

## Patient Perspectives

# How do outpatient cancer clinics perform?

Experiences and outcomes of care  
February and March 2015



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Please note there is the potential for minor revisions of data in this report.  
Please check the online version at **[bhi.nsw.gov.au](http://bhi.nsw.gov.au)** for any amendments.

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The conclusions in this report are those of BHI and no official endorsement by the NSW Minister for Health, the NSW Ministry of Health or any other NSW public health organisation is intended or should be inferred.

# Table of contents

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<b>Foreword</b>	<b>2</b>
<b>Summary</b>	<b>3</b>
<b>Setting the scene</b>	<b>5</b>
<b>Section 1 – Experiences of care in outpatient cancer clinics</b>	<b>15</b>
Thematic responses: NSW results	17
Overall experience of care	19
Aspects of care: All response categories	21
Access and timeliness before the visit	23
Access and timeliness during the visit	25
Physical environment and comfort	27
Addressing patient concerns	29
Respect and dignity	31
Information to support patients	33
Shared decision-making	35
Coordination and continuity	37
Hygiene and cleanliness	39
Patient-reported complications of care	41
Local health district overview and survey themes	43
Hospital overview and survey themes	45
Thematic overview: Barriers to access	47
<b>Section 2 – Patients who visited for chemotherapy, radiotherapy or surgery</b>	<b>49</b>
Aspects of patient care: Results by type of visit	51
Variation in accessibility and appropriateness	53
Visits for chemotherapy, radiotherapy or a surgical procedure: LHD and hospital overview	55
<b>Section 3 – Patients in an active treatment phase</b>	<b>57</b>
Symptom severity and self-efficacy scores: NSW results	59
Symptom severity scores: LHD and hospital results	61
Self-efficacy: Confidence in communicating and maintaining a positive attitude	63
Outcomes for patients in an active phase of treatment: Complications of care	65
<b>Appendices</b>	<b>67</b>
<b>References</b>	<b>79</b>
<b>Acknowledgements</b>	<b>80</b>

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# Foreword

The incidence of cancer in NSW is widely known – the lifetime risk of being diagnosed with cancer by age 85 is one in two for males and one in three for females.

Reporting on the care of people with cancer has typically focused on impact of treatments, such as survival following a diagnosis of cancer; reception of certain types of services, such as adherence by clinicians to evidence-based guidelines in cancer screening; or on measures of accessibility.

While these are important aspects for healthcare systems to examine, another perspective is missing: in NSW, we know very little about the experiences of people with cancer who are being treated, reviewed or receiving follow-up care. Patients receive such services in NSW public hospitals in outpatient cancer clinics. These clinics provide important and ongoing care, covering combinations of treatment options including anti-cancer drugs, radiation therapy and surgery.

The Bureau of Health Information (BHI) partnered with the Cancer Institute NSW (CINSW) to develop the Outpatient Cancer Clinics Survey, allowing us to reflect on the experiences of people with cancer attending outpatient cancer care clinics. This report describes the feedback provided by more than 3,700 people who responded to a specifically-designed questionnaire about their experiences of care at cancer outpatient clinics.

This report builds on an ongoing collaboration between BHI and CINSW and is the third report produced jointly. Together, these reports help to grow our understanding of how well the healthcare system in NSW is responding to the expectations and needs of people who are living with cancer. In particular, this latest report contains the first systematic and detailed information on patient self-efficacy and an assessment of how well their treatment-related symptoms are controlled.

“ Giving voice to people living with cancer who received advice and treatment in public hospital outpatient clinics, sheds light on the overall performance of hospitals and local health districts in delivering care that responds to their expectations and needs. ”

Patients are primary participants in, and witnesses of, the care they receive. Giving voice to people living with cancer who received advice and treatment in public hospital outpatient clinics, sheds light on the overall performance of hospitals and local health districts in delivering care that responds to their expectations and needs. It also enables us to assess more specifically, areas where care for people living with cancer could be improved.

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# Summary

This edition of *Patient Perspectives* summarises experiences and outcomes of care for 3,706 patients who visited a public outpatient cancer clinic during February or March 2015. The report is based on information collected using a specifically-designed questionnaire that was sent to 6,467 patients (response rate of 57%). The report presents results in three main sections:

- **Section 1** describes experiences and outcomes of care. Results are based on responses to 42 survey questions from all surveyed outpatients – including patients with cancer (90% of patients) and patients who visited a clinic for other reasons, such as radiotherapy for lupus (10% of patients).
- **Section 2** compares responses about a visit for chemotherapy, radiotherapy or a surgical procedure (34% of patients) with those for other reasons. It then examines variation in responses about visits for chemotherapy, radiotherapy or a surgical procedure using a subset of 15 questions regarding accessibility and appropriateness of care.
- **Section 3** compares responses from patients who, at the time of survey completion (three months after the outpatient visit), were in an active treatment phase (30% of patients) with those from other patients. It then examines variation in responses from patients in an active treatment phase using 15 measures that address effectiveness of care.

## Section 1: All patients – Experience and outcome measures

Almost all patients who visited an outpatient cancer clinic rated the care they received as either ‘very good’ (83%) or ‘good’ (16%); and 92% said they would ‘speak highly’ of the clinic to friends and family.

### Accessibility and timeliness

Patients were generally able to get an appointment time that suited them (98%); said the time they waited for an appointment was ‘about right’ (92%); and their appointment started within 30 minutes of the scheduled time (81%).

Most reported no physical barriers to access, and had no difficulties entering or moving around the clinic. However, many patients encountered other access issues – 52% had a problem parking and 46% incurred out-of-pocket expenses as a result of their visit.

### Appropriateness of care

Almost all patients said they were ‘always’ treated with respect and dignity (97%); their cultural beliefs were ‘always’ respected (98%); and health professionals were ‘always’ kind and caring (95%).

Regarding communication, more than nine in 10 patients said health professionals ‘completely’ explained the purpose of new medications and they ‘definitely’ had enough time to discuss health issues with professionals. However, fewer said they were ‘completely’ informed about medication side effects (76%); or that a health professional ‘completely’ discussed with them their worries or fears (69%).

While 74% of patients said they were ‘definitely’ involved in decisions about their care and treatment (as much as they wanted to be), only 57% who needed a cancer care plan said they had one; and even fewer (47%) were ‘definitely’ asked for their ideas and preferences when developing their plan.

On questions about coordination and continuity – 91% of patients said they did not receive conflicting information from professionals; and 77% said professionals worked together in a ‘very good’ way.

Most patients said the clinic was ‘very clean’ (83%) and they ‘always’ saw health professionals wash their hands before touching them (68%).

Across the 42 survey questions, patients who visited a clinic in Northern NSW Local Health District (LHD) and Campbelltown Hospital responded more positively than NSW patients overall for 14 and 11 questions, respectively. Patients who visited a clinic in Western Sydney LHD and Westmead Hospital answered less positively for seven and eight questions, respectively.

## Section 2: Patients who visited for chemotherapy, radiotherapy or surgery – Accessibility and appropriateness measures

Responses from patients whose visit included chemotherapy, radiotherapy or a surgical procedure were more positive than those who visited for other reasons regarding access and cleanliness. They were more likely to have a cancer plan and be well informed about side effects to watch for, but were less positive regarding privacy and complications of care.

Patients who visited a clinic in Northern NSW LHD and Lismore Hospital responded more positively than the NSW result for three of the 15 accessibility and appropriateness questions. No LHD or hospital result was less positive than NSW for multiple questions.

## Section 3: Patients in an active cancer treatment phase – Effectiveness measures

Patients rated – at the time of survey completion – the severity of nine symptoms, such as anxiety, tiredness, pain and nausea; and measures of three dimensions of self-efficacy, including confidence in their ability to participate in care, obtain information and maintain a positive attitude. Those in an active treatment phase reported more severe symptoms and lower self-efficacy.

Almost two in 10 (18%) said that in the three months following their visit, they went to an emergency department because of cancer or cancer complications; and more specifically, 14% said they experienced a complication as a result of care they received at the clinic. Of those who experienced a complication, 18% said its impact was 'very serious'.

Across 15 effectiveness measures, patients who visited a clinic in Mid North Coast LHD, and Port Macquarie and Coffs Harbour hospitals were more positive for four or more, while those who visited the Chris O'Brien Lifehouse were less positive for six.

### Key findings – at a glance

- NSW outpatient cancer clinics perform well – almost all patients rated the care they received as 'very good' (83%) or 'good' (16%); and 92% would 'speak highly' of the clinic
- Patients responded most positively to questions about whether they were treated with respect
- While most patients answered questions about communication very positively, only three quarters said they were 'completely' informed about medication side effects
- Almost half of all patients had out-of-pocket expenses in relation to their visit, with parking and travel costs the most frequently mentioned
- Among patients who said they needed a cancer care plan, only six in 10 had one
- Of those with a cancer plan, fewer than half were 'definitely' asked for their ideas and preferences
- Complications of care were reported by 12% of all patients and by 14% of patients in an active treatment phase
- Of patients in an active treatment phase who had a complication, 18% said its impact was 'very serious' and 48% said it was 'fairly serious'
- Patients who visited clinics in some LHDs or hospitals responded more positively than the NSW result for a range of questions (Northern NSW, Campbelltown Hospital), while patients in other areas were less positive (Western Sydney, Westmead Hospital)
- Of those in an active phase of treatment, outcomes were more positive for patients who visited a clinic in Mid North Coast LHD, and Port Macquarie and Coffs Harbour hospitals while patients who visited Chris O'Brien Lifehouse responded less positively.

# Setting the scene



# Outpatient cancer clinics

Outpatient cancer clinics provide a range of different services, making an important and sustained contribution to patient pathways and outcomes.

Most people with cancer experience intensive episodes of active treatment that require frequent visits, as well as extended periods of intermittent support, monitoring and advice. Outpatient cancer clinics aim to provide care in a way that allows most patients to stay at home while undergoing diagnosis, treatment, follow-up and review.

This section sets the scene for the report, describing data collection and analytic methods and providing contextual information about how patient profiles and reasons for visiting an outpatient cancer clinic vary across NSW.



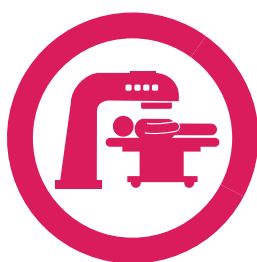
**Diagnostic test,  
x-ray or scan**



**Medical diagnosis  
or advice**



**Chemotherapy**



**Radiotherapy**



**Surgical procedure**



**Review of  
treatment**



**Regular  
check-up**

# About this report

Cancer is a group of diseases characterised by the uncontrolled growth of abnormal cells. There are about 200 different types of cancer, most of which are named for the organ or type of cell in which they start.<sup>1</sup>

Cancer touches on the lives of most people in NSW – either directly, or indirectly as a result of diagnosis and treatment of family members, friends or colleagues. It places a significant burden on individuals, their families, communities and the healthcare system.

Each year, almost 40,000 people in NSW are diagnosed with cancer.<sup>2</sup> In 2013, cancer was the underlying cause of 14,688 deaths – representing about 30% of the 50,396 deaths registered state-wide.<sup>3</sup> The risk of developing cancer by the age of 85 is one in two for males and one in three for females.<sup>2</sup>

## Using patient experiences to measure performance

Most cancer statistics and performance assessment efforts rely on information drawn from clinical registries or administrative databases. Reports about cancer generally focus on outcome measures (e.g. relative survival or mortality rates); on process measures (e.g. rates of adherence to evidence-based guidelines) or on accessibility measures (e.g. waiting times for radiotherapy).

Until recently, far less attention has been paid to performance assessment approaches that draw on patient surveys. In the past two years however, BHI has worked in collaboration with the Cancer Institute NSW to build robust and rigorous approaches to measuring experiences of care among people with cancer.<sup>4,5</sup>

Patients are valued as key informants about the quality of care in many health systems.<sup>6</sup> They are the central participants in their own care and are often the only common connection between different health professionals, specialties and sectors.

## Performance assessment

BHI reports are based on a framework that identifies six key dimensions of healthcare performance.<sup>7</sup> Each dimension addresses key questions:

### Accessibility: Healthcare, when and where needed

Are patients' and populations' needs met?  
How easy is it to obtain healthcare?

### Appropriateness: The right healthcare, the right way

Are evidence-based services provided in a technically proficient way?  
Are services responsive to patients' needs and expectations?

### Effectiveness: Making a difference for patients

Do healthcare services address patients' problems and improve their health?

### Efficiency: Value for money

Do healthcare services provide good value for the resources invested? Are there areas of duplication or waste?

### Equity: Health for all, healthcare that's fair

Is healthcare provided without discrimination on the basis of gender, age, race or other demographic factors? Is healthcare distributed fairly? Does everyone have the opportunity to reach their full health potential?

### Sustainability: Caring for the future

Is the system adapting to changing needs and expectations of patients, and to changing circumstances?

## Aspects of care

Patients are well placed to reflect on issues of accessibility, appropriateness and effectiveness of care – providing information that is not captured by administrative data or hospital records. Within these dimensions, there are a number of themes or aspects of care that are relevant to an assessment of performance in outpatient cancer clinics. Guideline documents, as published by Cancer Care Ontario in Canada<sup>8</sup> and the National Institute for Health and Care Excellence in the UK were used to guide the selection of survey questions to feature in the report and inform the thematic structure (Figure 1).

### Collaboration with Cancer Institute NSW

As a part of the NSW Cancer Plan 2011–15, the Cancer Institute NSW has committed to improving the experiences of patients with cancer and their carers. Recognising the potential insights into care that could flow from a systematic and rigorous assessment of the perspectives of patients with cancer, the Cancer Institute NSW and BHI have worked together to assess experiences of hospital care among people with cancer, as well as focusing on experiences and outcomes of care reported by outpatients.



Figure 1 Performance dimensions, domains and themes assessed in this report

Performance dimension	Domains	Themes
Overall experience of care		
Accessibility	Access and timeliness	Access and timeliness before the visit Access and timeliness during the visit Physical environment and comfort
	Personalised and responsive care	Addressing patient concerns Respect and dignity
Appropriateness	Communication and patient engagement	Information to support patient Shared decision-making
	Coordination and continuity	
	Hygiene and cleanliness	
Effectiveness	Outcomes	Complications
		Symptom severity and self-efficacy

# Data and methods

The Outpatient Cancer Clinics Survey sampled people who attended outpatient cancer clinics during February and March 2015. Surveys were mailed to a random sample of 6,467 people aged 18+ years who attended one of 26 hospitals (see Appendix 1). At the time of sampling, no patient-level data were available for hospitals in Far West, Murrumbidgee, Southern NSW and Hunter New England local health districts (LHDs).

For each hospital, the sample selected was proportional to the number of patients recorded in the WebNAP dataset, broken down by the Tier 2 outpatient treatment recorded. The six treatment types that were used for sampling were:

- Medical oncology (consultation)
- Medical oncology (treatment)
- Oncology
- Radiation oncology (consultation)
- Radiation oncology (treatment)
- Radiation oncology (simulation and planning).

Surveys were mailed approximately three months after the clinic visit. Respondents had the option of completing the survey online (and 20% did so). By the close of the survey, 3,706 responses had been received (response rate of 57%). All LHDs included in the survey had a response rate of at least 50%.

## Survey instrument

The results in this report draw on a tailored survey questionnaire developed by BHI and the Cancer Institute NSW. The questionnaire includes 75 closed response questions and two open comments questions.

The questionnaire uses two survey tools designed to measure outcomes for patients with cancer:

**1. The Edmonton Symptom Assessment System (ESAS)** is a tool for self-reporting of symptom intensity, initially developed for palliative care patients with cancer.<sup>9</sup> It consists of numerical rating scales for common symptoms of cancer and cancer treatment.<sup>10</sup> The ESAS measures respondents' rating of nine common symptoms on a 10-point rating scale of severity (e.g. from 0 for 'no pain' to 10 for the 'worst possible pain'). The version used in the NSW survey assessed how a respondent was feeling at the time of completing the questionnaire.<sup>11</sup>

**2. The Communication and Attitudinal Self-Efficacy scale for cancer (CASE-Cancer)** was developed as a tool to gauge cancer patients' confidence and ability to engage in their care.<sup>12</sup> The CASE-Cancer tool uses 12 questions to assess three dimensions: maintaining a positive attitude; understanding and participating in care; and seeking and obtaining information. The tool uses categorical response options that were translated into scores to make comparisons across clinics.

One of the strengths of the Outpatient Cancer Clinics Survey is that it captures experiences of patients in two timeframes. First it asks patients to recall a particular outpatient clinic visit that occurred approximately three months previously and to describe accessibility and appropriateness of care. Second, it asks patients at the time they completed the questionnaire, to reflect on effectiveness of care in terms of symptom severity, self-efficacy, confidence in communication and complications of care. However, this approach does have important limitations – there may be some recall bias, and for many patients, a specific experience or the attribution of outcomes to a particular visit, may be difficult.

## Analysis

Results were weighted so that the proportion of responses from each of the sampling strata was adjusted to match the number of patients sampled in each strata (facility and service type).

Analysis of most questions was performed using the SURVEYFREQ procedure in SAS v9.4. Score results for the ESAS and CASE-Cancer were analysed using the SURVEYMEAN procedure.

Statistical significance of comparisons was assessed using the 95% confidence intervals of the estimate of interest (hospital or LHD results) compared to the NSW estimate. Where confidence intervals did not overlap, there was deemed to be a statistically significant difference between the two estimates.

Due to the small numbers of respondents from some hospitals, power to detect differences between the outpatient services and NSW results is reduced.

## International context

Patient surveys from other healthcare systems can provide context and insight about the relative strengths and weaknesses of patient care in NSW. However, the availability of comparative information for this report is limited. Results for two questions were available for three Canadian provinces: Ontario (2014–15 survey)<sup>13</sup>, Quebec (2013 survey)<sup>14</sup> and British Columbia (2012 survey)<sup>15</sup>. Questions addressed patient involvement in decisions (a nine percentage point range across all four surveys) and respect and dignity (a 12 percentage point range across all four surveys). Given the limited opportunities for benchmarking, no detailed international data are included in the report.

## Reporting

Results are reported for NSW, LHDs and hospitals. A reporting threshold of 30 or more respondents must be reached for public reporting. When reporting at aggregate levels, all respondents are included, regardless of whether there were sufficient respondents for public reporting at lower levels of analysis.

In summary tables, results are reported for Sydney/Sydney Eye Hospital and Chris O'Brien Lifehouse. However, given important differences, they are not directly comparable with other outpatient cancer clinics included in the report:

- Sydney/Sydney Eye Hospital (South Eastern Sydney LHD) differs from other clinics in terms of case mix – only 14% of patients said they had or have had cancer, compared to 90% for the entire NSW cohort
- Chris O'Brien Lifehouse differs in administrative and organisational arrangements. It is a not-for-profit integrated cancer treatment centre, contracted to provide services for some public patients. It is not managed by Sydney LHD, despite being located within that LHD's boundaries (see Appendix 4 for details).

Colour coding is used to identify statistically significant differences. Green represents results that are significantly more positive than the NSW result. Red represents results that are significantly less positive than the NSW result. For more information on methods, see the *Technical Supplement: Outpatient Cancer Clinics Survey 2015*.

## The cohort

Patients visit outpatient cancer clinics for a variety of reasons – both cancer and non-cancer related – and those with cancer are at different phases of care. For some analyses all patient responses were included, capturing experiences of those who have or have had cancer (90% of patients) as well as those who visited an outpatient cancer clinic for other reasons such as radiotherapy for lupus (10% of patients).

Patient subgroups were based on responses to two questions: the first asked patients about the reason for their visit to the clinic and the second asked about how their current cancer had responded to treatment (Figure 2).

## Exploring LHD and hospital case mix

Performance is compared at LHD and hospital levels. The survey does not collect information on specific cancers and survey results are not linked to patient medical records. Therefore, in order to explore differences in the type of patients seen, the information on reasons for visit (chemotherapy or radiotherapy or a surgical procedure versus other reasons) and the phase of cancer treatment

(undergoing an active treatment phase at the time of survey completion versus non-active treatment) – as described in Figures 2 and 3 – were cross tabulated, resulting in four distinct categories (Figure 3). The distribution of these four categories of patients varied considerably across LHDs and hospitals (Figure 4 and 5).

Figure 3 Purpose of visit and cancer treatment phase

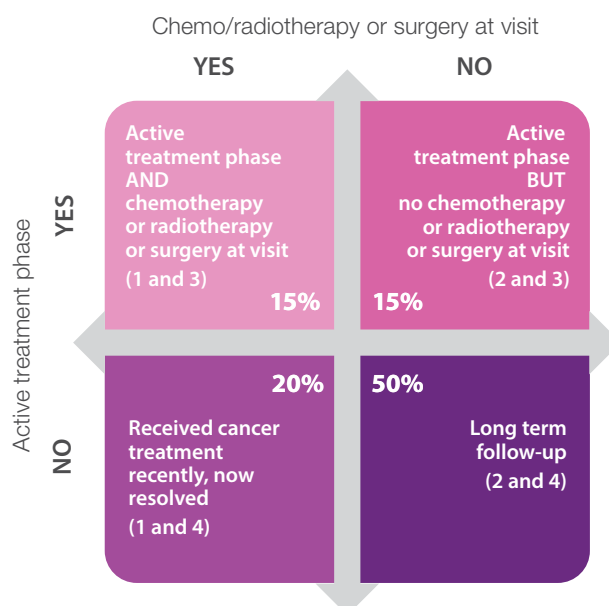


Figure 2 Respondents to the survey

Cohort	Survey question	Themes	
All patients	What was the purpose of this visit? (Q1)	<b>1. Chemotherapy, radiotherapy and/or a surgical procedure</b>	34%
		<b>2. Regular check-up, treatment review, medical diagnosis or advice, had tests, x-rays or scans (or received results of tests), surgery follow-up, other</b>	66%
Patients visiting outpatient cancer clinics for cancer (90% of all patients)	How has your current cancer responded to treatment? (Q60)	<b>3. In active treatment phase</b>	30%
		In the course of treatment and can't say how cancer has responded (24%)	
		Cancer is being treated again as did not respond fully to treatment (6%)	
		<b>4. Not in active treatment phase</b>	70%
Treatment was effective, no cancer signs or symptoms (45%)			
On 'watch and wait' (15%)			
Finished treatment, cancer still present (7%)			
Treatment not started (1%)			
Cancer not treated at all (1%)			

Figure 4 Understanding patient case mix: LHD variation

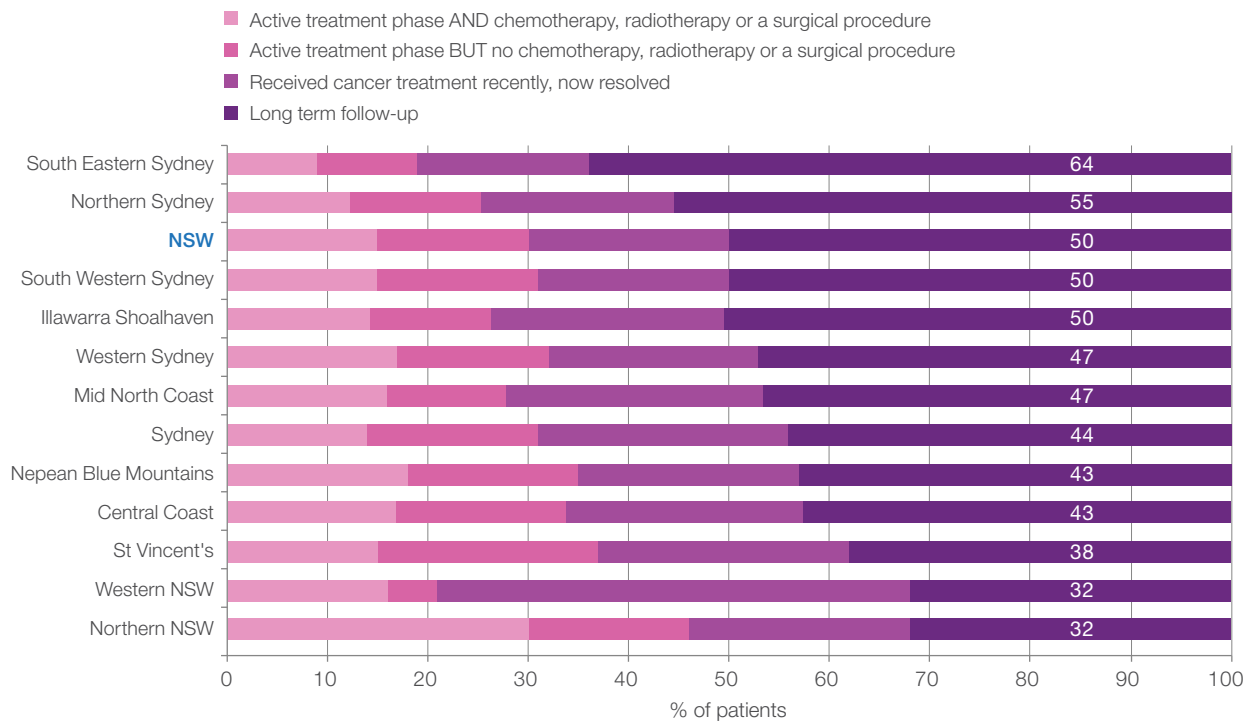
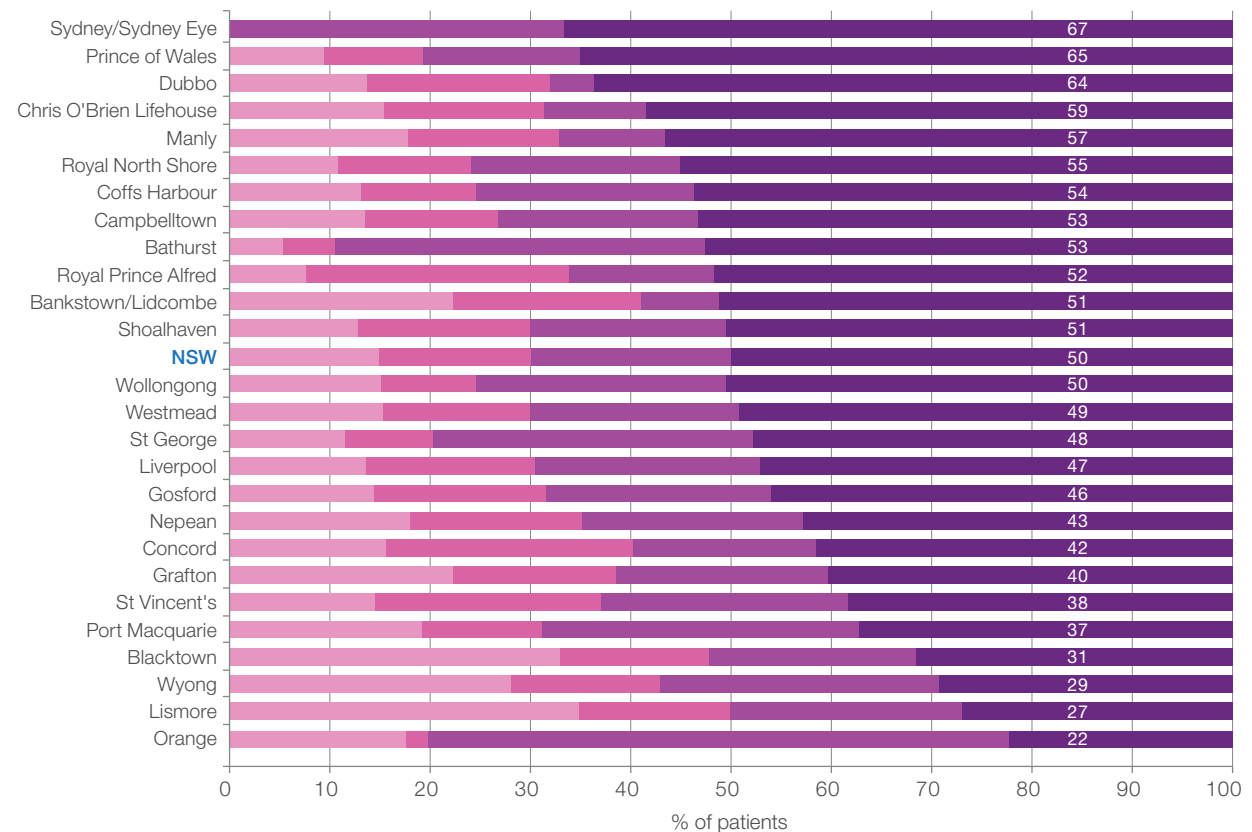


Figure 5 Understanding patient case mix: Hospital variation



Note: At the time of sampling, no data were available for hospitals in Far West, Murrumbidgee, Southern NSW and Hunter New England LHDs.

# Navigating the report

## Report structure

The report has three main sections:

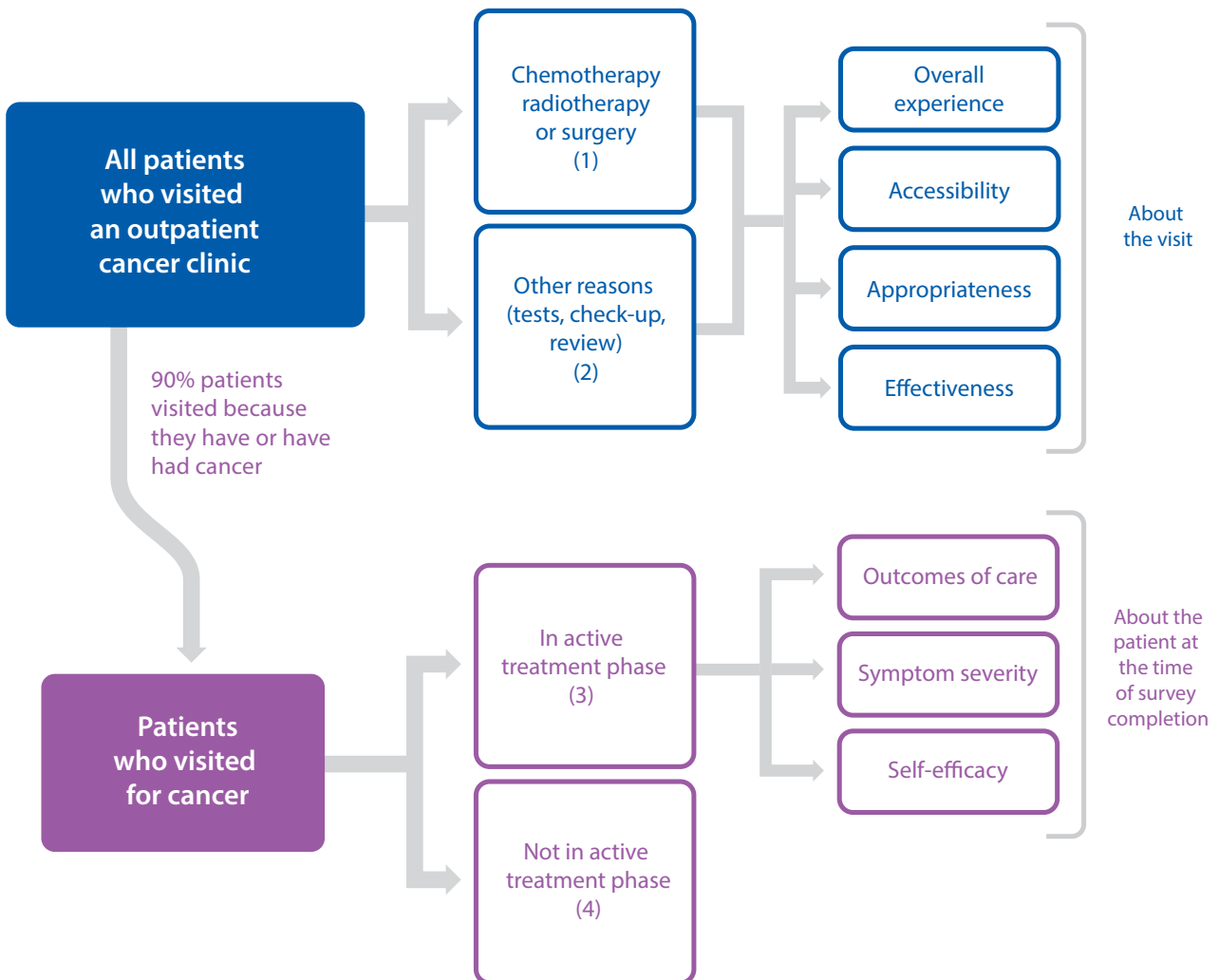
- **Section 1** describes experiences and outcomes for all patients who visited an outpatient cancer clinic, using six domains and 11 themes. For each theme, results are shown at a NSW, LHD and hospital level of analysis.
- **Section 2** compares survey responses about a visit for chemotherapy, radiotherapy or a surgical procedure (34% of patients) with those for other reasons. It then examines variation in responses from patients who visited for chemotherapy, radiotherapy or a surgical procedure across LHDs

and hospitals using a subset of 15 questions regarding accessibility and appropriateness of care.

- **Section 3** compares responses from patients who, at the time of survey completion (approximately three months after the outpatient visit), were in an active treatment phase (30% of patients) with those from other patients. It then examines variation in responses from patients in an active treatment phase across LHDs and hospitals using 15 measures that address effectiveness of care.

A flowchart is used throughout the report to illustrate the different subsets of patients and survey questions analysed (Figure 6).

Figure 6 Understanding the cohort of patients visiting outpatient cancer clinics



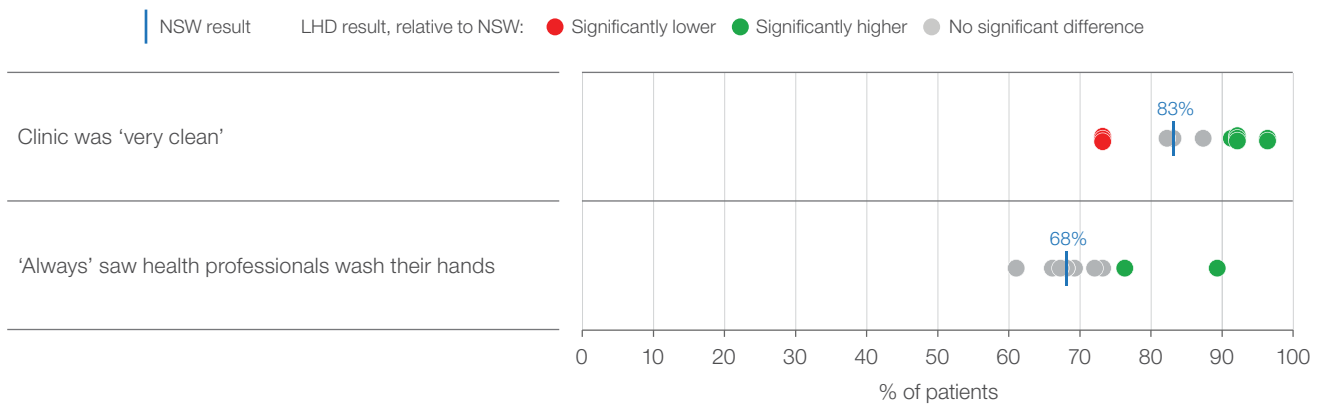


## Interpreting the graphs

**Example 1:** A 'string of pearls' graph is used to show the distribution of LHD results and highlight differences from the NSW result.

Each circle shows an LHD's result and highlights whether it is significantly different from the NSW result (shown as a blue line).

Example 1 Hygiene and cleanliness, percentage of patients who selected the most positive response category, LHD results relative to NSW



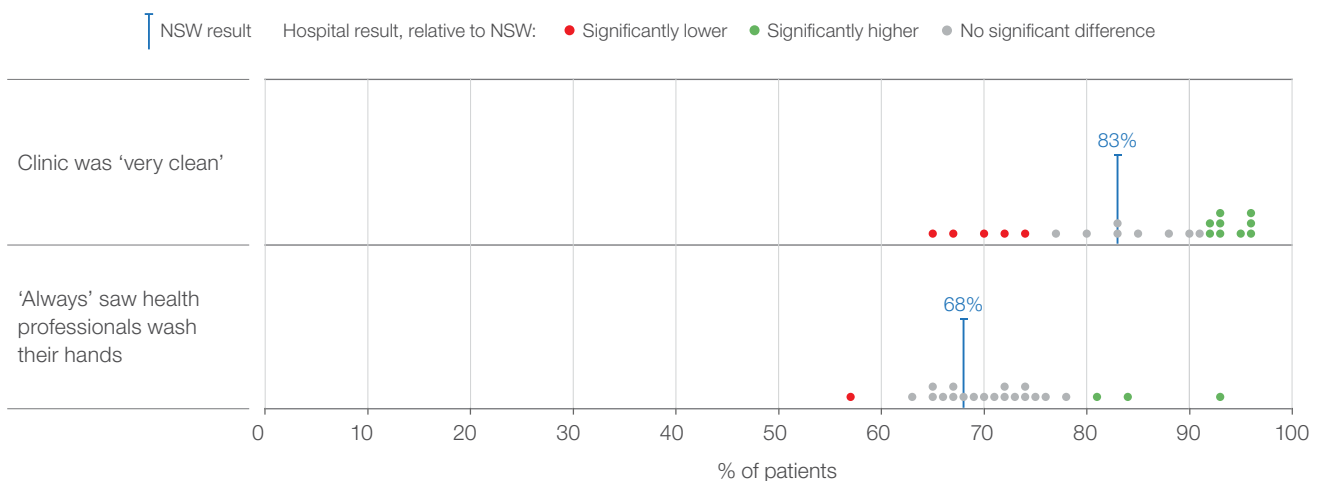
**Example 2:** 'Dot plots' show the distribution of results for hospitals and highlight differences from the NSW result.

patients who gave the response 'shown in inverted commas' (usually this is the most positive response category).

This example shows dot plots for responses to two survey questions, by hospital. Each plot shows the number of hospitals, by the percentage of their

Each circle shows a hospital's result and highlights whether it is significantly different from the NSW result.

Example 2 Hygiene and cleanliness, percentage of patients who selected the most positive response category, hospital results relative to NSW



Note: Hospitals/LHDs are identified if their results differ from the NSW result by more than 10 percentage points and reach statistical significance.

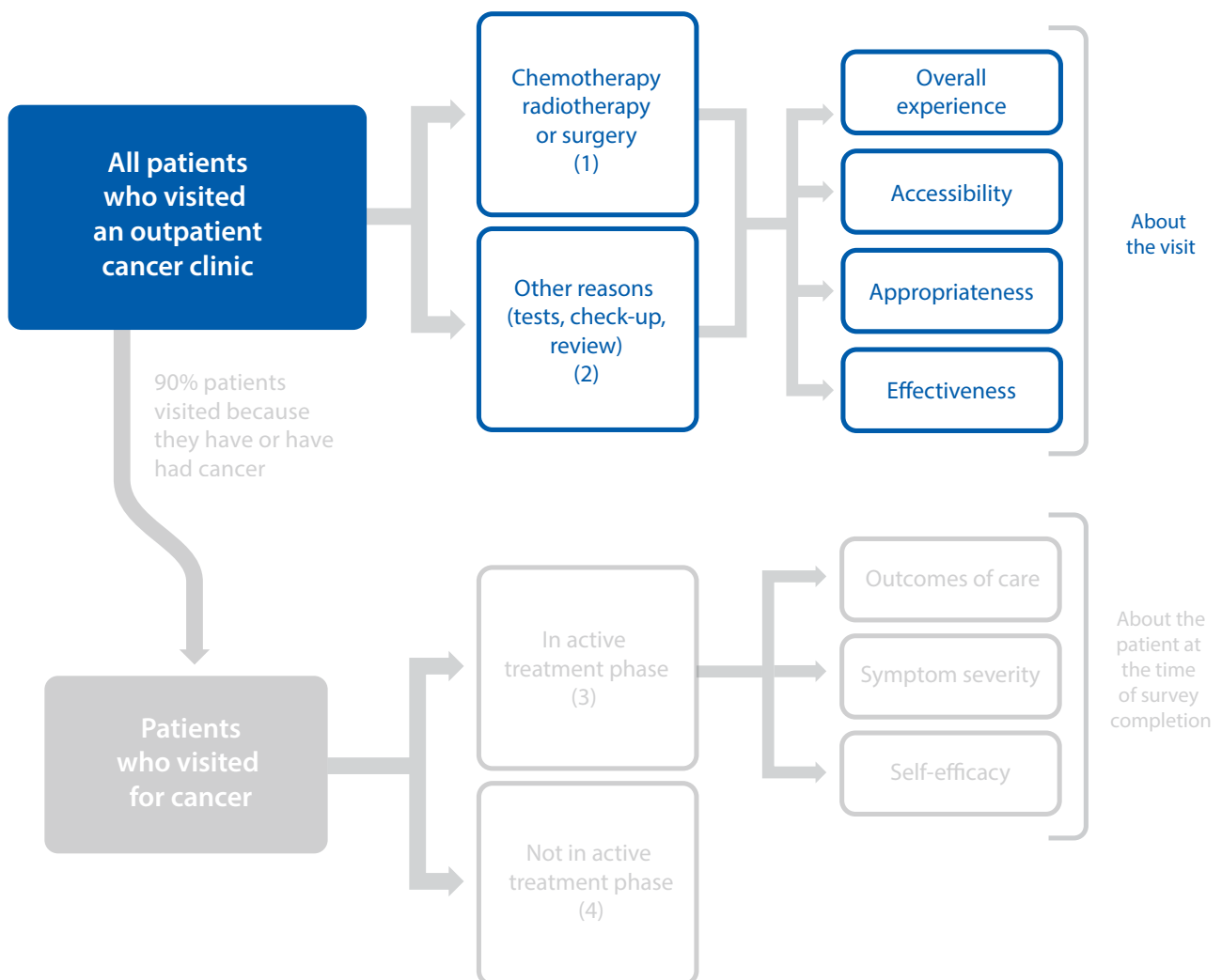
## SECTION 1

# Experiences of care in outpatient cancer clinics

# All patients who visited an outpatient cancer clinic: Experiences of care

**Section 1** describes patients' experiences of care in outpatient cancer clinics. Results are based on responses to 42 survey questions from all patients – including those who have, or have had, cancer (90% of patients) and those who visited an outpatient cancer clinic for other reasons, such as radiotherapy for lupus (10% of patients).

It presents information about variation across the state regarding patients' overall experience and for 10 thematic aspects of care. For each theme, results are shown at a NSW, LHD and hospital level of analysis.

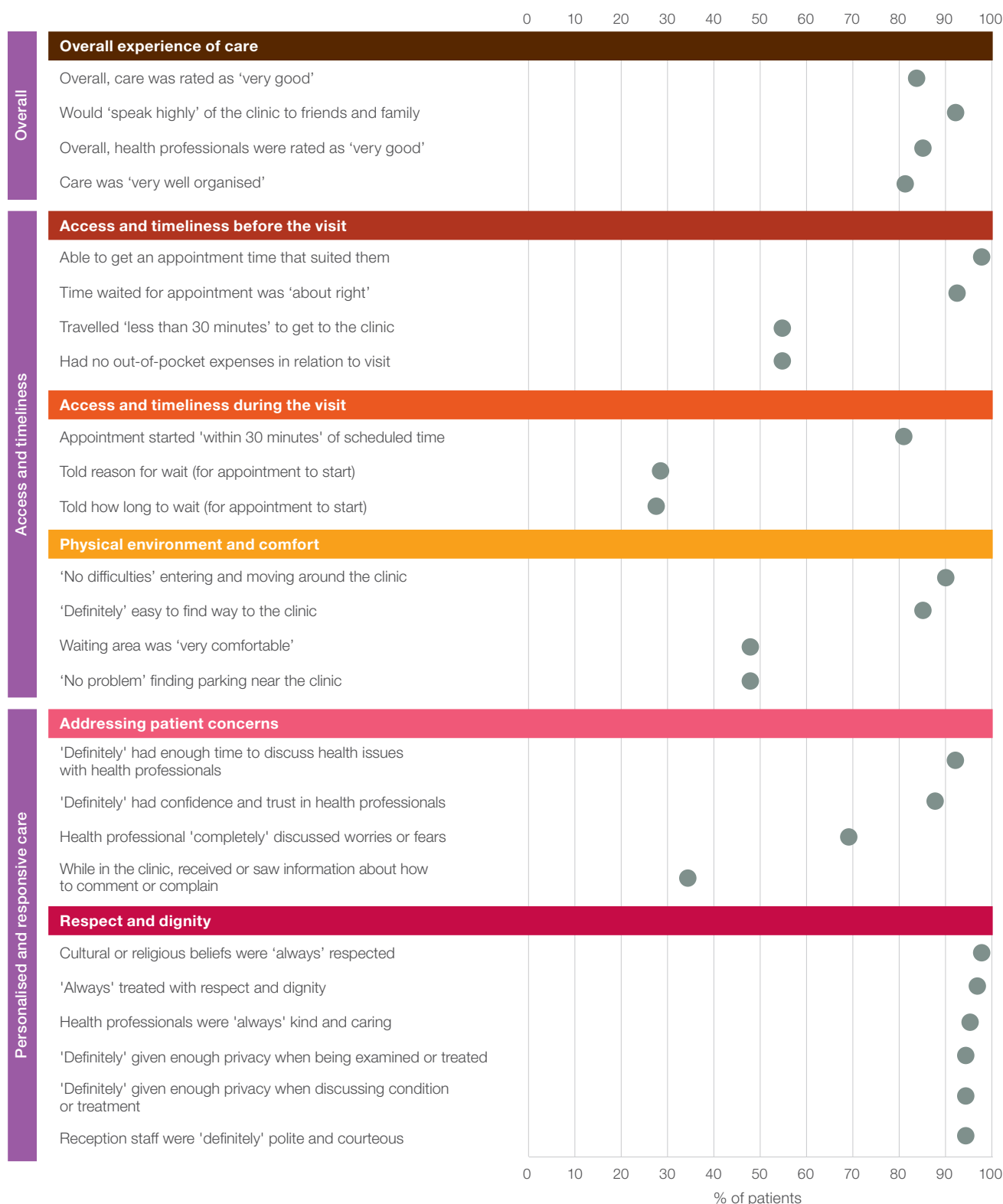


# Thematic responses: NSW results

Comparing across the report's themes on the basis of the 'top category' results (the percentage of NSW outpatients who selected the most positive response

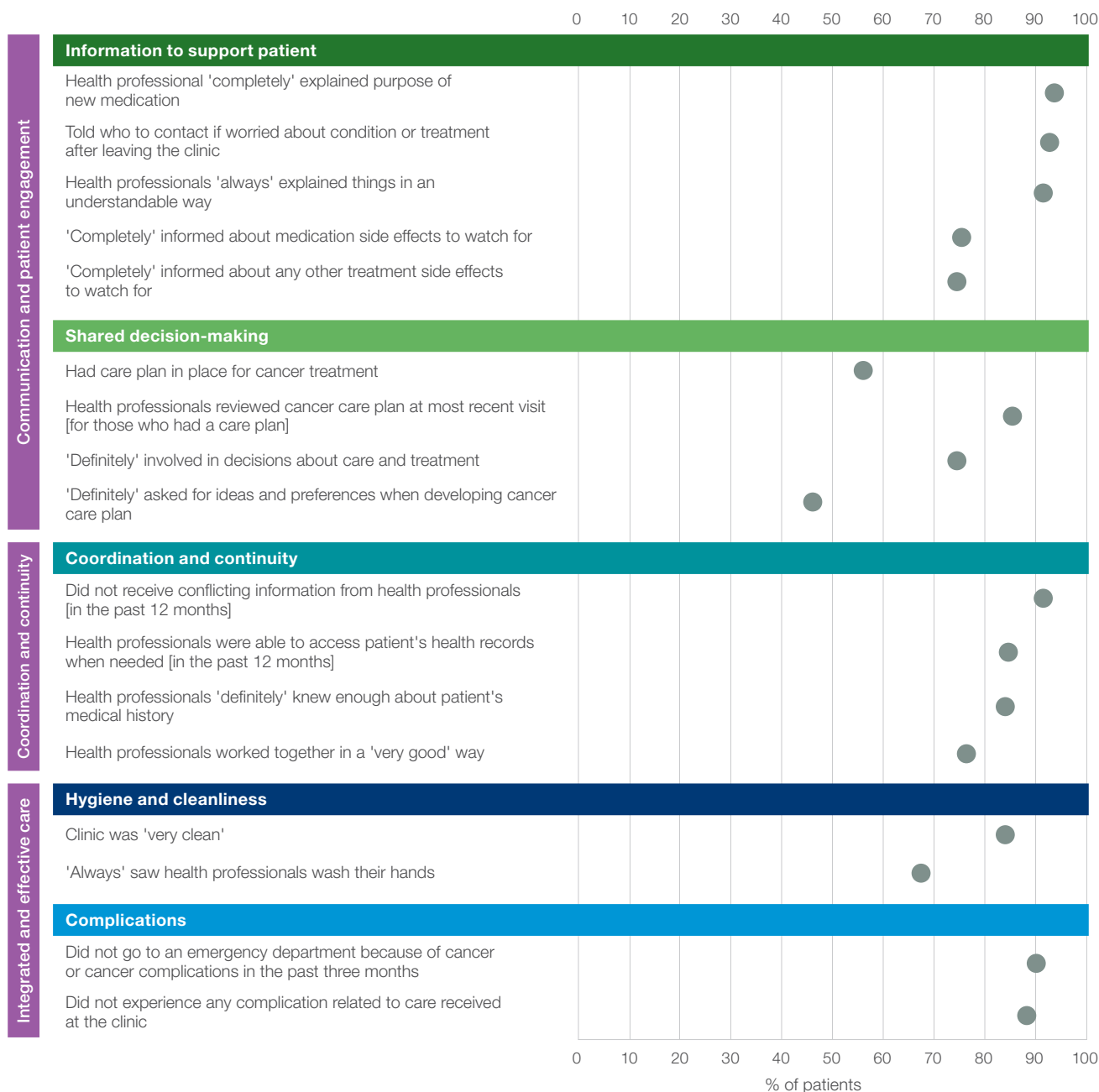
category for each question) shows that outpatient cancer clinics perform consistently well in treating their patients with respect and preserving patients' dignity.

Figure 7 Aspects of care, percentage of patients who selected the most positive response category, NSW



Note: Questions have been rephrased to a statement that includes the most preferable response option. To view the original questions mapped against these statements please see Appendix 3.

Questions where there is room for improvement focus on shared decision-making, punctuality, parking, comfort and information about patients' rights (Figure 7).



# Overall experience of care

## Almost all patients rated their experiences of care positively

Almost all patients who visited an outpatient cancer clinic said that their experience overall was 'very good' (83%) or 'good' (16%). Most said they would 'speak highly' of the clinic to friends and family (92%) (Figure 8).

Across LHDs, responses from patients who visited a clinic in Mid North Coast, Northern NSW and Western

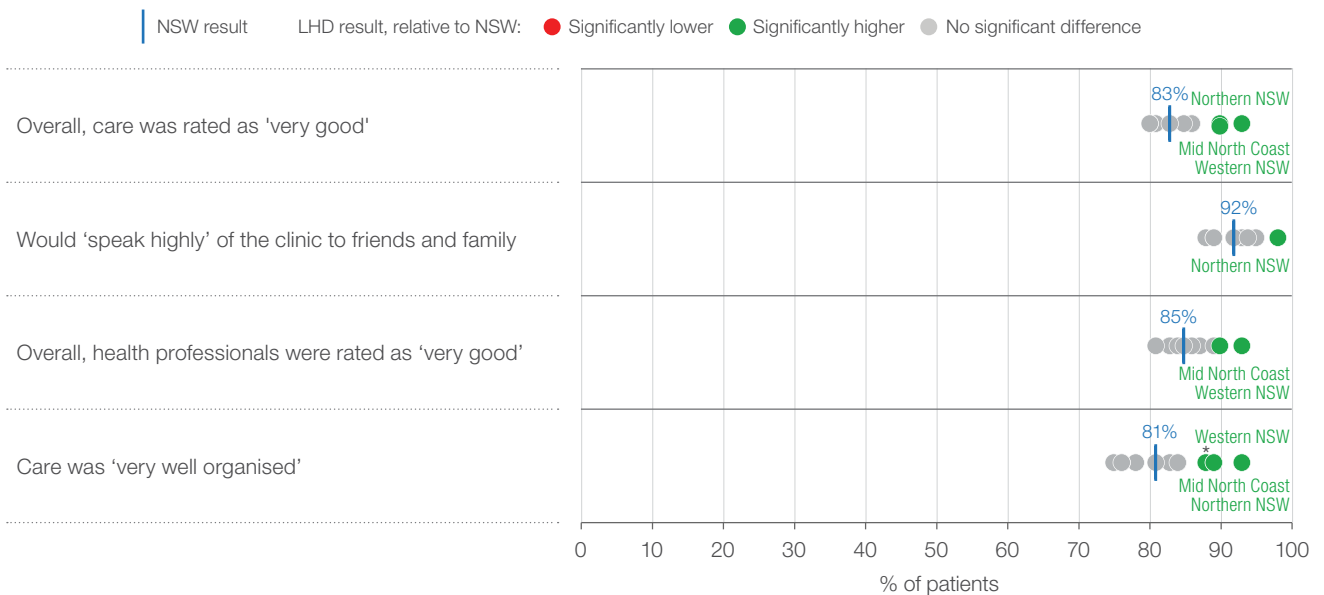
NSW were significantly more positive than the NSW result for three out of the four questions. No LHD results were significantly less positive than NSW (Figure 9).

At a hospital level, widest variation was seen in the proportion of patients who rated care overall as 'very good', ranging from 68% to 92% (Figure 10).

Figure 8 Overall experience of care, all response categories, NSW

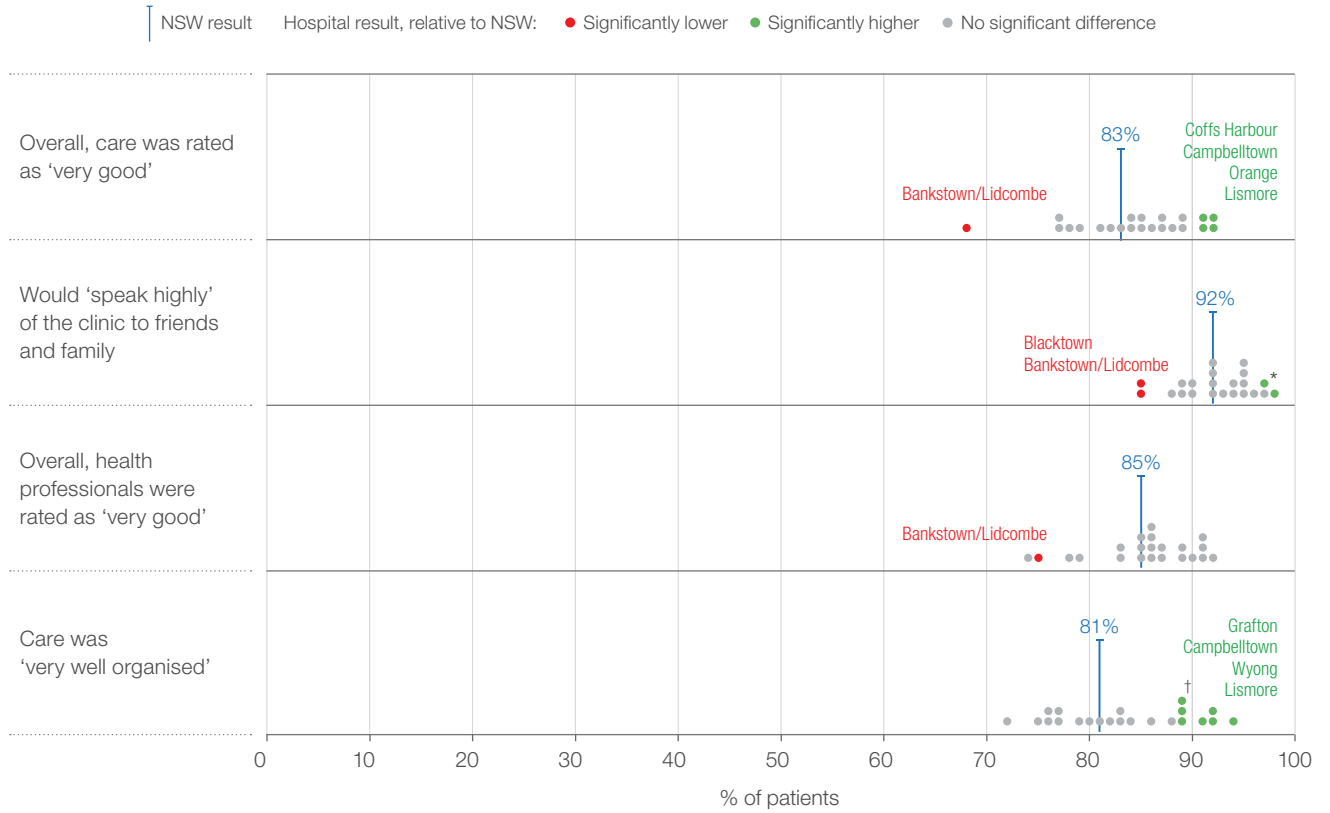


Figure 9 Overall experience of care, percentage of patients who selected the most positive response category, LHD results relative to NSW



\* Due to space limitations, the label for Illawarra Shoalhaven (green) is not shown.

Figure 10 Overall experience of care, percentage of patients who selected the most positive response category, hospital results relative to NSW



\* Due to space limitations, the labels for Campbelltown and Lismore (green) are not shown.

† Due to space limitations, the labels for Port Macquarie, Wollongong, and Coffs Harbour (green) are not shown.

# Aspects of care: All response categories

The survey included 38 questions that were relevant to 10 aspects of care. While most of the analyses in this section compare performance on the basis of the

percentage of patients who selected the most positive response category, Figure 11 shows NSW results for the full set of response categories.

Figure 11 Aspects of care, all response categories, NSW





	Questions	Responses
Respect and dignity	Were the health professionals kind and caring towards you?	95% ■ Yes, always ■ Yes, sometimes ■ No
	Were you given enough privacy when being examined or treated?	93% 6% ■ Yes, definitely ■ Yes, to some extent ■ No
	Were you given enough privacy when discussing your condition or treatment?	93% 6% ■ Yes, definitely ■ Yes, to some extent ■ No
	Were the reception staff polite and courteous?	93% 7% ■ Yes, definitely ■ Yes, to some extent ■ No
Information to support patient	Did a health professional at the clinic explain the purpose of this [new] medication in a way you could understand?	93% 7% ■ Yes, completely ■ Yes, to some extent ■ No
	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?	92% 8% ■ Yes ■ No
	Did the health professionals explain things in a way you could understand?	91% 8% ■ Yes, always ■ Yes, sometimes ■ No
	Did a health professional at the clinic tell you about medication side effects to watch for?	76% 19% 5% ■ Yes, completely ■ Yes, to some extent ■ No
	Were you given enough information about how to manage the side effects of any other treatment you received during this visit?	74% 20% 6% ■ Yes, completely ■ Yes, to some extent ■ No
Shared decision-making	Do you have a care plan for your cancer treatment? [for those who said they needed a care plan]	57% 43% ■ Yes ■ No
	At your most recent visit, did the health professionals review your care plan with you?	86% 14% ■ Yes ■ No
	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	74% 22% ■ Yes, definitely ■ Yes, to some extent ■ No
Coordination and continuity	Were you asked for your ideas and preferences when developing this [cancer care] plan?	47% 35% 18% ■ Yes, definitely ■ Yes, to some extent ■ No
	Did you ever receive conflicting information about your condition or treatment from the health professionals? [in last 12 months]	91% 9% ■ No ■ Yes
	Was there any time when the health professionals needed access to your health records and they were not available? [in last 12 months]	84% 6% 10% ■ No ■ Yes ■ Don't know/can't remember
	During this visit, did the health professionals know enough about your medical history?	83% 15% ■ Yes, definitely ■ Yes, to some extent ■ No
Hygiene and cleanliness	How would you rate how well the health professionals worked together?	77% 21% ■ Very good ■ Good ■ Neither good nor poor ■ Poor ■ Very poor
	How clean was the clinic?	83% 17% ■ Very clean ■ Fairly clean ■ Not very clean ■ Not at all clean
Complications	Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?	68% 10% 12% 10% ■ Yes, always ■ Yes, sometimes ■ No ■ Can't remember
	In the past three months, have you gone to an emergency department because of your cancer or cancer complications?	90% 10% ■ No ■ Yes
	During your visit or soon afterwards, did you experience any of the following complications or problems related to the care you received at the clinic?	88% 12% ■ None reported ■ Had complication

# Access and timeliness before the visit

## Almost all patients were able to get an appointment time that suited them

Accessibility depends upon healthcare services being available when and where patients need them. It incorporates issues of timeliness, approachability, and an absence of financial, psychological, cognitive and physical barriers to care.<sup>16</sup>

Access and timeliness are particularly important aspects of care for people with cancer. Delays and barriers to access can impact patient outcomes and wellbeing.<sup>17</sup> Minimising waiting times for key procedures and treatments is a central element of the OECD's framework for improving cancer survivorship.<sup>19</sup>

The survey results show that almost all patients were able to get an appointment time that suited them (98%), and the time they waited for an appointment was 'about right' (92%) (Figure 12).

There were however some important potential barriers to access. Only 54% of patients had a travel time of 'less than 30 minutes' to the clinic. The same proportion (54%) said they incurred no out-of-pocket expenses as a result of the visit.

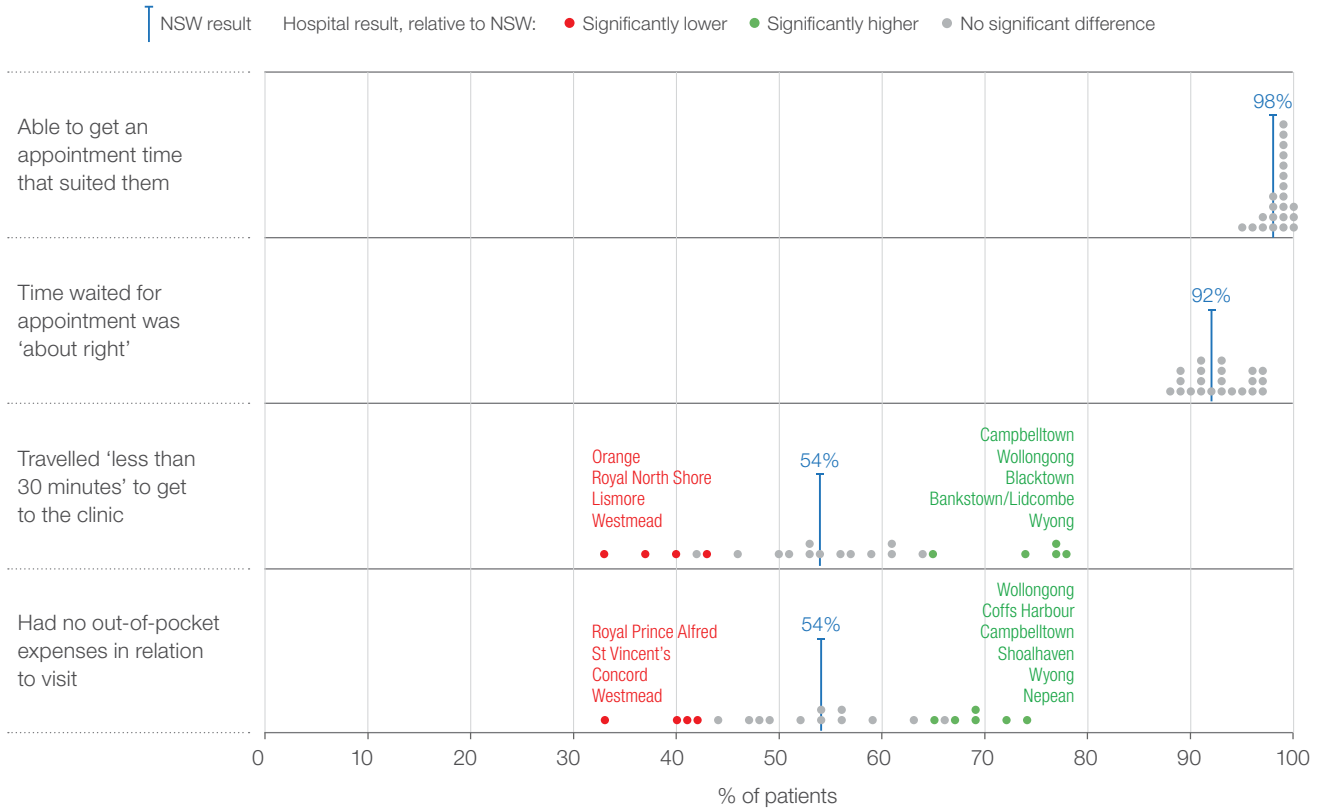
Across LHDs, responses from patients who visited a clinic in Illawarra Shoalhaven were significantly more positive than the NSW result for two of the four questions (Figure 12).

At a hospital level, there was little variation in the proportion of patients who said they were able to get an appointment time that suited them and whether the time they waited for an appointment was 'about right'. However, there was wide variation in the proportion of patients who travelled 'less than 30 minutes' to get to the clinic (ranging from 33% to 78%) and the proportion who said they incurred no out-of-pocket expenses (33% to 74%) (Figure 13).

Figure 12 Access and timeliness before the visit, percentage of patients who selected the most positive response category, LHD results relative to NSW



Figure 13 Access and timeliness before the visit, percentage of patients who selected the most positive response category, hospital results relative to NSW



# Access and timeliness during the visit

## For eight in 10 patients, appointments started punctually

Patients with cancer can, at various phases of treatment, be frequent visitors to an outpatient clinic. Punctuality of clinic appointments is important, both to minimise inconvenience and disruption to patients, as well as providing reassurance that services are well organised and efficient.

Among patients who visited an outpatient cancer clinic, 81% said their appointment started 'within 30 minutes' of the scheduled time. For those whose appointment did not start on time or early, 29% were told why they had to wait, while 28% were told how long they had to wait for the appointment to start (Figure 14).

Across LHDs, responses from patients who visited a clinic in Northern NSW and Western NSW were significantly more positive than the NSW result for all three of these questions. Responses from patients who visited a clinic in Western Sydney were significantly less positive than the NSW result for two of the three questions (Figure 14).

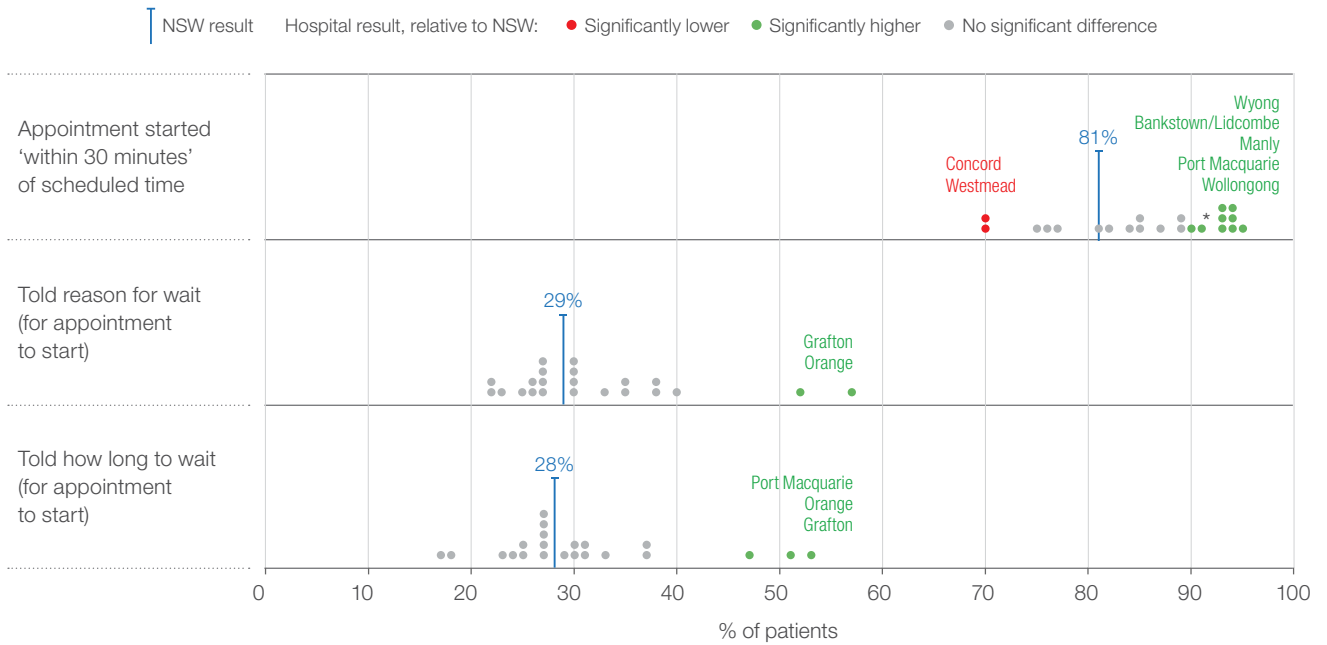
At a hospital level, there was wide variation in responses to all three questions. Variation was most pronounced in the proportion of patients who said they were told how long they would have to wait for their appointment to start, ranging from 17% to 53% (Figure 15).

Figure 14 Access and timeliness during the visit, percentage of patients who selected the most positive response category, LHD results relative to NSW



\* Due to space limitations, the label for Northern NSW (green) is not shown.

Figure 15 Access and timeliness during the visit, percentage of patients who selected the most positive response category, hospital results relative to NSW



\* Due to space limitations, the labels for Shoalhaven, Grafton, Coffs Harbour, Gosford (green) are not shown.

# Physical environment and comfort

## Nine in 10 patients had no difficulties entering and moving around the clinic but fewer than half had no problem finding parking

Easy and efficient access to the outpatient clinic and clean and welcoming waiting areas have been linked to better patient safety, lower levels of stress (as reported by staff) and lower operating costs.<sup>18</sup>

The majority of patients (90%) said they had 'no difficulties' entering or moving around the clinic and 85% said it was 'definitely' easy to find the clinic. However, fewer than half (48%) said the waiting area was 'very comfortable' and they had 'no problem' finding parking near the clinic (48%) (Figure 16).

Across LHDs, responses from patients who visited a clinic in Mid North Coast were significantly more positive than the NSW result for all four questions. Patients in Central Coast and Northern NSW were more positive for three questions. Conversely, responses from patients who visited a clinic in Western Sydney were less positive than the NSW result for three of the four questions (Figure 16).

At a hospital level, widest variation was in the proportion of patients who said they had 'no problem' finding parking near the clinic, ranging from 10% to 83% (Figure 17).

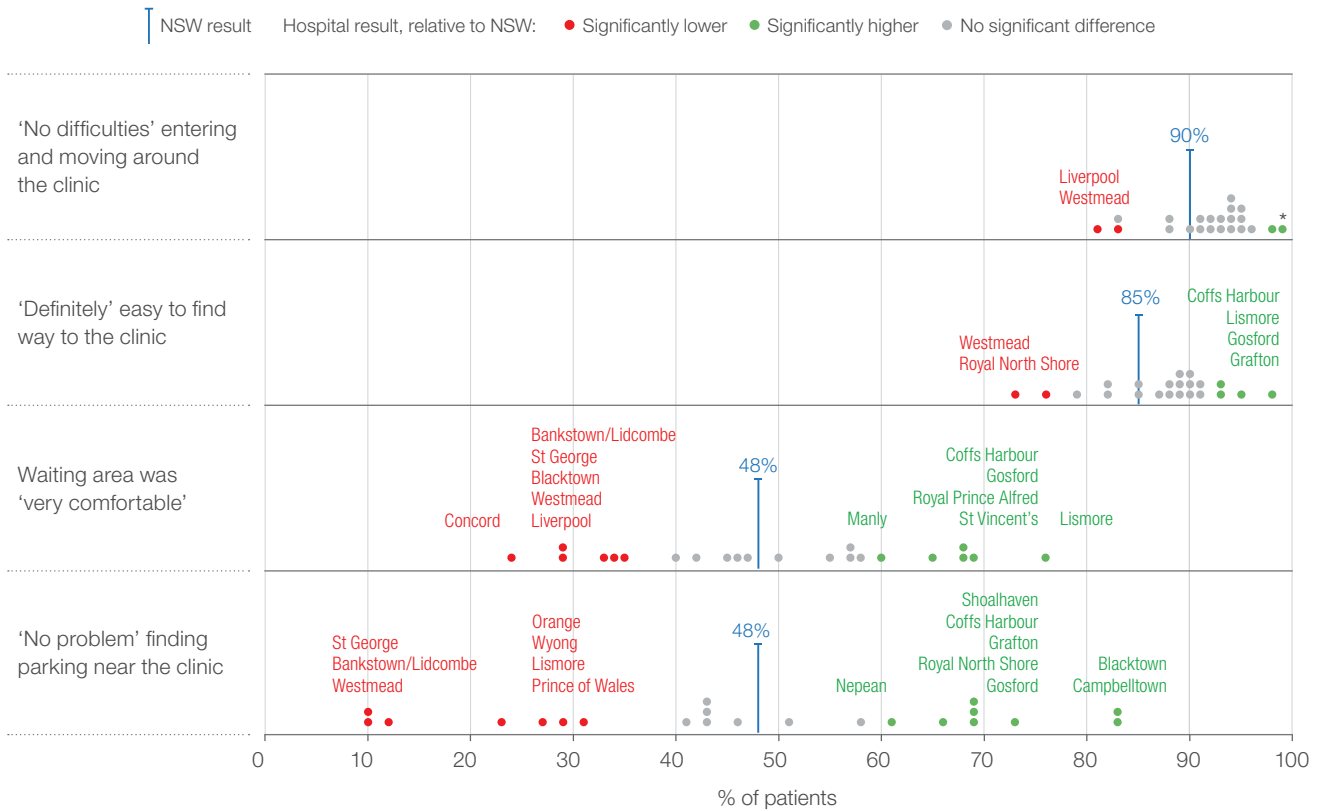
Figure 16 Physical environment and comfort, percentage of patients who selected the most positive response category, LHD results relative to NSW



\* Due to space limitations, the label for Mid North Coast (green) is not shown.

† Due to space limitations, the label for Illawarra Shoalhaven (green) is not shown.

Figure 17 Physical environment and comfort, percentage of patients who selected the most positive response category, hospital results relative to NSW



\* Due to space limitations, the labels for Coffs Harbour and Grafton (green) are not shown.

# Addressing patient concerns

## Nine in 10 patients said they definitely had enough time to discuss health issues with professionals

The quality of patient-professional interactions is shaped by factors such as: whether patients feel heard and understood; whether they have trust in clinicians; and whether they feel enabled to act on their own behalf.<sup>20,21</sup>

Nine in 10 patients said they 'definitely' had enough time to discuss health issues (92%), and they 'definitely' had confidence and trust in health professionals (88%). Among patients who said they had worries or fears, 69% said a health professional 'completely' discussed those worries and fears with them. A minority of patients (34%) said while they were in the clinic, they received or saw information about how to comment or complain about their care (Figure 18).

Across LHDs, responses from patients who visited a clinic in Northern NSW were significantly more positive than the NSW result for one of the four questions. Responses from patients who visited a clinic in South Eastern Sydney were significantly less positive than NSW for one question (Figure 18).

At a hospital level, widest variation was in the proportion of patients who said health professionals 'completely' discussed their worries or fears with them, with results ranging from 58% to 89% (Figure 19).

Figure 18 Addressing patient concerns, percentage of patients who selected the most positive response category, LHD results relative to NSW

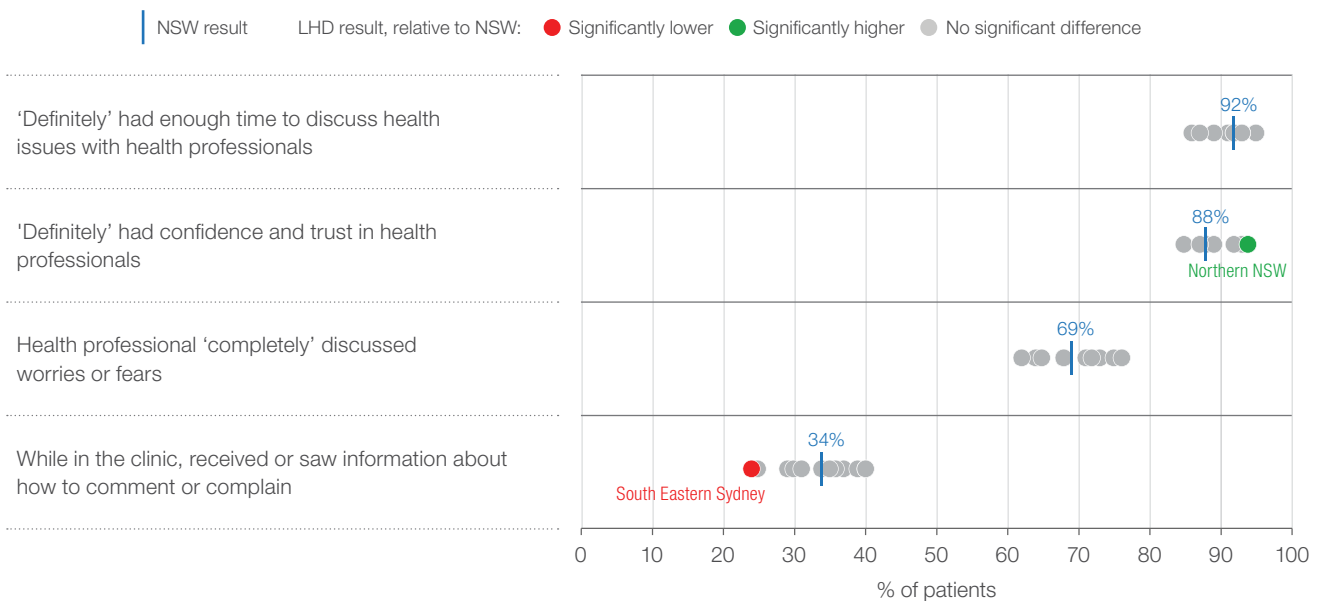
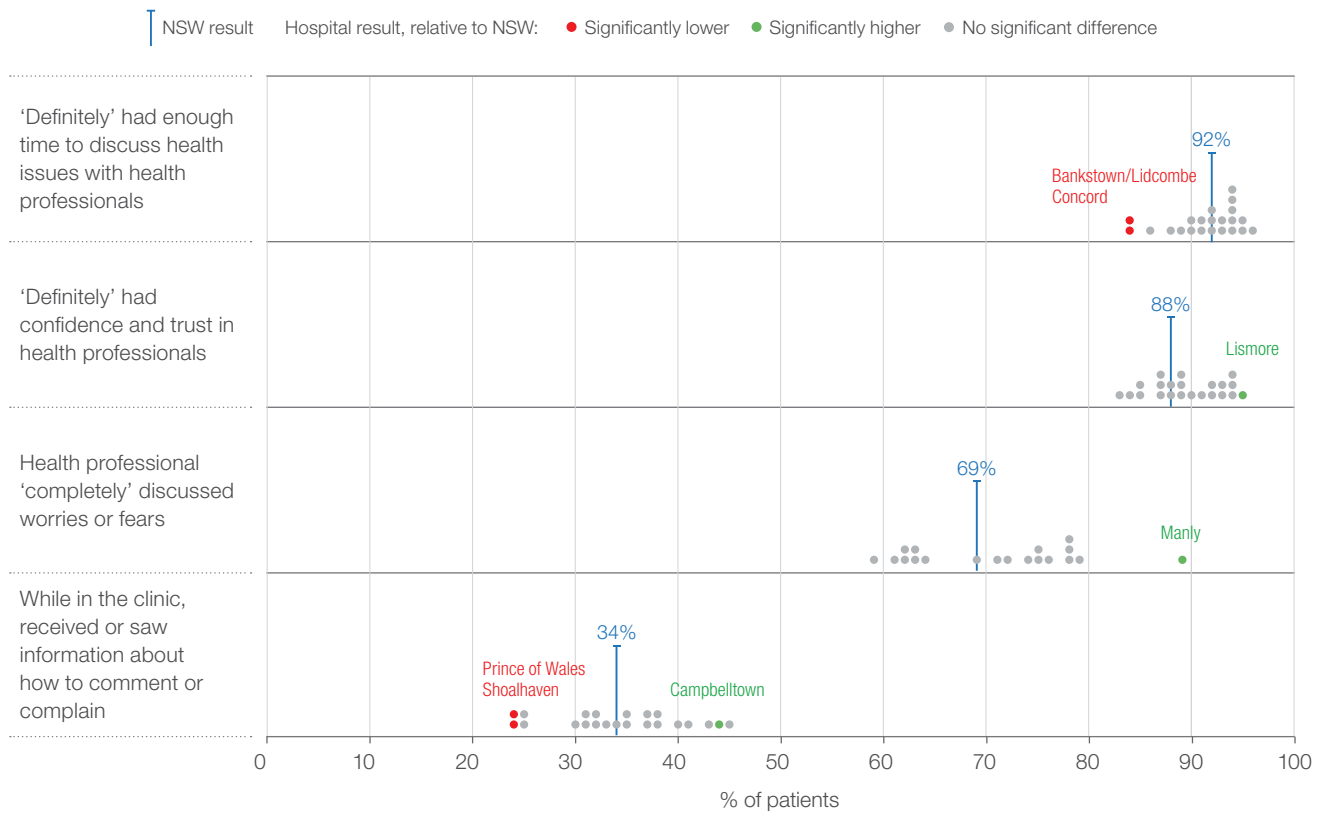




Figure 19 Addressing patient concerns, percentage of patients who selected the most positive response category, hospital results relative to NSW



# Respect and dignity

## Almost all patients said they were always treated with respect and dignity

Treating patients with respect – or with due regard for their feelings, values and rights – and in ways that protect their dignity, are central elements of performance. Respect and dignity are however difficult to measure directly; they are perception-based and are often better captured by assessing how the varied interactions with healthcare professionals meet patients’ expectations. There are a number of aspects of care that are generally considered to encapsulate respectfulness. Respecting privacy and dignity in NSW Health emphasises the importance of:

- Making patients and carers welcome – with staff introducing themselves; acknowledging patients by name, providing information about patient rights
- Communicating frequently and clearly
- Protecting privacy
- Respecting cultures and beliefs

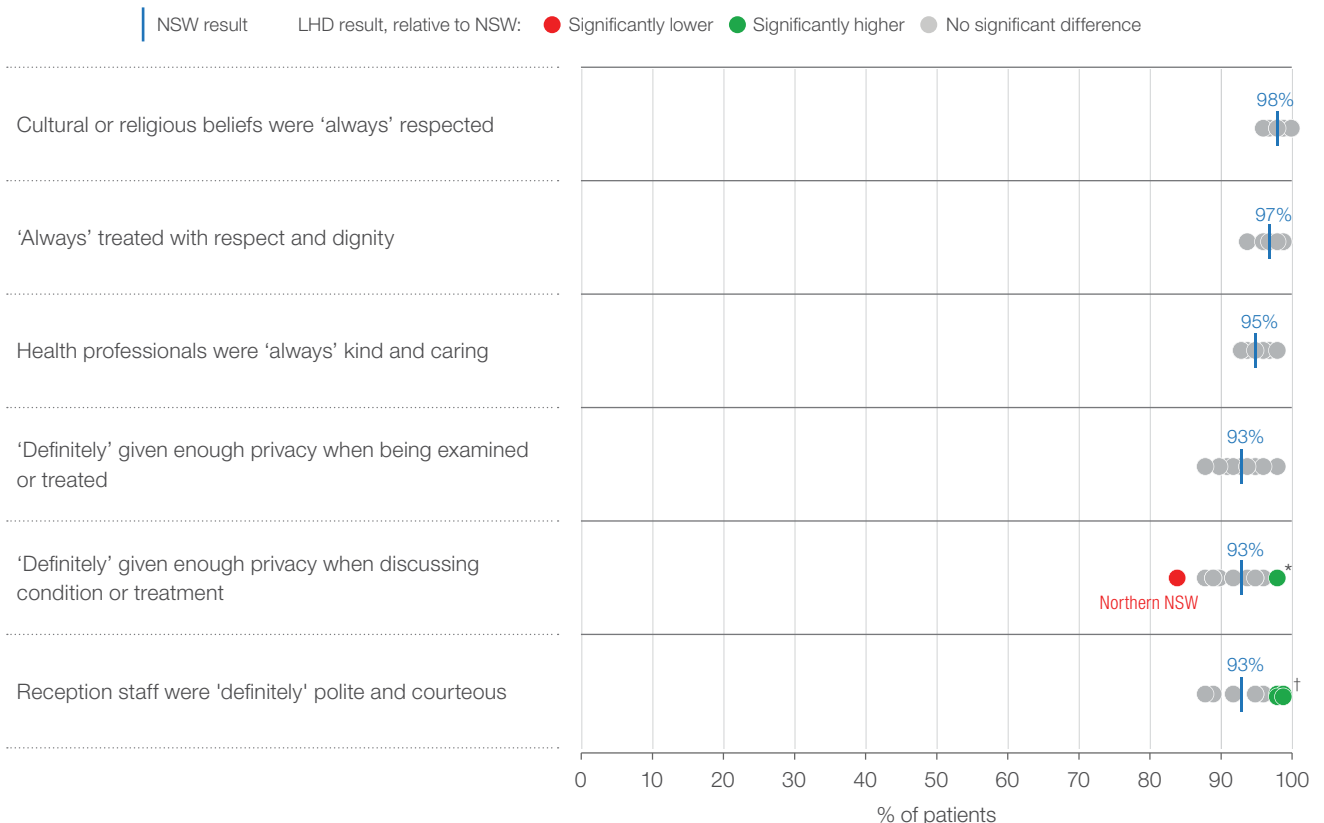
- Managing noise
- Avoiding mixed gender accommodation.<sup>20</sup>

Patients attending outpatient cancer clinics were very positive about the extent to which hospital staff were respectful of their beliefs and privacy. Almost all patients said: their cultural and religious beliefs were ‘always’ respected by staff (98%); they were ‘always’ treated with respect and dignity (97%); and health professionals were ‘always’ kind and caring (95%).

Across LHDs, responses from patients who visited a clinic in Nepean Blue Mountains were significantly more positive than the NSW result for two out of six questions (Figure 20).

At a hospital level, widest variation was in the proportion of patients who said reception staff were ‘definitely’ polite and courteous, with results ranging from 78% to 100% (Figure 21).

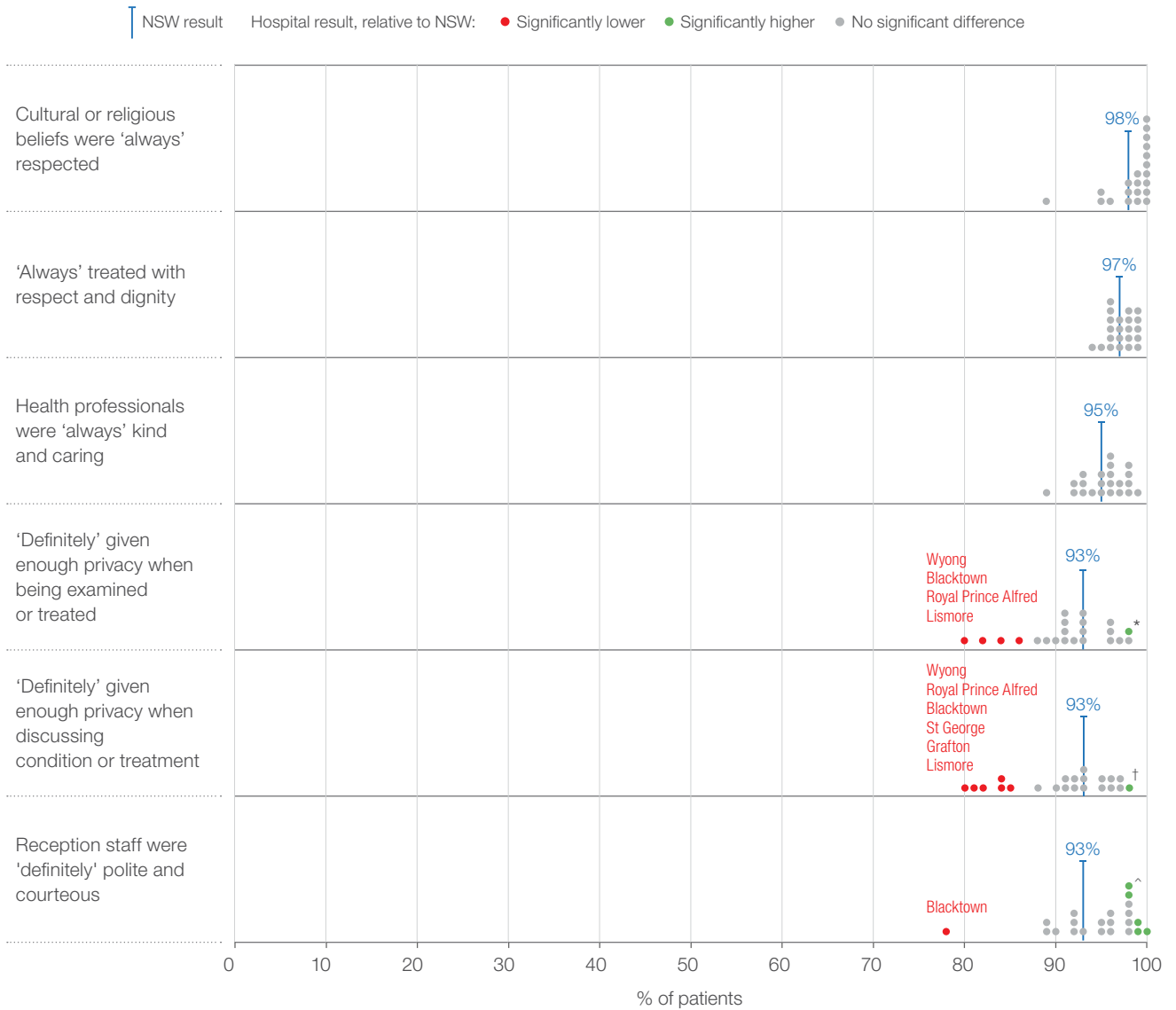
Figure 20 Respect and dignity, percentage of patients who selected the most positive response category, LHD results relative to NSW



\* Due to space limitations, the label for Nepean Blue Mountains (green) is not shown.

† Due to space limitations, the labels for Mid North Coast, Northern NSW, Nepean Blue Mountains and Western NSW (green) are not shown.

Figure 21 Respect and dignity, percentage of patients who selected the most positive response category, hospital results relative to NSW



\* Due to space limitations, the label for Campbelltown (green) is not shown.

† Due to space limitations, the label for Nepean (green) is not shown.

^ Due to space limitations, the labels for Coffs Harbour, Manly, Wyong, Nepean and Orange (green) are not shown.

# Information to support patients

## Most patients were told about the purpose of any new medication but only three-quarters of patients were completely informed about side effects

While there is a wealth of information available about cancer, it can be challenging for patients to access and fully understand what is relevant to them, and to apply it to their particular circumstances.<sup>16</sup> High quality cancer care ensures that a wide range of information is given to patients, in a format suitable for their needs.

The provision of information about medications is particularly important. Medications used in cancer treatment are often powerful and can have a range of side effects. Among patients who were prescribed new medication, 93% said that health professionals ‘completely’ explained the purpose of the new medication. A similar proportion said they were told who to contact if they were worried about their condition or treatment after leaving the clinic (92%) and that health professionals ‘always’ explained things

in an understandable way (91%). Fewer said they were ‘completely’ informed about medication side effects (76%) or were ‘completely’ told about other treatment side effects to watch for (74%) (Figure 22).

Across LHDs, responses from patients who visited a clinic in South Eastern Sydney were significantly less positive than the NSW result for the question regarding other treatment side effects to watch for (Figure 22).

At a hospital level, widest variation was in the proportion of patients who said a health professional ‘completely’ told them about other treatment side effects to watch for, with results ranging from 58% to 87% (Figure 23).

Figure 22 Information to support patients, percentage of patients who selected the most positive response category, LHD results relative to NSW

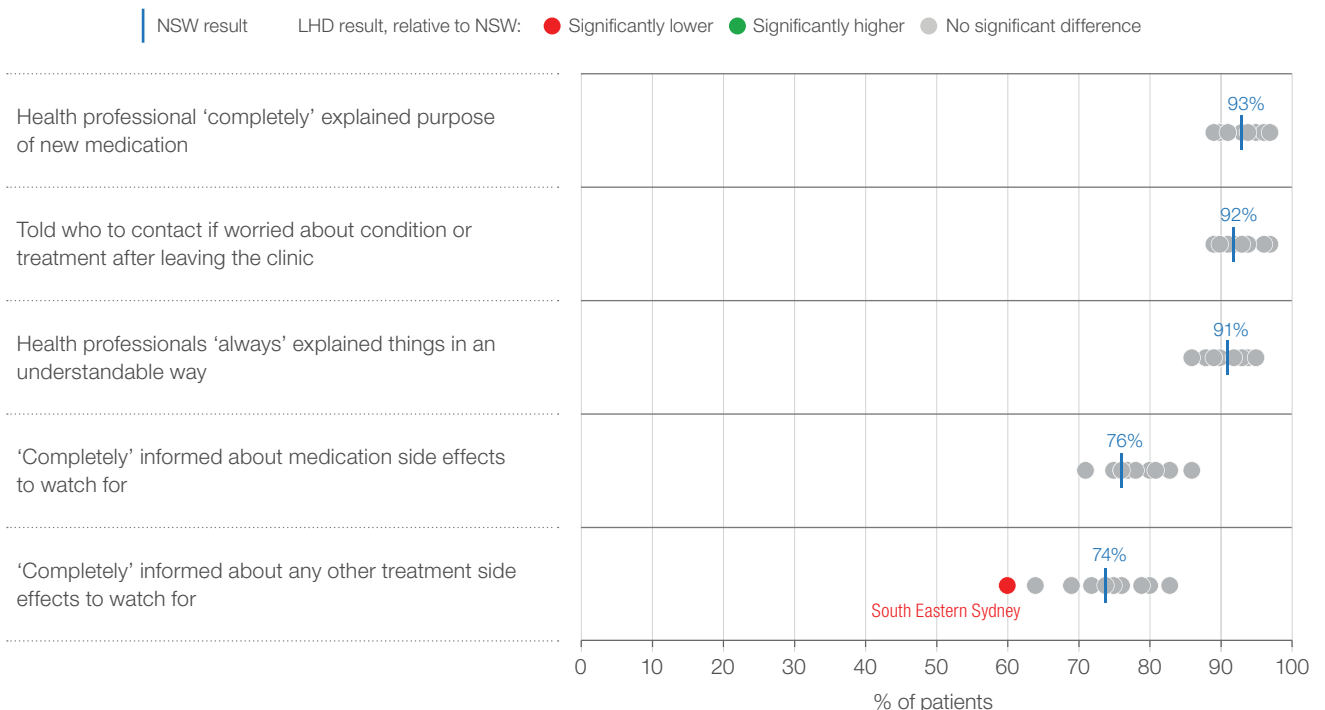
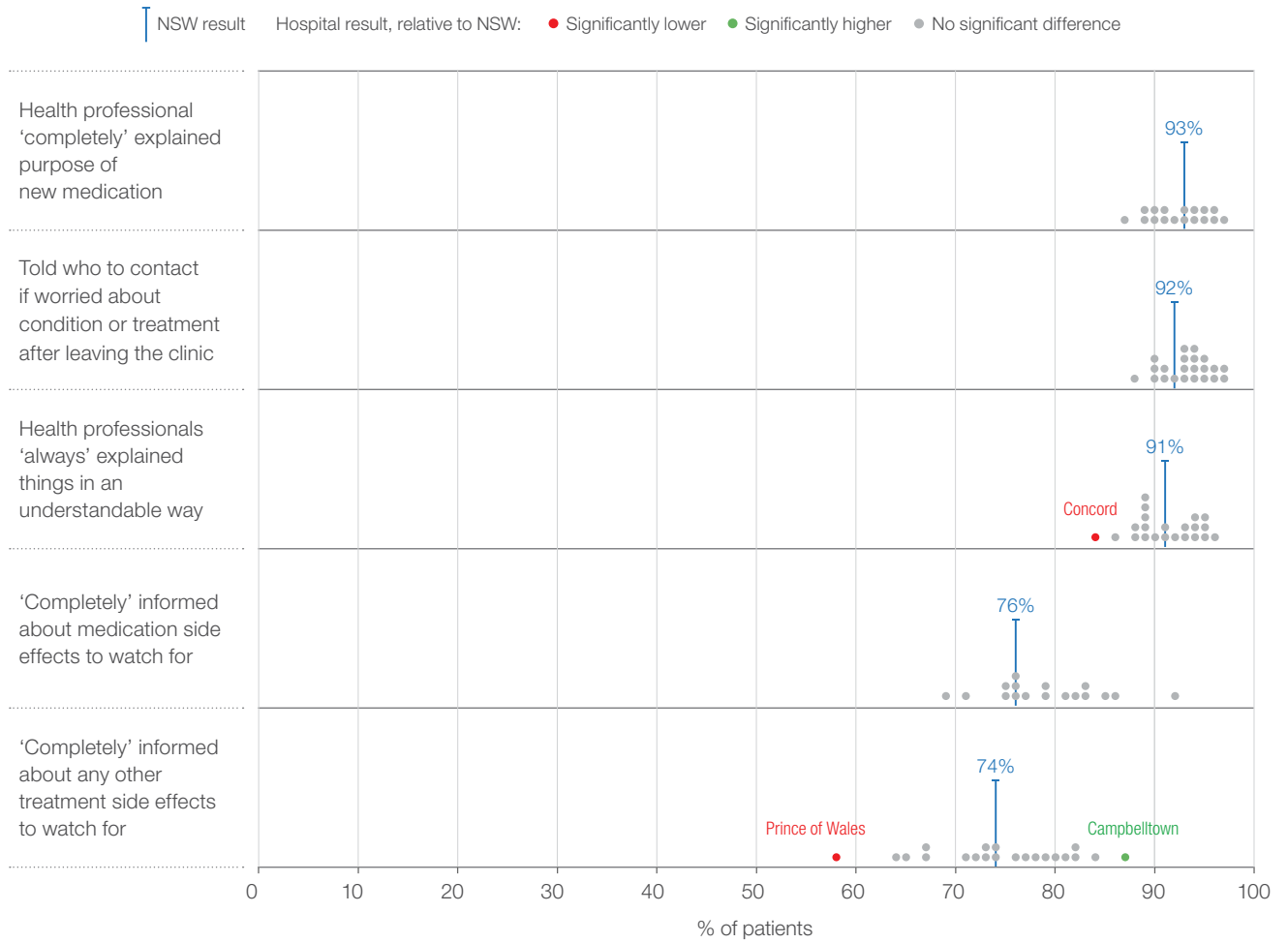


Figure 23 Information to support patients, percentage of patients who selected the most positive response category, hospital results relative to NSW



# Shared decision-making

## Across hospitals, between 33% and 66% of patients said they were definitely asked for ideas and preferences when developing their cancer care plan

When given the opportunity, most people with cancer want to be involved in decision-making about their care. Shared decision-making is a collaborative process that allows patients and health professionals to explore together different options for treatment and care, taking into account the best scientific evidence available, as well as patients' values and preferences.<sup>22</sup>

A cancer care plan is developed through shared decision-making processes. It is a vital document that sets out a patient's needs and goals for the treatment and management of their cancer.

While 74% of patients said they were 'definitely' involved in decisions about their care and treatment (as much as they wanted to be), only 57% who needed a cancer care plan said they had one;

and even fewer (47%) were 'definitely' asked for their ideas and preferences when developing their plan. For patients with a care plan, most (86%) said it was reviewed at their most recent visit (Figure 24).

Across LHDs, responses from patients who visited a clinic in Sydney were significantly more positive than the NSW result for the question regarding their participation in the development of their cancer care plan (Figure 24).

At a hospital level, widest variation was in the proportion of patients who said they were 'definitely' asked for ideas and preferences when developing their cancer care plan, ranging from 33% to 66% (Figure 25).

Figure 24 Shared decision-making, percentage of patients who selected the most positive response category, LHD results relative to NSW

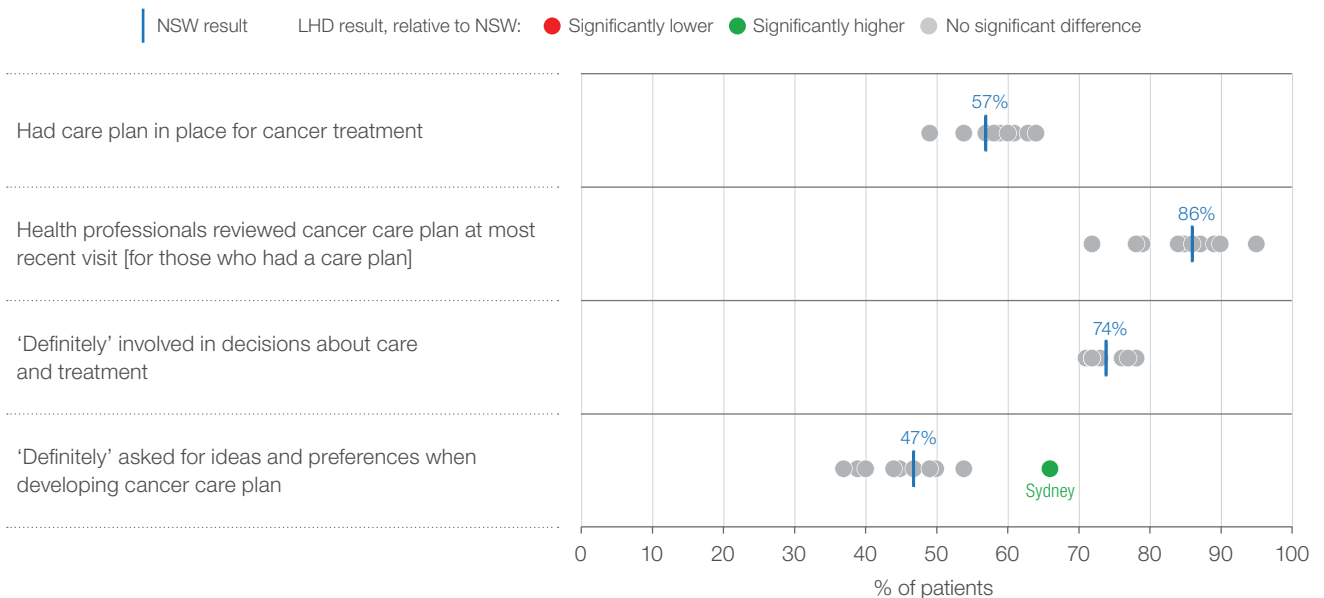
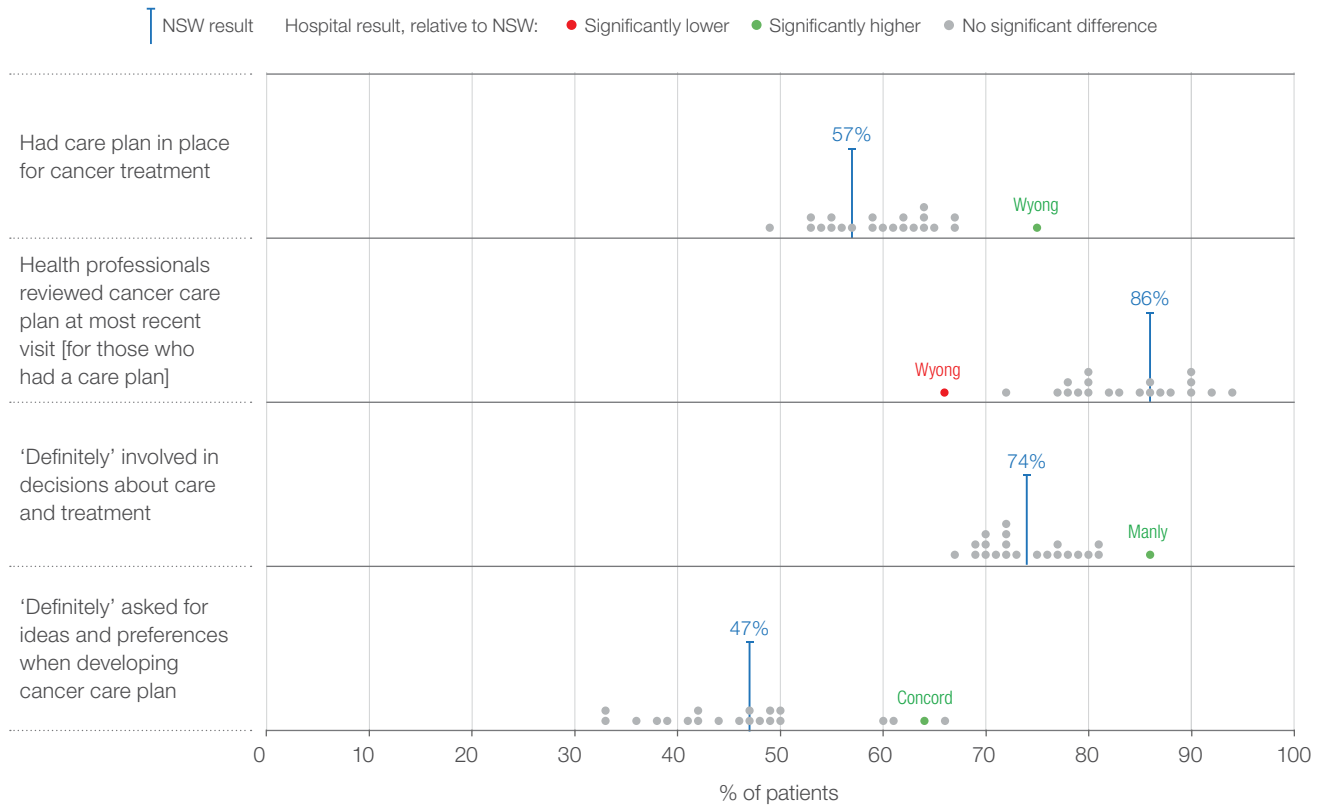


Figure 25 Shared decision-making, percentage of patients who selected the most positive response category, hospital results relative to NSW



# Coordination and continuity

## Most patients said they did not receive conflicting information and around three-quarters said health professionals worked well together

The complexity of cancer care and the number of interactions with different health professionals can be overwhelming for patients. Coordination of care between providers is important for all patients but particularly crucial for those with physical or psychosocial problems that develop in the course of cancer treatment.<sup>23</sup>

Favourable perceptions about continuity of care are correlated with better health outcomes.<sup>8</sup> Continuity of care during one phase of treatment has been shown to be predictive of fewer care needs in the following phases and associated with improved timeliness and information exchange at discharge.<sup>24,25</sup>

Questions addressing the theme of coordination and continuity were generally answered positively by patients. Most said health professionals ‘definitely’ knew enough about their medical history (83%) and said health professionals worked together in a ‘very good’ way (77%) (Figure 26).

Across LHDs, responses from patients who visited a clinic in Central Coast or Northern NSW were more positive than the NSW result for one out of four questions. No LHD recorded results that were significantly less positive than the NSW result (Figure 26).

At a hospital level, widest variation was in the proportion of patients who said health professionals worked together in a ‘very good’ way, ranging from 67% to 90% (Figure 27).

Figure 26 Coordination and continuity, percentage of patients who selected the most positive response category, LHD results relative to NSW

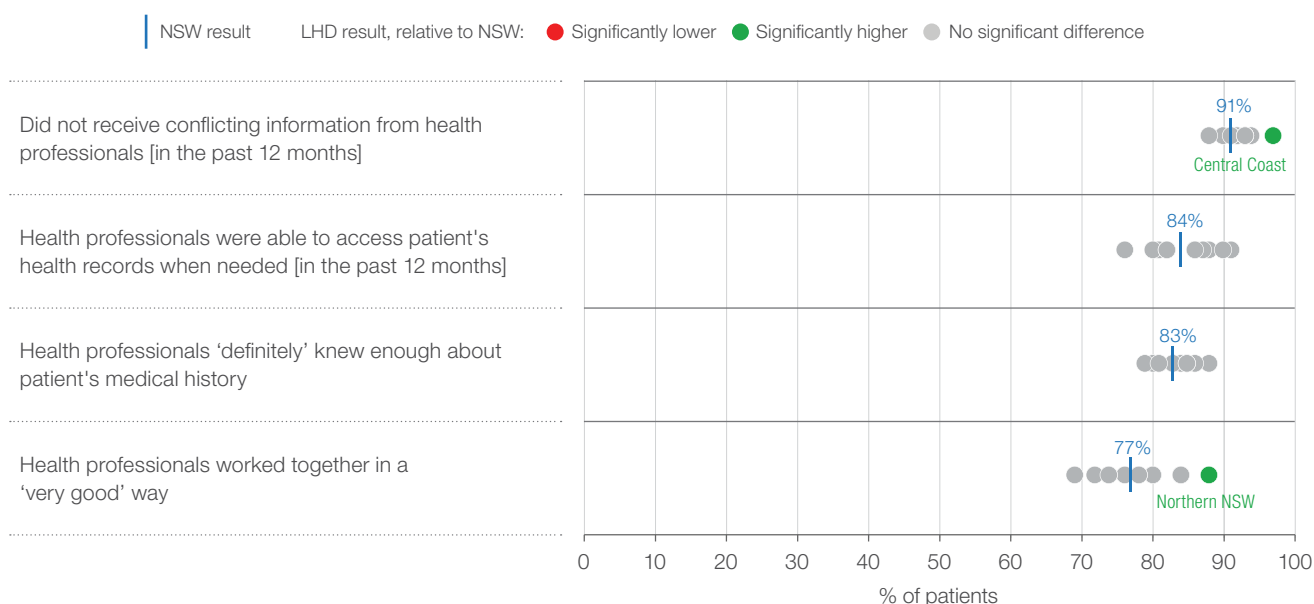
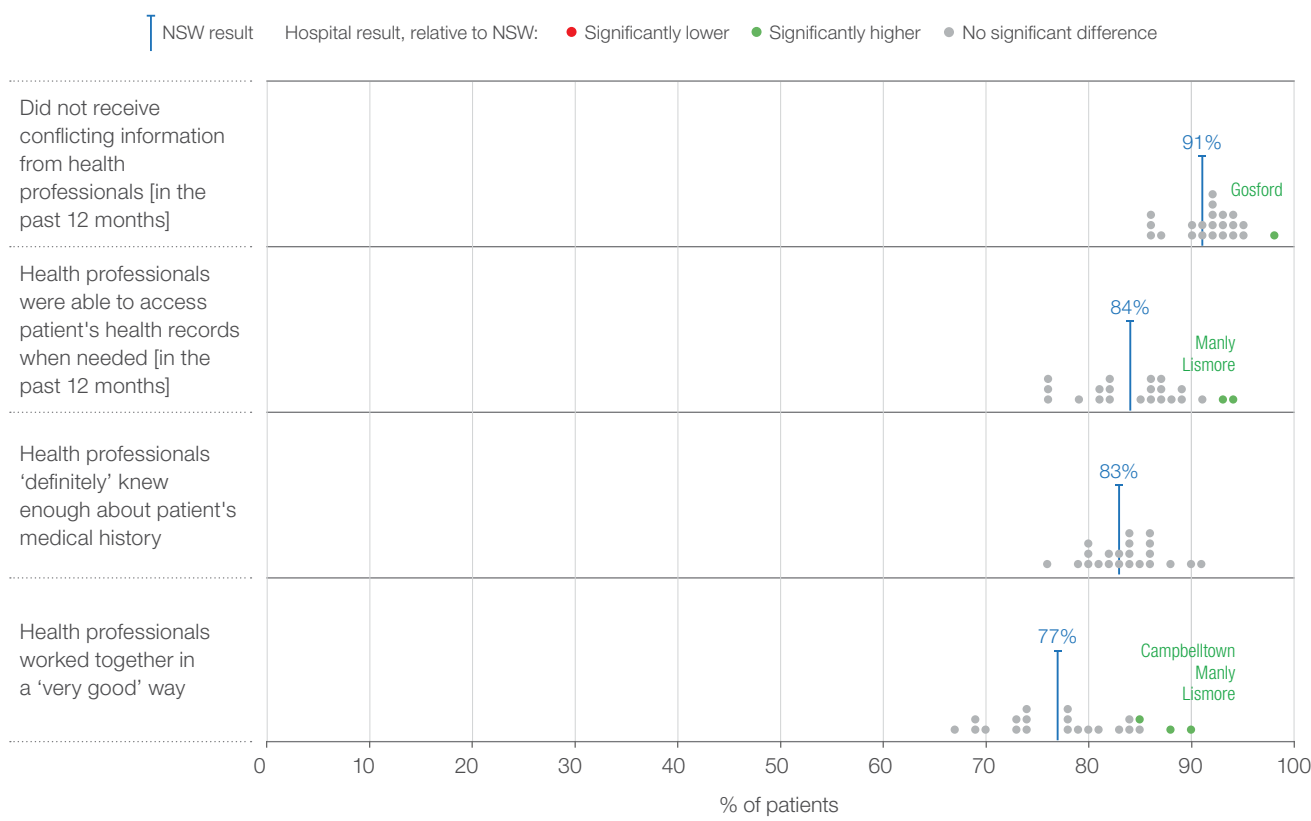




Figure 27 Coordination and continuity, percentage of patients who selected the most positive response category, hospital results relative to NSW



# Hygiene and cleanliness

## The proportion of patients who said they always saw health professionals wash their hands ranged from 57% to 93%

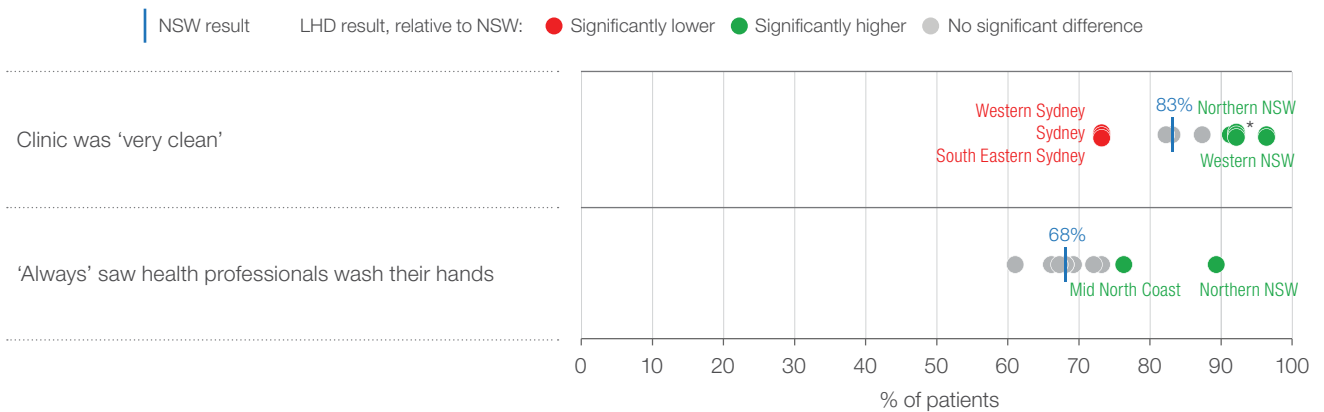
Hygiene is an important factor in the overall experience of patients and plays a crucial role in the safety of care for immunocompromised patients.

Across NSW, most patients (83%) said the clinic was 'very clean' and 68% said they 'always' saw health professionals wash their hands before they touched them (Figure 28).

Across LHDs, responses from patients who visited a clinic in Mid North Coast or Northern NSW were significantly more positive than the NSW result for both questions. Responses from patients who visited a clinic in South Eastern Sydney, Sydney and Western Sydney were significantly less positive than the NSW result about clinic cleanliness (Figure 28).

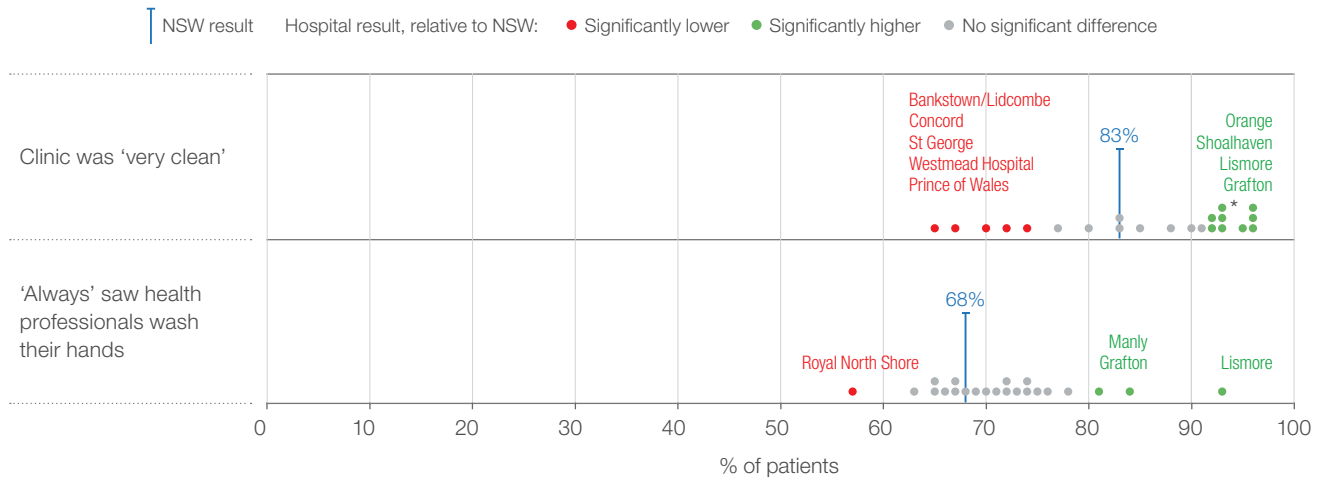
At a hospital level, widest variation was in the proportion of patients who said they 'always' saw health professionals wash their hands before they touched them, ranging from 57% to 93% (Figure 29).

Figure 28 Hygiene and cleanliness, percentage of patients who selected the most positive response category, LHD results relative to NSW



\* Due to space limitations, the labels for Central Coast, Illawarra Shoalhaven, Mid North Coast and St Vincent's (green) are not shown.

Figure 29 Hygiene and cleanliness, percentage of patients who selected the most positive response category, hospital results relative to NSW



\* Due to space limitations, the labels for Coffs Harbour, St Vincent's, Port Macquarie, Campbelltown and Wyong (green) are not shown.

# Patient-reported complications of care

## About one in 10 patients experienced a complication during or shortly after their visit

Cancer treatments are often potent and carry risks of side effects and complications. Effective cancer care minimises these complications and unplanned visits to the emergency department.

Across NSW, 10% of patients said at the time they completed the survey questionnaire, they had visited an emergency department in the time since their visit (approximately three months) because of their cancer or complications of care. Similarly, 12% said they experienced a complication or problem related to care received at the clinic, either during their visit or shortly afterwards (Figure 30).

Across LHDs, responses from patients who visited a clinic in Western NSW were significantly less positive than the NSW result for one of the two questions (Figure 30).

At a hospital level, widest variation was in the proportion of patients who said they did not experience any complication related to care received at the clinic, ranging from 76% to 96% (Figure 31).

Type of complication	% of patients
Any complication	12
Infection	3
Negative reaction to medication	3
Severe pain due to treatment	3
Severe anxiety or worry	3
Complications from tests or procedures	2
Other	2
Uncontrolled bleeding	0

Figure 30 Complications, percentage of patients who selected the most positive response category, LHD results relative to NSW

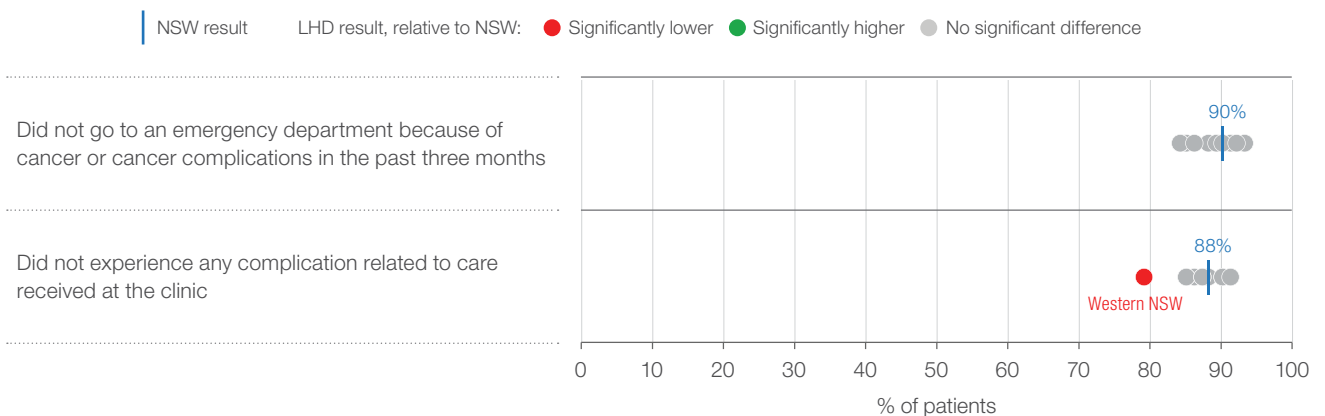
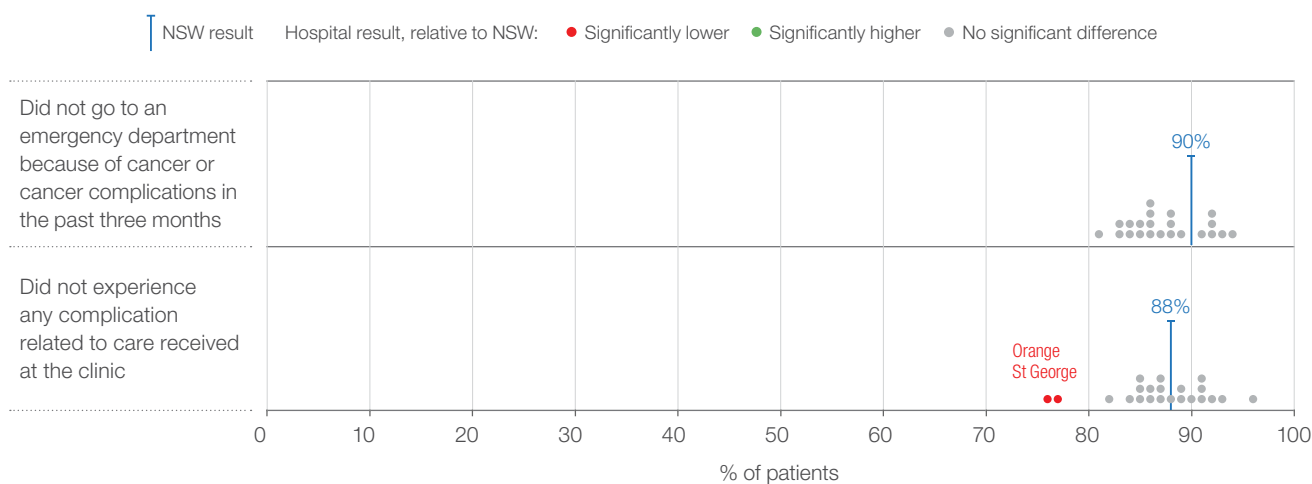


Figure 31 Complications, percentage of patients who selected the most positive response category, hospital results relative to NSW



### Interpreting these results

Figures 30 and 31 show responses in terms of the percentage of patients who said they did not experience a complication. This is to ensure that all of the thematic analyses in Section 1 can be interpreted the same way – that is, a lower percentage indicates poorer performance (red) and a higher percentage indicates better performance (green).

The figures show that 88% of patients in NSW did not experience a complication. This means that 12% of patients did experience a complication and that Western NSW LHD, and Orange and St George hospitals had more patients who said they experienced a complication.

### Patient-reported outcomes: More information

The Outpatient Cancer Clinics Survey featured two specialised sets of questions to measure short-term patient reported outcomes for symptom severity and self-efficacy. Most relevant for assessing outcomes of care among patients who are in an active phase of cancer treatment, results are shown in Section 3.

# Local health district overview and survey themes

Figure 32 Aspects of care, summary of LHD results relative to NSW (based on percentage of patients who selected the most positive response category)

Overall	Overall experience of care		<ol style="list-style-type: none"> <li>Overall, care was rated as 'very good'</li> <li>Would 'speak highly' of the clinic to friends and family</li> <li>Overall, health professionals were rated as 'very good'</li> <li>Care was 'very well organised'</li> </ol>
Access and timeliness	Access and timeliness before the visit		<ol style="list-style-type: none"> <li>Able to get an appointment time that suited them</li> <li>Time waited for appointment was 'about right'</li> <li>Travelled 'less than 30 minutes' to get to the clinic</li> <li>Had no out-of-pocket expenses in relation to visit</li> </ol>
	Access and timeliness during the visit		<ol style="list-style-type: none"> <li>Appointment started 'within 30 minutes' of scheduled time</li> <li>Told reason for wait (for appointment to start)</li> <li>Told how long to wait (for appointment to start)</li> </ol>
	Physical environment and comfort		<ol style="list-style-type: none"> <li>'No difficulties' entering and moving around the clinic</li> <li>'Definitely' easy to find way to the clinic</li> <li>Waiting area was 'very comfortable'</li> <li>'No problem' finding parking near the clinic</li> </ol>
Personalised and responsive care	Addressing patient concerns		<ol style="list-style-type: none"> <li>'Definitely' had enough time to discuss health issues with health professionals</li> <li>'Definitely' had confidence and trust in health professionals</li> <li>Health professional 'completely' discussed worries or fears</li> <li>While in the clinic, received or saw information about how to comment or complain</li> </ol>
	Respect and dignity		<ol style="list-style-type: none"> <li>Cultural or religious beliefs were 'always' respected</li> <li>'Always' treated with respect and dignity</li> <li>Health professionals were 'always' kind and caring</li> <li>'Definitely' given enough privacy when being examined or treated</li> <li>'Definitely' given enough privacy when discussing condition or treatment</li> <li>Reception staff were 'definitely' polite and courteous</li> </ol>
Communication and patient engagement	Information to support patient		<ol style="list-style-type: none"> <li>Health professional 'completely' explained purpose of new medication</li> <li>Told who to contact if worried about condition or treatment after leaving the clinic</li> <li>Health professionals 'always' explained things in an understandable way</li> <li>'Completely' informed about medication side effects to watch for</li> <li>'Completely' informed about any other treatment side effects to watch for</li> </ol>
	Shared decision-making		<ol style="list-style-type: none"> <li>Had care plan in place for cancer treatment</li> <li>Health professionals reviewed cancer care plan at most recent visit [for those who had a care plan]</li> <li>'Definitely' involved in decisions about care and treatment</li> <li>'Definitely' asked for ideas and preferences when developing cancer care plan</li> </ol>
Coordination and continuity	Coordination and continuity		<ol style="list-style-type: none"> <li>Did not receive conflicting information from health professionals [in the past 12 months]</li> <li>Health professionals were able to access patient's health records when needed [in the past 12 months]</li> <li>Health professionals 'definitely' knew enough about patient's medical history</li> <li>Health professionals worked together in a 'very good' way</li> </ol>
Hygiene and cleanliness	Hygiene and cleanliness		<ol style="list-style-type: none"> <li>Clinic was 'very clean'</li> <li>'Always' saw health professionals wash their hands</li> </ol>
Effective care	Complications		<ol style="list-style-type: none"> <li>Did not go to an emergency department because of cancer or cancer complications in the past three months</li> <li>Did not experience any complication related to care received at the clinic</li> </ol>

Note: Hospitals from Far West, Murrumbidgee, Southern NSW and Hunter New England could not be included as there were no data available at the time of sampling.

Central Coast      Illawarra Shoalhaven      Mid North Coast      Nepean Blue Mountains      Northern NSW      Northern Sydney      South Eastern Sydney      South Western Sydney      St Vincent's Health Network      Sydney      Western NSW      Western Sydney

**Overall experience of care**



**Access and timeliness before the visit**



**Access and timeliness during the visit**



**Physical environment and comfort**



**Addressing patient concerns**



**Respect and dignity**



**Information to support patient**



**Shared decision-making**



**Coordination and continuity**



**Hygiene and cleanliness**



**Complications**



LHD result, relative to NSW: ■ Significantly higher ■ Significantly lower ■ No significant difference  Data suppressed (<30 responses)

# Hospital overview and survey themes

Reviewing hospital-level results for all survey questions identify hospitals with consistent patterns of performance. Responses from patients who visited a clinic at Campbelltown Hospital were significantly more positive than the NSW result for 11 questions.

Responses from patients who visited Westmead Hospital were less positive than the NSW result for eight questions (Figure 33).

Figure 33 Aspects of care, summary of hospital results relative to NSW (based on the percentage of patients who selected the most positive response category)

Overall experience of care	1	Overall, care was rated as 'very good'
	2	Would 'speak highly' of the clinic to friends and family
	3	Overall, health professionals were rated as 'very good'
	4	Care was 'very well organised'
Access and timeliness before the visit	1	Able to get an appointment time that suited them
	2	Time waited for appointment was 'about right'
	3	Travelled 'less than 30 minutes' to get to the clinic
	4	Had no out-of-pocket expenses in relation to visit
Access and timeliness during the visit	1	Appointment started 'within 30 minutes' of scheduled time
	2	Told reason for wait (for appointment to start)
	3	Told how long to wait (for appointment to start)
Physical environment and comfort	1	'No difficulties' entering and moving around the clinic
	2	'Definitely' easy to find way to the clinic
	3	Waiting area was 'very comfortable'
	4	'No problem' finding parking near the clinic
Addressing patient concerns	1	'Definitely' had enough time to discuss health issues with health professionals
	2	'Definitely' had confidence and trust in health professionals
	3	Health professional 'completely' discussed worries or fears
	4	While in the clinic, received or saw information about how to comment or complain
Respect and dignity	1	Cultural or religious beliefs were 'always' respected
	2	'Always' treated with respect and dignity
	3	Health professionals were 'always' kind and caring
	4	'Definitely' given enough privacy when being examined or treated
	5	'Definitely' given enough privacy when discussing condition or treatment
	6	Reception staff were 'definitely' polite and courteous
Information to support patient	1	Health professional 'completely' explained purpose of new medication
	2	Told who to contact if worried about condition or treatment after leaving the clinic
	3	Health professionals 'always' explained things in an understandable way
	4	'Completely' informed about medication side effects to watch for
	5	'Completely' informed about any other treatment side effects to watch for
Shared decision-making	1	Had care plan in place for cancer treatment
	2	Health professionals reviewed cancer care plan at most recent visit [for those who had a care plan]
	3	'Definitely' involved in decisions about care and treatment
	4	'Definitely' asked for ideas and preferences when developing cancer care plan
Coordination and continuity	1	Did not receive conflicting information from health professionals [in the past 12 months]
	2	Health professionals were able to access patient's health records when needed [in the past 12 months]
	3	Health professionals 'definitely' knew enough about patient's medical history
	4	Health professionals worked together in a 'very good' way
Hygiene and cleanliness	1	Clinic was 'very clean'
	2	'Always' saw health professionals wash their hands
Complications	1	Did not go to an emergency department because of cancer or cancer complications in the past three months
	2	Did not experience any complication related to care received from the clinic



Responses from patients who visited a clinic at Sydney/Sydney Eye Hospital were significantly less positive than the NSW result for 10 questions. However, only 14% of respondents at this hospital attended for cancer.

More detail is provided in individual hospital profiles, available at [bhi.nsw.gov.au](http://bhi.nsw.gov.au)

	Bankstown/Lidcombe	Blacktown	Campbelltown	Chris O'Brien Lifehouse*	Coffs Harbour	Concord	Gosford	Grafton	Lismore	Liverpool	Manly	Napelan	Orange	Port Macquarie	Prince of Wales	Royal North Shore	Royal Prince Alfred	Shoalhaven	St George	St Vincent's	Sydney/Sydney Eye	Westmead	Wollongong	Wyong	NSW
1	68	77	91	79	91	77	85	87	92	78	89	83	92	89	82	84	86	87	79	81	69	84	85	88	83
2	85	85	97	94	95	90	92	97	98	92	92	95	95	95	88	94	96	92	89	89	81	90	94	93	92
3	75	79	89	81	90	78	85	86	92	83	91	85	91	91	85	86	89	87	74	83	64	86	87	86	85
4	79	80	92	76	89	72	82	91	94	75	83	83	88	89	76	77	81	86	77	84	75	76	89	92	81
1	99	97	99	97	99	95	99	99	99	98	100	97	99	100	96	99	99	98	99	98	97	98	99	100	98
2	82	89	95	93	89	89	97	97	94	93	96	90	91	93	88	91	93	91	91	96	74	93	96	97	92
3	77	77	65	48	54	56	61	61	40	64	53	53	33	46	57	37	42	50	59	51	10	43	74	78	54
4	44	59	69	47	67	41	63	54	66	48	52	74	54	56	56	47	33	69	49	40	51	42	65	72	54
1	94	82	85	75	93	70	93	91	87	81	94	75	89	94	76	84	85	90	77	89	39	70	95	93	81
2	30	23	38	29	27	27	33	52	35	30	35	27	57	40	26	30	22	27	30	26	37	22	38	25	29
3	27	17	37	30	30	24	31	53	31	30	27	25	51	47	25	27	23	33	27	27	24	18	37	29	28
1	90	95	92	93	98	88	91	99	95	81	93	95	93	94	92	91	94	94	88	94	91	83	83	96	90
2	82	89	89	93	93	90	95	98	93	87	88	91	85	88	82	76	90	91	85	89	75	73	79	90	85
3	29	33	47	65	66	24	68	55	76	35	60	40	46	58	42	50	68	57	29	69	26	34	57	45	48
4	10	83	83	63	69	41	73	69	29	46	43	61	23	43	31	69	58	66	10	51		12	43	27	48
1	84	88	95	88	94	84	93	94	92	94	94	95	90	96	89	93	92	91	90	86	85	94	91	92	92
2	84	89	93	83	94	87	88	93	95	85	92	92	94	91	88	89	94	87	83	85	80	87	89	90	88
3	59	61	78	58	74	64	72			75	89	76	62	78	63	62		79	63	71		69	75	78	69
4	38	37	44	40	37	35	40	41	32	38	34	30	45	43	24	31	32	24	33	25	23	35	31	25	34
1	95	99	99	93	100	98	98	100	95	96	100	100	100	99	100	99		100	89	100		98	100	100	98
2	97	96	99	97	98	96	95	99	98	98	97	99	99	98	94	96	97	96	96	96	92	99	98	97	97
3	93	95	98	95	96	92	92	97	99	96	98	97	98	98	94	96	93	95	89	93	93	95	96	96	95
4	91	82	98	96	96	93	93	91	86	97	93	98	93	90	96	96	84	91	88	92	90	89	91	80	93
5	91	82	97	94	97	93	92	84	85	96	93	98	92	95	95	96	81	91	84	88	90	90	93	80	93
6	89	78	98	89	98	92	96	98	98	96	98	99	100	98	90	95	92	95	93	92	79	89	96	99	93
1	90	95	92	94	93	87	89		95	96		97		94	91	89		93		91		90	96	94	93
2	91	92	96	89	97	96	90	95	94	93	95	93	94	97	91	88	95	90	94	90		93	93	94	92
3	86	89	93	91	93	84	90	95	92	94	94	95	95	96	89	89	89	91	88	88	67	89	94	91	91
4	76	83	81	68	86	79	85		82	76		76		79	83	77		75		71		69	75	92	76
5	65	77	87	75	79	67	67	84	82	81	80	72	82	73	58	74		71	73	64		74	76	78	74
1	57	64	67	47	64	61	62	56	65	53	55	54	64	63	53	59	67	55	62	49		60	59	75	57
2	87	82	88	91	85	94	90	80	77	92	80	79	83	90	86	90		78	78	72		86	80	66	86
3	67	72	81	74	77	70	72	81	76	69	86	78	70	80	71	75	79	72	70	77	66	72	73	69	74
4	38	46	42	58	50	64	41	42	60	39	61	44	33	48	50	47		36	66	47		49	49	33	47
1	92	87	91	86	93	92	98	90	95	86	92	92	93	94	91	92	86	93	86	90		94	95	94	91
2	76	86	87	78	89	79	88	85	93	89	94	91	82	87	81	86	81	87	82	76		82	86	76	84
3	86	84	88	85	90	86	85	84	82	84	91	80	80	86	83	83	84	80	76	79	83	81	82	86	83
4	67	73	85	80	79	73	84	85	90	69	88	78	83	80	69	74	70	78	74	78	58	74	81	84	77
1	65	77	93	84	92	67	91	96	96	80	83	83	95	93	74	88	85	96	70	92	63	72	90	93	83
2	65	76	71	69	78	66	72	84	93	67	81	69	74	74	63	57	67	73	70	68	34	65	72	75	68
1	85	86	92	89	92	86	86	81	85	88	87	93	88	89	94	91	84	86	83	84		92	88	83	90
2	85	87	85	91	88	87	86	90	92	89	93	85	77	82	91	91	96	86	76	87	93	91	89	84	88

Hospital result, relative to NSW: ■ Significantly higher ■ Significantly lower ■ No significant difference  Data suppressed (<30 responses)

Note: Bathurst Base and Dubbo Base hospitals are excluded due to insufficient responses (<30).

\* Chris O'Brien Lifehouse is not a NSW Health facility but is contracted to provide services to some public hospital patients.

# Thematic overview: Barriers to access

## Out-of-pocket expenses are incurred by about half of all outpatients

While most patients rated the care they received in the outpatient clinic positively, comprehensiveness of care and outcomes can be hindered by barriers to access.

These barriers include a lack of:

- Approachability (not knowing where to go)
- Acceptability (not having options that align with social, cultural and interpersonal needs and expectations)
- Availability (problems with appointment times or distance)
- Affordability (not able to pay for care if required)
- Appropriateness (not offered the right care).<sup>16</sup>

Patients who visited an outpatient clinic did encounter a range of barriers to accessing care. A minority of patients described barriers in terms of approachability, acceptability, availability and appropriateness. However, almost half of all patients said they had out-of-pocket expenses (Figure 35).

Across LHDs, the proportion of patients who said they had out-of-pocket expenses ranged from 26% in Nepean Blue Mountains to 62% in Sydney; and across hospitals from 26% in Nepean to 67% in Royal Prince Alfred (Figures 36).

Across hospitals, the proportion of patients who had out-of-pocket consultation fees ranged from 0% (Coffs Harbour) to 16% (Grafton). In most hospitals (15 of the 24 hospitals included in the analysis), fewer than 5% of patients had consultation fees [data not shown].

Figure 34 Barriers to access, all patients, NSW

Elements of accessibility	Patient-reported barriers
Do patients know where to seek healthcare?	5% of patients said it is not easy to get information about cancer
Are patients comfortable seeking healthcare?	2% of patients said their cultural and religious beliefs were not always respected
Can patients reach healthcare?	8% of patients said a long walk to the clinic caused them difficulties
	98% said they could get an appointment time that suited them
Does cost affect patients' ability to seek healthcare?	46% of patients had out-of-pocket expenses
	20% of patients had parking costs
	19% of patients had travel costs
	18% paid for medication
	4% of patients had consultation fees
Can patients engage with healthcare?	6% of patients said it was not easy to actively participate in decisions about their treatment

Figure 35 Percentage of patients with out-of-pocket expenses, any and by category, NSW

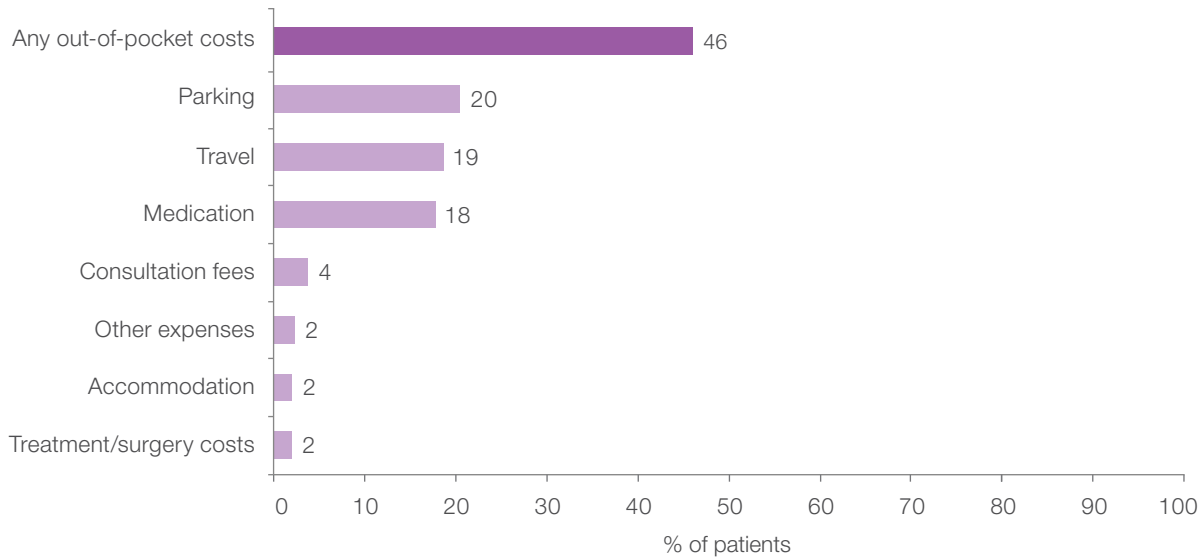
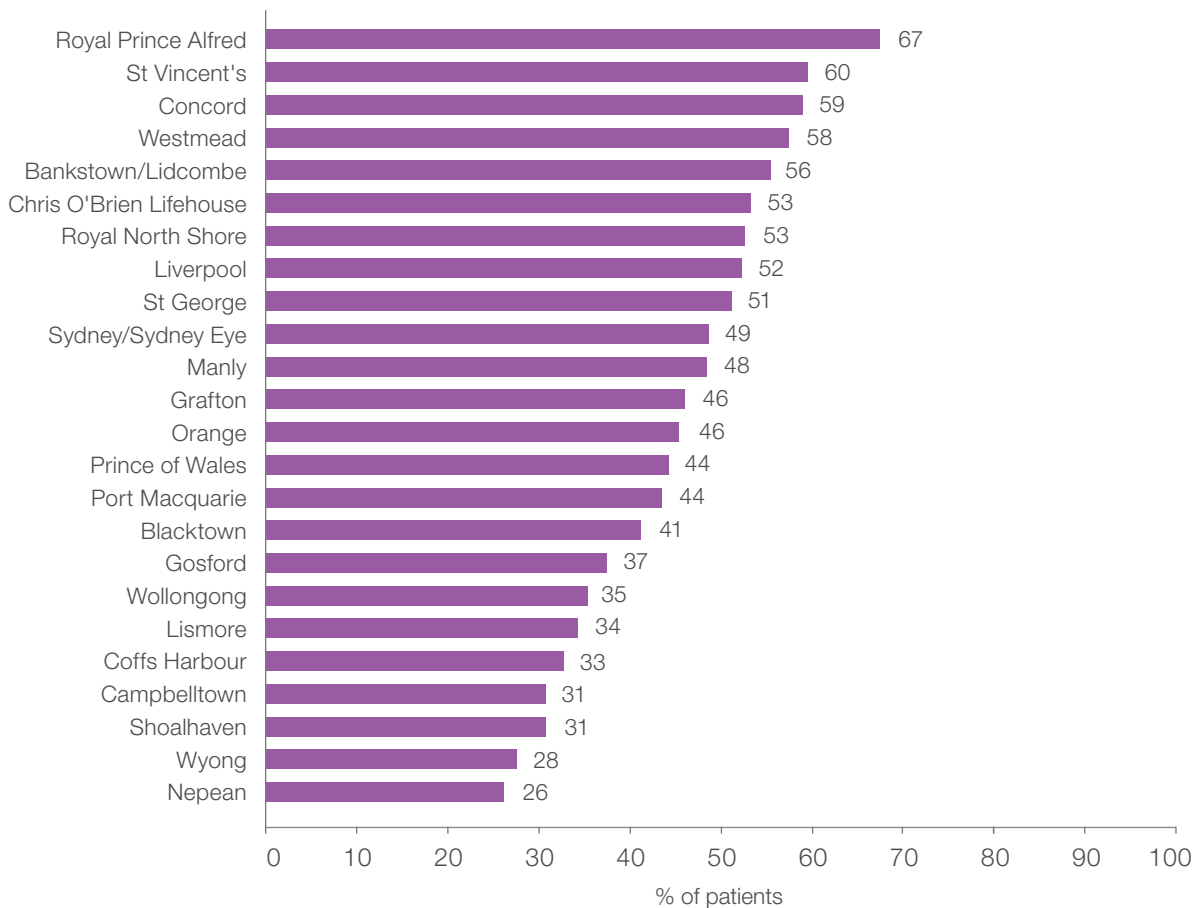


Figure 36 Percentage of patients with any out-of-pocket expenses, by hospital



## SECTION 2

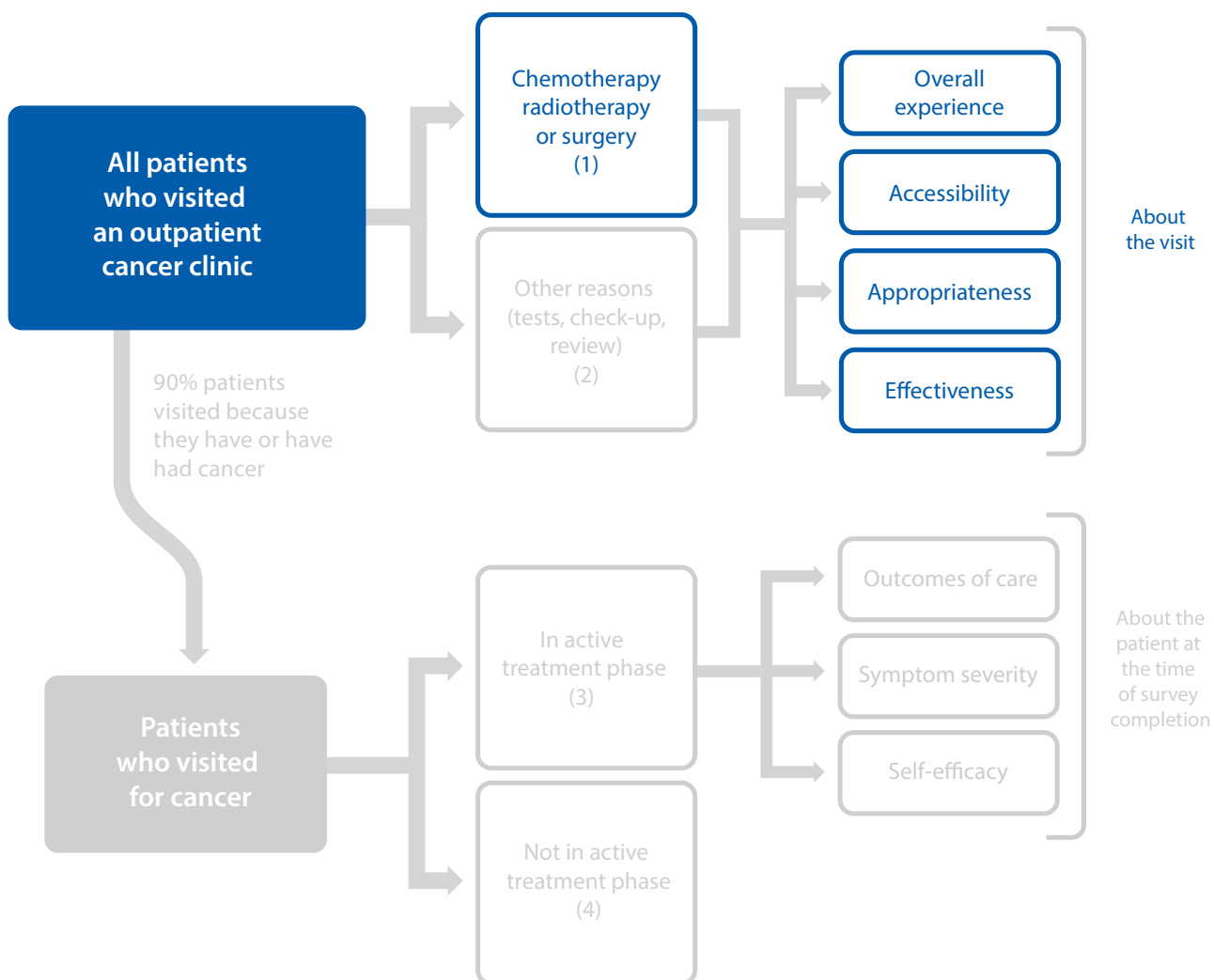
# Patients who visited for chemotherapy, radiotherapy or surgery

Accessibility and appropriateness measures

## Patients who visited for chemotherapy, radiotherapy or surgery

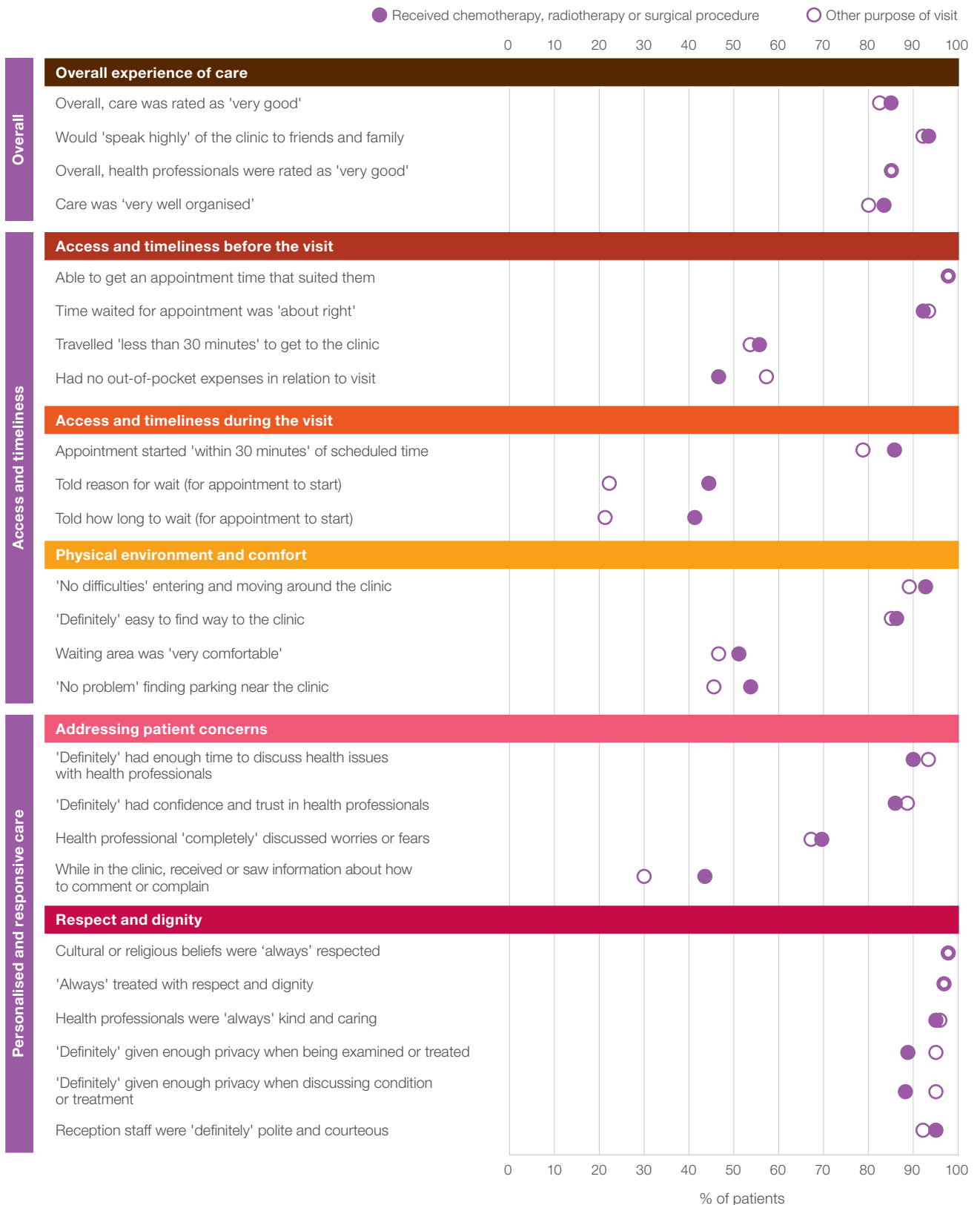
**Section 2** compares responses about a visit for chemotherapy, radiotherapy or a surgical procedure (34% of patients) with those about other types of visits.

It then examines variation in responses from patients who visited for chemotherapy, radiotherapy or a surgical procedure across LHDs and hospitals using a subset of 15 questions regarding accessibility and appropriateness of care.



# Aspects of patient care: Results by type of visit

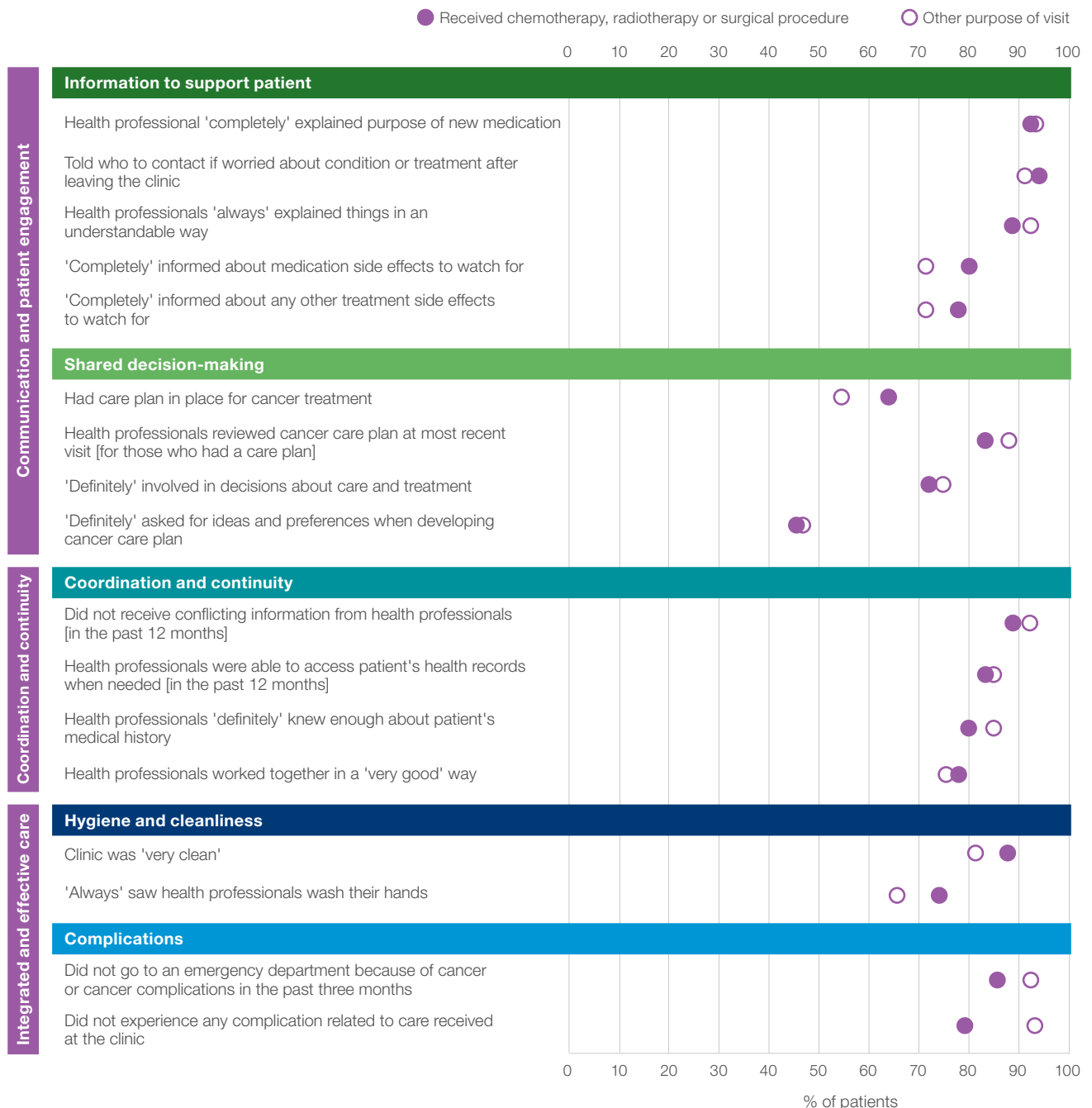
Figure 37 Aspects of outpatient care, percentage of patients who selected the most positive response category, by type of visit, NSW



Around one-third of patients (34%) visited an outpatient clinic for a course of chemotherapy, a fraction of radiotherapy or a surgical procedure.

Responses from patients whose visit included chemotherapy, radiotherapy or a surgical procedure were more positive than those who visited for other

reasons for questions about access, timeliness and cleanliness. They were more likely to have a cancer plan and be well informed about side effects to watch for but were less positive regarding privacy and complications (Figure 37).



# Variation in accessibility and appropriateness

## Most patients received timely care when visiting for chemotherapy, radiotherapy or surgery

Focusing on the subset of visits specifically for chemotherapy, radiotherapy or a surgical procedure provides a more homogeneous group of patients on which to compare performance in accessibility and appropriateness measures across LHDs and hospitals.

### Access and timeliness measures

Among patients who visited for chemotherapy, radiotherapy or a surgical procedure, 98% said they were able to get an appointment time that suited them. Most said the time waited for appointment was 'about right' (92%); appointments started 'within 30 minutes' of scheduled time (86%); and that they waited less than one month from booking an appointment to going to the clinic (84%).

Patients who visited a clinic in Central Coast LHD provided more positive responses than the NSW result for two of four questions on access and timeliness. Responses from patients in Illawarra

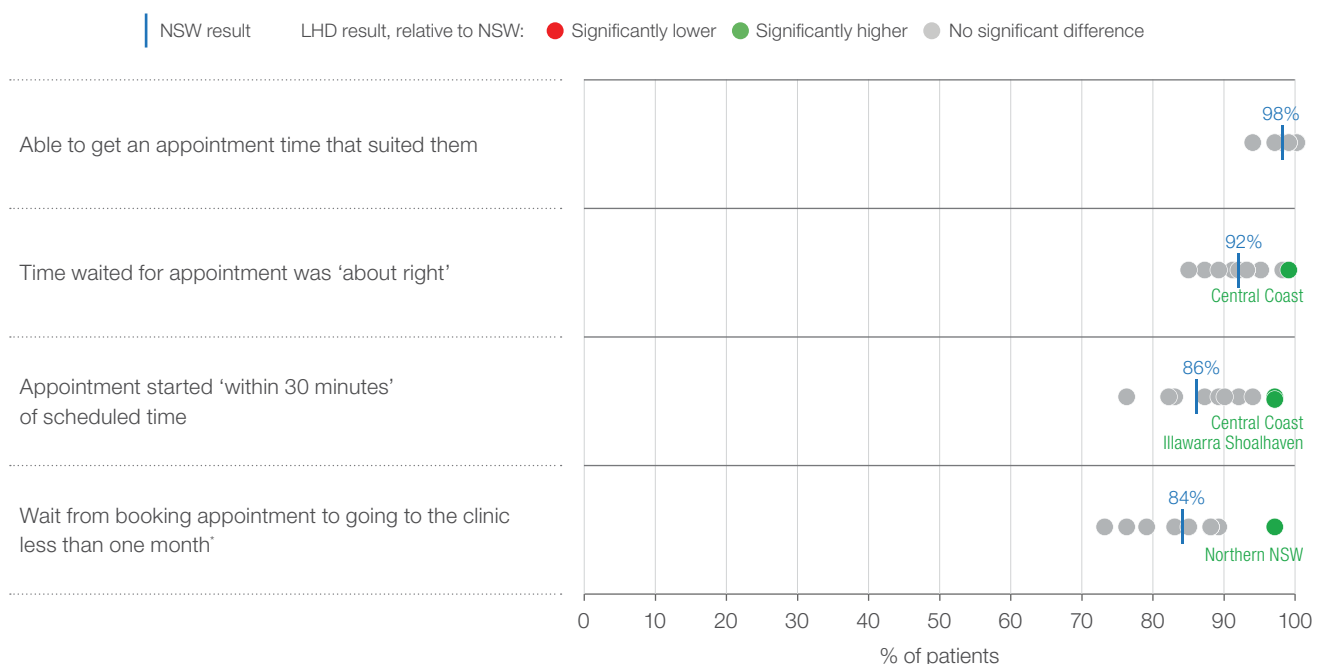
Shoalhaven and Northern NSW LHDs were significantly more positive than the NSW result for one question each. There were no questions for which an LHD's patients were significantly less positive than the NSW result (Figure 38).

### Appropriateness measures

Measures of appropriateness assess whether healthcare services are delivered in ways that are in accordance with evidence-based guidelines and responsive to patients' expectations and needs. Eleven questions from the survey relate to the appropriateness of care for patients visiting an outpatient clinic for chemotherapy, radiotherapy or surgical procedures.

Almost all patients (97%) visiting for chemotherapy, radiotherapy or surgical procedures said they were 'always' treated with respect and dignity. More than six in 10 (63%) said they had a care plan in place for their cancer treatment if they needed one.

Figure 38 Access and timeliness measures, percentage of patients who selected the most positive response category, visits for chemotherapy, radiotherapy or a surgical procedure, LHD results relative to NSW



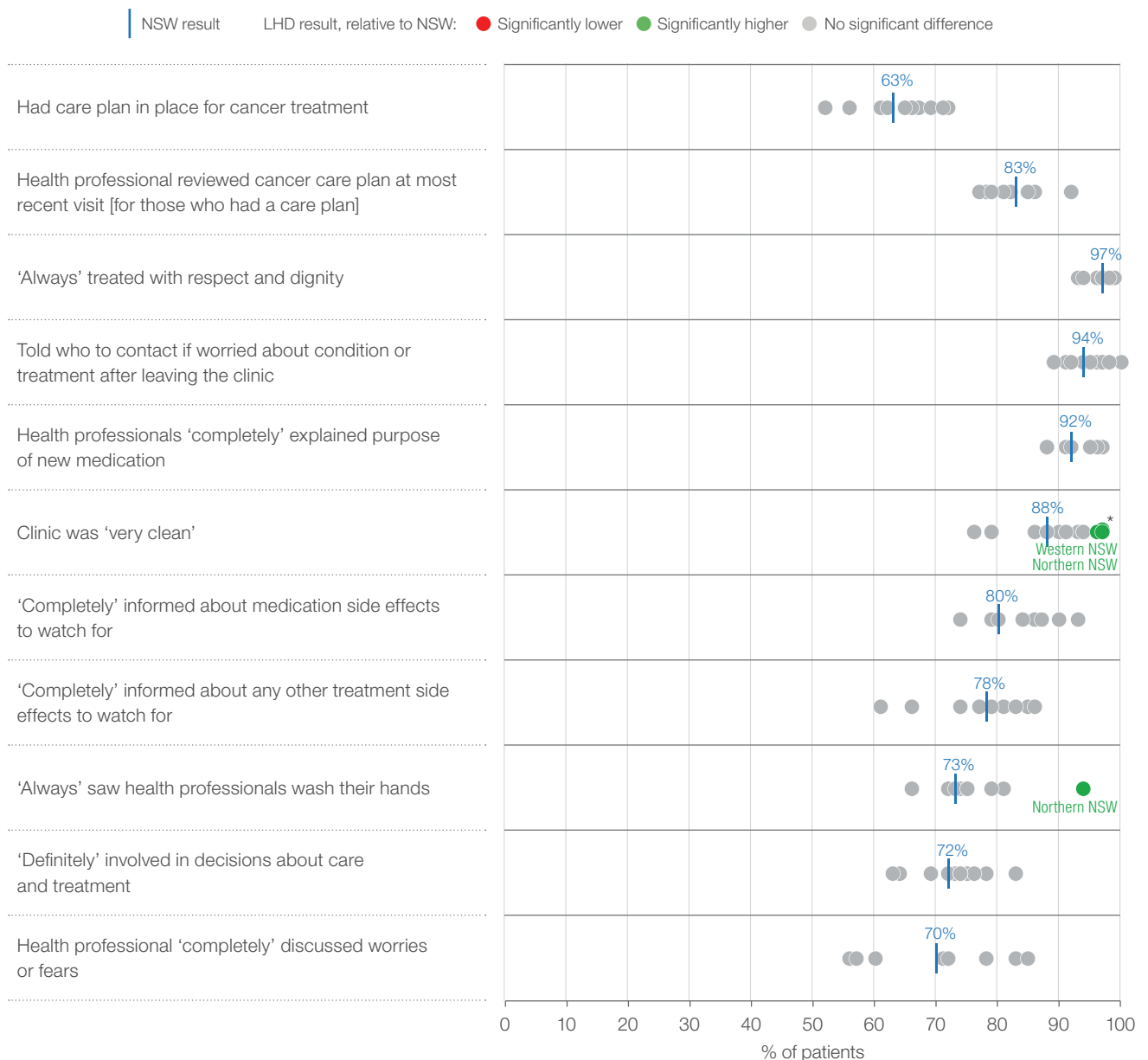
\* Not included in the set of 42 questions that make up the aspects of care in Section 1. Full results are available on Healthcare Observer [bhi.nsw.gov.au](http://bhi.nsw.gov.au)



Across LHDs, patients who visited an outpatient cancer clinic in Northern NSW were more positive than the NSW result for two questions: whether they 'always' saw health professionals wash their hands before touching them and whether the clinic was 'very clean'. Patients in Mid North Coast, and Western NSW also reflected positively on clinic cleanliness.

No LHD recorded results significantly less positive than NSW for any of the appropriateness measures (Figure 39).

**Figure 39** Appropriateness measures, percentage of patients who selected the most positive response category, visits for chemotherapy, radiotherapy or a surgical procedure, LHD results relative to NSW



\* Due to space limitations, label for Mid North Coast LHD is not shown.

# Visits for chemotherapy, radiotherapy or a surgical procedure: LHD and hospital overview

Responses from patients who visited a clinic in Northern NSW LHD were more positive than the NSW result for three of 15 questions.

No LHD's patients responded less positively than the NSW result for access and timeliness or appropriateness questions (Figure 40).

Figure 40 Accessibility and appropriateness measures, percentage of patients who selected the most positive response category, visits for chemotherapy, radiotherapy or a surgical procedure, LHD results relative to NSW

	Central Coast	Illawarra Shoalhaven	Mid North Coast	Nepean Blue Mountains	Northern NSW	Northern Sydney	South Eastern Sydney	St Vincent's Health Network	South Western Sydney	Sydney	Western NSW	Western Sydney	NSW
<b>Accessibility</b>													
1 Able to get an appointment time that suited them	99	98	100	94	100	98	97	99	100	99	99	97	98
2 Time waited for appointment was 'about right'	99	95	93	87	93	91	85	98	92	93	89	93	92
3 Appointment started 'within 30 minutes' of scheduled time	97	97	92	82	92	87	83	94	89	76	90	82	86
4 Waited less than one month to go to the clinic*	89	85	88	76	97	83	83	85	88	88	73	79	84
<b>Appropriateness</b>													
1 Had care plan in place for cancer treatment	71	65	72	52	67	66	56	61	69	71	65	62	63
2 Health professional reviewed cancer care plan at most recent visit [for those who had a care plan]	78	78	86		82	82	81	77	92		85	79	83
3 'Always' treated with respect and dignity	96	98	98	97	99	98	93	97	97	94	99	98	97
4 Told who to contact if worried about condition or treatment after leaving the clinic	94	97	100	91	97	97	89	96	97	98	95	92	94
5 Health professional 'completely' explained purpose of new medication	91	96	97		97	88	96		95	92		88	92
6 Clinic was 'very clean'	93	94	96	90	97	91	86	94	88	76	97	79	88
7 'Completely' informed about medication side effects to watch for	90	80	86		87	79	93		80	84		74	80
8 'Completely' informed about any other treatment side effects to watch for	77	79	81	74	85	77	61	66	86	83	79	77	78
9 'Always' saw health professionals wash their hands	81	75	74	79	94	66	66	72	75	73	75	66	73
10 'Definitely' involved in decisions about care and treatment	72	69	83	75	78	73	72	76	74	74	64	63	72
11 Health professionals 'completely' discussed worries or fears	83	78	85			71	56		60		57	72	70

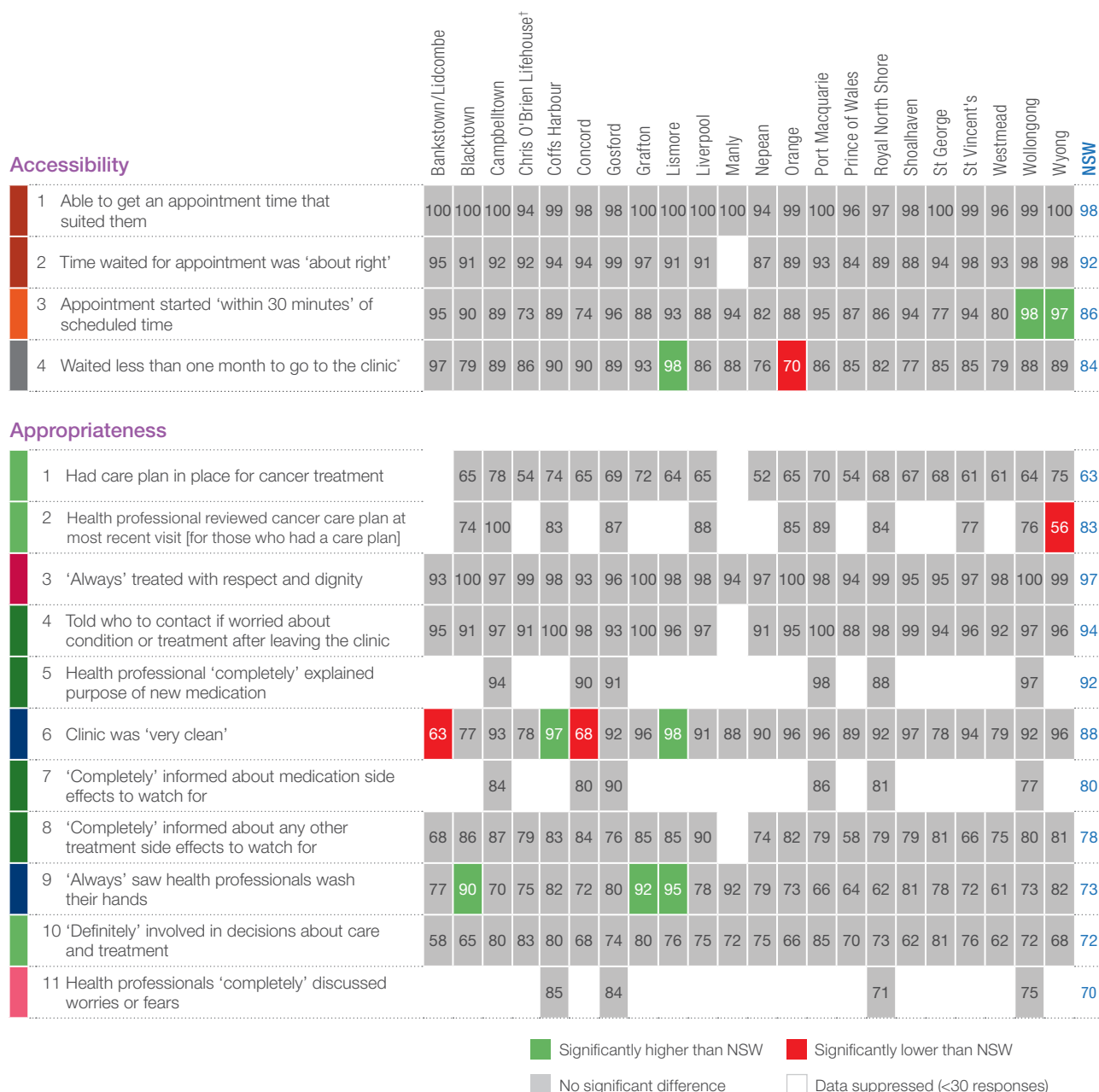
■ Significantly higher than NSW    
 ■ Significantly lower than NSW  
■ No significant difference    
 ■ Data suppressed (<30 responses)

\* Not included in the set of 42 questions that make up the aspects of care in Section 1. Full results are available on Healthcare Observer at [bhi.nsw.gov.au](http://bhi.nsw.gov.au)

At a hospital level, responses from patients who visited Lismore were more positive than the NSW result for three questions – those about waiting times for an appointment, cleanliness of the clinic and hand hygiene. For four hospitals – Bankstown/Lidcombe,

Concord, Orange and Wyong – responses from their patients were less positive than the NSW result for one question (Figure 41).

Figure 41 Accessibility and appropriateness measures, percentage of patients who selected the most positive response category, visits for chemotherapy, radiotherapy or a surgical procedure, hospital results relative to NSW



\* Not included in the set of 42 questions that make up the aspects of care in Section 1. Full results are available on Healthcare Observer at [bhi.nsw.gov.au](http://bhi.nsw.gov.au)

† Chris O'Brien Lifehouse is not a NSW Health facility but is contracted to provide services to some public hospital patients.

SECTION 3

# Patients in an active treatment phase

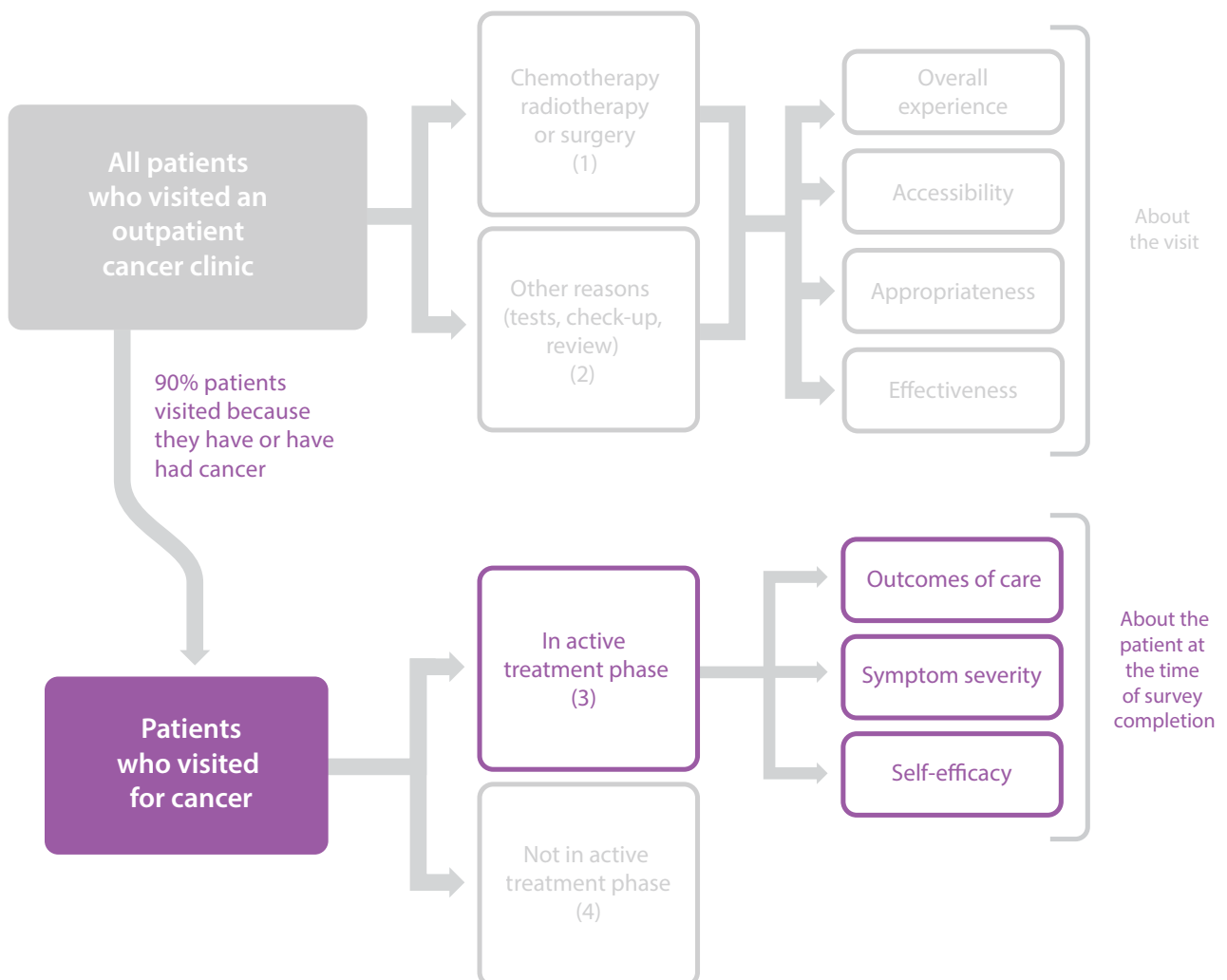
Effectiveness measures

## Patients who were undergoing active cancer treatment at the time of survey completion

**Section 3** compares responses from patients who, at the time of survey completion (approximately three months after the outpatient visit), were in an active treatment phase (30% of patients) with other patients. It then examines variation in responses from patients in an active treatment phase across LHDs and hospitals using 15 measures that address effectiveness of care.

It includes results from two specialised survey tools:

- Edmonton Symptom Assessment System (ESAS), which asks patients to rate symptom intensity
- Communication and Attitudinal Self-Efficacy scale for cancer (CASE-Cancer), which asks patients to reflect on how confident they are in their ability to understand and participate in their care; whether they can seek and obtain information; and maintain a positive attitude.



# Symptom severity and self-efficacy scores: NSW results

## Two specialised survey instruments to assess effectiveness of care

The Edmonton Symptom Assessment System (ESAS) is a tool for self-reporting of symptom intensity, initially developed for palliative care patients with cancer.<sup>10</sup> It consists of numerical rating scales for common symptoms of cancer and cancer treatment.<sup>9</sup> The ESAS system represents rating of respondents' nine common symptoms on a 10-point rating scale of severity (e.g. 'no pain' to 'worst possible pain').

The version of the tool used in the BHI and Cancer Institute NSW Outpatient Cancer Clinics Survey focused on how a respondent was feeling at the time of survey completion – approximately three months after their outpatient visit. Lower scores indicate better rating. Unsurprisingly, patients in active treatment had more pronounced symptoms than patients in non-active treatment (Figure 42).

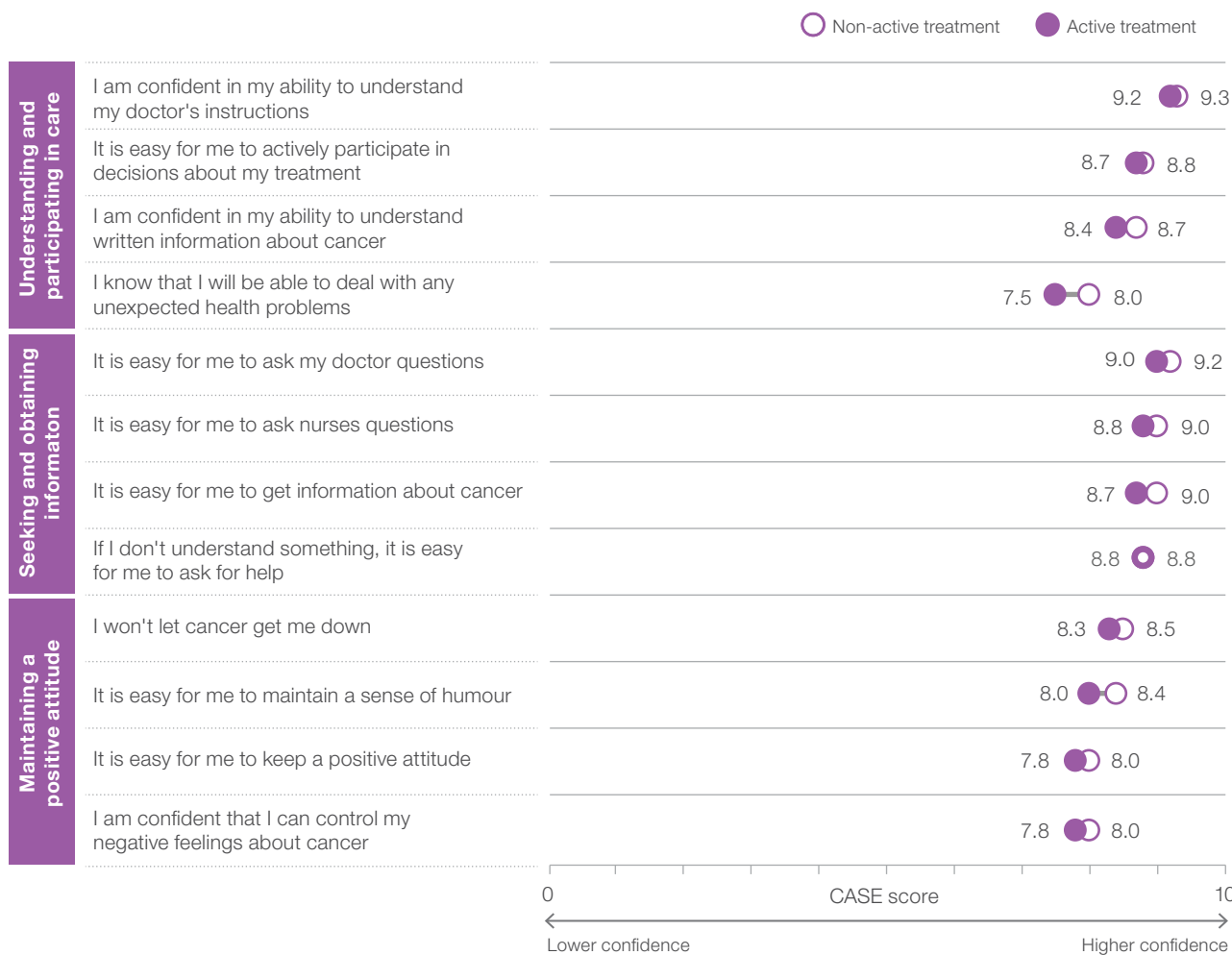
Figure 42 Symptom severity score at time of survey completion, patients with cancer in active and non-active treatment phase, NSW



The Communication and Attitudinal Self-Efficacy scale for cancer (CASE-Cancer) is a validated tool that assesses how well people with cancer can understand and participate in their care, how easily they can seek and obtain information and whether they can maintain a positive attitude.<sup>12</sup>

Higher scores indicate better rating. For most elements, patients in active treatment were slightly less positive than those in non-active treatment – this was most marked in patients’ confidence in their ability to deal with unexpected health problems and their ability to maintain a sense of humour (Figure 43).

Figure 43 CASE-Cancer score at time of survey completion, patients with cancer in active treatment and non-active treatment phase, NSW



# Symptom severity scores: LHD and hospital results

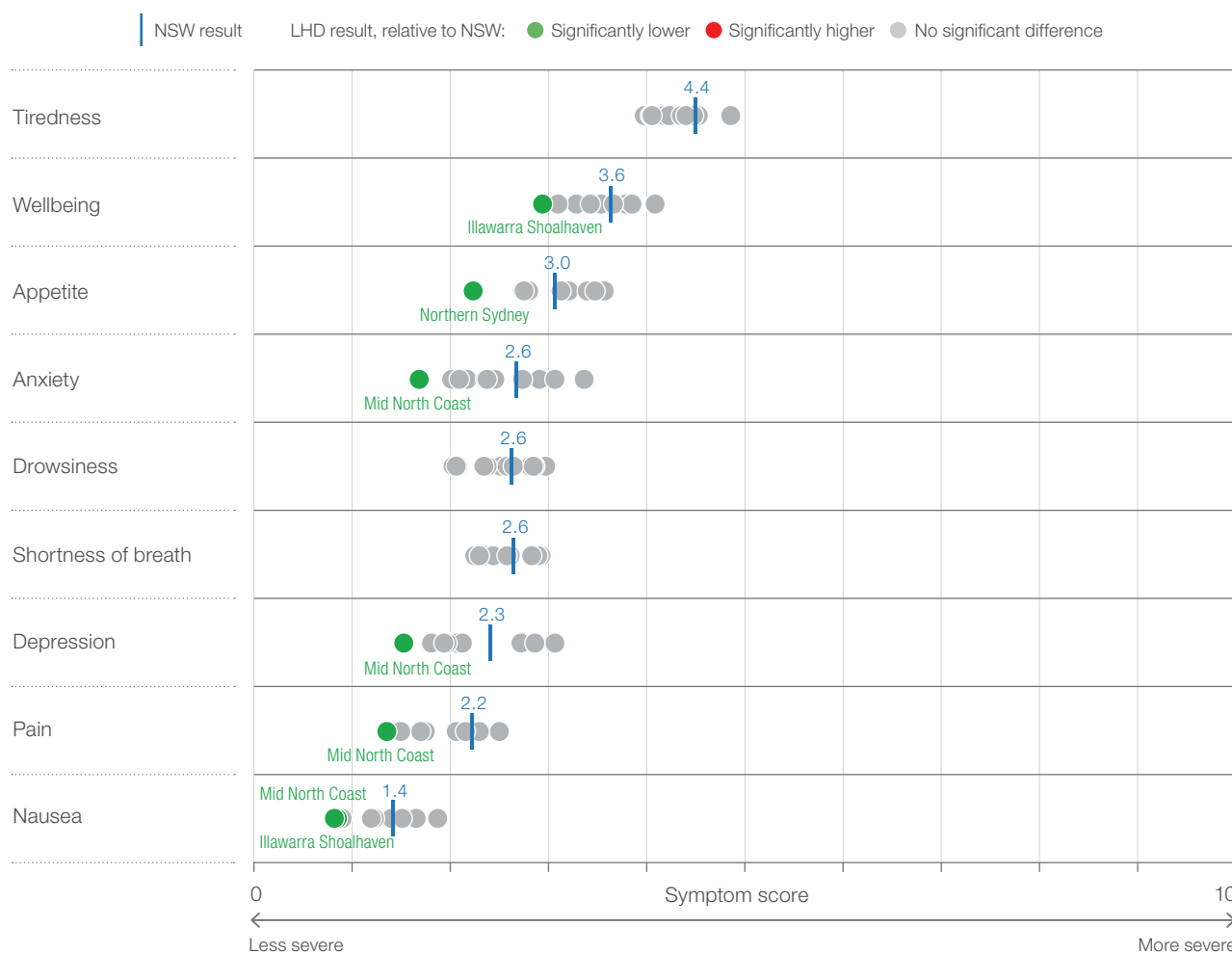
## Patient-reported symptom intensity score was highest for tiredness

Patients with cancer visiting outpatient clinics during their active treatment phase may experience physical and emotional symptoms that can impact their quality of life.<sup>26</sup>

Of the nine symptoms assessed, patients reported tiredness and poor general wellbeing to be the symptoms with the greatest intensity.

Across LHDs, symptom scores from patients in active treatment who visited a clinic in Mid North Coast were lower than the NSW result for anxiety, depression, pain and nausea. The widest variation in scores was seen in anxiety (Figure 44).

Figure 44 Symptom severity score at time of survey completion, patients in active treatment phase, LHD results relative to NSW



Notes: Western NSW is excluded from above analysis due to insufficient responses (<30). Scores are average values for each symptom.



At a hospital level, symptom assessment scores for patients in active treatment who visited Port Macquarie Hospital were lower than the NSW result for four of nine symptoms – anxiety, depression, pain and nausea. Symptoms or problems were rated to be more severe by patients who visited Chris O'Brien Lifehouse with regards to pain, depression, anxiety and feelings of wellbeing (Figure 45).

Figure 45 Symptom severity score at time of survey completion, patients in active treatment phase, hospital results relative to NSW

	Bankstown/Lidcombe	Blacktown	Campbelltown	Chris O'Brien Lifehouse*	Coffs Harbour	Concord	Gosford	Grafton	Lismore	Liverpool	Manly	Nepean	Port Macquarie	Royal North Shore	Shoalhaven	St Vincent's	Westmead	Wollongong	Wyong	NSW
Tiredness	5.0	4.8	4.0	5.2	4.2	4.2	4.3	4.8	4.3	4.4	4.0	4.5	3.7	4.1	3.6	4.2	4.2	4.1	4.8	4.4
Wellbeing	3.9	3.7	3.5	4.4	3.5	3.4	4.0	3.4	3.9	3.9	3.1	3.5	3.2	3.2	3.3	3.5	2.9	2.6	4.1	3.6
Appetite	3.1	4.1	3.1	3.7	2.7	2.8	3.4	3.8	3.3	3.1	2.2	3.1	2.7	2.2	3.0	3.4	2.4	2.5	3.2	3.0
Anxiety	3.3	2.8	1.9	3.8	1.9	2.6	2.7	2.2	2.4	3.4	1.9	2.1	1.3	2.0	2.3	2.4	2.2	1.8	3.2	2.6
Drowsiness	3.2	2.7	1.9	3.4	2.6	2.6	2.8	2.6	2.8	3.0	2.6	2.8	2.3	2.5	2.4	2.6	1.9	1.7	3.2	2.6
Shortness of breath	2.9	3.2	2.1	2.9	3.1	2.6	2.2	2.3	2.3	3.1	3.0	2.9	2.4	2.0	2.7	2.4	2.1	2.2	2.8	2.6
Depression	2.9	2.5	1.6	3.5	1.6	2.1	3.0	1.9	1.9	3.3	1.5	1.9	1.4	2.1	2.0	2.0	1.8	1.6	3.1	2.3
Pain	3.0	2.6	1.3	3.3	1.1	2.2	2.1	2.4	2.4	2.0	1.8	2.1	1.5	1.7	2.2	1.6	2.0	1.9	2.4	2.2
Nausea	1.8	2.4	1.1	2.1	0.8	1.1	1.3	1.5	1.4	2.2	0.9	1.6	0.8	1.4	1.3	1.5	0.5	0.4	2.0	1.4

Hospital result, relative to NSW: ■ Significantly less severe ■ Significantly more severe  
 No significant difference  Data suppressed (<30 responses)

Notes: Bathurst, Sydney/Sydney Eye, Dubbo, Orange, Prince of Wales, Royal Prince Alfred and St George are excluded from above analysis due to insufficient responses (<30). Scores are average values for each symptom.

\* Chris O'Brien Lifehouse is not a NSW Health facility but is contracted to provide services to some public hospital patients.

# Self-efficacy: Confidence in communicating and maintaining a positive attitude

## Patients were most confident in their ability to understand doctors' instructions

The Communication and Attitudinal Self-Efficacy scale for cancer (CASE-Cancer) asks patients to reflect on how confident they are in their ability to participate in their care; whether they can maintain a positive attitude; and their confidence in seeking, obtaining and understanding information.<sup>12</sup> CASE-Cancer has a four-option response scale: 'strongly disagree', 'slightly disagree', 'slightly agree' and 'strongly agree'.

Eight in ten patients in active treatment 'strongly agreed' that they were able to understand their doctor's instructions (79%); and that it was easy to ask questions of their doctor (79%) (Figure 46).

To compare results across LHDs and hospitals, the CASE-Cancer statements were aggregated into three themes and results translated into scores. Higher scores indicate better rating.

Figure 46 CASE-Cancer questions, patients in active treatment phase at time of survey completion, all response categories, NSW



Across LHDs, scores from patients who visited a clinic in Mid North Coast were significantly higher than the NSW result for two themes: seeking and obtaining information (9.4 out of 10) and understanding and participating in care (9.1 out of 10) (Figure 47).

At a hospital level, scores from patients who visited Coffs Harbour were significantly higher than the NSW

result for seeking and obtaining information (9.7 out of 10) and understanding and participating in care (9.3 out of 10).

In contrast, self-efficacy scores from patients visiting the Chris O'Brien Lifehouse were significantly lower than the NSW result for understanding and participating in care (7.6 out of 10) and maintaining a positive attitude (6.6 out of 10) (Figure 48).

Figure 47 Self-efficacy score at time of survey completion, patients in active treatment phase, LHD results relative to NSW

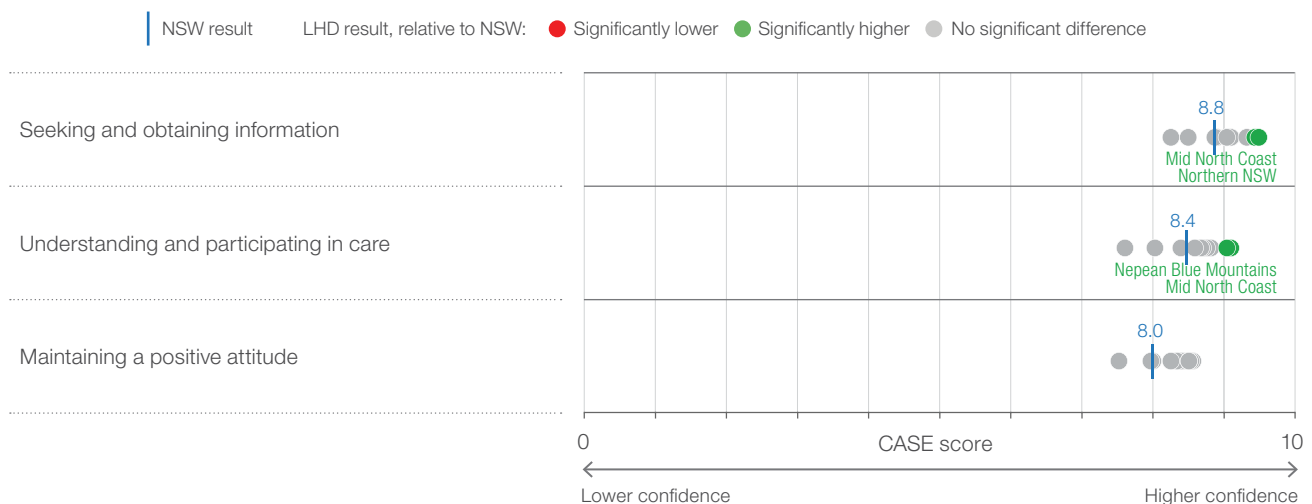


Figure 48 Self-efficacy score at time of survey completion, patients in active treatment phase, hospital results relative to NSW

	Bankstown/Lidcombe	Blacktown	Campbelltown	Chris O'Brien Lifehouse*	Coffs Harbour	Concord	Gosford	Grafton	Lismore	Liverpool	Manly	Nepean	Port Macquarie	Royal North Shore	Shoalhaven	St Vincent's	Westmead	Wollongong	Wyong	NSW	
Seeking and obtaining information	8.3	8.8	9.4	8.1	9.7	8.5	8.9	9.5	9.4	8.8	9.2	9.0	9.1	9.0	9.1	8.9	9.1	9.1	8.8	8.8	8.8
Understanding and participating in care	8.0	8.2	8.8	7.6	9.3	8.0	8.7		8.7	8.4	8.6	9.0	8.8	8.8	8.6	8.7	8.6	8.7	8.2	8.4	8.4
Maintaining a positive attitude	7.7	8.2	8.4	6.6	8.5	7.5	8.1	8.4	8.3	7.9	8.3	8.4	8.3	8.3	8.1	8.2	8.5	8.8	7.6	8.0	8.0

Hospital result, relative to NSW: ■ Significantly higher ■ Significantly lower ■ No significant difference  Data suppressed (<30 responses)

Note: Western NSW LHD, Bathurst, Sydney/Sydney Eye, Dubbo, Orange, Prince of Wales, Royal Prince Alfred and St George hospitals are excluded due to insufficient responses (<30). Results are generated by scoring the four response options and averaging the scores by theme.

\* Chris O'Brien Lifehouse is not a NSW Health facility but is contracted to provide services to some public hospital patients.

# Outcomes for patients in an active phase of treatment: Complications of care

## One in 10 patients in an active phase of their cancer treatment experienced a complication related to care at the clinic

Cancer treatment varies widely and is tailored to patients' age, health and stage of cancer. While all medical treatments have potential side effects or complications of care, the complexity and potency of cancer treatments can mean that patients are at heightened risk of complications.

Among patients who at the time of survey completion were in an active cancer treatment phase, 18% said they went to an emergency department in the preceding three months, because of their cancer or a cancer complication and 14% said they experienced a complication related to care received at the clinic (Figure 49).

While no LHD's results differed significantly from the NSW result for these questions, there were some outliers: 29% of patients in Illawarra Shoalhaven said they went to an emergency department because of cancer or cancer complications in the preceding three months; and 25% of patients in St Vincent's Health Network said their symptoms got worse while they were waiting for their appointment (Figure 49).

Among patients who did experience a complication, 18% said its impact was 'very serious' and a further 48% said it was 'fairly serious' (Figure 50).

Across hospitals, the proportion of patients who said their symptoms or condition deteriorated while waiting for their outpatient appointment ranged from 2% to 25% but differences did not reach statistical significance (Figure 51).

Type of complication	% of patients in active treatment phase
Any complication	14
Infection	4
Severe anxiety or worry	4
Other	4
Negative reaction to medication	3
Severe pain due to treatment	3
Complications from tests or procedures	2
Uncontrolled bleeding	0

Figure 49 Percentage of patients who said a complication occurred, patients in active treatment phase at time of survey completion, LHD results relative to NSW

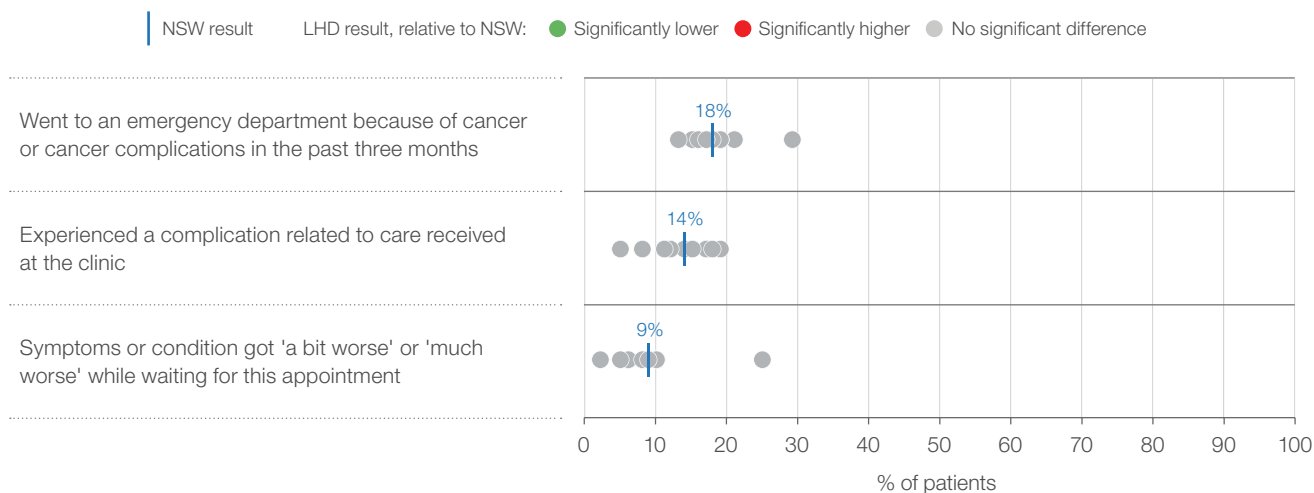


Figure 50 Percentage of patients reporting a complication and its impact, patients in active treatment phase at time of survey completion, NSW

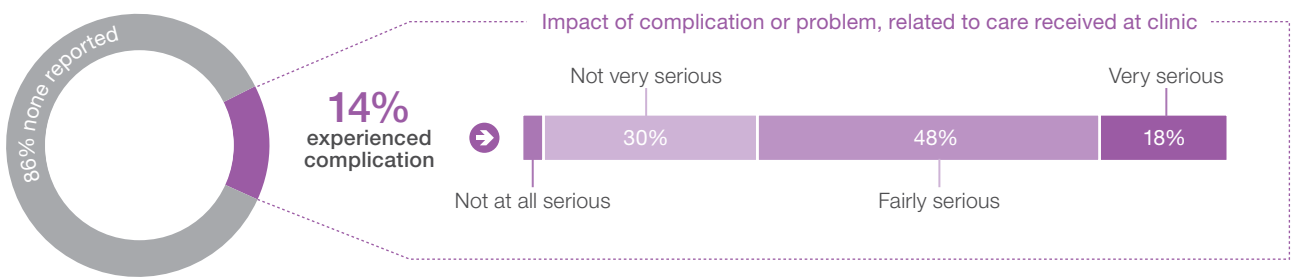
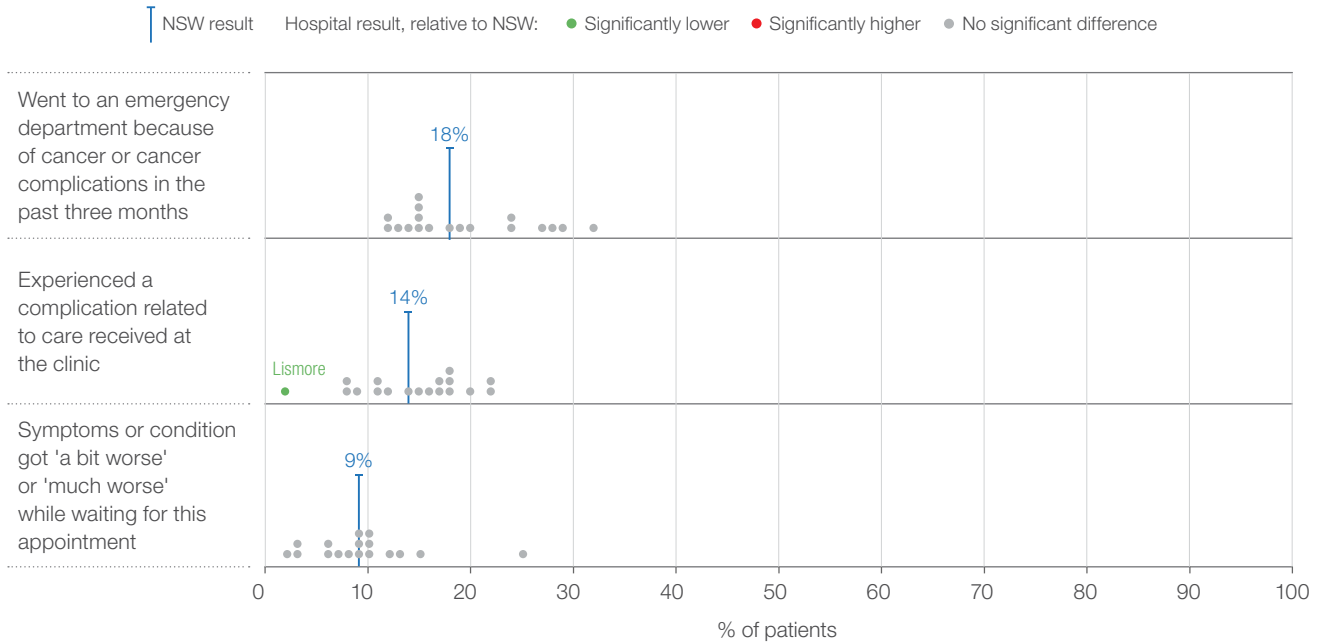


Figure 51 Percentage of patients who said a complication occurred, patients in active treatment phase at time of survey completion, hospital results relative to NSW





# Appendices

## Appendix 1: Sampling and response rates

Local health district	Respondents	Response rate
Central Coast	292	63.2%
Illawarra Shoalhaven	412	63.9%
Mid North Coast	416	68.3%
Nepean Blue Mountains	204	61.6%
Northern NSW	220	59.8%
Northern Sydney	331	58.9%
South Eastern Sydney	300	49.8%
St Vincent's Health Network	158	50.5%
South Western Sydney	494	51.8%
Sydney	222	51.4%
Western NSW	151	65.7%
Western Sydney	330	52.7%

Local health district	Facility name	Respondents	Response rate
Central Coast	Gosford Hospital	163	61.3%
	Wyong Hospital	129	65.8%
Illawarra Shoalhaven	Shoalhaven District Memorial Hospital	210	66.5%
	Wollongong Hospital	202	61.4%
Mid North Coast	Coffs Harbour Base Hospital	221	68.2%
	Port Macquarie Base Hospital	195	68.4%
Nepean Blue Mountains	Nepean Hospital	204	61.6%
Northern NSW	Grafton Base Hospital	104	65.0%
	Lismore Base Hospital	116	55.8%
Northern Sydney	Manly District Hospital	137	58.3%
	Royal North Shore Hospital	194	59.3%
South Eastern Sydney	Prince of Wales Hospital	175	52.6%
	St George Hospital	82	65.1%
	Sydney/Sydney Eye Hospital	43	30.1%
St Vincent's Health Network	St Vincent's Hospital, Darlinghurst	158	50.5%
	Bankstown/Lidcombe Hospital	141	46.8%
South Western Sydney	Campbelltown Hospital	195	60.6%
	Liverpool Hospital	158	47.9%
	Concord Hospital	158	58.1%
Sydney	Royal Prince Alfred Hospital	64	40.0%
	Bathurst Base Hospital	21	58.3%
Western NSW	Dubbo Base Hospital	25	58.1%
	Orange Health Service	105	69.5%
Western Sydney	Blacktown Hospital	145	50.2%
	Westmead Hospital	185	54.9%
N/A	Chris O'Brien Lifehouse*	176	52.7%
<b>NSW</b>		<b>3706</b>	<b>57.3%</b>

\* Chris O'Brien Lifehouse is not a NSW Health facility but is contracted to provide services to some public hospital patients.

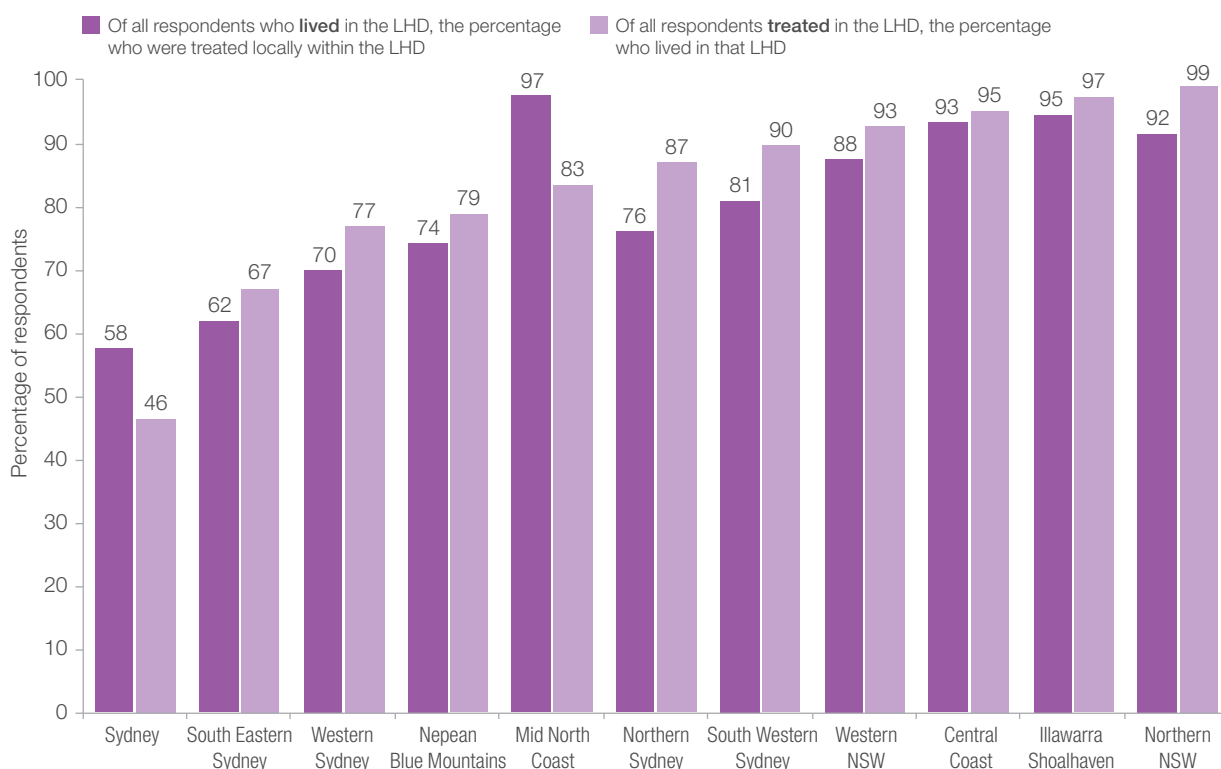


Most patients attending an outpatient cancer clinic receive care within their LHD of residence. However, some patients travel to other LHDs for care.

The proportion of survey respondents who visited a clinic in their LHD of residence varied across the state from 58% in Sydney LHD to 97% in Mid North Coast.

Among the respondents who visited a clinic in each LHD, the proportion who were 'local' or from that LHD ranged from 46% in Sydney LHD to 99% in Northern NSW (Figure 52).

Figure 52 Percentage of respondents treated in LHD of residence, by LHD



Notes: Postcodes were designated to LHDs on the basis of information from the NSW Ministry of Health. Chris O'Brien Lifehouse and St Vincent's Hospital Network are not geographically based and are excluded.

## Appendix 2: Purpose of visit, cancer attendance and treatment phase (unweighted)

Three survey questions were used to characterise outpatient cancer clinic visits:

- **Question 1:** What was the purpose of this visit?
- **Question 58:** Did you attend this clinic because you have had cancer?
- **Question 60:** How has your current cancer responded to treatment?

Responses to questions 1 and 60 were grouped for the purposes of analysis into:

### Question 1

1. Chemotherapy, radiotherapy and/or a surgical procedure
2. Regular check-up, treatment review, medical diagnosis or advice, had tests, x-rays or scans (or received results of tests), surgery follow-up, other

### Question 60

3. Active treatment phase
  - In the course of treatment and can't say how cancer has responded
  - Cancer is being treated again as did not respond fully to treatment
4. Not in active treatment phase
  - Treatment was effective, no cancer signs or symptoms
  - On 'watch and wait'
  - Finished treatment, cancer still present
  - Treatment not started
  - Cancer not treated at all

Unweighted data for responses by LHD and hospital are tabulated below. Note that throughout the report data are weighted and so figures differ slightly from those shown here.

Local health district	Received chemotherapy, radiotherapy or surgical procedure	Attended clinic for cancer	Active treatment phase
Central Coast	53%	96%	34%
Illawarra Shoalhaven	40%	91%	24%
Mid North Coast	43%	92%	27%
Nepean Blue Mountains	35%	82%	26%
Northern NSW	46%	88%	37%
Northern Sydney	32%	94%	24%
South Eastern Sydney	33%	78%	14%
St Vincent's Health Network	45%	95%	34%
South Western Sydney	35%	95%	28%
Sydney	29%	80%	31%
Western NSW	62%	97%	19%
Western Sydney	38%	84%	29%
<b>NSW</b>	<b>39%</b>	<b>90%</b>	<b>27%</b>

Facility name	Received chemotherapy, radiotherapy or surgical procedure	Attended clinic for cancer	Active treatment phase
Gosford Hospital	49%	96%	29%
Wyong Hospital	57%	95%	40%
Shoalhaven District Memorial Hospital	30%	87%	22%
Wollongong Hospital	50%	96%	26%
Coffs Harbour Base Hospital	38%	90%	25%
Port Macquarie Base Hospital	49%	94%	30%
Nepean Hospital	35%	82%	26%
Grafton Base Hospital	39%	85%	30%
Lismore Base Hospital	53%	91%	43%
Manly District Hospital	25%	94%	26%
Royal North Shore Hospital	37%	94%	23%
Prince of Wales Hospital	31%	87%	16%
St George Hospital	46%	93%	17%
Sydney/Sydney Eye Hospital	14%	14%	0%
St Vincent's Hospital, Darlinghurst	45%	95%	34%
Bankstown/Lidcombe Hospital	28%	92%	33%
Campbelltown Hospital	34%	97%	23%
Liverpool Hospital	42%	94%	28%
Concord Hospital	33%	92%	37%
Royal Prince Alfred Hospital	20%	50%	16%
Bathurst Base Hospital	38%	95%	10%
Dubbo Base Hospital	20%	96%	28%
Orange Health Service Hospital	76%	97%	19%
Blacktown Hospital	44%	75%	34%
Westmead Hospital	32%	91%	25%
Chris O'Brien Lifehouse*	34%	91%	27%

\* Chris O'Brien Lifehouse is not a NSW Health facility but is contracted to provide services to some public hospital patients.

# Appendix 3: Questions used in the analyses

✓ included in denominator    × not included in denominator    response category used in measure

	Original question	Reported measure	Response options in questionnaire	
Overall experience of care	Overall, how would you rate the care you received in the clinic?	Overall, care was rated as 'very good'	<input checked="" type="checkbox"/> Very good <input checked="" type="checkbox"/> Good <input checked="" type="checkbox"/> Neither good nor poor	<input checked="" type="checkbox"/> Poor <input checked="" type="checkbox"/> Very poor
	If asked about your clinic experience by friends and family, how would you respond?	Would 'speak highly' of the clinic to friends and family	<input checked="" type="checkbox"/> I would speak highly of the clinic <input checked="" type="checkbox"/> I would neither speak highly nor be critical	<input checked="" type="checkbox"/> I would be critical of the clinic
	Overall, how would you rate the health professionals who treated you?	Overall, health professionals were rated as 'very good'	<input checked="" type="checkbox"/> Very good <input checked="" type="checkbox"/> Good <input checked="" type="checkbox"/> Neither good nor poor	<input checked="" type="checkbox"/> Poor <input checked="" type="checkbox"/> Very poor
	How well organised was the care you received in the clinic?	Care was 'very well organised'	<input checked="" type="checkbox"/> Very well organised <input checked="" type="checkbox"/> Fairly well organised	<input checked="" type="checkbox"/> Not well organised
Access and timeliness before the visit	Were you able to get an appointment time that suited you?	Able to get an appointment time that suited them	<input checked="" type="checkbox"/> Yes <input checked="" type="checkbox"/> No	<input checked="" type="checkbox"/> I didn't have an appointment arranged in advance
	Do you think the amount of time you waited [from booking this appointment to the time you went to the clinic] was...?	Time waited for appointment was 'about right'	<input checked="" type="checkbox"/> About right <input checked="" type="checkbox"/> Slightly too long	<input checked="" type="checkbox"/> Much too long <input checked="" type="checkbox"/> Don't know/can't remember
	How long did it take you to travel to the clinic for this appointment?	Travelled 'less than 30 minutes' to get to the clinic	<input checked="" type="checkbox"/> Less than 30 minutes <input checked="" type="checkbox"/> 30 to 59 minutes <input checked="" type="checkbox"/> 1 hour to under 2 hours	<input checked="" type="checkbox"/> 2 hours to under 3 hours <input checked="" type="checkbox"/> 3 hours or more <input checked="" type="checkbox"/> Don't know/can't remember
	Did you have to pay any of the following out of pocket expenses in relation to this visit?*	Had no out-of-pocket expenses in relation to visit	<input checked="" type="checkbox"/> None reported <input checked="" type="checkbox"/> Had out-of-pocket costs	
Access and timeliness during the visit	How long after the scheduled appointment time did your appointment actually start?	Appointment started 'within 30 minutes' of scheduled time	<input checked="" type="checkbox"/> On time, or early <input checked="" type="checkbox"/> Less than 15 minutes <input checked="" type="checkbox"/> 15 to 29 minutes <input checked="" type="checkbox"/> 30 to 59 minutes	<input checked="" type="checkbox"/> 1 hour to under 2 hours <input checked="" type="checkbox"/> 2 hours or more <input checked="" type="checkbox"/> I didn't have an appointment <input checked="" type="checkbox"/> Don't know/can't remember
	Were you told why you had to wait [for appointment to start]?	Told reason for wait (for appointment to start)	<input checked="" type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
	Were you told how long you had to wait [for appointment to start]?	Told how long to wait (for appointment to start)	<input checked="" type="checkbox"/> Yes <input checked="" type="checkbox"/> No	
Physical environment and comfort	Did any of the following cause you difficulties when entering and moving around the clinic?*	'No difficulties' entering and moving around the clinic	<input checked="" type="checkbox"/> None reported <input checked="" type="checkbox"/> Had difficulties	
	At the hospital, was it easy to find your way to the clinic?	'Definitely' easy to find way to the clinic	<input checked="" type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	<input checked="" type="checkbox"/> No
	How comfortable was the waiting area?	Waiting area was 'very comfortable'	<input checked="" type="checkbox"/> Very comfortable <input checked="" type="checkbox"/> Fairly comfortable	<input checked="" type="checkbox"/> Not very comfortable <input checked="" type="checkbox"/> Not at all comfortable
	Was there a problem finding parking near the clinic?	'No problem' finding parking near the clinic	<input checked="" type="checkbox"/> Yes, a big problem <input checked="" type="checkbox"/> Yes, a small problem	<input checked="" type="checkbox"/> No problem <input checked="" type="checkbox"/> I did not need parking
Addressing patient concerns	Did you have enough time to discuss your health issue with the health professionals you saw?	'Definitely' had enough time to discuss health issues with health professionals	<input checked="" type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	<input checked="" type="checkbox"/> No
	Did you have confidence and trust in the health professionals?	'Definitely' had confidence and trust in health professionals	<input checked="" type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	<input checked="" type="checkbox"/> No
	Did a health professional discuss your worries or fears with you?	Health professional 'completely' discussed worries or fears	<input checked="" type="checkbox"/> Yes, completely <input checked="" type="checkbox"/> Yes, to some extent	<input checked="" type="checkbox"/> No
	While in the clinic, did you receive or see any information about how to comment or complain about your case?	While in the clinic, received or saw information about how to comment or complain	<input checked="" type="checkbox"/> Yes <input checked="" type="checkbox"/> No	<input checked="" type="checkbox"/> Don't know/can't remember
Respect and dignity	Were your cultural or religious beliefs respected by the clinic staff?	Cultural or religious beliefs were 'always' respected	<input checked="" type="checkbox"/> Yes, always <input checked="" type="checkbox"/> Yes, sometimes	<input checked="" type="checkbox"/> No, my beliefs were not respected <input checked="" type="checkbox"/> My beliefs were not an issue
	Were you treated with respect and dignity while you were at the clinic?	'Always' treated with respect and dignity	<input checked="" type="checkbox"/> Yes, always <input checked="" type="checkbox"/> Yes, sometimes	<input checked="" type="checkbox"/> No
	Were the health professionals kind and caring towards you?	Health professionals were 'always' kind and caring	<input checked="" type="checkbox"/> Yes, always <input checked="" type="checkbox"/> Yes, sometimes	<input checked="" type="checkbox"/> No

\* Multiple response options could be selected for this question. Missing responses and response option 'None of these/None' were included under 'None reported'.

✓ included in denominator    × not included in denominator    response category used in measure

	Original question	Reported measure	Response options in questionnaire	
Respect and dignity	Were you given enough privacy when being examined or treated?	'Definitely' given enough privacy when being examined or treated	<input type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	✓ No
	Were you given enough privacy when discussing your condition or treatment?	'Definitely' given enough privacy when discussing condition or treatment	<input type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	✓ No
	Were the reception staff polite and courteous?	Reception staff were 'definitely' polite and courteous	<input type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	✓ No
Information to support	Did a health professional at the clinic explain the purpose of this [new] medication in a way you could understand?	Health professional 'completely' explained purpose of new medication	<input type="checkbox"/> Yes, completely <input checked="" type="checkbox"/> Yes, to some extent	✓ No
	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?	Told who to contact if worried about condition or treatment after leaving the clinic	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	× I did not need this type of information × Don't know/can't remember
	Did the health professionals explain things in a way you could understand?	Health professionals 'always' explained things in an understandable way	<input type="checkbox"/> Yes, always <input checked="" type="checkbox"/> Yes, sometimes	✓ No
	Did a health professional at the clinic tell you about medication side effects to watch for?	'Completely' informed about medication side effects to watch for	<input type="checkbox"/> Yes, completely <input checked="" type="checkbox"/> Yes, to some extent	✓ No
	Were you given enough information about how to manage the side effects of any other treatment you received during this visit?	'Completely' informed about any other treatment side effects to watch for	<input type="checkbox"/> Yes, completely <input checked="" type="checkbox"/> Yes, to some extent	✓ No × I did not need this type of information
Shared decision-making	Do you have a care plan for your cancer treatment? [for those who said they needed a care plan]	Had care plan in place for cancer treatment	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	× I did not need one × Don't know/can't remember
	At your most recent visit, did the health professionals review your care plan with you?	Health professionals reviewed cancer care plan at most recent visit [for those who had a care plan]	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	× Not applicable as I did not have a care plan before this visit × Don't know/can't remember
	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	'Definitely' involved in decisions about care and treatment	<input type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	✓ No × I did not want or need to be involved
	Were you asked for your ideas and preferences when developing this [cancer care] plan?	'Definitely' asked for ideas and preferences when developing cancer care plan	<input type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	✓ No × Don't know/can't remember
Coordination and continuity	Did you ever receive conflicting information about your condition or treatment from the health professionals? [in last 12 months]	Did not receive conflicting information from health professionals	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	× Not applicable - I was always treated by the same person
	Was there any time when the health professionals needed access to your health records and they were not available? [in last 12 months]	Health professionals were able to access patient's health records when needed	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	✓ Don't know/can't remember
	During this visit, did the health professionals know enough about your medical history?	Health professionals 'definitely' knew enough about patient's medical history	<input type="checkbox"/> Yes, definitely <input checked="" type="checkbox"/> Yes, to some extent	✓ No
	How would you rate how well the health professionals worked together?	Health professionals worked together in a 'very good' way	<input type="checkbox"/> Very good <input checked="" type="checkbox"/> Good <input type="checkbox"/> Neither good nor poor	✓ Poor ✓ Very poor × Not applicable – only saw one
Hygiene and cleanliness	How clean was the clinic?	Clinic was 'very clean'	<input type="checkbox"/> Very clean <input checked="" type="checkbox"/> Fairly clean	✓ Not very clean ✓ Not at all clean
	Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?	'Always' saw health professionals wash their hands	<input type="checkbox"/> Yes, always <input checked="" type="checkbox"/> Yes, sometimes <input type="checkbox"/> No, I did not see this	× Not applicable to my visit ✓ Can't remember
Complications	In the past three months, have you gone to an emergency department because of your cancer or cancer complications?	Did not go to an emergency department because of cancer or cancer complications in the past three months	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	× Don't know/can't remember
	During your visit or soon afterwards, did you experience any of the following complications or problems related to the care you received at the clinic?*	Did not experience any complication related to care received at the clinic	<input type="checkbox"/> None reported	✓ Had complication or problem

\* Multiple response options could be selected for this question. Missing responses and response option 'None of these/None' were included under 'None reported'.

# Appendix 4: Sydney LHD and Chris O'Brien Lifehouse

The Chris O'Brien Lifehouse (Lifehouse) is an integrated cancer hospital that offers public and private patients, their families and carers, access to a full range of outpatient services. Although the Lifehouse is not a NSW health facility, it was included in the survey to provide a more complete picture of provision of outpatient cancer clinic services in NSW.

A review of the source of funding of patients, found 34% of Lifehouse patients were funded by services contracted by LHDs and another 65% were funded by the Medicare Benefits Schedule (MBS). Of those patients who were funded through services contracted by LHDs, 63% (38 patients) had Sydney

LHD as their LHD of residence, while 37% (22 patients) were from outside of Sydney LHD (Figure 53). The inclusion or exclusion of Lifehouse from Sydney LHD changes results for that LHD (Figure 54).

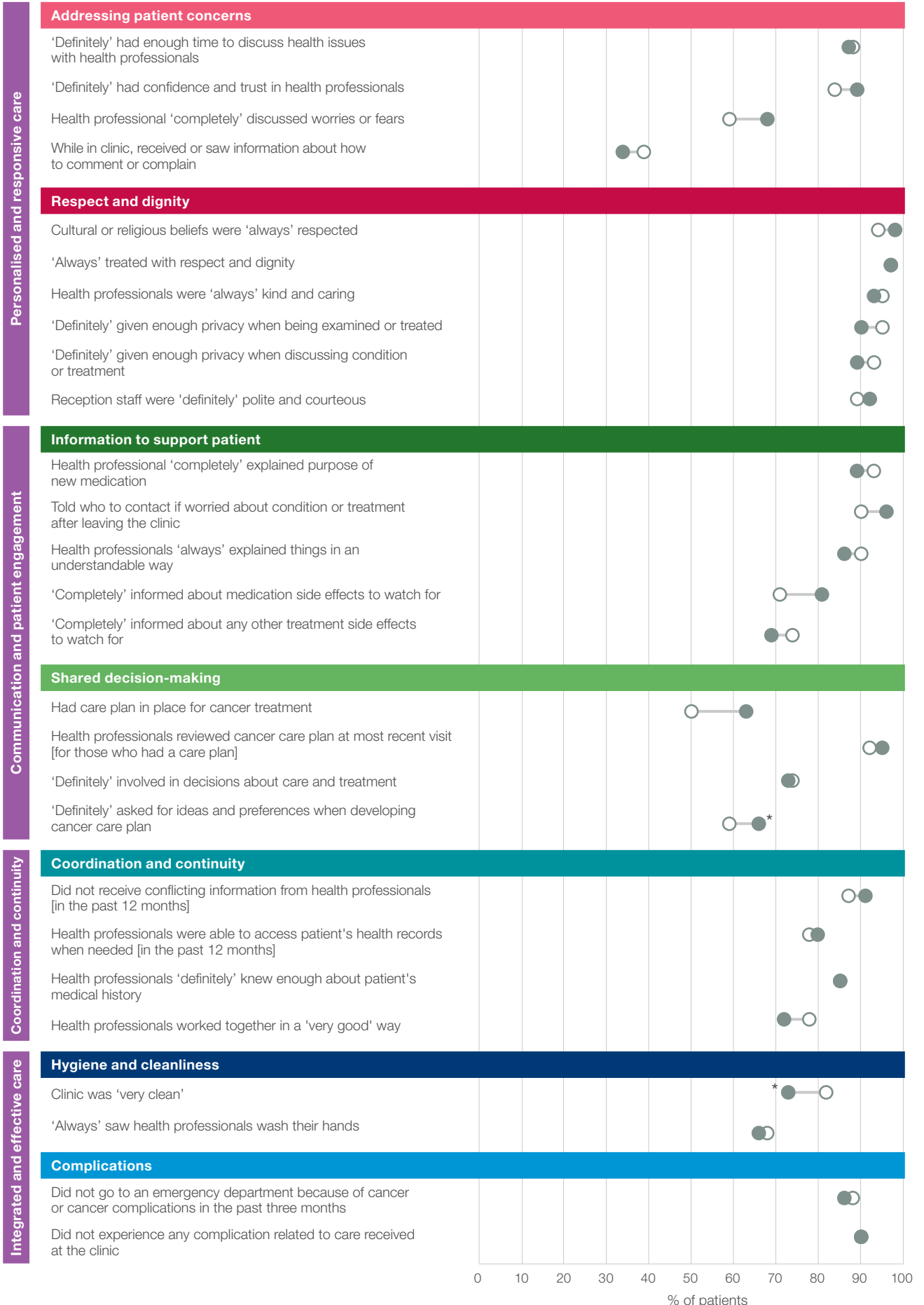
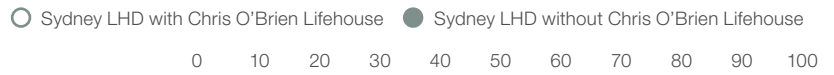
Figure 53 Chris O'Brien Lifehouse patients by LHD of residence and funding source

LHD of residence	LHD-funded	MBS-funded	Other
Sydney LHD	38	70	1
Outside Sydney LHD	22	45	0
<b>Total</b>	<b>60</b>	<b>115</b>	<b>1</b>

Figure 54 Aspects of care, percentage of patients who selected the most positive response category, Sydney LHD with and without Chris O'Brien Lifehouse



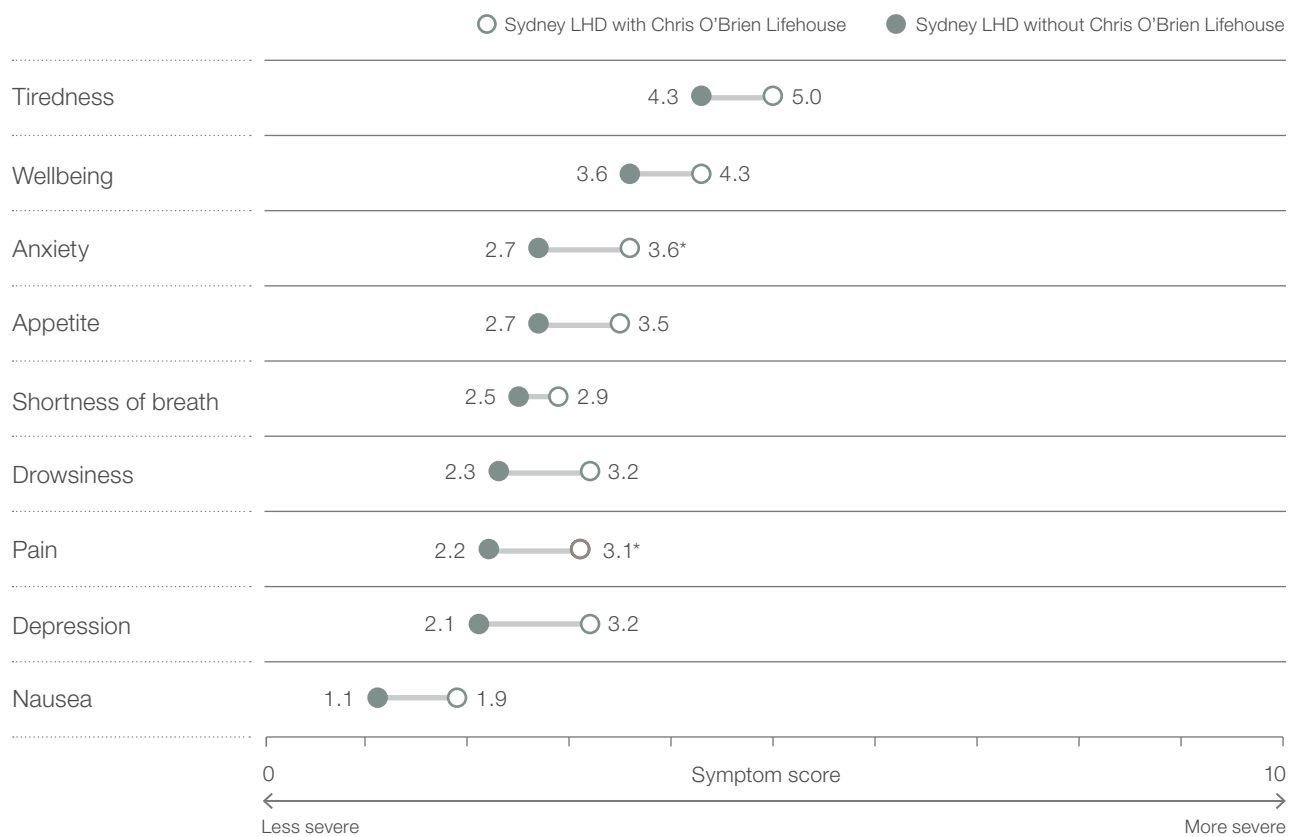
\* Significantly different to NSW result.



\* Significantly different to NSW result.

Results for ESAS and CASE-Cancer scores were more favourable for Sydney LHD when Lifehouse was excluded (Figure 55 and 56)

Figure 55 ESAS score at time of survey completion for patients in active treatment, results for Sydney LHD with and without Chris O'Brien Lifehouse



\* Significantly different to NSW result.



Figure 56 CASE-Cancer score at time of survey completion for patients in active treatment, results for Sydney LHD with and without Chris O'Brien Lifehouse, relative to NSW result



\* Significantly different to NSW result.

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## About the Bureau of Health Information

The Bureau of Health Information (BHI) is a board-governed organisation that provides independent information about the performance of the NSW public healthcare system.

BHI was established in 2009 to provide system-wide support through transparent reporting.

BHI supports the accountability of the healthcare system by providing regular and detailed information to the community, government and healthcare professionals. This in turn supports quality improvement by highlighting how well the healthcare system is functioning and where there are opportunities to improve.

BHI manages the NSW Patient Survey Program, gathering information from patients about their experiences in public hospitals and other healthcare facilities.

BHI publishes a range of reports and tools that provide relevant, accurate and impartial information about how the health system is measuring up in terms of:

- Accessibility – healthcare when and where needed
- Appropriateness – the right healthcare, the right way
- Effectiveness – making a difference for patients
- Efficiency – value for money
- Equity – health for all, healthcare that's fair
- Sustainability – caring for the future.

BHI's work relies on the efforts of a wide range of healthcare, data and policy experts. All of our assessment efforts leverage the work of hospital coders, analysts, technicians and healthcare providers who gather, codify and report data. Our public reporting of performance information is enabled and enhanced by the infrastructure, expertise and stewardship provided by colleagues from NSW Health and its pillar organisations.

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