

# Development of the Admitted Children and Young Patient Survey 2015

## Background

Every 12 months, each annual survey in the NSW Patient Survey Program is reviewed to ensure it is performing appropriately and collecting the information that is intended. In 2014, the Admitted Children and Young Patients Survey (CYPS) was implemented for the first time consisting of two questionnaires: the Admitted Children questionnaire (designed for children aged under 8 years with completion by a parent/caregiver) and the Admitted Young Patients questionnaire (designed for children and adolescents aged 8 to 17 years with completion by a combination of the parent/caregiver and the patient). In February 2015, results from CYPS 2014 were reviewed to contribute to the redevelopment of the CYPS for 2015 patients.

The CYPS is intended to run on a three year cycle, with all facilities surveyed in year one and only the three children's tertiary facilities<sup>1</sup> surveyed in years two and three. Reflecting this three year cycle, only small changes were intended for the survey for years two and three, with a focus on consistency over time. The next major redevelopment of the questionnaires is scheduled for February 2017. This document summarises the changes to the questionnaires from 2014 to 2015.

## Methods

### *Analysis of historic CYPS data*

An analysis of the first two quarters of 2014 CYPS survey data was undertaken to support the questionnaire review. This analysis determined the following for each question:

- 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 past) 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 are 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 category) to understand if any questions appear to be duplicating the same aspect of care (using the Pearson method).

### *Approval of changes*

Before finalisation of survey changes, recommendations are made and assessed at a number of levels, as follows:

1. Following the aforementioned review, the survey team at BHI compile recommendations to present to the BHI Chief Executive (CE)

<sup>1</sup> Children's Hospital Westmead, Sydney Children's Hospital and John Hunter Hospital (Children's)

2. Following the CE's review, a revised draft questionnaire and summary of changes is provided to the survey program's Strategic Advisory Committee (SAC)
3. When final changes are agreed upon with the SAC and signed off by the BHI CE, the questionnaire is provided to the external contractor for layout in design, printing and mailing.

Throughout this document, 'U8' refers to the questionnaire for patients aged under eight years while '8+' refers to the questionnaire for those aged eight years and over.

## Summary of changes for Admitted Children Survey (U8 survey)

The following lists the changes. Rationale and evidence for changes can be found in the following section.

Q number (2014)	Question	Change
8	Were the staff you saw on your arrival to hospital polite and courteous?	Replaced 'saw' with 'met'
25	Were the doctors polite and courteous?	Deleted
29	Were the nurses polite and courteous?	Deleted
31-33	Other health professionals questions (who received care from, if polite and courteous, confidence and trust in them)	Deleted these questions
48	While in hospital, did you receive, or see, any information about patients' rights, including how to comment or complain?	Reworded question to 'While in hospital, did you receive or see any information about how to comment or complain about your child's care?'
49	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?	Changed 'complications as a result of surgery' to 'complications as a result of an operation or surgical procedure'  Changed 'complications as a result of tests or procedures' to 'complications as a result of tests, x-rays or scans'  Added an instruction to select all the response categories that apply
51	In your opinion, were members of the hospital staff open with you about this complication or problem?	Added 'Not applicable, as it happened after my child left' to response set
59	Did a health professional discuss the purpose with you and/or your child?	Underlined 'purpose'
67	Was your child given or prescribed medication to take at home?	Added 'any <u>new</u> ' in front of 'medication'
68	Did a health professional in the hospital explain the purpose of this medication in a way you could understand?	Underlined 'purpose'
69	Did a health professional in the hospital tell you about medication side effects to watch for?	Underlined 'side effects'
74	What were the main reasons for the delay?	Changed response category 'They had to wait for an ambulance/transport' to 'They had to wait for an ambulance or hospital transport'
78	Did you want to make a complaint about something that happened in hospital?	Moved the last response category ('No, I did not want to make a complaint') to the first position.

82, 83	<p>In the <u>week before</u> your child's hospital stay, how difficult was it for them to carry out their normal daily activities (e.g. physical activity, play, going to school or day-care)?</p> <p>About <u>one month after</u> your child's discharge from hospital, how difficult was it for them to carry out their normal daily activities?</p>	<p>Changed last response category from 'They were not able to at all' to 'Too difficult to do'</p>
N/A	<p>Changes to cover letter.</p>	<p>Addition of an extra sentence directing respondents to view results on Healthcare Observer. Addition of new logo and use of the acronym BHI. Reordering paragraphs.</p>

## Summary of changes for Admitted Young Patients Survey (8+ survey)

In 2015, the Admitted Young Patients Survey questionnaire was split into two to account for the capacity and tendency of adolescents aged 16 and 17 to answer the entire questionnaire themselves. A new questionnaire was therefore produced for this age group, which addressed them throughout, rather than predominantly the parent/carer, as was the case in 2014.

To aid comparability between questionnaires, this new questionnaire was based on the 2015 Young Patients Survey, with minor edits. The majority of changes consisted of rephrasing the questions to ask about 'you' instead of 'your child'. In addition to this, questions that were previously included in the young patient self-completion section of the questionnaire were integrated into the relevant sections of the questionnaire. In these cases, the language was adjusted to reflect the older age of the patient and where appropriate, to make the questions similar to those in the other two questionnaires. These changes included the following:

Q number (8+ 2015)	Question (2015 Admitted Young Patient Survey for 8-15 year olds)	Change (for 2015 Admitted Young Patient Survey for 16-17 year olds)
28	Were you allowed to remain with your child when they were being treated (excluding surgery)?	In addition to rephrasing to ask the patient directly, a 'not applicable' response category was added
37, 38	Did you (the patient's parents or carers) make use of the overnight facilities at the hospital?  And  How would you rate the overnight facilities for parents or carers at the hospital?	Deleted
40	Was there a problem finding parking near the hospital?	Deleted
69, 70	Which language do you (the parent/carer) mainly speak at home?  And  Was an interpreter provided when you (the parent/carer) or your child needed one?	Moved to the 'About You' section and rephrased to ask about patient's language only
81, 82	Were the <u>doctors</u> kind and caring?  And  Were the <u>nurses</u> kind and caring?	Added 'towards you?' to the end of each question
84, 85, 87, 91	Various	Changed response category 'Yes, sort of' to 'Yes, to some extent'
84	Did a doctor or nurse discuss your worries or fears with you?	Split the question into two questions: whether the patient had worries or fears; and whether a health professional discussed them with the patient
83, 84	Did the doctors and nurses explain things in a way you	Changed 'doctors and nurses' to 'health

	could understand? And Did a doctor or nurse discuss your worries or fears with you?	professionals'
87	Did the hospital room suit someone your age?	Changed to 'Was the room or ward suitable for someone your age?'
91	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Changed response category 'I was not well enough' to 'Not applicable to my situation'
92	Overall, how would you rate the care you received while in hospital?	Changed response category term 'bad' to 'poor'
93, 94	What did you think was really good about your hospital visit? And What could have been better?	Deleted and replaced by a rephrased Q78 and Q79
NA	'About you (The Parent or Carer)' section	Deleted

The questionnaire designed for 8 to 15 year olds remained largely as it was in 2014 when it was used for 8 to 17 year olds. The following lists the changes. Rationale and evidence for these changes can be found in the following section.

Q number (2014)	Question	Change
8	Were the staff you saw on your arrival to hospital polite and courteous?	Replaced 'saw' with 'met'
20	Were the doctors polite and courteous?	Deleted
23	Were the nurses polite and courteous?	Deleted
24-26	Other health professionals questions (who received care from, if polite and courteous, confidence and trust in them)	Deleted
37	While in hospital, did you receive, or see, any information about patients' rights, including how to comment or complain?	Reworded question to 'While in hospital, did you receive or see any information about how to comment or complain about your child's care?'
38	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?	Changed 'complications as a result of surgery' to 'complications as a result of an operation or surgical procedure'.  Changed 'complications as a result of tests or procedures' to 'complications as a result of tests, x-rays or scans'.

		Added an instruction to select all the response categories that apply.
40	In your opinion, were members of the hospital staff open with you about this complication or problem?	Added 'Not applicable, as it happened after my child left' to response set
47	Did a health professional discuss the purpose with you and/or your child?	Underlined 'purpose'
55	Was your child given or prescribed medication to take at home?	Added 'any <u>new</u> ' in front of 'medication'
56	Did a health professional in the hospital explain the purpose of this medication in a way you could understand?	Underlined 'purpose'
57	Did a health professional in the hospital tell you about medication side effects to watch for?	Underlined 'side effects'
62	What were the main reasons for the delay?	Changed response category 'They had to wait for an ambulance/transport' to 'They had to wait for an ambulance or hospital transport'
66	Did you want to make a complaint about something that happened in hospital?	Moved the last response category ('No, I did not want to make a complaint') to the first position.
70, 71	In the <u>week before</u> your child's hospital stay, how difficult was it for them to carry out their normal daily activities (e.g. physical activity, play, going to school or day-care)?  About <u>one month after</u> your child's discharge from hospital, how difficult was it for them to carry out their normal daily activities?	Changed last response category from 'They were not able to at all' to 'Too difficult to do'
N/A	Changes to cover letter.	Addition of an extra sentence directing respondents to view results on Healthcare Observer. Addition of new logo and use of the acronym BHI. Reordering paragraphs.

## Details of changes

### Question 8 (U8 and 8+ surveys)

#### Current question

Were the staff you saw on your arrival to hospital polite and courteous?

- Yes, always
- Yes, sometimes
- No

#### Action

Replaced 'saw' with 'met'.

#### Rationale

The change was made to clarify that the question is asking about staff the patient interacted with rather than those they just saw on arrival.

### Questions 25 (U8 survey) and 20 (8+ survey)

#### Current questions

Were the doctors polite and courteous?

- Yes, always
- Yes, sometimes
- No

### ...and Questions 29 (U8 survey) and 23 (8+ survey)

#### Current question

Were the nurses polite and courteous?

- Yes, always
- Yes, sometimes
- No

#### Action

Removal of these questions.

#### Rationale

This change was made to reflect a recent change in the Adult Admitted Patient Survey (AAPS) 2015. Cognitive testing for the Small and Rural Hospitals Survey showed these questions were asking about the same component of care as 'kind and caring'. In the case of the U8 survey where the parents answer the questions on whether the doctors and nurses were 'kind and caring' and 'polite and courteous', there is a high correlation between the two (0.69 for doctor questions, 0.76 for nurse questions). While we don't have the equivalent data for the admission phase, survey development work with patients has suggested that politeness is more important at this earlier point of care. BHI consulted with the survey program's Implementation Advisory Committee on whether these questions were being used as KPIs and, after receiving a negative response, they were deleted.



**Other health professionals (section) – Questions 31-33 (U8 survey) and 24-26 (8+ survey)****Current questions**

31/24. Which, if any, of the following other health professionals did your child receive care or treatment from during this hospital stay? *Please x all the boxes that apply to you or your child*

- Dietician
- Occupational therapist
- Pharmacist
- Physiotherapist
- Psychologist
- Radiographer (X-ray, ultrasound, MRI)
- Social worker
- Speech pathologist
- Other (Please write in \_\_\_\_\_ )
- None of these

32/25. Were these other health professionals polite and courteous?

- Yes, always
- Yes, sometimes
- No

33/26. Did you have confidence and trust in these other health professionals treating your child?

- Yes, always
- Yes, sometimes
- No

**Action**

Removal of these questions.

**Rationale**

These questions represented similar performance issues to those seen in the evaluation of AAPS 2014, for which it was decided they would be removed going forward.

While 37% (U8) to 53% (8+) of respondents saw other health professionals, populations of the specific health professionals are so small that discrimination between them is very difficult. Furthermore, the first question in this series, being a multi-response question, means that respondents select multiple health professionals, making the subsequent questions difficult to analyse in response to a particular type of professional. Hence, the data is not informative and was not seen as useful to LHDs and facilities for the formation of policy or the review of staff.

Additionally, the initial question in the series has a missing rate of 5% in each questionnaire, potentially indicating a lack of understanding of the section, uncertainty about which professionals were seen or a high cognitive burden for this question.

**Questions 48 (U8 survey) and 37 (8+ survey)****Current question**

While in hospital, did you receive, or see, any information about patients' rights, including how to comment or complain?

- Yes
- No
- Don't know/can't remember

**Action**

Removed the reference to 'your rights as a patient' and changed question wording to:

'While in hospital, did you receive or see any information about how to comment or complain about your child's care?'

**Rationale**

This question had similar issues to the same question seen in the AAPS 2014 questionnaire resulting in a change of wording in AAPS. It has a very high proportion of 'don't know' responses (around 40% for each survey). Cognitive testing indicates that the term 'rights' is not one that many respondents are familiar with in regards to their patient experience, causing some uncertainty in responding. Also, while respondents may have seen signs posted in the hospitals, many did not read them or failed to register the connection between those posters and this question. Often, posters promoting patient rights are lost among other posters and pamphlets on the ward.

The modified version of the question was cognitively tested and no issues were identified in the understanding of this new version.

**Questions 49 (U8 survey) and 38 (8+ survey)****Current question**

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?

- An infection
- Uncontrolled bleeding
- A negative reaction to medication
- Complications as a result of surgery
- Complications as a result of tests or procedures
- A blood clot
- A pressure wound or bed sore
- A fall
- Any other complication or problem
- None of these

**Action**

Changed 'complications as a result of surgery' to 'complications as a result of an operation or surgical procedure'.

Changed 'complications as a result of tests or procedures' to 'complications as a result of tests, x-rays or scans'. Added an instruction to select all the response categories that apply.

**Rationale**

Change made to match the updated AAPS 2015 and to allow better comparison between this question and others asking about 'tests, x-rays or scans' or an 'operation or surgical procedure'.

**Questions 51 (U8 survey) and 40 (8+ survey)**

## Current question

In your opinion, were members of the hospital staff open with you about this complication or problem?

- Yes, completely
- Yes, to some extent
- No

## Action

Added 'Not applicable, as it happened after my child left' option.

## Rationale

Change suggested for same reason it was changed for AAPS 2015. For those people who experience a complication after leaving hospital, this question was not appropriate in its original format.

**Questions 59 (U8 survey) and 47 (8+ survey)**

## Current question

Did a health professional discuss the purpose with you and/or your child?

- Yes, always
- Yes, sometimes
- No, did not discuss with me and/or my child
- Don't know/can't remember

## Action

Underlined 'purpose'.

## Rationale

Change made for AAPS 2015 also. Review of the survey results has provided evidence that underlining key words in questions does have an impact on how people respond, specifically, decreasing the proportion of missing responses. In this case, it may help to distinguish the focus of the question, as it appears in a series of four questions on the subject of tests.

**Questions 67 (U8 survey) and 55 (8+ survey)**

## Current question

Was your child given or prescribed medication to take at home?

- Yes
- No

## Action

Added 'any new' in front of medication.

## Rationale

Change made for AAPS 2015 also. The question is followed by two questions about whether health professionals discussed the purpose and side-effects of the medication with the patient, in line with the series of questions asked in

the ED Patient Survey. However, the ED survey asks about new medications and these subsequent questions are more relevant to patients with new medication.

### Questions 68 and 69 (U8 survey) and 56 and 57 (8+ survey)

#### Current questions

68/69. Did a health professional in the hospital explain the purpose of this medication in a way you could understand?

- Yes, completely
- Yes, to some extent
- No

56/57. Did a health professional in the hospital tell you about medication side effects to watch for?

- Yes, completely
- Yes, to some extent
- No

#### Action

Underlined 'purpose' and 'side effects'.

#### Rationale

Change made for AAPS 2015 also. Review of the survey results has provided evidence that underlining key words in questions does have an impact on how people respond, specifically, decreasing the proportion of missing responses. In this case, it may help to distinguish the focus of each question, as they appear in a series of four questions on the subject of medication.

### Questions 74 (U8 survey) and 62 (8+ survey)

#### Current questions

What were the main reasons for the delay?

- They had to wait for medicines
- They had to wait to see the doctor
- They had to wait for an ambulance/transport
- They had to wait for the letter for the GP
- They were not well enough
- Some other reason
- Don't know/can't remember

#### Action

Changed category from 'ambulance/transport' to 'ambulance or hospital transport'.

#### Rationale

Change made for AAPS 2015 also to make the response category more relevant to the hospital performance and prevent people from responding in relation to waiting to be picked up by a relative, etc.

**Questions 78 (U8 survey) and 66 (8+ survey)****Current question**

Did you want to make a complaint about something that happened in hospital?

- Yes, and I did complain
- Yes, but I did not complain
- No, I did not want to make a complaint

**Action**

Changed order or response categories so that the 'No' option is first.

**Rationale**

Change made for AAPS 2015 also. This question had difficult routing instructions due to the ordering of the response categories. Reordering was intended to make the instructions clearer for respondents.

**Questions 82 and 83 (U8 survey) and 70 and 71 (8+ survey)****Current questions**

82/83. In the week before your child's hospital stay, how difficult was it for them to carry out their normal daily activities (e.g. physical activity, play, going to school or day-care)?

- Not at all difficult
- Only a little difficult
- Somewhat difficult
- Very difficult
- They were not able to at all

70/71. About one month after your child's discharge from hospital, how difficult was it for them to carry out their normal daily activities?

- Not at all difficult
- Only a little difficult
- Somewhat difficult
- Very difficult
- They were not able to at all

**Action**

Changed last category to 'Too difficult to do'.

**Rationale**

Change made for AAPS 2015 also. The wording for the last response category did not fit with the other options. More consistent terminology would be 'too difficult to do' and this was tested in the Small and Rural Hospitals Survey cognitive testing and found to work well.

### Changes to cover letter (both surveys)

#### Action

Three main changes to the cover letter were made:

- Addition of an extra line directing respondents to view the results of the surveys on *Healthcare Observer*
- Addition of new logo and use of the acronym BHI instead of 'the Bureau'
- Reordering of some paragraphs.

#### Rationale

Changes made in line with changes for BHI and survey branding and to make the reference to the completion of the survey online more obvious (to encourage uptake of this mode). As far as the reference to *Healthcare Observer*, there is evidence that directing respondents to results of surveys they participate in increases uptake of future surveys. Now that BHI has *Healthcare Observer* live, we are able to direct respondents to the results. Additionally, healthcare consumers are one of BHI's stakeholder groups and to date we have not actively promoted our survey results to them.