

Technical Supplement: Outpatient Cancer Clinics Survey 2015

July 2016

Revision History

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Please note that there is the potential for minor revisions of data in this report. Please check the online version at bhi.nsw.gov.au for any amendments

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 2015 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

bhi.nsw.gov.au/nsw_patient_survey_program

Outpatient Cancer Clinics Survey

In 2015, 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 second 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 2015, the survey focussed 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 (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 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 (90% of patients) were being treated or receiving follow-up services for cancer care.

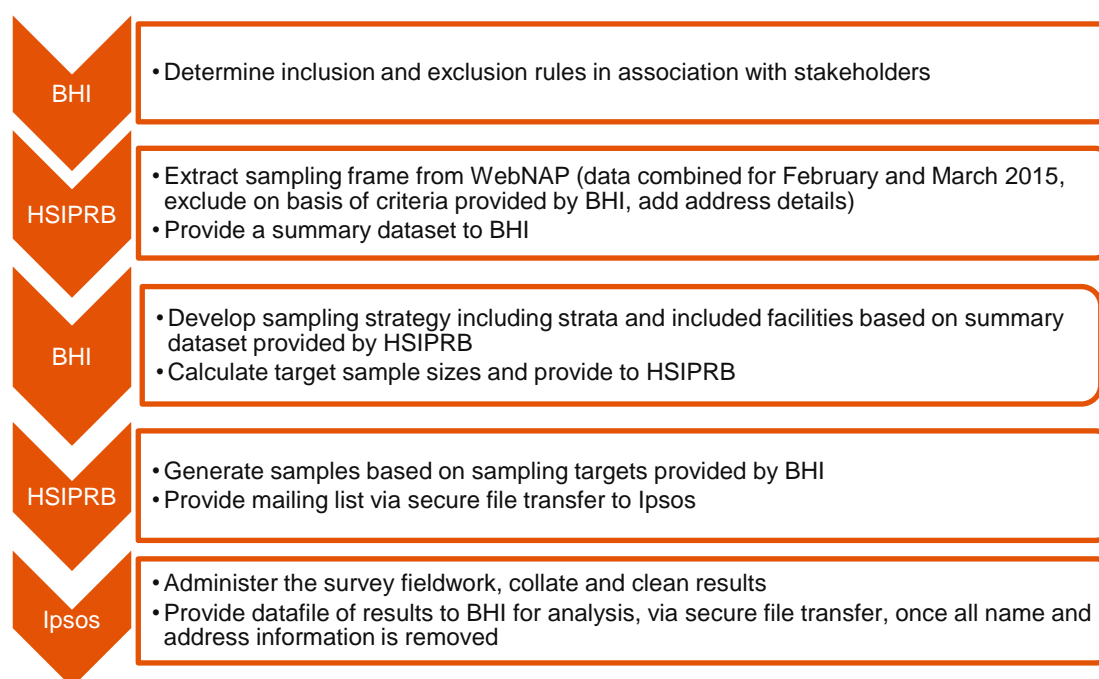
Producing the survey samples

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 Health Systems Performance Information and Reporting Branch (HSPIRB) (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 2015



Drawing the sample

In line with the 2014 Outpatient Survey and advice from the Ministry, the sampling frame for COPS 2015 was the WebNAP database. This database is held by the Ministry and BHI does not have access to confidential patient-level data in WebNAP. Because of this, sample sizes for each hospital in COPS 2015 were calculated on the basis of preliminary aggregated data provided by HSIPRB.

WebNAP data limitations

There were a number of challenges associated with the use of WebNAP for COPS and Outpatient Survey sampling, as described below:

- WebNAP has a mixture of aggregated occasions of service data and patient-level data. Only patient-level data can be used for mailing the survey so many of the facilities cannot be included.
- It is not compulsory for hospitals to provide personal details such as address and full name including title (Mr, Mrs, Ms etc.), even when providing patient-level data – records without this information cannot be included in the survey
- The quality of the WebNAP data varies both by LHD and hospital, as well as over time. For instance, a hospital or LHD may have uploaded patient-level data for some months and only aggregated data for other months. LHDs are also able to delete data from the WebNAP system at any time, for any period of time. Therefore, it is not possible to know the coverage of the sampling frame and, for example, whether hospitals were not available because they had no clinics or because they were not supplying data.
- Because WebNAP data are only provided to BHI at an aggregated level by HSIPRB, it is not possible to stratify the sampling by age group
- Access to the database is restricted to Ministry staff. As a result, sample size calculations were based on aggregate data provided prior to actual sampling.
- Early versions of the WebNAP sampling frame provided to BHI for COPS 2015 were not de-duplicated for patients who attended the clinic more than once, so the number of unique patients had to be estimated.

Despite these limitations, WebNAP remains the best database for sampling outpatient services.

For COPS 2015, the sampling frames were defined as attendees during February and March 2015, with the date of attendance used to define eligible records. At the time of sampling for this survey, there were no data in WebNAP for any hospital in Hunter New England LHD hospitals, including the major cancer treatment centres of John Hunter Hospital and the Calvary Mater Newcastle. This was not seen in early versions of the sampling frame and, due to the short lead time for this survey, the sampling had to continue without these facilities being included.

In addition, no patient-level data for Tier 2 categories were available for Far West, Murrumbidgee or Southern NSW LHDs.

Definition of NSW outpatient cancer clinics

Outpatient cancer clinics eligible for the survey were identified in WebNAP. Only clinics from the six cancer-related Tier 2 classifications shown in Table 1 were included in the sample.

Table 1: Tier 2 services included for sampling and reporting, COPS 2015

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 HSIPRB, who undertook the sampling for this survey.

Inclusions

- Persons aged 18 years and older who visited a NSW public hospital outpatient cancer service
- Random sample of patients who received care from an outpatient service in February and March 2015
- 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 17 years and under
- Patients with subsequent death notifications
- Sydney Children's Hospital and 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

HSIPRB extracted the sampling frame on the basis of the inclusion and exclusion criteria provided by BHI, including patient name and address information. The data is 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 HSI PRB, 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 February and March 2015.

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

χ^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 (± 0.07).

The sample size calculation aimed for a confidence interval around an expected proportion of 0.8 of ± 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 HSI PRB 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 26 sampled facilities and the total number of cancer outpatients eligible for sampling versus outpatients sampled for the survey for 2015 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%.
- Scope of the survey specified only patients aged 18 years and over would be included and that the Sydney Children’s Hospital or Children’s Hospital at Westmead would be excluded. However, 178 patients aged 0–17 years old were included in the sample the Ministry provided to Ipsos for mailing; 176 of these patients were at Sydney Children’s Hospital or Children’s Hospital at Westmead. A decision was made by BHI to exclude these responses from reporting.

Expected sample versus actual sample

Although the aggregate data on which sample sizes were based were assumed to be already de-duplicated and have had all exclusions applied, the sampling summary provided by the Ministry showed that there were 2,000 fewer patients in the sample than were expected. Because the response rate for COPS 2015 was higher than estimated, the number of responses was still sufficient to allow the full reporting planned for (Table 2).

Table 2: Expected number of surveys to be mailed and expected responses, COPS 2015

Number of eligible patients	Expected mailings	Actual mailings (in-scope)	Expected number of responses (30% RR)	Actual number of responses
24,274	8,318	6,467	2,496	3,706

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 2015, the completeness of responses was very high, with 99% of respondents answering more than 47 questions and 95% answering more than 59 questions in the questionnaire. One respondent answered none of the questions, with the exception of the free-text questions at the end of the questionnaire – this respondent was excluded from further analysis.

Calculation of response rate

The response rate is the proportion of people sampled in the survey that actually completed and returned their survey form. The response rate, number of mailings and the patient population distribution are reported for NSW in Table 3. Additional tables present the actual number of surveys mailed to eligible patients, the number of responses received and the response rate, by LHD and hospital (Tables 4 and 5 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 3: Patient population distribution and corresponding number of surveys mailed, COPS 2015

Eligible patient population	Mailings (in scope)	Population in mailings	Total responses	Response rate
24,274	6,467	26.6%	3,706	57.3%

Table 4: Sample size and response rates by LHD, COPS 2015

LHD	Surveys mailed (in scope)	Survey responses	Response rate
Central Coast	462	292	63.2%
Far West*	-	-	-
Hunter New England*	-	-	-
Illawarra Shoalhaven	645	412	63.9%
Mid North Coast	609	416	68.3%
Murrumbidgee*	-	-	-
Nepean Blue Mountains	331	204	61.6%
Northern NSW	368	220	59.8%
Northern Sydney	562	331	58.9%
South Eastern Sydney	602	300	49.8%
South Western Sydney	953	494	51.8%
Southern NSW*	-	-	-
St Vincent's Health Network	313	158	50.5%
Sydney	432	222	51.4%
Western NSW	230	151	65.7%
Western Sydney	626	330	52.7%
Chris O'Brien Lifehouse	334	176	52.7%
NSW total	6,467	3,706	57.3%

* Several LHDs were excluded as there were no outpatient cancer records in WebNAP to allow sampling.

Table 5: Sample size and response rates by hospital, COPS 2015

Hospital name	Surveys mailed	Survey responses	Response rate
Bankstown / Lidcombe Hospital	301	141	46.8%
Concord Hospital	272	158	58.1%
Gosford Hospital	266	163	61.3%
Liverpool Hospital	330	158	47.9%
Nepean Hospital	331	204	61.6%
Prince of Wales Hospital	333	175	52.6%
Royal North Shore Hospital	327	194	59.3%
Royal Prince Alfred Hospital	160	64	40.0%
St George Hospital	126	82	65.1%
St Vincent's Hospital	313	158	50.5%
Westmead Hospital	337	185	54.9%
Wollongong Hospital	329	202	61.4%
Sydney/Sydney Eye Hospital	143	43	30.1%
Blacktown Hospital	289	145	50.2%
Campbelltown Hospital	322	195	60.6%
Coffs Harbour Base Hospital	324	221	68.2%
Dubbo Base Hospital*	43	25	58.1%
Lismore Base Hospital	208	116	55.8%
Manly District Hospital	235	137	58.3%
Orange Health Service	151	105	69.5%
Port Macquarie Base Hospital	285	195	68.4%
Shoalhaven and District Memorial Hospital	316	210	66.5%
Wyong Hospital	196	129	65.8%
Chris O'Brien Lifehouse	334	176	52.7%
Bathurst Base Hospital*	36	21	58.3%
Grafton Base Hospital	160	104	65.0%
NSW total	6,467	3,706	57.3%

Weighting of data

The protocol of the NSW Patient Survey Program 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 2015 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 6). 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 6: Tier 2 outpatient cancer clinics presented by hospital, COPS, February and March 2015

Hospital name	Medical oncology (treatment)	Radiation oncology (treatment)	Radiation therapy – simulation and planning	Medical oncology (consultation)	Radiation oncology (consultation)	Oncology
Bankstown / Lidcombe Hospital	Yes			Yes	Yes	Yes
Bathurst Base Hospital					Yes	
Blacktown Hospital	Yes			Yes		
Campbelltown Hospital		Yes		Yes		
Coffs Harbour Base Hospital		Yes	Yes	Yes	Yes	Yes
Concord Hospital	Yes			Yes		
Dubbo Base Hospital					Yes	
Gosford Hospital	Yes	Yes		Yes	Yes	Yes
Grafton Base Hospital				Yes	Yes	Yes
Lifehouse Australia	Yes	Yes		Yes	Yes	Yes
Lismore Base Hospital	Yes			Yes		Yes
Liverpool Hospital	Yes	Yes		Yes	Yes	Yes
Manly District Hospital	Yes			Yes		
Nepean Hospital	Yes	Yes	Yes	Yes	Yes	Yes
Orange Health Service		Yes	Yes		Yes	
Port Macquarie Base Hospital		Yes	Yes	Yes	Yes	Yes
Prince of Wales Hospital	Yes	Yes	Yes	Yes	Yes	Yes
Royal North Shore Hospital		Yes	Yes	Yes	Yes	Yes
Royal Prince Alfred Hospital	Yes			Yes		
Shoalhaven and District Memorial Hospital	Yes	Yes	Yes	Yes	Yes	Yes
St George Hospital						Yes
St Vincent's Hospital	Yes	Yes		Yes		
Sydney/Sydney Eye Hospital				Yes		
Westmead Hospital	Yes	Yes		Yes	Yes	Yes
Wollongong Hospital	Yes	Yes	Yes	Yes	Yes	Yes
Wyong Hospital	Yes			Yes	Yes	

Demographic characteristics of respondents to COPS

Table 7 presents the percentage of patients in each LHD, Tier 2, age or sex group, at each stage of the survey. Of the four columns with data:

- 1) Percentage in sampling frame – this is the percentage of patients in each category in the dataset of eligible patients used to generate sample (WebNAP extract, February and March 2015)
- 2) Percentage in sample mailed – the percentage of patients in each category provided by the Ministry to Ipsos for mailing
- 3) Percentage of respondents (unweighted) – the raw/unadjusted percentage of respondents
- 4) Percentage of respondents (weighted) – the weighted percentage of respondents in the final data contributing to reported results.

Table 7: Demographic characteristics of patients and COPS respondents, COPS 2015

Demographic variable	Sub-group	Percentage in sampling frame	Percentage in sample mailed	Percentage of respondents (Unweighted)	Percentage of respondents (Weighted)
LHD	CCLHD	4.9	7.1	7.9	4.9
	FWLHD	-	-	-	-
	HNELHD	-	-	-	-
	ISLHD	9.3	10.0	11.1	9.3
	MLHD	-	-	-	-
	MNCLHD	5.9	9.4	11.2	5.9
	NBMLHD	9.4	5.1	5.5	9.4
	NNSWLHD	1.6	5.7	5.9	1.6
	NSLHD	6.7	8.7	8.9	6.7
	SCHN	-	-	-	-
	SESLHD	8.7	9.3	8.1	8.7
	SNSWLHD	-	-	-	-
	SVHN	3.3	4.8	4.3	3.3
	SWSLHD	15.7	14.7	13.3	15.7
	SYDLHD	14.5	11.8	10.7	14.5
WNSWLHD	1.9	3.6	4.1	1.9	
WSLHD	18.2	9.7	8.9	18.2	
Tier 2 Outpatient Clinic Service	Medical oncology (treatment) – 10.11	14.3	22.5	21.8	14.3
	Radiation oncology (treatment) – 10.12	5.3	8.1	8.8	5.3
	Radiation therapy – simulation and planning – 10.20	3.1	3.5	3.8	3.1
	Medical oncology (consultation) – 20.42	37.0	34.8	32.8	37.0
	Radiation oncology (consultation) – 20.43	28.2	16.8	18.2	28.2
	Oncology – 40.52	12.2	14.2	14.7	12.2
Age group	18-34	n/a [#]	3.5	1.4	1.5
	35-54	n/a [#]	19.0	13.7	15.5
	55-74	n/a [#]	51.2	54.4	54.1
	75+	n/a [#]	26.4	30.5	28.9
Gender	Male	n/a [#]	47.4	48.9	48.7
	Female	n/a [#]	52.6	51.1	51.3

[#] Sample summaries provided by the Ministry are summarised only by strata variables. As gender and age group were not strata variables for COPS 2015, this information is not available.

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 2015, no hospital had a response rate lower than 30%.

With regards to suppression due to fewer than 30 respondents at a hospital, Bathurst Base Hospital and Dubbo Base Hospital were suppressed and not reported.

Statistical analysis

Data were analysed for the entire February to March 2015 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, gender, language spoken at home, long-standing health conditions, quintile of socio-economic 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 ask 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 2015.

The BHI document, *Guide to Interpreting Differences* (bhi.nsw.gov.au/nsw_patient_survey_program), provides information in understanding comparison of results. However, 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)¹ 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)² 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.

¹ 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

² 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

Exclusions from reporting

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 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. Due to this, results for Sydney/Sydney Eye are not presented in graphs showing the distribution of results across hospitals.
- Chris O'Brien Lifehouse differs in administrative and organisational arrangements. It is a not-for-profit integrated cancer treatment centre, contracted to provide some services for public patients. It is not managed by Sydney LHD, despite being located within that LHD's boundaries. Due to differences in patient case-mix, results for the Chris O'Brien Lifehouse are not presented in graphs showing the distribution of results across hospitals.

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 2015 sampling frame

Appendix Table 1: Eligible patients, sampled patients and proportion sampled by hospital, COPS 2015

Hospital name	Total eligible patients	Total sampled	Percentage sampled
Bankstown / Lidcombe Hospital	664	301	45.3%
Concord Hospital	403	272	67.5%
Gosford Hospital	988	266	26.9%
Liverpool Hospital	2,009	330	16.4%
Nepean Hospital	2,286	331	14.5%
Prince of Wales Hospital	1,837	333	18.1%
Royal North Shore Hospital	1,380	327	23.7%
Royal Prince Alfred Hospital	189	160	84.7%
St George Hospital	130	126	96.9%
St Vincent's Hospital	790	313	39.6%
Westmead Hospital	3,871	337	8.7%
Wollongong Hospital	1,437	329	22.9%
Sydney/Sydney Eye Hospital	146	143	97.9%
Blacktown Hospital	541	289	53.4%
Campbelltown Hospital	1,134	322	28.4%
Coffs Harbour Base Hospital	881	324	36.8%
Dubbo Base Hospital	80	43	53.8%
Lismore Base Hospital	222	208	93.7%
Manly District Hospital	244	235	96.3%
Orange Health Service	333	151	45.3%
Port Macquarie Base Hospital	546	285	52.2%
Shoalhaven and District Memorial Hospital	817	316	38.7%
Wyong Hospital	207	196	94.7%
Chris O'Brien Lifehouse	2,933	334	11.4%
Bathurst Base Hospital	42	36	85.7%
Grafton Base Hospital	164	160	97.6%
NSW total	24,274	6,467	26.6%

Appendix 2: Missing and “don’t know” responses

Appendix Table 2: Proportion of “don’t know” and missing responses, by question, COPS 2015

Question number	Question text	Missing %	Don't know %	Missing + don't know %*
1	What was the purpose of this visit?	1.2	-	1.2
2	Were you able to get an appointment time that suited you?	1.1	-	1.1
3	Did you have any of the following difficulties when making this appointment?	4.4	-	4.4
4	From the time you booked this appointment to the time you went to the clinic, how long did you wait?	6.6	4.8	11.5
5	Do you think the amount of time you waited [from booking this appointment to the time you went to the clinic] was...?	4.7	2.4	7.1
6	How much did your symptoms or condition stop you from carrying out your normal daily activities (for example, eating, dressing or using the bathroom) while you waited for this appointment?	5.0	-	5.0
7	While you were waiting for this appointment, did your symptoms or condition...?	4.1	2.8	6.9
8	How long did it take you to travel to the clinic for this appointment?	1.4	0.1	1.5
9	What was your main form of transport to the clinic?	2.5	-	2.5
10	Was there a problem finding parking near the clinic?	0.6	-	0.6
11	At the hospital, was it easy to find your way to the clinic?	1.5	-	1.5
12	Did any of the following cause you difficulties when entering and moving around the clinic?	1.8	-	1.8
13	Were the reception staff polite and courteous?	1.5	-	1.5
14	Did you feel you had enough privacy when talking with the receptionist?	3.2	-	3.2
15	How long after the scheduled appointment time did your appointment actually start?	2.7	1.0	3.7
16	Did you experience any inconvenience or problems as a result of the wait?	0.8	-	0.8
17	Were you told how long you had to wait [for appointment to start]?	1.7	-	1.7
18	Were you told why you had to wait [for appointment to start]?	2.7	-	2.7
19	How comfortable was the waiting area?	1.9	-	1.9
20	How clean was the clinic?	1.2	-	1.2
21	Were you given enough privacy when being examined or treated?	1.6	-	1.6
22	Were you given enough privacy when discussing your condition or treatment?	2.1	-	2.1
23	Who did you see during this visit?	1.5	-	1.5

Question number	Question text	Missing %	Don't know %	Missing + don't know %*
24	Did you have enough time to discuss your health issue with the health professionals you saw?	1.6	-	1.6
25	Did the health professionals explain things in a way you could understand?	1.6	-	1.6
26	During this visit, did the health professionals know enough about your medical history?	1.6	-	1.6
27	How would you rate how well the health professionals worked together?	1.5	-	1.5
28	Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?	2.2	7.9	10.1
29	Did you have worries or fears about your condition or treatment?	2.3	-	2.3
30	Did a health professional discuss your worries or fears with you?	3.3	-	3.3
31	Did you have confidence and trust in the health professionals?	1.9	-	1.9
32	Were the health professionals kind and caring towards you?	2.2	-	2.2
33	Overall, how would you rate the health professionals who treated you?	1.0	-	1.0
34	Do you have a care plan for your cancer treatment?	3.8	4.9	8.7
35	Was your care plan developed by health professionals from this clinic?	5.2	-	5.2
36	Were you asked for your ideas and preferences when developing this [cancer care] plan?	5.4	4.4	9.8
37	At your most recent visit, did the health professionals review your care plan with you?	5.0	4.6	9.6
38	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	2.7	-	2.7
39	Were you treated with respect and dignity while you were at the clinic?	1.5	-	1.5
40	Were your cultural or religious beliefs respected by the clinic staff?	3.1	-	3.1
41	Were you given, or prescribed, any new medication to take at home?	2.5	-	2.5
42	Did a health professional at the clinic explain the purpose of this medication in a way you could understand?	3.8	-	3.8
43	Did a health professional at the clinic tell you about medication side effects to watch for?	4.3	-	4.3
44	Were you given enough information about how to manage the side effects of any other treatment you received during this visit?	3.8	-	3.8
45	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?	2.7	1.8	4.5
46	While in the clinic, did you receive, or see, any information about your rights as a patient, including how to comment or complain?	3.5	26.8	30.3
47	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?	3.4	-	3.4
48	Was the impact of this complication or problem ...?	4.8	-	4.8
49	In your opinion, were the clinic staff open with you about this complication or problem?	4.6	-	4.6
50	Did you have to pay any of the following out of pocket expenses in relation to this visit?	3.3	1.8	5.1

Question number	Question text	Missing %	Don't know %	Missing + don't know %*
51	How long have you been attending this cancer clinic?	1.7	-	1.7
52	In the last 12 months, how many times have you visited this cancer clinic?	2.6	-	2.6
53	Was there any time when the health professionals needed access to your health records and they were not available? [in last 12 months]	1.2	10.3	11.5
54	Did you ever receive conflicting information about your condition or treatment from the health professionals? [in last 12 months]	2.7	-	2.7
55	Overall, how would you rate the care you received in the clinic?	1.3	-	1.3
56	How well organised was the care you received in the clinic?	1.5	-	1.5
57	If asked about your clinic experience by friends and family, how would you respond?	2.2	-	2.2
58	Did you attend this clinic because you have or have had cancer?	1.7	-	1.7
59	Is this the first time you have had cancer?	3.6	-	3.6
60	How has your current cancer responded to treatment?	6.7	-	6.7
61	How long has it been since you first received treatment for this cancer?	1.1	0.9	2.1
62	What treatment have you received for your cancer?	0.9	-	0.9
63	In the past three months, have you gone to an emergency department because of your cancer or cancer complications?	2.9	0.4	3.3
64	CASE-cancer survey (modified)			
65	Edmonton Symptom Assessment System (ESAS)			
66	Age [#]	2.9	-	2.9
67	Gender [#]	1.4	-	1.4
68	Highest level of education completed	4.0	-	4.0
69	Language mainly spoken at home	1.8	-	1.8
70	Did you need, or would you have liked, to use a professional interpreter at any stage while you were at the clinic?	2.6	-	2.6
71	Was a professional interpreter provided when you needed one?	0.8	-	0.8
72	Aboriginal and/or Torres Strait Islander	3.2	-	3.2
73	Which, if any, of the following long-standing conditions do you have (including age related conditions)?	4.2	-	4.2
74	Who completed this survey?	2.1	-	2.1
75	Do you give permission for the Bureau of Health Information to link your survey answers to health records relating to you?	3.9	-	3.9

* 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 gender 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 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.

Appendix Table 3: Derived measures, COPS 2015

Derived measure	Original question	Derived measure categories	Original question responses
The purpose of the visit was for active treatment	What was the purpose of this visit?	<ul style="list-style-type: none"> Chemotherapy, radiotherapy or a surgical procedure 	<ul style="list-style-type: none"> Chemotherapy Radiotherapy Surgical procedure
		<ul style="list-style-type: none"> Other purpose of visit 	<ul style="list-style-type: none"> Have tests, X-rays or scans Receive test, X-ray or scan results Medical diagnosis or advice Regular check-up Review of treatment Follow-up after surgery Other
Had no difficulties entering and moving around the clinic	Did any of the following cause you difficulties when entering and moving around the clinic?	<ul style="list-style-type: none"> Had difficulties 	<ul style="list-style-type: none"> A long walk No ramp/only stairs No lift/elevator Narrow walkways/halls/doorways No accessible toilets Some other difficulty
		<ul style="list-style-type: none"> No difficulties 	<ul style="list-style-type: none"> I had no difficulties Missing

Derived measure	Original question	Derived measure categories	Original question responses
Had no out-of-pocket expenses in relation to visit	Did you have to pay any of the following out of pocket expenses in relation to this visit?	<ul style="list-style-type: none"> Had out-of-pocket expenses None reported 	<ul style="list-style-type: none"> Consultation fees Medication Treatment/surgery costs Travel Parking Accommodation Other related expenses None of these – I had no expenses Don't know/can't remember
Did not experience any complication related to care received from the clinic	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?	<ul style="list-style-type: none"> Had complication None reported 	<ul style="list-style-type: none"> Infection Uncontrolled bleeding Unexpected negative reaction to medication Complications as a result of tests or procedures Severe pain due to the treatment Severe anxiety or worry A pressure wound or bed sore A fall Any other complication or problem (other than common side-effects from treatment) None of these Missing
The stage of my cancer journey is 'under active treatment'	How has your current cancer responded to treatment?	<ul style="list-style-type: none"> Active treatment Not in active treatment 	<ul style="list-style-type: none"> 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 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

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.