Outpatient Cancer Clinics Survey 2019

Technical Supplement

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bureau of health information

BUREAU OF HEALTH INFORMATION
1 Reserve Road
St Leonards NSW 2065
Australia
Telephone: +61 2 9464 4444
bhi.nsw.gov.au

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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). 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 a survey vendor to support data collection, while BHI conducts all survey development and analysis.

The aim of the NSW Patient 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). The survey program is guided by the NSW Patient Survey Program Strategy 2019–22, which ensures that all patient surveys maximise benefits to patients and deliver unique value for the NSW health system.

This document outlines the sampling methodology, data management and analysis of the results of the Outpatient Cancer Clinics Survey 2019.

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 2019 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 2019 survey is the fifth undertaken, following surveys in 2015, 2016, 2017 and 2018.

For changes in the questionnaire content between the Outpatient Cancer Clinics Survey 2018 and the Outpatient Cancer Clinics Survey 2019, please refer to the development report on BHI's website.

In addition to NSW public facilities, this survey 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 facilities, 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

This survey targets outpatient cancer clinics that mainly provide oncology, chemotherapy and radiotherapy services as defined in the Independent Hospital Pricing Authority (IHPA) Non-admitted Services Classification (Tier 2).

BHI also identified additional clinics that mainly provide care for people with cancer (see Drawing the sample, page 5). All clinics in public facilities 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 haematology-related services unrelated to cancer of the blood. In the Outpatient Cancer Clinics Survey 2019, 79% of respondents said they attended the clinic because they have or have had cancer (compared with 81% in 2018).

Producing survey samples

The NSW Patient Survey Program assures patients that their responses will be confidential and no identifying information will be given to the facilities they attended. BHI does this through a number of mechanisms, including:

- data suppression (results for LHDs and facilities with fewer than 30 responses are suppressed)
- reporting aggregated results
- anonymisation of patient comments
- segregation of roles when constructing the survey samples (Figure 1).

The sampling method for the NSW Patient Survey Program is a collaboration between BHI, the survey vendor and the Ministry's Systems Information and Analytics (SIA) branch (see Figure 1). The Ministry's Enterprise Data Warehouse for Analysis Reporting and Decisions (EDWARD) Non-admitted Patient (NAP) Activity data mart is the main source of data for the sampling frame.

Since 2018, Westmead Hospital and Westmead Breast Cancer Institute have been sampled and reported separately. In previous years these facilities' results were combined as Westmead Hospital.

Figure 1 Organisational responsibilities in sampling and survey processing, Outpatient Cancer Clinics Survey 2019

BHI	• Determine inclusion and exclusion rules in association with stakeholders.
SIA	• Extract sampling frame from NAP data mart based on data for patients attending clinics in November 2019. Include on basis of criteria provided by BHI. • Provide a summary dataset to BHI.
BHI	• Identify facilities that are missing from the summary dataset. • Develop sampling strategy based on summary dataset provided by SIA. • Calculate target sample sizes and provide to SIA. • Liaise with LHDs to request specific data extracts from facilities missing from the summary dataset.
SIA	• Receive extracts from private and other facilities requiring manual extracts. • Undertake cleaning of data and deduplication across all surveys in effect. • Generate samples based on sampling targets provided by BHI. • Provide mailing list via secure file transfer to the survey vendor.
Survey vendor	• Administer the survey fieldwork, collate and clean results. • Provide data file of results to BHI for analysis, via secure file transfer of de-identified unit record file.

Inclusion criteria

The questionnaire asked patients to reflect on their visit to the clinic in November 2019. Where patients had multiple visits, their most recent visit was retained for sampling.

Clinics in public facilities were defined using the following process:

1. All clinics were defined as providing one of the seven cancer services as defined in the IHPA Non-Admitted Services Classification (Tier 2), presented in Table 1. Sydney Children's Hospital, Randwick and The Children's Hospital at Westmead were excluded as most patients from these facilities are under the age of 18.
2. Clinics classified as cancer services 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 1). 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 1). 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 or where there were data quality issues in the NAP dataset, BHI approached the LHD to request a unit-level data extract be supplied directly to SIA to allow sampling to occur.

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

Table 1 Tier 2 services included for sampling, Outpatient Cancer Clinics Survey 2019

Tier 2 code	Tier 2 name
10.11	Chemotherapy Treatment
10.12	Radiation Therapy – Treatment
10.20	Radiation Therapy – Simulation and Planning
20.39	Gynaecological Oncology
20.42	Medical Oncology – Consultation
20.43	Radiation Therapy – Consultation
40.52	Oncology
Other	Other Tier 2 services related to cancer treatments

Screening and target calculation

Once all unit-level data extracts from the LHDs were received, SIA created the initial sampling frame based on the inclusion criteria. This file was then combined with the patient name and address information.

Exclusions

Before finalisation, the sampling frame passed through the following exclusion checks to identify patients to be excluded from the sampling frame:

- Invalid address (including those with addresses listed as hotels, motels, nursing homes, community services, Mathew 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
- Recorded as deceased according to the NSW Registry of Birth Deaths and Marriages and/or Agency Performance and Data Collection, prior to the sample being provided to the survey vendor.

The result was considered by BHI as the final sampling frame.

Targets for sampling

A target was set of 1,000 patients per clinic. This means that any clinic with less than 1,000 eligible patients is subject to a census, while random sampling took place for any clinic 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 49 facility locations of the included cancer clinics and the total number of patients eligible for sampling, compared with patients sampled for the 2019 survey, is provided in Appendix 1.

Drawing the sample

The sampling frame for the Outpatient Cancer Clinics Survey 2019 was based on data in the Ministry's EDWARD NAP Activity data mart. Where there were data quality issues in the NAP dataset, LHDs provided unit-level data extracts directly to SIA.

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 facilities provided a manual unit-level data extract from clinics that they considered appropriate for inclusion.

For the Outpatient Cancer Clinics Survey 2019, the sampling frames were defined as patients aged 18+ years who attended one of the included NSW outpatient cancer clinics during November 2019. The date of attendance was used to define eligible patients to participate in the survey.

As BHI does not have access to confidential non-admitted patient data, sample sizes for each facility were calculated based on aggregated clinic-level data provided by SIA.

Southern NSW LHD was not sampled in 2018 due to information system updates occurring at that time, however, they were sampled in 2019.

Data collection and analysis

Data collection

Patients sampled received a paper questionnaire and were given the option to complete the questionnaire online. Respondents were asked to return (for paper questionnaire) or submit (for electronic questionnaire) their completed questionnaire to the survey vendor. Paper questionnaires were scanned for fixed response options and manually entered in the case of free text fields.

All text entry fields were checked for potential identifiers (e.g. mention of patient or staff names and contact details) and to remove offensive language, and any that were found were replaced with 'XXXX'. However, on rare occasions, details may not be detected by coders, and these comments should be anonymised on detection by LHDs, who are provided comments for their facilities.

Following this, each record was checked for any completion errors. Reasonable adjustments were made, such as removing responses where the respondent did not correctly follow the instructions or where the respondent provided multiple answers to a single response question.

At the end of this process, the survey vendor transferred the prepared de-identified records securely to BHI's servers, all of which are password protected with limited staff access.

The process of data collection ensures that BHI does not have access to names and contact details to ensure confidentiality of respondents. This process also ensures that, in the context of BHI's reporting function, identifying information can never be reported to LHDs or publicly released.

For the Outpatient Cancer Clinics Survey 2019, the data was collected from patients who visited selected cancer clinics in November 2019.

Data analysis

For the Outpatient Cancer Clinics Survey 2019, there were 26,464 questionnaires mailed and 13,009 responses received.

Completeness of questionnaires

Survey completeness is a measure of how many questions each respondent answered as a proportion of all questions in the questionnaire. The completeness of responses was very high overall, with respondents answering, on average, 63 of the 78 non-text questions (this includes questions that were correctly skipped).

Response rate

The response rate is the percentage of people sampled who actually completed and returned or submitted their responses. 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 facility (Tables 3 and 4, respectively). For reasons of data quality and patient confidentiality, facilities 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 2019

Eligible patient population	Mailings (in scope)	Population in mailings (%)	Total respondents	Response rate (%)
38,860	26,464	68	13,009	49

Table 3 Sample size and response rates by LHD, Outpatient Cancer Clinics Survey 2019

Local health district	Mailings (in scope)	Total respondents	Response rate (%)
Central Coast	1,448	823	57
Far West	56	31	55
Hunter New England	2,482	1,400	56
Illawarra Shoalhaven	1,892	1,130	60
Mid North Coast	1,727	963	56
Murrumbidgee	141	70	50
Nepean Blue Mountains	987	512	52
Northern NSW	1,517	717	47
Northern Sydney	1,007	522	52
South Eastern Sydney	2,809	1,222	44
Southern NSW	473	295	62
St Vincent's Health Network	981	376	38
South Western Sydney	2,599	1,128	43
Sydney	1,991	847	43
Western NSW	1,588	746	47
Western Sydney	2,632	1,172	45

Table 4 Sample size and response rates by facility, Outpatient Cancer Clinics Survey 2019

Facility	Mailings (in scope)	Total respondents	Response rate (%)
Armidale Hospital	222	113	51
Bankstown-Lidcombe Hospital	633	207	33
Bathurst Health Service	383	173	45
Bega Valley Community Health	84	56	67
Blacktown Hospital	988	453	46
Bourke Street Health Service	107	69	64
Broken Hill Health Service	56	31	55
Calvary Mater Newcastle	1,001	606	61
Campbelltown Hospital	978	517	53
Chris O'Brien Lifehouse (private)	990	398	40
Coffs Harbour Health Campus	986	511	52
Concord Repatriation General Hospital	992	433	44
Cooma Hospital and Health Service	17	9	53
Cowra Health Service	40	23	58
Dubbo Base Hospital	528	219	41
Eurobodalla Community Health	186	113	61
Gosford Hospital	991	567	57
Goulburn Community Health Service	21	13	62
Grafton Base Hospital	236	113	48
Griffith Base Hospital	98	47	48
John Hunter Hospital	154	71	46
Lachlan Health Service – Parkes	20	4	20
Lismore Base Hospital	526	287	55
Liverpool Hospital	988	404	41
Manning Hospital	338	205	61
Milton Ulladulla Hospital	73	50	68
Moree Hospital	76	33	43
Muswellbrook Hospital	67	34	51
Nepean Hospital	987	512	52
Orange Health Service	617	327	53
Port Macquarie Base Hospital	741	452	61
Prince of Wales Hospital	1,002	473	47
Riverina Cancer Care Centre (private)	493	282	57
Royal Hospital for Women	401	137	34
Royal North Shore Hospital	1,007	522	52

Facility	Mailings (in scope)	Total respondents	Response rate (%)
Royal Prince Alfred Hospital	999	414	41
Shoalhaven District Memorial Hospital	823	508	62
South East Regional Hospital	58	35	60
St George Hospital	1,017	450	44
St Vincent's Hospital Sydney	981	376	38
Sutherland Hospital	389	162	42
Sydney Adventist Hospital (private)	651	375	58
Tamworth Hospital	624	338	54
The Tweed Hospital	755	317	42
Westmead Breast Cancer Institute	642	255	40
Westmead Hospital	1,002	464	46
Wollongong Hospital	996	572	57
Wyong Hospital	457	256	56
Young Health Service	43	23	53

Note: Facilities with fewer than 30 responses cannot be reported for data quality and confidentiality reasons.

Weighting of data

Survey responses were weighted to optimise the degree to which results were representative of the experiences and outcomes of the overall patient population. At the LHD and NSW levels, weights also ensured that the different sampling proportions used at the facility level were accounted for, so that LHD results were not unduly influenced by small facilities that had larger sampling proportions.

A weight was calculated for respondents in each stratum (facility) using the following equation:

$$w_i = \frac{N_i}{n_i}$$

where:

N_i = total number of patients eligible for the survey in the ith stratum

n_i = number of respondents in the ith stratum.

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

One of the aims of sample weights is to ensure that, after weighting, the characteristics of the respondents closely reflect the characteristics of the patient population. 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 shows demographic characteristics of respondents against the patient population.

The four columns denote:

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 2019)
2. percentage of sample mailed – the percentage of patients in each category provided by the Ministry to the survey vendor for mailing
3. percentage of respondents (unweighted) – respondents to the survey, not adjusted for unequal sampling
4. percentage of respondents (weighted) – respondents to the survey, adjusted by weighting to be representative of the patient population.

Table 5 Demographic characteristics of patient population and respondents, Outpatient Cancer Clinics Survey 2019

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	4
	Far West	0	0	0	0
	Hunter New England	12	9	11	12
	Illawarra Shoalhaven	6	7	9	6
	Mid North Coast	5	7	7	5
	Murrumbidgee	0	1	1	0
	Riverina Cancer Care Centre (private)	1	2	2	1
	Nepean Blue Mountains	4	4	4	4
	Northern NSW	4	6	6	4
	Northern Sydney	4	4	4	4
	Chris O'Brien Lifehouse (private)	2	2	3	2
	South Eastern Sydney	10	11	9	10
	South Western Sydney	12	10	9	12
	Southern NSW	1	2	2	1
	St Vincent's Health Network	4	4	3	4
	Sydney	6	8	7	6
	Sydney Adventist Hospital (private)	7	4	3	7
	Western NSW	4	6	6	4
	Western Sydney	13	10	9	13
Age stratum	18–34	#	5	2	2
	35–54	#	18	11	12
	55–74	#	50	54	54
	75+	#	27	33	32
Sex	Female	#	55	52	52
	Male	#	45	48	48

Information is not available.

Reporting

Confidentiality

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

The following facilities have been suppressed for public reporting of the Outpatient Cancer Clinics Survey 2019 because they have fewer than 30 respondents:

- Lachlan Health Service – Parkes
- Cooma Hospital and Health Service
- Goulburn Community Health Service
- Cowra Health Service
- Young Health Service.

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

Broken Hill Hospital had enough respondents to be publicly reported for the first time in 2019.

Suppression rules

For suppression at the facility or LHD level, if the number of respondents was fewer than 30, results for that facility were suppressed. If the number of respondents was between 30 and 49 with at least a 20% response rate, or more than 49 with less than a 20% response rate, results were checked for representativeness of the NSW patient population for key patient characteristics (age, sex). If these results were found to be representative of the NSW population, results were publicly released and accompanied by an 'interpret with caution' note. If found not to be representative of the NSW population, results were suppressed for that facility.

For questions asking about types of complications (i.e. experienced an infection, uncontrolled bleeding, a negative reaction to medication, complications as a result of surgery), results are reported at NSW level because of low prevalence at the facility and LHD level. However, the combined complication prevalence (i.e. had any complication) is reported at all levels. No statistical comparison was done for these questions, as the survey data currently do not capture information on patient clinical conditions that might influence results for these questions.

Reporting of private facilities

Chris O'Brien Lifehouse, Sydney Adventist Hospital and Riverina Cancer Care Centre are private facilities that are also contracted to provide services to public patients and therefore were included in this survey and reported at the facility 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

Data were analysed in SAS V9.4 using 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 status.

The result (percentage) for each response option in the questionnaire was 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 'don't know/can't remember' responses for questions that ask about a third party (e.g. if family had enough opportunity to talk to a doctor) or when the percentage responding with this option was greater than 10%.

It is assumed that no bias is introduced by the way patients who did not respond to the whole survey, or did not respond to specific questions, are handled. This is because it is also assumed these patients did so randomly and therefore any missing responses do not relate to the experience of care.

When reporting on questions 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.

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

Interpret with caution

All data collected using 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 fewer than 200.

Results should be interpreted with caution if the number of respondents was between 30 and 49 with at least a 20% response rate, or more than 49 with less than a 20% response rate. For the Outpatient Cancer Clinics Survey 2019, there were five reportable facilities that had between 30 and 49 respondents with at least a 20% response rate, and no facilities with less than a 20% response rate.

Reporting by population group

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

- Age group
- Cancer type
- Sex
- Education level
- Language spoken at home
- Presence of any longstanding health condition
- Quintile of disadvantage
- Rurality of residence
- Purpose of visit.

ESAS and CASE-Cancer

The Outpatient Cancer Clinics Survey 2019 questionnaire also included two validated question sets that are used internationally to assess cancer symptoms and patient attitudes. The Edmonton Symptom Assessment System (ESAS)[1] 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)[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.

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 2019. 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

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

To enable fairer comparisons at the facility level 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, cancer type and language) into account. Therefore, when a facility is flagged as having a significantly higher or lower result than NSW, this reflects differences in patient experiences rather than differences that can be explained by the mix of characteristics among a facility's patients.

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

The standardised comparison is currently only applied at the facility level and not at LHD level.

Methodology

The survey asks patients questions about different aspects of their care, such as accessibility and timeliness, the physical environment of the facility, safety and hygiene, communication and information, and whether they were treated with respect and dignity.

For survey questions related to aspects of care, the percentage of respondents who selected the most positive response option 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 facilities 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, =1 to number of facilities
- b_i is the vector of random intercepts (facilities), i=1 to number of facilities.

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 considers which patient characteristics may be consistently associated with more positive or less positive reported experiences.

Information regarding rurality of patients and socioeconomic status (SES) was also considered as these factors may relate to response tendency. However, BHI chose not to include factors such as rurality or SES as they may reflect differences in care. Instead, analyses of results by these patient groups are presented in BHI's interactive data portal, Healthcare Observer, to allow facilities to see which patient groups reported more or less positive experiences of care. A list of all patient characteristics considered for inclusion in the model for standardised comparisons and how they were sourced is 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 only standardises comparisons for experience of care questions by adjusting patient, not clinical or health, 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 Breast Bowel (colon, rectal, anus) Lung Skin/melanoma Upper gastrointestinal (oesophagus, stomach, liver, pancreatic, bile ducts) Gynaecological (e.g. ovarian, endometrial, cervical) Brain or spinal column Head and neck Blood (e.g. lymphoma, leukaemia, marrow, lymph nodes) Other (e.g. bone, mesothelioma, thyroid) Cancer type not yet known Missing (including those who attended the clinics for reasons other than cancer)

Table 7 presents a list of covariates considered for adjustment by selection stage. 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.[3]

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, covariates that marginally improved the model were excluded by comparing the models' AIC values, to define a parsimonious number of patient-related covariates to use in standardised comparisons. Covariates that were not part of patient characteristics (e.g. whether patients were staying overnight or had same-day admission) were not included in the testing. This is because standardised comparisons are intended to control for differences in patient characteristics only, and some of these factors were considered to be under the control of facility management rather than patients.

Table 7 Covariates considered for adjustment for comparisons at each selection stage

	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	✓	✓		

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.

Age, sex, education, language spoken at home and cancer type were chosen for adjustment for the comparison model.

Model-based comparisons

The model calculates an estimate for each facility'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 facility 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 facility with reference to an 'average' facility. The p-value for each facility intercept estimate was used to determine if the facility 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 facility random intercept was greater than 0, the facility 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 facility was flagged as having a less positive result than NSW.
- If the p-value was greater than the significance level, the facility was flagged grey as not significantly different to NSW.
- For results 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 one comparison in 100 (from one 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.

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 the Adult Admitted Patient Survey (AAPS) and Emergency Department Patient Survey (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.

Statistical software

SAS software version 9.4 was used for all statistical analyses. The PROC SURVEYFREQ procedure was used to adjust for the sampling weights when calculating the percentages and related confidence intervals.

The PROC GIMMIX procedure and 'weight statement' was used for performing logistic mixed models[4] to compare hospital results with NSW, adjusting for covariates and sampling weights.

The calculation of percentages and standardised comparisons were adjusted for sampling weights using these SAS procedures.

Appendix 1

Facility locations of the cancer clinics included in the Outpatient Cancer Clinics Survey 2019 sampling frame

Table 8 Eligible patients, sampled patients and proportion sampled by facility, Outpatient Cancer Clinics Survey 2019

Facility	Total eligible patients	Total sampled	Percentage sampled (%)
Armidale Hospital	226	226	100
Bankstown-Lidcombe Hospital	647	647	100
Bathurst Health Service	388	388	100
Bega Valley Community Health	85	85	100
Blacktown Hospital	1,028	1,004	98
Bourke Street Health Service	109	109	100
Broken Hill Health Service	58	58	100
Calvary Mater Newcastle	3,097	1,017	33
Campbelltown Hospital	1,014	1,003	99
Chris O'Brien Lifehouse (private)	2,851	1,004	35
Coffs Harbour Health Campus	1,006	1,003	100
Concord Repatriation General Hospital	1,381	1,004	73
Cooma Hospital and Health Service	17	17	100
Cowra Health Service	41	41	100
Dubbo Base Hospital	541	541	100
Eurobodalla Community Health	188	188	100
Gosford Hospital	1,245	1,007	81
Goulburn Community Health Service	25	25	100
Grafton Base Hospital	238	238	100
Griffith Base Hospital	101	101	100
John Hunter Hospital	156	156	100
Lachlan Health Service - Parkes	20	20	100
Lismore Base Hospital	537	537	100
Liverpool Hospital	3,089	1,007	33
Manning Hospital	345	345	100
Milton Ulladulla Hospital	77	77	100
Moree Hospital	76	76	100
Muswellbrook Hospital	67	67	100
Nepean Hospital	1,601	1,006	63
Orange Health Service	630	630	100
Port Macquarie Base Hospital	758	758	100
Prince of Wales Hospital	1,443	1,012	70
Riverina Cancer Care Centre (private)	506	506	100

Facility	Total eligible patients	Total sampled	Percentage sampled (%)
Royal Hospital for Women	407	407	100
Royal North Shore Hospital	1,544	1,017	66
Royal Prince Alfred Hospital	1,127	1,003	89
Shoalhaven District Memorial Hospital	837	837	100
South East Regional Hospital	58	58	100
St George Hospital	1,553	1,033	67
St Vincent's Hospital Sydney	1,472	1,003	68
Sutherland Hospital	398	398	100
Sydney Adventist Hospital (private)	659	659	100
Tamworth Hospital	636	636	100
The Tweed Hospital	768	768	100
Westmead Breast Cancer Institute	643	643	100
Westmead Hospital	3,309	1,011	31
Wollongong Hospital	1,348	1,009	75
Wyong Hospital	467	467	100
Young Health Service	43	43	100
NSW total	**38,860**	**26,895**	**69**

Appendix 2

Unweighted percentage of missing and 'Don't know' responses

Table 9 Percentage of 'Don't know' and/or missing responses by question, Outpatient Cancer Clinics Survey 2019

Number	Question	Missing %	Don't know %	Missing + Don't know %*
1	What was the purpose of this visit?	2.65		2.65
2	How long did it take you to travel to the clinic for this appointment?	1.81	0.22	2.02
3	Did you need parking for your clinic visit?	3.31		3.31
4	Did you have any of the following issues with parking during this visit?	2.99		2.99
5	Were the reception staff polite and courteous?	0.69		0.69
6	How long after the scheduled appointment time did your appointment actually start?	2.40	2.50	4.90
7	Were you told how long you had to wait [for appointment to start]?	4.35		4.35
8	How comfortable was the waiting area?	0.75		0.75
9	How comfortable was the treatment area?	1.08		1.08
10	How clean was the treatment area?	0.56		0.56
11	Who did you see during this visit?	1.58		1.58
12	Did you have enough time to discuss your health issue with the health professionals you saw?	1.59		1.59
13	Did the health professionals explain things in a way you could understand?	1.97		1.97
14	During this visit, did the health professionals know enough about your medical history?	1.69		1.69
15	How would you rate how well the health professionals worked together?	1.48		1.48
16	Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?	1.94	9.80	11.75
17	Did you have worries or fears about your condition or treatment?	2.46		2.46
18	Did a health professional discuss your worries or fears with you?	3.29		3.29
19	Did you have confidence and trust in the health professionals?	1.88		1.88
20	Were the health professionals kind and caring towards you?	1.85		1.85
21	Overall, how would you rate the health professionals who treated you?	1.92		1.92
22	When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options?	2.81		2.81
23	Did a health professional at the clinic tell you about the risks and benefits of the treatment options?	2.08		2.08
24	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	2.32		2.32
25	Did a health professional at the clinic explain the next steps of your care and treatment in a way you could understand?	2.97		2.97
26	Did you ever receive conflicting information about your condition or treatment from the health professionals?	3.21		3.21
27	Do you have a written care plan for your current or ongoing care?	4.19	6.07	10.26
28	Were you asked about your preferences for care and treatment when developing this plan?	4.06	10.94	15.00

Number	Question	Missing %	Don't know %	Missing + Don't know %*
29	At your November visit, did the health professionals review your care plan with you?	3.39	7.27	10.67
30	Did you receive any treatment during this visit (chemotherapy, radiotherapy, surgery or other treatments)?	2.51		2.51
31	Did a health professional at the clinic explain what would be done during your treatment in a way you could understand?	4.14		4.14
32	Did a health professional at the clinic tell you about possible side effects of your treatment?	4.74		4.74
33	Were you given enough information about how to manage the side effects of your treatment?	5.19		5.19
34	During this visit, were you given, or prescribed, any new medication to take at home?	2.68		2.68
35	Did a health professional at the clinic explain the purpose of this [new] medication in a way you could understand?	2.21		2.21
36	Did a health professional at the clinic tell you about side effects of this medication to watch for?	2.66		2.66
37	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?	2.34	2.75	5.09
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?	2.74	1.15	3.90
39	Were you treated with respect and dignity while you were at the clinic?	0.88		0.88
40	Were you given enough privacy when being examined or treated?	1.52		1.52
41	Were you given enough privacy when discussing your condition or treatment?	1.53		1.53
42	Were you ever treated unfairly for any of the reasons below?	4.43		4.43
43	Were your cultural or religious beliefs respected by the clinic staff?	3.09		3.09
44	During your visit or soon afterwards, did you experience any of the following complications or problems?	3.67		3.67
45	Was the impact of this complication or problem...?	3.66		3.66
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]?	4.00		4.00
47	In the past three months, have you gone to an emergency department because of complications related to the care you received?	3.01	0.88	3.90
48	Did a staff member at this clinic ask you if you smoked/used tobacco?	2.24	16.80	19.04
49	At the time of your clinic visit, how often were you smoking/using tobacco?	2.70	.	2.70
50	Has a staff member at this clinic done any of the following in the past year?	4.62	7.87	12.48
51	Overall, how would you rate the care you received at the clinic?	1.01		1.01
52	If asked about your clinic experience by friends and family, how would you respond?	1.15		1.15
53	How well organised was the care you received at the clinic?	1.51		1.51
54	[At this cancer clinic over the past six months] How much were your out-of-pocket expenses for medication related to these visits?	2.28	3.47	5.75

Number	Question	Missing %	Don't know %	Missing + Don't know %*
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)?	2.60	4.16	6.76
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)?	2.44	3.05	5.49
57	Did you attend this clinic because you have or have had cancer?	2.34		2.34
58	Is this the first time you have had cancer?	4.29		4.29
59	What was the main type of cancer you were receiving care for at this clinic?	7.77		7.77
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...	3.06		3.06
61	How has your current cancer responded to treatment?	7.23		7.23
62	How long has it been since you first received treatment for this cancer?	2.45	0.61	3.06
63	In the past three months, what treatment have you received for your cancer?	4.22		4.22
64_01	Rating of cancer symptom severity: Pain	4.71		4.71
64_02	Rating of cancer symptom severity: Tiredness	5.21		5.21
64_03	Rating of cancer symptom severity: Nausea	5.15		5.15
64_04	Rating of cancer symptom severity: Depression	4.95		4.95
64_05	Rating of cancer symptom severity: Anxiety	5.25		5.25
64_06	Rating of cancer symptom severity: Drowsiness	5.48		5.48
64_07	Rating of cancer symptom severity: Loss of appetite	5.73		5.73
64_08	Rating of cancer symptom severity: Wellbeing	6.25		6.25
64_09	Rating of cancer symptom severity: Shortness of breath	4.93		4.93
65_01	I know that I will be able to deal with any unexpected health problems	7.36		7.36
65_02	I am confident in my ability to understand written information about cancer	6.11		6.11
65_03	I am confident in my ability to understand my doctor's instructions	5.57		5.57
65_04	It is easy for me to actively participate in decisions about my treatment	6.51		6.51
65_05	I won't let cancer get me down	5.86		5.86
65_06	It is easy for me to keep a positive attitude	5.65		5.65
65_07	It is easy for me to maintain a sense of humour	5.93		5.93
65_08	I am confident that I can control my negative feelings about cancer	6.25		6.25
65_09	If I don't understand something, it is easy for me to ask for help	5.81		5.81
65_10	It is easy for me to ask nurses questions	6.23		6.23
65_11	It is easy for me to ask my doctor questions	5.39		5.39
65_12	It is easy for me to get information about cancer	5.98		5.98
66	What year were you born?	1.86		1.86
67	What is your gender?	1.50		1.50

Number	Question	Missing %	Don't know %	Missing + Don't know %*
68	What is the highest level of education you have completed?	2.35		2.35
69	Language mainly spoken at home	1.42		1.42
70	Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic?	1.69		1.69
71	Did the clinic provide an interpreter when you needed one?	3.37		3.37
72	Aboriginal and/or Torres Strait Islander	2.52		2.52
73	Did you receive support, or the offer of support, from an Aboriginal Health Worker during your November visit to the clinic?	4.32	12.23	16.55
74	Which, if any, of the following longstanding conditions do you have (including age-related conditions)?	4.27		4.27
75	Does this condition(s) cause you difficulties with your day-to-day activities?	3.09		3.09
76	Are you a participant of the National Disability Insurance Scheme (NDIS)?	3.41	6.29	9.70
77	Who completed this survey?	1.90		1.90
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)?	12.25		12.25

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

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 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, please refer to the Data Dictionary: Quintile of disadvantage on BHI's 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 (see definitions below).

Results are weighted as described in this report.

Numerator

The number of survey respondents who selected a specific response option/s to a certain question, minus exclusions.

Denominator

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

Exclusions

For derived measures, the following are usually excluded:

- Response: 'don't know/can't remember' or similar non-committal response
- Response: invalid (i.e. respondent was meant to skip a question but did not)
- Response: 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.

Table 10 shows the questions and responses used in the construction of the derived measures.

Table 10 Derived measures for the Outpatient Cancer Clinics Survey 2019

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
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
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

Derived measure	Question	Derived measure categories	Response options
Had a written care plan	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
Experienced a complication	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 Missing
Complication or problem occurred during clinic visit	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

Derived measure	Question	Derived measure categories	Response options
Given information or other help to quit smoking by clinic staff	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
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	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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