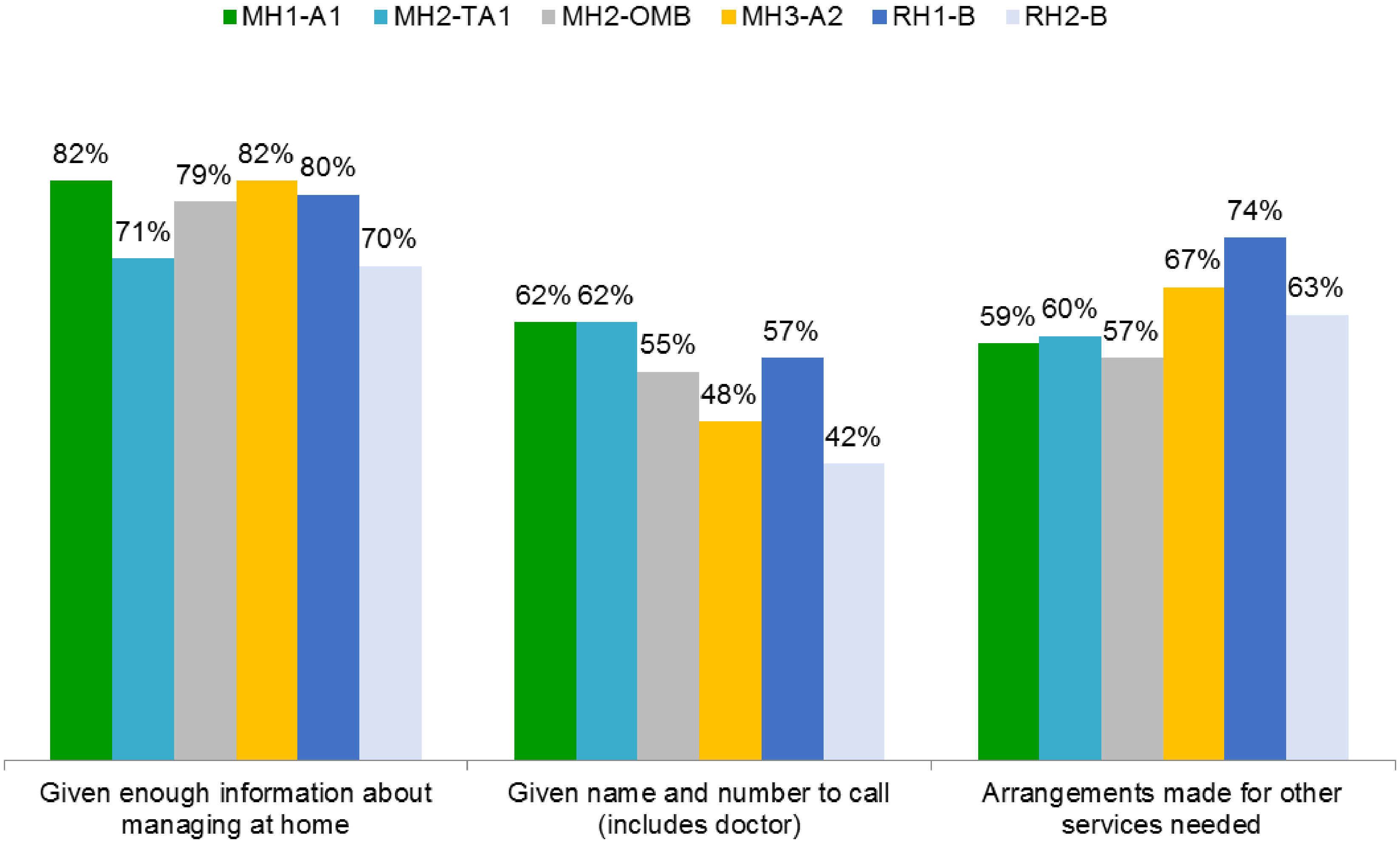


Figure 4 Proportion of patients indicating that on discharge they 1) received enough information about managing at home; 2) received a name and number to contact if they had questions (includes receiving only doctors numbers); 3) hospital staff arranged services needed after discharge, by health service



There were some differences in patients’ experiences regarding their discharge and provision of information or services to help manage at home (Figure 4). Approximately 70 per cent of patients having surgery at MH2-TA1 and RH2-B thought they were given enough information about managing at home when they were discharged compared to nearly 80 per cent of patients having surgery at other pilot study health services. Similarly, among patients who thought they needed some services to help their recovery post discharge, 57 per cent of those from MH2-OMB compared to 74 per cent from RH1-B indicated these had been arranged.

6.4.4. Overall satisfaction

Overall satisfaction with surgical care was high, with 77 per cent of patients having surgery at a pilot study health service very satisfied with the care they received.

Ninety per cent of patients having surgery at a pilot study health service thought they were treated with respect and dignity by staff delivering this care.

> *‘Staff were excellent. My stay in hospital was very professionally managed. I enjoyed being in a ward of four patients.’ (kidney cancer patient, metropolitan hospital*

> *‘I was very disappointed that the surgeon did not visit me in the ward the next day. Also, my partner who was waiting to see me after surgery was not told what was wrong – she waited five hours before seeing me.’ (bladder cancer patient, regional hospital)*
>
> *I had very caring and professional services during my ten days at X hospital.’ (colorectal cancer patient, regional hospital)*

> Totally satisfied with the anaesthetist, their empathy, humanity and professionalism. They came to see me prior to being wheeled into the anaesthetic section and chatted in a friendly manner. In contrast, no one from the surgery team appeared and to this day, although I was told who my surgeon *was, I did not meet them prior to the surgery and not sure who operated on me. Disappointing not to be greeted by my surgeon before the operation.’* (endometrial cancer patient, metropolitan hospital)

> *All staff were friendly and helpful. Very good culture. Management and staff should be very proud.’ (colorectal cancer patient, metropolitan hospital)*

6.5. Radiotherapy

This section describes care experiences among patients having radiotherapy for cancer. For this survey, two radiotherapy centres were located in Melbourne and one was located in regional Victoria. Ninety per cent of patients from RH1-B having radiotherapy had their radiotherapy at that health service. In contrast, 71 per cent of patients from MH2-A1 having radiotherapy had their radiotherapy at that health service.

For all patients having radiotherapy (n = 586), 31 per cent had radiotherapy within the previous six months, 33 per cent had radiotherapy six to 12 months previously and 28 per cent had radiotherapy

12 to 24 months previously. Twenty per cent of patients having radiotherapy thought they had little input into the decision regarding where to have this treatment, 36 per cent thought they made this decision with their doctor and six per cent indicated they made the decision with little input from their doctor.

Nineteen per cent (n = 109) of all patients having radiotherapy indicated they stayed away from home when having radiotherapy. Of patients who had to stay away from home, 31 per cent indicated that staff from the health service arranged accommodation for them, 10 per cent indicated that their doctor's staff made accommodation arrangements, and 43 per cent indicated they or their family/friends arranged accommodation.

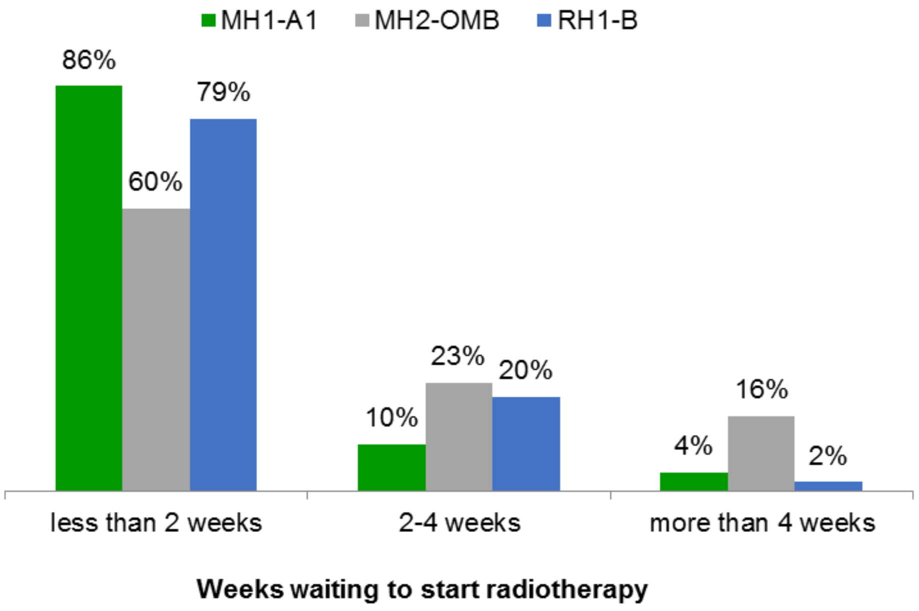
In general, most patients were very positive about the care they received while having radiotherapy.

6.5.1. Length of wait for treatment to start

Across all patients having radiotherapy, 65 per cent indicated they had treatment within two weeks of being ready for treatment, 22 per cent had treatment between two and four weeks and eight per cent waited longer than one month. Of the 129 patients waiting longer than two weeks for treatment to commence, 12 per cent said this was due to a personal decision to wait, while 67 per cent indicated it was due to hospital waiting times, of which they were informed.

Sixty-six per cent of patients having radiotherapy at a pilot study health service started treatment within two weeks of being ready for it, compared to 59 per cent of patients having radiotherapy elsewhere. However, this difference was not statistically significant. After excluding people who choose to wait longer than two weeks to commence radiotherapy, waiting times differed between the pilot study health services ($p < 0.01$), with 99 per cent of patients at RH1-B and 96 per cent of patients at MH1-A1 treated within one month of being ready to start radiotherapy compared to 84 per cent of patients at MH2-OMB. The proportion of patients waiting less than two weeks, two to four weeks and over four weeks at the different health services are shown in Figure 5.

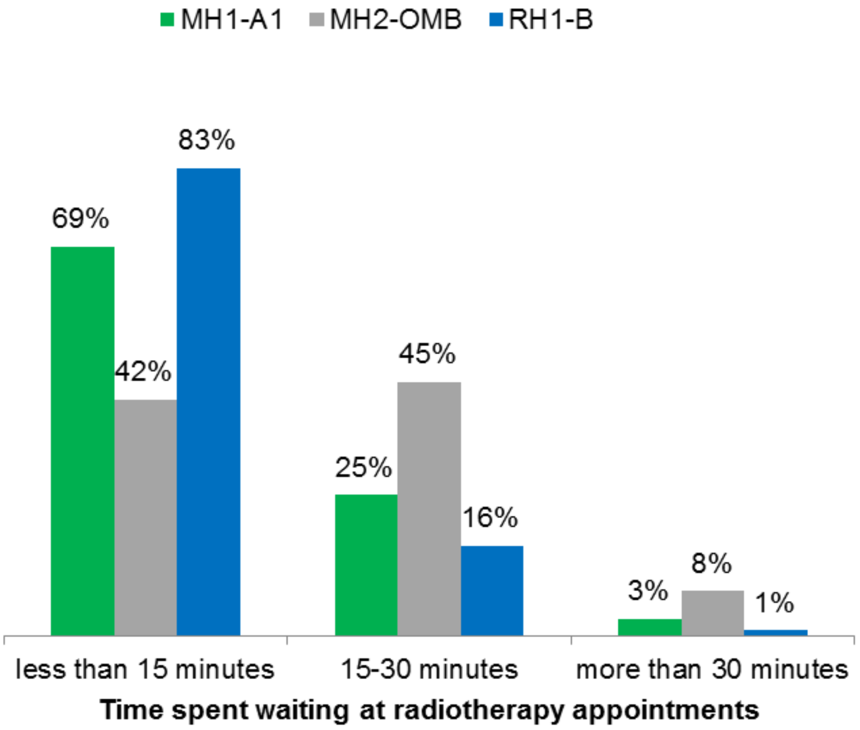
Figure 5 Proportion of patients waiting less than two weeks, two and four weeks and over four weeks to start radiotherapy by health service (participants waiting longer than two weeks by choice excluded from analyses)



6.5.2. Waiting times at appointments

Across the three pilot study health services, 66 per cent of patients having radiotherapy indicated they generally waited less than 15 minutes for their appointments. However, as Figure 6 shows, waiting times differed between health services, with, for example, 83 per cent of patients treated at RH1-B waiting less than 15 minutes compared to 42 per cent of patients at MH2-OMB.

Figure 6 Usual waiting times for radiotherapy appointments, by health service

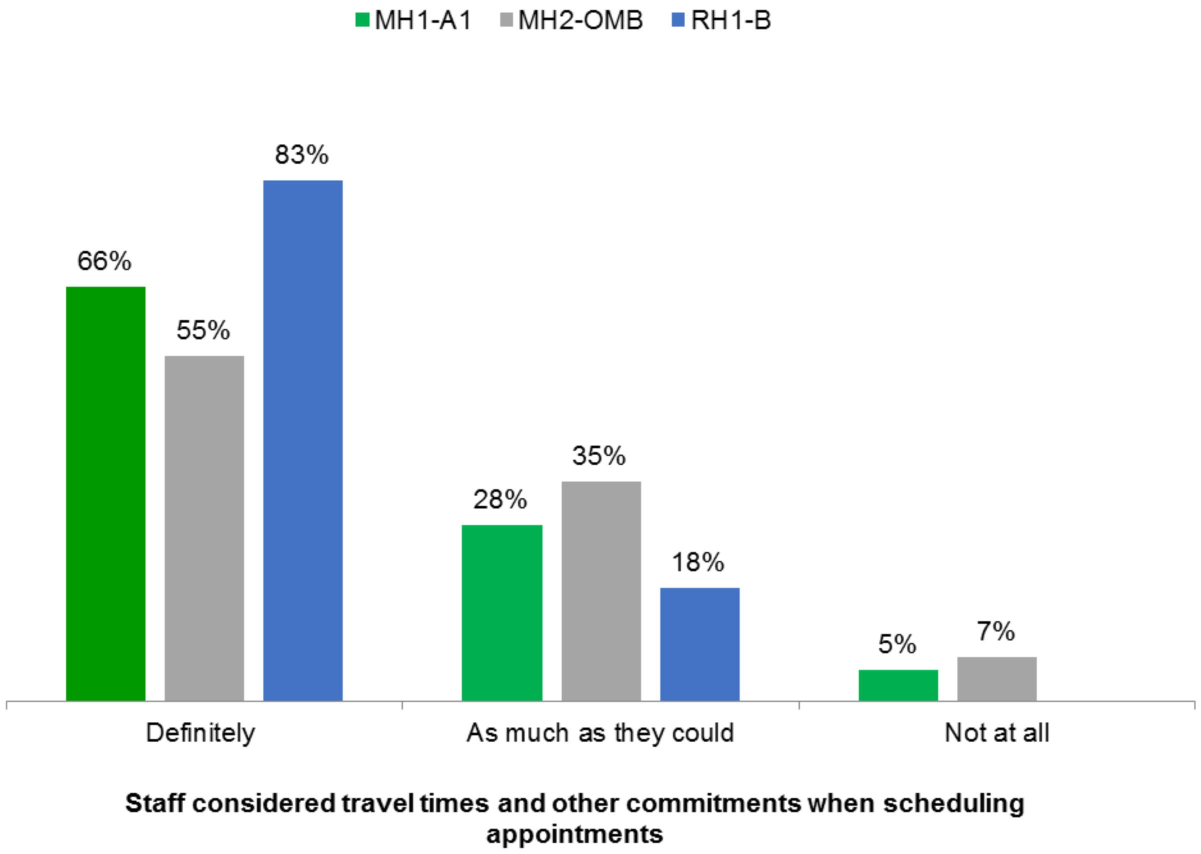


6.5.3. Scheduling appointments

Seventeen per cent of patients having radiotherapy indicated that travel times or other commitments were not an issue for them when scheduling appointments. Of the remaining patients, 67 per cent thought staff definitely took these factors into account when arranging appointment times and 29 per cent indicated staff considered them as much as possible. Overall, five per cent of patients thought their travel times and other commitments were not considered when making appointments, with this more likely to be reported by patients attending metropolitan health services. Patients attending RH1-B were more likely to report staff definitely considered travel times and other commitments when scheduling appointments ($p < 0.05$) (Figure 7).

> *'My appointments were always on time and if I was running late they were very accommodating.' (breast cancer patient, metropolitan hospital)*

Figure 7 Degree staff considered patient travel times and other commitments when scheduling radiotherapy appointments, by health service



6.5.4. Information provided before treatment

Of patients treated at a pilot study health services, 99 per cent definitely received information on how long treatment would take, 94 per cent definitely received information on what would happen during treatment, 90 per cent received information on how you might feel at end of treatment, and 87 per cent definitely received information on how to manage any side effects from treatment. Slightly fewer patients (79%) reported receiving information about how long it might take to recover from radiotherapy, and only 74 per cent were given information about how to manage any stress or anxiety. Eighty-eight per cent of patients indicated that health professionals checked they understood the information provided.

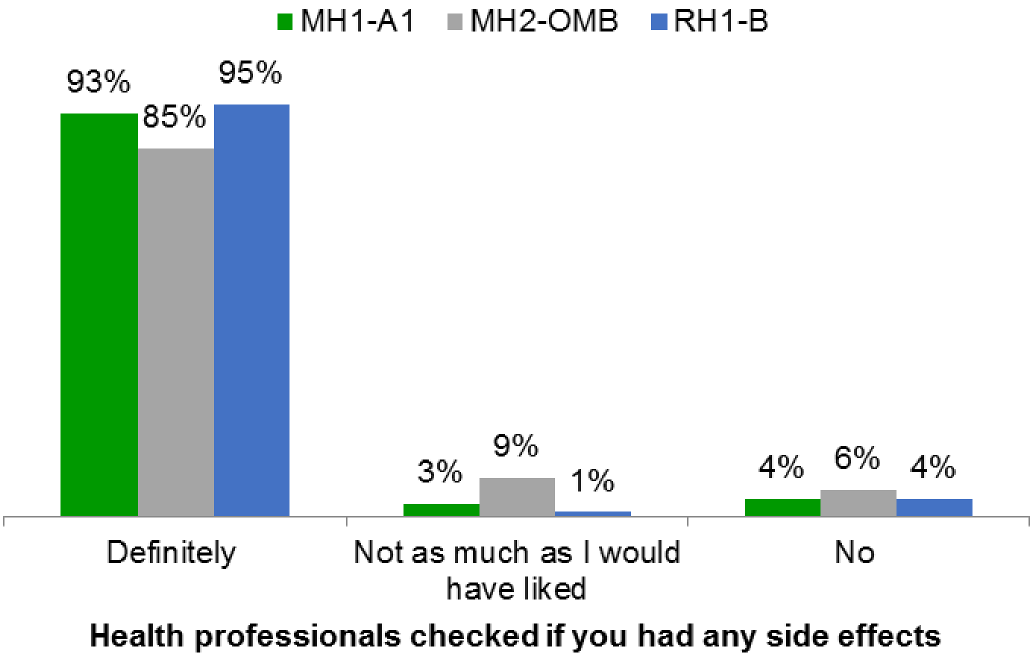
The provision of information did not differ between health services.

6.5.5. Management of side effects

Across the three health services, 89 per cent of patients having radiotherapy indicated that health professionals regularly checked if they had any side effects from treatment, four per cent indicated that health professionals did not do this as frequently as they would have liked and five per cent indicated this did not happen. As shown in Figure 8, the proportion reporting health professionals checked for side effects differed across health services ($p < 0.05$).

Eighty-six per cent of patients experiencing side effects from radiotherapy thought staff did everything they could to help manage them and this did not differ between health services.

Figure 8 Proportion of patients indicating health professionals checked if they had any side effects from radiotherapy, by health service



6.5.6. Health professionals' assistance

Just over 80 per cent (82%) of patients reported that health professionals involved in their radiotherapy checked if they needed help or assistance with things such as diet or physical movements, while 12 per cent reported this did not happen. There was some difference in patients reports of this across health services, with 93 per cent of patients at RH1-B reporting this, compared to 77 per cent at MH1-A1 and 88 per cent at MH2-OMB ($p = 0.01$). Seventy-three per cent of all patients reported that health professionals checked if they needed any help managing emotions and this did not differ between health services. After excluding patients who did not need assistance, 67 per cent of patients indicated that health professionals checked if they needed assistance travelling to or from treatment, and this did not differ between health services. Across the three health services, 89 per cent of patients indicated that they received a contact number to call if they had any concerns relating to their radiotherapy, and this did not differ across health services.

6.5.7. Car parking availability

For those whom car parking was relevant, there were differences in patients' satisfaction with car parking facilities across health services ($p < 0.01$). The proportion of patients indicating they were very satisfied and the proportion indicating they were dissatisfied with car parking facilities are shown in Table 11. Patients indicating this question was not relevant to them were excluded from this analysis. Satisfaction with car parking facilities was highest at RH1-B.

> *'The parking at the hospital can be difficult at times, especially during peak times.' (breast cancer, regional hospital)*
>
> *'The car park was very expensive.' (breast cancer patient, metropolitan hospital)*

Table 11 Proportion of patients very satisfied with car parking facilities at their radiotherapy treatment centre*

Response	MH1-A1 (%)	MH2-OMB (%)	RH1-B (%)	Total (%)
Very satisfied	27	28	48	31
Dissatisfied/very dissatisfied	14	18	6	14

*patients indicating this questions was not relevant excluded

6.5.8. Overall satisfaction

Overall satisfaction with radiotherapy care was high, with 88 per cent of patients having radiotherapy at a pilot study health service very satisfied with the care they received. Almost all patients (98%) thought that staff treated them with respect and dignity throughout their radiotherapy treatment.

> *'All the staff at [radiotherapy centre] were amazing, the respect and care given to me was outstanding and made my experience a lot easier.' (colorectal cancer patient, metropolitan hospital)*

> *'All the staff were kind, caring and considerate and tried to make everything as easy as possible including music.' (breast cancer patient, regional hospital)*

> *The radiotherapy was always done with ease and proficient staff who always made sure I was comfortable and always checked to make sure I had enough cream.' (breast cancer patient, metropolitan hospital)*

6.6. Chemotherapy

This section describes the care experiences of patients having chemotherapy treatment. All health services participating in the study provided chemotherapy to patients. Seventy-eight per cent of patients having chemotherapy had their chemotherapy at one of the pilot study health services.

For all patients having chemotherapy (n = 690), 21 per cent had this treatment within the previous six months, while another 29 per cent had this treatment six to 12 months earlier. Thirty-seven per cent of patients having chemotherapy indicated that they made the decision where to have treatment together with their doctor, 20 per cent indicated that they led they decision process, while 19 per cent indicated that their doctor choose the health service with little input from them.

Thirteen per cent of patients (n = 86) having chemotherapy stayed away from home when having chemotherapy. Forty-one patients indicated they or their family/friends arranged accommodation for them while they were away from home, 21 said the health service staff arranged accommodation for them and seven indicated that their doctor's staff arranged their accommodation.

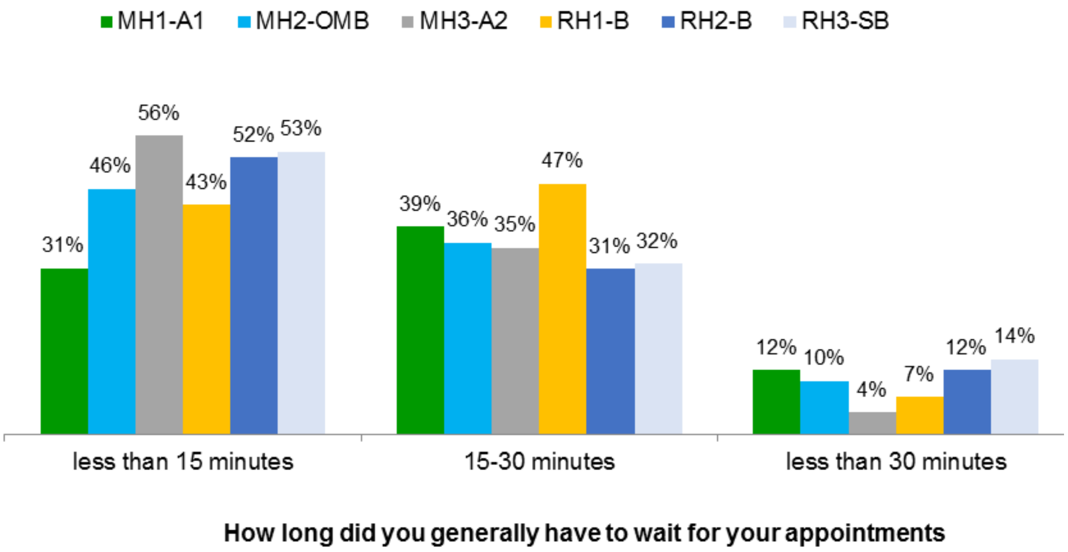
6.6.1. Length of wait for treatment to start

Of all patients having chemotherapy, 57 per cent indicated that they had treatment within two weeks of being ready to start, with another 26 per cent having treatment within two to four weeks. Although there were slight differences in the length of time patients at different health services had to wait before commencing chemotherapy, these differences were not statistically significant. Overall, 83 per cent of patients having chemotherapy at a pilot study health service commenced chemotherapy within four weeks of being ready to start treatment.

6.6.2. Waiting times at appointments

Excluding patients who had chemotherapy in the form of a pill and those who did not recall, 46 per cent of patients treated at the pilot study health services indicated they generally had their chemotherapy treatment within 15 minutes of their appointment time, with another 38 per cent reporting they generally waited between 15 and 30 minutes. Approximately 12 per cent of patients reported generally waiting longer than 30 minutes at their appointments. Waiting times differed across health services ($p < 0.01$), with 31 per cent of patients having chemotherapy at MH1-A1 waiting less than 15 minutes, compared to 56 per cent of patients at MH3-A2 (Figure 9).

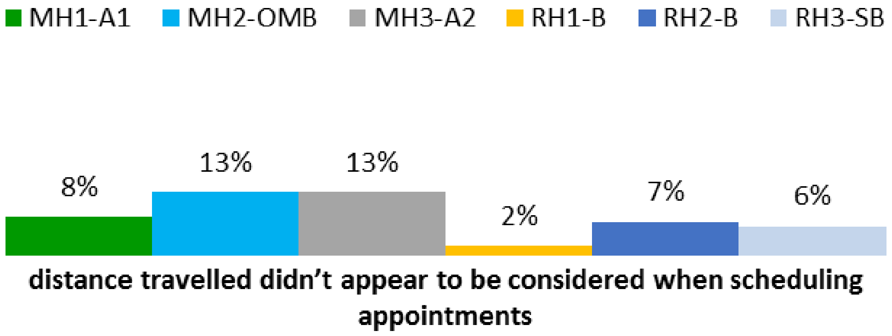
Figure 9 Proportion of patients waiting less than 15 minutes, 15 and 30 minutes and over 30 minutes for their chemotherapy appointment, by health service



6.6.3. Scheduling appointments

Sixteen per cent of patients having chemotherapy at pilot study health services indicated that travel time or other commitments were not an issue when scheduling appointments. Of the remaining patients, eight per cent indicated that staff did not take these issues into account when scheduling appointments. This differed significantly across health services as shown in Figure 10.

Figure 10 Proportion of patients reporting staff did not seem to consider the distance they needed to travel when scheduling appointments, by health service (patients where distance wasn't an issue excluded)



6.6.4. Information provided before treatment

In general, information provision regarding chemotherapy was excellent at all health services. Among patients attending pilot study health services, nearly all indicated they had received enough information regarding: how the treatment would be given (95%); how long treatment would last (94%); the possibility of going to an emergency department (93%) with 88 per cent receiving a card explaining their chemotherapy that they could take the emergency department if needed.

However, 16 per cent of patients thought they did not receive enough information, or did not receive any information about how they would feel at the end of their chemotherapy, and 25 per cent indicated they did not receive enough information or any information about managing stress in relation to their chemotherapy.

Ten per cent of patients thought they did not receive or did not receive enough information about what side effects they might experience, and 11 per cent thought they did not receive enough information about how to manage side effects at home.

Information provision did not differ across the pilot study health services.

> *'I can't help feeling that somehow I missed on fully grasping the implications of any specific side effects that might plague me later on. In my case it was the more or less sudden appearance of peripheral neuropathy due to taking thalidomide daily after my stem-cell transplant.' (multiple myeloma patient, metropolitan hospital)*

6.6.5. Management of side effects

Care regarding side effects was generally very high, with 95 per cent of patients having chemotherapy indicating that health professionals checked if they had any side effects from treatment. Two per cent of patients would have liked health professionals to ask about side effects more frequently. Frequency of health professionals checking for side effects was similar across health services.

After excluding the four per cent of patients who did not experience any side effects from chemotherapy, most patients (90%) thought health professionals involved in their chemotherapy treatment did everything they could to help manage any side effects experienced, nine per cent thought more could have been done to manage their side effects. Patient reports of side effect management did not differ significantly between health services.

6.6.6. Health professionals' assistance

Eighty-eight per cent of patients indicated that health professionals checked if they needed any help or assistance with issues like diet or physical movement. Nearly all patients (95%) indicated they were given a telephone number to contact if they had concerns regarding their chemotherapy.

Overall, 66 per cent of patients reported that health professionals checked if they needed any assistance with travel to and from the chemotherapy centre. The proportion of patients reporting this was highest at RH3-SB (84%) and lowest at the MH1-A1 (50%) ($p < 0.01$).

6.6.7. Car parking availability

Among patients for whom this was relevant, there were differences in satisfaction levels regarding the availability of car parking at their chemotherapy centre. The least satisfied patients attended the metropolitan health centres for their chemotherapy (Table 12). The most satisfied patients attended RH2-B.

> *'Car park fees are too high.' (bladder cancer patient, metropolitan hospital)*

Table 12 Proportion of chemotherapy patients 'very satisfied', 'dissatisfied' and 'very dissatisfied' with the availability of car parking by health service

Response	**MH1-A1 (%)**	**MH2-OMB (%)**	**MH3-A2 (%)**	**RH1-B (%)**	**RH2-B (%)**	**RH3-SB (%)**	**Total (%)**
Very satisfied	27	30	24	46	64	36	38
Dissatisfied	5	12	12	6	5	14	9
Very dissatisfied	3	6	9	1	2	9	5

6.6.8. Overall satisfaction

Overall satisfaction with chemotherapy care was high, with 84 per cent of patients having chemotherapy very satisfied with the care they received. Almost all patients (98%) thought that they were treated with respect and dignity while having chemotherapy.

> *'The staff, especially the nurses and doctors, were really professional in their jobs, but most of all they were compassionate and behaved more like family and friends. Their passion for looking after cancer patients was evident at all times.' (breast cancer patient, metropolitan hospital)*

> *'The staff in the chemotherapy were amazing, so caring and helpful.' (oesophageal cancer patient, regional hospital)*

> *'I found the [hospital] day chemo staff to be absolutely fantastic. The girls at the front desk were always joking and making encouraging comments while booking appointments and weigh-ins. The nurses were always chasing blood test results from my pathology provider. They would be chatting like old friends whilst taking obs and finding out about side effects or symptoms. Sometimes my haematologist would pop in during treatment to see how I was going.' (lymphoma patient, metropolitan hospital)*

> *'The receptionist was always cheerful, considerate and up for a chat, and started to consider me as one of the regulars. The pharmacist was always contactable whenever I had questions re medication and helpful with advice when I was using herbal remedies. All the nurses were very professional and could have a laugh when warranted. My medical oncologist team were very supportive, never let me feel like I was taking up too much of their time, always reassuring me through the good, the bad, and the ugly times.' (uterine cancer patient, metropolitan hospital)*

6.7. Emergency department experiences

Three hundred and twenty-six patients (35%) indicated they had attended an emergency department since their cancer diagnosis because they felt very ill, with 15 per cent attending an emergency department more than once. Of these patients, 67 per cent were admitted to hospital as a result of their emergency department attendance.

Twenty per cent of patients indicated they waited less than 10 minutes before seeing a doctor at the emergency department, with another 38 per cent indicating they waited between 10 and 30 minutes (Table 13).

> *'The queue waiting to see the triage nurse went out the door, onto the pavement. I queued for over an hour alongside other sick people who were coughing and sneezing either side of me – this was the very thing I was supposed to be avoiding.' (lymphoma patient, metropolitan hospital)*

> *'The emergency department seemed understaffed at the time I was there (midnight onwards).' (prostate cancer patient, metropolitan hospital)*

Table 13 Last time you were at the emergency department, how long did you have to wait before you saw the doctor?

Attended emergency department	< 10 minutes	10–30 minutes	30–60 minutes	1–2 hours	2–4 hours	> 4 hours
Number	64	121	47	35	24	19
Per cent	20%	38%	15%	11%	8%	6%

While the majority of patients (80%) thought their condition was well managed while they attended the emergency department, 16 per cent thought their condition was not managed well. In addition, 18 per cent were not confident that all or most of the staff at the emergency department they attended had the skills to look after them.

6.8. Follow-up care

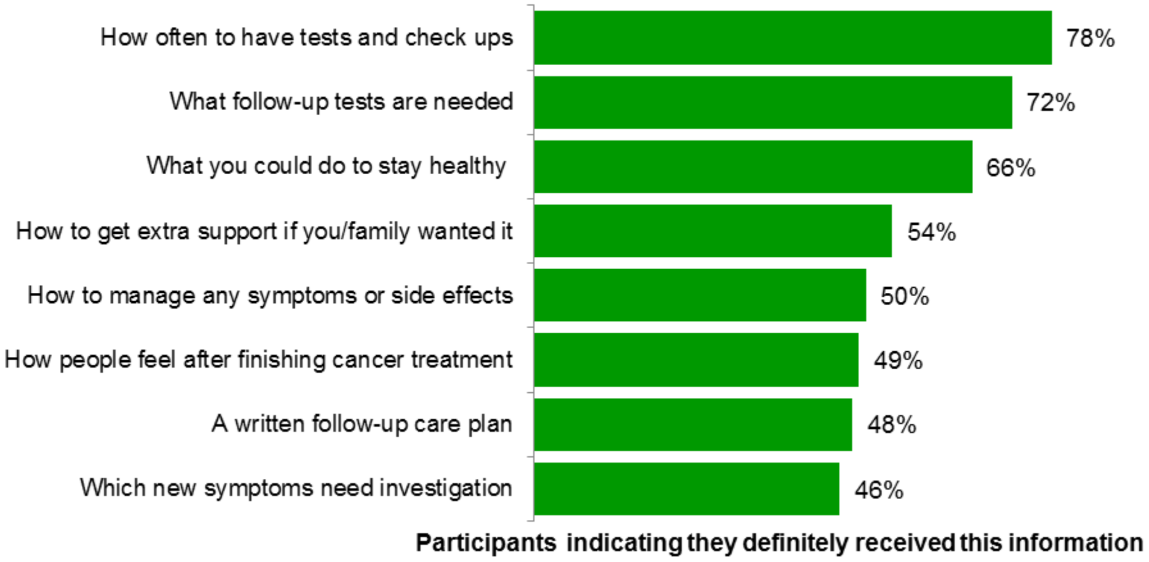
Patients who had finished treatment were asked to report on different aspects of their follow-up care. In this section the experiences of follow-up care is examined for patients who had all their treatment at one of the pilot study health services, because it is assumed that follow-up care would be delivered through these health services as well. Patients recruited through the radiotherapy centre attached to MH1-A1 were excluded from these analyses, because only approximately 25 per cent of patients having surgery, had surgery at this health service. Patients recruited through RH3-SB were also excluded, because data on other treatment modalities and follow-up care were not collected. Five hundred and sixty-four patients completing the survey received all their treatment at one of the pilot study health services.

> *'I was told I would see one of the specialists every three months. I understand there is a form regarding follow-up care plans, but I have not been given one (yet).' (breast cancer patient, regional hospital)*

6.8.1. Information provision

Between 66 per cent and 78 per cent of patients received information about follow-up tests needed, how often they would require tests or check-ups and how to stay healthy (Figure 11). Most room for improvement was in the area of providing information regarding how patients might feel after finishing treatment, how to get extra support if needed and which new symptoms might need investigation, with only between 46 per cent and 54 per cent of patients indicating that they received enough information about these issues.

Figure 11 Proportion of patients having all their treatment at one of the pilot study health services indicating they definitely received specific follow-up information



6.8.2. Scheduling of follow-up appointments

Thirty per cent of patients indicated that scheduling of follow-up appointments was not an issue for them. Of those patients where scheduling was an issue (n = 387), 22 per cent did not think their appointment scheduling took into account their travel times or other commitments. In addition, 16 per cent of all patients did not think that their appointments and tests were coordinated to reduce the time they had to spend going to and from medical appointments, and 21 per cent thought that this only happened sometimes.

> *'Waiting times at clinics is often more than one hour after appointment times.' (lymphoma patient, metropolitan hospital)*

6.8.3. GP involvement in follow-up care

Sixteen patients indicated that they did not have a regular GP. Of patients with a regular GP, 80 per cent thought their GP had a good understanding of the follow-up care they needed.

6.9. Overall care

This section reports on patients' views of their overall care, including how well information was shared between different health professionals or healthcare services. The responses of patients who had all their treatment at one of the pilot study health services are reported below.

6.9.1. Health professional contact person

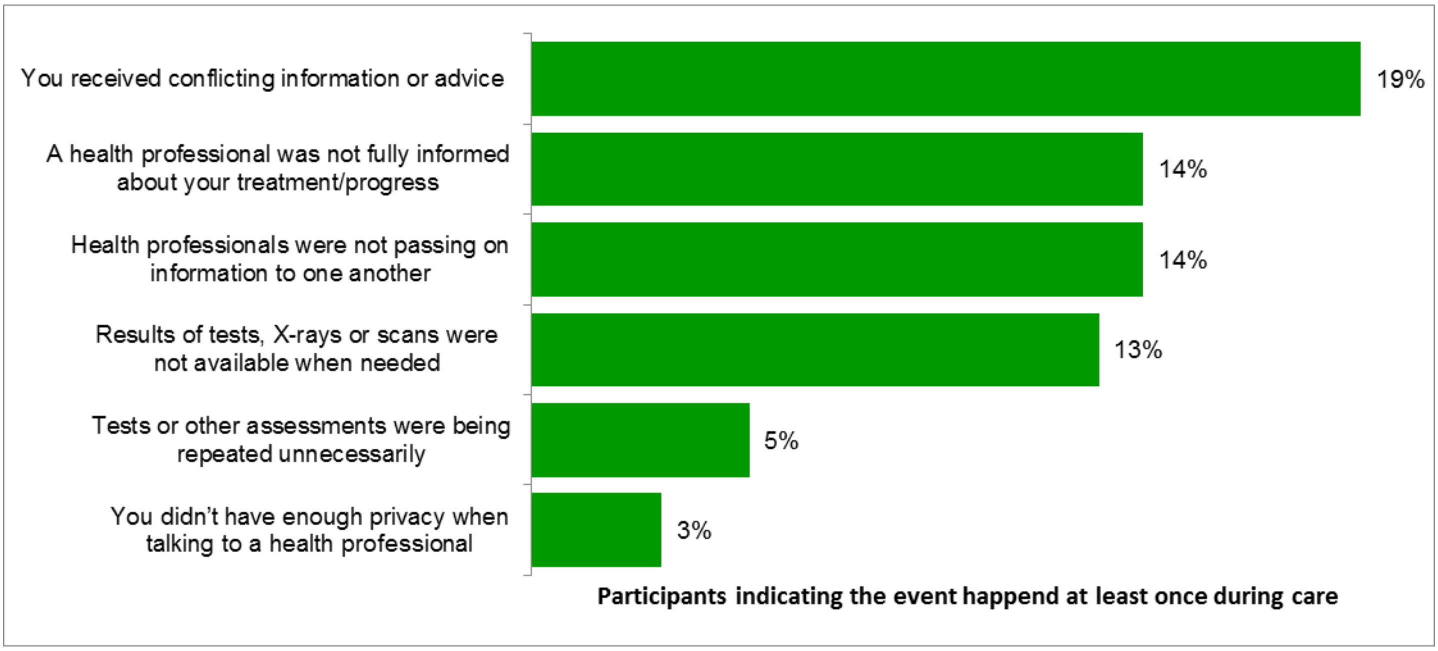
Among patients having all their treatment at one of the pilot study health services, 76 per cent indicated there had been a health professional they could contact if they needed help or advice throughout treatment. This did not differ significantly between health services. However, in response to a question asking whether they were given the name of a clinical nurse specialist who would be in charge of their care, only 43 per cent said they had. The proportion of patients reporting that they had access to a clinical nurse specialist differed between health services ($p < 0.01$), with 44 per cent of patients having all their treatment at RH1-A2 reporting this, 41 per cent of patients from MH2-A1, 29 per cent of patients at RH2-A2 and 28 per cent of patients at MH3-A1.

6.9.2. Information exchange between health professionals

Most patients reported that health professionals involved in their care worked well together (93% rated this as very good/excellent). After excluding people who weren't sure or who couldn't recall, most patients reported that results of tests were available when needed (88%). After excluding people who couldn't recall, the most commonly reported negative communication events concerned receiving conflicting information from health professionals (19% indicated this happened at least once) and health professionals not being fully informed about their treatment or progress (14% indicated this happened at least once). Six per cent of patients thought tests were being repeated unnecessarily (Figure 12).

> *'Conflicting information, ill-informed specialists, tests misplaced so had to be repeated, test/X-rays/scans not available to specialists during appointments so no information on deteriorating condition, information between surgeons and specialist conflicting, concerns not being taken seriously.' (appendiceal cancer patient, regional hospital)*
>
> *'I was sent for blood tests from the oncology department as well as the haematology department as a result I had two blood tests within four weeks of each one on two occasions, which I could not understand if this was necessary.' (multiple myeloma patient, metropolitan hospital)*

Figure 12 Proportion of patients reporting that particular events happened at least once during their care

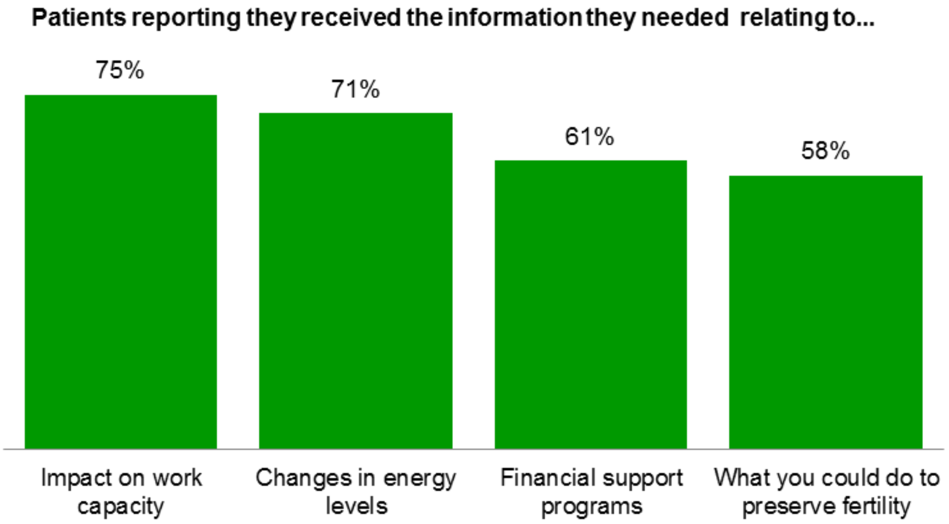


6.10. Information provision

This section describes patients' views regarding information provision by health professionals during their care. Results are reported for patients attending pilot study health services for all of their treatment.

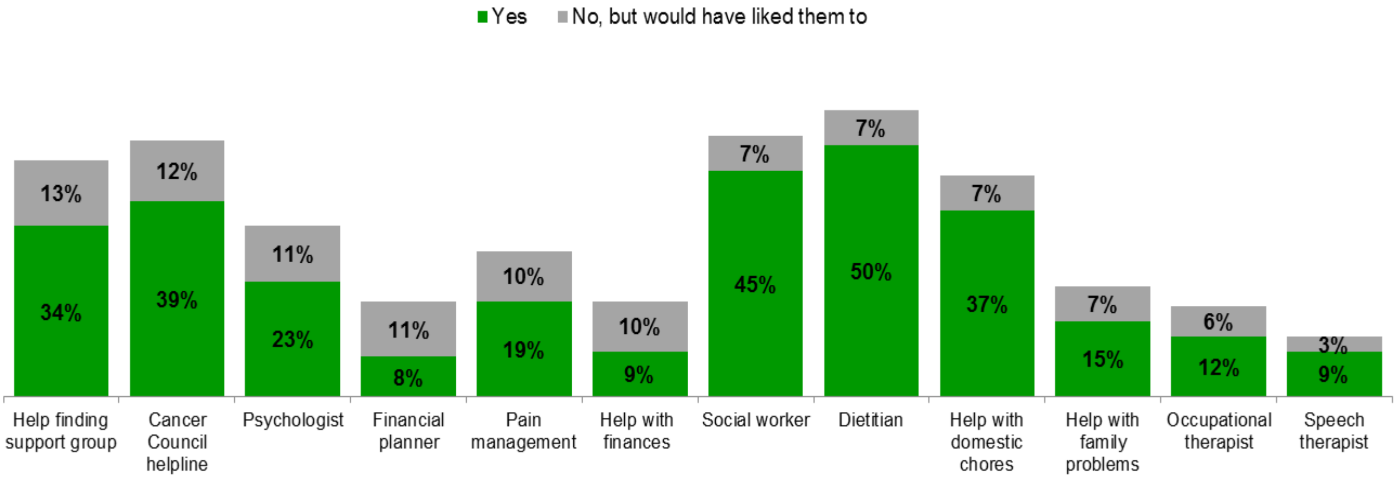
The majority of patients at pilot study health services who wanted information relating to the impact of treatment on their capacity to work, changes in their energy levels and financial support programs were provided with this information by health professionals (Figure 13). While there were some small differences in the provision of information across health services, these differences were not statistically significant. Approximately 58 per cent of patients who thought that fertility preservation was relevant to them received information about this.

Figure 13 For patients having all their care at a pilot study health service and wanting information, provision of information by health professionals



Patients were asked if health professionals discussed or referred them to a number of different allied health or support services. As Figure 14 shows, health professionals most commonly discussed the need for a social worker, dietitian or help with domestic chores. Services the greatest proportion of patients wanted health professionals to discuss with them were: the cancer help line (12%), access to a psychologist (11%), finding a support group (13%), pain management (10%) and accessing a financial planner (11%) (Figure 14).

Figure 14 Proportion of patients treated only at pilot study health services indicating that health professionals asked them about use of different services and the proportion indicating they would have liked information about these services



6.11. Impact of a health professional contact on care experiences

This section reports on the care experiences of patients who had a clinical nurse specialist contact, those having a healthcare team contact and those indicating that they did not have a health professional contact. Patients indicating both a clinical nurse specialist contact and a healthcare team member contact were categorised into the clinical nurse specialist group. The proportion of patients at each pilot study health service reporting a health professional contact is shown in Table 14. The majority of patients at each health service reported a health professional contact. The largest proportion of patients not having a health professional contact was at MH3-A2 (34%).

Table 14 Proportion of patients at each health service reporting access to a clinical nurse specialist, healthcare team member or no health professional contact person

Type	MH1-A1 (%)	MH2-A1 (%)	MH3-A2 (%)	RH1-B (%)	RH2-B (%)	Total (%)
Clinical nurse specialist	55	41	34	50	44	46
Healthcare team member	34	30	32	28	38	32
No contact person	11	30	34	22	18	22

Table 15 shows that the proportion of patients wanting more information about support services was greater for those patients without a health professional contact than those with access to either a clinical nurse specialist or a healthcare team member.

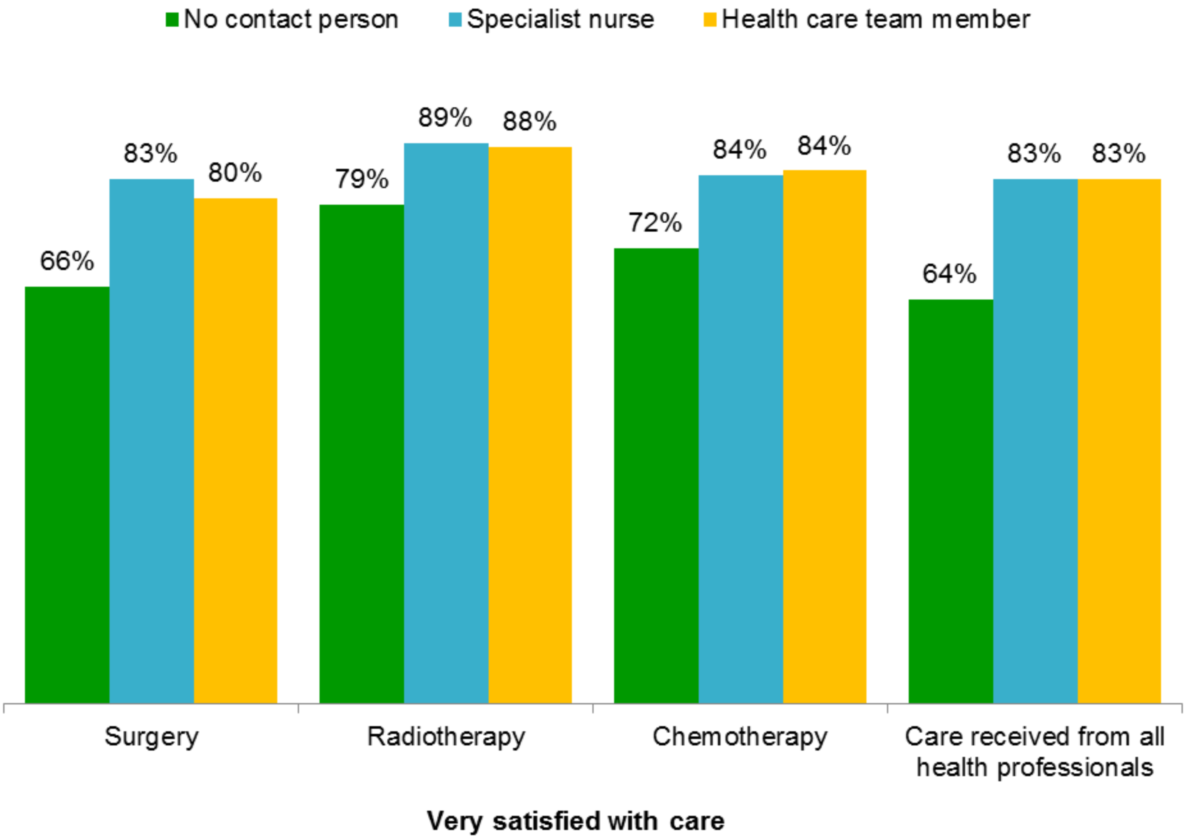
Table 15 Proportion of patient wanting to receive more information about different allied health and support services by access to a health professional contact

Support type	No contact person (%)	Clinical nurse specialist (%)	Healthcare team member (%)
Social worker	15	5	6
Psychologist	18	10	8
Dietitian	17	7	5
Speech therapist	7	3	1
Occupational therapist	11	5	5
Pain management	23	8	6
Cancer Council Helpline	24	6	9
Financial planner	19	13	9
Help with domestic chores	10	8	5
Help with family problems	13	6	5
Help with finances	19	10	9
Help finding support groups	22	11	10

There was little difference in the proportion of patients wanting information about the different allied health and support services among those with access to either a clinical nurse specialist or a healthcare team member. The greatest difference was found for information about a financial planner, with slightly more patients with access to a clinical nurse specialist (13%) wanting information about this service than patients with a healthcare team member contact (9%).

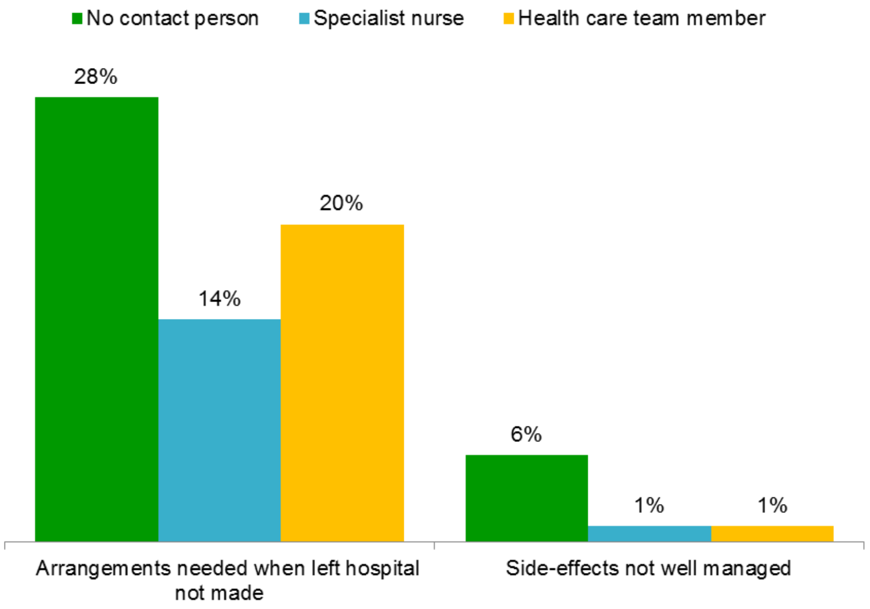
A significantly greater proportion of patients with a health professional contact were very satisfied with their surgical care ($p < 0.05$) and the care they received from all health professionals ($p < 0.01$). Although satisfaction levels for radiotherapy care and chemotherapy care were slightly greater for those with a health professional contact than for those without a contact, these differences were not statistically significant (Figure 15).

Figure 15 Proportion of patients reporting they were very satisfied with their surgical, radiotherapy, chemotherapy care and care received from all health professionals by access to a health professional contact



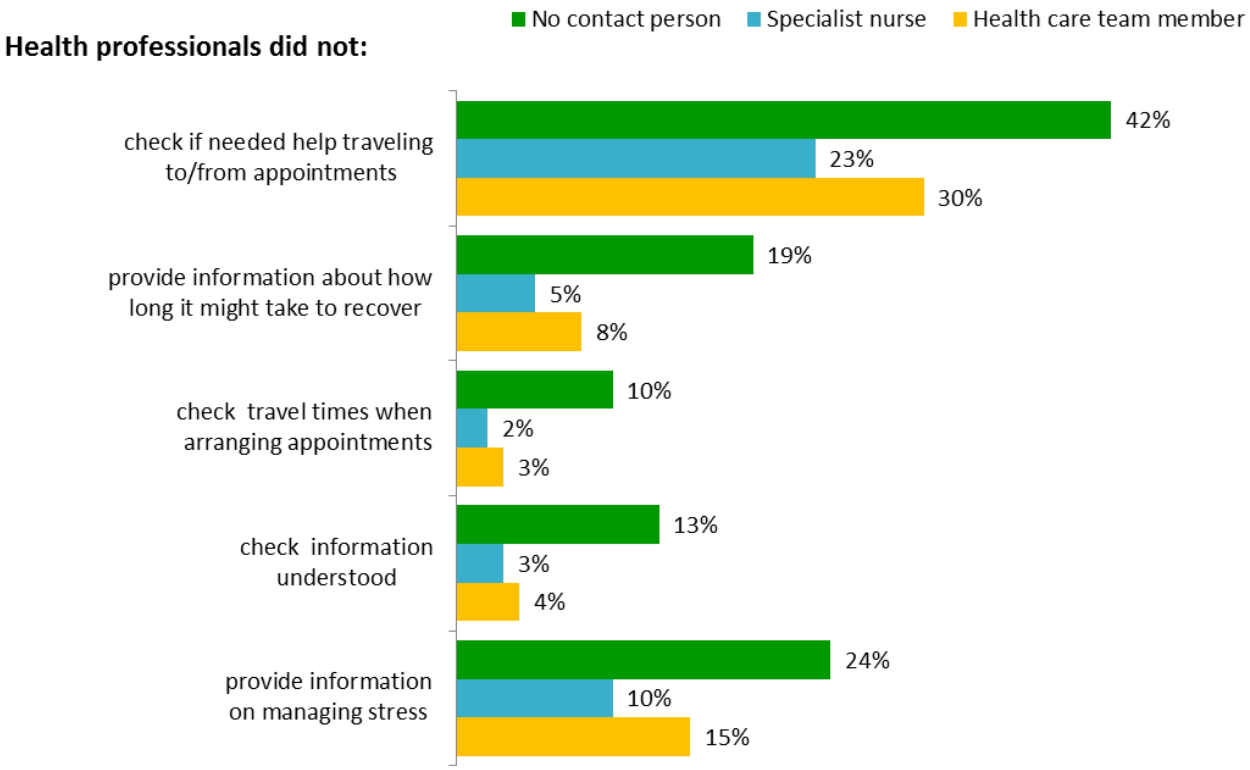
Figures 16 and 17 demonstrate different surgical and radiotherapy experiences for patients with or without a health professional contact. For surgery, patients without a health professional contact were more likely to report that arrangements needed for them to manage at home after surgery were not made and that side effects were not managed well (Figure 16).

Figure 16 Percentage of patients reporting arrangements needed at home were not made and side effects after surgery were not managed well by access to a health professional contact



For radiotherapy, patients without a health professional contact were more likely to report that health professionals did not check if they needed help with various issues, including travelling to and from appointments, checking about distance travelled when scheduling appointments and whether information provided was understood. Patients without a health professional contact were also less likely to indicate they had received information about managing stress and recovery times from radiotherapy (Figure 17).

Figure 17 Proportion of patients reporting health professionals did not do different tasks during radiotherapy by access to a health professional contact



Patients without a health professional contact were more likely to report that their follow-up appointment schedule was not coordinated (31% for no contact, 11% clinical nurse specialist, 15% healthcare team member) ($p < 0.01$). Additionally, patients without a health professional contact were more likely to report there was at least one time during their care that they wanted to make a complaint ($p < 0.01$) (19% no contact, 15% clinical nurse specialist, 12% healthcare team member).

6.12. Care experience for patients treated in public and private hospitals

Cancer care in Victoria can be delivered in the public hospital system and the private hospital system. The focus of the report has been to examine the care experiences of patients treated in different public health services across Victoria. Because patients completing the survey provided the name of the hospital where they had their cancer treatments, it is possible to identify patients having surgery, radiotherapy and chemotherapy in the private hospital system. Using data from pilot study 1 and the current pilot study, the experiences of patients treated for cancer in the public and private systems were examined. Table 16 shows the proportion of patients across the two pilot studies having different treatments in the private or public system.

Table 16 Number and proportion of patients having surgery, radiotherapy or chemotherapy in the public or private health system

(data from pilot studies 1 and 2 combined)

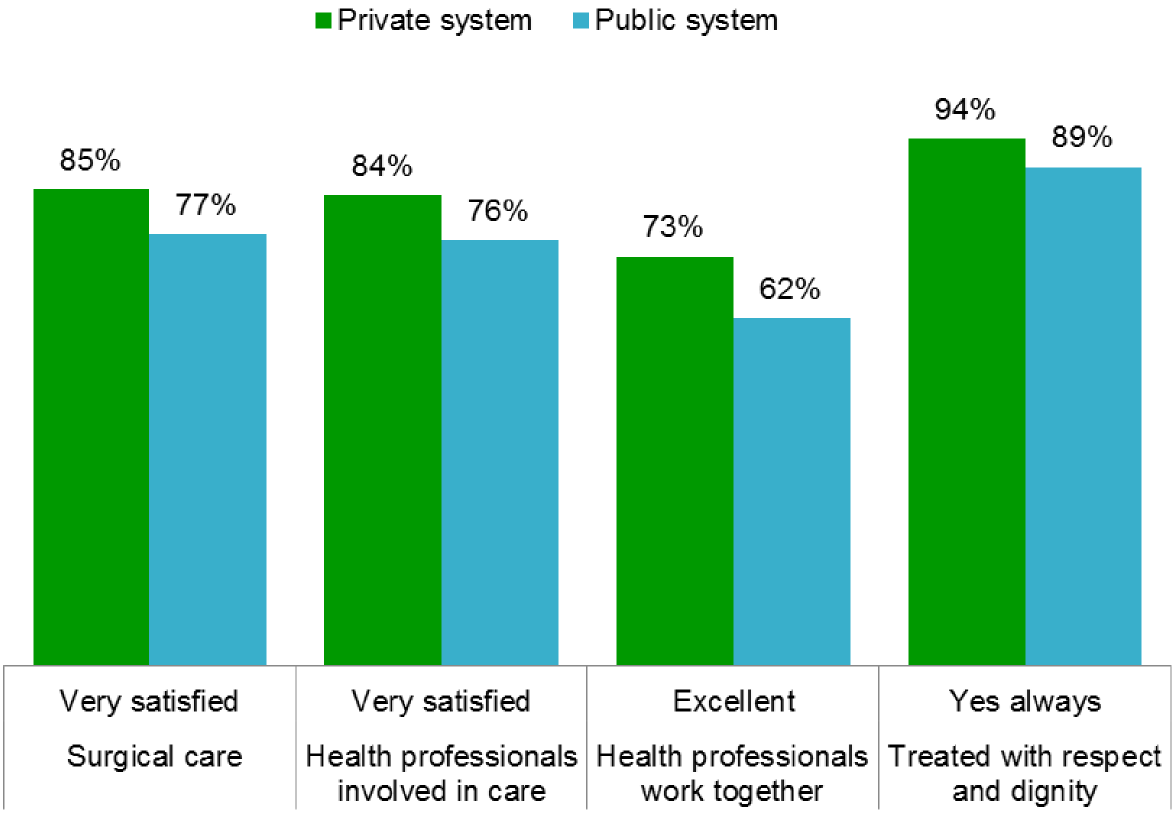
Treatment type	Private system N (%)	Public system N (%)	Total n
Surgery	211 (20%)	838 (80%)	1049
Radiotherapy	49 (11%)	381 (89%)	430
Chemotherapy	75 (9%)	779 (91%)	854

Because the number of patients having radiotherapy or chemotherapy in the private system was relatively small, in this section the experiences of patients having surgery in the public or private system are examined.

6.12.1. Surgery

Satisfaction with surgical care, perceptions of health professionals working well together and being treated with respect and dignity while in hospital for public and private patients are shown in Figure 18. In general, a greater proportion of patients treated in the private system reported being very satisfied with the care they received, and thought health professionals worked very well together. However, the only statistically significant difference in private and public patients' experiences related to their perceptions of health professionals working together, with a greater proportion of patients treated in the private system rating this as excellent (73%) compared to patients in the public system (62%; $p < 0.05$).

Figure 18 Levels of satisfaction with surgical care and health professionals for patients having surgery in the public or private health system



A greater proportion of patients in the private system had surgery within two weeks of being ready for surgery (67%) compared to patients in the public system (33%) ($p < 0.001$).

Provision of information about surgery was generally similar in the two systems (Table 17), although slightly more patients in the private system reported receiving this information than patients in the public system (Table 17). Significantly more patients in the private system indicated they received information about what would happen after surgery than patients in the public system ($p < 0.01$).

A greater proportion of patients having surgery in the private system reported that health professionals explained things in a way they could understand ($p < 0.05$).

Table 17 Proportion of surgical patients definitely receiving information about various topics and that staff undertook different actions while they were in hospital, by healthcare system

Category	Information and action type	Private system (%)	Public system (%)	p-value
Definitely received information about:	How to prepare for surgery	96	91	0.11
	What it would be like after surgery	85	75	0.23
	Information on possible side effects from surgery	83	75	0.14
	Information about what would happen next	93	83	0.00
	Information about managing at home	79	76	0.81
Staff actions while in hospital	Arrangements needed to manage at home made	33	40	0.07
	Organised services you needed to recover	45	48	0.28
	Side-effects well managed	67	68	0.35
	Staff assisted within a reasonable time	60	54	0.07
	Toilets were very clean	90	68	0.00
	Appointments and tests were coordinated	62	51	0.06

The likelihood of having surgery in the private system differed by cancer type, with 39 per cent of breast and prostate cancer patients having surgery in the private system compared to 16 per cent of patients with other types of cancer. To examine whether surgical care experiences for private patients was influenced by the greater likelihood of breast and prostate cancer patients being included in this group, two sets of further analyses were conducted. In the first set, breast and prostate patients were excluded, and analyses shown in Table 17 were repeated. In the second set of analyses the care experiences of breast and prostate cancer patients treated privately or publicly were examined.

Results from the first set of analyses were similar to those presented in Table 17, with slightly greater proportion of patients in the private system indicating they definitely received information about the various areas of their care, although none of these differences were statistically significant. For items assessing staff actions, a greater proportion of private than public patients reported that the different actions happened, although again, these differences were generally not statistically significant. Similar to results shown in Table 17, the only statistically significant difference was for the cleanliness of toilets, where a greater proportion of private (91%) than public (61%) patients agreed that the toilets were clean ($p < 0.01$).

The experiences of breast and prostate cancer patients treated in the public or private system were very similar, with, for instance, 96 per cent of patients in both systems saying they received information about how to prepare for surgery, 87 per cent of private patients and 85 per cent of public patients receiving information about what it would be like after surgery, 84 per cent of private patients and 83 per cent of public patients receiving information about side effects and 94 per cent of private patients and 89 per cent of public patients receiving information about what would happen next. Additionally, in both groups, 59 per cent indicated that a member of the hospital staff was available to help them within a reasonable time. However, a greater proportion of private (88%) than public (74%) patients reported that the toilets were very clean, which was significant at the $p = 0.08$ level.

The two groups did differ on the contact information they received at discharge ($p < 0.01$). For this question, 29 per cent of private patients indicated they only had the name of their doctor and 44 per cent said they had the name of someone at the hospital to call. In contrast, only five per cent of public patients indicated they received the contact details of their doctor, while 54 per cent were given the name of someone at the hospital to call.

These analyses suggest that differences found in the care experiences of public and private sector patients are not simply due to the greater proportion of breast and prostate cancer patients in the private system.

6.12.2. Follow-up care

Data from pilot study 2 was used to examine the experiences of follow-up care in the private and public system. Data from pilot study 1 could not be used in these analyses, because the location for follow-up care was not collected. Three hundred and two patients (32%) completing pilot study 2 indicated that their follow-up care was conducted in the private system by nominating either a private hospital or consultant rooms as the location for their follow-up care. Follow-up care experiences for patients followed up in the private or public system are examined.

Reported experiences of follow-up care were similar for patients regardless of which system they had this care in. As Table 18 shows, a similar proportion of patients in the two systems received a written follow-up plan, and similar proportions indicated that they received information about what to do to stay healthy, what tests and follow-up they would need and what new symptoms may need further investigation. However, a greater proportion of patients having follow-up care in the private system reported that staff considered their travel times or other commitments when scheduling appointments ($P < 0.05$).

Additionally, a greater proportion of public patients (34%) than private patients (26%) indicated that they did not receive information about how people commonly feel after finishing cancer treatment.

The influence of the larger proportion of breast and prostate cases being treated in the private system on follow-up care experiences reported in Table 18 was examined using the procedure reported above. Excluding breast and prostate cancer patients, there were no differences in the follow-up care experiences of patients in the private or public system, with proportions reporting that they received information about the different care areas being very similar in the two sectors.

Table 18 Proportion of patients reporting that different events happened during their follow-up care, by healthcare system

Category	Information and action type	Private system (%)	Public system (%)	p-value
Definitely received information about:	How to get extra support of information if you or family wanted it	51	53	0.69
	How people feel after finishing treatment	53	50	0.08
	Things you could do to stay healthy	62	67	0.53
	Which new symptoms need investigation	47	45	0.79
	How often you need to have tests or check-ups	81	75	0.79
	A written follow-up plan	42	49	0.34
	What follow-up tests you would need	72	69	0.85
	Managing side effects	52	52	0.85
Staff actions	Travel, work or other commitments considered when scheduling appointments	59	46	0.02
	Appointments and tests were coordinated	64	58	0.24
	Results never not available for appointments	77	71	0.08

Analyses examining the care experience of breast and prostate cancer patients treated in the private and public system also show that experiences were generally very similar in the two sectors. The only statistically significant difference was in patients’ reports of whether travel and other commitments were considered by staff when scheduling appointments, with 67 per cent of private patients saying staff did this as much as possible, compared to 45 per cent of public patients (p < 0.02).

6.13. How do findings from pilot study 2 compare with those from pilot study 1?

The first pilot study in this program of work was conducted in 2012–13, and assessed the care experiences of patients attending one metropolitan health service that was a Tertiary Category A1 hospital (P1-MH4-A1), and two regional health services with one classified as Regional Category B (P1-RH4-B) and the other classified as Regional Category A2 (P1-RH5-A2). This section examines findings from both pilot studies to examine care experiences and levels of satisfaction for surgical, radiotherapy and chemotherapy care at the different pilot study health services.

6.13.1. Satisfaction with care across health services

Figures 19, 20 and 21 show the proportion of patients reporting that they were very satisfied with the care they received when having surgery, chemotherapy or radiotherapy at the health services involved in pilot study 1 and pilot study 2. Figure 22 shows the proportion of patients who were very satisfied with the care they received from all health professionals involved in their care at each health service.

Satisfaction ratings for surgery were generally high, with between 69 per cent and 85 per cent of patients at the different health services very satisfied with the surgical care they received (Figure 19). Differences in the satisfaction levels across the health services were not statistically significant.

The proportion of patients who were very satisfied with their chemotherapy care at the different health services ranged from 78 per cent to 93 per cent. Differences between health services were not statistically significant (Figure 20).

Satisfaction ratings for radiotherapy did differ significantly between health services, with the lowest levels found at P1-MH4-A1 (79%) and the highest levels found at RH2-B (92%) (Figure 21).

Figure 22 shows the proportion of patients who were very satisfied with the care they received from all health professionals involved in their care at each health services. The proportion of patients who were very satisfied ranged between 71 per cent at MH3-A2 to 86 per cent at RH1-B.

Figure 19 Proportion of patients very satisfied with their surgical care, by health service

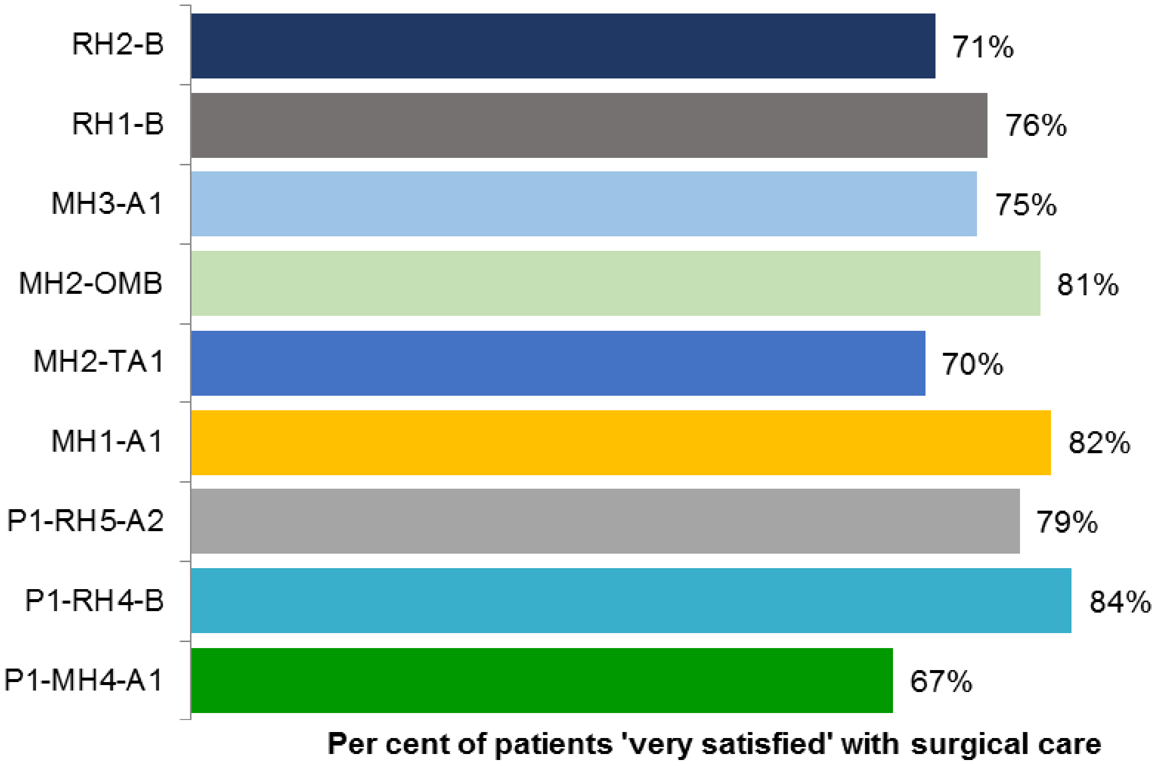


Figure 20 Proportion of patients very satisfied with their chemotherapy care, by health service

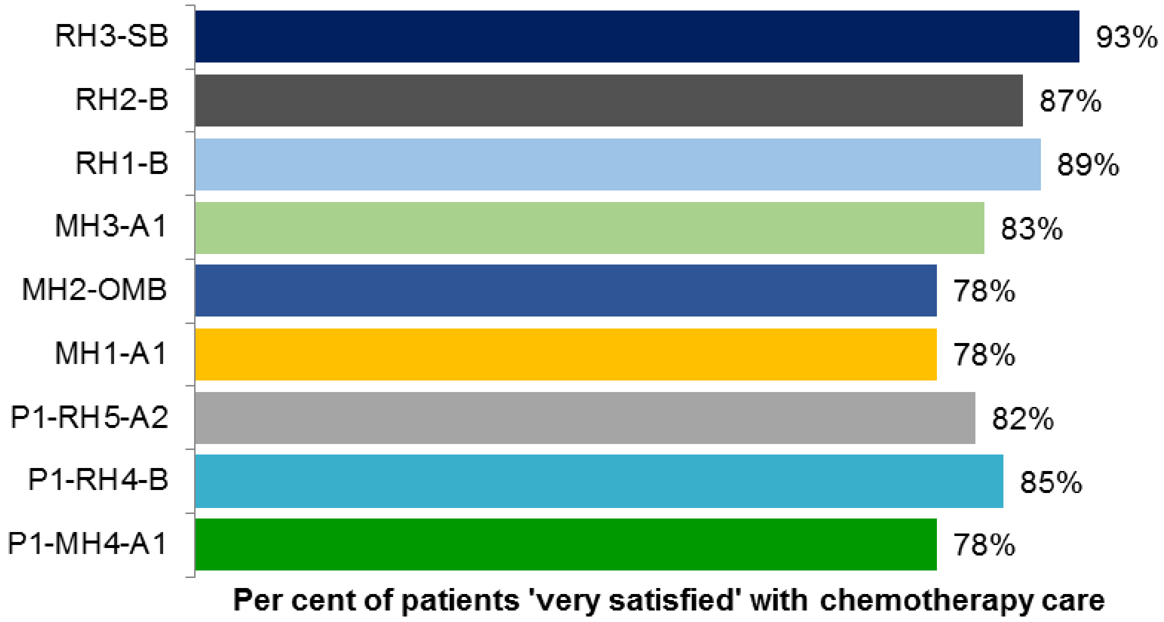


Figure 21 Proportion of patients very satisfied with their radiotherapy care, by health service

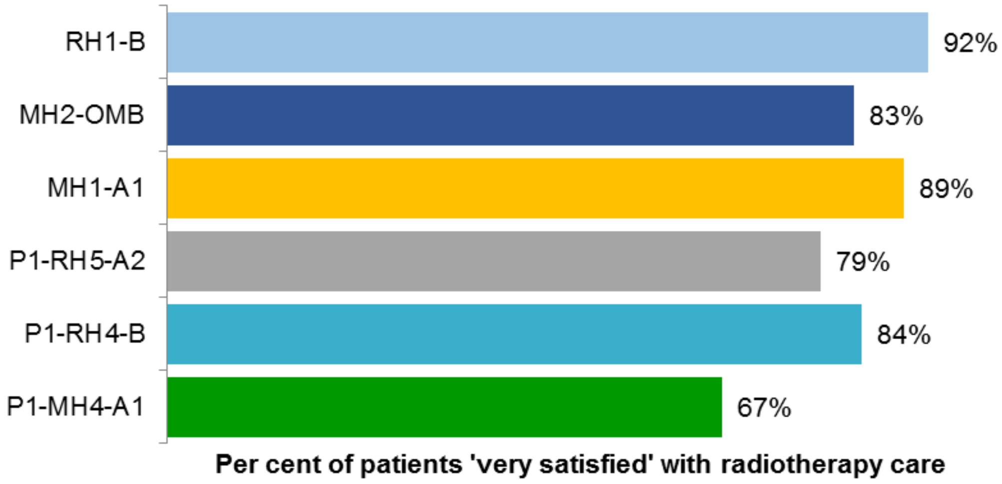
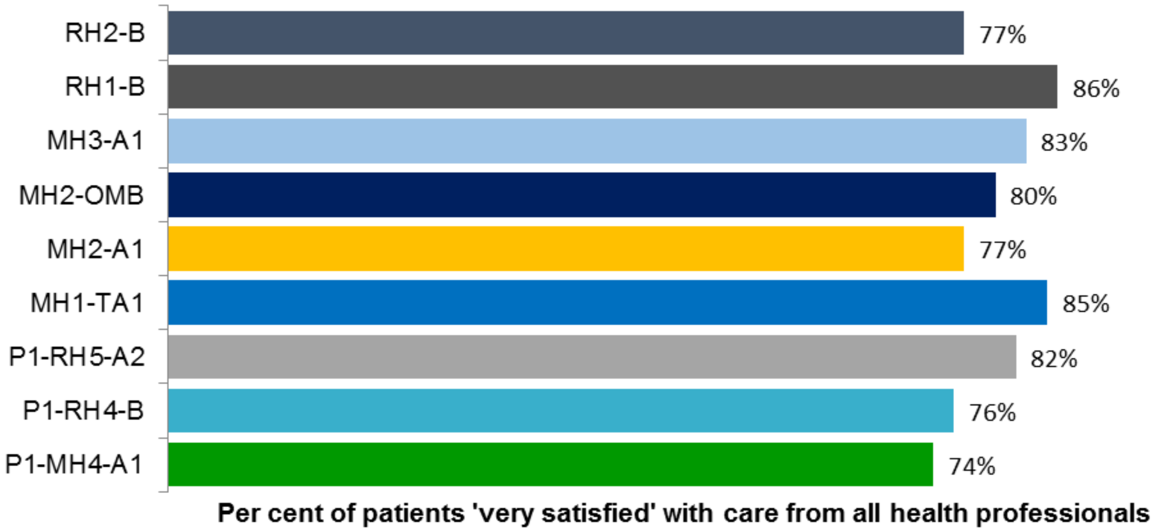


Figure 22 Proportion of patients very satisfied with the care received from all health professionals involved in their care, by health service



6.13.2. Respect and dignity

The majority of patients at all health services indicated they were always treated with respect and dignity by health professionals during their surgical, chemotherapy and radiotherapy care (Table 19).

Table 19 Proportion of patients indicating they were always treated with respect and dignity by staff when having: 1) surgery 2) chemotherapy and 3) radiotherapy by health service

Study group	Health service	Treated with respect and dignity during:		
		Surgery (%)	Chemotherapy (%)	Radiotherapy (%)
Pilot study 1	P1-MH4-A1	84	96	94
	P1-RH4-A2	96	100	100
	P1-RH5-A2	91	100	97
Pilot study 2	MH1-A1	96	99	99
	MH2-A1	89	96	96
	MH3-A2	89	98	-
	RH1-B	91	99	97
	RH2-B	87	99	-
	RH3-SB	-	98	-

6.13.3. Response to survey request

The response rate achieved for the two pilot studies differed, with a higher response rate obtained for pilot study 2 (57%) than pilot study 1 (45%). The lower response rate for pilot study 1 may have resulted from the mailout period including the Christmas / New Year period and the January summer holiday period. A recommendation from pilot study 1 was to avoid the summer period for approaching patients and to include 2 reminder letters. These recommendations were adopted in pilot study 2, and this may have contributed to the higher response rate achieved.

The mix of cancer types of patients responding to pilot study 1 and pilot study 2 differed, with a greater proportion of the sample in pilot study 2 having breast cancer (pilot study 2: 25%; pilot study 1: 11%). The proportion of lymphoma patients was slightly greater in pilot study 2 (15%) than pilot study 1 (10%).

6.13.4. Diagnosis process

Similar proportions of patients in the two pilot studies learned their diagnosis from their GP (pilot study 1: 22%; pilot study 2: 19%). At diagnosis, patients in the two pilot studies were less likely to receive information about who they could contact for support (pilot study 1: 45%; pilot study 2: 51%) or how to access more information (pilot study 1: 42% pilot study 2: 49%) than receiving information about treatment options (pilot study 1: 75%; pilot study 2: 74%). Both pilot studies found that compared to patients told their diagnosis by a surgeon, those told by a GP were less likely to understand their diagnosis, less likely to have received information in a format they were happy with and less likely to feel that the doctor encouraged them to ask questions.

6.13.5. Surgery

The proportion of patients having surgery within four weeks of being ready in the two pilot studies was similar (pilot study 1: 68%; pilot study 2: 73%). Provision of information about the surgery was similar in the two pilot studies, with, for example, 80 per cent of patients in pilot study 2 indicating they received enough information about what it would be like after surgery, compared to 85 per cent in pilot study 1. In both studies, approximately 20 per cent of all patients who experienced side effects after surgery did not think they were managed well by staff. However, while in pilot study 2 this proportion was similar across health services, in pilot study 1, a greater proportion of patients from P1-MH4-A1 (35%) than P1-RH5-A2 (11%) thought this was the case. In pilot study 2, approximately 50 per cent of patients across all health services indicated they could get a staff member to assist them within a reasonable time, which was lower than the 65 per cent of all patients in pilot study 1. However, the 50 per cent found in metropolitan health services taking part in pilot study 2 was similar to the proportion found in the metropolitan health service participating in pilot study 1.

Overall, a similar proportion of patients indicated they received enough information at discharge about managing at home in pilot study 1 (79%) as in pilot study 2 (76%). However, a greater proportion of patients who thought they needed assistance post-discharge reported that arrangements had been made for these services in pilot study 1 (80%) than in pilot study 2 (62%).

6.13.6. Radiotherapy

Experiences of radiotherapy were similar for patients in pilot study 1 and pilot study 2. In both pilot studies a similar proportion of patients waited less than 30 minutes for their radiotherapy appointments. Provision of information about treatment was high in both pilot studies, with, for example, 94 per cent of patients in pilot study 2 and 96 per cent of patients in pilot study 1 indicating they received information about what would happen during treatment. In both studies nearly 90 per cent of patients indicated health professionals checked they understood the information provided (pilot study 1: 86%; pilot study 2: 87%).

In both pilot studies, the majority of patients indicated that health professionals regularly checked if they had any side effects (pilot study 1: 86%; pilot study 2: 91%). However, while in pilot study 1, this proportion did not differ across health services, in pilot study 2, there was a significant effect of health service, with only approximately 82 per cent of patients at MH1-A1 reporting this, compared to 92 per cent of patients from RH1-B. A greater proportion of patients in pilot study 2 (82%) than pilot study 1 (72%) reported that health professionals checked if they needed help or assistance with things such as diet and physical movements.

Overall, fewer radiotherapy patients were very satisfied with car parking facilities in pilot study 2 (31%) than pilot study 1 (47%). Satisfaction with car parking facilities was substantially less at the two metropolitan health services in pilot study 2 (29% and 26%) than the metropolitan health service in pilot study 1 (P1-MH4-A1: 55%).

6.13.7. Chemotherapy

While in general, care experiences of patients having chemotherapy at health services in pilot study 1 and pilot study 2 were similar, there were some differences. A greater proportion of patients having chemotherapy at health services in pilot study 2 reported having treatment within 30 minutes of their appointed time (83%) compared to the proportion found in pilot study 1 (68%).

Provision of information about chemotherapy was similar across the two pilot studies, with, for example, 93 per cent of patients in pilot study 2 and 90 per cent in pilot study 1 reporting that they received enough information about the possibility of going to an emergency department. In both studies approximately 20 per cent of patients thought they did not receive enough information about how they would feel at the end of chemotherapy treatment (pilot study 1: 19%; pilot study 2: 23%).

The proportion of patients in pilot study 1 (15%) and pilot study 2 (11%) reporting that they did not receive enough information about managing side effect at home was similar.

Care regarding side effects was high in both surveys, with 93 per cent of patients in pilot study 1 and 94 per cent of patients in pilot study 2 reporting that health professionals regularly checked if they had any side effects from treatment. Additionally, 86 per cent of patients with side effects in pilot study 1 and 89 per cent in pilot study 2 reported that health professionals did everything they could to manage these side effects.

6.13.8. Emergency department care

In both studies approximately 30 per cent of patients reported attending an emergency department for care related to their cancer treatment (pilot study 1: 31%; pilot study 2: 28%). A slightly greater proportion of patients in pilot study 2 (57%) than pilot study 1 (43%) reported waiting up to 30 minutes before seeing a health professional. Twenty-four per cent of patients attending an emergency department in pilot study 1 and 18 per cent of patients in pilot study 2 were not confident that all or most of the staff had the skills needed to look after them.

6.13.9. Follow-up care

Patients in pilot study 2 were less likely to report that they had received information about the follow-up tests needed, how often they would require tests or check-ups, how to stay healthy, how to manage any side effects or symptoms, what new symptoms needed investigation and how people commonly feel after finishing cancer treatment than were patients in pilot study 1.

6.13.10. Overall care

In both surveys, approximately three-quarters of patients reported there had been a health professional they could contact if they needed help or advice throughout their treatment (pilot study 1: 78%; pilot study 2: 76%). Additionally, in both surveys most patients reported that the exchange of information between health professionals was very good (pilot study 1: 86%; pilot study 2: 91%), and that test results were available when needed (pilot study 1: 85%; pilot study 2: 85%). In pilot study 1, 21 per cent reported receiving conflicting information from health professionals at least once, and 19 per cent reported that they had encountered a health professional who did not seem fully informed about their treatment or progress at least once. In pilot study 2, 19 per cent and 14 per cent reported these events respectively.

Among patients for whom this information was relevant, similar proportions in pilot study 1 and pilot study 2 reported receiving information about the impact of treatment on their work capacity (pilot study 1: 81%; pilot study 2: 74%), energy levels (pilot study 1: 74%; pilot study 2: 70%), financial support programs (pilot study 1: 64%; pilot study 2: 63%) and fertility preservation (pilot study 1: 60%: pilot study 2: 58%).

7. Conclusions

This study aimed to examine several methodological questions that arose from an initial pilot study testing the feasibility of assessing Victorian cancer patients' experiences of care. A key question arising from that initial pilot study was whether responses to the survey and response rates were positively influenced by the survey request coming from the health service where patients had their cancer care. The current study examines this issue by randomising patients to receive the survey request from the health service treating them or from the department. The current study found that overall response rates and survey responses were the same for both survey request conditions, suggesting that using the treating health service to request survey completion will not introduce a positive bias into study results. It also suggests that response rates will not be adversely affected if the survey invitation comes from the department.

The second question this pilot study examined was whether response rates could be increased if two reminder letters were incorporated into the study methodology and the mailout was not conducted over the Christmas / summer holiday period. The current study achieved a response rate of 57 per cent, which was higher than the 45 per cent response rate achieved for pilot study 1.

A modular version of the survey was used for patients recruited through RH2-SB, with patients only completing questions assessing their chemotherapy care. The response rate achieved for this health service (65%) was slightly higher than the overall response rate for the study (57%). While the higher response rate could be due to the shorter survey, because the response rate for another regional health service using the full survey was approximately 60 per cent, other factors may also contribute to the higher response.

Similar to the findings from pilot study 1, the majority of patients participating in pilot study 2 were very satisfied with the care they received, with 77 per cent of patients having surgery, 88 per cent of patients having radiotherapy and 84 per cent of those having chemotherapy very satisfied. Additionally, 90 per cent of patients having surgery, 98 per cent of those having radiotherapy and 98 per cent of those having chemotherapy reported that health professionals involved in their care treated them with respect and dignity. However, despite the high levels of satisfaction, the survey highlights some areas of care that could be improved, in particular, information provision regarding possible long-term effects of treatment, access to emotional and practical support and provision of information regarding possible emotional and physical responses at the end of treatment.

> *'I found those in the oncology department were all kind and helpful, considerate in every way, and professional in the way they provided the treatment.' (leukaemia patient, regional hospital)*

Similar to findings from pilot study 1, this study found that surgeons play a key role in the treatment of cancer patients. In the current study, 71 per cent of patients had surgery for their cancer, and 35 per cent of patients reported that surgeons gave them their diagnosis. Patients told their diagnosis by their surgeon reported better experiences regarding information provision than if they were told their diagnosis by a GP. However, less than 50 per cent of patients told their diagnosis by a surgeon or a GP reported receiving information about who they could contact for support or how to get more information about their cancer.

In pilot study 1, all patients approached about the study were identified through the VAED. This database contains a record of all admitted episodes of care in Victorian hospitals. Seventy-one per cent of patients participating in pilot study 1 had surgery for their cancer, with 41 per cent having chemotherapy and 37 per cent having radiotherapy. In contrast, in pilot study 2, 71 per cent of respondents had surgery, 70 per cent had chemotherapy and 60 per cent had radiotherapy. The difference in the treatment profile of patients in the two studies is likely due to the use of patient lists from two treatment-specific centres (radiotherapy and chemotherapy) to recruit patients into the survey. Examination of the cancers of patients recruited through the two treatment-specific patient lists and the VAED, highlights a greater proportion of breast and prostate cancer patients in the sample recruited through the treatment-specific patient lists than the VAED. This difference reflects the cancers that are likely to receive radiotherapy and chemotherapy as part of their cancer care. If patient lists from treatment-specific centres are used to identify eligible patients for the survey, the impact on the resulting profile of patients completing the survey needs to be recognised.

Patients identified through the treatment-specific patient list of MH1-A1 completed the full survey, which included sections assessing surgical care, chemotherapy care, follow-up care and care overall. Few patients recruited through the radiotherapy centre at MH1-A1 had their surgery or chemotherapy at the health service. Instead, 61 per cent of these patients had surgical care at a metropolitan private hospital. Results from pilot study 1 suggest that using the VAED to identify patients for the study may result in relatively low numbers of patients undergoing radiotherapy or chemotherapy reducing the study's ability to produce reliable estimates of the radiotherapy and chemotherapy care experiences within a health service. Results from the current study suggest that using patient lists from treatment-specific centres to identify patients may not resolve this problem, because many patients attending a treatment specific centre may have their other treatments at other public hospitals or in the private sector.

Pilot study 1 found differences in the care experiences of patients treated at a metropolitan health service and those treated at regional health services, with patients attending the metropolitan health service generally reporting less positive care experiences. In the second pilot study this difference was not as clearly evident, and differences found varied by treatment modality. For instance, patients having surgery at RH2-B were less likely to report receiving enough information about managing at home at discharge than those having surgery at one of the metropolitan health services. Additionally, compared to patients having chemotherapy at regional health services, a greater proportion of patients at metropolitan health services reported that staff did not consider the distance they had to travel to attend appointments when scheduling their appointments.

> *'I have found the care, expertise and knowledge of the public health system to be first class. I have been treated well by health professionals. My current and only complaint about being confused at the conflicting information is not a reflection on the health professionals overall. Perhaps interpretation is the problem here.' (thyroid cancer patient, metropolitan hospital)*

Similar to pilot study 1's findings, 35 per cent of patients in the current study attended an emergency department as a result of their cancer. Of these patients, 67 per cent were admitted to hospital as a consequence of their emergency department attendance suggesting that most cancer patients appropriately attend emergency departments. The majority of patients (80%) attending the emergency department reported that their condition was well managed.

The survey tool included two questions assessing whether patients considered there was a health professional or a team of health professionals they could contact if they had any questions or needed assistance, and if they were given the name of a clinical nurse specialist who would be in charge of their care. Overall, 43 per cent of patients having all their treatment at a pilot study health service were given the name of a clinical nurse specialist, while 76 per cent indicated there was at least one health professional they could contact. Patients indicating that they had a health professional contact were more satisfied with their surgical and radiotherapy care. In addition, patients without a health professional contact were more likely to report a need for information regarding access to allied health services (for example, social worker) and access to supportive care services (Cancer Helpline). The results suggest that having a health professional contact can have a positive impact on patients' care experiences, and can aid them in accessing information. However, our results also suggest that this person does not have to be a nominated clinical nurse specialist, but rather can be a member of the healthcare team. It is likely that clear identification of this contact person to patients, providing patients with this person's contact details and informing patients that they can contact this health professional whenever needed, helps to make this role effective.

The survey used in pilot study 2 was a revised version of the one used in pilot study 1. While it excluded a section addressing hormonal therapy, it was still relatively long. Because less than half of the respondents in pilot study 2 (42%) had only one treatment modality for their cancer, most respondents had to complete most sections of the survey. Encouragingly, the length of the survey did not seem to impact survey participation adversely, because response rates were similar to that achieved at the health service using the shorter survey. However, in order to reduce the burden on patients, reviewing the items in the survey to identify items with ceiling or floor effects is warranted. Appendix B provides a list of items in each section where over 90 per cent of respondents provided the same answer. The inclusion of these items in future versions of the survey needs to be considered.

Combining data from pilot study 1 and pilot study 2, approximately 20 per cent of respondents had surgery for cancer in the private health system. Data from pilot study 2 suggests that approximately 32 per cent of patients had their follow-up care in the private system. There were few statistically significant differences in the surgical or follow-up care experiences of patients treated publicly and privately. Patients having their surgery privately were significantly more likely to report that they received information about what would happen next, and that their appointments were coordinated. They were also more likely to report that the toilets in the hospital were clean. Patients who had their follow-up care in the private system were more likely to report that their work, travel or other commitments were considered when scheduling appointments. Additionally, there was a suggestion that public patients were less likely to receive information about how people commonly feel after treatment compared to patients in the private system. However, in the main, results suggest that the care experiences of patients treated for cancer in the public and private sector were similar.

The Cancer Strategy and Development section of the department and Victorian cancer services aim to deliver quality cancer services that are patient centred. This survey of patients receiving care at six Victorian public health services confirm the findings from pilot study 1 that, in general, patients are very positive about the health care they receive, although it also found there was some room for improvement – especially in the delivery of emotional and supportive care.

This study demonstrates that surveying cancer patients about their care experiences is feasible, and can provide indicators of areas of care being delivered well, and areas where some improvement may benefit patients. Extending the survey to all health services that deliver cancer care in Victoria will provide a picture of how cancer patients across Victoria experience cancer care. This information can help to inform the development of new cancer care initiatives and, if the survey were repeated, it could help assess whether new initiatives to improve patient care experiences are experienced at the patient level.

> *Everyone from the very start was caring, kind and cared only for how I was [and] what the best treatment would be. I had faith in them and I cannot praise them enough.' (breast cancer patient, regional hospital)*

8. Recommendations

The initial pilot study demonstrated that people receiving cancer treatment and care in Victorian public hospitals are willing to complete a survey regarding their care experiences. This second pilot study highlights several methodological issues that need to be considered in future studies of patients, as well as several issues relating to the survey tool. In addition, findings from the pilot survey regarding patient care experiences have also suggested some areas of care that health services may learn from.

8.1. Survey methodology and survey tool recommendations

8.1.1. Conduct of survey

Recommendation 1: Conduct the study in a time period that does not include major holiday periods (for example, Christmas/Easter, major school holidays). The response rate achieved for pilot study 2 was higher than that achieved for pilot study 1. Unlike pilot study 1, pilot study 2 was not conducted over the Christmas / summer holiday period. Findings from pilot study 2 confirm the recommendation that future studies should be conducted outside major holiday periods.

Recommendation 2: Two reminders should be included in the planned approach to potential survey respondents. As recommended in pilot study 1, two reminders were used for the conduct of the study. Including the second reminder to respondents increased the gross return rate for the study by 12 per cent. Future studies should include two reminder mailouts. Following the strategy used for this study, the reminder system could involve a first reminder consisting of only a letter sent to patients approximately two weeks after the first approach, with the second reminder involving a letter and survey sent approximately 4–5 weeks after the first mailout. Approach letters need to inform patients that reminders will be sent if no response is received.

Recommendation 3: Patients’ vital status needs to be confirmed before the first approach, and also prior to the second reminder.

Recommendation 4: Pilot study 2 examined the impact of the survey invitation coming from patients’ health service or the department (DHHS). The study found no difference in overall response rates between the two invitation letter conditions. While at three health services, the hospital approach produced slightly higher response rates at two health services, the department letter produced a higher response. There was no difference in responses to survey items between the two conditions. Findings suggest that future studies could use either Department letterhead or the health service’s letterhead to invite patients into the study.

Recommendation 5: Identify a strategy to ensure patients who attend multiple health services are approached only once for the survey. Pilot study 2 used the VAED to identify eligible patients for the survey from four health services. A number of patients completing the survey indicated they attended two of health services participating in the pilot study for their cancer care. Identifying a strategy that could avoid approaching these patients twice would be appropriate. A possible strategy would be to use a linked data set between the VAED and the Victorian Cancer Registry (VCR). This linked data set would enable patients to be uniquely identified and approached only once about completing the survey.

Recommendation 6: If a VAED-VCR linked data set can be used to identify patients, explore the possibility of using the VCR to conduct the mailout to patients. If the department is used as the organisation inviting patients to complete the survey, the need for health service participation in the mailout may be reduced. If a linked VAED-VCR data set is used to identify patients for the study, it may be possible to use patient contact information from the VCR for the mailout. Because the VCR has access to the death register, using the VCR may aid in undertaking death checks before surveys are mailed out.

Recommendation 7: Using treatment-specific (for example, chemotherapy, radiotherapy) patient lists to identify patients for the survey is possible, and results in a larger number of patients reporting on their care experiences for these treatment modalities. However, the profile of patients attending treatment-specific centres may differ from the profile of cancer patients in general. In addition, many of the patients attending these centres may have their other cancer treatments at other health services, including private hospitals. Thus, using treatment-specific patient lists may not provide an adequate avenue for assessing the care experiences of patients having other cancer treatments at that health service. If treatment-specific patient lists are used to identify patients for the survey, explore the utility of using only a modular version of the survey tool.

Recommendation 8: A treatment-specific module version of the survey can be used and may result in a slightly higher response rate. However, using only a specific treatment module means information on the patient's treatment paths or follow-up will not be captured.

Recommendation 9: To ensure sufficient numbers of patients report on treatment experiences at the index health service, pilot study 2 increased the number of patients identified at each hospital for the survey. This resulted in larger number of patients having specific treatments at each health service; however, it also necessitated approaching patients who were diagnosed 20 months previously. To assess chemotherapy and radiotherapy care, it may be more appropriate to use treatment specific patient lists to identify patients and use survey modules.

8.1.2. Survey tool

Recommendation 10: For 13 items, 90 per cent or more respondents gave the same response. Review these items and determine whether they can be removed from the survey.

Recommendation 11: Turning treatment sections of the survey into stand-alone modules is possible. Develop a suite of survey modules allowing health services to select the modules they want to use.

Recommendation 12: Develop an online manual on how to administer the survey with guidelines for individual modules. Explore the possibility of providing statewide norms for item responses allowing health services to benchmark against these norms. In future iterations on the manual and survey, explore the possibility of providing hospital peer group norms for comparison (for example, Category A hospitals).

8.1.3. Future surveys

Recommendation 13: Benchmarking hospitals against their own results will provide information regarding care improvements. It is recommended to repeat the survey at regular intervals which may relate to the development cycles of the cancer action plan (every four years). Because there was little change in survey responses between pilot study 1 (2012–13) and pilot study 2 (2015), an appropriate survey frequency should be determined.

Recommendation 14: Pilot study 2 included several metropolitan and regional health services of a similar category (for example, Category A), allowing appropriate comparisons of results between health services**.** When conducting future studies, include several hospitals within the same category (for example, Category A) to enable appropriate comparisons between health services.

Recommendation 15: Pilot study 2 was conducted in English, and required patients to be able to read and write English. There is still a need to test the survey with people from a non-English speaking background. Translate the survey into several languages commonly spoken in Victoria and test the survey with these groups. Include use of translated surveys in next iteration of the survey. Use data from the VAED to identify the key languages of cancer patients in Victoria to assist with identifying appropriate languages for translation.

8.2. Patient care experiences

Findings from pilot study 2 were similar to those of pilot study 1. Therefore, recommendations from pilot study 1 are still relevant, and include:

8.2.1. Diagnosis and treatment planning

Recommendation 1: Provide GPs with resources and skills regarding delivering cancer diagnosis information to patients.

8.2.2. Side-effect management/management in emergency departments

Recommendation 2: Investigate the side effects patients thought were not managed well in different care areas (for example, surgery, radiotherapy) and develop strategies to address these.

Recommendation 3: Provide emergency department staff with greater information regarding the management of cancer patients attending emergency department.

8.2.3. Information provision

Recommendation 4: Ensure there is a member of the patient’s healthcare team who can act as a contact person for the patient. Provide patient with contact details of this healthcare team member, and ensure patients are aware they can contact them if they have any questions or need any information.

Recommendation 5: Investigate ways to provide patients with more information about side effects of treatment and management of side effects.

Recommendation 6: Investigate ways of ensuring patients receive information about supportive care programs and financial programs.

Recommendation 7: Investigate ways to ensure that patients who are concerned about their fertility are provided with information about fertility preservation and the possible impact of treatment on fertility.

8.2.4. Car parking

Recommendation 8: Ensure patients are informed about car parking arrangements they can access when receiving chemotherapy and radiotherapy treatments

.

9. Appendix A: Reponses to all items

Responses to questions in Section 1: Finding out what was wrong with you

Questions assessing diagnosis and information received at this time

Table A.1.1a How long was it between when you were referred to a specialist doctor or hospital clinic and your first appointment?

Category	< 2 weeks	2–4 weeks	> 1 month	Stayed with GP	Not sure / cannot remember	Other
All patients	606	273	127	5	60	27
	55.2%	24.9%	11.6%	0.5%	5.5%	2.5%

Table A.1.1b If more than two weeks or more than a month, was this due to:

Category	Personal decisions to wait	Specialist waiting times	Hospital waiting time	Other
All patients	14	199	88	35
	4.2%	59.2%	26.2%	10.4%

Table A.1.1c How long between when you were referred to a specialist doctor or hospital clinic and your first appointment by cancer type (Only cancers with more than 20 people reported. People staying with GP excluded)

Patient cancer type	< 2 weeks	2–4 weeks	> 1 month	Not sure / cannot remember	Other	Total
Breast	189	53	17	8	3	270
	70.0%	19.6%	6.3%	3.0%	1.1%	100.0%
Leukaemia	22	7	1	2	1	33
	66.7%	21.2%	3.0%	6.1%	3.0%	100.0%
Prostate	27	27	10	6	3	73
	37.0%	37.0%	13.7%	8.2%	4.1%	100.0%
Colorectal	45	21	13	4	1	84
	53.6%	25.0%	15.5%	4.8%	1.2%	100.0%
Lung	33	18	7	3	1	62
	53.2%	29.0%	11.3%	4.8%	1.6%	100.0%
Brain	32	3	0	2	3	40
	80.0%	7.5%	0.0%	5.0%	7.5%	100.0%
Uterus	9	10	2	1	0	22
	40.9%	45.5%	9.1%	4.5%	0.0%	100.0%
Multiple myeloma	32	16	9	5	3	65
	49.2%	24.6%	13.8%	7.7%	4.6%	100.0%
Kidney	9	10	3	2	1	25
	36.0%	40.0%	12.0%	8.0%	4.0%	100.0%
Lymphoma	86	26	26	11	4	153
	56.2%	17.0%	17.0%	7.2%	2.6%	100.0%
Bladder	10	21	10	6	2	49
	20.4%	42.9%	20.4%	12.2%	4.1%	100.0%
Throat/mouth	21	9	5	0	1	36
	58.3%	25.0%	13.9%	0.0%	2.8%	100.0%

Table A.1.2 Who gave you the result of the test that showed that you definitely had cancer?

Category	GP	Surgeon	Medical Oncologist	Radiation oncologist	Haematologist	Hospital doctor	Other
All patients	211	369	167	20	88	125	90
	19.7%	34.5%	15.6%	1.9%	8.2%	11.7%	8.4%

Table A.1.2.1 Who gave you the result of the test that showed that you definitely had cancer?

Patient cancer type	**GP**	**Surgeon**	**Medical oncologist**	**Radiation oncologist**	**Haematologist**	**Hospital doctor**	**Other**	**Total**
Breast	74	112	27	6	0	17	22	258
	28.7%	43.4%	10.5%	2.3%	0.0%	6.6%	8.5%	100.0%
Leukaemia	11	0	5	0	11	3	1	31
	35.5%	0.0%	16.1%	0.0%	35.5%	9.7%	3.2%	100.0%
Prostate	4	30	14	0	0	7	13	68
	5.9%	44.1%	20.6%	0.0%	0.0%	10.3%	19.1%	100.0%
Colorectal	6	51	8	0	0	9	8	82
	7.3%	62.2%	9.8%	0.0%	0.0%	11.0%	9.8%	100.0%
Lung	10	16	20	5	1	3	3	58
	17.2%	27.6%	34.5%	8.6%	1.7%	5.2%	5.2%	100.0%
Brain	3	16	4	1	0	10	6	40
	7.5%	40.0%	10.0%	2.5%	0.0%	25.0%	15.0%	100.0%
Uterus	2	5	7	0	0	4	2	20
	10.0%	25.0%	35.0%	0.0%	0.0%	20.0%	10.0%	100.0%
Multiple myeloma	15	4	11	0	22	7	1	60
	25.0%	6.7%	18.3%	0.0%	36.7%	11.7%	1.7%	100.0%
Kidney	7	11	1	0	0	3	3	25
	28.0%	44.0%	4.0%	0.0%	0.0%	12.0%	12.0%	100.0%
Lymphoma	29	17	30	1	37	16	7	137
	21.2%	12.4%	21.9%	.7%	27.0%	11.7%	5.1%	100.0%
Bladder	10	23	5	1	0	7	1	47
	21.3%	48.9%	10.6%	2.1%	0.0%	14.9%	2.1%	100.0%
Throat/mouth	2	17	3	2	1	6	3	34
	5.9%	50.0%	8.8%	5.9%	2.9%	17.6%	8.8%	100.0%

Table A.1.3 When you were told you had cancer, did you understand the doctor's explanation of what was wrong with you?

Category	**Yes completely**	**Yes most of it**	**Yes some of it**	**No**	**Not sure / cannot remember**
All patients	738	291	80	21	7
	64.9%	25.6%	7.0%	1.8%	0.6%

Table A.1.4 When you were told you had cancer, did your doctor encourage you to ask questions?

Category	Yes	No	It wasn't necessary I wanted to ask questions	I did not want to ask questions	Not sure / cannot remember
All patients	805	60	154	33	44
	73.4%	5.5%	14.1%	3.0%	4.0%

Table A.1.5 When you were told you had cancer:

Question	All patients	Yes Definitely	Yes I think so	No I do not think so	No definitely not	Not sure / cannot remember
a. Were you given information about your cancer in a format that you were happy with?	Number	779	253	37	35	16
	Per cent	69.6%	22.6%	3.3%	3.1%	1.4%
b. Were you given information about the treatment options for your cancer?	Number	801	182	50	41	10
	Per cent	73.9%	16.8%	4.6%	3.8%	0.9%
c. Were you told how you could get more information?	Number	525	168	218	116	35
	Per cent	49.4%	15.8%	20.5%	10.9%	3.3%
d. Were you given information about who you could contact for support?	Number	538	168	197	117	37
	Per cent	50.9%	15.9%	18.6%	11.1%	3.5%

Table A.1.6 After getting your diagnosis, did a health professional go through the information about your cancer and your treatment options again?

Category	Yes at another appointment	Yes, over the phone	Yes, informally	No, but I would have liked them to	No but not necessary	Not sure / cannot remember
All patients	897	23	13	53	101	37
	79.8%	2.0%	1.2%	4.7%	9.0%	3.3%

Table A.1.7 Did the health professionals involved in your diagnosis talk to you with respect and understanding?

Category	Yes always	Yes sometimes	No	Not sure / cannot remember
All patients	1051	63	18	10
	92.0%	5.5%	1.6%	0.9%

Table A.1.8 Did the health professionals involved in your diagnosis ask if your family or friends needed any information or support?

Category	Yes, definitely	Yes, I think so	No, not at all	Family did not need this	Family not involved	Not sure / cannot remember
All patients	504	259	166	101	28	72
	44.6%	22.9%	14.7%	8.9%	2.5%	6.4%

Responses to questions in Section 2: Deciding on treatment

Questions assessing experiences in deciding on treatment including type of information received, patient involvement and whether health professionals checked understanding of information.

Table A.2.1 Were you involved as much as you wanted to be in decisions about your care and treatment?

Category	Yes, definitely	Yes, to some extent	No	I did not want to be/not well enough/did not want to be involved	Only one treatment suitable	Not sure / cannot remember
All patients	803	190	24	17	90	7
	71.0%	16.8%	2.1%	1.5%	8.0%	0.6%

Table A.2.2 Did you have treatment for your cancer?

Category	Yes	No
All patients	1133	21
	98.2%	1.8%

Table A.2.3a Were possible short-term side effects of the treatment explained to you before your cancer treatment started?

Category	Yes, definitely	Yes, to some extent	No, I would have liked this information	No, researched this myself	Not sure / cannot remember
All patients	854	194	17	11	18
	78.1%	17.7%	1.6%	1.0%	1.6%

Table A.2.3b Were possible long-term side effects of the treatment explained to you before your cancer treatment started?

Category	Yes, definitely	Yes, to some extent	No, I would have liked this information	No, I researched this myself	Not sure / cannot remember
All patients	648	268	75	28	57
	60.2%	24.9%	7.0%	2.6%	5.3%

Table A.2.4 Did the health professionals involved in your care check that you understood the information provided to you about the side effects of treatment?

Category	Yes, definitely	Yes, to some extent	No	I did not receive this information	Not sure / cannot remember
All patients	725	271	45	11	36
	66.6%	24.9%	4.1%	1.0%	3.3%

Table A.2.5 Did the health professionals encourage you to ask questions about your treatment options?

Category	Yes, definitely	Yes to some extent	No	Not sure / cannot remember
All patients	769	221	74	25
	70.6%	20.3%	6.8%	2.3%

Table A.2.6 Once your treatment was decided on, did a health professional give you information regarding what treatment would involve, how long it would take to complete all treatment and how long it might take to recover?

Category	Yes, and adequate information	Yes, but not adequate information	Did not receive any information	Not sure / cannot remember
All patients	986	68	34	9
	89.9%	6.2%	3.1%	0.8%

Table A.2.7 Before you started any treatment, did a health professional organise for you to see any other health professionals who may have been able to help with issues that may arise from your treatment?

Category	Yes. referred to services	No but I would have liked to have been	No, as not needed	Not sure / cannot remember
All patients	769	221	74	25
	70.6%	20.3%	6.8%	2.3%

Responses to questions in Section 3: Surgery

Questions assessing experiences of surgery including how long patients waited to have surgery, information received before surgery on any costs, what would happen during and after surgery, health professionals interactions after surgery and satisfaction with surgery care.

Table A.3.1 Number of patients having surgery for their cancer

Category	Number of patients having surgery	%
Surgery at five pilot study health services	402	55.8%
Surgery at other treatment centres	319	44.2%
All patients	721	71.1%

Table A.3.2 How long ago did you have this surgery?

Category	< 3 months ago	3–6 months ago	6–12 months ago	12–24 months ago	> 2 years ago	Not sure / cannot remember
Five pilot study health services	34	46	134	137	44	1
	8.6%	11.6%	33.8%	34.6%	11.1%	0.3%
Other treatment centres	20	26	103	125	34	0
	6.5%	8.4%	33.4%	40.6%	11.0%	0.0%
All patients	54	72	237	262	78	1
	7.7%	10.2%	33.7%	37.2%	11.1%	0.1%

Table A.3.3 Who made decision to have your surgery at this hospital?

Category	I did	I did after considering doctors opinion	My doctor and I together	Doctor made decision after considering my opinion	Doctor made decision	Other	Not sure / cannot remember
Five pilot study health services	35	53	138	55	80	29	4
	8.9%	13.5%	35.0%	14.0%	20.3%	7.4%	1.0%
Other treatment centres	19	41	122	42	68	15	3
	6.1%	13.2%	39.4%	13.5%	21.9%	4.8%	1.0%
All patients	54	94	260	97	148	44	7
	7.7%	13.4%	36.9%	13.8%	21.0%	6.2%	1.0%

Table A.3.4 Did you have any bills associated with your surgery that you had to pay?

Category	No	Yes and health insurance covered costs completely	Yes and health insurance covered some costs	Yes I had bills to pay
Five pilot study health services	341	15	10	32
	85.7%	3.8%	2.5%	8.0%
Other treatment centres	106	26	135	44
	34.1%	8.4%	43.4%	14.1%
All patients	447	41	145	76
	63.0%	5.8%	20.5%	10.7%

Table A.3.5 Before you had surgery, were you told or given information about the costs you would have to pay?

Category	Yes, fully informed	Yes, but not full amount	No	Not sure / cannot remember
Five pilot study health services	66	9	61	21
	42.0%	5.7%	38.9%	13.4%
Other treatment centres	131	43	47	22
	53.9%	17.7%	19.3%	9.1%
All patients	197	52	108	43
	49.3%	13.0%	27.0%	10.8%

Table A.3.6a How long did you wait until you actually had surgery?

Category	< 2 weeks	2–4 weeks	> 1 month	Not sure / cannot remember
Five pilot study health services	115	166	83	13
	29.9%	43.1%	21.6%	3.4%
Other treatment centres	175	74	46	9
	56.1%	23.7%	14.7%	2.9%
All patients	290	240	129	22
	41.6%	34.4%	18.5%	3.2%

Table A.3.6b If waited longer than two weeks:

Category	Personal decision	Surgery waiting times – kept updated	Surgery waiting times – not kept informed	Other
Five pilot study health services	7	151	22	9
	3.7%	79.9%	11.6%	4.8%
Other treatment centres	15	53	5	11
	17.9%	63.1%	6.0%	13.1%
All patients	22	204	27	20
	8.1%	74.7%	9.9%	7.3%

Table A.3.7 Did the health professional involved in your surgery ask if your family or friends needed any information or support?

Category	Yes, regularly	Yes, occasionally	No never	No as family or friends were not involved	Not sure / cannot remember
Five pilot study health services	137	98	79	37	44
	34.7%	24.8%	20.0%	9.4%	11.1%
Other treatment centres	137	63	58	21	28
	44.6%	20.5%	18.9%	6.8%	9.1%
All patients	274	161	137	58	72
	39.0%	22.9%	19.5%	8.3%	10.3%

Table A.3.8 Before having surgery were you given information about:

Question	Category	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
a. How to prepare for surgery?	Five pilot study health services	357	8	11	15
		91.3%	2.0%	2.8%	3.8%
	Other treatment centres	288	6	13	4
		92.6%	1.9%	4.2%	1.3%
	All patients	645	14	24	19
		91.9%	2.0%	3.4%	2.7%
b. What it would be like after surgery?	Five pilot study health services	292	29	31	15
		79.6%	7.9%	8.4%	4.1%
	Other treatment centres	242	23	25	11
		80.4%	7.6%	8.3%	3.7%
	All patients	534	52	56	26
		79.9%	7.8%	8.4%	3.9%

Table A.3.9 Were you given:

Question	Category	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
a. Information about to manage side effects of surgery?	Five pilot study health services	286	37	35	20
		75.7%	9.8%	9.3%	5.3%
	Other treatment centres	238	27	25	12
		78.8%	8.9%	8.3%	4.0%
	All patients	524	64	60	32
		77.1%	9.4%	8.8%	4.7%
b. Information about what would happen next?	Five pilot study health services	310	26	16	16
		84.2%	7.1%	4.3%	4.3%
	Other treatment centres	264	22	10	6
		87.4%	7.3%	3.3%	2.0%
	All patients	574	48	26	22
		85.7%	7.2%	3.9%	3.3%

Table A.3.10 During your hospital stay, how often did the doctors, nurses and other health professional caring for you explain things in a way you could understand?

Category	All of the time	Most of the time	Some of the time	Rarely	Never	Not sure / cannot remember
Five pilot study health services	215	137	29	6	4	8
	53.9%	34.3%	7.3%	1.5%	1.0%	2.0%
Other treatment centres	182	106	13	6	3	4
	58.0%	33.8%	4.1%	1.9%	1.0%	1.3%
All patients	397	243	42	12	7	12
	55.7%	34.1%	5.9%	1.7%	1.0%	1.7%

Table A.3.11a Did you have worries or fears about your condition or treatment while you were in hospital?

Category	Yes	No
Five pilot study health services	137	260
	34.5%	65.5%
Other treatment centres	109	205
	34.7%	65.3%
All patients	246	465
	34.6%	65.4%

Table A.3.11b If yes, did a health professional discuss these worries or concerns with you?

Category	Yes, completely	Yes, to some extent	No	Not sure / cannot remember
Five pilot study health services	66	52	22	7
	44.9%	35.4%	15.0%	4.8%
Other treatment centres	55	42	11	8
	47.4%	36.2%	9.5%	6.9%
All patients	121	94	33	15
	46.0%	35.7%	12.5%	5.7%

Table A.3.12 When you were in hospital for your surgery, were side effects from surgery well managed?

Category	Yes, completely	Yes, to some extent	No	I did not have any side effects from surgery	Not sure / cannot remember
Five pilot study health services	279	59	5	47	2
	71.2%	15.1%	1.3%	12.0%	0.5%
Other treatment centres	217	54	7	34	0
	69.6%	17.3%	2.2%	10.9%	0.0%
All patients	496	113	12	81	2
	70.5%	16.1%	1.7%	11.5%	0.3%

Table A.3.13 Were you in pain while in hospital after your surgery for cancer?

Category	Yes	No
Five pilot study health services	220	172
	56.1%	43.9%
Other treatment centres	162	152
	51.6%	48.4%
All patients	382	324
	54.1%	45.9%

Table A.3.14 Do you think hospital staff did everything they could to help manage your pain?

Category	Yes, definitely	Yes, to some extent	No	Not sure / cannot remember
Five pilot study health services	209	35	4	1
	83.9%	14.1%	1.6%	0.4%
Other treatment centres	152	19	9	2
	83.5%	10.4%	4.9%	1.1%
All patients	361	54	13	3
	83.8%	12.5%	3.0%	0.7%

Table A.3.13 If you needed assistance, were you able to get a member of staff to help you within a reasonable timeframe?

Category	Yes, all of the time	Yes, most of the time	Some of the time	Never	I did not need assistance	Not sure / cannot remember
Five pilot study health services	215	143	16	4	18	2
	54.0%	35.9%	4.0%	1.0%	4.5%	0.5%
Other treatment centres	179	94	15	3	20	2
	57.2%	30.0%	4.8%	1.0%	6.4%	0.6%
All patients	394	237	31	7	38	4
	55.4%	33.3%	4.4%	1.0%	5.3%	0.6%

Table A.3.14 While you were in hospital for your surgery, did a health professional organise other services you may have needed to help with your recovery?

Category	Yes I saw all the other services I needed	Yes I saw some other services but I think I needed more	No I did not see any other services but I think I needed to	I did not need any other services	Not sure / cannot remember
Five pilot study health services	176	20	20	143	6
	48.2%	5.5%	5.5%	39.2%	1.6%
Other treatment centres	165	17	21	132	9
	48.0%	4.9%	6.1%	38.4%	2.6%
All patients	341	37	41	275	15
	48.1%	5.2%	5.8%	38.8%	2.1%

Table A.3.15 Did you feel you were treated with respect and dignity while you were in the hospital?

Category	Yes, always	Yes, sometimes	No	Not sure / cannot remember
Five pilot study health services	355	34	5	2
	89.6%	8.6%	1.3%	0.5%
Other treatment centres	286	22	5	1
	91.1%	7.0%	1.6%	0.3%
All patients	641	56	10	3
	90.3%	7.9%	1.4%	0.4%

Table A.3.16 When you were discharged from hospital, were you given enough information about how to manage at home?

Category	Yes, Completely	Yes, to some extent	No	No but I researched this myself	Not sure / cannot remember
Five pilot study health services	303	67	17	5	6
	76.1%	16.8%	4.3%	1.3%	1.5%
Other treatment centres	243	51	13	4	3
	77.4%	16.2%	4.1%	1.3%	1.0%
All patients	546	118	30	9	9
	76.7%	16.6%	4.2%	1.3%	1.3%

Table A.3.17 When you were discharged from hospital were you given a telephone number to contact if you had concerns or questions about your condition or treatment?

Category	I was only given my doctor's number	I was given the name and number of someone at the hospital	I was given a hospital number to call but didn't have anyone's name	No I wasn't given any number to call	Not sure / cannot remember
Five pilot study health services	43	165	93	38	47
	11.1%	42.7%	24.1%	9.8%	12.2%
Other treatment centres	65	126	46	28	35
	21.7%	42.0%	15.3%	9.3%	11.7%
All patients	108	291	139	66	82
	15.7%	42.4%	20.3%	9.6%	12.0%

Table A.3.18 Thinking about when you left hospital, were adequate arrangements made by the hospital staff for any services you needed?

Category	Yes, completel	Yes, to some extent	No	I did not need any services	Not sure / cannot remember
Five pilot study health services	132	37	40	182	9
	33.0%	9.2%	10.0%	45.5%	2.2%
Other treatment centres	115	18	29	146	6
	36.6%	5.7%	9.2%	46.5%	1.9%
All patients	247	55	69	328	15
	34.6%	7.7%	9.7%	45.9%	2.1%

Table A.3.19 How clean were the toilets and bathrooms that you used while in hospital?

Category	Very clean	Fairly clean	Not very clean	Not at all clean	Not sure / cannot remember
Five pilot study health services	264	110	15	4	7
	66.0%	27.5%	3.8%	1.0%	1.8%
Other treatment centres	244	56	7	4	4
	77.5%	17.8%	2.2%	1.3%	1.3%
All patients	508	166	22	8	11
	71.0%	23.2%	3.1%	1.1%	1.5%

Table A.3.20 Overall how satisfied were you with the treatment you received from all health professionals involved in your surgery?

Category	Very satisfied	Satisfied	Neither satisfied or dissatisfied	Dissatisfied	Very dissatisfied
Five pilot study health services	299	76	10	3	3
	76.5%	19.4%	2.6%	0.8%	0.8%
Other treatment centres	251	50	5	3	1
	81.0%	16.1%	1.6%	1.0%	0.3%
All patients	550	126	15	6	4
	78.5%	18.0%	2.1%	0.9%	0.6%

Responses to questions in Section 4: Radiotherapy

Questions assessing experiences of radiotherapy including how long patients waited, information received about treatment, health professionals checking about side effects or service needs, waiting at appointments, travel needs and satisfaction.

Table A.4.1 Number of patients having radiotherapy for their cancer

Category	Number of patients having radiotherapy	%
Radiotherapy at three pilot study health services	475	81.1
Radiotherapy at other treatment centres	111	18.9
All patients	586	60.3

Table A.4.2 How long ago did you first have radiotherapy?

Category	< 3 months ago	3–6 months ago	6–12 months	12–24 months ago	> 2 years ago	Not sure / cannot remember
Three pilot study health services	45	97	168	136	17	1
	9.7%	20.9%	36.2%	29.3%	3.7%	0.2%
Other treatment centres	20	15	18	27	28	1
	18.3%	13.8%	16.5%	24.8%	25.7%	0.9%
All patients	65	112	186	163	45	2
	11.3%	19.5%	32.5%	28.4%	7.9%	0.3%

Table A.4.3 Who made decision to have radiotherapy at this hospital?

Category	I did	I did after considering doctor's opinion	My doctor and I made the decision together	Doctor made decision after considering my opinion	Doctor made decision	Other	Not sure / cannot remember
Three pilot study health services	26	68	165	74	95	29	2
	5.7%	14.8%	35.9%	16.1%	20.7%	6.3%	0.4%
Other treatment centres	6	19	36	19	18	3	2
	5.8%	18.4%	35.0%	18.4%	17.5%	2.9%	1.9%
All patients	32	87	201	93	113	32	4
	5.7%	15.5%	35.8%	16.5%	20.1%	5.7%	0.7%

Table A.4.4 Did you have any bills associated with your radiotherapy that you had to pay?

Category	No	Yes, but my health insurance covered costs completely	Yes, and my health insurance covered some costs	Yes I had bills to pay
Three pilot study health services	408	17	19	21
	87.7%	3.7%	4.1%	4.5%
Other treatment centres	77	2	7	18
	74.0%	1.9%	6.7%	17.3%
All patients	485	19	26	39
	85.2%	3.3%	4.6%	6.9%

Table A.4.5 Were you told of any out-of-pocket costs you might have to pay?

Category	Yes, fully informed	Yes but not full amount	No	Not sure / cannot remember
Three pilot study health services	105	6	40	24
	60.0%	3.4%	22.9%	13.7%
Other treatment centres	41	6	8	5
	68.3%	10.0%	13.3%	8.3%
All patients	146	12	48	29
	62.1%	5.1%	20.4%	12.3%

Table A.4.6a Did you stay away from home while receiving radiotherapy?

Category	Yes	No
Three pilot study health services	74	392
	15.9%	84.1%
Other treatment centres	35	69
	33.7%	66.3%
All patients	109	461
	19.1%	80.9%

Table A.4.6b If yes, who arranged this accommodation?

Category	Self/family	Staff at hospital	Doctor's staff	Not sure / cannot remember	Other
Three pilot study health services	39	19	6	1	10
	52.0%	25.3%	8.0%	1.3%	13.3%
Other treatment centres	8	15	5	1	5
	23.5%	44.1%	14.7%	2.9%	14.7%
All patients	47	34	11	2	15
	43.1%	31.2%	10.1%	1.8%	13.8%

Table A.4.7a How long did you wait until you actually had radiotherapy?

Category	< 2 weeks	2–4 weeks	> 1 month	Not sure	Other
Three pilot study health services	306	96	39	22	1
	65.9%	20.7%	8.4%	4.7%	0.2%
Other treatment centres	62	29	8	7	0
	58.5%	27.4%	7.5%	6.6%	0.0%
All patients	368	125	47	29	1
	64.6%	21.9%	8.2%	5.1%	0.2%

Table A.4.7b If you waited longer than two weeks:

Category	Personal decision	Radiotherapy waiting times – kept updated	Radiotherapy waiting times – not kept informed	Other
All patients	15	86	9	19
	11.6%	66.7%	7.0%	14.7%

Table A.4.8 Before having radiotherapy were you given information about:

Information type	Category	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
a. How to prepare for radiotherapy?	Three pilot study health services	419	8	29	7
		90.5%	1.7%	6.3%	1.5%
	Other treatment centres	89	3	8	6
		84.0%	2.8%	7.5%	5.7%
	All patients	508	11	37	13
		89.3%	1.9%	6.5%	2.3%
b. What would happen when treatment was given?	Three pilot study health services	430	13	6	7
		94.3%	2.9%	1.3%	1.5%
	Other treatment centres	90	4	3	6
		87.4%	3.9%	2.9%	5.8%
	All patients	520	17	9	13
		93.0%	3.0%	1.6%	2.3%
c. How long the radiotherapy treatment would go for?	Three pilot study health services	444	4	0	2
		98.7%	0.9%	0.0%	0.4%
	Other treatment centres	97	0	1	2
		97.0%	0.0%	1.0%	2.0%
	All patients	541	4	1	4
		98.4%	0.7%	0.2%	0.7%
d. How to manage any anxiety or stress?	Three pilot study health services	331	23	61	34
		73.7%	5.1%	13.6%	7.6%
	Other treatment centres	77	2	14	9
		75.5%	2.0%	13.7%	8.8%
	All patients	408	25	75	43
		74.0%	4.5%	13.6%	7.8%
e. How to manage any side effects?	Three pilot study health services	397	25	22	8
		87.8%	5.5%	4.9%	1.8%
	Other treatment centres	88	4	6	5
		85.4%	3.9%	5.8%	4.9%
	All patients	485	29	28	13
		87.4%	5.2%	5.0%	2.3%
f. How you might feel at the end of	Three pilot study health services	407	26	15	5
		89.8%	5.7%	3.3%	1.1%

Information type	Category	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
treatment?	Other treatment centres	92	2	6	5
		87.6%	1.9%	5.7%	4.8%
	All patients	499	28	21	10
		89.4%	5.0%	3.8%	1.8%
g. How long it might take to recover from having radiotherapy?	Three pilot study health services	362	43	33	18
		79.4%	9.4%	7.2%	3.9%
	Other treatment centres	80	5	11	6
		78.4%	4.9%	10.8%	5.9%
	All patients	442	48	44	24
		79.2%	8.6%	7.9%	4.3%

Table A.4.9 Did a health professional check you understood the information provided to you?

Category	Yes	No	Not sure / cannot remember
Three pilot study health services	406	22	36
	87.5%	4.7%	7.8%
Other treatment centres	89	4	14
	83.2%	3.7%	13.1%
All patients	495	26	50
	86.7%	4.6%	8.8%

Table A.4.10 Did staff take into account how far you had to travel or other commitments when arranging times for your appointments?

Category	Yes, definitely	Yes, as much as they could	No, not at all	Travel times or other commitments were not a problem	Not sure / cannot remember
Three pilot study health services	255	110	15	77	6
	55.1%	23.8%	3.2%	16.6%	1.3%
Other treatment centres	65	22	5	11	4
	60.7%	20.6%	4.7%	10.3%	3.7%
All patients	320	132	20	88	10
	56.1%	23.2%	3.5%	15.4%	1.8%

Table A.4.11 On average how long did you have to wait at your appointments?

Category	< 15 minutes	15–30 minutes	30–60 minutes	1–2 hours	> 2 hours	Not sure / cannot remember
Three pilot study health services	298	121	20	1	4	7
	66.1%	26.8%	4.4%	0.2%	0.9%	1.6%
Other treatment centres	52	42	7	1	2	1
	49.5%	40.0%	6.7%	1.0%	1.9%	1.0%
All patients	350	163	27	2	6	8
	62.9%	29.3%	4.9%	0.4%	1.1%	1.4%

Table A.4.12 Did a health professional check if you had any side effects or symptoms?

Category	Yes	Yes but not as often as I would have liked	No	Not sure / cannot remember
Three pilot study health services	411	18	18	14
	89.2%	3.9%	3.9%	3.0%
Other treatment centres	87	4	10	4
	82.9%	3.8%	9.5%	3.8%
All patients	498	22	28	18
	88.0%	3.9%	4.9%	3.2%

Table A.4.13 Do you think health professionals did everything they could to help you manage side effects?

Category	Yes, definitely	Yes, to some extent	No	I did not, have side effects	Not sure / cannot remember
Three pilot study health services	375	55	6	27	2
	80.6%	11.8%	1.3%	5.8%	0.4%
Other treatment centres	79	14	1	11	1
	74.5%	13.2%	0.9%	10.4%	0.9%
All patients	454	69	7	38	3
	79.5%	12.1%	1.2%	6.7%	0.5%

Table A.4.14 Did you feel you were treated with respect and dignity while in hospital?

Category	Yes, always	Yes, sometimes	No	Not sure / cannot remember
Three pilot study health services	459	8	0	0
	98.3%	1.7%	0.0%	0.0%
Other treatment centres	104	2	1	1
	96.3%	1.9%	0.9%	0.9%
All patients	563	10	1	1
	97.9%	1.7%	0.2%	0.2%

Table A.4.15 Did health professionals check if you needed any help or assistance with things like diet or eating or physical movement?

Category	Yes	No	Not sure / cannot remember
Three pilot study health services	376	56	28
	81.7%	12.2%	6.1%
Other treatment centres	86	15	6
	80.4%	14.0%	5.6%
All patients	462	71	34
	81.5%	12.5%	6.0%

Table A.4.16 Did health professionals check if you needed any assistance with managing your emotional state?

Category	Yes	No	Not sure / cannot remember
Three pilot study health services	335	73	52
	72.8%	15.9%	11.3%
Other treatment centres	75	20	10
	71.4%	19.0%	9.5%
All patients	410	93	62
	72.6%	16.5%	11.0%

Table A.4.17 Did health professionals check if you needed any help or assistance with travelling to and from your appointments?

Category	Yes	No	Not sure / cannot remember
Three pilot study health services	278	133	46
	60.8%	29.1%	10.1%
Other treatment centres	70	23	13
	66.0%	21.7%	12.3%
All patients	348	156	59
	61.8%	27.7%	10.5%

Table A.4.18 Were you given a telephone number to contact if you had concerns or questions about your condition or treatment?

Category	Yes	No	Not sure / cannot remember
Three pilot study health services	412	27	24
	89.0%	5.8%	5.2%
Other treatment centres	83	12	11
	78.3%	11.3%	10.4%
All patients	495	39	35
	87.0%	6.9%	6.2%

Table A.4.19 Did health professionals ask if your family/friends needed information or support?

Category	Yes, regularly	Yes, occasionally	No, never	No family/friends involved	Not sure / cannot remember
Three pilot study health services	140	103	77	76	65
	30.4%	22.3%	16.7%	16.5%	14.1%
Other treatment centres	41	29	18	12	7
	38.3%	27.1%	16.8%	11.2%	6.5%
All patients	181	132	95	88	72
	31.9%	23.2%	16.7%	15.5%	12.7%

Table A.4.20 How satisfied were you with the availability of car parking at treatment centre?

Category	Very satisfied	Satisfied	Neither	Dissatisfied	Very dissatisfied	Not applicable
Three pilot study health services	117	148	63	37	12	85
	25.3%	32.0%	13.6%	8.0%	2.6%	18.4%
Other treatment centres	43	34	11	4	5	10
	40.2%	31.8%	10.3%	3.7%	4.7%	9.3%
All patients	160	182	74	41	17	95
	28.1%	32.0%	13.0%	7.2%	3.0%	16.7%

Table A.4.21 Overall how satisfied were you with the treatment you received from all health professionals involved in your radiotherapy?

Category	Very satisfied	Satisfied	Neither	Dissatisfied
Three pilot study health services	411	52	4	0
	88.0%	11.1%	0.9%	0.0%
Other treatment centres	89	16	2	1
	82.4%	14.8%	1.9%	0.9%
All patients	500	68	6	1
	87.0%	11.8%	1.0%	0.2%

Responses to questions in Section 5: Chemotherapy

Questions assessing experiences of chemotherapy including how long patients waited, information received about treatment, health professionals checking about side effects or service needs, waiting at appointments, travel needs and satisfaction.

Table A.5.1 Number of patients having chemotherapy for their cancer

Category	Number of patients having chemotherapy	%
Chemotherapy at six pilot study health services	539	78.1
Chemotherapy at other treatment centres	151	21.9
All patients	690	69.9%

Table A.5.2 When did you start chemotherapy for the first time?

Category	< 3 months ago	3–6 months ago	6–12 months	12–24 months ago	> 2 years ago	Not sure / cannot remember
Six pilot study health services	46	69	155	164	89	3
	8.7%	13.1%	29.5%	31.2%	16.9%	0.6%
Other treatment centres	9	19	38	49	28	0
	6.3%	13.3%	26.6%	34.3%	19.6%	0.0%
All patients	55	88	193	213	117	3
	8.2%	13.2%	28.8%	31.8%	17.5%	0.4%

Table A.5.3 Who made decision to have chemotherapy at hospital?

Category	I did	I did after considering doctor’s opinion	My doctor and I together	Doctor made decision after considering my opinion	Doctor made decision with little or no input from me	Other	Not sure / cannot remember
Six pilot study health services	42	70	194	91	96	32	4
	7.9%	13.2%	36.7%	17.2%	18.1%	6.0%	0.8%
Other treatment centres	7	16	54	24	28	3	2
	5.2%	11.9%	40.3%	17.9%	20.9%	2.2%	1.5%
All patients	49	86	248	115	124	35	6
	7.4%	13.0%	37.4%	17.3%	18.7%	5.3%	0.9%

Table A.5.4. Did you have any bills associated with your chemotherapy that you had to pay?

Category	No	Yes but my health insurance covered costs completely	Yes and my health insurance covered some costs	Yes I had bills to pay
Six pilot study health services	360	18	26	130
	67.4%	3.4%	4.9%	24.3%
Other treatment centres	71	9	33	24
	51.8%	6.6%	24.1%	17.5%
All patients	431	27	59	154
	64.2%	4.0%	8.8%	23.0%

Table A.5.5 Before you started chemotherapy, were you told of any out-of-pocket costs you might have to pay?

Category	Yes, fully informed	Yes, but not full amount	No	Not sure / cannot remember
Six pilot study health services	122	34	81	51
	42.4%	11.8%	28.1%	17.7%
Other treatment centres	55	11	15	9
	61.1%	12.2%	16.7%	10.0%
All patients	177	45	96	60
	46.8%	11.9%	25.4%	15.9%

Table A.5.6a Did you stay away from home while receiving chemotherapy?

Category	Yes	No
Six pilot study health services	61	474
	11.4%	88.6%
Other treatment centres	25	117
	17.6%	82.4%
All patients	86	591
	12.7%	87.3%

Table A.5.6b If yes, who arranged accommodation?

Category	Self/family	Staff at hospital	Doctor's staff	Other
Six pilot study health services	31	16	5	10
	50.0%	25.8%	8.1%	16.1%
Other treatment centres	10	5	2	4
	47.6%	23.8%	9.5%	19.0%
All patients	41	21	7	14

	49.4%	25.3%	8.4%	16.9%

Table A.5.7a How long did you wait until you actually had chemotherapy?

Category	< 2 weeks	2–4 weeks	> 1 month	Not sure / cannot remember	Other
Six pilot study health services	291	133	51	35	5
	56.5%	25.8%	9.9%	6.8%	1.0%
Other treatment centres	71	47	8	11	0
	51.8%	34.3%	5.8%	8.0%	0.0%
All patients	362	180	59	46	5
	55.5%	27.6%	9.0%	7.1%	0.8%

Table A.5.7b If waited longer than two weeks, this was due to:

Category	Personal decision	Chemotherapy waiting times – kept updated	Chemotherapy waiting times – not kept informed	Other
All patients	10	98	5	31
	6.9%	68.1%	3.5%	21.5%

Table A.5.8 Before having chemotherapy were you given information about:

Information	Category	Yes I was given this information	Yes but I would have liked more	No I was not given this information	Not sure / cannot remember
a. How to prepare for chemotherapy?	Six pilot study health services	465	15	21	28
		87.9%	2.8%	4.0%	5.3%
	Other treatment centres	120	5	5	5
		88.9%	3.7%	3.7%	3.7%
	All patients	585	20	26	33
		88.1%	3.0%	3.9%	5.0%
b. How treatment would be given?	Six pilot study health services	502	14	8	8
		94.4%	2.6%	1.5%	1.5%
	Other treatment centres	132	4	3	0
		95.0%	2.9%	2.2%	0.0%
	All patients	634	18	11	8
		94.5%	2.7%	1.6%	1.2%
c. How long chemotherapy treatment would go for?	Six pilot study health services	490	14	11	6
		94.0%	2.7%	2.1%	1.2%
	Other treatment centres	135	2	3	2
		95.1%	1.4%	2.1%	1.4%

Information	Category	Yes I was given this information	Yes but I would have liked more	No I was not given this information	Not sure / cannot remember
	All patients	625	16	14	8
		94.3%	2.4%	2.1%	1.2%
d. How to manage any anxiety or stress?	Six pilot study health services	352	32	100	41
		67.0%	6.1%	19.0%	7.8%
	Other treatment centres	93	14	23	7
		67.9%	10.2%	16.8%	5.1%
	All patients	445	46	123	48
		67.2%	6.9%	18.6%	7.3%
e. How you would feel at the end of treatment?	Six pilot study health services	404	33	51	34
		77.4%	6.3%	9.8%	6.5%
	Other treatment centres	104	14	15	4
		75.9%	10.2%	10.9%	2.9%
	All patients	508	47	66	38
		77.1%	7.1%	10.0%	5.8%
f. What side effects you might experience from chemotherapy?	Six pilot study health services	471	41	9	7
		89.2%	7.8%	1.7%	1.3%
	Other treatment centres	114	16	6	1
		83.2%	11.7%	4.4%	0.7%
	All patients	585	57	15	8
		88.0%	8.6%	2.3%	1.2%
g. How to manage any side effects of chemotherapy at home?	Six pilot study health services	454	38	21	15
		86.0%	7.2%	4.0%	2.8%
	Other treatment centres	113	13	11	1
		81.9%	9.4%	8.0%	0.7%
	All patients	567	51	32	16
		85.1%	7.7%	4.8%	2.4%
h. The possibility of going to emergency department if you had a bad response to chemotherapy?	Six pilot study health services	495	14	15	6
		93.4%	2.6%	2.8%	1.1%
	Other treatment centres	125	4	9	3
		88.7%	2.8%	6.4%	2.1%
	All patients	620	18	24	9
		92.4%	2.7%	3.6%	1.3%

Table A.5.9 Did health professionals check you understood the information provided to you?

Category	Yes	No	Not sure / cannot remember
Six pilot study health services	469	19	48
	87.5%	3.5%	9.0%
Other treatment centres	124	8	11
	86.7%	5.6%	7.7%
All patients	593	27	59
	87.3%	4.0%	8.7%

Table A.5.10 Did staff take into account how far you had to travel or other commitments when arranging times for your appointments?

Category	Yes, definitely	Yes, as much as they could	No, not at all	Travel times or other commitments not a problem	Not sure / cannot remember
Six pilot study health services	269	126	38	85	6
	51.3%	24.0%	7.3%	16.2%	1.1%
Other treatment centres	65	35	13	20	7
	46.4%	25.0%	9.3%	14.3%	5.0%
All patients	334	161	51	105	13
	50.3%	24.2%	7.7%	15.8%	2.0%

Table A.5.11 On average how long did you have to wait at your chemotherapy appointment?

Category	<15 minutes	15–30 minutes	30–60 minutes	1–2 hours	> 2 hours	Not sure / cannot remember
Six pilot study health services	237	200	48	10	2	18
	45.7%	38.5%	9.2%	1.9%	0.4%	3.5%
Other treatment centres	59	41	15	4	4	13
	43.1%	29.9%	10.9%	2.9%	2.9%	9.5%
All patients	296	241	63	14	6	31
	45.1%	36.7%	9.6%	2.1%	0.9%	4.7%

Table A.5.12 Did health professionals check if you had any side effects or symptoms?

Category	Yes	Yes, but not as often as I would have liked	No	Not sure / cannot remember
Six pilot study health services	505	12	12	5
	94.6%	2.2%	2.2%	0.9%
Other treatment centres	128	5	8	3
	88.9%	3.5%	5.6%	2.1%
All patients	633	17	20	8
	93.4%	2.5%	2.9%	1.2%

Table A.5.13 Do you think health professionals did everything they could to help you manage side effects?

Category	Yes, definitely	Yes, to some extent	No	I did not have side effects	Not sure / cannot remember
Six pilot study health services	457	48	3	20	3
	86.1%	9.0%	0.6%	3.8%	0.6%
Other treatment centres	114	19	3	7	0
	79.7%	13.3%	2.1%	4.9%	0.0%
All patients	571	67	6	27	3
	84.7%	9.9%	0.9%	4.0%	0.4%

Table A.5.14 Did health professionals treat you with respect and dignity?

Category	Yes, always	Yes, sometimes	No
Six pilot study health services	524	11	0
	97.9%	2.1%	0.0%
Other treatment centres	138	5	1
	95.8%	3.5%	0.7%
All patients	662	16	1
	97.5%	2.4%	0.1%

Table A.5.15 Did health professionals check if you needed any help or assistance with things like diet or eating etc?

Category	Yes	No	Not sure / cannot remember
Six pilot study health services	469	38	28
	87.7%	7.1%	5.2%
Other treatment centres	117	17	9
	81.8%	11.9%	6.3%
All patients	586	55	37
	86.4%	8.1%	5.5%

Table A.5.16 Did health professionals check if you needed any help or assistance with managing your emotional state?

Category	Yes	No	Not sure / cannot remember
Six pilot study health services	423	73	37
	79.4%	13.7%	6.9%
Other treatment centres	105	29	9
	73.4%	20.3%	6.3%
All patients	528	102	46
	78.1%	15.1%	6.8%

Table A.5.17 Did health professionals check if you needed any help or assistance with travelling to or from your appointments?

Category	Yes	No	Not sure / cannot remember
Six pilot study health services	346	134	44
	66.0%	25.6%	8.4%
Other treatment centres	79	42	17
	57.2%	30.4%	12.3%
All patients	425	176	61
	64.2%	26.6%	9.2%

Table A.5.18 Were you given a phone number to contact if you had concerns?

Category	Yes	No	Not sure / cannot remember
Six pilot study health services	504	19	9
	94.7%	3.6%	1.7%
Other treatment centres	130	8	5
	90.9%	5.6%	3.5%
All patients	634	27	14
	93.9%	4.0%	2.1%

Table A.5.19 Were you given a card that explained your chemotherapy to show if you needed to go to the emergency department (ED)?

Category	Yes	No	Not sure / cannot remember
Six pilot study health services	467	46	18
	87.9%	8.7%	3.4%
Other treatment centres	114	25	4
	79.7%	17.5%	2.8%
All patients	581	71	22
	86.2%	10.5%	3.3%

Table A.5.20 Did health professionals ask if your family/friends needed information or support?

Category	Yes, regularly	Yes, occasionally	No, never	No, family/friends involved	Not sure / cannot remember
Six pilot study health services	249	135	62	34	52
	46.8%	25.4%	11.7%	6.4%	9.8%
Other treatment centres	52	33	25	15	18
	36.4%	23.1%	17.5%	10.5%	12.6%
All patients	301	168	87	49	70
	44.6%	24.9%	12.9%	7.3%	10.4%

Table A.5.21 How satisfied were you with the availability of car parking at treatment centre?

Category	Very satisfied	Satisfied	Neither	Dissatisfied	Very dissatisfied
Six pilot study health services	197	189	65	44	25
	37.9%	36.3%	12.5%	8.5%	4.8%
Other treatment centres	41	40	29	21	5
	30.1%	29.4%	21.3%	15.4%	3.7%
All patients	238	229	94	65	30
	36.3%	34.9%	14.3%	9.9%	4.6%

Table A.5.22 Overall how satisfied were you with the treatment you received from all health professionals involved in your chemotherapy?

Category	Very satisfied	Satisfied	Neither	Dissatisfied	Very dissatisfied
Six pilot study health services	448	75	8	3	0
	83.9%	14.0%	1.5%	0.6%	0.0%
Other treatment centres	112	28	0	1	1
	78.9%	19.7%	0.0%	0.7%	0.7%
All patients	560	103	8	4	1
	82.8%	15.2%	1.2%	0.6%	0.1%

Responses to questions in Section 6: emergency department

Questions assessing wait at emergency department, confidence in staff and feeling safe while waiting

Table A.6.1 Have you felt so ill from your cancer or cancer treatment that you have had to go to an emergency department?

Category	Yes only once	Yes more than once	Yes but it was before my cancer was diagnosed	No, never
All patients	189	137	19	603
	19.9%	14.5%	2.0%	63.6%

Tables A.6.2 to A.6.5 show results from patients who had been to an emergency department since their cancer diagnosis.

Table A.6.2 Last time you were at an emergency department how long did you have to wait before you saw the doctor?

Category	< 10 minutes	10–30 minutes	30 min-1 hour	1–2 hours	2–4 hours	> 4 hours	Not sure / cannot remember
All emergency department patients	64	121	47	35	24	19	10
	20.0%	37.8%	14.7%	10.9%	7.5%	5.9%	3.1%

Table A.6.3 Did you feel your condition was well managed while you were in the waiting area of the emergency department?

Category	Yes, conditioned well managed	No, condition not well managed	Not sure / cannot remember
All emergency department patients	260	53	11
	80.2%	16.4%	3.4%

Table A.6.4 Do you think the health professionals in emergency department had the knowledge and skills needed to look after you?

Category	Yes, all or most of them did	Only a few of them seemed to	No	Not sure / cannot remember
All emergency department patients	259	39	20	6
	79.9%	12.0%	6.2%	1.9%

Table A.6.5 Were you admitted into a hospital as a result of your consultation with the doctors in an emergency department?

Category	Yes	No
All emergency department patients	215	106
	67.0%	33.0%

Responses to questions in Section 7: Follow-up care

Questions assessing follow-up care including provision of information on tests needed, how to stay well, symptoms to monitor, appointment scheduling and provision of information.

Table A.7.1 Which doctor is mainly in charge of your follow-up care (multiple responses allowed)

Category	Surgeon	Haematologist	Radiation oncologist	GP	Medical oncologist	Other	Other medical doctor	Not sure
Patients having all treatment at the pilot study health services	182	123	137	176	185	24	42	34
	32.3%	21.8%	24.3%	31.2%	32.8%	4.3%	7.4%	6.0%
Patients having treatment at several different centres	175	43	139	98	196	19	19	7
	49.3%	12.1%	39.2%	27.6%	55.2%	5.4%	5.4%	2.0%
All participants	357	166	276	274	381	43	61	41
	22.30%	10.40%	17.30%	17.10%	23.80%	2.70%	3.80%	2.60%

Table A.7.2 Was work or other commitments, or how far you had to travel, considered when scheduling your appointments?

Category	Yes, definitely	Yes, as much as it could	No not at all	This wasn't an issue for me	Not sure / cannot remember
All treatment at the pilot study health services	178	123	86	167	7
	31.7%	21.9%	15.3%	29.8%	1.2%
Treatment at several different centres	137	66	50	91	6
	39.1%	18.9%	14.3%	26.0%	1.7%
All participants	315	189	136	258	13
	34.6%	20.7%	14.9%	28.3%	1.4%

Table A.7.3 Were your appointments and tests coordinated by health professionals to reduce the time you would spend going to and from your medical appointments?

Category	Yes, definitely	Yes, sometimes	No	Not sure / cannot remember
All treatment at the pilot study health services	315	120	91	38
	55.9%	21.3%	16.1%	6.7%
Treatment at several different centres	193	83	53	17
	55.8%	24.0%	15.3%	4.9%
All participants	508	203	144	55
	55.8%	22.3%	15.8%	6.0%

Table A.7.4 When you have seen your doctor, how often have test results or other information needed for your appointment not been available to your doctor?

Category	Never	Once or twice	3-4 times	5+times	Not sure / cannot remember
All treatment at the pilot study health services	375	109	23	15	44
	66.3%	19.3%	4.1%	2.7%	7.8%
Treatment at several different centres	255	68	14	2	14
	72.2%	19.3%	4.0%	0.6%	4.0%
All participants	630	177	37	17	58
	68.6%	19.3%	4.0%	1.8%	6.3%

Table A.7.5 When you had finished your cancer treatment were you given:

Information	Category	Yes, and it was adequate	Yes, but I would have liked more	No	Not sure / cannot remember
a. A written plan that included information about your follow-up care?	All treatment at the pilot study health services	250	19	209	40
		48.3%	3.7%	40.3%	7.7%
	Treatment at several different centres	149	13	147	14
		46.1%	4.0%	45.5%	4.3%
	All participants	399	32	356	54
		47.4%	3.8%	42.3%	6.4%
b. Information about what follow-up tests you would need?	All treatment at the pilot study health services	372	45	86	17
		71.5%	8.7%	16.5%	3.3%
	Treatment at several different centres	219	40	56	9
		67.6%	12.3%	17.3%	2.8%
	All participants	591	85	142	26
		70.0%	10.1%	16.8%	3.1%
c. Information about things you could do to stay healthy (for example, information about exercise, diet, stopping smoking)?	All treatment at the pilot study health services	339	41	103	31
		66.0%	8.0%	20.0%	6.0%
	Treatment at several different centres	210	24	74	14
		65.2%	7.5%	23.0%	4.3%
	All participants	549	65	177	45
		65.7%	7.8%	21.2%	5.4%
d. Information about which new symptoms need investigation?	All treatment at the pilot study health services	232	37	181	56
		45.8%	7.3%	35.8%	11.1%
	Treatment at several different centres	134	26	120	29
		43.4%	8.4%	38.8%	9.4%
	All participants	366	63	301	85
		44.9%	7.7%	36.9%	10.4%

Information	Category	Yes, and it was adequate	Yes, but I would have liked more	No	Not sure / cannot remember
e. Information about how people feel after finishing cancer treatment?	All treatment at the pilot study health services	251	44	170	43
		49.4%	8.7%	33.5%	8.5%
	Treatment at several different centres	166	35	94	22
		52.4%	11.0%	29.7%	6.9%
	All participants	417	79	264	65
		50.5%	9.6%	32.0%	7.9%
f. Information about how to get extra support if you or your family wanted it?	All treatment at the pilot study health services	274	36	152	47
		53.8%	7.1%	29.9%	9.2%
	Treatment at several different centres	158	26	109	25
		49.7%	8.2%	34.3%	7.9%
	All participants	432	62	261	72
		52.2%	7.5%	31.6%	8.7%
g. Information about how often you would need to have tests or check-ups?	All treatment at the pilot study health services	412	48	54	16
		77.7%	9.1%	10.2%	3.0%
	Treatment at several different centres	246	34	43	5
		75.0%	10.4%	13.1%	1.5%
	All participants	658	82	97	21
		76.7%	9.6%	11.3%	2.4%

Table A.7.6 When you had finished your cancer treatment were you given information about how to manage any ongoing symptoms or side effects?

Category	Yes	Yes, but I would have liked more	No	I did not have any side effects or ongoing symptoms	Not sure / cannot remember
All treatment at the pilot study health services	268	63	80	99	22
	50.4%	11.8%	15.0%	18.6%	4.1%
Treatment at several different centres	176	49	48	34	13
	55.0%	15.3%	15.0%	10.6%	4.1%
All participants	444	112	128	133	35
	52.1%	13.1%	15.0%	15.6%	4.1%

Table A.7.7 Does your GP have a good understanding of the follow-up care you need?

Category	Yes	No	I don’t have a regular GP	Not sure / cannot remember
All treatment at the pilot study health services	428	50	16	58
	77.5%	9.1%	2.9%	10.5%
Treatment at several different centres	267	26	13	29
	79.7%	7.8%	3.9%	8.7%
All participants	695	76	29	87
	78.4%	8.6%	3.3%	9.8%

Responses to questions in Section 8: Information

Questions assessing information received, including information about allied health and support services.

Table A.8.1 Did you get enough information from health professionals about:

Information	Category	I received all the information I wanted	I received some information but would have liked more	No not at all	I didn't need information about this issue	Not sure / cannot remember
a. The possible impact of treatment on your capacity to work or do activities?	All treatment at the pilot study health services	388	64	68	64	17
		64.6%	10.6%	11.3%	10.6%	2.8%
	Treatment at several different centres	253	49	47	28	7
		65.9%	12.8%	12.2%	7.3%	1.8%
	All participants	641	113	115	92	24
		65.1%	11.5%	11.7%	9.3%	2.4%
b. The possible changes in your energy level?	All treatment at the pilot study health services	378	63	90	39	21
		64.0%	10.7%	15.2%	6.6%	3.6%
	Treatment at several different centres	263	62	41	11	6
		68.7%	16.2%	10.7%	2.9%	1.6%
	All participants	641	125	131	50	27
		65.8%	12.8%	13.4%	5.1%	2.8%
c. What you could do to preserve your fertility?	All treatment at the pilot study health services	133	16	80	283	26
		24.7%	3.0%	14.9%	52.6%	4.8%
	Treatment at several different centres	74	7	41	217	9
		21.3%	2.0%	11.8%	62.4%	2.6%
	All participants	207	23	121	500	35
		23.4%	2.6%	13.7%	56.4%	4.0%

Table A.8.2 Did health professionals talk to you about any financial support program you might have been able to use?

Category	Yes, someone talked to me about financial support	No, but I would have liked someone to do this	No I did not need any financial support services	Not sure / cannot remember
All treatment at the pilot study health services	137	87	347	40
	22.4%	14.2%	56.8%	6.5%
Treatment at several different centres	118	57	197	18
	30.3%	14.6%	50.5%	4.6%
All participants	255	144	544	58
	25.5%	14.4%	54.3%	5.8%

Table A.8.3 Did you feel like you could ask the health professionals involved in your care questions that you had?

Category	Yes, definitely	Yes, to some extent	No	Not sure / cannot remember
All treatment at the pilot study health services	499	95	22	3
	80.6%	15.3%	3.6%	0.5%
Treatment at several different centres	338	46	6	2
	86.2%	11.7%	1.5%	0.5%
All participants	837	141	28	5
	82.8%	13.9%	2.8%	0.5%

Table A.8.4 Did a health professional talk to you about the following services?

Health Professional	Category	Yes	No, but I would have liked them to	No, but I didn’t need them to	Not sure / cannot remember
a. Social worker	All treatment at the pilot study health services	258	41	254	19
		45.1%	7.2%	44.4%	3.3%
	Treatment at several different centres	158	26	167	14
		43.3%	7.1%	45.8%	3.8%
	All participants	416	67	421	33
		44.4%	7.2%	44.9%	3.5%
b. Psychologist	All treatment at the pilot study health services	116	56	312	32
		22.5%	10.9%	60.5%	6.2%
	Treatment at several different centres	95	38	187	24
		27.6%	11.0%	54.4%	7.0%
	All participants	211	94	499	56
		24.5%	10.9%	58.0%	6.5%
c. Dietitian	All treatment at the pilot study health services	280	40	222	16
		50.2%	7.2%	39.8%	2.9%
	Treatment at several different centres	179	34	135	11
		49.9%	9.5%	37.6%	3.1%
	All participants	459	74	357	27
		50.1%	8.1%	38.9%	2.9%
d. Speech therapist	All treatment at the pilot study health services	47	15	424	21
		9.3%	3.0%	83.6%	4.1%
	Treatment at several different centres	22	12	287	14
		6.6%	3.6%	85.7%	4.2%
	All participants	69	27	711	35
		8.2%	3.2%	84.4%	4.2%
e. Occupational Therapist	All treatment at the pilot study health services	61	28	393	25
		12.0%	5.5%	77.5%	4.9%
	Treatment at several different centres	44	24	252	20
		12.9%	7.1%	74.1%	5.9%
	All participants	105	52	645	45
		12.4%	6.1%	76.2%	5.3%
f. Pain management specialist	All treatment at the pilot study health services	97	52	342	28
		18.7%	10.0%	65.9%	5.4%
	Treatment at several different centres	53	37	237	22
		15.2%	10.6%	67.9%	6.3%
	All participants	150	89	579	50
		17.3%	10.3%	66.7%	5.8%
g. Cancer Helpline	All treatment at the pilot study health services	210	62	235	32
		39.0%	11.5%	43.6%	5.9%

Health Professional	Category	Yes	No, but I would have liked them to	No, but I didn’t need them to	Not sure / cannot remember
	Treatment at several different centres	151	30	154	21
		42.4%	8.4%	43.3%	5.9%
	All participants	361	92	389	53
		40.3%	10.3%	43.5%	5.9%
h. Financial planner/services	All treatment at the pilot study health services	43	56	377	33
		8.4%	11.0%	74.1%	6.5%
	Treatment at several different centres	26	50	242	18
		7.7%	14.9%	72.0%	5.4%
	All participants	69	106	619	51
		8.2%	12.5%	73.3%	6.0%

Table A.8.5 Did health professionals ask you if you needed any help or assistance with the following:

Assistance type	Category	Yes	No, but I would have liked them to	I didn’t need assistance with this	Not sure / cannot remember
a. Domestic chores (e.g. cooking or cleaning etc.)?	All treatment at the pilot study health services	222 37.2%	41 6.9%	319 53.5%	14 2.3%
	Treatment at several different centres	123 32.5%	31 8.2%	217 57.4%	7 1.9%
	All participants	345 35.4%	72 7.4%	536 55.0%	21 2.2%
b. Family problems?	All treatment at the pilot study health services	87 15.4%	39 6.9%	422 74.8%	16 2.8%
	Treatment at several different centres	70 18.7%	26 6.9%	271 72.3%	8 2.1%
	All participants	157 16.7%	65 6.9%	693 73.8%	24 2.6%
c. Working out childcare while having treatment?	All treatment at the pilot study health services	28 5.1%	12 2.2%	502 91.1%	9 1.6%
	Treatment at several different centres	23 6.2%	15 4.0%	329 88.4%	5 1.3%
	All participants	51 5.5%	27 2.9%	831 90.0%	14 1.5%
d. Your finances (accessing your superannuation, illness insurance, income protection etc.)?	All treatment at the pilot study health services	48 8.5%	56 9.9%	439 77.8%	21 3.7%
	Treatment at several different centres	27 7.2%	50 13.4%	286 76.5%	11 2.9%
	All participants	75 8.0%	106 11.3%	725 77.3%	32 3.4%
e. Finding support groups or other services that put you in contact with other people who have had cancer?	All treatment at the pilot study health services	196 33.8%	76 13.1%	279 48.1%	29 5.0%
	Treatment at several different centres	154 40.2%	43 11.2%	174 45.4%	12 3.1%
	All participants	350 36.3%	119 12.4%	453 47.0%	41 4.3%

Table A.8.6 Did any member of your healthcare team discuss with you the possibility of you taking part in cancer research?

Category	Yes, I was happy for them to do this	Yes, but I was not happy for them to do this	No, but I would have liked them to	No, and I am glad they did not	Not sure / cannot remember
All treatment at the pilot study health services	203	17	121	115	141
	34.0%	2.8%	20.3%	19.3%	23.6%
Treatment at several different centres	135	7	84	61	90
	35.8%	1.9%	22.3%	16.2%	23.9%
All participants	338	24	205	176	231
	34.7%	2.5%	21.0%	18.1%	23.7%

Table A.8.7 Did you feel you could talk with the health professionals (HP) involved in your care about complementary or alternative therapies?

Category	Yes, with all HP	Yes, with some HP	No, not at all	I did not want to talk about this issue	Not interested in this	Not sure / cannot remember
All treatment at the pilot study health services	168	71	92	47	163	51
	28.4%	12.0%	15.5%	7.9%	27.5%	8.6%
Treatment at several different centres	114	52	54	33	110	17
	30.0%	13.7%	14.2%	8.7%	28.9%	4.5%
All participants	282	123	146	80	273	68
	29.0%	12.7%	15.0%	8.2%	28.1%	7.0%

Responses to questions in Section 9: Overall care

Questions assessing overall care, including access to a health professional or clinical nurse specialist, experiences of receiving conflicting information, repeating tests unnecessarily and perceptions of how well staff worked together..

Table A.9.1 Throughout your care and treatment, has there been a health professional (HP) or a team of HPs you could contact if you had any questions or needed help or advice

Category	Yes, at least one HP I could contact throughout treatment	Yes, there was someone I could contact but not all the time	No	Not sure / cannot remember
Patients having all treatment at the pilot study health services	458	67	49	33
	75.5%	11.0%	8.1%	5.4%
Patients having treatment at several different centres	320	41	13	15
	82.3%	10.5%	3.3%	3.9%
All participants	778	108	62	48
	78.1%	10.8%	6.2%	4.8%

Table A.9.2 Throughout your treatment, has there been a time when:

Situation	Category	No Never	Once	2–3 times	4 or more times	Not sure / cannot remember
a. You received conflicting information or advice from different doctors or health professionals?	All treatment at the pilot study health services	479	65	42	4	16
		79.0%	10.7%	6.9%	0.7%	2.6%
	Treatment at several different centres	302	50	26	4	11
		76.8%	12.7%	6.6%	1.0%	2.8%
	All participants	781	115	68	8	27
		78.2%	11.5%	6.8%	0.8%	2.7%
b. You thought a health professional involved in your care was not fully informed about your treatment and /or your progress?	All treatment at the pilot study health services	489	41	32	4	23
		83.0%	7.0%	5.4%	0.7%	3.9%
	Treatment at several different centres	321	34	16	7	11
		82.5%	8.7%	4.1%	1.8%	2.8%
	All participants	810	75	48	11	34
		82.8%	7.7%	4.9%	1.1%	3.5%

Situation	Category	No Never	Once	2–3 times	4 or more times	Not sure / cannot remember
c. You thought tests or other assessments were being repeated unnecessarily	All treatment at the pilot study health services	541	12	19	2	12
		92.3%	2.0%	3.2%	0.3%	2.0%
	Treatment at several different centres	361	14	3	2	9
		92.8%	3.6%	0.8%	0.5%	2.3%
	All participants	902	26	22	4	21
		92.5%	2.7%	2.3%	0.4%	2.2%
d. The results of your tests, X-rays or scans were not available when they were needed for an appointment?	All treatment at the pilot study health services	504	38	28	3	19
		85.1%	6.4%	4.7%	0.5%	3.2%
	Treatment at several different centres	321	37	21	3	6
		82.7%	9.5%	5.4%	0.8%	1.5%
	All participants	825	75	49	6	25
		84.2%	7.7%	5.0%	0.6%	2.6%
e. You thought the health professionals involved in your care were not passing on information to one another?	All treatment at the pilot study health services	484	37	37	7	24
		82.2%	6.3%	6.3%	1.2%	4.1%
	Treatment at several different centres	321	19	28	8	12
		82.7%	4.9%	7.2%	2.1%	3.1%
	All participants	805	56	65	15	36
		82.4%	5.7%	6.7%	1.5%	3.7%
f. You didn't feel you had enough privacy when talking to a health professional about your needs, concerns or any other aspect of your treatment?	All treatment at the pilot study health services	565	4	6	4	13
		95.4%	0.7%	1.0%	0.7%	2.2%
	Treatment at several different centres	369	5	4	3	6
		95.3%	1.3%	1.0%	0.8%	1.6%
	All participants	934	9	10	7	19
		95.4%	0.9%	1.0%	0.7%	1.9%

Table A.9.3 Which doctor/s were in charge of your care (multiple responses allowed)?

Category	Surgeon	Haematologist	Medical oncologist	Radiation oncologist	GP	Other medical doctor	Other	Not sure who is/was in charge
All treatment at the pilot study health services	323	169	261	203	289	51	36	26
	51.8%	27.1%	41.8%	32.5%	46.3%	8.2%	5.8%	4.2%
Treatment at several different centres	273	67	276	239	193	35	19	9
	68.9%	16.9%	69.7%	60.4%	48.7%	8.8%	4.8%	2.3%
All participants	596	236	537	442	482	86	55	35
	24.1%	9.6%	21.7%	17.9%	19.5%	3.5%	2.2%	1.4%

Table A.9.4 Were you given the name of a clinical nurse specialist who would be in charge of your care?

Category	Yes	No	Not sure / cannot remember
All treatment at the pilot study health services	264	282	70
	42.9%	45.8%	11.4%
Treatment at several different centres	233	136	27
	58.8%	34.3%	6.8%
All participants	497	418	97
	49.1%	41.3%	9.6%

Table A.9.5 How easy is it for you to contact your clinical nurse specialist?

Category	Easy	Sometimes easy, sometimes difficult	Difficult	I have not tried to contact them
All treatment at the pilot study health services	179	50	7	50
	62.6%	17.5%	2.4%	17.5%
Treatment at several different centres	146	40	6	44
	61.9%	16.9%	2.5%	18.6%
All participants	325	90	13	94
	62.3%	17.2%	2.5%	18.0%

Table A.9.6 The last time you spoke to your clinical nurse specialist, did she/he listen carefully to you?

Category	Yes, definitely	Yes, to some extent	No
All treatment at the pilot study health services	241	25	4
	89.3%	9.3%	1.5%
Treatment at several different centres	201	16	6
	90.1%	7.2%	2.7%
All participants	442	41	10
	89.7%	8.3%	2.0%

Table A.9.7 When you have important questions to ask your clinical nurse specialist, how often do you get answers you can understand?

Category	All or most of the time	Some of the time	Rarely or never	I do not ask any questions
All treatment at the pilot study health services	240	13	2	22
	86.6%	4.7%	0.7%	7.9%
Treatment at several different centres	190	14	4	19
	83.7%	6.2%	1.8%	8.4%
All participants	430	27	6	41
	85.3%	5.4%	1.2%	8.1%

Table A.9.8 Were the different treatment centres involved in your care informed about the care you had received at the other centres?

Category	Yes, seemed well informed	Yes, although some information seemed to be missing	No, there seemed to be little or not sharing of information	Only treated at one treatment centre	Not sure/ cannot remember
All treatment at the pilot study health services	305	37	16	215	38
	49.9%	6.1%	2.6%	35.2%	6.2%
Treatment at several different centres	270	40	17	46	22
	68.4%	10.1%	4.3%	11.6%	5.6%
All participants	575	77	33	261	60
	57.2%	7.7%	3.3%	25.9%	6.0%

Table A.9.9 If you needed an interpreter at your appointments, was a hospital/treatment centre interpreter available for you?

Category	Yes, at most or all appointments	Yes, at some appointments	No, an interpreter was never available	No, one talked to me about this	I did not need an interpreter	Not sure/ cannot remember
All treatment at the pilot study health services	21	4	1	3	581	1
	3.4%	0.7%	0.2%	0.5%	95.1%	0.2%
Treatment at several different centres	12	4	1	1	368	0
	3.1%	1.0%	0.3%	0.3%	95.3%	0.0%
All participants	33	8	2	4	949	1
	3.3%	0.8%	0.2%	0.4%	95.2%	0.1%

Table A.9.10 Was your GP kept informed about your condition and treatment?

Category	Yes GP seemed very well informed	Yes to some extent	No GP did not know much	I do not have a regular GP	Not sure/ cannot remember
All treatment at the pilot study health services	420	145	33	8	27
	66.4%	22.9%	5.2%	1.3%	4.3%
Treatment at several different centres	270	81	19	2	26
	67.8%	20.4%	4.8%	0.5%	6.5%
All participants	690	226	52	10	53
	66.9%	21.9%	5.0%	1.0%	5.1%

Table A.9.11 How would you rate how well the doctors and nurses involved in your cancer care worked together?

Category	Excellent	Very good	Good	Fair	Poor
All treatment at the pilot study health services	425	161	32	9	6
	67.1%	25.4%	5.1%	1.4%	0.9%
Treatment at several different centres	272	96	23	7	1
	68.2%	24.1%	5.8%	1.8%	0.3%
All participants	697	257	55	16	7
	67.5%	24.9%	5.3%	1.6%	0.7%

Table A.9.12 How satisfied were you with the overall care you received from all health professionals involved in your treatment?

Category	Excellent	Very good	Good	Fair	Poor
All treatment at the pilot study health services	499	113	10	6	3
	79.1%	17.9%	1.6%	1.0%	0.5%
Treatment at several different centres	322	67	8	2	1
	80.5%	16.8%	2.0%	0.5%	0.2%
All participants	821	180	18	8	4
	79.6%	17.5%	1.7%	0.8%	0.4%

Table A.9.13 Was there a time when you were so unhappy with your treatment that you wanted to or did complain about it?

Category	Yes, at least one time	No, my care was generally fine	No, my care was excellent	Not sure/ cannot remember
All treatment at the pilot study health services	82	175	363	7
	13.1%	27.9%	57.9%	1.1%
Treatment at several different centres	69	87	240	1
	17.4%	21.9%	60.5%	0.3%
All participants	151	262	603	8
	14.7%	25.6%	58.9%	0.8%

Responses to questions in Section 10: Demographics

This section provides information on who completed the survey and includes information on sex, age and self -reported health status of participants.

Table A.10.1 Sex

Category	Male	Female
All patients	512	615
	45.4%	54.6%

Table A.10.2 Language spoken at home

Category	English	Other
All patients	1019	62
	94.3%	5.7%

Table A.10.3 Are you of Aborignal and/or Torres Strait Islander origin?

Category	No	Yes, Aboriginal and/or Torres Strait Islander
All patients	1108	7
	99.4%	0.6%

Table A.10.4 How would you rate your current health?

Category	Excellent	Very good	Good	Fair	Poor
All patients	158	361	372	173	44
	14.3%	32.6%	33.6%	15.6%	4.0%

Appendix B: Items where 90 per cent or more of respondents gave the same response

1. Finding out what was wrong with you

Table A.1.7 Did the health professionals involved in your diagnosis talk to you with respect and understanding?

Yes always	Yes sometimes	No	Not sure / cannot remember
1051	63	18	10
92.0%	5.5%	1.6%	0.9%

2. Deciding on your treatment

No items

3. Surgery

Table A.3.8 Were you given information about how to prepare for surgery?:

Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
645	14	24	19
91.9%	2.0%	3.4%	2.7%

Table A.3.15 Did you feel you were treated with respect and dignity while you were in the hospital?

Yes, always	Yes, sometimes	No	Not sure / cannot remember
641	56	10	3
90.3%	7.9%	1.4%	0.4%

4. Radiotherapy

Table A.4.8 Before having radiotherapy were you given information about:

Information	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
b. What would happen when treatment was given	520	17	9	13
	93.0%	3.0%	1.6%	2.3%
c. How long the radiotherapy treatment would go for?	541	4	1	4
	98.4%	0.7%	0.2%	0.7%

Table A.4.14 Did you feel you were treated with respect and dignity while in hospital?

Yes, always	Yes, sometimes	No	Not sure / cannot remember
563	10	1	1
97.9%	1.7%	0.2%	0.2%

5. Chemotherapy

Table A.5.8 Before having chemotherapy were you given information about:

Information	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure / cannot remember
b. How treatment would be given?	634	18	11	8
	94.5%	2.7%	1.6%	1.2%
c. How long chemotherapy treatment would go for?	625	16	14	8
	94.3%	2.4%	2.1%	1.2%
A.5.8h. The possibility of going to emergency department if you had a bad response to chemotherapy?	620	18	24	9
	92.4%	2.7%	3.6%	1.3%

Table A.5.12 Did health professionals check if you had any side effects or symptoms?

Yes	Yes, but not as often as I would have liked	No	Not sure / cannot remember
633	17	20	8
93.4%	2.5%	2.9%	1.2%

Table A.5.14 Did health professionals treat you with respect and dignity?

Yes, always	Yes, sometimes	No
662	16	1
97.5%	2.4%	0.1%

7. Follow-up

No Items

8. Information received

No Items

9. Overall care

Table A.9.2 Throughout your treatment, has there been a time when:

Situation	No, Never	Once	2–3 times	4 or more times	Not sure / cannot remember
c. You thought tests or other assessments were being repeated unnecessarily	902	26	22	4	21
	92.5%	2.7%	2.3%	0.4%	2.2%
f. You didn’t feel you had enough privacy when talking to a health professional about your needs, concerns or any other aspect of your treatment?	934	9	10	7	19
	95.4%	0.9%	1.0%	0.7%	1.9%