

Victorian cancer patients' care experiences in 2015

Developing a survey to measure experiences across the
cancer treatment pathway

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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

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Introduction and overview

The Victorian Government is committed to ensuring that Victorians have the best possible experience of the cancer treatment and care system. This is a goal of the *Victorian cancer plan 2016-2020* which provides a framework for improving cancer outcomes for all Victorians.

The Department of Health and Human Services commissioned Cancer Council Victoria to develop and pilot test a survey and methodology to assess Victorian cancer patients' experiences of medical care. This patient experience survey can be used to inform both individual service improvements and ongoing reforms on a statewide basis.

To develop the survey, Cancer Council Victorian undertook two pilot studies. Appendix 1 provides an overview of the process to develop the survey. This report describes findings from the second pilot study, undertaken in 2015 and outlines:

- recommendations for conducting the survey
- what we learnt about patients' experience of cancer care
- opportunities to respond to the recommendations to improve cancer care.

This work has led to the creation of a toolkit and database that can be used by health services and Integrated Cancer Services to understand how Victorian cancer patients experience the care they receive at the local service level. This information can be used to understand how and where care can improve statewide.

About the survey

The second pilot of the patient experience survey included responses from a total of 1160 patients (57% response rate) treated for cancer at six health services (three metropolitan and three regional). The patients completed a self-administered survey assessing their cancer care experiences.

The survey covers the cancer treatment pathway, including diagnosis, treatment planning, treatment and follow-up. The survey captures information on a range of experiences across three treatment modalities - surgery, chemotherapy and radiotherapy.

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.

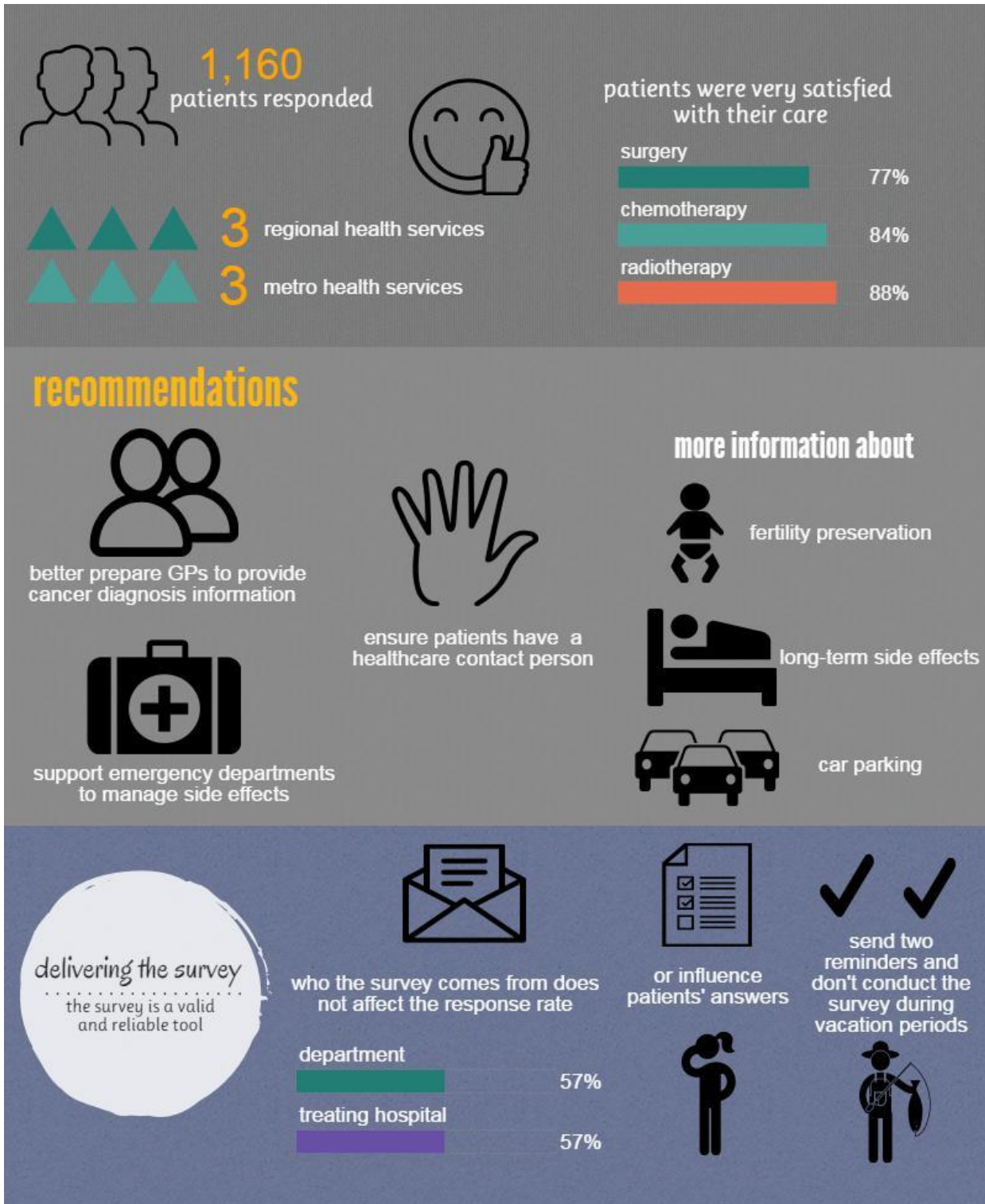
This pilot study looked at both the care experiences and learnings about the survey methodology. Embedded within the study was a randomised trial to examine the influence of the organisation sending out the survey on survey responses; differences in the profile of patients recruited into the study through treatment specific patient lists or through a hospital-wide data base of inpatient episodes of care.

A technical report outlining the methodology and the complete findings from pilot study 2 is available at www.health.vic.gov.au/cancer.

A summary of the findings of the second pilot study is provided on the following page.

Summary of the patient experience survey

In 2015 Cancer Council Victoria and the Department of Health and Human Services completed a second pilot study to create a valid and reliable cancer patient experience survey for health services.



Survey results

The second 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 survey provides information about care experiences including information provision, communication, access to supportive care services, respect and waiting times.

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.

1.1. Method

Six health services participated in the second 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 the 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. 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.

To examine the impact of using the health service to invite patients to complete the survey, 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.

1.2. Findings regarding survey methodology

The second pilot study included an embedded randomised trial which examined the impact of the survey request coming from the patients' treating hospital or the 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. In general, there was little difference in the response rates achieved in the two conditions within the individual health services.
- 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 the summer vacation period 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.

- 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.

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.

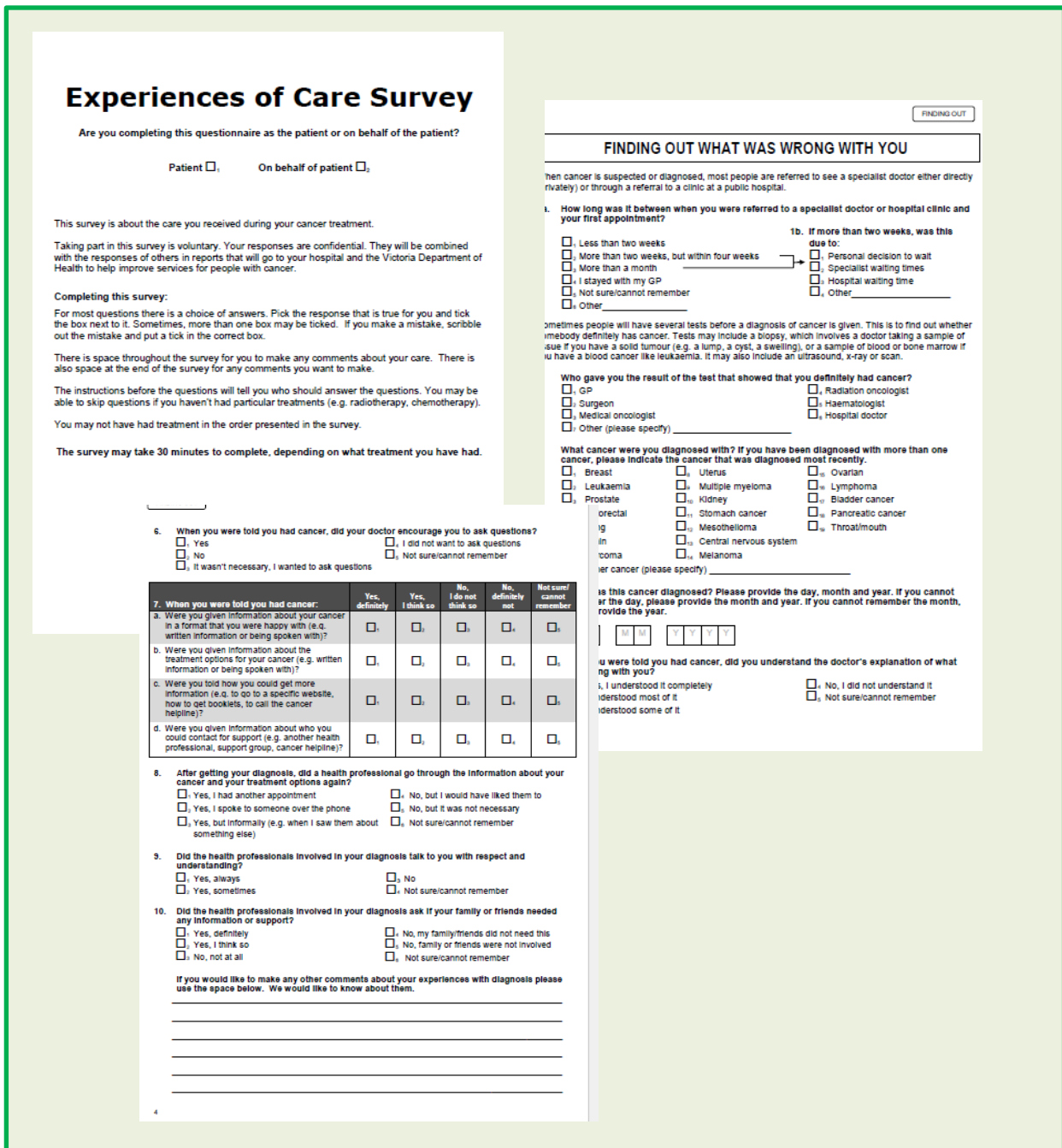


Figure 1: examples of questionnaire pages.

1.3. 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.

Most patients (97%) 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. Common treatments were surgery (71%), chemotherapy (60%) and radiotherapy (60%).

Most commonly patients were told their diagnosis by a surgeon (35%) followed by their GP (19%). 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, were given information about their cancer in a format they were happy with and were given information about their different treatment options, than were patients told their cancer diagnosis by a GP.

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.

What was good...

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 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.

Opportunities for improvement

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)

'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)

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. The 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.

Improving 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:

Diagnosis and treatment planning

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

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.

Information provision

Recommendation 4: Ensure there is a member of the patient's healthcare team that can act as a key 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.

Car parking

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

Survey methodology and survey tool recommendations

Conducting the survey

Recommendation 1: Conduct the study in a time period that does not include major vacation 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 second study. Including the second reminder to respondents increased the 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. 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 sent.

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, consider 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.

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).

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. This would require translation of the survey into several languages commonly spoken in Victoria and testing 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.

Opportunities to improve care experiences

The **Victorian cancer plan 2016-2020** (the cancer plan) provides a framework to improve cancer outcomes for all Victorians. A summary of the cancer plan is provided below.



A key goal of the cancer plan is to ensure that Victorians have the best possible experience of the cancer treatment and care system. There are reform initiatives underway which are consistent with the patient experience survey pilots' recommendations to improve cancer patient's experiences, and contribute to the goals of the cancer plan.

These initiatives include:

- **Implementing Optimal Care Pathways, and monitoring variations against best practice.** The Optimal Care Pathways (OCPs) are a framework for the delivery of consistent, safe, high-quality and evidence-based care for people with cancer. The OCPs have been developed for 15 tumour types, and include a suite of resources to support clinicians and people with cancer to better understand the care pathway, and to improve communication and access to supportive care.
- **Refresh supportive care resources.** Victoria has established systematic approaches to identifying and managing the supportive care needs of cancer patients. There is a strong and continuing focus on building and refreshing the workforce skills and competency in supportive care approaches. This also includes a focus on building self-sufficiency to enable cancer patients, their families and carers to seek information, peer support, referral and supportive care services at all stages of the pathway.
- **Measuring and monitoring self-reported care experiences and treatment impacts.** A focus on quality of life and other patient-reported outcome measures will provide better understanding of treatment impacts. Work is also underway to support and develop self-management programs for cancer patients, and implement service reforms to better support patients in preventing and managing the side effects associated with treatment.

For more information and to download a copy of the Victorian cancer plan 2016-2020 go to www.health.vic.gov.au/cancer

Delivering the survey

The Victorian patient experience survey has been developed based on two pilot surveys. The survey has proven to be a valid and appropriate survey tool and method to capture data on patients' experience of care.

This work has led to the creation of a toolkit and database that can be used by health services and Integrated Cancer Services to conduct their own survey to understand how patients experience the care they receive at the local level. This information can be used to understand how and where care can improve statewide.

The following tools and resources that will be provided to support the roll out of the survey

- An access database to support analysis of local survey results
- A survey manual
- A data manual

Health services that want to deliver the survey can find further tools and resources at <https://www2.health.vic.gov.au/about/health-strategies/cancer-care>.

Appendix 1: Survey development process

