

# Technical Supplement: Outpatient Cancer Clinics Survey 2016

May 2018

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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.

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# NSW Patient Survey Program

The NSW Patient Survey Program began sampling patients in NSW public facilities from 2007. Up to mid-2012, the program was coordinated by the NSW Ministry of Health (Ministry) using questionnaires obtained under license from NRC Picker. Ipsos Social Research Institute (Ipsos) was contracted to manage the logistics of the survey program. Responsibility for the NSW Patient Survey Program was transferred from the Ministry to the Bureau of Health Information (BHI) in July 2012, with Ipsos continuing as the contracted partner to manage logistics.

The aim of the program is to measure and report on patients' experiences of care in public healthcare facilities in New South Wales (NSW), on behalf of the Ministry and the local health districts (LHDs). The results are used as a source of performance measurement for individual hospitals, LHDs and NSW as a whole.

This document outlines the sampling methodology, data management and analysis of the 2016 Outpatient Cancer Clinics Survey (COPS).

For more information on how to interpret results and statistical analysis of differences between facilities and NSW, please refer to the *Guide to Interpreting Differences* on BHI's website at [bhi.nsw.gov.au/nsw\\_patient\\_survey\\_program](http://bhi.nsw.gov.au/nsw_patient_survey_program)

# Outpatient Cancer Clinics Survey

In 2016, the Outpatient Cancer Clinics Survey (COPS) was run as part of the revised NSW Patient Survey Program administered by BHI. The survey was designed in collaboration with Cancer Institute NSW.

This is the fourth time a survey of outpatients has been conducted as part of the NSW Patient Survey Program since responsibility for the program moved to BHI. In 2014, the Outpatient Survey sampled across a broad range of outpatient services, including allied health, orthopaedics, medical, and oncology. In 2016, the survey focused on the experiences of patients attending outpatient services provided by cancer clinics.

## **Definition of an 'outpatient'**

Outpatients are those patients whose care is provided by a hospital but are not admitted for care. The types of services these patients receive vary greatly and include allied health services (such as physiotherapy, social work, nutrition and psychology), dental care, dialysis, cancer treatment, medical services and surgery preparations and follow-up. The way these services are provided varies widely, with the most common being in a regular clinic operated by medical staff.

In this survey, outpatient clinics defined as oncology, chemotherapy and radiotherapy were included. Whilst not all patients attending these cancer clinics actually have or have had cancer (for example, lupus patients are treated in chemotherapy outpatient clinics with cytotoxins), the majority (87% of patients) were being treated or receiving follow-up services for cancer care.

## Producing the survey samples

The survey program assures patients that their responses will be confidential and that staff at hospitals will not be able to identify individual patients. BHI does this through a number of mechanisms, including:

- data suppression (of results based on fewer than 30 respondents)
- reporting aggregated results
- de-identification of patient comments
- segregation of roles when constructing survey samples (see below).

The sampling method for the NSW Patient Survey Program requires collaboration between staff at BHI, Ipsos and the Ministry's System Information and Analytics (SIA) branch (see Figure 1). All surveys of outpatients use data obtained from the Ministry's WebNAP database.

Figure 1 Organisational responsibilities in sampling and survey processing, COPS 2016

<b>BHI</b>	<ul style="list-style-type: none"> <li>• Determine inclusion and exclusion rules in association with stakeholders</li> </ul>
<b>SIA</b>	<ul style="list-style-type: none"> <li>• Extract sampling frame from WebNAP (data combined for February and March 2016, exclude on basis of criteria provided by BHI, add address details)</li> <li>• Provide a summary dataset to BHI</li> </ul>
<b>BHI</b>	<ul style="list-style-type: none"> <li>• Develop sampling strategy including strata and included facilities based on summary dataset provided by SIA</li> <li>• Calculate target sample sizes and provide to SIA</li> </ul>
<b>SIA</b>	<ul style="list-style-type: none"> <li>• Generate samples based on sampling targets provided by BHI</li> <li>• Provide mailing list via secure file transfer to Ipsos</li> </ul>
<b>Ipsos</b>	<ul style="list-style-type: none"> <li>• Administer the survey fieldwork, collate and clean results</li> <li>• Provide datafile of results to BHI for analysis, via secure file transfer, once all name and address information is removed</li> </ul>

## Drawing the sample

The sampling frame for COPS 2016 was the NSW non-admitted patient database. As BHI does not have access to confidential non-admitted patient data, sample sizes for each hospital were calculated based on aggregated clinic-level data provided by SIA.

For COPS 2016, the sampling frames were defined as attendees at NSW outpatient cancer clinics during November 2016, with the date of attendance used to define eligible records.

## Definition of NSW outpatient cancer clinics

Outpatient cancer clinics eligible for the survey were identified in the non-admitted patient extract provided by SIA. Clinics were defined using a two-step process:

1. All clinics defined as belonging to one of the six cancer clinic types as presented in Table 1
2. Addition of extra clinics identified as having 'cancer', 'oncol\*', 'radiation', 'radioth\*', 'chemo\*' and 'melanoma' in the clinic name AND approved for inclusion by the Director of Cancer Services (or equivalent) for each LHD (see "Other" column in Table 6).

Table 1 Tier 2 services included for sampling and reporting, COPS 2016

Tier 1 name	Tier 2 code	Tier 2 name	Reporting
Chemotherapy	10.11	Medical oncology (treatment)	Chemotherapy
Oncology	10.12	Radiation oncology (treatment)	Radiotherapy
Oncology	10.20	Radiation therapy – simulation and planning	Radiotherapy
Oncology	20.42	Medical oncology (consultation)	Oncology
Oncology	20.43	Radiation oncology (consultation)	Radiotherapy
Oncology	40.52	Oncology	Oncology

## Specifying inclusions and exclusions

BHI specified the following inclusion and exclusion criteria to SIA, who undertook the sampling for this survey.

### Inclusions

- Persons aged 18+ years who visited a NSW public hospital outpatient cancer service
- Random sample of patients who received care from an outpatient service in November 2016
- Outpatients in hospitals within the A1 to C2 peer groups (using 2011 peer group definitions)
- Patient allocated to one of the Tier 2 groups specified in Table 1.

### Exclusions

- All occasions of service where the location of care is away from the hospital (off-site)
- Facilities that did not provide patient-level data (refer to 'WebNAP data limitations' section on the previous page)
- Persons aged 0–17 years
- Patients with subsequent death notifications

- Sydney Children’s Hospital, Randwick and The Children’s Hospital at Westmead
- Facilities with peer group lower than C2
- Facilities with fewer than 100 cancer outpatients.

Where patients had multiple visits within the sampling month, they were included for their most recent visit. The questionnaire asks patients to respond to the survey based on their most recent visit.

### Screening

SIA extracted the sampling frame on the basis of the inclusion and exclusion criteria provided by BHI, including patient name and address information. The data are passed through additional checks as presented below.

### Exclusions

- Invalid address (including those with addresses listed as hotels, motels, nursing homes, Community Services, Matthew Talbot hostel, 100 William Street, army quarters, jails, unknown)
- Invalid name (including twin, baby of)
- Invalid date of birth
- On the ‘do not contact’ list
- Sampled in the previous six months for any BHI patient survey
- Had a death recorded according to the NSW Birth Deaths and Marriages Registry and/or the Agency Performance and Data Collection, prior to the sample being provided to Ipsos.

The data following these exclusions is defined by BHI as the final sampling frame.

A summary of the sampling frame was provided to BHI in order to determine sample sizes. These sample sizes were split proportionately across Tier 2 clinic types within each hospital as described below.

The targets were provided to SIA, who then sampled from the patient-level data and provided the required fields to Ipsos for mailing.



## Sample size determination

Sample size was calculated at the hospital level.

The hospital targets were based on the aggregated WebNAP outpatient data from November 2016.

The required sample size for each hospital (i) was estimated using Equation 1.

### Equation 1

$$s_i = \frac{\chi^2 N_i P(1 - P)}{d^2(N_i - 1) + \chi^2 P(1 - P)}$$

Where:

$s_i$  = estimated sample size for hospital  $i$

$\chi^2$  = tabulated value of chi-squared with one degree of freedom at 5% level of significance (3.841)

$N_i$  = population in hospital  $i$ , as reported in the data provided to BHI from WebNAP

$P$  = expected proportion giving the most positive response to the question on satisfaction with overall care (0.8), based on previous levels of response to patient surveys

$d$  = degree of accuracy of the 95% confidence interval expressed as a proportion ( $\pm 0.07$ ).

The sample size calculation aimed for a confidence interval around an expected proportion of 0.8 of  $\pm 0.07$  at the hospital level.

The required number of mailings at the hospital level is obtained by multiplying the sample size by the inverse of the expected response rate of 30%.

Within each hospital, the sample was stratified by Tier 2 clinic type proportional to the population sizes. Therefore target sample sizes were provided to SIA by Tier 2 clinic type within each hospital. Within the Tier 2 clinic type, patients were sampled using simple random sampling without replacement.

A list of the 51 sampled facilities and the total number of cancer outpatients eligible for sampling versus outpatients sampled for the survey for 2016 is provided in Appendix 1.

With regards to these calculations:

- The sample size calculation assumes simple random sampling. This, and differences in the response rate between strata, may result in some estimates having wider confidence intervals than expected, even when the prevalence is 80%.
- The scope of the survey specified only patients aged 18+ years would be included and that the Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead would be excluded.

# Data management

## Data collection

Upon completion of a hard copy or online survey, the respondent returns or submits the completed survey to Ipsos. Paper format surveys are scanned for fixed response options and manually entered in the case of free text fields

Once all of the data are collated into a single dataset, all names and addresses are removed. Also, all text entry fields are checked for potential identifiers (names of patients and doctors, telephone numbers, etc.) and any that are found are replaced with 'XXXX'.

Following this, each record is checked for any errors in completion and reasonable adjustments (known as 'cleaning') are made to the dataset, for example, removing responses where the patient has not correctly followed questionnaire instructions or provided multiple answers to a single response question.

At the end of this process, Ipsos uses a secure Ministry system to transfer data from their servers to BHI's secure servers, all of which are password protected with limited staff access.

At no stage does BHI, who analyse the data, have access to the names and contact details of the respondents. This ensures respondent answers remain confidential and identifying data can never be publicly released.

# Data analysis

## Completeness of survey questionnaires

In COPS 2016, the completeness of responses was very high, with 99% of respondents answering up to 74 out of 78 questions.

## Calculation of response rate

The response rate is the proportion of people sampled in the survey who actually completed and returned their survey form. The response rate, number of mailings and patient population distribution are reported for NSW in Table 2. Additional tables present the actual number of surveys mailed to eligible patients, the number of responses received and the response rate, by local health district (LHD) and hospital (Tables 3 and 4 respectively). For reasons of data quality and patient confidentiality, any hospital or LHD with fewer than 30 responses is not publicly reported, although these responses are still included in LHD and NSW totals.

Table 2 Patient population distribution and corresponding number of surveys mailed, COPS 2016

Eligible patient population	Mailings (in scope)	Population in mailings	Total responses	Response rate
31,006	21,474	72%	12,024	56%

Table 3 Sample size and response rates by LHD, COPS 2016

LHD	Surveys mailed (in scope)	Survey responses	Response rate
Central Coast Local Health District	1,321	807	61%
Chris O'Brien Lifehouse	973	489	50%
Far West Local Health District	39	18	46%
Hunter New England Local Health District	2,377	1,328	58%
Illawarra Shoalhaven Local Health District	1,589	1,016	64%
Mid North Coast Local Health District	1,806	1,196	66%
Murrumbidgee Local Health District	115	65	56%
Nepean Blue Mountains Local Health District	964	573	59%
Northern NSW Local Health District	1,047	602	57%
Northern Sydney Local Health District	1,086	644	59%
Riverina Cancer Care Centre	354	215	61%
South Eastern Sydney Local Health District	1,331	602	45%
South Western Sydney Local Health District	2,506	1,288	51%
Southern NSW Local Health District	441	260	59%
St Vincent's Health Network	695	328	47%

LHD	Surveys mailed (in scope)	Survey responses	Response rate
Sydney Local Health District	1,372	629	46%
Sydney Adventist Hospital	556	360	65%
Western NSW Local Health District	1,341	778	58%
Western Sydney Local Health District	1,561	826	52%
<b>NSW Total</b>	<b>21,474</b>	<b>12,024</b>	<b>56%</b>

Table 4 Sample size and response rates by hospital, COPS 2016

Hospital name	Surveys mailed	Survey responses	Response rate
Armidale Hospital	195	108	55%
Bankstown–Lidcombe Hospital	582	263	45%
Bathurst Health Service	210	130	62%
Bega Valley Community Health	51	35	69%
Blacktown Hospital	580	314	54%
Bourke Street Health Service	101	70	69%
Broken Hill Base Hospital	39	18	46%
Calvary Mater Newcastle	978	594	61%
Campbelltown Hospital	964	542	56%
Chris O'Brien Lifehouse	973	489	50%
Coffs Harbour Health Campus	978	623	64%
Concord Repatriation General Hospital	705	365	52%
Cooma Hospital and Health Service	38	21	55%
Cowra Health Service	12	8	67%
Deniliquin Health Service	4	2	50%
Dubbo Base Hospital	427	239	56%
Eurobodalla Community Health	170	103	61%
Gosford Hospital	966	563	58%
Goulburn Base Hospital and Health Service	22	14	64%
Grafton Base Hospital	101	60	59%
Griffith Base Hospital	47	29	62%
Griffith Community Health	25	10	40%
John Hunter Hospital	171	75	44%
Lachlan Health Service–Parkes	14	6	43%
Lismore Base Hospital	403	259	64%
Liverpool Hospital	960	483	50%

Hospital name	Surveys mailed	Survey responses	Response rate
Manly Hospital	121	79	65%
Manning Hospital	271	157	58%
Milton Ulladulla Hospital	15	9	60%
Moree Hospital	65	28	43%
Mudgee Health Service	15	9	60%
Muswellbrook Hospital	42	26	62%
Nepean Hospital	964	573	59%
Orange Health Service	663	386	58%
Port Macquarie Base Hospital	828	573	69%
Prince of Wales Hospital	978	449	46%
Queanbeyan Hospital and Health Service	59	17	29%
Riverina Cancer Care Centre	250	163	65%
Riverina Cancer Care Centre/Wagga Wagga Hospital	104	52	50%
Royal Hospital for Women	353	153	43%
Royal North Shore Hospital	965	565	59%
Royal Prince Alfred Hospital	667	264	40%
Shoalhaven District Memorial Hospital	672	446	66%
St Vincent's Hospital Sydney	695	328	47%
Sydney Adventist Hospital*	556	360	65%
Tamworth Hospital	655	340	52%
The Tweed Hospital	543	283	52%
Westmead Hospital	981	512	52%
Wollongong Hospital	902	561	62%
Wyong Hospital	355	244	69%
Young Health Service	39	24	62%
<b>NSW Total</b>	<b>21,474</b>	<b>12,024</b>	<b>56%</b>

\*Sydney Adventist Hospital also includes Radiation Oncology Institute, Wahroonga.

## Weighting of data

The NSW Patient Survey Program's protocol is to, when possible, 'weight' data to account for differences (bias) in the probability of sampling and the likelihood of different patient groups to respond. Weighting makes the results more representative of the overall patient population, making the data more useful for the purposes of decision-making and service improvement.

Different hospitals have different mixes of clinical services and this needed to be taken into account when considering the aggregated hospital-level results. The 2016 COPS results were weighted by taking the ratio of the number of eligible patients to the number of respondents at the Tier 2 clinic type level within each hospital (Table 5). This ensures that a hospital-level result more accurately represents the patient population attending cancer-related outpatient services at the hospital.

\* Facilities with less than 30 responses cannot be reported for data quality and confidentiality reasons.

**Table 5 Tier 2 outpatient cancer clinics presented by hospital, COPS, November 2016**

Hospital name	Medical oncology (treatment) 10.11	Radiation oncology (treatment) 10.12	Radiation therapy – simulation and planning 10.20	Medical oncology (consultation) 20.42	Radiation oncology (consultation) 20.43	Oncology 40.52	Other (Tier 2 codes confirmed as cancer outpatient clinics)
Armidale Hospital	Yes			Yes		Yes	
Bankstown–Lidcombe Hospital	Yes			Yes	Yes	Yes	Yes
Bathurst Health Service	Yes			Yes	Yes		
Bega Valley Community Health	Yes						Yes
Blacktown Hospital	Yes	Yes		Yes	Yes	Yes	
Bourke Street Health Service	Yes					Yes	Yes
Broken Hill Hospital	Yes						
Calvary Mater Newcastle	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Campbelltown Hospital	Yes	Yes		Yes			Yes
Chris O'Brien Lifehouse	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Coffs Harbour Health Campus	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Concord Repatriation General Hospital	Yes			Yes			
Cooma Hospital and Health Service	Yes					Yes	Yes
Cowra Health Service	Yes						
Deniliquin Health Service							
Dubbo Base Hospital	Yes			Yes	Yes	Yes	
Eurobodalla Community Health	Yes			Yes		Yes	Yes
Gosford Hospital	Yes	Yes	Yes	Yes	Yes		Yes
Goulburn Base Hospital and Health Service						Yes	Yes
Grafton Base Hospital				Yes		Yes	
Griffith Base Hospital							
Griffith Community Health Centre						Yes	
John Hunter Hospital				Yes		Yes	Yes

Hospital name	Medical oncology (treatment) 10.11	Radiation oncology (treatment) 10.12	Radiation therapy – simulation and planning 10.20	Medical oncology (consultation) 20.42	Radiation oncology (consultation) 20.43	Oncology 40.52	Other (Tier 2 codes confirmed as cancer outpatient clinics)
Lachlan Health Service– Parkes	Yes						
Lismore Base Hospital	Yes	Yes	Yes		Yes	Yes	
Liverpool Hospital	Yes	Yes		Yes	Yes		Yes
Manly Hospital	Yes			Yes			
Manning Base Hospital	Yes			Yes		Yes	Yes
Milton Ulladulla Hospital	Yes						Yes
Moree Hospital	Yes			Yes		Yes	
Mudgee Health Service				Yes			
Muswellbrook Hospital	Yes			Yes		Yes	
Nepean Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Orange Health Service	Yes	Yes	Yes	Yes	Yes	Yes	
Port Macquarie Base Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Prince of Wales Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Queanbeyan Hospital and Health Service	Yes					Yes	Yes
Riverina Cancer Care Centre/ Wagga Wagga Hospital				Yes		Yes	Yes
Royal Hospital for Women							Yes
Royal North Shore Hospital	Yes			Yes		Yes	Yes
Royal Prince Alfred Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shoalhaven District Memorial Hospital	Yes			Yes		Yes	Yes
St Vincent's Hospital Sydney	Yes	Yes	Yes		Yes	Yes	Yes
Sydney Adventist Hospital*	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tamworth Hospital	Yes			Yes		Yes	
The Tweed Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Westmead Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wollongong Hospital	Yes			Yes			Yes
Wyangong Hospital				Yes			

\* Sydney Adventist Hospital also includes Radiation Oncology Institute, Wahroonga.

# Tier 2 classifications not available for these hospitals.

## Demographic characteristics of respondents to COPS

Table 6 presents the percentage of patients by LHD, Tier 2 outpatient clinic service type, age and sex at each stage of the survey. Of the four columns with data:

- Percentage in sampling frame – this is the percentage of patients in each category in the dataset of eligible patients used to generate the sample (WebNAP extract, February and March 2016).
- Percentage in sample mailed – the percentage of patients in each category provided by the Ministry to Ipsos for mailing.
- Percentage of respondents (unweighted) – the raw/unadjusted percentage of respondents.
- Percentage of respondents (weighted) – the weighted percentage of respondents in the final data contributing to reported results.

**Table 6** Demographic characteristics of patients and COPS respondents, COPS 2016

Demographic variable	Sub-group	Percentage in sampling frame	Percentage in sample mailed	Percentage of respondents (unweighted)	Percentage of respondents (weighted)
LHD	Central Coast	4	6	7	5
	Chris O'Brien Lifehouse	11	5	4	9
	Far West	0	0	0	0
	Hunter New England	18	11	11	15
	Illawarra Shoalhaven	7	7	8	5
	Murrumbidgee	0	1	1	1
	Mid North Coast	8	8	10	7
	Nepean Blue Mountains	7	5	5	5
	Northern NSW	2	5	5	4
	Northern Sydney	1	5	5	4
	Riverina Cancer Care Centre	0	1	1	1
	South Eastern Sydney	6	6	5	6
	Southern NSW	1	2	2	2
	St Vincent's Health Network	2	3	3	2
	South Western Sydney	9	12	11	10
	Sydney	3	6	5	5
	Sydney Adventist Hospital	1	3	3	2
	Western NSW	4	6	7	5
Western Sydney	17	7	7	14	



Demographic variable	Sub-group	Percentage in sampling frame	Percentage in sample mailed	Percentage of respondents (unweighted)	Percentage of respondents (weighted)
Tier 2 Outpatient Clinic Service*	Medical oncology (treatment) – 10.11	17	18	18	16
	Radiation oncology (treatment) – 10.12	13	4	4	4
	Radiation therapy – simulation and planning – 10.20	11	1	2	2
	Medical oncology (consultation) – 20.42	16	33	33	37
	Radiation oncology (consultation) – 20.43	13	13	15	16
	Oncology – 40.52	14	10	10	9
	Other	15	14	12	12
Age group	18–34	#	5	2	2
	35–54	#	20	14	15
	55–74	#	51	56	55
	75+	#	24	29	28
Sex	Female	#	56	54	55
	Male	#	44	46	45

## Case-mix bias

As seen in Table 6, there are differences between the composition of outpatients in the hospital population (“Percentage in sampling frame”) compared with the “percentage of respondents (weighted)”, including for the composition by Tier 2. While there is insufficient information available in the administrative non-admitted patient datasets to be able to comment on severity of patient, the difference in Tier 2 composition shows that patients attending for radiation oncology (treatment) and radiation therapy – simulation and planning, are underrepresented in the final respondent population, while medical oncology is overrepresented. For advanced users of the data, this composition should be considered when interpreting results.

# Reporting

## Confidentiality

BHI does not receive any confidential patient information. The process of mailing of surveys and collation of responses are carried out by Ipsos on behalf of BHI. All personal identifiers, such as name and address, are removed from the data before it is provided to BHI.

Only aggregated data are published – data at the individual patient level are never published in BHI reports. To further ensure that respondents are not identifiable, BHI only publishes results that include a minimum of 30 respondents. In addition, results are considered for suppression at hospital or LHD level if the response rate is less than 30%, although the responses are included in higher level aggregated results. For COPS 2016, no hospital had a response rate lower than 29%.

With regards to suppression due to fewer than 30 respondents at a hospital, Broken Hill Health Service, Cooma Hospital and Health Service, Cowra Health Service, Deniliquin Health Service, Goulburn Base Hospital and Health Service, Griffith Base Hospital, Griffith Community Health, Milton Ulladulla Hospital, Moree Hospital, Mudgee Health Service, Muswellbrook Hospital, Lachlan Health Service–Parkes, Queanbeyan Hospital and Health Service, and Young Health Service were suppressed and not reported.

Data from Far West Local Health District are not reported due to having fewer than 30 respondents and because the sample came from a different period. Data from hospitals in Murrumbidgee Local Health District are not reported at facility level in these results because there are fewer than 30 respondents at all hospitals, but do contribute to the NSW results.

## Reporting of private facilities

Results for Sydney Adventist Hospital and Riverina Cancer Care Centre participated in the survey for the first time in 2016 and their results contribute to the overall NSW results.

Chris O'Brien Lifehouse, who also participated in the 2015 survey, is the only private facility reported at the hospital level. Chris O'Brien Lifehouse differs in administrative and organisational arrangements from public hospitals. It is a not-for-profit integrated cancer treatment centre, contracted to provide services for some public patients. Chris O'Brien Lifehouse is not managed by Sydney LHD, despite being located within that LHD's boundaries. Therefore, caution is advised when comparing results from Chris O'Brien Lifehouse to public hospitals in the survey.

## Statistical analysis

Data were analysed for the entire November 2016 period. Analysis was undertaken in SAS V9.4 using the SURVEYFREQ procedure using a finite population correction factor and the Copper Pearson adjustment for confidence interval calculation. Strata variables were Tier 2 classification and 'hospital'. Scored questions were analysed using the SURVEYMEANS procedure with finite population correction and the same strata variables as used in the SURVEYFREQ procedure.

Results were generated for each question in the survey at the NSW, LHD and hospital level. In addition, results were reported:

- for patients receiving chemotherapy, radiotherapy or a surgical procedure\*
- for patients in active treatment\*
- by age, highest level of education, sex, language spoken at home, longstanding health conditions, quintile of socioeconomic disadvantage, rurality of hospital and rurality of patient residence (in Healthcare Observer only).

\* See Appendix 3 for responses included in these groups.

Unless otherwise specified, missing responses and those who responded 'don't know/can't remember' to questions were excluded from analysis. The exception is when the 'don't know/can't remember' response is used for a question that asks about a third party (e.g. if family had enough opportunity to talk to doctor) or when the percentage responding with this option is over 10%. When reporting on questions that are used to filter respondents through the questionnaire rather than asking about hospital performance, the 'don't know/can't remember' option and missing responses are also reported. Appendix 2 presents the rates of missing or 'don't know' responses for COPS 2016.

The BHI document, *Guide to Interpreting Differences* ([bhi.nsw.gov.au/nsw\\_patient\\_survey\\_program](http://bhi.nsw.gov.au/nsw_patient_survey_program)), provides information in understanding comparison of results. Testing conducted by BHI identifies results that are statistically different (i.e. not due to chance). Sometimes, hospitals and LHDs are not identified as significantly different even though they have a lower result than another hospital that is marked as being significantly worse. This is often due to the number of patients from each hospital – hospitals with more respondents allow us to more accurately analyse if results are truly (statistically) different. In addition, some differences in results between facilities may be due to differences in the demographic profile of patients attending those facilities. BHI is currently developing methods to standardise survey results in order to account for differences in patient mix and to optimise direct comparisons.

The COPS questionnaire also included two validated survey tools, which are used internationally to assess cancer care and patient attitudes – these are discussed in the following sections. The SURVEMEANS procedure was used to analyse the data for these scales. As with the SURVEYFREQ procedure, finite population correction factor was applied, and the strata were Tier 2 classification and 'hospital'.

## Analysis of the ESAS

The Edmonton Symptom Assessment System (ESAS)<sup>1</sup> was developed in Canada and is one of the most common tools used for patient-reporting of cancer symptom severity. The tool asks patients to rate nine common cancer-related symptoms on a 10-point rating scale, with zero meaning the symptom is not being experienced (e.g. 'no pain') and 10 being the worst possible severity.

Results for the ESAS are presented by the average for each symptom at hospital, LHD and NSW level.

## Analysis of the CASE–cancer

The Communication and Attitudinal Self-Efficacy scale for cancer (CASE–cancer)<sup>2</sup> asks 12 questions that can be used to construct three dimensions about the patient's self-efficacy and attitude:

- maintaining a positive attitude
- understanding and participating in care
- seeking and obtaining information.

Results for the CASE–cancer are presented in two ways:

- The percentage of patients reporting the top category response option of 'strongly agree' for each of the 12 questions
- Dimension scores: The results presented for the three dimensions are generated using scores. Each response option is converted to a score ranging from 0–10 (strongly agree = 10; slightly agree = 6.67; slightly disagree = 3.33; strongly disagree = 0), then results are averaged across the four questions comprising each dimension. Respondents must have answered at least three of the four components of a dimension for their scores to be included in the total.

## Determination of statistical significance at 0% and 100%

Confidence intervals around results that are universally positive or negative are not created by the SURVEYFREQ procedure with the specifications described above. Therefore, it is not possible to determine if such a result is significantly different from the NSW result using overlapping 95% confidence intervals. BHI is exploring alternative methods for comparison. However, as an interim method, BHI will report results as significantly higher than NSW if the next lowest value, at that level of analysis, is significantly higher than NSW. For example, at the hospital level, if Hospital A has a result of 100% and the next highest result for the same question is 99% and significantly higher than the NSW result, then the result for Hospital A will be inferred as significantly higher than the NSW result. Results of 0% are treated similarly.

## Cancer type

The 2016 Outpatient Cancer Clinic Survey includes a question asking patients to identify the type of cancer they were receiving care for at the clinic (Q60). This question was developed by the Cancer Institute NSW based on prevalence of cancer types across NSW and provides 11 response options to select from, including an "other" category. Both the chartpack and supporting data tables present performance data by cancer type.

<sup>1</sup> Bruera E, et al (1991) The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *Journal of Palliative Care* 7: 6–9

<sup>2</sup> Wolf MS, et al (2005) Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). *Patient Education and Counseling* 57(3): 333-341

Statistical analyses of this question have also been conducted using overlapping 95% confidence intervals, as discussed above. These comparisons have not taken into account patients' case-mix when comparing between each cancer type with NSW. This is because, while it is possible to control for some of the effects of patient case-mix variation, the quality and fields available in the non-admitted patient data do not permit comprehensive standardisation. In addition, unlike many indicators sourced from administrative data, patient experience measure reflect properties that should not vary based on the case-mix of patients, such as being treated with kindness, respect and dignity, and being given answers patients could understand to their questions.

The data table presenting results for cancer type allows for stratification of type of cancer to facilitate understanding of the clinical mix of patients.

## Calculation of percentages

The result (percentage) for each response option in the questionnaire is determined using the following method:

### **Numerator**

The (weighted) number of survey respondents who selected a specific response option to a certain question, minus exclusions.

### **Denominator**

The (weighted) number of survey respondents who selected any of the response options to a certain question, minus exclusions.

### **Calculation**

= numerator/denominator x 100

The results are weighted for most questions. They are not weighted for questions relating to demographics or self-reported health status.

In some cases, the results from several responses are combined to form a 'derived measure', as indicated in the reporting. For information about how these measures are developed, please see Appendix 3.

# Appendix 1:

## Facilities included in the COPS 2016 sampling frame

Table 1 Eligible patients, sampled patients and proportion sampled by hospital, COPS 2016

Hospital name	Total eligible patients	Total sampled	Percentage sampled
Armidale Hospital	225	200	89%
Bankstown–Lidcombe Hospital	653	600	92%
Bathurst Health Service	239	219	92%
Bega Valley Community Health	57	52	91%
Blacktown Hospital	685	609	89%
Bourke Street Health Service	127	105	83%
Broken Hill Health Service	46	39	85%
Calvary Mater Newcastle	3,571	1,000	28%
Campbelltown Hospital	1,086	1,000	92%
Chris O'Brien Lifehouse	3,012	1,000	33%
Coffs Harbour Health Campus	1,254	1,000	80%
Concord Repatriation General Hospital	782	728	93%
Cooma Hospital and Health Service	50	39	78%
Cowra Health Service	12	12	100%
Deniliquin Health Service	4	4	100%
Dubbo Base Hospital	505	444	88%
Eurobodalla Community Health	210	175	83%
Gosford Hospital	1,092	1,000	92%
Goulburn Community Health Service	32	25	78%
Grafton Base Hospital	117	104	89%
Griffith Base Hospital	67	49	73%
Griffith Community Health	27	26	96%
John Hunter Hospital	197	177	90%
Lachlan Health Service–Parkes	21	16	76%
Lismore Base Hospital	447	419	94%
Liverpool Hospital	1,721	1,000	58%

Hospital name	Total eligible patients	Total sampled	Percentage sampled
Manly Hospital	140	127	91%
Manning Hospital	342	289	85%
Milton Ulladulla Hospital	18	16	89%
Moree Hospital	75	67	89%
Mudgee Health Service	17	15	88%
Muswellbrook Hospital	55	44	80%
Nepean Hospital	1,778	1,000	56%
Orange Health Service	785	686	87%
Port Macquarie Base Hospital	958	863	90%
Prince of Wales Hospital	1,522	1,000	66%
Queanbeyan Hospital and Health Service	64	63	98%
Riverina Cancer Care Centre	352	259	74%
Riverina Cancer Care Centre/Wagga Wagga Hospital	121	114	94%
Royal Hospital for Women	377	356	94%
Royal North Shore Hospital	1,177	998	85%
Royal Prince Alfred Hospital	759	678	89%
Shoalhaven District Memorial Hospital	770	698	91%
St Vincent's Hospital Sydney	833	735	88%
Sydney Adventist Hospital*	1,492	1,282	86%
Tamworth Hospital	757	679	90%
The Tweed Hospital	621	568	92%
Westmead Hospital	4,048	1,000	25%
Wollongong Hospital	1,017	936	92%
Wyong Hospital	407	374	92%
Young Health Service	45	39	87%
<b>NSW Total</b>	<b>33,914</b>	<b>22,223</b>	<b>66%</b>

\*Sydney Adventist Hospital also includes Radiation Oncology Institute, Wahroonga.



## Appendix 2: Missing and 'don't know' responses

Table 2 Proportion of 'don't know' and missing responses, by question, COPS 2016

Question number	Question text	Missing %	Don't know %	Missing+ Don't know %*
1	What was the purpose of this visit?	1.8	-	1.8
2	How long did it take you to travel to the clinic for this appointment?	1.0	0.1	1.1
3	What was your main form of transport to the clinic?	2.1	-	2.1
4	Did you have any of the following issues with parking during this visit?	1.9	-	1.9
5	Were the reception staff polite and courteous?	0.8	-	0.8
6	How long after the scheduled appointment time did your appointment actually start?	2.4	1.0	3.5
7	Were you told how long you had to wait [for appointment to start]?	5.6	-	5.6
8	How comfortable was the waiting area?	0.7	-	0.7
9	How comfortable was the treatment area?	1.3	-	1.3
10	How clean was the treatment area?	0.5	-	0.5
11	Who did you see during this visit?	1.8	-	1.8
12	Did you have enough time to discuss your health issue with the health professionals you saw?	1.8	-	1.8
13	Did the health professionals explain things in a way you could understand?	2.2	-	2.2
14	During this visit, did the health professionals know enough about your medical history?	1.9	-	1.9
15	How would you rate how well the health professionals worked together?	1.7	-	1.7
16	Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?	2.3	6.6	8.9
17	Did you have worries or fears about your condition or treatment?	2.7	-	2.7
18	Did a health professional discuss your worries or fears with you?	3.7	-	3.7
19	Did you have confidence and trust in the health professionals?	2.1	-	2.1
20	Were the health professionals kind and caring towards you?	2.1	-	2.1

Question number	Question text	Missing %	Don't know %	Missing+ Don't know %*
21	Overall, how would you rate the health professionals who treated you?	2.1	-	2.1
22	When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options?	3.1	-	3.1
23	Did a health professional at the clinic tell you about the risks and benefits of the treatment options?	1.9	-	1.9
24	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	2.6	-	2.6
25	Did a health professional at the clinic explain the next steps of your care and treatment in a way you could understand?	3.2	-	3.2
26	Do you have a written care plan for your treatment?	4.5	5.8	10.2
27	Was your care plan developed by health professionals from this clinic?	2.9	4.5	7.4
28	Were you asked about your preferences for care and treatment when developing this plan?	3.5	10.2	13.7
29	At your latest visit, did the health professionals review your care plan with you?	3.6	4.2	7.8
30	Did you receive any treatment during this visit? (e.g. chemotherapy, radiotherapy, surgery or other treatments)	2.5	-	2.5
31	Did a health professional at the clinic explain what would be done during your treatment in a way you could understand?	5.6	-	5.6
32	Did a health professional at the clinic tell you about possible side effects of your treatment?	6.2	-	6.2
33	Were you given enough information about how to manage the side effects of your treatment?	6.6	-	6.6
34	Were you given, or prescribed, any new medication to take at home?	2.9	-	2.9
35	Did a health professional at the clinic explain the purpose of this medication in a way you could understand?	3.5	-	3.5
36	Did a health professional at the clinic tell you about medication side effects to watch for?	3.9	-	3.9
37	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?	2.4	2.0	4.4
38	Did a health professional at the clinic give your family or someone close to you enough information to help care for you at home?	3.0	1.1	4.1
39	Were you treated with respect and dignity while you were at the clinic?	1.0	-	1.0
40	Were you given enough privacy when being examined or treated?	1.6	-	1.6

Question number	Question text	Missing %	Don't know %	Missing+ Don't know %*
41	Were you given enough privacy when discussing your condition or treatment?	1.7	-	1.7
42	Were you ever treated unfairly for any of the reasons below?	4.6	-	4.6
43	Were your cultural or religious beliefs respected by the clinic staff?	3.3	-	3.3
44	During your visit or soon afterwards, did you experience any of the following complications or problems? (other than common side-effects from treatment)	4.3	-	4.3
45	Was the impact of this complication or problem...?	4.1	-	4.1
46	In your opinion, were the health professionals open with you about this complication or problem?	4.9	-	4.9
47	In the past three months, have you gone to an emergency department because of complications related to the care you received?	2.8	0.5	3.3
48	How much were your out-of-pocket expenses for medication related to these visits?	2.5	3.6	6.1
49	How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these visits (excluding medication)?	2.8	3.9	6.7
50	How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)?	2.5	3.1	5.6
51	How long have you been attending this cancer clinic?	2.2	-	2.2
52	In the last 12 months, how many times have you visited this cancer clinic?	2.3	-	2.3
53	Was there any time when the health professionals needed access to your health records and they were not available?	1.6	10.9	12.5
54	Did you ever receive conflicting information about your condition or treatment from the health professionals?	2.4	-	2.4
55	Overall, how would you rate the care you received in the clinic?	1.2	-	1.2
56	How well organised was the care you received in the clinic?	1.2	-	1.2
57	If asked about your clinic experience by friends and family, how would you respond?	1.4	-	1.4
58	Did you attend this clinic because you have or have had cancer?	2.1	-	2.1
59	Is this the first time you have had cancer?	4.9	-	4.9
60	What type of cancer were you receiving care for at this clinic?	9.0	-	9.0

Question number	Question text	Missing %	Don't know %	Missing+ Don't know %*
61	Which of the following statements best describes how well you are able to carry out ordinary tasks and daily activities? Over the past month I would generally rate my activity as...	3.7	-	3.7
62	How has your current cancer responded to treatment?	7.4	-	7.4
63	How long has it been since you first received treatment for this cancer?	1.3	0.4	1.7
64	In the past three months, what treatment have you received for your cancer?	3.1	-	3.1
65	Edmonton Symptom Assessment System (ESAS)	-	-	-
66	CASE-cancer survey (modified)	-	-	-
67	Age #	2.2	-	2.2
68	Sex #	1.5	-	1.5
69	Highest level of education completed	3.9	-	3.9
70	Language mainly spoken at home	1.7	-	1.7
71	Did you need, or would you have liked, to use a professional interpreter at any stage while you were at the clinic?	2.2	-	2.2
72	Did the hospital provide an interpreter when you needed one?	4.0	-	4.0
73	Aboriginal and/or Torres Strait Islander	2.3	-	2.3
74	Which, if any, of the following longstanding conditions do you have (including age related conditions)?	4.4	-	4.4
75	Which of the following best describes your smoking status?	2.1	0.5	2.7
76	Has a health professional at this clinic advised you to quit smoking?	9.9	1.4	11.3
77	Who completed this survey?	2.0	-	2.0
78	Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you?	9.9	-	9.9

\* Percentages for this column may not equal the sum of the 'missing %' and 'Don't know %' columns because they were calculated using unrounded figures.

# For respondents who did not answer these questions, information about age and sex were substituted with age and sex fields from administrative data (from the Health Information Exchange).

# Appendix 3: Derived measures

## Definition

Derived measures are those for which results are calculated indirectly from respondents' answers to a survey question. These tend to be from questions that contain a 'not applicable' type response option and are used to gather information about the array of patients' needs.

Derived measures involve the grouping together of more than one response option to a question. The derived measure 'Quintile of Disadvantage' is an exception to this rule (for more information on this, refer to this data dictionary document on the BHI website at [bhi.nsw.gov.au/nsw\\_patient\\_survey\\_program](http://bhi.nsw.gov.au/nsw_patient_survey_program)

## Statistical methods

Results are expressed as the percentage of respondents who chose a specific response option or options for a question. The reported percentage is calculated as the numerator divided by the denominator (defined earlier in this Technical Supplement).

Results are weighted as described in this report.

## Inclusions

The following questions and responses were used in the construction of the derived measures.

Table 3 Appendix Table 3: Derived measures, COPS 2016

Derived measure	Original question	Derived measure categories	Original question responses
Visit included chemotherapy, immunotherapy, radiotherapy, surgical procedure	Q1. What was the purpose of this visit?	Chemotherapy, Radiotherapy, Immunotherapy and/or surgical	Chemotherapy
			Radiotherapy
			Immunotherapy or hormone therapy
			Surgical procedure
		Other purpose of visit	Have tests, X-rays or scans
			Receive test, X-ray or scan results
			Medical diagnosis or advice
			Follow-up after surgery
			Treatment review
			Regular check-up/long-term follow-up
Other reason			
Issues with parking	Q4. Did you have any of the following issues with parking during this visit?	Had issues with parking	No car park at the clinic
			The car park was full
			Too few disabled parking spaces
			Expensive parking fees

Derived measure	Original question	Derived measure categories	Original question responses
			Had to walk a long way from the car park
		Didn't have issues with parking	None of these issues
Saw multiple health professionals	Q15. How would you rate how well the health professionals worked together?	Saw 2+ health professionals	Very good
			Good
			Neither good nor poor
			Poor
			Very poor
		Saw 1 health professional	Not applicable – only saw one
Be involved in decisions about care and treatment	Q24. Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Were involved	Yes, definitely
			Yes, to some extent
			No
		Were not involved	I did not want or need to be involved
Needed a written care plan for your treatment	Q26. Do you have a written care plan for your treatment?	Needed a written care plan	Yes
			No
			Did not need a written care plan
		Don't know/can't remember	Don't know/can't remember
Treated unfairly	Q42. Were you ever treated unfairly for any of the reasons below?	Treated unfairly	Your age
			Your sex
			Your ethnic background
			Your religion
			Your sexual orientation
			A disability that you have
			Marital status
			Something else
		Not treated unfairly	I was not treated unfairly
Had religious or cultural beliefs to consider	Q43. Were your cultural or religious beliefs respected by the clinic staff?	Had beliefs to consider	Yes, always
			Yes, sometimes
			No, my beliefs were not respected
		Beliefs not an issue	My beliefs were not an issue

Derived measure	Original question	Derived measure categories	Original question responses
During your visit or soon afterwards, did you experience any of the following complications or problems? (other than common side-effects from treatment)	Q44. During your visit or soon afterwards, did you experience any of the following complications or problems? (other than common side-effects from treatment)	Had complication	An infection
			Uncontrolled bleeding
			An unexpected negative reaction to medication
			Complications as a result of tests or procedures
			Severe pain due to the treatment
			Severe anxiety or worry
		Any other complication or problem	
		None reported	None
In your opinion, were the health professionals open with you about this complication or problem?	Q46. In your opinion, were the health professionals open with you about this complication or problem?	Occurred in clinic	Yes, completely
			Yes, to some extent
		No	
		Occurred after I left	Not applicable, as it happened after I left
How much were your out-of-pocket expenses for medication related to these visits?	Q48. How much were your out-of-pocket expenses for medication related to these visits?	Less than \$500	Zero (\$0)
			\$1 to less than \$100
			\$100 to less than \$500
		\$500 or more	\$500 to less than \$1,000
			\$1,000 or more
How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these visits (excluding medication)?	Q49. How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these visits (excluding medication)?	Less than \$500	Zero (\$0)
			\$1 to less than \$100
			\$100 to less than \$500
		\$500 or more	\$500 to less than \$1,000
			\$1,000 or more
How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)?	Q50. How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)?	Less than \$500	Zero (\$0)
			\$1 to less than \$100
			\$100 to less than \$500
		\$500 or more	\$500 to less than \$1,000
			\$1,000 or more
In the last 12 months, how many times have you visited this cancer clinic?	Q52. In the last 12 months, how many times have you visited this cancer clinic?	More than once	2 to 3 times
			4 to 8 times
			More than 8 times

Derived measure	Original question	Derived measure categories	Original question responses
		Once	Once
Currently undergoing active treatment	Q62. How has your current cancer responded to treatment?	Active treatment phase	I am in the course of treatment and I can't tell yet how my cancer has responded  My cancer is being treated again because it has not responded fully to treatment
		Non-active treatment phase	Treatment has not yet started for this cancer  The treatment has been effective and I have no signs or symptoms of cancer  I have finished the course of treatment but my cancer is still present  I am not in active treatment but I am on Watch and Wait  My cancer has not been treated at all
In the past three months, did you receive treatment for your cancer?	Q64. In the past three months, what treatment have you received for your cancer?	Yes	Radiotherapy  Chemotherapy (including hormone therapy, immunotherapy and targeted drug therapy)  Surgery  Other treatment (e.g. bone marrow transplant)
		No	I have not received treatment in the past three months

## Exclusions

For derived measures, the following responses are excluded:

- 'Don't know/can't remember' or similar non-committal response (with the exception of questions where the rate of this response was over 10% and questions that refer to the experience of a third party such as a family/carer)
- Invalid (i.e. respondent was meant to skip a question but did not)
- Missing (with the exception of questions that allow multiple responses or a 'none of these' option, to which the missing responses are combined to create a 'none reported' variable).

## Interpretation of indicator

The higher the percentage, the more respondents fall into that response category.