# Outpatient Cancer Clinics Survey 2018

## Technical Supplement

October 2019

bureau of health information

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

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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 New South Wales (NSW) Patient Survey Program began sampling patients in NSW public health 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. Responsibility for the NSW Patient Survey Program was transferred from the Ministry to the Bureau of Health Information (BHI) in 2012.

BHI has a contract with Ipsos Public Affairs (Ipsos) to support data collection, while BHI conducts all survey analysis.

The aim of the survey program is to measure and report on patients' experiences in public healthcare facilities in NSW, on behalf of the Ministry and local health districts (LHDs).

This document outlines the sampling methodology, data management and analysis of the Outpatient Cancer Clinics Survey 2018.

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**

## Outpatient Cancer Clinics Survey

The Outpatient Cancer Clinics Survey 2018 was undertaken as part of the NSW Patient Survey Program, administered by BHI. The survey was designed in collaboration with the Cancer Institute NSW, though all analyses are conducted by BHI. The 2018 survey is the fourth undertaken, following surveys in 2015, 2016 and 2017.

This survey also includes three private facilities that are contracted by LHDs to treat public patients. The results are used as a source of performance measurement for individual hospitals, LHDs and NSW as a whole. In particular, the Cancer Institute NSW uses the results of the Outpatient Cancer Clinics Survey in their discussions with LHDs as part of the Reporting for Better Cancer Outcomes program.

### Definition of an outpatient cancer clinic

Outpatient care is provided by a hospital but patients are not admitted. This survey targets outpatient cancer clinics that mainly provide oncology, chemotherapy and radiotherapy services based on the Tier 2 classification of clinics.

BHI also identified additional clinics that mainly provide care for people with cancer (see Drawing the sample, page 6). All clinics in public hospitals identified for participation in the survey were approved for inclusion by the relevant LHD directors of Area Cancer Services, or their equivalent in rural settings.

Patients also attend these clinics for treatment for reasons other than cancer, such as haemoatolgy-related services unrelated to cancer of the blood. In the Outpatient Cancer Clinics Survey 2018, 81% of respondents said they attended the clinic because they have or have had cancer (compared with 82% in 2017).

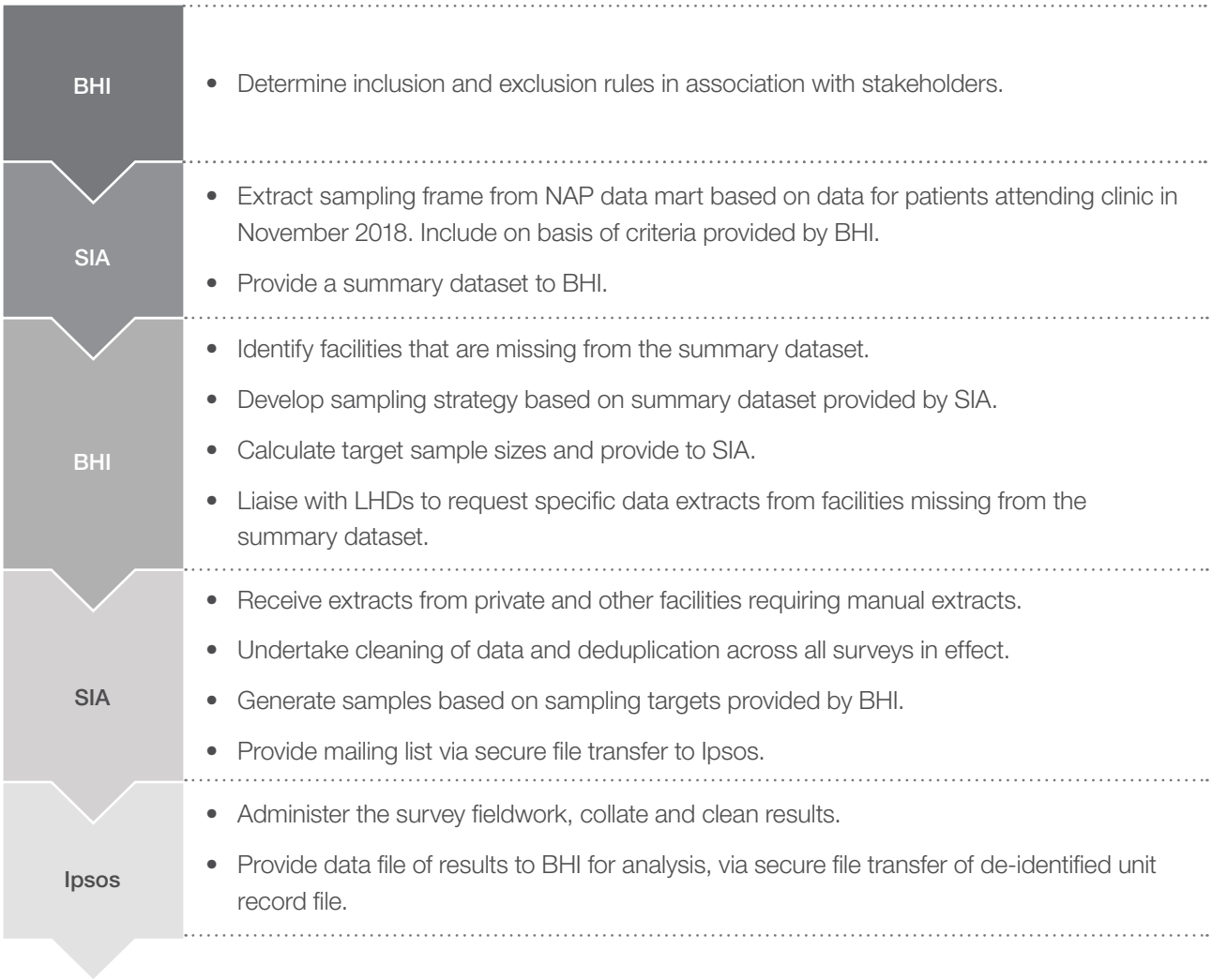
# Producing survey samples

The NSW Patient Survey Program assures patients their responses will be confidential and that staff at facilities will not be able to identify individual patients. BHI achieves this through a number of mechanisms, including:

- reporting aggregated results
- data suppression (of results based on fewer than 30 respondents)
- de-identification of patient comments
- segregation of roles when constructing survey samples (Figure 1).

The sampling method for the NSW Patient Survey Program is a collaboration between staff at BHI, Ipsos and the Ministry's System Information and Analytics (SIA) branch (see Figure 1). The main source of data for the sampling frame is the Ministry's EDWARD Non-admitted Patient (NAP) Activity Data Mart.

Figure 1 Organisational responsibilities in sampling and survey processing, Outpatient Cancer Clinics Survey 2018



# Inclusion criteria

Clinics in public hospitals were defined using the following process:

1. All clinics were defined as belonging to one of the seven cancer clinic types presented in Table 1, except those in Sydney Children's Hospital Randwick or The Children's Hospital at Westmead. These are excluded as most patients from these facilities are under the age of 18.

2. Clinics were added where the following terms were in their title: 'cancer', 'oncol*', 'radiation', 'radioth*', 'chemo*', 'breast', 'melanoma' and 'haema*' in the clinic name AND approved for inclusion by the Director Area Cancer Services (or equivalent) for each LHD (see 'Other' column in Table 5). Clinics anticipated to have at least 80% of patients being treated for cancer were eligible for inclusion.

3. Addition of extra clinics such as haematology and genetics that were identified by the Director Area Cancer Services at their discretion and requested to be included in the survey (see 'Other' column in Table 5). Cancer patients had to make up at least 80% of the patients seen at a clinic to be eligible for inclusion.

4. If unit level data were not available through the NAP data mart, BHI approached the LHD directly to request a data extract be supplied to SIA to allow sampling to occur. If this was not possible then the facility was not able to be included in the survey.

5. Clinics in private facilities were identified by the management of the hospital, and a data extract supplied directly to SIA.

The questionnaire asked patients to reflect on their visit to the clinic in November 2018. Where patients had multiple visits they were included for their most recent visit.

Table 1 Tier 2 services included for sampling, Outpatient Cancer Clinics Survey 2018

| Tier 2 code | Tier 2 name |
|---|---|
| 10.11 | Medical oncology (treatment) |
| 10.12 | Radiation oncology (treatment) |
| 10.20 | Radiation therapy – simulation and planning |
| 20.39 | Gynaecology oncology |
| 20.42 | Medical oncology (consultation) |
| 20.43 | Radiation oncology (consultation) |
| 40.52 | Oncology |
| Other | Other |

* Starting with

## Screening and target calculation

Once SIA received all data extracts and the complete sampling frame on the basis of these inclusion criteria, including patient name and address information, the data were 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
- invalid date of birth
- on the 'do not contact' list
- sampled in the previous six months for any BHI patient survey currently underway
- 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.

For sampling purposes, clinics at Westmead Breast Cancer Institute were treated as a separate entity to other Westmead clinics.

A target was set of 1,000 patients per facility. This means that any facility with less than 1,000 eligible patients is subject to a census, while random sampling took place for any facility with more than 1,000 patients. Where sampling occurred, allocation of the sample was applied approximately proportional to clinic size to provide an allocation more representative across the clinics.

The list of the 44 facilities included and the total number of outpatients eligible for sampling compared with outpatients sampled for the 2018 survey for is provided in Appendix 1.

# Drawing the sample

The sampling frame for the Outpatient Cancer Clinics Survey 2018 was based on data in the NSW non-admitted patient database (EDWARD Non-admitted Patient [NAP] Activity Data Mart). Due to data quality issues in the NAP dataset, BHI contacted one data manager to provide unit-level data extracts directly to SIA for one LHD. Data for the private facilities were provided through a data request.

Three private facilities were included in the survey scope. These facilities – Chris O'Brien Lifehouse, Riverina Cancer Care Centre and Sydney Adventist Hospital – are contracted by LHDs to provide services for public patients. All three private hospitals provided a manual data extract from clinics that they considered appropriate for inclusion.

Facilities in Southern NSW LHD were not sampled due to information system updates occurring at that time.

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 the Outpatient Cancer Clinics Survey 2018, the sampling frames were defined as patients aged 18+ years who attended one of the included NSW outpatient cancer clinics during November 2018. The date of attendance was used to define eligible patients to participate in the survey.

# Data collection and analysis

## Data collection

Respondents are asked to return (paper-based) or submit (electronically) their completed questionnaire to Ipsos. Paper format questionnaires are scanned for fixed response options and manually entered in the case of free text fields. All text entry fields are checked for potential identifiers (e.g. names of patients and doctors, telephone numbers) and any that are found are replaced with 'XXXX'.

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

At the end of this process, Ipsos transfers data securely to BHI's servers, all of which are password protected with limited staff access.

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

## Data analysis

For the Outpatient Cancer Clinics Survey 2018, there were 24,097 questionnaires mailed and 11,378 responses.

### Completeness of questionnaires

Survey completeness is a measure of how many questions each respondent answered as a proportion of all questions in the questionnaire. In the Outpatient Cancer Clinics Survey 2018, the completeness of responses was very high, with 99% of respondents answering at least 39 out of 78 questions (ignoring questions that only have free-text responses).

### Response rate

The response rate is the proportion of people sampled in the survey who actually completed and returned their questionnaire. The response rate, number of mailings and patient population distribution are reported in Table 2 for NSW. 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 3 and 4, respectively). For reasons of data quality and patient confidentiality, hospitals or LHDs with fewer than 30 respondents are not publicly reported, although these responses are still included in LHD and NSW totals.

Table 2 Eligible NSW population, sample and respondents, Outpatient Cancer Clinics Survey 2018

| Eligible patient population | Mailings (in scope) | Population in mailings | Total respondents | Response rate (%) |
|---|---|---|---|---|
| 37,643 | 24,097 | 64% | 11,378 | 47% |

Table 3 Sample size and response rates by LHD, Outpatient Cancer Clinics Survey 2018

| Local health district | Mailings (in scope) | Total respondents | Response rate (%) |
|---|---|---|---|
| Central Coast | 1,311 | 663 | 51 |
| Far West | 75 | 26 | 35 |
| Hunter New England | 2,491 | 1,298 | 52 |
| Illawarra Shoalhaven | 1,740 | 935 | 54 |
| Mid North Coast | 1,714 | 965 | 56 |
| Murrumbidgee | 141 | 58 | 41 |
| Nepean Blue Mountains | 948 | 477 | 50 |
| Northern NSW | 1,258 | 578 | 46 |
| Northern Sydney | 994 | 455 | 46 |
| South Eastern Sydney | 2,335 | 961 | 41 |
| St Vincent's Health Network | 942 | 349 | 37 |
| South Western Sydney | 2,481 | 1,098 | 44 |
| Sydney | 1,861 | 792 | 43 |
| Western NSW | 1,203 | 555 | 46 |
| Western Sydney | 2,638 | 1,182 | 45 |

Note: Southern NSW LHD was not sampled in 2018 due to information system updates that were occurring at the time. Private facilities are not included in this table as they are not managed by LHDs.

Table 4 Sample size and response rates by hospital, Outpatient Cancer Clinics Survey 2018

| Hospital | Mailings (in scope) | Total respondents | Response rate (%) |
|---|---|---|---|
| Armidale Hospital | 277 | 125 | 45 |
| Bankstown-Lidcombe Hospital | 605 | 226 | 37 |
| Bathurst Health Service | 246 | 116 | 47 |
| Blacktown Hospital | 918 | 414 | 45 |
| Broken Hill Health Service* | 68 | 23 | 34 |
| Calvary Mater Newcastle | 989 | 578 | 58 |
| Campbelltown Hospital | 889 | 483 | 54 |
| Chris O'Brien Lifehouse | 983 | 421 | 43 |
| Coffs Harbour Health Campus | 971 | 502 | 52 |
| Concord Repatriation General Hospital | 918 | 412 | 45 |
| Cowra Health Service* | 17 | 10 | 59 |
| Dareton Primary Care & Community Health* | 7 | 3 | 43 |
| Dubbo Base Hospital | 394 | 146 | 37 |
| Gosford Hospital | 933 | 461 | 49 |
| Grafton Base Hospital | 99 | 53 | 54 |
| Griffith Base Hospital* | 67 | 27 | 40 |
| John Hunter Hospital | 182 | 89 | 49 |
| Lachlan Health Service – Parkes* | 34 | 12 | 35 |
| Lismore Base Hospital | 435 | 235 | 54 |
| Liverpool Hospital | 987 | 389 | 39 |
| Manning Hospital | 312 | 175 | 56 |
| Milton Ulladulla Hospital | 54 | 31 | 57 |
| Moree Hospital* | 93 | 28 | 30 |
| Muswellbrook Hospital* | 62 | 27 | 44 |
| Nepean Hospital | 948 | 477 | 50 |
| Orange Health Service | 512 | 271 | 53 |
| Port Macquarie Base Hospital | 743 | 463 | 62 |
| Prince of Wales Hospital | 935 | 393 | 42 |
| Riverina Cancer Care Centre | 474 | 273 | 58 |
| Royal Hospital for Women | 393 | 127 | 32 |
| Royal North Shore Hospital | 994 | 455 | 46 |
| Royal Prince Alfred Hospital | 943 | 380 | 40 |
| Shoalhaven District Memorial Hospital | 804 | 442 | 55 |
| St George Hospital | 848 | 373 | 44 |
| St Vincent's Hospital Sydney | 942 | 349 | 37 |

| Hospital | Mailings (in scope) | Total respondents | Response rate (%) |
|---|---|---|---|
| Sutherland Hospital | 159 | 68 | 43 |
| Sydney Adventist Private Hospital | 508 | 292 | 57 |
| Tamworth Hospital | 576 | 276 | 48 |
| The Tweed Hospital | 724 | 290 | 40 |
| Westmead Breast Cancer Institute | 734 | 293 | 40 |
| Westmead Hospital | 986 | 475 | 48 |
| Wollongong Hospital | 882 | 462 | 52 |
| Wyong Hospital | 378 | 202 | 53 |
| Young Health Service | 74 | 31 | 42 |

*Facilities with fewer than 30 responses cannot be reported for data quality and confidentiality reasons.
Note: Beginning in 2018, Westmead Hospital and Westmead Breast Cancer Institute are sampled and reported separately. Previously they were combined as Westmead Hospital.

## Weighting of data

NSW Patient Survey Program protocol is to 'weight' data to account for differences in the probability of sampling. Weighting makes the results more representative of the overall patient population, so the data are more useful for decision-making and service improvement.

The Outpatient Cancer Clinics Survey 2018 results were weighted at the hospital level to ensure the results at LHD and NSW levels were representative of the differing volumes of eligible patients in each facility.

Different facilities have different mixes of clinical services and demographic distribution, but due to small numbers, it was not possible to adjust weights to account for these differences. This issue should be taken into account when comparing results from different facilities. Supplementary Data Tables provide detail regarding social, demographic and health status differences in patients seen at different facilities.

## Comparing weighted and unweighted patient characteristics

The aim of weighting is to ensure that the distribution of the weighted sample represents the eligible population appropriately for any variables used in the weighting. As weighting was only undertaken at the facility level, representativeness within facilities, for instance by age group or Tier 2 is not assured. Table 5 presents the percentage of patients by LHD, Tier 2 outpatient clinic service type, age and sex at each stage of the survey. The data include:

1. percentage eligible in sampling frame – the percentage of patients in each category in the dataset of eligible patients used to generate the sample (NAP data mart or manual extract, November 2018)
2. percentage of 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 5 Sample size and response rates by hospital, Outpatient Cancer Clinics Survey 2018

| Demographic variable | Sub-group | % eligible in sampling frame | % of sample mailed | % of respondents (unweighted | % of respondents (weighted) |
|---|---|---|---|---|---|
| LHD (or private facility) | Central Coast | 4 | 5 | 6 | 5 |
| | Far West | 0 | 0 | 0 | 0 |
| | Hunter New England | 14 | 10 | 11 | 13 |
| | Illawarra Shoalhaven | 6 | 7 | 8 | 6 |
| | Murrumbidgee | 0 | 1 | 1 | 0 |
| | Murrumbidgee Private | 1 | 2 | 2 | 1 |
| | Mid North Coast | 8 | 7 | 8 | 6 |
| | Nepean Blue Mountains | 2 | 4 | 4 | 3 |
| | Northern NSW | 3 | 5 | 5 | 4 |
| | Northern Sydney | 5 | 4 | 4 | 6 |
| | Northern Sydney Private | 0 | 2 | 3 | 1 |
| | South Eastern Sydney | 9 | 10 | 8 | 8 |
| | St Vincent's Health Network | 2 | 4 | 3 | 4 |
| | South Western Sydney | 9 | 10 | 10 | 12 |
| | Sydney | 3 | 8 | 7 | 6 |
| | Sydney Private | # | 4 | 4 | 8 |
| | Western NSW | 2 | 5 | 5 | 3 |
| | Western Sydney | 11 | 11 | 10 | 13 |
| Tier 2 Outpatient Clinic Service | Medical oncology (treatment) – 10.11 | # | 18 | 18 | 17 |
| | Radiation oncology (treatment) – 10.12 | # | 6 | 7 | 7 |
| | Radiation therapy – simulation and planning – 10.2 | # | 1 | 1 | 1 |
| | Gynaecology oncology - 20.39 | # | 2 | 2 | 3 |
| | Medical oncology (consultation) – 20.42 | # | 31 | 30 | 32 |
| | Radiation oncology (consultation) – 20.43 | # | 12 | 14 | 14 |
| | Oncology – 40.52 | # | 8 | 8 | 7 |
| | Other | # | 22 | 20 | 20 |
| Age stratum | 18–34 | # | 5 | 2 | 2 |
| | 35–54 | # | 19 | 11 | 12 |
| | 55–74 | # | 51 | 55 | 55 |
| | 75+ | # | 25 | 32 | 31 |
| Sex | Female | # | 56 | 53 | 53 |
| | Male | # | 44 | 47 | 47 |

# Sample summaries provided by the Ministry are summarised only by strata variables. As Tier 2, sex and age group were not strata variables for the Outpatient Cancer Clinics Survey 2018, this information is not available.

# Reporting

## Confidentiality

BHI does not receive any confidential patient information and only publishes aggregated data and statistics. Each question must include a minimum of 30 respondents at reporting level (facility, LHD or NSW) for it to be reported to ensure there are enough respondents for reliable estimates to be calculated. This also ensures that patient confidentiality and privacy are protected.

The following hospitals have been suppressed for public reporting of the Outpatient Cancer Clinics Survey 2018 because they have fewer than 30 respondents:

- Far West
- Broken Hill
- Cowra
- Dareton
- Griffith
- Moree
- Muswellbrook
- Parkes

Respondents' results, however, will still contribute to their respective LHD and to the NSW results.

For the Outpatient Cancer Clinics Survey 2018, all reportable hospitals had a response rate of at least 25%.

## Reporting of private facilities

Chris O'Brien Lifehouse, Sydney Adventist Hospital, and Riverina Cancer Care Centre are private facilities that are contracted to provide services for some public patients and therefore are included in this survey and reported at the hospital level. These facilities differ in administrative and organisational arrangements from public facilities. Although they are contracted to provide services for some public patients, they are not under the management of the LHD in which they are located. Therefore, caution is advised when comparing results from Chris O'Brien Lifehouse, Sydney Adventist Hospital or Riverina Cancer Care Centre with public facilities in the survey. These facilities are not included in LHD-level results, but are included in the overall NSW results.

## Statistical analysis

Analysis was undertaken in SAS V9.4 with the SURVEYFREQ procedure, using a finite population correction factor and the Clopper Pearson adjustment for confidence interval calculation. 'Facility' was included as a strata variable. 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 weighted for all questions, with the exception of questions related to socio-demographic characteristics and self-reported health.

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** – the numerator/denominator x 100.

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 was used for a question that asked about a third party (e.g. if family had enough opportunity to talk to the doctor) or when the percentage responding with this option was more than 10%.

When reporting on questions that are used to filter respondents through the questionnaire rather than asking about facility performance, the 'don't know/can't remember' option and missing responses were also reported. Appendix 2 presents the rates of missing or 'don't know' responses for the Outpatient Cancer Clinics Survey 2018.

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

## Interpret with caution

All sample surveys are subject to sampling error (i.e. the difference between results based on surveying a selection of respondents, and the results if all people who received care were surveyed). The true result is expected to fall within the 95% confidence interval 19 times out of 20.

Where the confidence interval was wider than 20 percentage points, results are noted with a "*" to indicate 'interpret with caution'. In addition, percentages of 0 or 100, which do not have confidence intervals, are also noted as 'interpret with caution' where the number of respondents is less than 200.

## Reporting by population group

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

- Age group
- Cancer type
- Sex
- Education level
- Language spoken at home
- Has long-standing health condition or not
- Quintile of disadvantage
- Rurality of patient residence
- Country of birth.

## ESAS and CASE-Cancer

The Outpatient Cancer Clinics Survey 2018 questionnaire also includes two validated question sets that are used internationally to assess cancer symptoms and patient attitudes. The Edmonton Symptom Assessment System (ESAS)[3] was developed in Canada and is one of the most commonly used tools 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 indicating the symptom is not being experienced (e.g. 'no pain') and 10 being the worst possible severity. The Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer)[4] 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.

For both measures, respondents were asked to rate their symptoms and attitudes at the time of completing the questionnaire as opposed to thinking back to their clinic visit in November 2018. Because of the time lag between the clinic visit and completing the questionnaire, and not knowing what might have happened to the patient during that time, these measures do not necessarily reflect the performance of a facility. Therefore, the results are not reported by BHI as measures of performance.

## Standardised comparisons

Until now, BHI's approach to comparisons between hospitals and NSW-level results in BHI reports relied on a basic method (overlapping confidence intervals) to determine if the experiences reported for each hospital differed significantly from the NSW result. While this method is commonly used to highlight differences in survey results, it cannot take into account differences in the mix of patient characteristics across facilities.

To enable fairer comparisons across facilities and as part of the implementation of standardised comparisons, BHI reporting now takes the mix of patient characteristics at each facility (including age, sex, education level, and language) into account. Therefore, when a hospital is flagged as having a significantly higher or lower result than NSW, this is more likely to reflect differences in patient experiences and less likely to reflect differences in the facility's patient mix.

The difference between the former and new methods might not be entirely due to adjustment for patient characteristics. It could also be partly due to the different method used for identifying the outliers (i.e. overlapping confidence intervals vs. p-values).

## Methodology

For performance-related survey questions, the percentage of respondents who selected the most positive response category was compared between each facility and NSW. For example, one question asked patients: Were you given enough privacy when being examined or treated? It had the following response options:

- Yes, always
- Yes, sometimes
- No.

In this case, the most positive response is "Yes, always" (i.e. the event), and the other two responses are grouped together for the analyses (i.e. the reference group).

Logistic regression mixed models were used for all analyses, with hospitals as random intercept terms. Patient characteristics were fixed covariates in the model.

For each performance question in the survey, the most positive response option was treated as the 'event' and the other response options were grouped to create a binary dependent variable.

The general formula for the logistic mixed model is:

$$g\big(E(Y_i)\big) = \boldsymbol{\beta X_i} + b_i Z_i$$
$$b_i \sim N(0; D)$$

where:

- the link function $g(\cdot)$ is the logistic function $g(\pi_{ij}) = \log\left(\frac{\pi_{ij}}{1-\pi_{ij}}\right)$
- $\boldsymbol{X_i}$ is the design matrix for fixed effect covariates
- $\boldsymbol{\beta}$ is the vector containing estimates for fixed effect covariates
- $Z_i$ is the design matrix for random effects, $i$=1 to number of hospitals
- $b_i$ is the vector of random intercepts (hospitals), $i$=1 to number of hospitals

## Covariate selection

Differences in patient experiences between groups may reflect differences in experiences of care. However, they may also reflect differences in expectations or the way various groups tend to respond to surveys. To enable fairer comparisons across facilities, the enhanced reporting method will look at which patient characteristics may be consistently associated with more positive or less positive reported experiences.

Information regarding rurality of patients and socio-economic status (SES) were also considered as they may relate to response tendency. However, BHI chose not to include factors such as rurality or SES as these factors may reflect differences in care. Instead, analyses of results by these patient groups will be presented in BHI's interactive data portal, Healthcare Observer, to allow hospitals to see which patient groups reported more or less positive experience of care. A list of all patient characteristics considered for inclusion in the model proposed for standardised comparisons and how they were sourced are included in Table 6.

Information on patient health status such as self-reported overall health or mental health status could also influence both experiences of care and responding tendency, but were not considered for inclusion in the model. Currently BHI is only standardising comparisons for experience of care questions by adjusting patient, not clinical, characteristics.

For age and sex, missing values were filled in using administrative data. Following this, there was no missing data for age and sex. Missing data for other patient characteristics were included in all analyses as an extra category in the model. Missing data in performance-related questions were excluded from all analyses.

Table 6 Patient characteristics considered for adjustment

| Variable | Source | Categories |
|---|---|---|
| Age | Survey question, or using administrative data if missing | 18-34, 35-54, 55-74, 75+ |
| Sex | Survey question, or using administrative data if missing | Male, Female |
| Education | Survey question | Completed Year 12, trade/technical certificate/diploma, university degree, postgraduate degree, missing |
| Language mainly spoken at home | Survey question | English, language other than English, missing |
| Proxy response | Survey question | The patient, the patient with help, other people on patient's behalf, missing |
| Patient type | Survey question | Non-cancer patients, active treatment phase, receiving treatment at visit, active treatment phase, follow-up visit, non-active treatment phase but receiving treatment at visit, non-active treatment phase, follow-up visit, missing |
| Cancer type | Survey question | Prostate<br>Breast<br>Bowel (colon, rectal, anus)<br>Lung<br>Skin/melanoma<br>Upper gastrointestinal (oesophagus, stomach, liver, pancreatic, bile ducts)<br>Gynaecological (e.g. ovarian, endometrial, cervical)<br>Brain or spinal column<br>Head and neck<br>Blood (e.g. lymphoma, leukaemia, marrow, lymph nodes)<br>Other (e.g. bone, mesothelioma, thyroid)<br>Cancer type not yet known<br>Missing (including those who attended the clinics for reasons other than cancer) |

These patient characteristics were then passed through two selection stages, as follows:

1. Univariate models were fitted for each patient characteristic (covariate) for all performance-related questions in the survey. Covariates with $p<0.1$ in the univariate models for at least 50% of the questions were considered for inclusion in the multivariate model.

2. Multivariate logistic mixed models were fitted across all performance-related questions in the survey using the covariates selected from stage one, with age and sex included in all models. Forward stepwise modelling was used based on the equation above, including age, sex and all additional covariates added appropriately following a forward stepwise approach. Selected interaction terms were also tested.

Within each outcome (i.e. performance-related survey question) the models were ranked by the Akaike Information Criterion (AIC) – the model with the smallest AIC value was assigned the highest rank of 1. The AIC was recommended as an appropriate method for selecting models where different fixed effects are included as it applies a penalty for the number of covariates in order to protect against model overfitting.[1]

The following values were obtained:

- Number of questions for which the model was ranked first
- Mean rank across all questions
- Mean AIC value across all questions.

These values were used to identify the optimal model to create adjusted comparisons for the survey results, with each survey from the NSW Patient Survey Program assessed independently. That is, the optimal model had a high count of 1st ranking, a low mean rank, and a low mean AIC relative to other models, across all performance-related questions in the survey.

Finally, we excluded covariates that marginally improved the model by comparing the models' AIC values, to define a parsimonious number of patient-related covariates to use in standardised comparisons. We also excluded covariates that were not part of patient characteristics (e.g. whether patients were staying overnight or had same-day admission).

This is because standardised comparisons are intended to control for differences only in patient characteristics, and some of these factors were considered to be under the control of hospital management rather than patients.

In all cases, further assessments of the AIC summary values indicated that the smaller model had results very similar to those with the hospital factors included (e.g. stay type, admission type). The remaining covariates were then used in the final model to adjust for each performance-related question to create the standardised comparisons. Table 7 presents a list of covariates that were considered for adjustment by selection stage and survey.

## Model-based comparisons

The model calculates an estimate for each hospital's random intercept, and produces a p-value to indicate how likely these estimates are different from the average, or NSW value.

The exponential values of the estimated hospital random intercepts, based on the random intercept logistic regression model, can be used to estimate the odds of a positive experience (e.g. 'very good' for overall care question) for the hospital with reference to an 'average' hospital. The p-value for each hospital intercept estimate was used to determine if the hospital was significantly different from NSW, when adjusted for patient characteristics, using the following guidelines:

- If the p-value was less than the significance level (0.01) and the solution for the hospital random intercept was greater than 0, the hospital was flagged as having a more positive result than NSW.
- If the p-value was less than the significance level and the random effect solution was less than 0, the hospital was flagged as having a less positive result than NSW.
- If the p-value was greater than the significance level, the hospital was flagged grey as not significantly different to NSW.
- If a result has been flagged as 'interpret with caution', comparisons are not highlighted due to the lack of precision in the result.

When making multiple comparisons there is an increased likelihood of flagging a difference that is not 'real', but due to chance. To mitigate this issue, a p-value of 0.01 was used to reduce the likelihood of identifying differences due to chance to 1 comparison in 100 (from 1 in 20, with the more commonly used p-value of 0.05). Sampling weights were used in all models to ensure the comparisons were representative of the NSW patient population.

Table 7 Covariates considered for adjustment for comparisons at each selection stage by survey.

| | Available for adjustment | Passed univariate model selection threshold (stage 1) | Passed multivariate model selection threshold (stage 2) | After consultation with expert panel and confirmed by sensitivity analyses |
|---|---|---|---|---|
| Age | ✓ | ✓ | ✓ | ✓ |
| Sex | ✓ | ✓ | ✓ | ✓ |
| Education | ✓ | ✓ | ✓ | ✓ |
| Language spoken at home | ✓ | ✓ | ✓ | ✓ |
| Cancer type | ✓ | ✓ | ✓ | ✓ |
| Patient type | ✓ | ✓ | | |

## Statistical software

SAS software version 9.4 was used for all statistical analyses (Copyright © 2018 SAS Institute Inc. SAS and all other SAS Institute Inc. product or service names are registered trademarks or trademarks of SAS Institute Inc., Cary, NC, USA. SAS 9.4 [English]). PROC GLIMMIX procedure was used for performing logistic mixed models.

## Sensitivity analyses

For the Outpatient Cancer Clinics Survey 2017, cancer type was statistically significant ($p<0.1$) in the univariate models for 36 out of 42 performance questions, therefore it proved to be a strong variable for adjustment.

Additionally, it was suggested that the four-covariate model with age, sex, education level and language spoken at home for AAPS and EDPS may also be appropriate for the Outpatient Cancer Clinics Survey. This model was compared with the five-covariate model including cancer type.

The results from AIC were very similar between the two models (average AIC=6847 vs. 6857 for full vs. reduced model). However, due to clinical importance, cancer type was retained in the final model for adjustment.

# Appendix 1

## Facilities included in the Outpatient Cancer Clinics Survey 2018 sampling frame

Table 8 Eligible patients, sampled patients and proportion sampled by hospital, Outpatient Cancer Clinics Survey 2018

| Hospital | Total eligible patients | Total sampled | Percentage sampled |
|---|---|---|---|
| Armidale | 285 | 285 | 100% |
| Bankstown-Lidcombe | 616 | 616 | 100% |
| Bathurst | 253 | 253 | 100% |
| Blacktown | 1,073 | 942 | 88% |
| Broken Hill | 73 | 73 | 100% |
| Calvary Mater Newcastle | 3,250 | 1,013 | 31% |
| Campbelltown | 956 | 919 | 96% |
| Chris O'Brien Lifehouse – Public Contracted Services | 3,106 | 1,009 | 32% |
| Coffs Harbour | 1,223 | 998 | 82% |
| Concord | 1,329 | 933 | 70% |
| Cowra | 17 | 17 | 100% |
| Dareton | 7 | 7 | 100% |
| Dubbo | 417 | 417 | 100% |
| Gosford | 1,335 | 965 | 72% |
| Grafton | 103 | 103 | 100% |
| Griffith | 68 | 68 | 100% |
| John Hunter | 190 | 190 | 100% |
| Parkes | 36 | 36 | 100% |
| Lismore | 448 | 448 | 100% |
| Liverpool | 2,954 | 1,006 | 34% |
| Manning | 331 | 331 | 100% |
| Milton Ulladulla | 55 | 55 | 100% |
| Moree | 98 | 98 | 100% |
| Muswellbrook | 63 | 63 | 100% |
| Nepean | 1220 | 986 | 81% |
| Orange | 529 | 529 | 100% |
| Port Macquarie | 882 | 771 | 87% |
| Prince of Wales | 1504 | 956 | 64% |
| Riverina | 483 | 483 | 100% |
| Royal Hospital for Women | 396 | 396 | 100% |
| Royal North Shore | 2,195 | 1,011 | 46% |
| Royal Prince Alfred | 1,108 | 952 | 86% |
| Shoalhaven | 826 | 817 | 99% |
| St George | 875 | 875 | 100% |

| Hospital | Total eligible patients | Total sampled | Percentage sampled |
|---|---|---|---|
| St Vincent's | 1,460 | 967 | 66% |
| Sutherland | 165 | 165 | 100% |
| Sydney | 529 | 529 | 100% |
| Tamworth | 590 | 589 | 100% |
| The Tweed | 792 | 733 | 93% |
| Westmead Breast Cancer | 739 | 739 | 100% |
| Westmead | 3,218 | 1,008 | 31% |
| Wollongong | 1,380 | 908 | 66% |
| Wyong | 391 | 391 | 100% |
| Young | 75 | 75 | 100% |
| **NSW total** | **37,643** | **24,725** | **66%** |

# Appendix 2

## Missing and 'don't know' responses

Table 9 Proportion of 'don't know' and missing responses, by question, Outpatient Cancer Clinics Survey 2018

| Number | Question | Missing % | Don't know % | Missing + Don't know %* |
|---|---|---|---|---|
| 1 | What was the purpose of this visit? | 2.6 | | 2.6 |
| 2 | How long did it take you to travel to the clinic for this appointment? | 2.0 | 0.2 | 2.2 |
| 3 | Did you need parking for your clinic visit? | 3.2 | | 3.2 |
| 4 | Did you have any of the following issues with parking during this visit? | 3.5 | | 3.5 |
| 5 | Were the reception staff polite and courteous? | 0.7 | | 0.7 |
| 6 | How long after the scheduled appointment time did your appointment actually start? | 2.2 | 2.6 | 4.8 |
| 7 | Were you told how long you had to wait [for appointment to start]? | 5.3 | | 5.3 |
| 8 | How comfortable was the waiting area? | 0.8 | | 0.8 |
| 9 | How comfortable was the treatment area? | 1.0 | | 1.0 |
| 10 | How clean was the treatment area? | 0.6 | | 0.6 |
| 11 | Who did you see during this visit? | 1.7 | | 1.7 |
| 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? | 2.1 | | 2.1 |
| 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? | 1.5 | | 1.5 |
| 16 | Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you? | 2.0 | 8.2 | 10.3 |
| 17 | Did you have worries or fears about your condition or treatment? | 2.5 | | 2.5 |
| 18 | Did a health professional discuss your worries or fears with you? | 3.1 | | 3.1 |
| 19 | Did you have confidence and trust in the health professionals? | 2.0 | | 2.0 |
| 20 | Were the health professionals kind and caring towards you? | 1.9 | | 1.9 |
| 21 | Overall, how would you rate the health professionals who treated you? | 1.9 | | 1.9 |
| 22 | When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options? | 2.9 | | 2.9 |
| 23 | Did a health professional at the clinic tell you about the risks and benefits of the treatment options? | 2.3 | | 2.3 |
| 24 | Were you involved, as much as you wanted to be, in decisions about your care and treatment? | 2.4 | | 2.4 |
| 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 | Did you ever receive conflicting information about your condition or treatment from the health professionals? | 3.1 | | 3.1 |
| 27 | Do you have a written care plan for your current or ongoing care? | 3.9 | 6.0 | 9.9 |

| Number | Question | Missing % | Don't know % | Missing + Don't know %* |
|---|---|---|---|---|
| 28 | Were you asked about your preferences for care and treatment when developing this plan? | 4.4 | 10.8 | 15.2 |
| 29 | At your November visit, did the health professionals review your care plan with you? | 4.3 | 7.5 | 11.7 |
| 30 | Did you receive any treatment during this visit (chemotherapy, radiotherapy, surgery or other treatments)? | 2.7 | | 2.7 |
| 31 | Did a health professional at the clinic explain what would be done during your treatment in a way you could understand? | 4.1 | | 4.1 |
| 32 | Did a health professional at the clinic tell you about possible side effects of your treatment? | 4.7 | | 4.7 |
| 33 | Were you given enough information about how to manage the side effects of your treatment? | 5.0 | | 5.0 |
| 34 | During this visit, were you given, or prescribed, any new medication to take at home? | 2.7 | | 2.7 |
| 35 | Did a health professional at the clinic explain the purpose of this [new] medication in a way you could understand? | 2.7 | | 2.7 |
| 36 | Did a health professional at the clinic tell you about side effects of this medication to watch for? | 3.2 | | 3.2 |
| 37 | Were you told who to contact if you were worried about your condition or treatment after you left the clinic? | 2.2 | 2.5 | 4.7 |
| 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? | 2.6 | 1.4 | 4.1 |
| 39 | Were you treated with respect and dignity while you were at the clinic? | 1.00 | | 1.00 |
| 40 | Were you given enough privacy when being examined or treated? | 1.67 | | 1.67 |
| 41 | Were you given enough privacy when discussing your condition or treatment? | 1.77 | | 1.77 |
| 42 | Were you ever treated unfairly for any of the reasons below? | 4.54 | | 4.54 |
| 43 | Were your cultural or religious beliefs respected by the clinic staff? | 3.18 | | 3.18 |
| 44 | During your visit or soon afterwards, did you experience any of the following complications or problems? | 3.96 | | 3.96 |
| 45 | Was the impact of this complication or problem...? | 3.35 | | 3.35 |
| 46 | In your opinion, were the health professionals open with you about this complication or problem [that you experienced during or soon after your visit]? | 3.06 | | 3.06 |
| 47 | In the past three months, have you gone to an emergency department because of complications related to the care you received? | 2.59 | 0.84 | 3.44 |
| 48 | Did a staff member at this clinic ask you if you smoked/used tobacco? | 2.28 | 16.96 | 19.24 |
| 49 | At the time of your clinic visit, how often were you smoking/using tobacco? | 2.39 | | 2.39 |
| 50 | Has a staff member at this clinic done any of the following in the past year? | 3.87 | 8.41 | 12.28 |
| 51 | Overall, how would you rate the care you received at the clinic? | 0.90 | | 0.90 |
| 52 | If asked about your clinic experience by friends and family, how would you respond? | 1.33 | | 1.33 |
| 53 | How well organised was the care you received at the clinic? | 1.49 | | 1.49 |

| Number | Question | Missing % | Don't know % | Missing + Don't know %* |
|---|---|---|---|---|
| 54 | [At this cancer clinic over the past six months] How much were your out-of-pocket expenses for medication related to these visits? | 2.33 | 4.28 | 6.61 |
| 55 | [At this cancer clinic over the past six months] How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these visits (excluding medication)? | 2.53 | 4.60 | 7.13 |
| 56 | [At this cancer clinic over the past six months] How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)? | 2.42 | 3.24 | 5.66 |
| 57 | Did you attend this clinic because you have or have had cancer? | 2.25 | | 2.25 |
| 58 | Is this the first time you have had cancer? | 4.51 | | 4.51 |
| 59 | What was the main type of cancer you were receiving care for at this clinic? | 7.70 | | 7.70 |
| 60 | 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... | 3.65 | | 3.65 |
| 61 | How has your current cancer responded to treatment? | 7.01 | | 7.01 |
| 62 | How long has it been since you first received treatment for this cancer? | 2.25 | 0.53 | 2.78 |
| 63 | In the past three months, what treatment have you received for your cancer? | 3.88 | | 3.88 |
| 66 | What year were you born? | 1.76 | | 1.76 |
| 67 | What is your sex? | 1.39 | | 1.39 |
| 68 | What is the highest level of education you have completed? | 2.36 | | 2.36 |
| 69 | Language mainly spoken at home | 1.35 | | 1.35 |
| 70 | Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic? | 1.46 | | 1.46 |
| 71 | Did the clinic provide an interpreter when you needed one? | 4.67 | | 4.67 |
| 72 | Aboriginal and/or Torres Strait Islander | 2.46 | | 2.46 |
| 73 | Did you receive support, or the offer of support, from an Aboriginal Health Worker during your November visit to the clinic? | 5.65 | 7.34 | 12.99 |
| 74 | Which, if any, of the following longstanding conditions do you have (including age-related conditions)? | 4.03 | | 4.03 |
| 75 | Does this condition(s) cause you difficulties with your day-to-day activities? | 2.99 | | 2.99 |
| 76 | Are you a participant of the National Disability Insurance Scheme (NDIS)? | 3.42 | 7.22 | 10.64 |
| 77 | Who completed this survey? | 1.94 | | 1.94 |
| 78 | Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you (the patient)? | 12.27 | | 12.27 |
| 64 | Rating of cancer symptom severity: Pain | 5.30 | | 5.30 |
| 64 | Rating of cancer symptom severity: Tiredness | 5.82 | | 5.82 |
| 64 | Rating of cancer symptom severity: Nausea | 5.67 | | 5.67 |
| 64 | Rating of cancer symptom severity: Depression | 5.72 | | 5.72 |
| 64 | Rating of cancer symptom severity: Anxiety | 6.01 | | 6.01 |
| 64 | Rating of cancer symptom severity: Drowsiness | 6.28 | | 6.28 |

| Number | Question | Missing % | Don't know % | Missing + Don't know %* |
|---|---|---|---|---|
| 64 | Rating of cancer symptom severity: Loss of appetite | 6.32 | | 6.32 |
| 64 | Rating of cancer symptom severity: Wellbeing | 7.02 | | 7.02 |
| 64 | Rating of cancer symptom severity: Shortness of breath | 5.63 | | 5.63 |
| 65 | I know that I will be able to deal with any unexpected health problems | 8.08 | | 8.08 |
| 65 | I am confident in my ability to understand written information about cancer | 6.95 | | 6.95 |
| 65 | I am confident in my ability to understand my doctor's instructions | 6.21 | | 6.21 |
| 65 | It is easy for me to actively participate in decisions about my treatment | 7.30 | | 7.30 |
| 65 | I won't let cancer get me down | 6.64 | | 6.64 |
| 65 | It is easy for me to keep a positive attitude | 6.29 | | 6.29 |
| 65 | It is easy for me to maintain a sense of humour | 6.22 | | 6.22 |
| 65 | I am confident that I can control my negative feelings about cancer | 6.77 | | 6.77 |
| 65 | If I don't understand something, it is easy for me to ask for help | 6.23 | | 6.23 |
| 65 | It is easy for me to ask nurses questions | 6.90 | | 6.90 |
| 65 | It is easy for me to ask my doctor questions | 5.63 | | 5.63 |
| 65 | It is easy for me to get information about cancer | 6.28 | | 6.28 |

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

# 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)**.

### 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 10).

### Exclusions

For derived measures, the following responses were 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).

Table 10 Derived measures, Outpatient Cancer Clinics Survey 2018

| Derived measure | Question | Derived measure categories | Response options |
|---|---|---|---|
| Visit included chemotherapy, immunotherapy, radiotherapy, transfusion, surgical procedure | Q1. What was the purpose of this visit? To receive treatment | To receive treatment | Chemotherapy |
| | | | Radiotherapy |
| | | | Immunotherapy or hormone therapy |
| | | | Transfusion |
| | | | 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 |

| Derived measure | Question | Derived measure categories | Response options |
|---|---|---|---|
| Issues with parking | 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 carpark was full |
| | | | Too few disabled parking spaces |
| | | | Expensive parking fees |
| | | | 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 |
| Do you have a written care plan for your current or ongoing care? | Q27. Do you have a written care plan for your current or ongoing care? | Needed a written care plan | Yes |
| | | | No |
| | | Did not need a written care plan | I do not need one |
| | | 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 | Age |
| | | | Sex |
| | | | Aboriginal background |
| | | | Ethnic background |
| | | | Religion |
| | | | Sexual orientation |
| | | | Disability |
| | | | 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 | Question | Derived measure categories | Response options |
|---|---|---|---|
| During your visit or soon afterwards, did you experience any of the following complications or problems? | Q44. During your visit or soon afterwards, did you experience any of the following complications or problems? (derived measure) | Had complication | An infection |
| | | | Uncontrolled bleeding |
| | | | An unexpected negative reaction to medication |
| | | | A complication as a result of tests or procedures |
| | | | Severe pain due to the treatment |
| | | | Lymphoedema (chronic excessive swelling) |
| | | | Severe anxiety or worry |
| | | | Any other complication or problem |
| | | None reported | None<br>Missing |
| 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 left | Not applicable, as it happened after I left |
| Staff have advised to quit smoking, and/or offered to refer you to quitline or similar, offered nicotine replacement or provided other help to quit smoking | Q50. Has a staff member at this clinic done any of the following in the past year? | Yes | Advised you to quit smoking |
| | | | Offered to refer you to the Quitline or a smoking support service/professional |
| | | | Offered you nicotine replacement therapy (e.g. patches, gum) |
| | | | Provided other help to quit smoking |
| | | No | None of the above |

| Derived measure | Question | Derived measure categories | Response options |
|---|---|---|---|
| Currently undergoing active treatment | Q61. 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 |
| Received treatment in the past three months for your cancer | Q63. 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 |

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bureau of health information

# About the Bureau of Health Information

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

BHI was established in 2009 and supports the accountability of the healthcare system by providing regular and detailed information to the community, government and healthcare professionals. This in turn supports quality improvement by highlighting how well the healthcare system is functioning and where there are opportunities to improve.

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

BHI publishes a range of reports and information products, including interactive tools, that provide objective, accurate and meaningful information about how the health system is performing.

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

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