

# Admitted Children and Young Patients Survey 2018

Technical Supplement

December 2019

## **BUREAU OF HEALTH INFORMATION**

Level 11, 67 Albert Avenue  
Chatswood NSW 2067  
Australia  
Telephone: +61 2 9464 4444  
**bhi.nsw.gov.au**

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Please note there is the potential for minor revisions of data in this report.

Please check the online version at [bhi.nsw.gov.au](http://bhi.nsw.gov.au) for any amendments 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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# The 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 Admitted Children and Young Patients Survey (CYPS) 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](http://bhi.nsw.gov.au/nsw_patient_survey_program).

## Admitted Children and Young Patients Survey

CYPS is unique in the NSW Patient Survey Program. Since 2015, the survey has included three different questionnaires, based on the age of the patient. In 2018, the age cohorts of two of the three questionnaires were modified.

The first questionnaire is designed to be completed by the parent or carer of patients aged 0–7 years, asking about both the parent's and child's experiences of care. The second questionnaire, was previously sent to 8–15-year olds. This year it was designed for patients aged 8–13 years, to be completed by both the parent and the child. The first section of the questionnaire is designed for the parent alone, or the parent and child together. The second section of this survey is designed to be completed by the patient. This format is used because international literature and key stakeholders felt that it was important to understand the experiences of both the patient and their parent/carer which can often differ.

The third questionnaire is sent directly to patients aged 14–17 years and the parent is not required to respond to any questions. The change in age allocation occurred to align with NSW Health policy that young people can make their own health-related decisions from the age of 14. As many questions as possible were kept consistent between the three surveys to facilitate comparisons of the three groups and allow aggregate reporting of all patients aged 0–17 years. For changes in the questionnaire content between CYPS 2017 and CYPS 2018, please refer to the development report on BHI's website.

# Producing survey samples

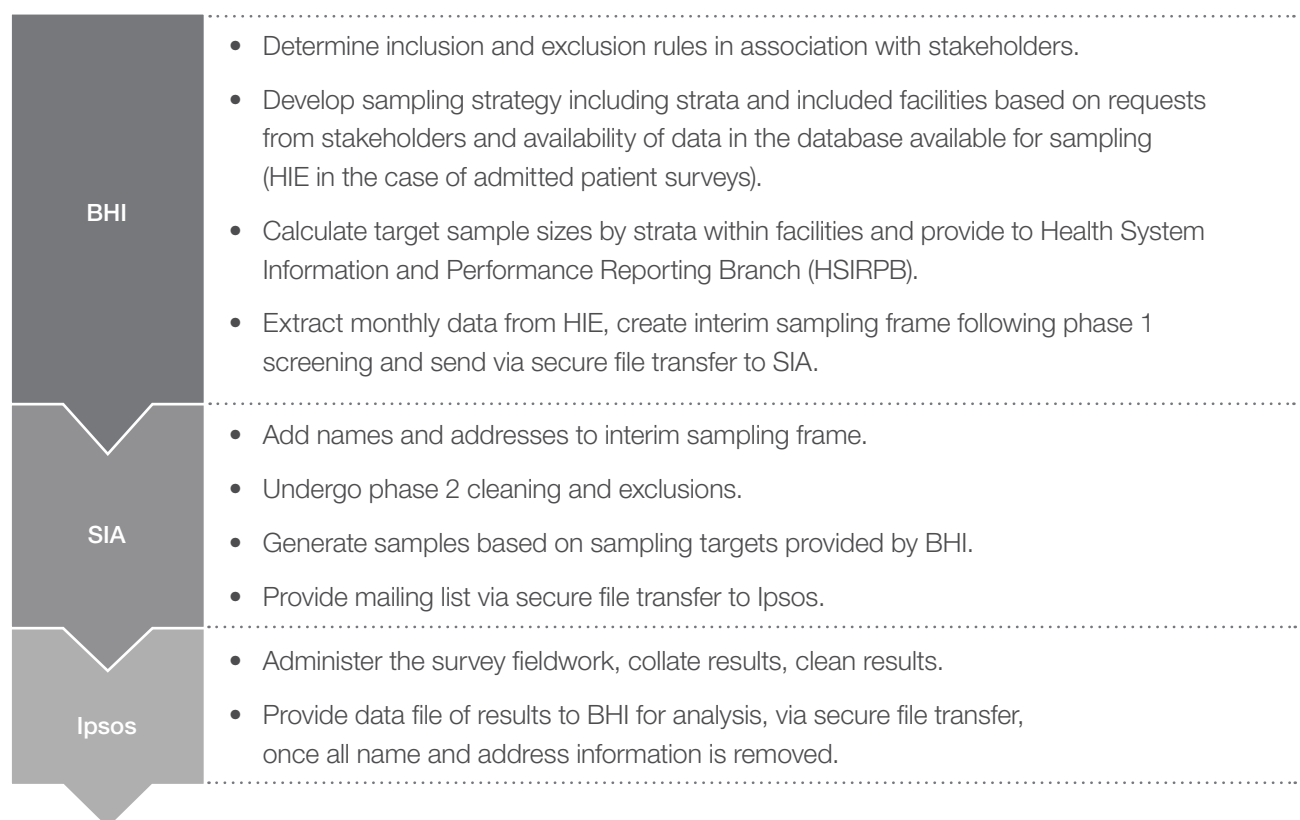
The survey program assures patients that their responses will be confidential and that staff at hospitals will not be able to determine who gave which response. BHI does this through a number of mechanisms, including:

- data suppression (results for fewer than 30 responses are suppressed)
- reporting aggregated results
- anonymisation of patient comments
- segregation of roles when constructing the survey samples (see below).

The sampling method for the survey program is a collaboration between BHI, Ipsos and the NSW Ministry of Health's Systems Information and Analytics (SIA) branch (see Figure 1). The main source of data for the sampling frame is the Health Information Exchange (HIE).

BHI has access to de-identified unit record hospital data from selected tables of the HIE database. Use of an encrypted patient number allows deduplication of patients within a hospital. For CYPS, sampling frames are downloaded on a monthly basis, with the date at discharge used to define eligible records. Sample sizes for each included hospital are calculated in advance, as explained later in this report.

Figure 1 Organisational responsibilities in sampling and survey processing, CYPS, January to December 2018



# Inclusion criteria

## Phase 1 screening

Admitted patient data pass through two phases of screening to create a sample frame of patients eligible to participate in the Admitted Children and Young Patients Survey. Phase 1 screening is conducted by BHI.

### Inclusions

- admitted patients aged 0–17 years
- admitted to a paediatric specialist hospital (peer group A2) or to a tertiary children's hospital (John Hunter Children's Hospital).

### Exclusions

- persons aged 18 years and over
- all unqualified babies (babies born without complication and in hospital for birth)
- patients who died during their hospital admission – mode of separation of 6 (death with autopsy) or 7 (death without autopsy)
- patients receiving acute and post-acute care (APAC) services
- patients who are not receiving either acute or rehabilitation care in hospital (i.e. not episode of care types 1 and 2)
- patients who were admitted to a psychiatric unit during the hospital stay
- patients with a personal history of self-harm (ICD-10 Z91.5) or who have intentionally self-harmed (ICD-10 X60-X84, Y87.0, Y34)
- patients with a family history of mental or behavioural disorders (ICD-10 Z81.8) and patients who have expressed suicidal ideation (ICD-10 R45.81)
- patient recorded with maltreatment syndromes (ICD-10 T74) in any diagnosis field, including neglect or abandonment, physical abuse, sexual abuse, psychological abuse, other maltreatment syndromes and maltreatment syndrome, unspecified

- patients who gave birth during their admission (ICD-10 Z37.0, Z37.2, O80-O84, or procedure codes of 90467, 90468, 90469, 90470 or 16520)
- patients who experienced a stillbirth (ICD-10 Z37.1, Z37.3, Z37.4, Z37.6, Z37.7)
- patients who experienced pregnancy with an abortive outcome (ICD-10 O00-O08)
- patients admitted for a termination of pregnancy procedure (ICD-10 35643-03, 35640-03)
- patients admitted for same day haemodialysis – code 13100-00 in any procedure fields
- same-day patients who stayed for less than three hours
- same-day patients transferred to another hospital
- patients recorded as receiving contraceptive management (ICD-10 Z30) in any diagnosis field, including general counselling and advice on contraception, surveillance of contraceptive drugs, surveillance of contraceptive device, other contraceptive management and contraceptive management, unspecified.

Where patients had multiple visits within the sampling month, their most recent hospital stay was retained for sampling. The questionnaire instructs the patient to respond to the survey based on their most recent admission in a particular month.

If the diagnosis code is known, then BHI excludes patients with the 'sensitive conditions' documented above. Patients with incomplete diagnosis coding are still offered the chance to participate in the survey program and are not excluded. This percentage was 5% in 2018.

## Phase 2 screening

BHI provides the interim sampling frame to SIA, which adds a patient name and address information. Data then undergo a second phase of screening. This results in exclusions for administrative/logistical reasons, or where death had been recorded after discharge, but before the final sampling frame is prepared.

### Exclusions

Patients meeting the following exclusion criteria are removed in this phase:

- 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 (including twin, baby of)
- invalid date of birth
- on the 'do not contact' list
- sampled in the previous six months for any BHI patient survey currently underway
- recorded as deceased according to the NSW Birth Deaths and Marriages Registry and/or Agency Performance and Data Collection, prior to the sample being provided to Ipsos.

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

# Drawing the sample

## Survey design

A stratified sample design was applied, with each hospital defined as a stratum. Within each hospital, patients were further stratified by the following variables:

- Age (0–7, 8–13 or 14–17 years) based on the age variable. Each of these age groups coincides with a different questionnaire
- Stay type: same-day or overnight admission, based on the start and end times of the last hospital stay in the month.

Sample sizes were calculated at the facility and age-group level. Simple random sampling without replacement was applied within each stay-type stratum.

## Calculation of sample sizes and reporting frequency

Monthly sample sizes were determined prior to the commencement of the survey year. These calculations were based on data extracted from the HIE for the previous 12-month period, using the inclusion and exclusion criteria described in Phase 1 screening.

The three tertiary paediatric facilities were sampled to allow for quarterly reporting.

The following equation was used to estimate the sample size at the hospital level:

$$S_i = \frac{\chi^2 N_i P(1-P)}{d^2(N_i-1) + \chi^2 P(1-P)} \times R_i \quad (1)$$

Where:

$S_i$  = desired sample size for facility-age group  $i$

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

$N_i$  = patient population of facility-age group  $i$

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

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

$R_i$  = number of reporting periods per year for facility-age group  $i$ .

Sample sizes were calculated for each age group separately, and allocated proportionately across each stratum of stay type.

Sample sizes were adjusted to account for expected response rates to ensure a sufficient number of patients participated from each hospital. For this survey, the expected response rate was 30% for all age groups.

Monthly survey targets were provided to SIA after dividing the adjusted sample size evenly by 12, and applying a minimum monthly sample size of at least four to each sampling stratum. For each month of sampling, SIA randomly selects patients within each hospital and stratum, with the aim of achieving the targets provided by BHI.



# 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 any errors in completion. Reasonable adjustments are made, such as removing responses where the respondent has not correctly followed questionnaire instructions or where the respondent has provided multiple answers to a single response 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 respondents. This ensures responses remain confidential and identifying data can never be publicly released.

## Data analysis

For CYPS 2018, there were 12,688 questionnaires mailed and 3,086 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. The completeness of responses was high overall, with respondents answering, on average, at least 78% of questions (Table 1).

Table 1 Survey completeness and response rate by age group, CYPS, January to December 2018

Survey	Number of questions (excluding free-text questions)	Average number answered	Response rate (unweighted)
0–7 years	93	73	24%
8–13 years	97	77	26%
14–17 years	84	67	23%

### Weighted response rate

Response rates were weighted to ensure that the overall survey response rate reflects that which would be observed if patients were sampled in proportion to the patient mix. Response rate is calculated as the number of eligible responses divided by the number of eligible mailed surveys.

The overall weighted response rate was 24%. By age group, the response rates were not weighted, and this ranged from 23% to 26% (Table 1). Response rates at the age group and hospital level are provided in Tables 2 and 3 respectively, later in the document.

## Weighting of data

Responses from the survey were weighted to optimise the degree to which results from respondents are representative of the experiences and outcomes of the overall patient population. At NSW level, weights also ensure that the different sampling proportions used at the facility level are accounted for.

For each reporting period, responses were weighted to match the population by stay type (same day or overnight) and age group within each hospitals.

An initial weight was calculated for respondents in each stratum using the following equation:

$$w_i = \frac{N_i}{n_i} \quad (2)$$

Where:

$N_i$  = total number of patients eligible for the survey in the  $i^{\text{th}}$  stratum

$n_i$  = number of respondents in the  $i^{\text{th}}$  stratum.

If the stratum cell size was five or fewer, cells were aggregated across stay types prior to weighting, provided the aggregation did not increase the weights allocated to the cell with the small sample size. Weights were not aggregated across age strata as

each age stratum is sent a different survey. In general, for surveys that include hospitals sampled on the basis of quarterly reporting, weights were calculated for each quarter of data. Otherwise, weights were calculated for 12 months of data combined. For the Admitted Children and Young Patients Survey 2018, weights were calculated separately for each quarter for all facilities. These weights were used for the analyses both at the quarterly and annual levels.

## Assessment of weights

Weights were assessed to ensure that undue emphasis was not applied to individual responses. The ratio of the maximum to median weight at the facility level was reviewed. For this survey, this ranged from 2.3 to 3.8.

The design effect (DEFF) estimates the increase in variance of estimates due to the complex sample design over that of a simple random sample. It is estimated as  $(1 + \text{coefficient of variance [weights]})$ . A DEFF of two indicates that the variance of estimates will be double the sample variance that would have been obtained if simple random sampling had been done. Sample sizes, response rates and DEFFs for hospitals is shown in Table 2.

Table 2 Sample size, response rates and design effects (DEFF), by hospital and overall, CYPS, January to December 2018

Name	Peer group	Surveys mailed	Survey responses	Response rate (weighted)	DEFF
John Hunter Children's Hospital	A1	4,114	926	23%	1.2
Sydney Children's Hospital, Randwick	A2	3,789	1,004	26%	1.4
The Children's Hospital at Westmead	A2	47,85	1,156	23%	1.6
Overall		12,688	3,086	24%	1.7

## 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.

Table 3 shows demographic characteristics of respondents against the patient population. The four columns denote:

1. percentage of patient population – the patient population prior to the phase 2 screening process
2. percentage of eligible population – final sampling frame from which the sample is drawn. Limited demographic variables are available at this level
3. percentage of respondents – respondents to survey, not adjusted for unequal sampling
4. percentage of respondents (weighted) – respondents to survey, adjusted by weighting to be representative of the patient population.

Table 3 Demographic characteristics of patient population and respondents, CYPS, January to December 2018

Demographic variable	Sub-group	% of patient population	% of eligible population	% of respondents (unweighted)	% of respondents (weighted)
LHD	Hunter New England	17	17	30	17
	Sydney Children's Hospitals Network	83	83	70	83
Peer group	A1	17	17	30	17
	A2	83	83	70	83
Age stratum	0–7	64	67	38	67
	8–13	24	23	36	23
	14–17	12	10	25	10
Stay type	Overnight	58	59	58	59
	Same day	42	41	42	41
Aboriginal status	Not Aboriginal	95	.	96	97
	Aboriginal and/or Torres Strait Islander	5	.	4	3
Gender	Male	58	.	56	57
	Female	42	.	44	43

# Reporting

## Confidentiality

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

## Statistical analysis

Data were analysed for the period from January to December 2018 combined, as well as by quarter. Analysis was undertaken in SAS V9.4 using the SURVEYFREQ procedure, with facility, age group and stay type as strata. Results were obtained for each individual survey question, and also aggregated across surveys where questions were considered sufficiently similar. 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.

In 2018, the age cohorts for the three questionnaires were changed so results from 2018 are not comparable to previous years.

Unless otherwise specified, missing responses and those who responded 'don't know / can't remember' to questions were excluded from analysis.

The exception is for '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 more than 10%.

When reporting on questions that are used to filter respondents through the questionnaire rather than asking about hospital performance, the 'don't know / can't remember' option and missing responses were also reported. Appendix 1 presents the rates of missing or 'don't know' responses for CYPS 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 2.

## Hospital comparisons

In accordance with the survey's three-year cycle, the Admitted Children and Young Patients Survey 2018 includes only the three public specialist paediatric hospitals in NSW: John Hunter Children's Hospital; Sydney Children's Hospital, Randwick; and The Children's Hospital at Westmead.

There is no statistical testing of differences applied to the three NSW specialist paediatric hospitals surveyed (i.e. flagging of hospital results as 'red' and 'green'). Since there are only three hospitals for 2018, the average of these three hospitals is not equivalent to a NSW result. Therefore, comparing each of these three hospitals' results with this average would not be meaningful or fair. The average result for these three hospitals, though, is displayed in Healthcare Observer.

## 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 reported for the following groups, levels and at the indicated reporting frequency outlined in Table 4.

Table 4 Levels of reporting, CYPS, January to December 2018

Grouping	Reporting frequency	NSW	Peer group	LHD	Paediatric hospitals
<b>All patients</b>					✓
<b>Age group:</b> self-reported – administrative data used where question on year of birth was missing or invalid					✓
<b>Gender:</b> self-reported – administrative data used where question on gender was missing or invalid					✓
<b>Language spoken at home</b>					✓
<b>Long-standing health condition</b>					✓
<b>Self-reported health status</b>	Annual				✓
<b>Stay type:</b> same day and overnight					✓
<b>Quintile of disadvantage:</b> based on the Australian Bureau of Statistics Index of Relative Socio-demographic Disadvantage					✓
<b>Country of birth:</b> from administrative data					✓
<b>Rurality of patient residence:</b> based on ARIA* category of postcode of respondent residence – outer regional, remote and very remote combined					✓

\* Accessibility/Remoteness Index of Australia is the standard Australian Bureau of Statistics measure of remoteness. For more information refer to [abs.gov.au/websitedbs/d3310114.nsf/home/remoteness+structure](https://abs.gov.au/websitedbs/d3310114.nsf/home/remoteness+structure)

# Appendix 1

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

Table 5 Proportion of 'Don't know' and missing responses for questions, 0–7 years, CYPS, January to December 2018

Number	Question text (0–7 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
1	Was your child's stay in hospital planned in advance or an emergency?	0.8		0.8
2	From the time a doctor said your child would need to go to hospital, how long did they have to wait to be admitted?	1.9	3.2	5.2
3	Do you think the amount of time your child waited to go to hospital was...?	1.7	2.4	4.1
4	Before your child's arrival, how much information about their hospital stay was given to you?	1.5	1.9	3.5
5	When your child arrived in hospital did they spend time in the emergency department?	0.3	0.8	1.2
6	Were the emergency department staff polite and courteous?	0.9	0.1	1.0
7	Do you think the amount of time your child spent in the emergency department was...?	0.9	1.3	2.2
8	Were the staff you met on your arrival to hospital polite and courteous?	0.8		0.8
9	Do you think the time your child had to wait from arrival at hospital until they were taken to their room or ward was...?	1.4	1.0	2.4
10	For most of your child's stay in hospital, what type of room or ward were they in?	0.9	1.3	2.3
11	Was the room or ward suitable for someone your child's age?	0.9		0.9
12	Were there things for your child to do (such as books, games and toys)?	0.9	2.5	3.5
13	How clean were the wards or rooms your child stayed in while in hospital?	0.6	0.9	1.5
14	How clean were the toilets and bathrooms that your child used while in hospital?	1.1	4.7	5.8
15	Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching your child?	0.8	14.0	14.8
16	Was your child given enough privacy during their hospital stay?	1.3		1.3
17	Was your child ever bothered by noise in the hospital?	0.9		0.9
18	Did your child have any hospital food during this stay?	1.1		1.1
19	How would you rate the hospital food?	1.0		1.0
20	Did your child have any special dietary needs (e.g. vegetarian, diabetic, food allergies, religious, cultural, or related to their treatment)?	1.4		1.4
21	Was the hospital food suitable for their dietary needs?	0.8		0.8
22	If you needed to talk to a doctor, did you get the opportunity to do so?	0.9		0.9
23	In your opinion, did the doctors who treated your child know enough about their medical history?	0.9		0.9

Number	Question text (0–7 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
24	Did you have confidence and trust in the doctors treating your child?	0.8		0.8
25	Were the doctors kind and caring towards your child?	0.9		0.9
26	In your opinion, did the nurses who treated your child know enough about their care and treatment?	0.9		0.9
27	Did you have confidence and trust in the nurses treating your child?	0.7		0.7
28	Were the nurses kind and caring towards your child?	0.7		0.7
29	Did the health professionals introduce themselves to your child?	1.2	1.9	3.1
30	Did the health professionals explain things in a way your child could understand?	1.2	0.9	2.1
31	Did the health professionals explain things in a way you [the parent/carer] could understand?	1.0		1.0
32	During your child's stay in hospital, how much information about their condition or treatment was given to you?	0.7		0.7
33	Did you receive contradictory information from health professionals in the hospital – for example, different opinions on your child's treatment?	0.8		0.8
34	Did you have worries or fears about your child's condition or treatment while in hospital?	0.4		0.4
35	Did a health professional discuss your worries or fears about your child with you?	0.9		0.9
36	Did your child have worries or fears about their condition or treatment while in hospital?	0.7	0.8	1.4
37	Did a health professional discuss your child's worries or fears with them?	0.5	1.1	1.6
38	Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?	0.5		0.5
39	Were you allowed to remain with your child when they were being treated (excluding surgery)?	0.7	0.8	1.4
40	How would you rate how well the health professionals worked together?	0.8		0.8
41	Did you feel your child was treated with respect and dignity while they were in the hospital?	0.5		0.5
42	Were your child's cultural or religious beliefs respected by the hospital staff?	1.2		1.2
43	While in hospital, did you receive or see any information about how to comment or complain about your child's care?	0.7	38.5	39.2
44	Not including the reason your child came to hospital, during their hospital stay, or soon afterwards, did they experience any of the following complications or problems?	1.0		1.0
45	Was the impact of this complication or problem...?	0.0		0.0
46	In your opinion, were members of the hospital staff open with you about this complication or problem?	0.0		0.0

Number	Question text (0–7 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
47	If your child was in pain, did the doctors and nurses do everything they could to help with their pain?	0.7		0.7
48	How much information were you given about the hospital facilities available to you and your child?	0.4		0.4
49	Did you (the patient's parents or carers) make use of the overnight facilities at the hospital?	0.9		0.9
50	How would you [the parent/carer] rate the overnight facilities for parents or carers at the hospital?	0.3		0.3
51	Were facilities available for parents and carers to make drinks or food?	0.8	13.4	14.2
52	Was there a problem finding parking near the hospital?	0.6		0.6
53	During your child's stay in hospital, did they have any tests, X-rays or scans?	0.8		0.8
54	Did a health professional discuss the purpose [of tests, x-rays or scans] with you and/or your child?	0.6	0.9	1.6
55	Did your child receive test, X-ray or scan results while they were still in hospital?	0.9		0.9
56	Did a health professional explain the test, X-ray or scan results in a way that you [the parent/carer] could understand?	0.8		0.8
57	Did you feel involved in decisions about your child's discharge from hospital?	0.8		0.8
58	At the time your child was discharged, did you feel that they were well enough to leave the hospital?	0.8		0.8
59	Thinking about when your child left hospital, were you given enough information about how to manage their care at home?	0.7		0.7
60	Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?	0.9		0.9
61	Did hospital staff tell you who to contact if you were worried about your child's condition or treatment after they left hospital?	0.8	8.7	9.5
62	Was your child given or prescribed any new medication to take at home?	0.8	2.4	3.3
63	Did a health professional in the hospital explain the purpose of this medication in a way you [the parent/carer] could understand?	0.7		0.7
64	Did a health professional in the hospital tell you about medication side effects to watch for?	0.9		0.9
65	Did the hospital provide you with a document summarising the care your child received in hospital (e.g. copy of the letter to your GP or a discharge summary)?	0.6	9.9	10.5
66	On the day your child left hospital, was their discharge delayed?	0.8		0.8
67	How long was the delay? [in discharge]	0.0	6.9	6.9
68	Did a member of staff explain the reason for the delay?	0.0		0.0
69	What were the main reasons for the delay?	1.9	5.7	7.7



Number	Question text (0–7 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
70	Overall, how would you rate the care your child received while in hospital?	0.4		0.4
71	How well organised was the care your child received in hospital?	0.5		0.5
72	If asked about your child's hospital experience by friends and family how would you respond?	0.5		0.5
73	Did you want to make a complaint about something that happened in hospital?	0.5		0.5
74	Why didn't you make a complaint?	0.8		0.8
75	Did the care and treatment received in hospital help your child?	0.3		0.3
76	Is the problem your child went to hospital for...?	1.3		1.3
77	In the week before your child's hospital stay, how difficult was it for them to carry out their normal daily activities?	1.7		1.7
78	About one month after your child's discharge from hospital, how difficult was it for them to carry out their normal daily activities?	1.7		1.7
79	Gender of parent/carer	0.3		0.3
80	Highest level of education completed by parent/carer	1.3		1.3
81	Language mainly spoken at home by parent/carer	1.3		1.3
82	Did you (the parent/carer) need, or would you have liked, to use an interpreter at any stage while your child was in hospital?	1.9		1.9
83	Did the hospital provide an interpreter when you needed one?	3.2		3.2
84	What year was your child born?	4.8		4.8
85	What is your child's gender?	0.3		0.3
86	Which, if any, of the following long-standing conditions does your child have?	1.3		1.3
87	Does this condition(s) cause your child difficulties with their day-to-day activities?	0.48		0.48
88	Is your child a participant of the National Disability Insurance Scheme (NDIS)?	0.5	2.9	3.4
89	In general, how would you rate your child's health?	0.3		0.3
90	Aboriginal and/or Torres Strait Islander origin of patient	0.6		0.6
91	Did your child see an Aboriginal Health Worker during their stay in hospital?	0	3.85	3.85
92	Who completed this survey?	0.4		0.4
93	Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to your child?	0.9		0.9

Table 6 Proportion of 'Don't know' and missing responses for questions, 8–13 years, CYPS, January to December 2018

Number	Question text (8–13 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
1	Was your child's stay in hospital planned in advance or an emergency?	0.8		0.8
2	From the time a doctor said your child would need to go to hospital, how long did they have to wait to be admitted?	1.9	2.6	4.5
3	Do you think the amount of time your child waited to go to hospital was...?	1.5	1.3	2.8
4	Before your child's arrival, how much information about their hospital stay was given to you?	1.7	2.6	4.3
5	When your child arrived in hospital did they spend time in the emergency department?	1.0	1.3	2.3
6	Were the emergency department staff polite and courteous?	0.2	0.3	0.5
7	Do you think the amount of time your child spent in the emergency department was...?	0.0	0.7	0.7
8	Were the staff you met on your arrival to hospital polite and courteous?	0.8		0.8
9	Do you think the time your child had to wait from arrival at hospital until they were taken to their room or ward was...?	0.9	0.9	1.9
10	For most of your child's stay in hospital, what type of room or ward were they in?	1.5	3.4	4.9
11	How clean were the wards or rooms your child stayed in while in hospital?	0.8	0.6	1.4
12	How clean were the toilets and bathrooms that your child used while in hospital?	0.6	1.9	2.5
13	Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching your child?	0.6	9.3	9.9
14	Was your child given enough privacy during their hospital stay?	0.9		0.9
15	Did your child have any special dietary needs (e.g. vegetarian, diabetic, food allergies, religious, cultural, or related to their treatment)?	0.8		0.8
16	Was the hospital food suitable for their dietary needs?	1.4		1.4
17	If you needed to talk to a doctor, did you get the opportunity to do so?	0.8		0.8
18	In your opinion, did the doctors who treated your child know enough about their medical history?	1.2		1.2
19	Did you have confidence and trust in the doctors treating your child?	1.1		1.1
20	In your opinion, did the nurses who treated your child know enough about their care and treatment?	0.8		0.8
21	Did you have confidence and trust in the nurses treating your child?	0.8		0.8
22	Did the health professionals explain things in a way you [the parent/carer] could understand?	0.8		0.8
23	During your child's stay in hospital, how much information about their condition or treatment was given to you?	0.6		0.6

Number	Question text (8–13 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
24	Did you receive contradictory information from health professionals in the hospital - for example, different opinions on your child's treatment?	0.8		0.8
25	Did you have worries or fears about your child's condition or treatment while in hospital?	0.7		0.7
26	Did a health professional discuss your worries or fears about your child with you?	0.5		0.5
27	Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?	0.5		0.5
28	Were you allowed to remain with your child when they were being treated (excluding surgery)?	0.6	0.4	1.0
29	How would you rate how well the health professionals worked together?	0.6		0.6
30	Did you feel your child was treated with respect and dignity while they were in the hospital?	0.5		0.5
31	Were your child's cultural or religious beliefs respected by the hospital staff?	1.1		1.1
32	Not including the reason your child came to hospital, during their hospital stay, or soon afterwards, did they experience any of the following complications or problems?	2.2		2.2
33	Was the impact of this complication or problem...?	2.1		2.1
34	In your opinion, were members of the hospital staff open with you about this complication or problem?	1.4		1.4
35	How much information were you given about the hospital facilities available to you and your child?	0.5		0.5
36	Did you (the patient's parents or carers) make use of the overnight facilities at the hospital?	1.3		1.3
37	How would you [the parent/carer] rate the overnight facilities for parents or carers at the hospital?	0.5		0.5
38	Were facilities available for parents and carers to make drinks or food?	0.7	11.9	12.6
39	Was there a problem finding parking near the hospital?	0.5		0.5
40	During your child's stay in hospital, did they have any tests, X-rays or scans?	0.6		0.6
41	Did a health professional discuss the purpose [of tests, x-rays or scans] with you and/or your child?	0.7	0.7	1.4
42	Did your child receive test, X-ray or scan results while they were still in hospital?	0.8		0.8
43	Did a health professional explain the test, X-ray or scan results in a way that you [the parent/carer] could understand?	0.8		0.8
44	Did you feel involved in decisions about your child's discharge from hospital?	0.8		0.8
45	At the time your child was discharged, did you feel that they were well enough to leave the hospital?	1.3		1.3
46	Thinking about when your child left hospital, were you given enough information about how to manage their care at home?	0.5		0.5

Number	Question text (8–13 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
47	Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?	0.7		0.7
48	Did hospital staff tell you who to contact if you were worried about your child's condition or treatment after they left hospital?	0.7	7.7	8.4
49	Was your child given or prescribed any new medication to take at home?	0.4	2.0	2.3
50	Did a health professional in the hospital explain the purpose of this medication in a way you [the parent/carer] could understand?	0.6		0.6
51	Did a health professional in the hospital tell you about medication side effects to watch for?	1.0		1.0
52	Did the hospital provide you with a document summarising the care your child received in hospital (e.g. copy of the letter to your GP or a discharge summary)?	0.7	10.1	10.8
53	On the day your child left hospital, was their discharge delayed?	0.8		0.8
54	How long was the delay? [in discharge]	0.4	3.5	4.0
55	Did a member of staff explain the reason for the delay?	1.3		1.3
56	What were the main reasons for the delay?	1.8	5.3	7.1
57	Overall, how would you rate the care your child received while in hospital?	0.4		0.4
58	How well organised was the care your child received in hospital?	0.4		0.4
59	If asked about your child's hospital experience by friends and family how would you respond?	0.9		0.9
60	While in hospital, did you receive or see any information about how to comment or complain about your child's care?	0.5	34.1	34.7
61	Did you want to make a complaint about something that happened in hospital?	0.6		0.6
62	Why didn't you make a complaint?	3.4		3.4
63	Did the care and treatment received in hospital help your child?	0.6		0.6
64	Is the problem your child went to hospital for...?	1.4		1.4
65	In the week before your child's hospital stay, how difficult was it for them to carry out their normal daily activities?	1.7		1.7
66	About one month after your child's discharge from hospital, how difficult was it for them to carry out their normal daily activities?	1.0		1.0
67	Gender of parent/carer	0.4		0.4
68	Highest level of education completed by parent/carer	1.3		1.3
69	Language mainly spoken at home by parent/carer	1.4		1.4
70	Did you (the parent/carer) need, or would you have liked, to use an interpreter at any stage while your child was in hospital?	1.2		1.2

Number	Question text (8–13 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
71	Did the hospital provide an interpreter when you needed one?	0.0		0.0
72	What year was your child born?	9.4		9.4
73	What is your child's gender?	0.4		0.4
74	In general, how would you rate your child's health?	0.3		0.3
75	Which, if any, of the following long-standing conditions does your child have?	1.7		1.7
76	Does this condition(s) cause your child difficulties with their day-to-day activities?	0.56		0.56
77	Is your child a participant of the National Disability Insurance Scheme (NDIS)?	0.0	3.1	3.1
78	Aboriginal and/or Torres Strait Islander origin of patient	0.5		0.5
79	Did your child see an Aboriginal Health Worker during their visit to the hospital?	0	3.85	3.85
80	Who completed the survey up to this point?	0.7		0.7
81	Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to your child?	5.4		5.4
84	Did the doctors and nurses introduce themselves to you?	3.8		3.8
85	Were the doctors kind and caring?	3.7		3.7
86	Were the nurses kind and caring?	3.8		3.8
87	Did the doctors and nurses explain things in a way you could understand?	3.8		3.8
88	Did a doctor or nurse discuss your worries or fears with you?	3.8		3.8
89	If you were in pain, did the doctors and nurses do everything they could to help with your pain?	3.8		3.8
90	How would you rate the hospital food?	3.7		3.7
91	Did the hospital room suit someone your age?	3.9		3.9
92	Were there things for you to do (such as books, games and toys)?	3.9	11.0	14.9
93	Were you given enough privacy during your hospital stay?	3.8		3.8
94	Were you ever bothered by noise in the hospital?	4.0		4.0
95	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	4.6		4.6
96	Overall, how would you rate the care you received while in hospital?	4.0		4.0
99	Who completed this section?	5.5		5.5

Table 7 Proportion of 'Don't know' and missing responses for question, 14–17 years, CYPS, January to December 2018

Number	Question text (14–17 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
1	Was your stay in hospital planned in advance or an emergency?	1.3		1.3
2	From the time a doctor said you would need to go to hospital, how long did you have to wait to be admitted?	2.2	7.2	9.4
3	Do you think the amount of time you waited to go to hospital was...?	2.0	3.0	5.0
4	Before your arrival, how much information about your hospital stay was given to you?	1.7	4.5	6.2
5	When you arrived in hospital did you spend time in the emergency department?	0.8	3.2	4.0
6	Were the emergency department staff polite and courteous?	2.0	0.6	2.5
7	Do you think the amount of time you spent in the emergency department was...?	2.0	3.1	5.1
8	Were the staff you met on your arrival to hospital polite and courteous?	0.2		0.2
9	Do you think the time you had to wait from arrival at hospital until you were taken to your room or ward was...?	1.2	4.0	5.2
10	For most of your stay in hospital, what type of room or ward were you in?	2.9	5.0	7.9
11	Was the room or ward suitable for someone your age?	1.7		1.7
12	Were there things for you to do (such as books and games)?	3.3	9.1	12.4
13	How clean were the wards or rooms you stayed in while in hospital?	1.4	0.8	2.2
14	How clean were the toilets and bathrooms that you used while in hospital?	1.4	3.2	4.6
15	Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching you?	1.5	12.7	14.2
16	Were you given enough privacy during your hospital stay?	1.8		1.8
17	Were you ever bothered by noise in the hospital?	2.2		2.2
18	How would you rate the hospital food?	1.7		1.7
19	Did you have any special dietary needs (e.g. vegetarian, diabetic, food allergies, religious, cultural, or related to your treatment)?	0.3		0.3
20	Was the hospital food suitable for your dietary needs?	0.6		0.6
21	If you needed to talk to a doctor, did you get the opportunity to do so?	0.9		0.9
22	In your opinion, did the doctors who treated you know enough about your medical history?	1.4		1.4
23	Did you have confidence and trust in the doctors treating you?	1.0		1.0
24	Were the doctors kind and caring towards you?	1.3		1.3

Number	Question text (14–17 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
25	In your opinion, did the nurses who treated you know enough about your care and treatment?	1.0		1.0
26	Did you have confidence and trust in the nurses treating you?	0.9		0.9
27	Were the nurses kind and caring towards you?	1.2		1.2
28	Did the health professionals introduce themselves to you?	1.0		1.0
29	Did the health professionals explain things in a way you could understand?	1.3		1.3
30	During your stay in hospital, how much information about your condition or treatment was given to you?	1.3		1.3
31	Did you receive contradictory information from health professionals in the hospital - for example, different opinions on your treatment?	1.4		1.4
32	Did you have worries or fears about your condition or treatment while in hospital?	0.5		0.5
33	Did a health professional discuss your worries or fears with you?	0.6		0.6
34	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	0.9		0.9
35	Was a family member or carer allowed to remain with you when you were being treated (excluding surgery)?	0.8	0.6	1.4
36	How would you rate how well the health professionals worked together?	0.5		0.5
37	Did you feel you were treated with respect and dignity while you were in the hospital?	0.6		0.6
38	Were your cultural or religious beliefs respected by the hospital staff?	1.7		1.7
39	While in hospital, did you receive or see any information about how to comment or complain about your care?	1.4	40.1	41.5
40	Not including the reason you came to hospital, during your hospital stay, or soon afterwards, did you experience any of the following complications or problems?	2.4		2.4
41	Was the impact of this complication or problem...?	0.6		0.6
42	In your opinion, were members of the hospital staff open with you about this complication or problem?	0.6		0.6
43	How much information were you given about the hospital facilities available to you?	0.9		0.9
44	Were facilities available for parents and carers to make drinks or food?	0.5	16.2	16.7
45	If you were in pain, did the doctors and nurses do everything they could to help with your pain?	0.6		0.6
46	During your stay in hospital, did you have any tests, X-rays or scans?	0.6		0.6
47	Did a health professional discuss the purpose of these tests, X-rays or scans with you?	1.8	2.6	4.4

Number	Question text (14–17 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
48	Did you receive test, X-ray or scan results while you were still in hospital?	1.6		1.6
49	Did a health professional explain the test, X-ray or scan results in a way that you could understand?	0.5		0.5
50	Did you feel involved in decisions about your discharge from hospital?	0.8		0.8
51	At the time you were discharged, did you feel that you were well enough to leave the hospital?	0.8		0.8
52	Thinking about when you left hospital, were you given enough information about how to manage your care at home?	0.8		0.8
53	Thinking about when you left hospital, were adequate arrangements made by the hospital for any services you needed?	0.8		0.8
54	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	0.9	12.8	13.7
55	Were you given or prescribed any new medication to take at home?	0.8	3.8	4.6
56	Did a health professional in the hospital explain the purpose of this medication in a way you could understand?	1.1		1.1
57	Did a health professional in the hospital tell you about medication side effects to watch for?	1.1		1.1
58	Did the hospital provide you with a document summarising the care you received in hospital (e.g. copy of the letter to your GP or a discharge summary)?	1.8	16.9	18.7
59	On the day you left hospital, was your discharge delayed?	0.9		0.9
60	How long was the delay? [in discharge]	0.5	9.3	9.8
61	Did a member of staff explain the reason for the delay?	0.5		0.5
62	What were the main reasons for the delay?	1.1	9.8	10.9
63	Overall, how would you rate the care you received while in hospital?	0.4		0.4
64	How well organised was the care you received in hospital?	0.4		0.4
65	If asked about your hospital experience by friends and family how would you respond?	0.8		0.8
66	Did you want to make a complaint about something that happened in hospital?	0.6		0.6
67	Why didn't you make a complaint?	2.7		2.7
68	Did the care and treatment received in hospital help you?	1.0		1.0
69	Is the problem you went to hospital for...?	1.3		1.3
70	In the week before your hospital stay, how difficult was it for you to carry out your normal daily activities?	1.5		1.5
71	About one month after your discharge from hospital, how difficult was it for you to carry out your normal daily activities?	1.2		1.2



Number	Question text (14–17 years)	Missing (%)	Don't know (%)	Missing + Don't know (%)*
72	What year were you born?	6.0		6.0
73	What is your gender?	0.4		0.4
74	Language mainly spoken at home by patient	0.8		0.8
75	Did you need, or would you have liked, to use an interpreter at any stage while you were in hospital?	4.5		4.5
76	Did the hospital provide an interpreter when you needed one?	0.0		0.0
77	In general, how would you rate your health?	0.8		0.8
78	Which, if any, of the following longstanding conditions do you have?	0.8		0.8
79	Does this condition(s) cause you difficulties with your day-to-day activities?	0.58		0.58
80	Are you a participant of the National Disability Insurance Scheme (NDIS)?	1.5	10.2	11.6
81	Aboriginal and/or Torres Strait Islander origin of patient	0.4		0.4
82	Did you see an Aboriginal Health Worker during your visit?	0	11.3	11.3
83	Who completed this survey?	0.9		0.9
84	Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to you?	3.8		3.8

# Appendix 2

## 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, please see the *Data Dictionary: Quintile of disadvantage*).

### Statistical methods

Results are weighted as described in this report.

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).

### 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.

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

**Table 8**      **Derived measures for the CYPS 2018 questionnaire, 0–7 and 8–13 years**

Derived measure	Actual question text (0–7 years / 8–13 years)	Derived measure categories	Actual question responses
Parent/carer needed to talk to a doctor	Q22/Q17. If you needed to talk to a doctor, did you get the opportunity to do so?	Needed to talk to doctor	Yes, always Yes, sometimes No, I did not get the opportunity
		No need to talk to doctor	I had no need to talk to a doctor
Parent/carer wanted information about patient's condition or treatment during stay	Q32/Q23. During your child's stay in hospital, how much information about their condition or treatment was given to you?	Wanted information	Not enough The right amount Too much
		Not applicable	Not applicable to my situation
Parent/carer wanted to be involved in decisions about child's care and treatment	Q38/Q27. Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?	Wanted involvement	Yes, definitely Yes, to some extent No
		Not applicable	I did not want or need to be involved Not applicable to our situation
Patient had cultural or religious beliefs to consider	Q42/Q31. Were your child's cultural or religious beliefs respected by the hospital staff?	Has beliefs to consider	Yes, always Yes, sometimes No, my child's beliefs were not respected
		Beliefs not an issue	My child's beliefs were not an issue
Patient experienced complication or problem during or shortly after hospital stay	Q44/Q32. Not including the reason your child came to hospital, during their hospital stay, or soon afterwards, did they experience any of the following complications or problems?	Experienced complication	An infection Uncontrolled bleeding A negative reaction to medication Complications as a result of an operation or surgical procedure Complications as a result of tests, x-rays or scans A blood clot A pressure wound or bed sore A fall Any other complication or problem
		None reported	None of these Missing

Derived measure	Actual question text (0–7 years / 8–13 years)	Derived measure categories	Actual question responses
Complication or problem occurred during hospital stay	Q46/Q34. In your opinion, were members of the hospital staff open with you about this complication or problem?	Occurred in hospital	Yes, completely Yes, to some extent No
		Occurred after left	Not applicable, as it happened after my child left
Patient experienced pain during stay (0–7 years)	Q47*. If your child was in pain, did the doctors and nurses do everything they could to help with their pain?	Had pain	Yes, definitely Yes, to some extent No
		Didn't have pain	My child was not in pain
Parent/carer needed information about the hospital facilities	Q48/Q35. How much information were you given about the hospital facilities available to you and your child?	Needed information	Not enough The right amount Too much
		Not applicable	Not applicable to our situation
Parent/carer needed parking	Q52/Q39. Was there a problem finding parking near the hospital?	Needed parking	Yes, a big problem Yes, a small problem No problem
		Didn't need parking	Not applicable – did not need parking
Parent/carer wanted to be involved in decisions about their child's discharge	Q57/Q44. Did you feel involved in decisions about your child's discharge from hospital?	Wanted involvement	Yes, definitely Yes, to some extent No, I did not feel involved
		Didn't want involvement	I did not want or need to be involved
Parent/carer needed information about how to manage child's care at home	Q59/Q46. Thinking about when your child left hospital, were you given enough information about how to manage their care at home?	Needed information	Yes, completely Yes, to some extent No, I was not given enough
		Didn't need information	I did not need this type of information
Patient needed services after discharge	Q60/Q47. Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?	Needed services	Yes, completely Yes, to some extent No, arrangements were not adequate
		Didn't need services	It was not necessary

Derived measure	Actual question text (0–7 years / 8–13 years)	Derived measure categories	Actual question responses
Patient experienced pain during stay (8–13 years)	Q88*. Did a doctor or nurse discuss your worries or fears with you?	Yes	Yes, completely Yes, sort of No, no-one discussed my worries and fears with me
		No	I did not have any worries or fears
Patient experienced pain during stay (8–13 years)	Q89*. If you were in pain, did the doctors and nurses do everything they could to help with your pain?	Had pain	Yes, definitely Yes, sort of No
		Didn't have pain	I was not in any pain
Patient had hospital food (8–13 years)	Q90*. How would you rate the hospital food?	Had hospital food	Very good Good Not good or bad Bad Very bad
		Didn't have hospital food	I did not have any hospital food
Patient has long-standing health condition	Q86/Q75. Which, if any, of the following long-standing conditions does your child have?	Has long-standing condition	Deafness or severe hearing impairment Blindness or severe vision impairment A long-standing illness (e.g. cancer, diabetes, respiratory disease) A long-standing physical condition A learning disability A mental health condition (e.g. depression, eating disorder) A neurological condition (e.g. ADHD)
		None reported	None of these Missing
Patient wanted involvement in decisions about their care and treatment (8–13 years)	Q95*. Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Wanted involvement	Yes, definitely Yes, sort of No
		Didn't want involvement	I did not want or need to be involved I was not well enough

\* Only included in one questionnaire.

Table 9 Derived measures for the CYPS 2018 questionnaire, 14–17 years

Derived measure	Actual question text (14–17 years)	Derived measure categories	Actual question responses
Patient had hospital food	Q18. How would you rate the hospital food?	Had hospital food	Very good Good Not good or bad Bad Very bad
		Didn't have hospital food	I did not have any hospital food
Patient needed to talk to a doctor	Q21. If you needed to talk to a doctor, did you get the opportunity to do so?	Needed to talk to doctor	Yes, always Yes, sometimes No, I did not get the opportunity
		No need to talk to doctor	I had no need to talk to a doctor
Patient wanted information about condition or treatment during stay	Q30. During your stay in hospital, how much information about your condition or treatment was given to you?	Wanted information	Not enough The right amount Too much
		Not applicable	Not applicable to my situation
Patient wanted involvement in decisions about their care and treatment?	Q34. Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Wanted involvement	Yes, definitely Yes, to some extent No
		Didn't want involvement	I did not want or need to be involved Not applicable to my situation
Patient had cultural or religious beliefs to consider	Q38. Were your cultural or religious beliefs respected by the hospital staff?	Has beliefs to consider	Yes, always Yes, sometimes No, my beliefs were not respected
		Beliefs not an issue	My beliefs were not an issue
Patient experienced complication or problem during or shortly after hospital stay	Q40. Not including the reason you came to hospital, during your hospital stay, or soon afterwards, did you experience any of the following complications or problems?	Experienced complication	An infection Uncontrolled bleeding A negative reaction to medication Complications as a result of an operation or surgical procedure Complications as a result of tests, X-rays or scans A blood clot A pressure wound or bed sore A fall Any other complication or problem
		None reported	None of these Missing

Derived measure	Actual question text (14–17 years)	Derived measure categories	Actual question responses
Complication or problem occurred during hospital stay	Q42. In your opinion, were members of the hospital staff open with you about this complication or problem?	Occurred in hospital	Yes, completely Yes, to some extent No
		Occurred after left	Not applicable, as it happened after I left
Patient needed information about the hospital facilities	Q43. How much information were you given about the hospital facilities available to you?	Needed information	Not enough The right amount Too much
		Not applicable	Not applicable to my situation
Patient experienced pain during stay	Q45. If you were in pain, did the doctors and nurses do everything they could to help with your pain?	Had pain	Yes, definitely Yes, to some extent No
		Didn't have pain	I was not in any pain
Patient wanted to be involved in decisions about their discharge	Q50. Did you feel involved in decisions about your discharge from hospital?	Wanted involvement	Yes, definitely Yes, to some extent No, I did not feel involved
		Didn't want involvement	I did not want or need to be involved
Patient needed information about how to manage care at home	Q52. Thinking about when you left hospital, were you given enough information about how to manage your care at home?	Needed information	Yes, completely Yes, to some extent No, I was not given enough
		Didn't need information	I did not need this type of information
Patient needed services after discharge	Q53. Thinking about when you left hospital, were adequate arrangements made by the hospital for any services you needed?	Needed services	Yes, completely Yes, to some extent No, arrangements were not adequate
		Didn't need services	It was not necessary
Patient has long-standing health condition	Q78. Which, if any, of the following long-standing conditions do you have?	Has long-standing condition	Deafness or severe hearing impairment Blindness or severe vision impairment A long-standing illness (e.g. cancer, diabetes, respiratory disease) A long-standing physical condition A learning disability A mental health condition (e.g. depression, eating disorder) A neurological condition (e.g. ADHD)
		None reported	None of these Missing

# References

1. SAS Documentation: Example Weighted Multilevel Model for Survey Data. [online] Available from: [http://support.sas.com/documentation/cdl/en/statug/66859/HTML/default/viewer.htm#statug\\_glimmix\\_examples23.htm](http://support.sas.com/documentation/cdl/en/statug/66859/HTML/default/viewer.htm#statug_glimmix_examples23.htm).





## 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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