

**THE PROSPECT PROGRAM**  
**(PATIENT RESPONSES: AN**  
**ONGOING SURVEY OF PEOPLE**  
**EXPERIENCING CANCER**  
**TREATMENT**  
**PILOT STUDY**

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# EXECUTIVE SUMMARY

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Patient perceptions of healthcare are increasingly being used to evaluate the quality of healthcare services. While quality measurement using patient-reported outcomes is currently taking place within individual Victorian hospitals, these are largely restricted to patient satisfaction surveys and often do not allow the targeted sampling of cancer patients as a special subgroup of hospital patients. Additionally, the survey instruments and methods of data collection may vary between institutions limiting comparisons of care between different health services. Hence there is a need for the development of a centralised mechanism for monitoring cancer patient experiences of care at the population level.

The PROSPECT Program aims to develop a state-wide system for monitoring the experiences of Victorian cancer patients. This will be done through regular cross sectional surveys of cancer patients recruited through the Victorian Cancer Registry (VCR). As this initiative is novel, a pilot study to test the acceptability of potential measures and recruitment procedures was conducted (postal versus telephone interview). This report presents the finding from the pilot study. CanNET Victoria funded an extension of the pilot study to include participants from the North Eastern Metropolitan Integrated service (NEMICS) and Hume Regional Integrated Cancer Service.

The pilot study adopted a cross-sectional design with participants from the Hume RICS, NEMICS and an 'other' ICS recruited through the Victorian Cancer Registry (VCR). In total, 936 people aged between 18 and 79 years and with a confirmed diagnosis of cancer were approached about study participation by the VCR. Of these, 48.4 % (N = 453) agreed to be contacted about study by the researchers. Four hundred and twenty-nine people with cancer (198 from an 'other' ICS, 168 from NEMICS and 63 from Hume) completed the survey; 209 via post and 220 via telephone interview. Six cases were removed from analyses due to a high percent of missing data, therefore the results presented in this report are based on survey data from 423 participants.

The mean age of participants was 59 years, with more females (n = 236) than males (n=187) in the study. The majority of participants were diagnosed with breast cancer (27%), followed by colorectal cancer (21%) and received their cancer diagnosis approximately 5 months prior to entering the study. For the purposes of this report, responses from participants completing the survey by mail or phone were combined for analyses.

## Key Findings

### *Patient Experience Measure*

The pilot study confirmed the acceptability of The Patient Experience Survey for cancer patients and suggests this tool is suitable for use in the state-wide Prospect program:

- 93% (N = 393) of participants felt the survey was clear and easy to understand.
- 96% (N = 405) did not feel any questions should be removed and 79.5% (N = 336) did not think further questions needed to be added.
- 4.5% (N = 19) of participants felt the survey was too long.

### *Patient Experiences of their Cancer Care*

Participants were asked to report on their experiences of cancer care at each critical phase in the illness trajectory: being told about their cancer diagnosis, planning for cancer treatment/management, preparing for surgery, chemotherapy and radiotherapy, having treatment for cancer, finishing cancer treatment and continuity of care and care co-ordination. Responses indicated that overall, participants' experience of the care was positive across the three ICS regions.

Events that were reported to occur less frequently included:

- Information provision at the time of diagnosis; when planning for cancer treatment and management; and when finishing cancer treatment
- Keeping the patient's general practitioner (GP) well informed of the patient's cancer care.
- Psychosocial support from health professionals across the majority of critical cancer phases

When comparing differences between the ICS regions, it appeared that study participants from the 'other ICS' were more likely to experience the care events during each of the critical phases of cancer care. Regarding cancer type, compared to other cancer types, participants diagnosed with breast cancer more frequently experienced the care events.

### Recommendations

This report makes a number of recommendations that may assist in improving consumer's experience of their cancer care:

1. To develop a system for monitoring and assessing consumer's experiences over time. This would allow some insight about whether efforts to address gaps in care identified in this report result in improvements in patients' experiences of care over time.
2. Information provision:
  - Systematic approach to assessing patient information needs at initial diagnosis and when planning for cancer treatment.
  - Improving health professionals directly involved in patient care awareness of avenues to meet the informational needs of their patients.

- Follow-up protocols throughout cancer care to ensure informational needs are continuing to be assessed and met.

### 3. Continuity of Care

- Strengthening pathways of information sharing and communication between ICS and GPs (e.g. referral protocols, care plans).

### 4. Psychosocial Support

- Systematic approach for assessing patient supportive care needs early in cancer care.
- Support to develop mechanisms to assist in co-ordinating and identifying psychosocial support needs throughout a patient's cancer care.
- Professional development for health professionals directly involved in patient care to increase awareness of identifying patients who have unmet supportive care needs.

# INTRODUCTION

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Quality in health care comprises three inter-related components: the quality of the technical care provided, the quality of the patient-provider interaction; and the quality of the facilities where services are provided.<sup>1</sup> Quality can be assessed by using data on processes of care or outcomes of care.<sup>2</sup> Population outcomes such as incidence and mortality, for example, are routinely used as indicators of progress in cancer care. There has been increasing interest, however, in the collection of population data on patient-reported perceptions of care as indicators of quality<sup>3</sup>. Unlike measures that are driven by clinicians or the health system, these assess outcomes of care as seen from the patient perspective<sup>4</sup>. Such outcomes include quality of life; supportive care needs and patient experiences of care and provide an important indicator of the quality of the interpersonal, supportive and service aspects of healthcare.

While quality measurement using patient-reported outcomes takes place within individual Victorian hospitals, there are several limitations to the data collected<sup>5</sup>. First, these are largely restricted to patient satisfaction surveys rather than broader aspects of patient experiences, and second, survey methods often do not allow the targeted sampling of cancer patients as a special subgroup of hospital patients. Thirdly, the survey instruments and methods of data collection may vary between institutions limiting comparisons of care between different health services. Hence there is a need for a centralised mechanism for monitoring cancer patient experiences of care at the population level.

Assessment of patient experiences provides a mechanism for identifying where a health service can focus its efforts on quality improvement. When such assessments are done on a regular basis they also provide a means to track improvements in care and to monitor the impact of changes to the structure or organisation of services, quality improvement initiatives or other changes to health care policy and practice. The PROSPECT program (Patient Responses: an Ongoing Survey of People Experiencing Cancer Treatment) will provide a mechanism for monitoring the care experiences of Victorian cancer patients at the population level. This will be done through regular cross sectional surveys of people recruited through the Victorian Cancer Registry. As this initiative is novel, a pilot study to test the acceptability of potential measures and recruitment procedures was conducted.

## Study Aim

The pilot study aimed to: 1) examine the acceptability and feasibility of potential measures and methods that could be used in the PROSPECT program; 2) to determine cancer patients' experiences of care in three Integrated Cancer Services in Victoria.

# METHOD

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## Design

Cross-sectional survey of cancer patients with a nested randomised controlled trial to compare data collection methods.

## Participants

People who met the following eligibility criteria were invited to participate in the study: 1) confirmed diagnosis of invasive cancer; 2) aged 18- 79 years of age; 3) registered with the Victorian Cancer Registry (VCR) within 4 months' of diagnosis; 4) English speaking; 5) Residing in Hume or the North Eastern Metropolitan (NEMICS) Integrated Cancer Services (ICS) regions or an 'other' Integrated Cancer Service (ICS) region of Victoria. People with a previous diagnosis of cancer or who were judged unsuitable to participate (e.g. due to cognitive impairment) by their treating clinician were excluded.

## Procedure

The Victorian Cancer Registry (VCR) identified a consecutive sample of people meeting the eligibility criteria. The VCR contacted the notifying clinician of each eligible person to confirm eligibility. Clinicians were asked to contact the registry within four weeks if they were aware of any reason why the person should not be approached for the study. Those identified as not suitable for participation by their clinician were excluded. At this point eligible people were randomly allocated to either telephone or post data collection group.

The VCR wrote to eligible people, providing them with a brief overview of the study and asking if they agreed to the research team contacting them about study participation. Depending on the person's study allocation, the information included in the letter indicated that the study would involve either a telephone interview or completing a survey mailed to them. The VCR obtained written consent from each person to release their contact details to the research team. Those in the post condition were mailed a survey and reply paid envelope by the research team. Return of the survey was considered consent. Up to two reminder letters were sent to non-responders. Those in the interview condition were contacted by a trained interviewer and asked to participate in a Computer Assisted Telephone Interview at a convenient time. Verbal consent was obtained prior to commencing the interview.

## Measures

*Demographics:* Participants were asked to report basic demographic details including marital status, occupation, highest level of education and household income.

*Critical Cancer Care Events Survey:* This survey was developed to assess cancer patients' experiences of their medical and psychosocial care. The survey instrument was developed using the Psychosocial Guidelines for the Care of Adults with Cancer<sup>6</sup> as a framework, with items asking participants to report on their experiences of care including information provision, distress management and continuity of care. The survey focuses on care provided at critical phases of the illness trajectory such as diagnosis, treatment planning, treatment, treatment completion and continuity and co-ordination of care. Respondents were asked to indicate whether each care event occurred using a 4-point response scale ranging from 1 "Yes, definitely" to 4 "No, definitely not."

*Health-related quality of life:* The Functional Assessment of Cancer Therapy –General (FACT-G) assessed quality of life. This 27-item scale has been developed and validated for use with cancer patients and displays high internal consistency (overall scale  $\alpha = .89$ )<sup>7</sup>. It assesses 4 domains of quality of life (physical well-being, family well-being; emotional well being, functional well being) and an overall quality of life score. Higher scores reflect higher quality of life in each domain.

*Anxiety and Depression:* The Hospital Anxiety and Depression Scale (HADS) is a 14-item scale that contains both an anxiety and depression subscale<sup>8</sup>. The scale has high internal consistency ( $\alpha = .80$  for the anxiety subscale and  $\alpha = .81$  for the depression subscale) and high test retest reliability<sup>18</sup>. Higher scores reflect greater anxiety and depression. A score under 7 on each scale is taken as indicating normal levels of anxiety or depression.

*Acceptability feedback:* All participants provided brief acceptability feedback on the time taken to complete the survey, the acceptability of the measures, and preferred mode of administration.

## Data management and analysis

Telephone interview data was entered in real time using the WinCATI program. Self-completed questionnaire data was entered into Epidata. The datasets were combined and data analyses undertaken using SPSS. Descriptive statistics such as means, frequencies, percentages and ranges were computed for all data. ANOVA analyses were used to compare mean scores on the domains of the Critical Cancer Care Events survey across the main types of cancer for study participants and the three ICSSs.

# RESULTS

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## Consent Rates

Of the 936 eligible people with cancer identified by the VCR, 453 (48.4%) agreed to release their contact details to the researchers. Of these 453, 227 were randomised to the telephone condition and 226 to the post condition. Four hundred and twenty-nine (94.7%) people with cancer consented to study participation by either returning their completed survey through the mail (209 (92%)) or completing the telephone interview (220 (97%)). Six cases were removed from analyses due to a high percent of missing data, therefore the results presented in this report are based on survey data from 423 participants. Table 1 provides a summary of the recruitment progress for each of the participating regions.

**Table 1**  
Recruitment Progress

	Other ICS	NEMICS	Hume	Total
Identified	434	383	119	936
VCR Consent	214	168	71	453
Study Consent	198	168	63	429
Analyses	195	168	60	423

## Participant Characteristics

Table 2 presents the characteristics of the sample. The mean age of participants was 59 years, with more females (n = 236) than males (n=187) in the study. The majority of participants were married (75.4%), most participants had a secondary level of education with 38.6% indicating this was the highest level of education obtained. Around half the sample were not working (52.1%) at study participation.

In relation to cancer diagnosis, the majority were diagnosed with breast cancer (27%) and received their cancer diagnosis approximately 5 months prior to entering the study. Approximately ninety percent of participants reported having surgery, with just over a third also having chemotherapy (38.1%) and 23% having radiotherapy. Many participants reported experiencing other health problems in addition to their cancer diagnosis, the main problems including arthritis (20.4%), diabetes (7.7%) and heart disease (6.8%).

Participants were asked if they had accessed any services offered by The Cancer Council Victoria (CCV) since being diagnosed with cancer. Information booklets produced by CCV were utilised the most (74.9%), followed by the CCV website (22.7%) and Helpline (8.3%).

Preferences regarding methods of completing the survey were also ascertained. Frequencies indicated that the majority of participants rated the method they were randomised into as their first preference. That is 78.6% of participants allocated to the mail condition ranked 'paper and returning by mail' as their first preference for completing the survey and 79% of participants allocated to the phone condition

ranked this as their first preference. For the purposes of this report, data from the two data collection methods were combined for analyses.

**Table 2**  
**Demographic characteristics of participants**

		N (%)
Age	Range (years)	20-78
	Mean (years)	59.38
Gender	Male	187 (44.2%)
	Female	236 (55.8%)
Education	Primary school	60 (14.2%)
	Secondary school	162 (38.6%)
	Certificate or Diploma	100 (23.6%)
	University Degree	96 (22.7%)
Marital Status	Married	319 (75.4%)
	Defacto/ Live with partner	27 (6.4%)
	Separated/divorced	32 (7.6%)
	Widowed	21 (5%)
	Single/never married	13 (3.1%)
	Relationship but not living together	8 (1.9%)
Living situation <sup>a</sup>	Alone	52 (12.4%)
	Partner	331 (78.6%)
	Children/partner's children	67 (15.9%)
	Grandchildren/ partner's grandchildren	4 (1%)
	Parents/in-laws	3 (.7%)
	Other family members	9 (2.1%)
	Friends	1 (0.2%)
	Housemates	4 (1.0%)
Current employment	Full-time	95 (22.5%)
	Part-time	50 (11.8%)
	Casual	14 (3.3%)
	Not working	220 (52.1%)
	Other	34 (8)
Employment prior to diagnosis	Full-time	136 (32.2%)
	Part-time	57 (13.5)
	Casual	21 (5%)
	Not working	177 (41.9%)
	Other	21 (5%)
Private health insurance	Yes	274 (64.8%)
Time since diagnosis	Mean months	5 months
Cancer site	Breast	114 (27%)
	Colorectal	89 (21%)
	Prostate	68 (16.1%)
	Lung	18 (4.3%)
	Other	134 (31.7%)
Treatment <sup>a</sup>	Surgery	381 (90.1%)
	Chemotherapy	161 (38.1%)
	Radiotherapy	96 (22.7%)

<sup>a</sup>Multiple response item

## Patient Experiences (Critical Cancer Care Events Survey)

Participants' views about the content, readability and length of the Critical Cancer Care Events survey were assessed. Overall, 93% (N = 393) of participants felt the survey was clear and easy to understand. Ninety-six percent (N = 405) did not feel any questions should be removed and 79.5% (N = 336) did not think further questions needed to be added. Only 4.6% (N = 19) of participants felt the survey was too long.

When completing the Critical Cancer Care Events survey, participants were asked to indicate on a 4-point scale (1 = yes definitely, 2 = yes I think so, 3 = no, I don't think so, 4 = no, definitely not) the type of experience they had at particular phases in their cancer care. Tables 3 to 10 present a summary of participants' responses for each section of the survey. The percentages in the table represent the proportion of participants who responded 'yes definitely', 'yes I think so', 'no, I don't think so' or 'no, definitely not' for each item.

**Table 3**

Section 1: When you were told about your cancer

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>When my doctor told me that I had cancer:</i></b>					
It was at a face-to-face appointment.	Other ICS	177 (91.7%)	1 (0.5%)	2 (1.0%)	13 (6.7%)
	NEMICS	152 (92.1%)	0 (0%)	0 (0%)	13 (7.9%)
	Hume	53 (89.8%)	1 (1.5%)	0 (0%)	5 (8.5%)
	<b>Total</b>	<b>392 (91.8%)</b>	<b>2 (0.5%)</b>	<b>2 (0.5%)</b>	<b>31 (7.4%)</b>
I was told before the appointment that I could have a friend or family member with me if I wanted to.	Other ICS	62 (34.8%)	20 (11.2%)	21 (11.8%)	75 (42.1%)
	NEMICS	58 (37.4%)	16 (10.3%)	23 (14.8%)	58 (37.4%)
	Hume	18 (32.7%)	3 (5.5%)	8 (20.0%)	23 (41.8%)
	<b>Total</b>	<b>138 (35.6%)</b>	<b>39 (10.1%)</b>	<b>55 (14.2%)</b>	<b>156 (40.2%)</b>
I clearly understood the explanation my doctor had given me.	Other ICS	154 (84.6%)	16 (8.8%)	7 (3.8%)	5 (2.7%)
	NEMICS	134 (83.2%)	19 (11.8%)	6 (3.7%)	2 (1.2%)
	Hume	51 (89.5%)	6 (10.5%)	0 (0%)	0 (0%)
	<b>Total</b>	<b>339 (84.8%)</b>	<b>41 (10.3%)</b>	<b>13 (3.3%)</b>	<b>7 (1.8%)</b>
<b><i>When I was told that I had cancer my doctor:</i></b>					
Encouraged me to ask any questions that I had.	Other ICS	158 (81.4%)	16 (8.2%)	12 (6.2%)	8 (4.1%)
	NEMICS	131 (79.9%)	18 (11.0%)	7 (4.3%)	8 (4.9%)
	Hume	45 (77.6%)	13 (12.1%)	5 (8.6%)	1 (1.7%)
	<b>Total</b>	<b>334 (80.3%)</b>	<b>41 (9.9%)</b>	<b>24 (5.8%)</b>	<b>17 (4.1%)</b>
Showed that he/she understood how I was feeling.	Other ICS	125 (67.9%)	37 (20.1%)	12 (6.5%)	10 (5.4%)
	NEMICS	98 (60.9%)	44 (27.3%)	11 (6.8%)	8 (5.0%)
	Hume	37 (66.1%)	11 (19.6%)	6 (10.7%)	2 (3.6%)
	<b>Total</b>	<b>260 (64.8%)</b>	<b>92 (22.9%)</b>	<b>29 (7.2%)</b>	<b>20 (5.0%)</b>

Table 3 (cont)

## Section 1: When you were told about your cancer

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
Encouraged me to talk about how I was feeling.	Other ICS	94 (51.1%)	29 (15.8%)	24 (13.0%)	37 (20.1%)
	NEMICS	78 (48.8%)	29 (18.1%)	27 (16.9%)	26 (16.3%)
	Hume	26(46.4%)	11 (19.6%)	9 (16.1%)	10 (17.9%)
	Total	198 (49.5%)	69 (17.3%)	60 (15.0%)	73 (18.3%)
Asked if I wanted to be given information on the likely outcome of treatment at that appointment or later.	Other ICS	88 (47.8%)	30(16.3%)	27 (14.7%)	39 (21.2%)
	NEMICS	85 (52.5%)	29 (17.9%)	14 (8.6%)	34 (21.0%)
	Hume	27 (48.2%)	11 (19.6%)	5 (8.9%)	13 (23.2%)
	Total	200 (49.8%)	70 (17.4%)	46 (11.4%)	86 (21.4%)
<b><i>Within a reasonable time of being told that I had cancer:</i></b>					
I was given written information about cancer.	Other ICS	145 (75.1%)	6 (3.1%)	11 (5.7%)	31 (16.1%)
	NEMICS	115 (69.7%)	12 (7.3%)	14 (8.5%)	24 (14.5%)
	Hume	46 (80.7%)	4 (7.0%)	0 (0%)	7 (12.3%)
	Total	306 (73.7%)	22 (5.3%)	25 (6.0%)	62 (14.9%)
I was given a sheet with suggestions about questions that I might like to ask at my next appointment.	Other ICS	80 (43.5%)	21 (11.4%)	21 (11.4%)	52 (28.3%)
	NEMICS	50 (31.3%)	26 (16.3%)	33 (20.6%)	50 (32.5%)
	Hume	22 (39.3%)	10 (17.9%)	6 (10.7%)	29 (43.3%)
	Total	152 (38.0%)	57 (14.3%)	60 (15.0%)	132 (32.5%)
I was told how I could get further information about cancer e.g. websites, booklets, cancer helpline.	Other ICS	119 (63.3%)	13 (6.9%)	14 (7.4%)	42(22.3%)
	NEMICS	91 (56.2%)	21 (13.0%)	12 (7.4%)	38 (23.5%)
	Hume	37 (64.9%)	7 (12.3%)	3 (5.3%)	10 (17.5%)
	Total	247 (60.7%)	41 (10.1%)	29 (7.1%)	90 (22.1%)
<b><i>Overall, when I was diagnosed with cancer:</i></b>					
I received good quality care	Other ICS	176 (90.3%)	11 (5.6%)	4 (2.1%)	4 (2.1%)
	NEMICS	142 (86.1%)	20 (12.1%)	2 (1.2%)	1 (0.6%)
	Hume	49 (81.7%)	11 (18.3%)	0 (0%)	0 (0%)
	Total	367 (87.4%)	42 (10.0%)	6 (1.4%)	5 (1.2%)

Table 3 presents items relating to the experiences of patients when their doctor told them they definitely had cancer. Overall, participants indicated that they received good quality care (87.4% 'yes definitely') at this stage, with the majority reporting that their diagnosis was given to them face-to-face (91.8%), was clearly explained (84.8%) and that they were encouraged to ask questions (80.3%). However, across all the Integrated Cancer Services (ICS) fewer participants were provided with options regarding how to obtain more information about their diagnosis. For example, only 38% of participants were definitely given an information sheet with questions they might like to ask at their next appointment, 50% were asked if they wanted to be given information about the likely outcome of a treatment and 60.7% were informed about how they could obtain further information about their diagnosis. The data also show that less than half of the participants felt that they were encouraged to talk

about their emotional response to the diagnosis and only around a third felt they were told to bring someone along to the appointment.

Table 4 presents items relating to patients' experiences during the cancer planning phase of their treatment. Items referred to the care received from any health professional involved in their care (e.g. doctors, nurses, social workers etc). While the majority of participants felt that overall, the health professionals assisted them in making a decision they were comfortable with (81.4% 'yes definitely'), it appears that across the ICSs health professionals were not frequently checking the quantity of information needed by participants (32.1%) or providing relevant information. Less than 70% percent indicated that their health professional gave them information about the advantages and disadvantages (68.6%) and long-term side effects (64.9%) of the different treatment options and approximately 62% reported that their health professionals provided information regarding supportive or counselling services. However, only 40.5% reported that their health professionals checked their concerns regarding practical issues and 46.3% indicated that their health professionals asked permission to discuss their case with other health professionals.

**Table 4.**  
Section 2: Planning cancer treatment / management

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>The doctor(s) involved in planning my cancer treatment/management:</i></b>					
Gave me information about the advantages and disadvantages of different treatment options.	Other ICS	141 (74.2%)	17 (8.9%)	9 (4.7%)	23 (12.1%)
	NEMICS	105 (63.6%)	23 (13.9%)	14 (8.5%)	23 (13.9%)
	Hume	36 (64.3%)	6 (10.7%)	7 (12.5%)	7 (12.5%)
	Total	282 (68.6%)	46 (11.2%)	30 (7.3%)	53 (12.9%)
Gave me information on the possible short-term side effects of treatment(s).	Other ICS	161 (85.2%)	10 (5.3%)	2 (1.1%)	16 (8.5%)
	NEMICS	127 (78.4%)	13 (8.0%)	2 (1.2%)	20 (12.3%)
	Hume	45 (80.4%)	6 (10.7%)	0 (0%)	5 (8.9%)
	Total	333 (81.8%)	29 (7.1%)	4 (1.0%)	41 (10.1%)
Gave me information on the possible long-term side effects of treatment(s).	Other ICS	137 (72.9%)	15 (8.0%)	15 (8.0%)	21 (11.2%)
	NEMICS	91 (56.9%)	23 (14.4%)	21 (13.1%)	25 (15.6%)
	Hume	33 (61.1%)	7 (13.0%)	6 (11.1%)	8 (14.8%)
	Total	261 (64.9%)	45 (11.2%)	42 (10.4%)	54 (13.4%)
Asked my permission to discuss my case with other health professionals (i.e. a multidisciplinary team).	Other ICS	89 (48.4%)	18 (9.8%)	45 (24.5%)	32 (17.4%)
	NEMICS	69 (42.9%)	20 (12.4%)	46 (28.6%)	26 (16.1%)
	Hume	27 (49.1%)	9 (16.4%)	8 (14.5%)	11 (20.0%)
	Total	185 (46.3%)	47 (11.8%)	99 (24.8%)	69 (17.3%)

Table 4. (cont)

## Section 2: Planning cancer treatment / management

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>When my cancer treatment was being planned a health professional:</i></b>					
Asked me how much information I wanted.	Other ICS	55 (30.6%)	38 (21.1%)	40 (22.2%)	47 (26.1%)
	NEMICS	52 (32.3%)	22 (13.7%)	49 (30.4%)	38(23.6%)
	Hume	19 (36.5%)	10 (19.2%)	12 (23.1%)	11 (21.2%)
	Total	126 (32.1%)	70 (17.8%)	101 (25.7%)	96 (24.4%)
Encouraged me to ask any questions about treatment.	Other ICS	148 (77.9%)	27 (14.2%)	7 (3.7%)	8 (4.2%)
	NEMICS	120 (72.7%)	22 (13.3%)	10 (6.1%)	13 (7.9%)
	Hume	41 (74.5%)	6 (10.9%)	4 (7.3%)	4 (7.3%)
	Total	309 (75.4%)	55 (13.4%)	21 (5.1%)	25 (6.1%)
Gave me information about support services (e.g. the cancer helpline, support groups or other services).	Other ICS	129 (69.4%)	17 (9.1%)	10 (5.4%)	30 (16.1%)
	NEMICS	87 (53.7%)	22 (13.6%)	16 (9.9%)	37 (22.8%)
	Hume	31 (58.5%)	10 (18.9%)	2 (3.8%)	10 (18.9%)
	Total	247 (61.6%)	49 (12.2%)	28 (7.0%)	77 (19.2%)
Told me that counselling services were available if I wanted them.	Other ICS	119 (63.6%)	23 (12.3%)	17 (9.1%)	28 (15.0%)
	NEMICS	78 (48.8%)	20 (12.5%)	23 (14.4%)	39 (24.4%)
	Hume	33 (61.1%)	7 (13.0%)	5 (9.3%)	9 (16.7%)
	Total	230 (57.4%)	50 (12.5%)	45 (11.2%)	76 (19.0%)
Checked if I had concerns about practical issues such as childcare, finances, or transport to and from the hospital.	Other ICS	89 (48.9%)	28 (15.4%)	27 (14.8%)	38 (20.9%)
	NEMICS	50 (31.6%)	16 (10.1%)	35 (22.2%)	57 (36.1%)
	Hume	20 (37.7%)	5 (9.4%)	12 (22.6%)	16 (30.2%)
	Total	159 (40.5%)	49 (12.5%)	74 (18.8%)	111(28.2%)
<b><i>Overall:</i></b>					
The health professionals involved in my care helped me to make a treatment decision that I was comfortable with.	Other ICS	156 (80.8%)	24 (12.8%)	2 (1.1%)	6 (3.2%)
	NEMICS	134 (80.7%)	21 (12.7%)	7 (4.2%)	4 (2.4%)
	Hume	47 (77.8%)	7(13.0%)	4 (7.4%)	1 (1.9%)
	Total	332 (81.4%)	52 (12.7%)	13 (3.2%)	11 (2.7%)

Only participants who had surgery (N = 381) were required to complete the section relating to experiences around surgery. As shown in Table 5, generally participants felt as well prepared for surgery as possible (82.4% 'yes definitely'). However only around 28% of participants indicated that 'yes definitely' they received information about managing stress or anxiety before the surgery. It appears that more attention was provided to psychosocial care post surgery, with 71% of participants across all ICS reported that they were able to discuss concerns or fears with a health professional at follow-up.

**Table 5**  
Section 3: Preparing for surgery

	Region **	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b>Before having surgery for cancer I was given information about:</b>					
Where to go in the hospital for surgery.	Other ICS	162 (95.9%)	3 (1.8%)	1 (.6%)	3 (1.8%)
	NEMICS	135 (88.8%)	11 (7.2%)	2 (1.3%)	4 (2.6%)
	Hume	45 (83.3%)	5 (9.3%)	3 (5.6%)	1 (1.9%)
	Total	342 (91.2%)	19 (5.1%)	6 (1.6%)	8 (2.1%)
What would happen during surgery	Other ICS	156 (90.7%)	7 (4.1%)	2 (1.2%)	7 (4.1%)
	NEMICS	121 (80.1%)	19 (12.6%)	6 (4.0%)	5 (3.3%)
	Hume	43 (79.6%)	8 (14.8%)	1 (1.9%)	2 (3.7%)
	Total	320 (84.9%)	34 (9.0%)	9 (2.4%)	14 (3.7%)
How to manage any feelings of anxiety or stress <i>before</i> surgery (e.g. relaxation exercises).	Other ICS	53 (31.9%)	21 (12.7%)	40 (24.1%)	52 (31.3%)
	NEMICS	35 (23.5%)	18 (12.1%)	50 (33.6%)	46 (30.9%)
	Hume	16 (30.2%)	2 (3.8%)	15 (28.3%)	20 (37.7%)
	Total	104 (28.3%)	41 (11.1%)	105 (28.5%)	118 (32.1%)
What I could do <i>after</i> surgery to manage any pain or discomfort.	Other ICS	134 (80.2%)	17 (10.2%)	9 (5.4%)	7 (4.2%)
	NEMICS	97 (64.2%)	28 (18.5%)	17 (11.3%)	9 (6.0%)
	Hume	35 (64.8%)	9 (16.7%)	4 (7.4%)	6 (11.1%)
	Total	266 (71.5%)	54 (14.5%)	30 (8.1%)	22 (5.9%)
<b>Throughout my surgery planning and follow up:</b>					
One surgeon was responsible for overseeing my surgical care.	Other ICS	152 (88.9%)	6 (3.5%)	2 (1.2%)	11 (6.4%)
	NEMICS	134 (88.2%)	9 (5.9%)	4 (2.6%)	5 (3.3%)
	Hume	42 (77.8%)	5 (9.3%)	4 (7.4%)	3 (5.6%)
	Total	328 (87.0%)	20 (5.3%)	10 (2.7%)	19 (5.0%)
I was able to talk to a health professional about any concerns or fears I had about surgery.	Other ICS	132 (78.1%)	22 (13.0%)	5 (13.0%)	10 (5.9%)
	NEMICS	99 (66.0%)	24 (16.0%)	16 (10.7%)	11 (7.3%)
	Hume	33 (61.1%)	10 (18.5%)	6 (11.1%)	5 (9.3%)
	Total	264 (70.8%)	56 (15.0%)	27 (7.2%)	26 (7.0%)
<b>Overall:</b>					
I felt as well prepared as possible for surgery.	Other ICS	151 (88.3%)	14 (8.2%)	3 (1.8%)	3 (1.8%)
	NEMICS	120 (79.5%)	29 (19.2%)	0 (.0%)	2 (1.3%)
	Hume	38 (71.7%)	12 (22.6%)	2 (3.8%)	1 (1.9%)
	Total	309 (82.4%)	55 (14.7%)	5 (1.3%)	6 (1.6%)

\*\*Frequencies are based only on patients who had surgery:

Other ICS N = 172

NEMICS N = 154

Hume N = 55

Total N = 381

**Table 6**  
Section 4: Preparing to start chemotherapy

	Region**	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>Before starting chemotherapy for the first time I was given information about:</i></b>					
Where to go in the hospital for chemotherapy treatment.	Other ICS	61 (93.8%)	0 (.0%)	3 (4.6%)	1 (1.5%)
	NEMICS	66 (89.2%)	3 (4.1%)	0 (.0%)	5 (6.8%)
	Hume	17 (81.0%)	1 (4.8%)	2 (9.5%)	1 (4.8%)
	Total	144 (90.0%)	4 (2.5%)	5 (3.1%)	7 (4.4%)
Why the chemotherapy was necessary.	Other ICS	64 (97.0%)	1 (1.5%)	1 (1.5%)	0 (0%)
	NEMICS	70 (93.3%)	4 (5.3%)	0 (.0%)	1 (1.3%)
	Hume	18 (90.0%)	2 (10.0%)	0 (0%)	0 (.0%)
	Total	152 (94.4%)	7 (4.3%)	1 (.6%)	1 (.6%)
How the treatment would be given (e.g. through a needle/drip or a tablet that you swallow).	Other ICS	62 (93.9%)	3 (4.5%)	1 (1.5%)	0 (0%)
	NEMICS	71 (95.9%)	2 (2.7%)	0 (.0%)	1 (1.4%)
	Hume	17 (85.0%)	1 (5.0%)	2 (10.0%)	0 (.0%)
	Total	150 (93.8%)	6 (3.8%)	3 (1.9%)	1 (.6%)
How to manage any feelings of anxiety or stress before having chemotherapy for the first time (e.g. relaxation exercises).	Other ICS	27 (42.9%)	10 (15.9%)	9 (14.3%)	17 (27.0%)
	NEMICS	30 (41.1%)	11 (15.1%)	13 (17.8%)	19 (26.0%)
	Hume	5 (25.0%)	4 (20.0%)	6 (30.0%)	5 (25.0%)
	Total	62 (39.7%)	25 (16.0%)	28 (17.9%)	41 (26.3%)
<b><i>Throughout my chemotherapy treatment and follow up:</i></b>					
One doctor was responsible for overseeing my chemotherapy treatment.	Other ICS	44 (66.7%)	4 (6.1%)	3 (4.5%)	15 (22.7%)
	NEMICS	56 (74.7%)	3 (4.0%)	9 (12.0%)	7 (9.3%)
	Hume	16 (76.2%)	4 (19.0%)	1 (4.8%)	0 (.0%)
	Total	116 (71.6%)	11 (6.8%)	13 (8.0%)	22 (13.6%)
I was able to talk to a health professional about any concerns or fears I had about chemotherapy.	Other ICS	55 (85.9%)	7 (10.9%)	1 (1.6%)	1 (1.6%)
	NEMICS	60 (81.1%)	10 (13.5%)	2 (2.7%)	2 (2.7%)
	Hume	16 (80.0%)	4 (20.0%)	0 (.0%)	0 (.0%)
	Total	131 (82.9%)	21 (13.3%)	3 (1.9%)	3 (1.9%)
I was given information about what I could do to manage any physical side effects at home.	Other ICS	55 (85.9%)	7 (10.9%)	1 (1.6%)	1 (1.6%)
	NEMICS	65 (87.8%)	6 (8.1%)	1 (1.4%)	2 (2.7%)
	Hume	16 (76.2%)	3 (14.3%)	2 (9.5%)	0 (.0%)
	Total	136 (85.5%)	16 (10.1%)	4 (2.5%)	3 (1.9%)

**Table 6 (cont)****Section 4: Preparing to start chemotherapy**

	Region**	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b>Overall:</b>					
I felt as well prepared as possible for starting chemotherapy.	Other ICS	58 (87.9%)	8 (12.1%)	0 (.0%)	0 (.0%)
	NEMICS	58 (77.3%)	13 (17.3%)	1 (1.3%)	3 (4.0%)
	Hume	14 (66.7%)	3 (14.3%)	4 (19.0%)	0 (.0%)
	Total	130 (80.2%)	24 (14.8%)	5 (3.1%)	3 (1.9%)

\*\*Frequencies are based only on patients who had chemotherapy:

Barwon N = 65

NEMICS N = 75

Hume N = 21

Total N = 161

For those patients who received chemotherapy (N = 161) and radiotherapy (N = 96), their experiences around being prepared for these treatments was rated favourably in the three regions (see Tables 6 & 7). Approximately 90% (responses ranging from 83% to 98%) of the participants reported that 'yes definitely' they received practical information (e.g. locations of treatment) and treatment information (information about the treatment, side effects). On the other hand approximately 40 to 43% indicated that 'yes definitely' they received psychosocial support (e.g. managing feelings of anxiety).

**Table 7****Section 5: Preparing to start radiotherapy**

	Region**	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>Before starting radiotherapy for the first time I was given information about:</i></b>					
Where to go in the hospital for radiotherapy treatment.	Other ICS	44 (95.7%)	1 (2.2%)	0 (.0%)	1 (2.2%)
	NEMICS	33 (94.3%)	1 (2.9%)	1 (2.9%)	0 (.0%)
	Hume	15 (100.0%)	0 (.0%)	0 (.0%)	0 (.0%)
	Total	92 (95.8%)	2 (2.1%)	1 (1.0%)	1 (1.0%)
Why the radiotherapy was necessary.	Other ICS	46 (100.0%)	0 (0%)	0 (0%)	0 (0%)
	NEMICS	35 (97.2%)	1 (2.8%)	0 (.0%)	0 (0%)
	Hume	14 (93.3%)	0 (.0%)	1 (6.7%)	0 (0%)
	Total	95 (97.9%)	1 (1.0%)	1 (1.0%)	0 (0%)

**Table 7 (cont)**  
**Section 5: Preparing to start radiotherapy**

	Region**	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
What would happen when the treatment was given (e.g. how I would be positioned during treatment; being in a room by myself as the treatment was given).	Other ICS	46 (100.0%)	0 (.0%)	0 (.0%)	0 (.0%)
	NEMICS	31 (86.1%)	2 (5.6%)	2 (5.6%)	1 (2.8%)
	Hume	14 (93.3%)	1 (6.7%)	0 (.0%)	0 (.0%)
	Total	91 (83.8%)	3 (3.1%)	2 (2.1%)	1 (1.0%)
How to manage any feelings of anxiety or stress <i>before</i> having radiotherapy for the first time (e.g. relaxation exercises).	Other ICS	25 (56.8%)	2 (4.5%)	9 (20.5%)	8 (18.2%)
	NEMICS	10 (27.8%)	10 (27.8%)	12 (33.3%)	4 (11.1%)
	Hume	6 (40.0%)	1 (6.7%)	5 (33.3%)	3 (20.0%)
	Total	41 (43.2%)	13 (13.7%)	26 (27.4%)	15 (15.8%)
<b><i>Throughout my radiotherapy treatment and follow-up:</i></b>					
One doctor was responsible for overseeing my radiotherapy treatment	Other ICS	32 (72.7%)	1 (2.3%)	6 (13.6%)	5 (11.4%)
	NEMICS	22 (62.9%)	6 (17.1%)	2 (5.7%)	5 (14.3%)
	Hume	9 (60.0%)	1 (6.7%)	2 (13.3%)	3 (20.0%)
	Total	63 (67.0%)	8 (8.5%)	10 (10.6%)	13 (13.8%)
I was able to talk to a health professional about any concerns or fears I might have about radiotherapy.	Other ICS	42 (95.5%)	2 (4.5%)	0 (0%)	0 (0%)
	NEMICS	31 (88.6%)	4 (11.4%)	0 (0%)	0 (.0%)
	Hume	14 (93.3%)	0 (.0%)	0 (0%)	1 (6.7%)
	Total	87 (92.6%)	6 (6.4%)	0 (0%)	1 (1.1%)
I was given information about what I could do to manage any physical side effects at home.	Other ICS	41 (93.2%)	3 (6.8%)	0 (.0%)	0 (.0%)
	NEMICS	31 (88.6%)	2 (5.7%)	1 (2.9%)	1 (2.9%)
	Hume	13 (86.7%)	0 (.0%)	0 (.0%)	2 (13.3%)
	Total	85 (90.4%)	5 (5.3%)	1 (1.1%)	3 (3.2%)
<b><i>Overall:</i></b>					
I felt as well prepared as possible for starting radiotherapy.	Other ICS	43 (93.3%)	3 (6.7%)	0 (.0%)	0 (.0%)
	NEMICS	29 (82.9%)	5 (14.3%)	1 (2.9%)	0 (.0%)
	Hume	14 (93.3%)	0 (.0%)	0 (.0%)	1 (6.7%)
	Total	85 (89.5%)	8 (8.4%)	1 (1.1%)	1 (1.1%)

\*\*Frequencies are based only on patients who had radiotherapy:

Other ICS N = 45

NEMICS N = 36

Hume N = 15

Total N = 96

Items in Table 8 assess patient's experience of care whilst they were having any treatment for cancer. Generally participants reported that 'yes definitely' any problems during treatment were managed well (77%), including side effects (73%) and pain (75%), with participants from the other ICS demonstrating slightly higher

percentages. Similarly to other sections of the survey, psychosocial support (e.g. support for family 34.3%; emotional support for patients 35.5%) was less frequently reported as being provided or offered.

**Table 8**

**Section 6: Having treatment for cancer**

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>When I was having treatment for cancer:</i></b>					
On most visits to the hospital a health professional asked if I had any side effects or symptoms.	Other ICS	127 (78.4%)	12 (7.4%)	11 (6.8%)	12 (7.4%)
	NEMICS	101 (65.2%)	22 (14.2%)	18 (11.6%)	14 (9.0%)
	Hume	30 (62.5%)	7 (14.6%)	4 (8.3%)	7 (14.6%)
	Total	258 (70.7%)	41 (11.2%)	33 (9.0%)	33 (9.0%)
Side effects of treatment that I experienced were well managed.	Other ICS	129 (81.1%)	14 (8.8%)	6 (3.8%)	10 (6.3%)
	NEMICS	99 (66.0%)	35 (23.3%)	10 (6.7%)	3 (6.4%)
	Hume	33 (70.2%)	7 (14.9%)	4 (8.5%)	6 (4.0%)
	Total	261 (73.3%)	56 (15.7%)	20 (5.6%)	19 (5.3%)
The hospital staff asked if my family needed more information or support (i.e. help with practical or emotional issues).	Other ICS	74 (46.8%)	16 (10.1%)	24 (15.2%)	44 (27.8%)
	NEMICS	34 (22.5%)	24 (15.9%)	43 (28.5%)	50 (33.1%)
	Hume	14 (29.8%)	5 (10.6%)	8 (17.0%)	20 (42.6%)
	Total	122 (34.3%)	45 (12.6%)	75 (21.1%)	114 (32.0%)
I was regularly asked how I was dealing with the emotional side of cancer treatment	Other ICS	66 (42.3%)	22 (14.15)	26 (16.7%)	42 (26.9%)
	NEMICS	44 (28.9%)	25 (16.4%)	35 (23.0%)	16 (34.0%)
	Hume	16 (34.0%)	8 (17.0%)	7 (14.9%)	48 (31.6%)
	Total	126 (35.5%)	55 (15.5%)	68 (19.2%)	106 (29.9%)
On most visits to the hospital, a health professional asked if I had any pain.	Other ICS	116 (72.0%)	23 (14.3%)	6 (3.7%)	16 (9.9%)
	NEMICS	103 (66.9%)	19 (12.3%)	16 (10.4%)	16 (10.4%)
	Hume	32 (68.1%)	5 (10.6%)	5 (10.6%)	5 (10.6%)
	Total	251 (69.3%)	47 (13.0%)	27 (7.5%)	37 (10.2%)
<b><i>If you had pain at any time during your treatment please answer the next question:</i></b>					
My pain was well managed.	Other ICS	90 (88.2%)	8 (7.8%)	1 (1.0%)	3 (2.9%)
	NEMICS	63 (61.8%)	32 (31.4%)	3 (2.9%)	4 (3.9%)
	Hume	21 (65.6%)	8 (25.0%)	2 (6.3%)	1 (3.1%)
	Total	152 (75.2%)	38 (18.8%)	6 (3.0%)	8 (3.4%)
<b><i>Overall:</i></b>					
Problems I had during treatment were managed well.	Other ICS	137 (84.6%)	18 (11.1%)	3 (1.9%)	4 (2.5%)
	NEMICS	111 (71.2%)	39 (25.0%)	3 (1.9%)	3 (1.9%)
	Hume	35 (72.9%)	8 (16.7%)	4 (8.3%)	1 (2.1%)
	Total	283 (77.3%)	65 (17.8%)	10 (2.7%)	8 (2.2%)

Table 9 shows the responses of participants regarding experiences of completing treatment. For the majority of participants, the provision of information regarding follow-up tests (78%) and when to have follow-up tests (79%) occurred frequently. However, only 31% of the participants reported 'yes definitely' they were given a written plan for follow-up, 52% were informed how to manage ongoing symptoms or side effects (with a noticeable difference in responses between Other ICS (64)% and NEMICS (41%) and 27% were informed about symptoms relating to recurrence (again with higher proportions for Other ICS (34%) as opposed to NEMICS (18%). Similar to other sections of the survey, proportions of respondents indicating 'yes definitely' for items relating to psychosocial care were low. Twenty-seven percent were informed about emotional reactions relating to finishing treatment and 49% were advised were they could get extra support.

**Table 9**

**Section 7: Finishing cancer treatment**

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
<b><i>Towards the end of cancer treatment I was given:</i></b>					
A written plan about my follow-up care over the next 6 months.	Other ICS	28 (30.8%)	9 (9.9%)	10 (11.0%)	44 (48.4%)
	NEMICS	24 (30.0%)	1 (1.3%)	15 (18.8%)	40 (50.0%)
	Hume	9 (33.3%)	2 (7.4%)	3 (11.1%)	12 (44.4%)
	<b>Total</b>	<b>61 (30.8%)</b>	<b>12 (6.1%)</b>	<b>28 (14.1%)</b>	<b>96 (48.5%)</b>
<b><i>Towards the end of cancer treatment I was given information about:</i></b>					
Which follow up tests I might need.	Other ICS	75 (79.8%)	9 (9.6%)	3 (3.2%)	7 (7.4%)
	NEMICS	66 (77.6%)	4 (4.7%)	3 (3.5%)	12 (14.1%)
	Hume	20 (71.4%)	3 (10.7%)	0 (.0%)	5 (17.9%)
	<b>Total</b>	<b>161 (77.8%)</b>	<b>16 (7.7%)</b>	<b>6 (2.9%)</b>	<b>24 (11.6%)</b>
When I would need to have follow-up tests.	Other ICS	75 (81.5%)	8 (8.7%)	3 (3.3%)	6 (6.5%)
	NEMICS	66 (78.6%)	7 (8.3%)	0 (.0%)	11 (13.1%)
	Hume	19 (70.4%)	3 (11.1%)	0 (.0%)	5 (18.5%)
	<b>Total</b>	<b>160 (78.8%)</b>	<b>18 (8.9%)</b>	<b>3 (1.5%)</b>	<b>22 (10.8%)</b>
How to manage any ongoing symptoms or side effects.	Other ICS	59 (64.1%)	7 (7.6%)	7 (7.6%)	19 (20.7%)
	NEMICS	34 (41.0%)	11 (13.3%)	12 (14.5%)	26 (31.3%)
	Hume	12 (44.4%)	4 (14.8%)	2 (7.4%)	9 (33.3%)
	<b>Total</b>	<b>105 (52.0%)</b>	<b>22 (10.9%)</b>	<b>21 (10.4%)</b>	<b>54 (26.7%)</b>
Which new symptoms might mean that cancer has come back.	Other ICS	31 (34.4%)	9 (10.0%)	9 (10.0%)	41 (45.6%)
	NEMICS	15 (18.1%)	8 (9.6%)	16 (19.3%)	44 (53.0%)
	Hume	8 (29.6%)	3 (11.1%)	6 (22.2%)	10 (37.0%)
	<b>Total</b>	<b>54 (27.0%)</b>	<b>20 (10.0%)</b>	<b>31 (15.5%)</b>	<b>95 (47.5%)</b>

**Table 9 (cont)****Section 7: Finishing cancer treatment**

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
What I could do to stay as healthy as possible in the future (e.g. information about exercise, diet, stopping smoking).	Other ICS	51 (54.8%)	13 (14.0%)	7 (7.5%)	22 (23.7%)
	NEMICS	35 (41.7%)	15 (17.9%)	12 (14.3%)	22 (26.2%)
	Hume	11 (40.7%)	5 (18.5%)	3 (11.1%)	8 (29.6%)
	Total	97 (47.5%)	33 (16.2%)	22 (10.8%)	52 (25.5%)
How people commonly feel emotionally after finishing treatment.	Other ICS	31 (34.1%)	18 (19.8%)	8 (8.8%)	34 (37.4%)
	NEMICS	17 (20.5%)	12 (14.5%)	13 (15.7%)	41 (49.4%)
	Hume	7 (25.0%)	3 (10.7%)	5 (17.9%)	13 (46.4%)
	Total	55 (27.2%)	33 (16.3%)	26 (12.9%)	88 (43.6%)
Where I could get extra support if I needed it.	Other ICS	59 (61.5%)	10 (10.4%)	6 (6.3%)	21 (21.9%)
	NEMICS	31 (36.9%)	13 (15.5%)	13 (15.5%)	27 (32.1%)
	Hume	12 (44.4%)	5 (18.5%)	5 (18.5%)	5 (18.5%)
	Total	102 (49.3%)	28 (13.5%)	24 (11.6%)	53 (25.6%)
<b><i>Overall, toward the end of cancer treatment:</i></b>					
I knew where I could get help for any problems related to cancer that might come up over the next few months.	Other ICS	76 (78.4%)	11 (11.3%)	5 (5.2%)	5 (5.2%)
	NEMICS	57 (67.1%)	13 (15.3%)	7 (8.2%)	9 (9.4%)
	Hume	20 (71.4%)	2 (7.1%)	1 (3.6%)	5 (17.9%)
	Total	153 (72.9%)	26 (12.4%)	13 (6.2%)	18 (8.6%)

The final section of the survey asked about participants' experiences regarding the continuity of care they received throughout their cancer experience and the co-ordination of their care (see Table 10). The majority of participants reported their continuity of care to be favourable. Eighty-eight percent of participants indicated that 'yes definitely' a health professional was available to discuss care and that health professionals appeared well informed (81%), however, GPs do not appear to be kept as well informed as other health professionals (70%), and this was more so in the Hume region (60%). Most participants reported a preference to see the same doctor throughout their care and follow-up (91% 'yes definitely'). For those participants who had more than one hospital involved in their care, only 61% felt that the hospitals were definitely informed about the care they were receiving from each hospital.

**Table 10**  
Section 8: Continuity of care and care co-ordination

	Region	Yes, definitely	Yes, I think so	No, I don't think so	No, definitely not
I prefer to see the same doctor(s) throughout my treatment and follow-up.	Other ICS	177 (93.2%)	9 (4.7%)	4 (2.1%)	0 (.0%)
	NEMICS	148 (85.7%)	10 (6.1%)	5 (3.0%)	1 (0.6%)
	Hume	48 (85.7%)	4 (7.1%)	2 (3.6%)	2 (3.6%)
	<b>Total</b>	<b>373 (91.0%)</b>	<b>23 (5.6%)</b>	<b>11 (2.7%)</b>	<b>3 (0.7%)</b>
<b><i>From when I was diagnosed until now:</i></b>					
There has been a health professional whom I could contact if I had any questions about my care.	Other ICS	173 (91.1%)	7 (3.7%)	7 (3.7%)	3 (1.6%)
	NEMICS	141 (87.0%)	10 (6.2%)	5 (3.1%)	6 (3.7%)
	Hume	46 (80.7%)	6 (10.5%)	4 (7.0%)	1 (1.8%)
	<b>Total</b>	<b>360 (88.0%)</b>	<b>23 (5.6%)</b>	<b>16 (3.9%)</b>	<b>10 (2.4%)</b>
My GP has been kept well informed about my cancer care.	Other ICS	146 (75.3%)	35 (18.0%)	8 (4.1%)	5 (2.6%)
	NEMICS	112 (67.9%)	38 (23.0%)	9 (5.5%)	6 (3.6%)
	Hume	34 (59.6%)	15 (26.3%)	6 (10.5%)	2 (3.5%)
	<b>Total</b>	<b>292 (70.2%)</b>	<b>88 (21.2%)</b>	<b>23 (5.5%)</b>	<b>13 (3.1%)</b>
The health professionals involved in my care appeared well informed about my cancer care.	Other ICS	164 (86.3%)	22 (11.6%)	2 (1.1%)	2 (1.1%)
	NEMICS	131 (79.9%)	27 (16.5%)	6 (3.7%)	0 (.0%)
	Hume	37 (67.3%)	13 (23.6%)	4 (7.3%)	1 (1.8%)
	<b>Total</b>	<b>332 (81.2%)</b>	<b>62 (15.2%)</b>	<b>12 (2.9%)</b>	<b>3 (0.7%)</b>
<b><i>If more than one hospital was involved in your care, please answer the following questions. The hospitals involved in my care:</i></b>					
Were well informed about the care I received from other hospitals or health services.	Other ICS	46 (65.7%)	16 (22.9%)	5 (7.1%)	3 (4.3%)
	NEMICS	37 (56.1%)	20 (30.3%)	5 (7.6%)	4 (6.1%)
	Hume	20 (60.6%)	9 (27.3%)	2 (6.1%)	2 (6.1%)
	<b>Total</b>	<b>103 (60.9%)</b>	<b>45 (26.6%)</b>	<b>12 (7.1%)</b>	<b>9 (5.3%)</b>
Co-ordinated my appointments to suit my needs.	Other ICS	53 (75.7%)	5 (7.1%)	6 (8.6%)	6 (8.6%)
	NEMICS	48 (71.6%)	11 (16.4%)	4 (6.0%)	4 (6.0%)
	Hume	23 (69.7%)	7 (21.2%)	1 (3.0%)	2 (6.1%)
	<b>Total</b>	<b>124 (72.9%)</b>	<b>23 (13.5%)</b>	<b>11 (6.5%)</b>	<b>12 (7.1%)</b>

Table 11 presents the average number of items that received a 'yes definitely' response for each Section of The Critical Care Events Survey. A total mean score is shown as well as separate mean scores for each of the ICS. This was calculated by counting the number of items in each section that a patient gave a score of 1 indicating 'yes definitely'. A high mean score indicates that for this critical phase of cancer care most participants definitely experience the majority of the care events. A low score reflect few participants definitely experience the care event and indicates that participants' experiences in this area could be improved. As can be seen in Table

11, mean scores on all the sections were over half the range of scores, indicating that majority of items included in the sections were responded to as 'yes definitely'. This suggests that most participants experience the actions that the psychosocial guidelines suggest should happen during care. However for several items, mean scores were just around the half-way mark for the range, suggesting that improvements in participants' experiences of care during these phases are needed. For instance, the mean score on the section assessing treatment planning/management was 5.8 with a maximum score of 10. In addition, the mean score for the section having treatment was 3.8 with a maximum of 8, again suggesting participants' experiences in this phase of care could be improved. Overall, means were slightly higher for participants in the other ICS region than from NEMICS and Hume regions.

**Table 11**

Mean scores for items responded 'yes definitely' for each Section in The Critical Care Cancer Events Survey.

Section	Range	Other ICS		NEMICS		Hume		Total	
		Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
1:Told you had cancer	0-11	7.07	(2.63)	6.75	(2.86)	6.85	(3.07)	6.91	(2.79)
2:Planning Treatment/ Management	0-10	6.28	(2.69)	5.43	(2.91)	5.45	(3.22)	5.83	(2.88)
3:Preparing for surgery	0-7	5.47	(1.44)	4.81	(1.68)	4.58	(2.09)	5.07	(1.68)
4:Preparing for Chemotherapy	0-8	6.43	(1.44)	6.35	(1.71)	5.67	(1.98)	6.29	(1.65)
5:Preparing for radiotherapy	0-8	6.78	(1.52)	6.11	(1.90)	6.60	(1.55)	6.50	(1.69)
6:Having treatment	0-8	4.18	(2.46)	3.57	(2.24)	3.32	(2.57)	3.81	(2.41)
7:Finishing treatment	0-9	5.21	(2.35)	4.65	(2.28)	4.82	(2.72)	4.97	(2.38)
8:Continuity and Co-ordination	0-7	4.10	(1.54)	3.88	(1.61)	3.73	(2.26)	3.96	(1.69)

The association between the care experiences in each of the critical care phases and ICS region shown in Table 11 is described in detail below. We also examined the association between care experiences and type of cancer the participant had. For these analyses the cancer types were classified as: breast, colorectal, prostate, lung and other. A summary of these findings is presented below.

### *Section 1: When you were told you had cancer*

There was no difference in participants' experiences of being told of the cancer care across the three ICS. There was a significant difference in experience of care between the different cancer sites ( $f(4, 418) = 9.23, p = .00$ ). Participants diagnosed with colorectal cancer reported fewer critical care events in this phase of their cancer care than those participants with other cancers (Prostate mean = 8.1; Breast mean = 7.6; Lung mean = 7.3; Other mean = 6.2; Colorectal mean = 6.2).

### *Section 2: Planning cancer treatment/ management*

Significant differences were evident between the ICS regions ( $f(2, 420) = 4.51, p = .01$ ) with participants from the other ICS region having higher scores than those from the other two regions (Other ICS mean=6.3; NEMICS mean=5.4; Hume mean=5.4). Experience of cancer treatment planning also differed by cancer type ( $f(4, 418) = 17.13, p = .00$ ) with participants with breast cancer having higher scores than participants with other types of cancer (Breast mean = 7.2; Prostate mean = 6.7; Lung mean = 5.7; Colorectal mean = 5.2; Other mean = 4.6).

### *Section 3: Preparing for Surgery*

Mean scores differed slightly between the ICS regions ( $f(2, 378) = 9.31, p = .00$ ) with participants from the other ICS having higher scores than those from the other two ICSs (other ICS mean=5.5; NEMICS mean=4.8; Hume mean=4.6). Significant differences in experiences around preparing for surgery were found between type of cancer with participants with "other" cancers experiencing less critical care events than those with the more common cancer (Prostate mean = 5.6; Breast mean = 5.5; Lung mean = 5.4; Colorectal mean = 4.8; Other mean = 4.5) ( $f(4, 376) = 6.99, p = .00$ ).

### *Section 4: Preparing for Chemotherapy*

Experiences of critical care events around chemotherapy did not differ by cancer type or ICS region.

### *Section 5: Preparing for Radiotherapy*

As the majority of participants receiving radiotherapy were women with breast cancer comparisons between cancer types were not appropriate. Experiences of critical care events around radiotherapy did not differ by ICS region.

### *Section 6: Having treatment for cancer*

Experiences around having treatment differed across the ICS regions with participants from the other ICS experiencing more of the critical events around treatment than participants from the other two regions (Other ICS mean=4.2; NEMICS mean=3.6; Hume mean=3.3) ( $f(2, 410) = 4.37, p = .01$ ). Differences in experiences between cancer types were of borderline significance ( $f(4, 408) = 2.36, p = .05$ ) with lower scores found for those participants with "other" cancer types (Breast mean = 4.2; Lung mean = 4.8; Prostate mean = 3.6; Colorectal mean = 3.7; Other mean = 3.5).

### Section 7: Finishing cancer treatment

As only 105 participants had finished treatment when they completed the survey, numbers in each cancer types are relatively low. For this reason significance testing was not conducted to determine whether experiences differed by cancer type.

There were no differences in experiences of finishing treatment between the ICS regions.

### Section 8: Continuity of Care and Care Co-ordination

There were no differences in participants' experiences around continuity of care between cancer types or the ICS regions.

## Psychosocial Functioning

Mean scores for psychological distress (HADS) and quality of life (FACT-G) appear in Table 12. As demonstrated in Table 12, mean scores were fairly similar across the three regions for each of the psychosocial domains. Mean scores for anxiety and depression were low (4.00 and 3.00 respectively), with only six percent of participants having possible clinical anxiety and three percent with clinical depression. Overall reported quality of life was relatively high (88 out of a possible 108) and participants showed good physical, social, emotional and functional well-being.

**Table 12**

Psychological distress and quality of life mean scores

Scale	Domain	Range	Other ICS		NEMICS		Hume		Total	
			Mean	SD	Mean	SD	Mean	SD	Mean	SD
1: Psychological Distress <sup>‡</sup>	Anxiety	0 – 21	4.05	3.59	3.71	3.62	4.66	4.28	4.00	3.71
	Depression	0 – 21	3.04	3.23	2.78	2.62	3.58	3.34	3.01	3.02
2: Quality of Life (FACT – G) <sup>‡</sup>	Physical Well-being	0 – 28	22.85	5.89	23.42	4.77	23.07	5.19	23.11	5.36
	Social/ Family	0 – 28	22.94	4.99	22.54	4.62	23.27	4.75	22.84	4.81
	Well-being	0 – 24	19.82	4.59	20.34	3.87	19.67	4.44	20.00	4.30
	Emotional Well-being	0 – 28	21.48	5.81	22.70	4.71	20.82	5.37	21.87	5.37
	Functional Well-being	0 – 108	87.10	16.88	89.68	13.23	87.20	14.92	88.08	15.32

<sup>‡</sup> higher scores indicate higher levels of anxiety or depression

<sup>‡</sup> higher scores indicate higher levels of quality of life

## DISCUSSION

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The aim of this pilot study was two fold. First, this study aimed to examine the acceptability and feasibility of a newly developed survey tool to assess cancer patients' experiences throughout their cancer care. Second, this pilot study aimed to determine cancer patients' experiences of care in three Integrated Cancer Services in Victoria.

### Critical Cancer Care Events Survey

Results from this study showed the acceptability of The Critical Cancer Care Events survey as an assessment tool of cancer patients' experience of care and suggests this tool is suitable for use in the state-wide PROSPECT program. The content, useability, readability and length of the survey were rated favourably and more than ninety percent of study participants did not feel further questions needed to be added to obtain an accurate representation of their cancer care experience. The survey also appeared to discriminate between different subgroups of patients such as those in different ICS and with different types of cancer.

The use of patient experience reports is an important area and one that warrants further attention. This approach enables the assessment of patient perceptions of care and identification of areas of care that can be targeted for quality improvement. Further, as the items within the survey were derived from guidelines for psychosocial care<sup>6,9</sup>, survey results give an indication of guideline adoption. Hospitals and services can use this information to focus on specific areas of improvement, strategic decision making, managing the expectations of patients care and to benchmark services. Consumer groups may also use this information to inform advocacy activities. These efforts may result in frameworks and processes to support delivery of care that is responsive to patient needs, values and preferences.

The Critical Cancer Care Events survey provides a method of assessing patients' cancer care experiences and results presented here suggest this measurement tool can be used across systems of care (e.g. ICS regions) in Victoria and with large populations. Without a consistent measurement strategy, it is not possible to identify whether gaps in services or supports for people with cancer are consistent across health regions or track improvements in care over time. In addition, this tool moves beyond looking at patient satisfaction with care to provide information that relates to quality indicators of care and therefore can assist in working toward the goal of providing excellent psychosocial care for people with cancer.

Overall, the pilot study was able to provide preliminary data on the usefulness of the Critical Cancer Care Events survey as an assessment tool of cancer care experiences from the patients' perspective and suggests further testing of this tool for reliability and validity is warranted.

## Patient Experiences of their Cancer Care

Responses to the Critical Cancer Care Events survey indicated that overall, participants' experience of the care was positive. Information provision at the time of diagnosis and when planning for cancer treatment and management were reported as occurring less frequently than other aspects of care. This finding concurs with a number of other Australian surveys.<sup>10,11</sup> This is of concern because Level I evidence suggests that meeting cancer patients' information needs promotes psychological well-being and improves understanding of the disease,<sup>12</sup> which can enable patients to feel empowered and in control of their care<sup>13</sup>. Provision of sensory and procedural information as well as psychosocial support prior to treatment reduces distress and enhances physical and psychosocial recovery.<sup>14,15</sup> The current findings suggest a need for health care services to adopt a more systematic approach to assessing patient information needs and providing information to meet those needs.

Gaps in information provision were also identified for those finishing cancer treatment. Despite recommendations that all patients receive a written care plan at treatment completion<sup>16</sup>, only 33% of participants reported that they were definitely given a written plan for follow-up. Twenty-eight percent were informed about symptoms relating to recurrence and half of the participants were 'definitely' informed about the management of ongoing symptoms or side effects. A lack of post-treatment support may leave patients feeling anxious and stressed about the 'unknown'<sup>17</sup> and go from feeling supported during treatment to suddenly feeling unsupported.

GPs are thought to play an important role in ensuring continuity of care for people with cancer<sup>18,19</sup>. This role is considered to be even more important in regional areas<sup>6</sup> where access to specialist care may be limited, and where there may be greater need for GP assistance in linking patients into local supports and services. Only 60% of participants in the Hume region reported their GP was definitely being kept informed about their cancer care. There is a need for further research to establish the role of GPs in cancer care, and the potential benefits of different ways of involving GPs in cancer care.

Participants did not perceive that health professionals routinely provided them with psychosocial support. This was particularly evident when preparing for treatment (surgery, chemotherapy and radiotherapy) and whilst having treatment. These findings concur with those of the NSW Patient Satisfaction survey that indicated low levels of satisfaction with emotional support<sup>11</sup>. Provision of psychosocial support including having the opportunity to discuss fears and concerns with a member of the treatment team reduces psychological distress, and improves adjustment post treatment<sup>18</sup>. This suggests a need for cancer services to co-ordinate pathways for psychosocial support early in the disease trajectory and have processes for identifying and addressing psychosocial needs. This may require a more systematic

approach for linking patients with available services both within the hospital (e.g. counselling services) and outside of the hospital.

When comparing differences between the ICS regions, it appears that study participants from the 'other ICS' were more likely to experience the care events during each of the critical phases of cancer care. This was particularly notable for the 'planning cancer/treatment / management', 'preparing for surgery' and 'having treatment for cancer' phases. Further investigation is needed to assist in our understanding of why differences between the ICS regions are occurring. Possible causes that could be investigated include differences in resources, staff training, or processes or structures to support the provision of psychosocial care. Regarding cancer type, it appears that breast cancer patients more frequently experienced the care events compared to other cancer types. This may be due to the introduction of the breast cancer nurse that increases the likelihood that breast cancer patients receive information and support through their entire cancer journey.

## Conclusion

The pilot study confirmed the acceptability of The Patient Experience Survey for cancer patients and suggests this tool is suitable for use in the state-wide Prospect program.

# RECOMMENDATIONS

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This report makes a number of recommendations that may assist in improving consumer's experience of their cancer care:

1. To develop a system for monitoring and assessing consumer's experiences over time. This would allow some insight about whether efforts to address gaps in care identified in this report result in improvements in patients' experiences of care over time.
2. Information provision:
  - Systematic approach to assessing patient information needs at initial diagnosis and when planning for cancer treatment.
  - Professional development for health professionals directly involved in patient care to increase awareness of avenues to meet informational needs.
  - Follow-up protocols throughout cancer care to ensure informational needs are continuing to be assessed and met.
3. Continuity of Care
  - Strengthening pathways of information sharing and communication between ICS and GPs (e.g. referral protocols, care plans).
4. Psychosocial Support
  - Systematic approach for assessing patient supportive care needs early in cancer care,
  - Support to develop mechanisms to assist in co-ordinating and identifying psychosocial support needs throughout a patient's cancer care.
  - Professional development for health professionals directly involved in patient care to increase awareness of identifying patients who have unmet supportive care needs.

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