

Admitted Children and Young Patients Survey 2018

Development Report

December 2019

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

Background

In 2017, the Bureau of Health Information (BHI) reviewed the Admitted Children and Young Patients Survey (CYPS) 2017 questionnaire to inform any content changes required for the 2018 survey. 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.

BHI reviews all recurrent surveys before they are repeated to ensure the questionnaire is still appropriate for the NSW context and all questions remain optimal. CYPS has three questionnaires, each specific to the age of the patient (see page 2 for further information).

This document summarises the changes to the CYPS 2017 questionnaire. Please refer to previous CYPS development reports available at bhi.nsw.gov.au for more information about how previous questionnaires were developed. These reports include details such as stakeholder consultation and engagement, questionnaire development, sampling methodology, and additional development notes.

Method

The review of the questionnaire focused on a methodological analysis of the 2017 data, as well as an evaluation of the use of survey data for reporting on the performance of NSW public hospitals for admitted children and young patient experiences. The resulting changes and rationales are presented in this document.

BHI's analysis of CYPS 2017 data to test the quality of questions and questionnaire design included an examination of the following:

- response patterns for each question, including rates of item non-response (not answering a question when they should have), invalid responses (selecting more than one answer to a single response question or answering a question they should have skipped) and non-specific responses, such as 'don't know', 'can't remember' or 'not applicable to me'
- ceiling and floor effects of response categories (responses where almost all patients were very positive or very negative, with little variation between hospitals) using the scored mean, standard deviation and skewness of responses
- correlations between questions (using the most positive response option) to understand if any questions appear to be duplicating the same aspect of care (using the Pearson method).

Following the analysis of the 2017 questionnaire content and data, proposed changes were discussed and agreed upon. The final version of the 2018 questionnaire was reviewed and signed off by BHI's Chief Executive.

Questionnaire versions

CYPS 2018 comprised three questionnaires, based on the patient's age at the time of their hospital admission:

- A questionnaire completed by **parents of children aged 0–7** with 95 questions.
- A questionnaire with 83 questions completed by **parents of children aged 8–13**, and a section of 15 questions completed by **children aged 8–13**.

Note that for CYPS 2017, the age category captured by this questionnaire was 8–15.

- A questionnaire completed by **young people aged 14–17** with 85 questions.

Note that for CYPS 2017, the age category captured by this questionnaire was 16–17.

The change in age categories between the 2017 and 2018 questionnaires was made following the advice of the Ministry of Health's Youth Services Team and legal branch. Due to the low risk of harm arising from completing the questionnaire, BHI was advised to lower the age of patient consent from 16 years to 14 years. A note was added to the questionnaire invitation letter to explain this and inform young patients that they could ask a parent or carer to help them complete the questionnaire, should they require it.

Overview of changes: 0–7 years questionnaire

A short summary of amended questions and sections is outlined below. Details of changes are explained in the following section.

New questions

- Q87, Q88, Q91.

Modified questionnaire content

- Modified questions and/or response options:
 - Q83, Q86.
- Modified formatting to questions and/or response options:
 - Q90, Q93.
- Modified section:
 - Pain.

Overview of changes: 8–13 years questionnaire

A short summary of amended questions and sections is outlined below. Details of changes are explained in the following section.

New questions

- Q76, Q77, Q79.

Modified questionnaire content

- Modified questions and/or response options:
 - Q70, Q71, Q75.
- Modified formatting to questions and/or response options:
 - Q5, Q40, Q53, Q60, Q78, Q81.

Overview of changes: 14–17 years questionnaire

A short summary of amended questions and sections is outlined below. Details of changes are explained in the following section.

New questions

- Q79, Q80, Q82.

Modified questionnaire content

- Modified questions and/or response options:
 - Q76, Q78.
- Modified formatting to questions and/or response options:
 - Q18, Q81, Q84.
- Modified sections:
 - Your Treatment & Care
 - Information and Access
 - Pain.

Details of changes: 0–7 years questionnaire

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q83	Q83	<p>Did the hospital provide an interpreter when you needed one?</p> <ul style="list-style-type: none"> • Yes, always • Yes, sometimes • No • I did not need the hospital to provide a professional interpreter 	<p>Modified response option</p> <p>Added 'professional' to the response option 'I did not need the hospital to provide a professional interpreter'</p>	<p>This change was introduced to clarify the definition of 'interpreter'.</p>
Q86	Q86	<p>Which, if any, of the following long-standing conditions does your child have?</p> <p>Please X <u>all</u> the boxes that apply to your child</p> <ul style="list-style-type: none"> • Deafness or severe hearing impairment • Blindness or severe vision impairment • A longstanding illness (e.g. cancer, diabetes, respiratory disease) • A longstanding physical condition • An intellectual disability • A mental health condition (e.g. depression, eating disorder) • A neurological condition (e.g. ADHD) • <u>None</u> of these.....Go to Q89 	<p>Modified response options</p> <p>Changed 'long-standing' to 'longstanding'</p> <p>Replaced 'A learning disability' with 'An intellectual disability'</p> <p>Instructions added to response options</p> <p>Directional arrow for options one to seven 'Go to Q89' instruction added to '<u>None</u> of these'</p>	<p>This change was made to align with the BHI style guide.</p> <p>Intellectual disability is the preferred term to use in Australia.</p> <p>Directional arrow and 'Go to Q89' instruction was introduced as the new questions (Q87–88) added in 2018 were only applicable to the cohort of patients who had longstanding conditions.</p>

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
n/a	Q87	Does this condition(s) cause your child difficulties with their day-to-day activities? <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No 	New	This question was added for consistency with other BHI patient survey questionnaires.
n/a	Q88	If your child a participant of the National Disability Insurance Scheme (NDIS)? <ul style="list-style-type: none"> • Yes • No • Don't know 	New	This question was added for consistency with other BHI patient survey questionnaires.
Q88	Q90	Is your child of Aboriginal origin, Torres Strait Islander origin, or both? <ul style="list-style-type: none"> • Yes, Aboriginal • Yes, Torres Strait Islander • Yes, both Aboriginal and Torres Strait Islander • No..... Go to Q92 	Instructions added to response options Directional arrow for options one to three 'Go to Q92' instruction added to 'No'	Directional arrow and 'Go to Q92' instruction were introduced as the new question (Q91) added in 2018 is only applicable to the cohort of patients whose parent/carer identified them as Aboriginal/Torres Strait Islander or both.
n/a	Q91	Did your child see an Aboriginal Health Worker during their stay in hospital? <ul style="list-style-type: none"> • Yes • No • Don't know/can't remember 	New	This question was added for consistency with other BHI patient survey questionnaires.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q90	Q93	<p>The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to your child which are maintained by various NSW and Commonwealth agencies (including your child's hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your child's health care information for the two years before and after their visit will allow us to better understand how different aspects of the care provided by health facilities are related to the health and use of health services of their patients.</p> <p>Your child's information will be treated in the strictest confidence. We will receive the linked information after your child's name and address have been removed. We will not report any results which may identify you or your child as an individual and your responses will not be accessible to the people who looked after your child.</p> <p>Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to your child?</p>	<p>Reformatted question Selected text bolded</p> <p>Spelling error fixed 'Anay' changed to 'any'</p>	<p>Selected text was bolded to reinforce key content.</p> <p>Spelling error corrected.</p>

Section 2017	Section 2018	Updated section (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q52	Q47	Pain	Sections moved 'Pain' appears before 'Information and Access'	The 'Pain' section was moved to appear before the 'Information and Access' section to provide space for new questions and to better support the flow of the questionnaire.

Details of changes: 8–13 years questionnaire

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q5	Q5	When your child arrived in hospital did they spend time in the emergency department? <ul style="list-style-type: none"> • Yes.....Go to Q6 • No.....Go to Q8 • Don't know/can't remember.....Go to Q8 	Instruction added to response option 'Go to Q6' instruction added to 'Yes'	'Go to Q6' instruction was introduced as the location of the question was changed and the directional arrow could not be used.
Q32	Q60	While in hospital, did you receive or see any information about how to comment or complain about your child's care?	Question moved Moved from 'Your Child's Treatment & Care' to 'Overall'	This question was moved to make space for new questions and to better support the flow of the questionnaire.
Q41	Q40	During your child's stay in hospital, did they have any tests, X-rays or scans? <ul style="list-style-type: none"> • Yes • No..... Go to Q44 	Reformatted response option 'Go to' instruction for 'Yes' was removed and replaced by a directional arrow	Directional arrow was introduced as the location of the question was changed and the 'Go to' instruction would have been redundant.
Q54	Q53	On the day your child left hospital, was their discharge delayed? <ul style="list-style-type: none"> • Yes • No..... Go to Q57 	Reformatted response option 'Go to' instruction for 'Yes' was removed and replaced by a directional arrow	Directional arrow was introduced as the location of the question was changed and the 'Go to' instruction would have been redundant.
Q70	Q70	Did you (the parent/carer) need, or would have liked, to use an interpreter at any stage while your child was in hospital?	Modified question Added 'your child' and changed 'were' to 'was'	This change was introduced to clarify that the question refers to when the child was in hospital and not the patient/carer.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q71	Q71	<p>Did the hospital provide an interpreter when you needed one?</p> <ul style="list-style-type: none"> • Yes, always • Yes, sometimes • No • I did not need the hospital to provide a professional interpreter 	<p>Modified response option</p> <p>Added 'professional' to the response option 'I did not need the hospital to provide a professional interpreter'</p>	<p>This change was introduced to clarify the definition of 'interpreter'.</p>
Q74	Q75	<p>Which, if any, of the following long-standing conditions does your child have?</p> <p>Please X <u>all</u> the boxes that apply to your child</p> <ul style="list-style-type: none"> • Deafness or severe hearing impairment • Blindness or severe vision impairment • A longstanding illness (e.g. cancer, diabetes, respiratory disease) • A longstanding physical condition • An intellectual disability • A mental health condition (e.g. depression, eating disorder) • A neurological condition (e.g. ADHD) • <u>None</u> of these.....Go to Q78 	<p>Modified response options</p> <p>Changed 'long-standing' to 'longstanding'</p> <p>Replaced 'A learning disability' with 'An intellectual disability'</p> <p>Instructions added to response options</p> <p>Directional arrow for options one to seven 'Go to Q78' instruction added to '<u>None</u> of these'</p>	<p>This change was made to align with the BHI style guide.</p> <p>Intellectual disability is the preferred term to use in Australia.</p> <p>Directional arrow and 'Go to Q78' instruction were introduced as the new questions (Q76–77) added in 2018 were only applicable to the cohort of patients who had longstanding conditions.</p>

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
n/a	Q76	Does this condition(s) cause your child difficulties with day-to-day activities? <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No 	New	This question was added for consistency with other BHI patient survey questionnaires.
n/a	Q77	If your child a participant of the National Disability Insurance Scheme (NDIS)? <ul style="list-style-type: none"> • Yes • No • Don't know 	New	This question was added for consistency with other BHI patient survey questionnaires.
Q76	Q78	Is your child of Aboriginal origin, Torres Strait Islander origin, or both? <ul style="list-style-type: none"> • Yes, Aboriginal • Yes, Torres Strait Islander • Yes, both Aboriginal and Torres Strait Islander • No..... Go to Q80 	Instructions added to response options Directional arrow for options one to three 'Go to Q80' instruction added to 'No'	Directional arrow and 'Go to Q80' instruction were introduced as the new question (Q79) added in 2018 was only applicable to the cohort of patients whose parent/carer identified them as Aboriginal/Torres Strait Islander or both.
n/a	Q79	Did your child see an Aboriginal Health Worker during their visit to the hospital? <ul style="list-style-type: none"> • Yes • No • Don't know/can't remember 	New	This question was added for consistency with other BHI patient survey questionnaires.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q78	Q81	<p>The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to your child which are maintained by various NSW and Commonwealth agencies (including your child's hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your child's health care information for the two years before and after their visit will allow us to better understand how different aspects of the care provided by health facilities are related to the health and use of health services of their patients.</p> <p>Your child's information will be treated in the strictest confidence. We will receive the linked information after your child's name and address have been removed. We will not report any results which may identify you or your child as an individual and your responses will not be accessible to the people who looked after your child.</p> <p>Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to your child?</p>	<p>Modified question</p> <p>Selected text bolded</p>	Selected text was bolded to reinforce key content.

Details of changes: 14–17 years questionnaire

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q18	Q18	How would you rate the hospital food? <ul style="list-style-type: none"> • Very good • Good • Not good or bad • Bad • Very bad • I did not have any hospital food..... Go to Q21 	<p>Instructions added to response options</p> <p>Directional arrows for all answer options added</p>	Directional arrows were introduced as the location of the question was changed and arrows needed to assist respondents with the flow of the questions.
Q76	Q76	Did the hospital provide an interpreter when you needed one? <ul style="list-style-type: none"> • Yes, always • Yes, sometimes • No <p>I did not need the hospital to provide a professional interpreter</p>	<p>Modified response option</p> <p>Added 'professional' to the response option 'I did not need the hospital to provide a professional interpreter'</p>	This change was introduced to clarify the definition of 'interpreter'.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q77	Q78	<p>Which, if any, of the following long-standing conditions do you have?</p> <p>Please X <u>all</u> the boxes that apply to you</p> <ul style="list-style-type: none"> • Deafness or severe hearing impairment • Blindness or severe vision impairment • A longstanding illness (e.g. cancer, diabetes, respiratory disease) • A longstanding physical condition • An intellectual disability • A mental health condition (e.g. depression, eating disorder) • A neurological condition (e.g. ADHD) • <u>None</u> of these.....Go to Q81 	<p>Modified response options</p> <p>Changed 'long-standing' to 'longstanding'</p> <p>Replaced 'A learning disability' with 'An intellectual disability'</p> <p>Instructions added to response options</p> <p>Directional arrow for options one to seven 'Go to Q81' instruction added to '<u>None</u> of these'</p>	<p>This change was made to align with the BHI style guide.</p> <p>Intellectual disability is the preferred term to use in Australia.</p> <p>Directional arrow and 'Go to Q81' instruction were introduced as the new questions (Q79–80) added in 2018 were only applicable to the cohort of patients who had longstanding conditions.</p>
n/a	Q79	<p>Does this condition(s) cause you difficulties with your day-to-day activities?</p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No 	New	<p>This question was added for consistency with other BHI patient survey questionnaires.</p>

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
n/a	Q80	Are you a participant of the National Disability Insurance Scheme (NDIS)? <ul style="list-style-type: none"> • Yes • No • Don't know 	New	This question was added for consistency with other BHI patient survey questionnaires.
Q79	Q81	Are you of Aboriginal origin, Torres Strait Islander origin, or both? <ul style="list-style-type: none"> • Yes, Aboriginal • Yes, Torres Strait Islander • Yes, both Aboriginal and Torres Strait Islander • No..... Go to Q83 	Instructions added to response options Directional arrow for options one to three 'Go to Q83' instruction added to 'No'	Directional arrow and 'Go to Q83' instruction were introduced as the new question (Q82) added in 2018 was only applicable to the cohort of patients who identified themselves as Aboriginal/Torres Strait Islander or both.
n/a	Q82	Did you see an Aboriginal Health Worker during your visit? <ul style="list-style-type: none"> • Yes • No • Don't know/can't remember 	New	This question was added for consistency with other BHI patient survey questionnaires.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q81	Q84	<p>The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to you which are maintained by various NSW and Commonwealth agencies (including your hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your health care information for the two years before and after your visit will allow us to better understand how different aspects of the care provided by health facilities are related to the health and use of health services of their patients.</p> <p>Your information will be treated in the strictest confidence. We will receive the linked information after your name and address have been removed. We will not report any results which may identify you as an individual and your responses will not be accessible to the people who looked after you.</p> <p>Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to you?</p>	<p>Modified question</p> <p>Selected text bolded</p>	Selected text was bolded to reinforce key content.

Section 2017	Section 2018	Updated section (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q28–42	Q28–45	Your Treatment & Care	Questions added	Questions from the 'Information and Access' and 'Pain' sections were incorporated into the 'Your Treatment & Care' section to better support the flow of the questionnaire.
Q43–45	n/a	n/a	Section headings deleted Information and Access Pain	