



Ipsos
Social Research Institute

Development Report Appendices:

2014 Admitted Children and Young Patients Survey

Prepared for the Bureau of Health Information

November 2015

Contact details

BUREAU OF HEALTH INFORMATION

Level 11, Sage Building

67 Albert Avenue

Chatswood NSW 2067

Australia

Telephone: +61 2 9464 4444

www.bhi.nsw.gov.au

IPSOS SOCIAL RESEARCH INSTITUTE

Level 13, 168 Walker St

North Sydney NSW 2060

Australia

Telephone: +61 2 9900 5100

<http://ipsos.com.au/>

Ipsos SRI project reference: 11-043092

Ipsos SRI project contacts: Andy Cubie, Jessica Elgood and Robert McPhedran

This work is copyright. It may be reproduced in whole or in part for study or training purposes subject to the inclusion of an acknowledgement of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above requires written permission from the **Bureau of Health Information, Level 11, Sage Building, Chatswood, NSW 2067**. Copyright Bureau of Health Information 2015.

Suggested citation:

Ipsos Social Research Institute. Development Report: Admitted Children and Young Patients Survey. Sydney (NSW); 2015.

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

TABLE OF CONTENTS

Appendix A: Admitted Children and Young Patients focus group and interview qualitative composition	1
Appendix B: Admitted Children and Young Patients Emergency Department focus group discussion guide	2
Appendix C: Admitted Children and Young Patients focus groups discussion guide	7
Appendix D: CYPS Stakeholder engagement	14
Appendix E: Stakeholder interview discussion guide	18
Appendix F: Stakeholder interview contact email	21
Appendix G: Additional details for statistical analyses	22
Appendix H: Profile of cognitive interview participants	33
Appendix I: Cognitive interview discussion guide/prompts	35
Appendix J: Potential question areas	37
Appendix K: CYPS development table	43
Appendix L: Survey questions relevant to the National Safety and Quality Health Service Standards and the Australian Charter of Healthcare Rights	104
Appendix M: Final Admitted Children survey	117
Appendix N: Final Admitted Young Patients Survey	129
Appendix O: Cover letter for Admitted Young Patients Survey for those aged 16 and 17	141

APPENDIX A: ADMITTED CHILDREN AND YOUNG PATIENTS FOCUS GROUP AND INTERVIEW QUALITATIVE COMPOSITION

Table 1: Patient focus group and in-depth interview composition

		Number of individuals in each group				
		Group1	Group 2	Group 3	Group 4	In-depth interviews
Gender	Male	1	4	2	3	3
	Female	6	5	7	6	3
Age of parent/ carer	25-34	2	4	5	3	
	35-44	5	5	4	6	
Age of patient	Under 10	5	4	9		
	10-13	2	4		4	
	14-17		1		5	6
Total all groups		7	9	9	9	6

APPENDIX B: ADMITTED CHILDREN AND YOUNG PATIENTS EMERGENCY DEPARTMENT FOCUS GROUP DISCUSSION GUIDE

Bureau of Health Information Emergency Patients Group Discussion Guide

Objective: to understand the emergency patient experience and, crucially, the aspects that are most important in creating a positive or negative experience. This research will help inform development of the Emergency patient survey for the Bureau.

The following is intended as a guide for the key topics to be introduced by the moderator during the discussion. However, as we want this element of the research to indicate the most important aspects of the patient experience *from the patient perspective*, prompting will be kept to a minimum.

The times allocated next to each section are approximate timings only to help the moderator ensure key areas are addressed within the available time (group duration: approx. 2 hrs).

The first level bullet points are key questions – second level bullets are prompts to be used only if not already raised in the discussion.

Introduction & Warm-Up (10 minutes)

- Welcome and thank for attendance.
- Introduce self and client observers (if applicable)
- State aim of discussion – The Ipsos Social Research Institute is conducting this research on behalf of the Bureau of Health Information. We want to better understand the experiences of people who have been cared for in the Emergency Departments of hospitals in NSW. What you tell us today will ultimately help to create a survey for NSW Emergency Department patients. The results of this survey will be used to improve services provided by the hospitals you use.

IF ASKED FOR FURTHER INFO: The Bureau of Health Information was set up in 2009 to measure the performance of the public health system in NSW. The Bureau produces reports for the government, for people who work in health care, and for the community.

The Bureau produces regular reports on hospital performance including information on how many patients are visiting NSW hospitals, how long patients waited in emergency departments, and how many elective surgeries were performed within recommended waiting times. Other reports identify areas for improvement and examine how the health system in NSW compares to other states in Australia and other countries.

The Bureau delivers this information for decision makers to use in order to improve health care and patient care in NSW. All of their reports are available on their website at www.bhi.nsw.gov.au.

Confirm...

- Duration of meeting (2 hrs)
- Open and frank feedback welcomed
- Own perspective is important...what you actually think!
- No right or wrong answers
- Everyone to participate, but one person speaking at a time
- Moderator may need to move the conversation on to new topic occasionally to make sure key areas are covered in the time we have
- No need to share the reason why you were in hospital, the details of your treatment, or any other personal information – we are interested in what your experience as a patient was like overall
- If you have been to the Emergency Department a number of times, please concentrate on the most recent occasion
- Confidentiality assured
- Permission for audio taping
- Please turn off mobile phones

ASK PARTICIPANTS TO SPLIT INTO PAIRS (starting with the two people to the left and then each pair around the table)

- “Please have a 2 minute discussion in your pairs so you can briefly introduce your partner to the rest of the group – e.g. name, how long ago they were in hospital, whether they arrived to the Emergency Department via ambulance or not, and their overall impression of their stay in the Emergency Department”.

GROUP DISCUSSION

Feedback session around the table on their partner’s experiences of care.

Overall/top of mind impressions (10 minutes)

- First, please how would you explain the process of visiting the Emergency Department to someone who has never been through it? What is each stage in the process from when you arrive to when you leave?
- Please can you tell me what stood out most from your experience of being an emergency patient in hospital? Why?
- What were the best and worst aspects?

“We’re now going to talk in a bit more detail about each stage of your experience...”

Arrival (10 minutes)

“Thinking about your journey to and arrival at the Emergency Department”

- Can you tell us about your experience of getting to the Emergency Department?
 - How easy or difficult was this? Why?
 - IF BY AMBULANCE – prompt on wait time, communication, pain management, etc.

“Thinking now about what happened when you first arrived at the Emergency Department...”

- What were your first impressions?
- What happened when you first arrived?
 - What instructions or information were you given?
- What could have been done better at this stage?
- **Thinking about what you have just described, what is most important for providing the best possible experience for patients when they first arrive at the Emergency Department?**

Assessment (10 minutes)

“Thinking now about when you were waiting to be seen in the Emergency Department...”

- At what stages during your time in the Emergency Department did you have to wait? How long for?
- How did you find the experience of waiting to be seen in Emergency Department?
 - What made easier or harder?
 - How well informed did you feel about what was going on/what to expect?
 - Were you able to get the attention of staff if necessary?
- What could have improved this period of waiting in the Emergency Department?
- **Thinking about what you have just described, what is most important to you as a patient when waiting to be seen in the Emergency Department?**

Receiving care in the Emergency Department (10 minutes)

“Thinking about the care you received in the Emergency Department...”

- What do you remember most about the care you received in the Emergency Department?
- How would you describe how you were treated by the doctors and nurses?

- Did you have any tests while in the Emergency Department?
 - How were they? Were the results communicated to you before you left?
- How well was your pain managed?
- How much opportunity was there to ask questions? How well did doctors and nurses explain things to you?
- If you were with family or friends in Emergency Department, what was their experience like?
- Overall, what was good and bad about the care you received?
- What could have made the experience better?
- **Thinking about what you have just described, what aspects are most important to you as patient when receiving care from doctors or nurses in the Emergency Department?**

Facilities (5 minutes)

IF NOT ALREADY COVERED “Thinking about the facilities in the Emergency Department...”

- What did you think about the facilities in the Emergency Department - when you were waiting and when you were being treated?
 - E.g. privacy, cleanliness, food/drink
- **Thinking about what you have just described, what aspects of the facilities in the Emergency Department are most important to you as a patient?**

Leaving the Emergency Department (10 minutes)

“Thinking now about when it was time to leave the Emergency Department...”

- Can you explain what happened when it was time to leave the Emergency Department/to be admitted to the ward?
 - What was your experience of the process of being admitted/transferred from the Emergency Department (inc. wait times)?
- What information were you provided with before you left the Emergency Department? Was it sufficient?
- How did you feel when you left the Emergency Department? Why?
- What would have improved the process of leaving?
- **Thinking about what you have just described, what is most important to you as a patient when leaving the Emergency Department?**

Rating exercise (10 minutes)

Please write down individually how would you rate your overall experience in the Emergency Department (HAND OUT FORM - WITH RATING FROM VERY GOOD TO VERY POOR)?

- What are you main reasons for this rating?

Ranking exercise (40 minutes)

- Bearing in mind everything we have talked about so far, what are the aspects most important for making sure a visit to the Emergency Department is as good as possible for you as a patient? Please think about the whole process from when you arrived to when you left the Emergency Department.

WRITE RESPONSES ON A FLIP CHART

- Eventually we will be developing a questionnaire to get a good understanding of patients' experience of visiting the Emergency Department, so that services can be improved. Are there any other key areas we would need to ask about?

WRITE EACH RESPONSE ON A SEPARATE CARD AND LAY OUT ON TABLE
DUPLICATE CARDS AND SPLIT INTO 2 GROUPS

Looking at the areas we have here, can you between you rank them from the most to least important in terms of making the experience of visiting the Emergency Department is as good as possible for patients? It might help to think about how much difference each of things would make to you as a patient if they were done really badly or really well.

ASK A SPOKESPERSON FROM EACH GROUP TO FEEDBACK THE RESULTS

- **Can you explain why you have chosen this order?**
 - Were some easier to decide on than others?
 - Any disagreements?

ONCE AGREEMENT IS REACHED, TAKE A NOTE OF THE ORDER AGREED UPON

Thank and close (5 minutes)

Any final comments that should be taken into consideration?

Thank you all very much for your time and for sharing your experiences. HAND OUT INCENTIVES.

APPENDIX C: ADMITTED CHILDREN AND YOUNG PATIENTS FOCUS GROUPS DISCUSSION GUIDE

Bureau of Health Information Admitted Children and Admitted Young Patients Discussion Guide

Objective: to understand the admitted patient experience for children and young people and, crucially, the aspects that are most important in creating a positive or negative experience. This research will help inform development of the Children and Young People patient survey for the Bureau.

The following is intended as a guide for the key topics to be introduced by the moderator during the discussion. However, as we want this element of the research to indicate the most important aspects of the patient experience *from the patient perspective*, prompting will be kept to a minimum.

The times allocated next to each section are approximate timings only to help the moderator ensure key areas are addressed within the available time (group duration: approx. 1½ - 2 hrs).

The first level bullet points are key questions – second level bullets are prompts to be used only if not already raised in the discussion.

Introduction & Warm-Up (10 minutes)

- Welcome and thank for attendance.
- Introduce self and client observers (if applicable)
- State aim of discussion – The Ipsos Social Research Institute is conducting this research on behalf of the Bureau of Health Information. We want to better understand the experiences of children and young people who have been cared for as admitted patients in public hospitals in NSW. What you tell us today will ultimately help to create a NSW Health Children and Young People survey. The results of this survey will be used to improve services provided by the hospitals you use.

IF ASKED FOR FURTHER INFO: The Bureau of Health Information was set up in 2009 to measure the performance of the public health system in NSW. The Bureau produces reports for the government, for people who work in health care, and for the community.

The Bureau produces regular reports on hospital performance including information on how many patients are visiting NSW hospitals, how long patients waited in emergency departments, and how many elective surgeries were performed within recommended waiting times. Other reports identify areas for improvement and examine how the health system in NSW compares to other states in Australia and other countries.

The Bureau delivers this information for decision makers to use in order to improve health care and patient care in NSW. All of their reports are available on their website at www.bhi.nsw.gov.au.

Confirm...

- Duration of meeting (1½ -2 hrs)
- Open and frank feedback welcomed
- Own perspective is important...what you actually think! And what your child actually thought.
- No right or wrong answers
- Everyone to participate, but one person speaking at a time
- Moderator may need to move the conversation on to new topic occasionally to make sure key areas are covered in the time we have
- No need to share the reason why you were in hospital, the details of your treatment, or any other personal information – we are interested in what your experience as a patient was like overall
- If you have a child/children who have been admitted to hospital a number of times, please concentrate on the most recent occasion
- Confidentiality assured
- Permission for audio taping
- Please turn off mobile phones

ASK PARTICIPANTS TO SPLIT INTO PAIRS (starting with the two people to the left and then each pair around the table)

- “Please have a 2 minute discussion in your pairs so you can briefly introduce your partner to the rest of the group – e.g. name, how long ago their child/ children were in hospital, whether it was a planned admission, or via the Emergency Department, and their overall impression of their child/children’s stay in the hospital”.

INTRODUCE PARTNER TO GROUP

DISCUSSION

Overall/top of mind impressions (10 minutes)

MODERATOR TO TAKE NOTE OF WHETHER PARTICIPANT'S CHILD WAS ADMITTED AS AN EMERGENCY OR NON-EMERGENCY (I.E. PLANNED) PATIENT.

- What words would you use to describe your child's time in hospital? PROBE
- What were the best aspects?
- And what were the worst aspects?

"We're now going to talk in a bit more detail about each stage of your child's hospital experience..."

Before going to hospital (10 minutes)

"Thinking first about the events leading up to your child's admission to hospital, so before they arrived at hospital"

- What do you remember most about the lead-up to your child going to hospital?
- Was the process of them being referred to/transferred to hospital as you expected? Why/why not? What was good/bad about the process?

If time allows and not already mentioned prompt for (pay particular attention to what is spontaneous/unprompted):

- How much did you know about what your child's hospital visit would involve? What difference did this make to you/your child?
- Did your child have to wait for anything in the process of getting to hospital (e.g. for ambulance, waiting in ambulance, waiting for referral to hospital, having to see lots of different health professionals to get a referral etc.). How did this affect your child?
- **Thinking about what you have just described about the lead-up to your child being admitted to hospital, what is most important to your child as a patient at this stage?**

Admission process/arrival at hospital (10 minutes)

"Thinking now about what happened when your child first arrived at the hospital, before they were admitted to their ward/room..."

- How did they feel when they first arrived?
- What were your/your child's first impressions?
- What did you/your child like/dislike about it? Why?

- Was the experience of your child being admitted as you expected or different? How/why?

If time allows and not already mentioned prompt for (pay particular attention to what is spontaneous/unprompted):

- What did you think about the length of time it took for them to be admitted?
- What would the ideal admission process for your child be like? Why?
- **Thinking about what you have just described, what is most important for providing the best possible experience for child patients during the admission process?**

First impressions upon arrival in room/ward (5 minutes)

“Thinking now about when your child first arrived at their room/ward...”

- When they first arrived at their ward/room, what were your/your child’s first impressions? What did you like/dislike? What did your child like/dislike?
- What did you/your child think the experience of staying would be like, based on first impressions?
- At this stage, did your child know what to expect during their stay? How?
- HOW WAS THE EXPERIENCE OF EMERGENCY CHILD PATIENTS DIFFERENT FROM NON-EMERGENCY CHILD PATIENTS AT THIS STAGE? - ASK PARTICIPANTS TO COMPARE AND CONTRAST.

If time allows and not already mentioned prompt for (pay particular attention to what is spontaneous/unprompted):

- What would your child’s ideal experience of arriving at the ward/room be like?
- **Thinking about what you have just described, what is most important to your child as a patient when they first arrive at their room/ward?**

Stay on the ward/room (20 minutes)

“Now thinking about while your child was staying in hospital...”

- Were your first impressions right or did your views change over the course of their stay? How/why?
- How well were they looked after over the course of their stay?
- What made them feel well/badly looked after?
- What made their stay more/less comfortable?
- What made the most difference to the experience of your child staying in hospital

- Good / bad?
- HOW WAS THE EXPERIENCE OF EMERGENCY CHILD PATIENTS DIFFERENT FROM NON-EMERGENCY CHILD PATIENTS AT THIS STAGE? - ASK PARTICIPANTS TO COMPARE AND CONTRAST.

If time allows and not already mentioned prompt for (pay particular attention to what is spontaneous/unprompted):

- What did you think about the hospital staff (incl. doctors, nurses, surgeons, students, support staff) over the course of your child's time in hospital...?
 - How much confidence/trust did you/your child have in their skills?
 - How much did they seem to know about your child's condition/history?
 - How much opportunity were you given to ask questions? And was your child given opportunities to ask questions?
 - To what extent did they explain your child's condition, treatment, procedure, operation (incl. any risks and benefits) in a way that you/your child could understand?
 - Did you feel they were open with you about your child's treatment/condition?
- How quickly were your child's needs met?
 - If your child called for help or used the call button how quickly did help arrive?
- What did you think about cleanliness/hygiene during your child's stay?
 - Cleanliness of the room/ward, bathrooms, other shared areas
 - Did hospital staff wash or clean their hands before and after touching child patients?
- How well was your child's pain managed?
- What did your child think about the food?
- Did your child share the room/ward with another patient(s)? Was the room/ward mixed or single gender? Did this make much difference to your child's experience of being in hospital?
- How did you feel about the cost/out of pocket expenses associated with your child's stay in hospital?
- What would you ideally want your child's experience of staying in hospital to be like?
- **Thinking about what you have just described, what aspects are most important to your child as patient in hospital?**

Discharge (10 minutes)

“Thinking now about when it was time to leave the hospital...”

- How well do you think the discharge process was handled?
- What was good/bad about it?
- How well prepared to go home did you/your child feel? Why/why not?
- HOW WAS THE EXPERIENCE OF EMERGENCY CHILD PATIENTS DIFFERENT FROM NON-EMERGENCY CHILD PATIENTS AT THIS STAGE? - ASK PARTICIPANTS TO COMPARE AND CONTRAST.

If time allows and not already mentioned prompt for (pay particular attention to what is spontaneous/unprompted):

- Was there any delay to your child being discharged? How important was this to you/your child?
- Did you receive written or printed information on discharge? What did this deal with (summary of stay, future appointments/care arrangements, recovery advice, survey, etc)? How important was this written information to you?
- What would have ideally happened during the discharge stage?
- **Thinking about what you have just described, what is most important to you/your child during the discharge process?**

Ranking exercise (20-30 minutes)

- Bearing in mind everything we have talked about so far, what are the aspects most important for making sure your child’s stay in hospital is as good as possible for them as a patient? Please think about the whole process from the run up to admission to when they left hospital.
- Eventually we will be developing a questionnaire to get a good understanding of child patients’ experience of staying in hospital, so that services can be improved. Are there any other key areas we would need to ask about?

WRITE EACH RESPONSE ON A SEPARATE CARD.

- Looking at the areas we have here, can you between you rank them from the most to least important in terms of making the experience of children staying in hospital as good as possible for them as patients? It might help to think about how much difference each of things would make to your child as a patient if they were done really badly or really well.

PARTICIPANTS TO ORDER THE CARDS BY PRIORITY ON TABLE/FLOOR. PROBE FOR FEEDBACK ON THE ORDER OF THE CARDS, AND REASONS WHY.

- **Can you explain why you have chosen this order?**
 - Were some easier to decide on than others?
 - Any disagreements?

ONCE AGREEMENT IS REACHED, TAKE A NOTE OF THE ORDER AGREED UPON

Thank and close (5 minutes)

Any final comments that should be taken into consideration?

Thank you all very much for your time and for sharing your experiences. HAND OUT INCENTIVES.

APPENDIX D: CYPS STAKEHOLDER ENGAGEMENT

The research with key stakeholders encompassed two distinct processes: a pro forma response and stakeholder interviews.

Pro forma

The pro forma process endeavoured to engage as wide a variety of stakeholders as possible in the questionnaire development process. Its objective was to collect feedback on the question areas to be included in the CYPS from those who will ultimately use the research findings. The pro forma took the form of a spreadsheet, in which stakeholders provided the details of topic areas and/or questions they felt should be considered for inclusion in the questionnaire, according to the following fields:

- **Proposed area of care/question topic:** A summary of the stakeholder(s) area of interest
- **Reason for interest in that area of care:** Background on why they decided that question area was important to capture in this survey
- **Whether that question applied to a subset of patients and, if so, who they were**
- **How they would use data collected by that question area:** How they expected to use the data, whether in indicators of care or reports, to identify poor performance or to measure the effect of improvements in care, or to assist their own research
- **Suggested question phrasing:** to provide greater understanding of what they want collected

The complete pro forma can be found overleaf.

How to complete this pro forma

Date due: COB Monday 1 July 2013

The pro forma follows. We ask you to use one row for each new aspect of care or question topic. There are five columns you should complete for each question topic:

- **Aspect of care/question topic:** Summarise your area of interest to allow us to look for themes common to multiple stakeholders. Examples may include arrival at the emergency department or the courtesy and communication of staff.
- **What is your interest in this question topic?** This provides additional information that will help us shape and refine the question wording.
- **Whether this question topic is relevant to a particular group of patients (and if so who?)** Some questions are more relevant to particular groups of patients. For example, questions about pain management are asked of patients who experience pain. Does your question topic relate to a particular group of people?
- **How would you use responses collected about this question topic?** We would like to hear how you expect to use responses to these questions to assist us to develop the questionnaire.
- **If you have a particular question in mind, please let us know what it is.**

Admitted Children and Admitted Young Patient Survey - suggestions for new questionnaire content

Aspect of care/question topic	What is your interest in this question topic?	Is this question topic relevant to a particular group of patients?	How would you use responses to this question topic?	If you would like to suggest a particular question on this topic, please do this here

Stakeholders were invited to participate via an approach email from BHI. The distribution list included the following groups:

- Sydney Children's Hospital Network (SCHN)
- NSW Kids and Families
- Western NSW Local Health District (WNSWLHD)
- Association for the Wellbeing of Children in Healthcare (AWCH)
- Agency for Clinical Innovation (ACI)

Stakeholders often circulated the pro forma amongst colleagues before submitting to BHI.

Contributors to Pro Forma (all):

- Carmel Blayden, Allied Health Educator, Western Child Health Network
- Lynne Brodie, Agency for Clinical Innovation
- Kelly Dart, Far West Local Health District (LHD)
- Robyn Fowler, Child and Adolescent Mental Health Services Clinical Leader, Murrumbidgee LHD
- Michelle Honan, SCHN
- Lynn Khoury, Rural Locum
- Gayle Murphy, Murrumbidgee LHD
- Kim Olesen, Director of Nursing and Midwifery, South Eastern Sydney LHD
- Christine Quinn, Quality Accreditation Manager, Illawarra and Shoalhaven LHD
- Ellen Rawstron, Agency for Clinical Innovation
- Lynn Walker, Operations Manager KCYPF, John Hunter Children's Hospital
- Dorothy Wilson, Mid-North Coast LHD
- Hunter New England LHD
- Illawarra and Shoalhaven LHD
- Southern NSW LHD
- South West Sydney LHD
- Sydney LHD
- Western NSW LHD
- Western Sydney LHD
- Clinical Excellence Commission
- NSW Kids and Families
- Agency for Clinical Innovation, Intellectual Disability

Follow-up interviews

The stakeholder interviews built on the information given in the pro forma, to provide a more detailed understanding of why particular question areas were considered important for inclusion in the survey, rationale for particular question wording, and what those questions needed to cover. There was also an opportunity for new areas to be raised. A discussion guide was developed to ensure that key areas were covered (Appendix E).

Stakeholders were selected for follow-up interviews for a number of reasons including: where further detail/clarification was required; a new/unexpected area was suggested; or the area of specialisation was of particular interest to BHI. Ipsos then contacted each stakeholder to arrange an interview time.

Interviews were generally between 30 and 45 minutes in duration and took place with an individual stakeholder or with a group of colleagues who had contributed to the pro forma. The majority of interviews were conducted by telephone; a group of five stakeholders from NSW Kids and Families were interviewed face-to-face as a group. A total of 12 stakeholders were interviewed between 9-26 July 2013.

Stakeholder interviews (if permission given to be named):

- Professor David Bennett, Clinical Director, Youth Health and Wellbeing
- Mary Crum, Senior Analyst, Paediatric Healthcare
- Anne Cutler, PHT, Association for the Wellbeing of Children in Healthcare
- Kelly Dart, Acting NUM, Far West LHD
- Matthew Frith, Acting District Network Manager, Children Young People & Families Services, Hunter New England LHD
- Sally Gibson, Senior Manager, Youth Health and Wellbeing
- Robin Grinrod, member of Family Advisory Council, Westmead Hospital
- Elizabeth Harnett, Sydney Children's Hospital Network
- Margaret Kelly, Senior Manager, Paediatric Healthcare
- Dorkas Lau, Quality Manager, Sydney Children's Hospital
- Joyce Murphy, Sydney Children's Hospital Network
- Professor Les White, NSW Chief Paediatrician, NSW Kids and Families

APPENDIX E: STAKEHOLDER INTERVIEW DISCUSSION GUIDE

Bureau of Health Information
Admitted Children and Admitted Young Patients Survey
Stakeholder Interviews Discussion Guide
July 2013

Ipsos job ref: 12-047213-01

Objectives: to establish, and fully understand, the question areas considered most useful by stakeholders (in order to inform improvements to services). The interviews will build on the information provided in the pro forma, to provide a more detailed understanding of why particular question areas are considered important for inclusion in the survey, rationale for that particular wording, and what these questions need to cover. This research will inform development of the Admitted Children and Admitted Young Patients survey.

Interview length likely to be 30-45 mins

The following is intended as a guide for the key areas to be addressed in each interview. The exact content of the interview will primarily be driven by individual responses contained in the pro forma and probing on the suggestions made during the interview.

If a stakeholder submitted a pro forma, they will be asked to keep their responses in mind as they respond, but advised that additional comments will also be welcome.

IF ASKED FOR FURTHER INFO:

The Bureau of Health Information (BHI) was set up in 2009 to report on the performance of the public health system in NSW. It publishes regular reports for the government, for people who work in healthcare, and for the community.

These reports look at performance at a hospital-level and from a state-wide perspective. The hospital-level reports look at how many patients are visiting NSW hospitals, how long they waited in emergency departments and for elective surgeries, and how many surgeries were performed within recommended waiting times. The state-level reports look at how the system as a whole is performing on different indicators, where there is variation between hospitals, and where there are opportunities for people who work in healthcare to make improvements. These reports also look at how the healthcare system in NSW performs compared to the rest of Australia and other countries around the world.

BHI delivers this information for service providers to use in order to improve health care and patient care in NSW. All of their reports are available on their website at www.bhi.nsw.gov.au

Introduction

- Thank for participation.
- Introduce Ipsos and self
- State aim of the interview:
 - as above for those who have submitted a pro forma
 - for those who have not: we are interested in collecting ideas on topics or questions to be considered for the development of a newly designed Admitted Children and Young Patients Survey and want to understand how patient responses from these questions will be useful to you (if required, refer to email sent with pro forma for further details – appended)
- Reiterate that not everything can be included in questionnaire. Focus is on paediatric patients – limit to level of detail possible/Qs that relate to very specific groups only
- Request permission for audio taping

Key Questions

For stakeholders who have not submitted a pro forma only:

- What aspects of care, or question topics, are particularly important to include in the CYPS from your perspective?

For each aspect suggested/ in the pro forma:

You said you would like X aspect of care to be included in the questionnaire, can you tell me in more detail...

- Why do you feel this aspect of patient care needs to be covered in the CYPS patient questionnaire?
- How will you use this information to improve patient care?
- Why did you chose X question to assess this aspect of care?
- What impact would it have if this question area could not be included?

Additional topics for discussion:

- Does this question area relate to quality standards/accreditation?
- Is any evidence from other sources available in relation to this questionnaire? If so, why is it also important to include in this survey?

- Are there any other topics that you have thought of since the pro forma was returned that you want to discuss?
- If so, please tell us what you hope to achieve, how you would use the information and how important you think it is.

Note: we may need to challenge suggestions, for example:

- *Will patients be able to answer this question reliably – will they know in the first place? What about 3 months after experience? Will they understand the Q/terminology?*
- *IF QS APPLY TO A VERY SMALL SUB-SECTION OF PATIENTS ONLY – we may not be able to include Qs that apply to very specific/small groups of patients only, so are there any questions about the paediatric patient experience would be particularly important to that group, but also relevant to others?*

Thank and close

In conclusion, do you have any final comments about the CYPS or the survey program in general that you would like to make?

Ascertain and record two levels of acknowledgement/permissions:

- 1) Stakeholder/s listed in the development report as a key stakeholder and contributor (specific comments will not be attributed to individuals or specific facilities/departments – any verbatim comments used will be anonymous).
- 2) Transcripts/attribution comments made available to BHI for review and to assist shaping of questionnaire content.

Thank you very much for your time.

APPENDIX F: STAKEHOLDER INTERVIEW CONTACT EMAIL

Dear colleagues,

As part of the NSW Patient Survey Program, we would like to invite you to contribute to the development of the Child and Young Person Patient Survey. The NSW Patient Survey Program seeks to collect information about patient's experience of care from NSW Health services in ways that are robust, statistically meaningful and representative of the patients using each hospital or facility.

The questionnaires for the survey program are being redeveloped, benefitting from a review of national and international literature, focus groups with recent patients and analysis of historic NSW survey data. As part of this process, the Bureau is contacting stakeholders to identify which questionnaire topics are most useful to inform the improvement to services.

The pro forma - please return by COB Mon 1 July 2013.

We are interested in collecting ideas on topics or questions to be included in the Child and Young Person Patient Survey and how including those topics will be useful to you. Please focus on those areas that are most important to you as there will be a limit to the length of the questionnaire.

Attached is a pro forma and it highlights how we would like it to be completed. Using one row for each new question you want included, please consider:

- The aspect of care or question topic
- Why you are interested in this question topic
- Whether this question topic is relevant to a particular subgroup of patients (and if so, who?)
- How you would use data collected about this question topic
- Whether you would like to suggest a particular question on this topic for inclusion in the survey.

You may wish to also include ideas contributed by your colleagues within your organisation on this pro forma.

After you return the pro forma, we may contact you again for more detail on your suggested content. If this does happen, you will be contacted by the Bureau's survey contractor, IPSOS Social Research Institute, who will conduct the interview. If you do not wish to be contacted, please note this in your return email.

Please add your name to the file name of the pro forma sheet and return it to me (efty.stavrou@bhi.nsw.gov.au) by Mon 1st July 2013.

Many thanks,
Efty

Efty Stavrou PhD, MAppSc (Research)
Senior Researcher
Bureau of Health Information

APPENDIX G: ADDITIONAL DETAILS FOR STATISTICAL ANALYSES

Factor analysis

For general paediatric patients who completed the 2007-2011 Paediatric Patient Surveys (Table 2; those who did not fill in the pain, surgery or ICU sections of the survey), the factor that accounted for the most variance – 21.86% of the total variance – was the heterogeneous *Facilities and food* factor. This factor comprised questions that related to: the cleanliness of the facility and room; accuracy of receiving food orders; courtesy of food health staff; taste of the food; ease of understanding the directions and signs outside the facility; and volume within the facility. The Cronbach's alpha value of .90 indicates excellent reliability. However, this high reliability may relate to the positioning of the questions and use of the same scale rather than the fact that these questions are measuring the same latent construct. This is supported given that the questions strongly correlated with this factor included 'cleanliness of the facility', 'courtesy and helpfulness of the staff that served your child's food' and 'cleanliness of the bathrooms and toilets'. The factor that accounted for the second highest amount of variance was *Discharge information* (which accounted for 14.09% of the total variance). This factor was more homogenous than the aforementioned *Facilities and food* factor, encompassing questions relating to provision of information at discharge. The reliability of this factor was very good, with a Cronbach alpha value of .85. Other factors that contributed substantively to the variance included the aspects of *Doctors* (11.82%) and *Family involvement* (8.04%). The factor that accounted for the least amount of variance was *Provision of information to a child patient*, which accounted for 6.10% of the total variance. This item also had questionable reliability (alpha=0.64).

Conversely, the factor that accounted for the most variance for paediatric patients who experienced pain was *Nurses*, which accounted for 14.49% of the total variance. This factor comprised questions pertaining to nurse availability; their provision of information; and their responsiveness. The Cronbach's alpha value of .92 indicates excellent reliability and suggests that these questions are measuring the same latent construct. The factor that accounted for the second largest contribution to variance was *Doctors* (11.28% of the total variance). This factor had very good to excellent reliability, with a Cronbach's alpha of .89. Other factors that accounted for a substantial proportion of the variance included *Discharge information* (10.44%), *Communication* (10.31%) and *Facilities* (9.81%). Variables that accounted for less variance included *Food* (5.74%), *Hygiene* (4.84%) and *Discharge conversations* (4.33%). All factors in this analysis had good to excellent reliability (with alphas ranging from .83-.92).

For paediatric surgery patients, *Facilities and food* was again the factor that accounted for the most variance (19.11% of the total variance). This factor comprised many of the same questions, and displayed similarly high level of reliability to the factor observed in the general paediatric patient analysis, with a Cronbach's alpha value of .90. *Doctors* (12.78%), *Nurses* (12.54%) and *Discharge information* (8.11%) were once again prominent in this analysis, with Cronbach's alpha

values of .88, .90 and .79 respectively. One unique factor in the factor analysis for surgery patients was the presence of the *Operation* factor. This factor comprised questions relating to provision of information about the surgery and anaesthesia, as well as a question relating to the discussion of fears and anxieties relating to the surgery. While this factor only accounted for 6.30% of the total variance, it had acceptable reliability, with a Cronbach's alpha of .73.

The factor analysis for paediatric **ICU patients** yielded similar results to analyses mentioned above. *Facilities and food* accounted for the most variance (23.03%), and had excellent reliability (alpha=.90). *Doctors* (14.75%) and *Nurses* (12.76%) also accounted for substantial proportions of the variance. However, despite comprising similar questions, these had lower reliability than their counterparts in the other analyses (.76 and .77 respectively), suggesting that they may be measuring different latent constructs for ICU patients. Further, the factor analysis for ICU patients also yielded an *ICU nurses* factor (12.46% of the variance). This factor comprised questions pertaining to the ICU nurses, and displayed acceptable validity (alpha=.78).

Table 2: 2007-2011 Paediatric Patient Surveys – general paediatric patient factor analysis

Survey and filter	Factor	Questions	Item/total correlations	Variance accounted for (%)	α
Paediatric - general patients	Facilities and food	Q87. Cleanliness of the facility	.751	21.86	.90
		Q90. Accuracy of receiving food items that were ordered for your child	.733		
		Q89. Courtesy and helpfulness of the staff that served your child's food	.740		
		Q88. Cleanliness of the room	.739		
		Q92. Temperature of the food	.706		
		Q91. Taste of the food	.652		
		Q84. Ease of understanding directions and signs inside and outside the hospital	.562		
		Q86. Keeping noise levels to a minimum	.599		
	Discharge information	Q71. Were you told about what danger signals about your child's illness or surgery or procedure to watch out for after he or got home	.697	14.09	.85
		Q70. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, playing sports or returning to school?	.668		
		Q68. A lot of people have difficulty taking medicine at home. Did anyone in the hospital teach you how to give your child his or her new medicines?	.607		
		Q74. Did someone on the hospital staff teach you what you needed to know to care for your child at home?	.689		
		Q69. Were you told about side effects to watch for from your child's new medicines?	.670		
	Doctors	Q13. Were the doctors available to answer your questions or concerns when you needed them	.634	11.82	.80
		Q18. How would you rate the availability of the doctors?	.707		
		Q17. How would you rate the courtesy of the doctors?	.667		
		Q16. Did the doctors pay enough attention to your experiences and suggestions in caring for your child?	.629		
		Q12. Did you know which doctor was in charge of your child's care in hospital?	.431		
	Family involvement	Q29. Would you have liked more involvement in making the decisions about your child's hospital care?	.473	8.04	.61
		Q42. Did family members or someone close to your child ever have to do something or say something to staff to be sure that your child's medical needs were met	.353		
		Q75. Would you have liked a doctor to have spent more time with you discussing how to care for your child at home?	.438		
Hygiene	Q50. Did your healthcare providers/staff clean their hands after providing care for your child?	.835	7.81	0.91	
	Q49. Did your healthcare providers/staff wash or clean their hands before providing care for your child?	.835			
Provision of information to child patient	Q35. While your child was in the hospital, was he or she given any information about his or her condition?	.477	6.10	0.64	
	Q36. Was the information about his or her condition discussed with your child in a way he or she could understand?	.477			

Table 3: 2007-2011 Paediatric Patient Surveys – paediatric patients who experienced pain factor analysis

Survey and filter	Factor	Questions	Item/total correlations	Variance accounted for (%)	α
Paediatric - pain patients	Nurses	Q19. Were the nurses available to answer your questions or concerns when you needed them?	.740	14.49	0.92
		Q23. How would you rate the courtesy of the nurses?	.770		
		Q22. Did the nurses pay enough attention to your experiences and suggestions in caring for your child?	.774		
		Q21. When you had important questions about your child to ask the nurses, did you get answers you could understand?	.736		
		Q24. How would you rate the availability of the nurses?	.791		
		Q20. Did you have confidence and trust in the nurses caring for your child?	.741		
		Q37. When you or your child used the call button to get help, was the response quick enough?	.655		
		Q34. When your child needed help getting to the bathroom, did he or she get it in time?	.571		
		Q32. Was it easy for your child to find someone on the hospital staff to talk to about his or her concerns?	.658		
		Q26. During your child's stay, did nurses inform you about what medicines your child was being given and why?	.540		
	Doctors	Q18. How would you rate the availability of the doctors?	.723	11.28	0.89
		Q17. How would you rate the courtesy of the doctors?	.765		
		Q13. Were the doctors available to answer your questions or concerns when you needed them?	.669		
		Q16. Did the doctors pay enough attention to your experiences and suggestions in caring for your child?	.747		
		Q14. Did you have confidence and trust in the doctors caring for your child?	.722		
		Q15. When you had important questions about your child to ask the doctors, did you get answers you could understand?	.699		
	Discharge information	Q70. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, play?	.669	10.44	.85
		Q74. Did someone on the hospital staff teach you what you needed to know to care for your child at home?	.711		
		Q71. Were you told about what danger signals about your child's illness or surgery or procedure to watch out for after he or got home?	.698		
		Q69. Were you told about side effects to watch for from your child's new medicines?	.670		
		Q68. A lot of people have difficulty taking medicine at home. Did anyone in the hospital teach you how to give your child?	.567		
		Q72. Were you told who to call with questions or concerns about caring for your child at home?	.508		
	Communication	Q36. Was the information about his or her condition discussed with your child in a way he or she could understand?	.683	10.31	.85
		Q38. Did someone explain to your child the tests that were being done in a way he or she could understand?	.649		
		Q39. Did you feel comfortable asking medical staff questions about your child's condition or treatment?	.618		
		Q40. Did you feel you had a care provider who had full understanding of your child's condition and treatment?	.667		
		Q31. How much information about your child's condition or treatment were you given?	.604		
		Q35. While your child was in the hospital, was he or she given any information about his or her condition?	.483		
		Q67. Did someone explain when your child would be allowed to go home?	.477		
		Q43. Were you given as much information as you wanted about your child's rights and responsibilities as a patient?	.563		
Facilities	Q87. Cleanliness of the facility	.762	9.81	.83	
	Q88. Cleanliness of the room	.734			
	Q84. Ease of understanding directions and signs inside and outside the hospital	.605			
	Q86. Keeping noise levels to a minimum	.648			
	Q85. Availability of parking	.484			
Food	Q91. Taste of the food	.779	5.74	.86	
	Q92. Temperature of the food	.803			
	Q90. Accuracy of receiving food items that were ordered for your child	.639			
Hygiene	Q49. Did your healthcare providers/staff wash or clean their hands before providing care for your child?	.821	4.84	.90	
	Q50. Did your healthcare providers/staff clean their hands after providing care for your child?	.821			
Discharge conversations	Q75. Would you have liked a doctor to have spent more time with you discussing how to care for your child at home?	.745	4.33	.85	
	Q76. Would you have liked a nurse to have spent more time with you discussing how to care for your child at home?	.745			

Table 4: 2007-2011 Paediatric Patient Surveys – paediatric patients who had surgery factor analysis

Survey and filter	Factor	Questions	Item/total correlations	Variance accounted for (%)	α
Paediatric - surgery patients	Facilities and food	Q87. Cleanliness of the facility	.764	19.11	.90
		Q92. Temperature of the food	.735		
		Q89. Courtesy and helpfulness of the staff that served your child's food	.746		
		Q90. Accuracy of receiving food items that were ordered for your child	.757		
		Q91. Taste of the food	.708		
		Q88. Cleanliness of the room	.750		
		Q86. Keeping noise levels to a minimum	.685		
		Q84. Ease of understanding directions and signs inside and outside the hospital	.564		
	Doctors	Q85. Availability of parking	.475	12.78	.88
		Q16. Did the doctors pay enough attention to your experiences and suggestions in caring for your child?	.731		
		Q13. Were the doctors available to answer your questions or concerns when you needed them?	.679		
		Q18. How would you rate the availability of the doctors?	.727		
		Q17. How would you rate the courtesy of the doctors?	.728		
		Q15. When you had important questions about your child to ask the doctors, did you get answers you could understand?	.686		
	Nurses	Q14. Did you have confidence and trust in the doctors caring for your child?	.606	12.54	.90
		Q20. Did you have confidence and trust in the nurses caring for your child?	.728		
		Q21. When you had important questions about your child to ask the nurses, did you get answers you could understand?	.719		
		Q22. Did the nurses pay enough attention to your experiences and suggestions in caring for your child?	.748		
		Q19. Were the nurses available to answer your questions or concerns when you needed them?	.723		
		Q23. How would you rate the courtesy of the nurses?	.787		
	Discharge information	Q24. How would you rate the availability of the nurses?	.736	8.11	.79
		Q71. Were you told about what danger signals about your child's illness or surgery or procedure to watch out for after he or got home?	.677		
		Q74. Did someone on the hospital staff teach you what you needed to know to care for your child at home?	.607		
		Q70. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, play	.605		
Operation	Q72. Were you told who to call with questions or concerns about caring for your child at home?	.493	6.30	.73	
	Q53. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits and alternatives of the surgery?	.597			
	Q54. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits and alternatives of the anaesthesia?	.612			
Provision of information to child patient	Q57. Did anyone discuss your child's fears or anxieties about the surgery or procedure with your child?	.479	5.55	.65	
	Q35. While your child was in the hospital, was he or she given any information about his or her condition?	.320			
	Q36. Was the information about his or her condition discussed with your child in a way he or she could understand?	.608			
		Q38. Did someone explain to your child the tests that were being done in a way he or she could understand?	.493		

Table 5: 2007-2011 Paediatric Patient Surveys – paediatric patients who visited the ICU factor analysis

Survey and filter	Factor	Questions	Item/total correlations	Variance accounted for (%)	α
Paediatric - ICU patients	Facilities and food	Q88. Cleanliness of the room	.819	23.03	.90
		Q87. Cleanliness of the facility	.802		
		Q86. Keeping noise levels to a minimum	.658		
		Q84. Ease of understanding directions and signs inside and outside the hospital	.583		
		Q92. Temperature of the food	.725		
		Q89. Courtesy and helpfulness of the staff that served your child's food	.686		
		Q91. Taste of the food	.683		
	Doctors	Q13. Were the doctors available to answer your questions or concerns when you needed them	.651	14.75	.76
		Q15. When you had important questions about your child to ask the doctors, did you get answers you could understand?	.564		
		Q60. Were the doctors in the ICU available to answer your questions or concerns when you needed them?	.578		
		Q31. How much information about your child's condition or treatment were you given?	.437		
	Nurses	Q22. Did the nurses pay enough attention to your experiences and suggestions in caring for your child?	.701	12.76	.77
		Q21. When you had important questions about your child to ask the nurses, did you get answers you could understand?	.608		
		Q38. Did someone explain to your child the tests that were being done in a way he or she could understand?	.520		
	ICU nurses	Q20. Did you have confidence and trust in the nurses caring for your child?	.579	12.46	.78
		Q62. Were the nurses in the ICU available to answer your questions or concerns when you needed them?	.591		
Q63. Did you have confidence and trust in your child's nurses in the ICU?		.709			
Discharge information	Q68. A lot of people have difficulty taking medicine at home. Did anyone in the hospital teach you how to give your child	.327	8.89	.48	
	Q73. Did someone on the hospital staff tell you when your child should see a doctor for a follow-up visit?	.327			

Missing response analysis

Table 6: Missing responses* for the 2007-2011 Paediatric Patient Surveys

Question	Missing %	Question	Missing %
Q1. Was your child's hospital stay in hospital planned in advance or not?	0.9	Q52. Did your child have surgery or a procedure while he or she was at the hospital?	1.2
Q2. Were you given a choice of admission dates for your child?	0.7	Q53. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits, and alternatives of the anesthesia?	0.9
Q3. Overall, from the time you were first told your child needed to be admitted to hospital, how long did he/she wait to be admitted?	2.3	Q54. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits, and alternatives of the anesthesia?	1.2
Q4. How do you feel about the length of time he/she was on the waiting list before his/her admission to hospital?	2.2	Q55. Before your child's surgery or procedure, did the surgeon or any of your doctors answer your questions in a way you could understand?	0.8
Q5. Was your child's admission date changed by the hospital?	0.7	Q56. After your child's surgery or procedure, were the results explained to you in a way you could understand?	0.8
Q6. How well organised was the care your child received in the hospital?	1.8	Q57. Did anyone discuss your child's fears or anxieties about the surgery or procedure?	1.9
Q7. While you were in the emergency department, did you get enough information about your child's medical condition and treatment?	3.1	Q58. During this hospital stay, was your child in any of the following intensive care units?	5.1
Q8. How well organised was the admission process?	1.6	Q59. Did you know which doctor was in charge of your child's care in the ICU?	5.6
Q9. Was your child's wait too long before going to his or her ward or room?	2.2	Q60. Were the doctors in the ICU available to answer your questions or concerns?	6.5
Q10. If your child had to wait to go to his or her ward or room, did someone from the hospital explain the reason for the delay?	5.3	Q61. Did you have confidence and trust in the doctors in the ICU?	6.5
Q11. How would you rate the courtesy of the staff who admitted your child?	2.0	Q62. Were the nurses in the ICU available to answer your questions or concerns?	6.8
Q12. Did you know which doctor was in charge of your child's care in the hospital?	0.9	Q63. Did you have confidence and trust in your child's nurses in the ICU?	6.7
Q13. Were the doctors available to answer your questions or concerns?	1.0	Q64. Did the ICU staff let you stay with your child as much as you wanted?	6.9
Q14. Did you have confidence and trust in the doctors caring for your child?	1.0	Q65. Please rate the parent facilities in the ICU, such as sleep rooms or waiting rooms.	8.9
Q15. When you had important questions about your child to ask the doctors, did you get answers you could understand?	1.0	Q66. When your child was transferred out of the ICU, how well were you and your child prepared for the move?	8.6
Q16. Did the doctors pay enough attention to your experiences and suggestions in caring for your child?	1.5	Q67. Did someone explain when your child would be allowed to go home?	2.1
Q17. How would you rate the courtesy of the doctors?	1.2	Q68. A lot of children have difficulty taking medicines at home. Did anyone in the hospital teach you how to give your child his or her new medicines?	3.1
Q18. How would you rate the availability of the doctors?	1.3	Q69. Were you told about side effects to watch for from your child's new medicines?	2.7
Q19. Were the nurses available to answer your questions or concerns when you needed them?	0.6	Q70. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, playing sports, or returning to school?	4.0
Q20. Did you have confidence and trust in the nurses caring for your child?	0.7	Q71. Were you told what danger signals about your child's illness or surgery or procedure to watch for after he or she got home?	3.6
Q21. When you had important questions about your child to ask the nurses, did you get answers you could understand?	0.7	Q72. Were you told who to call with questions or concerns about caring for your child at home?	2.2
Q22. Did the nurses pay enough attention to your experiences and suggestions in caring for your child?	0.9	Q73. Did someone on the hospital staff tell you when your child should see a doctor for a follow-up visit?	2.2
Q23. How would you rate the courtesy of the nurses?	1.0	Q74. Did someone on the hospital staff teach you what you needed to know to care for your child at home?	2.1
Q24. How would you rate the availability of the nurses?	0.8	Q75. Would you have liked a doctor to have spent more time with you discussing how to care for your child at home?	2.6
Q25. When you were with your child, did you see care providers check your child's ID band or ask his or her name before giving any medications, treatment, or tests?	1.3	Q76. Would you have liked a nurse to have spent more time with you discussing how to care for your child at home?	2.2
Q26. During your child's stay, did nurses inform you about what medicines your child was being given and why?	1.0	Q77. How would you rate the way the doctors and nurses worked together?	0.8
Q27. Sometimes in the hospital one doctor or nurse will say one thing and another will say something quite different. Did this happen during your child's hospital stay?	1.2	Q78. How would you rate the hospital's policy for visiting and staying with your child?	0.8
Q28. Were you told who to ask for help if you or your child needed it?	1.4	Q79. Overall, how would you rate the care your child received at the hospital?	1.4
Q29. Would you have liked more involvement in making the decisions about your child's hospital care?	2.2	Q80. Using any number from 0 to 10, where 0 is the worst hospital and 10 is the best hospital possible, what number would you use to rate this visit by your child as an admitted patient?	1.4
Q30. How much did you participate in your child's care, such as feeding or bathing?	4.6	Q81. On this visit to hospital, was your child a same day patient only or did he or she stay in hospital for one or more nights?	1.9
Q31. How much information about your child's condition or treatment were you given?	1.3	Q82. Would you say that your child's hospital stay was...	1.2
Q32. Was it easy for your child to find someone on the hospital staff to talk to about his or her concerns?	5.2	Q83. Would you recommend this hospital to your family and friends?	1.2
Q33. If your child had any special nutrition needs, were you able to explain them to a member of the hospital staff?	2.6	Q84. Ease of understanding directions and signs inside and outside the Hospital.	0.8
Q34. When your child needed help in getting to the bathroom, did he or she get it in time?	4.1	Q85. Availability of parking	1.5
Q35. While your child was in the hospital, was he or she given any information about his or her condition?	2.6	Q86. Keeping noise levels to a minimum	1.2
Q36. Was the information about his or her condition discussed with your child in a way he or she could understand?	2.3	Q87. Cleanliness of the facility	1.4
Q37. When you or your child used the call button to get help, was the response quick enough?	1.7	Q88. Cleanliness of the room	1.7
Q38. Did someone explain to your child the tests that were being done in a way he or she could understand?	2.2	Q89. Courtesy and helpfulness of the staff that served your child's food	6.4
Q39. Did you feel comfortable asking medical staff questions about your child's condition or treatment?	1.0	Q90. Accuracy of receiving food items that were ordered for your child	9.6
Q40. Did you feel you had a care provider who had full understanding of your child's condition and treatment?	1.3	Q91. Taste of the food	9.7
Q41. Did you feel like your child was treated with respect and dignity while he/she was in the hospital?	1.2	Q92. Temperature of the food	9.6
Q42. Did family members or someone close to your child ever have to do something or say something to staff to be sure that your child's medical needs were met?	1.6	Q93. In general, how would you rate your child's health?	1.4
Q43. Were you given as much information as you wanted about your child's rights and responsibilities as a patient?	2.2	Q94. During the month of your hospital visit, how many days did illness or injury keep your child in bed all or part of the day?	4.2
Q44. Was your child ever in any pain?	1.5	Q95. Including this hospital stay, how many times in the last six months has your child been in a hospital overnight or longer?	2.2
Q45. Was the pain your child experienced in the hospital more than what you were told it would be?	3.8	Q96. For this stay in hospital you have been referring to, was your child treated as a:	1.4
Q46. Overall, how much pain medicine did your child get?	3.8	Q97. What is the highest level of education your child has completed?	2.8
Q47. Did the hospital staff do everything they could to help control your child's pain?	3.4	Q98. Is your child of Aboriginal or Torres Strait Island background?	1.2
Q48. Was a hand basin and/or alcohol hand wash available in your room or at your bedside?	6.3	Q99. What language do you normally speak at home?	11.4
Q49. Did your healthcare providers/staff wash or clean their hands before providing care for you?	6.3	Q100. Is your child male or female?	3.3
Q50. Did your healthcare providers/staff wash or clean their hands after providing care for you?	6.0	Q101. To which age group does your child belong?	1.9
Q51. Did you remind or prompt staff about hand washing before they provided care for you at any time during this stay?	6.1	Q102. Did the patient complete this survey?	1.4

*Q102 is an optional free text question and not applicable to this analysis.

Ceiling and floor effects

Table 7: Mean and skewness statistics* for the 2007-2011 Paediatric Patient Surveys

Question	Mean	Standard deviation	Skewness	Question	Mean	Standard deviation	Skewness
Q5. Was your child's admission date changed by the hospital?	94.0	15.5	-2.8	Q67. Did someone explain when your child would be allowed to go home?	78.1	30.2	-1.0
Q30. How much did you participate in your child's care, such as feeding or bathing?	93.9	19.4	-3.3	Q83. Would you recommend this hospital to your family and friends?	78.0	30.3	-1.0
Q73. Did someone on the hospital staff tell you when your child should see a doctor for a follow-up visit?	91.6	27.7	-3.0	Q38. Did someone explain to your child the tests that were being done in a way he or she could understand?	78.0	29.7	-1.0
Q41. Did you feel like your child was treated with respect and dignity while he/she was in the hospital?	90.2	22.4	-2.2	Q54. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits and alternatives of the surgery?	77.8	34.8	-1.3
Q64. Did the ICU staff let you stay with your child as much as you wanted?	90.0	25.0	-2.5	Q80. What number would you use to rate this hospital during your child's stay?	77.4	19.2	-1.2
Q46. Overall, how much pain medicine did your child get?	89.3	30.5	-2.5	Q79. Overall, how would you rate the care your child received at the hospital?	76.2	25.0	-1.0
Q82. Would you say that your child's hospital stay was?	88.6	25.8	-2.2	Q11. How would you rate the courtesy of the staff who admitted your child?	76.0	25.0	-0.9
Q55. Before your child's surgery or procedure, did the surgeon or any of your doctors answer your questions in a way you could understand?	87.7	24.9	-1.9	Q66. When your child was transferred out of the ICU, how well were you and your child prepared for the move?	75.8	31.2	-0.9
Q31. How much information about your child's condition or treatment were you given?	87.3	32.9	-2.2	Q17. How would you rate the courtesy of the doctors?	75.2	24.6	-0.9
Q49. Did your healthcare providers/staff wash or clean their hands before providing care for your child?	87.1	25.5	-1.8	Q43. Were you given as much information as you wanted about your child's rights and responsibilities as a patient?	75.1	35.0	-1.1
Q20. Did you have confidence and trust in the nurses caring for your child?	86.9	24.3	-1.6	Q33. If your child had any special nutrition needs, were you able to explain them to a member of the hospital staff?	74.7	34.0	-1.0
Q61. Did you have confidence and trust in the doctors in the ICU?	86.5	25.8	-1.8	Q7. While you were in the ED, did you get enough information about your child's medical condition and treatment?	74.1	31.9	-0.8
Q63. Did you have confidence and trust in your child's nurses in the ICU?	86.4	25.6	-1.7	Q71. Were you told about what danger signals about your child's illness or surgery or procedure to watch out for after he or got home?	73.7	37.1	-1.0
Q39. Did you feel comfortable asking medical staff questions about your child's condition or treatment?	86.1	25.6	-1.6	Q29. Would you have liked more involvement in making the decisions about your child's hospital care?	73.3	37.0	-1.0
Q56. After your child's surgery or procedure, were the results explained to you in a way that you could understand?	85.7	27.2	-1.8	Q70. Were you told what activities your child could or could not do when he or she got home, such as eating, bathing, play?	72.7	38.6	-1.0
Q53. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits and alternatives of the surgery?	85.3	28.8	-1.8	Q60. Were the doctors in the ICU available to answer your questions or concerns when you needed them?	71.9	33.1	-0.8
Q50. Did your healthcare providers/staff clean their hands after providing care for your child?	84.9	28.1	-1.7	Q9. Was your child's wait too long before going to his or her ward or room?	70.9	24.7	.3
Q62. Were the nurses in the ICU available to answer your questions or concerns when you needed them?	84.8	26.5	-1.5	Q77. How would you rate the way the doctors and nurses worked together?	69.9	25.9	-0.6
Q14. Did you have confidence and trust in the doctors caring for your child?	84.7	26.7	-1.5	Q24. How would you rate the availability of the nurses?	69.9	27.1	-0.6
Q21. When you had important questions about your child to ask the nurses, did you get answers you could understand?	84.6	25.6	-1.4	Q74. Did someone on the hospital staff teach you what you needed to know to care for your child at home?	69.9	38.8	-0.8
Q47. Did the hospital staff do everything they could to help control your child's pain?	84.6	28.1	-1.7	Q88. Cleanliness of the facility	69.1	24.6	-0.5
Q76. Would you have liked a nurse to have spent more time with you discussing how to care for your child at home?	84.2	29.5	-1.7	Q37. When you or your child used the call button to get help, was the response quick enough?	69.0	32.4	-0.6
Q22. Did the nurses pay enough attention to your experiences and suggestions in caring for your child?	82.7	27.6	-1.3	Q89. Courtesy and helpfulness of the staff that served your child's food	68.8	26.0	-0.5
Q15. When you had important questions about your child to ask the doctors, did you get answers you could understand?	82.7	27.6	-1.3	Q87. Cleanliness of the facility	67.2	24.9	-0.4
Q26. During your child's stay, did nurses inform you about what medicines your child was being given and why?	82.0	29.3	-1.4	Q32. Was it easy for your child to find someone on the hospital staff to talk to about his or her concerns?	67.1	34.2	-0.6
Q19. Were the nurses available to answer your questions or concerns when you needed them?	81.4	26.9	-1.1	Q90. Accuracy of receiving food items that were ordered for your child	66.2	27.5	-0.5
Q8. How well organised was the admission process?	80.8	28.2	-1.2	Q57. Did anyone discuss your child's fears or anxieties about the surgery or procedure with your child?	65.8	39.4	-0.6
Q75. Would you have liked a doctor to have spent more time with you discussing how to care for your child at home?	80.8	31.8	-1.4	Q3. Overall, from the time you were first told your child needed to be admitted to hospital, how long did he/she wait to be admitted?	65.7	34.8	-0.7
Q42. Did family members or someone close to your child ever have to do something or say something to staff to be sure that your child's medical needs were met?	80.8	31.8	-1.4	Q13. Were the doctors available to answer your questions or concerns when you needed them?	65.3	33.6	-0.4
Q34. When your child needed help getting to the bathroom, did he or she get it in time?	80.6	31.4	-1.4	Q84. Ease of understanding directions and signs inside and outside the hospital	64.6	25.3	-0.3
Q27. Sometimes in a hospital, one doctor or nurse will say one thing and another will say something quite different. Did this happen during your child's hospital stay?	80.5	30.9	-1.3	Q68. A lot of people have difficulty taking medicine at home. Did anyone in the hospital teach you how to give your child?	64.0	42.3	-0.6
Q4. How do you feel about the length of time he/she was on the waiting list for before his/her admission to hospital?	80.4	32.8	-1.4	Q86. Keeping noise levels to a minimum	61.2	25.7	-0.3
Q25. When you were with your child, did you see care providers check your child's ID band or ask his or her name before giving any medications, treatment or tests?	80.1	32.8	-1.4	Q69. Were you told about side effects to watch for from your child's new medicines?	59.1	42.6	-0.4
Q40. Did you feel you had a care provider who had full understanding of your child's condition and treatment?	79.5	30.2	-1.2	Q18. How would you rate the availability of the doctors?	57.6	29.4	-0.3
Q6. How well organised was the care your child received in the emergency department?	79.1	28.9	-1.0	Q92. Temperature of the food	55.2	27.1	-0.1
Q23. How would you rate the courtesy of the nurses?	79.0	23.9	-1.1	Q65. Please rate the parent facilities in the ICU, such as sleep rooms or waiting area	54.9	29.5	-0.2
Q36. Was the information about his or her condition discussed with your child in a way he or she could understand?	78.9	29.8	-1.1	Q91. Taste of the food	50.6	28.5	.0
Q16. Did the doctors pay enough attention to your experiences and suggestions in caring for your child?	78.9	30.4	-1.1	Q85. Availability of parking	38.9	32.7	.4
Q78. How would you rate the hospital's policy for visiting and staying with your child?	78.5	24.9	-1.1	Q45. Was the pain your child experienced in the hospital more than what you were told it would be?	18.8	33.2	1.5

*Q102 is an optional free text question and not applicable to this analysis.

Patient comment analysis

Table 8: Thematically coded comments to the open-ended question: 'If you could change one thing about the hospital, what would it be?'

Coded comments	Number of responses
Nothing / no improvements / happy with treatment / service / staff	9996
More staff / nurses / doctors / specialists / address staff shortages	7743
Upgrade facilities	6046
Waiting lists / waiting times	3959
More / improved / cheaper parking	3887
More caring / understanding / helpful staff / nurses / doctors / specialists	2834
Improve meals / food / quality / quantity	2297
Improved communication / information / explanations	2138
On-site services / facilities / all services available	1838
Increased funding	1524
More competent staff / nurses / doctors / specialists	1518
Other mentions	1213
Improved administrative / admission / discharge processes / better organised	1162
Waiting time in emergency	1136
More privacy	1103
Waiting time for appointments / in outpatients	1031
Waiting time in hospital for treatment	984
Cleaner conditions / rooms / bathrooms	881
Don't know	761
Comments relating to inadequate / poor pain management / treatment / medication / care	700
Upgrade equipment	610
Less noisy / able to sleep / rest	597
More comfortable accommodation / beds / chairs	546
Comments relating to reason for hospitalisation	376
Temperature control / too hot / too cold	282
Lack of continuity of doctor / contact with doctor / nurses / specialists	277
Hospital / clinic too far away / need to be closer to where I live	256
Staff / nurses / doctors / specialists that can be understood / better English speaking	245
Longer opening hours / more days / weekends / out of hours access to medical staff	144
Risk of infection / unhygienic practices	139
Overuse of emergency / used as GP	109
Security concerns	99
Visiting hours concerns / complaints	69
Get rid of smokers / stop smokers / enforce no smoking rules	41
Total respondents with comments	43543

A summary of the types of comments provided with regard to survey administration follows below, along with examples of verbatim responses from patients.

- **The survey applicability is questioned**

I have no reason to complete this survey as my daughter was seen by paediatrician at 36 hours old I was a patient at the hospital and already had a room at the ward. Thank you. My daughter is only 20 weeks old and did have not any need to fill this out sorry.

My son was over 16 and we visited adult emergency. I don't know why I was asked to undertake a paediatric survey.

That they do not send me anymore surveys to be done. My son is only 19 months old so he could not answer any of the questions I tend to think that surveys are a waste of time.

My child's stay was in 2 hospitals so if this survey is regarding XXX, I would change not a thing, but if this survey is regarding XXX hospital, their facilities are certainly not up to scratch.

This survey is in relation to XXX hospital. My daughter was originally treated and diagnosed at XXX hospital who unfortunately do not have a paediatrics ward, unbelievable but true.

- **Survey should be sent out closer to the date of discharge**

Survey needs to be sent out closer to discharge date. Details too difficult to remember.

The long waiting period I spent 3 hours to see a doctor a month ago (9-10am) on a weekday. It would have been more accurate if I fill this survey while in hospital or closer to the date I was there. Still appreciate your efforts.

- **Issues with treatment**

More staff on each shift to ease the load on working staff members and to utilise the beds that were empty and available. It was very clear that staff were overloaded and desperately trying to cope (and succeeding - however it was evident they were dealing with great levels of stress). Surveys such as these are helpful. Congratulations to the designer.

Better communication between doctors & nurses, sorry need to correct that - there was no communication between doctors & nurses. This survey is a joke - you don't ask the questions that really matter e.g. how come we sat for 6 days before anything was done for my child.

- **Noting who filled out the survey**

Parent completed survey for child. Pay the staff more as they do such as wonderful job especially consulting children.

A more decisive program for bed-wetters (children). This survey is rather confusing as it was addressed to my 8 year old son so have filled it out.

Please note survey was filled in by mother of 5 year old boy who received speech therapy.

- **The survey is too long**

Shorter surveys for day patients.

Please note: this survey took 20 minutes to fill out, as the answers needed to be thought about. Please be honest in your time estimation in your letter.

Shorten this bloody survey - who has time? It's too slow

This survey is ridiculously long. Questions were doubled up. Reduce questions and you may receive better response.

- **Other issues**

My daughter was admitted following a suicide attempt. I would have liked more information on why they thought it was okay to send her home the next day, I would have liked her kept in (at least they kept her overnight this time) I do not like that this was addressed to my daughter, she is a victim of crime and did not need to open mail to see a survey about her hospital stay following a suicide attempt. This could have been addressed to the parent/carer

Thank you for wanting to further care for patients through surveys

I hope the hospitals learn from surveys and do something to improve. XXX hospital listens to parents, I hope XXX do the same.

The question implied, is irrelevant if any changes to the public health system are not enforced regardless whether this is a survey or not, until the public see constructive changes in public hospitals, the feedbacks that you conduct are only useful if applied.

APPENDIX H: PROFILE OF COGNITIVE INTERVIEW PARTICIPANTS

Table 9: Round 1 - 8 interviews with parents/carers of admitted children aged 0-16

Round 1 characteristics		Number of interviews
Age of child	0-4	2
	5-8	2
	9-16	4
Gender of child	Male	4
	Female	4
CALD	Language other than English spoken at home	1
Admission type	Admitted from ED	6
	Planned in advance	2
Length of stay	1 night	3
	2 or 3 nights	3
	4 or more nights	2
Parent's educational attainment	Year 10 or under and aged 21+	1
TOTAL		8 interviews

Table 10: Round 2 - five individual interviews of parents/carers of admitted children aged under eight, 12 paired interviews of parents/carers and admitted children aged over eight

Round 2 characteristics		Number of interviews
Age of child	0-4	2
	5-7	4
	8-10	4
	11-13	3
	14-17	4
Gender of child	Male	9
	Female	8
CALD	Language other than English spoken at home	6
Admission type	Admitted from ED	12
	Planned in advance	5
Length of stay	1 night	8
	2 or more nights	9
TOTAL		5 interviews and 12 paired interviews

Table 11: Round 3 - 5 paired interviews with parents/carers of admitted children aged over 8

Round 3 characteristics		Number of interviews
Age of child	8-10	1
	10-14	3
	14-17	1
Gender of child	Male	2
	Female	3
CALD	Language other than English spoken at home	1
Admission type	Admitted from ED	3
	Planned in advance	2
Length of stay	1 night	4
	2 or 3 nights	1
TOTAL		5 paired interviews

APPENDIX I: COGNITIVE INTERVIEW DISCUSSION GUIDE/PROMPTS

Bureau of Health Information – Patient Survey Cognitive Testing Guide

Introduction (5 mins)

- Thank for participation and introduce self and the Ipsos Social Research Institute.
- State aim of discussion –The Bureau of Health Information (BHI) has asked us to conduct a postal survey among paediatric patients who have attended hospital. We are conducting these interviews to make sure the questions ‘work’ and are easy for patients to answer.
- Explain confidentiality and get permission to record.
- Mention incentive (\$50) and time (up to 1 hour)
- Intro to method:

I will ask you to complete the questionnaire exactly as you would do if it came through the post, but I will ask you to stop at the end of each section so I can ask you some questions.

These will mainly be about what you were thinking about when you responded to each question, rather than your actual response.

If you like, you can mention if you have any difficulties or if you don’t understand anything while you’re completing the survey and I will make a note of them to discuss at the end of each section. But I won’t be able to help you with interpreting the questions as this might change the way you respond – and we are really interested in how you interpret the questions.

We are testing the questionnaire, not you, so there are no right or wrong answers.

It’s really important that we know what you really think - I haven’t worked on this questionnaire myself so please feel free to criticise questions if they aren’t working for you.

The questionnaire is in draft format, so please excuse any typos and the formatting (it will be made more attractive for the final version!).

IF MENTIONED: Please ignore the small reference numbers at the end of each question – they’re just for my reference.

IF ASKED FOR FURTHER INFO: The Bureau of Health Information (BHI) was set up in 2009 to measure the performance of the public health system in NSW. BHI produces reports for the government, for people who work in health care, and for the community.

BHI produces regular reports on hospital performance including information on how many patients are visiting NSW hospitals, how long patients waited in emergency departments, and how many elective surgeries were performed within recommended waiting times. Other reports identify areas for improvement and examine how the health system in NSW compares to other states in Australia and other countries. BHI delivers this information for decision makers to use in order to improve health care and patient care in NSW. All of their reports are available on their website at www.bhi.nsw.gov.au.

Drafting note: Need to insert specific question testing notes into copy of questionnaire once questionnaire finalised for cognitive testing

General probes:

Observation Qs: you seemed to spend a little more time/hesitated/missed out/changed response/answered very quickly at QX – what were you thinking?

Was the answer you wanted to give missing from any of these questions (what)?

Which questions were easiest to answer, which were hardest? Why?

Were there any questions you weren't quite sure how to answer?

What else you would have liked to have commented on about your experience of being admitted to hospital?

Was it difficult to remember well enough to answer any of these Qs?

Were all these questions relevant to you or not?

Final probes:

Is there any important part of your experience as a patient that you think isn't covered by this questionnaire?

Which questions do you think are most important?

Were any questions unimportant or irrelevant to you?

Do you have any other feedback about the questionnaire?

APPENDIX J: POTENTIAL QUESTION AREAS

A list of potential question areas for inclusion in the CYPS was identified primarily from the patient discussion groups and stakeholder consultation, with reference to the rapid literature review and statistical analysis, as follows.

Emergency Department

- ease of parking
- length of wait for triage and treatment
- ED process explained
- informed of likely wait time and the reasons for delays
- length of waiting time in ED
- delays in procedures
- comfort of waiting room
- cleanliness of waiting room (including toys/play areas)
- staff checked on patients' condition (after triage)
- reception staff – politeness, empathy
- doctors and nurses (including triage) - politeness, empathy, competence, communication (with parents/carers and children)
- availability of age appropriate activities/entertainment
- security/safety in the waiting room and treatment area
- experience of arrival by ambulance
- effective pain management.

Pre-admission and admission

- ease of parking
- waiting lists – prior to admission
- opportunity to ask questions prior to admission
- fees for appointments prior to admission
- length of wait for treatment/procedure/admission
- informed of likely wait time
- comfort and cleanliness of the waiting area
- availability of age appropriate activities in the waiting area.

On the ward

- availability of age-appropriate activities, ideally including sociable/educational/non-screen-based activities
- admitted to a children's or adolescent ward/room
- in a designated treatment area attended by specialist paediatric staff

- in a room/area with children of a similar age
- reassuring/child-friendly environment
- privacy considerations
- hygiene and cleanliness of ward
- appetising food (suitable for children/young people)
- whether there was disturbance from other patients/their visitors.

Facilities

- availability of a play area in the hospital
- access to Wi-Fi provided to patients in the hospital
- were patient's educational needs met
- designated adolescent spaces in the hospital
- availability of an Aboriginal liaison officer
- were child siblings of the patient able to stay on the ward

Facilities for parents/carers

- appropriate overnight facilities
- information on available hospital facilities/services
- facilities to make a hot drink/to make or purchase food
- opportunities to meet with other patients away from the ward
- whether there were sibling care services provided in the hospital

Treatment

- accuracy of diagnosis/incidence of contradictory information
- confidence in the ability of doctors/nurses
- sufficient staffing levels and appropriate response times
- familiarity of staff with information already provided by patients
- whether staff collaborated with each other in the treatment of the patient (using multidisciplinary care)
- whether the patient felt that all the medical staff worked well together
- what was provided to the patient in order to prepare them for any operation/procedure that they undertook
- the location in which the treatment took place (e.g. the Emergency Department or the paediatric ward)
- the timeliness of the provision of medication
- the level of success of any interventions given for behavioural disorders
- the best aspects of patients' care
- the aspect of care that requires the most improvement
- patients' overall level of satisfaction with the treatment and care they receive

- why the parent/guardian brought their child to the ED
- whether the parent/guardian believed that their child could have been seen by the GP
- where the parent/guardian took their child after leaving the GP

Hygiene

- whether staff washed their hands or used sanitizers prior to care
- whether these hand hygiene practices were maintained after hours

Pain relief

- patients' perceptions on the adequacy of the assessment of their level of pain
- patients' perceptions of the adequacy of the pain relief provided to them
- whether the patient was sedated prior to their procedure or operation
- whether the parent or guardian was allowed to be present during anaesthesia/sedation
- how the pain management provided in the hospital could have been improved

Tests

- tests results provided to patients.

Adverse events

- whether the patient and/or their parent/guardian perceived that the treatment they received in hospital resulted in a negative outcome
- if so, whether a member of staff openly discussed the adverse event with the patient

Privacy

- whether the patient's privacy and confidentiality was explained to them and upheld
- whether there were inpatient areas allowing privacy in medical review

Characteristics and role of medical staff

- the friendliness of members of staff
- the level of empathy of staff
- the level of courtesy of staff
- the responsiveness of staff
- whether staff were approachable
- whether staff behaved in a patient, friendly and caring way towards children and parents/carers
- whether staff showed respect to patients from culturally diverse backgrounds including consideration of their cultural beliefs and practices

- patients' perceptions of whether the health workers seemed knowledgeable about working with young people
- the role of allied health professionals in the patients' treatment
- the services provided by allied health professionals
- whether the patient observed a range of health workers in the hospital

Communication

- whether staff were skilled in communicating with children
- whether staff introduced themselves to patients and their parents/guardians (including their position)
- whether staff answered questions, explained condition, next steps, reasons for tests/procedures, results etc. to children and parents/guardian
- whether staff tried to address children's worries and fears
- whether staff enquired about how patients were going in different parts of their life
- whether the patient or their parent/guardian knew who to talk to if they had any anxiety about their condition or treatment and whether they felt comfortable approaching them
- whether staff communication was appropriate for both the patients and their parents/guardians
- whether staff asked patients about other aspects of their life besides the reason for presentation
- whether doctors and nurses answered patients' questions adequately

Provision of information

- whether patients and their parents/guardians were provided with adequate information relating to the diagnosis and the illness
- whether the parent/guardian were informed about all the changes to the patient's care and the extent of the information (regarding treatment) provided to planned patients prior to their admission
- whether this information was provided in a timely manner
- whether an illness fact sheet was provided to the patient (wherever available)
- whether patients were provided with adequate information on the course of their treatment
- whether parents/guardians were provided with a care plan outlining their child's illness management
- whether patients were provided with adequate information on the medication(s) used in their treatment, as well as the reasons for using the medication(s);
- whether patients and their parents/guardians were made aware of any side effects of the medication(s) used in treatment
- whether doctors and nurses provided information on the patients' treatment in jargon-free language to both the patient and their parent/guardian
- whether the reasons for any delays in care or treatment were explained to the patient

- whether the patient and their parent/guardian were made aware of their rights as a patient
- whether the patient and their parent/guardian were made aware of the process for making a complaint
- whether information about the hospital's safety and quality performance was made available to the patient and/or their parent/guardian
- whether health workers provided information regarding support services to young carers and other patient groups
- whether the doctor provided the patient with information relating to when to present to a local hospital versus a tertiary centre
- whether the patient was provided with information on the prevention of Sexually Transmitted Infections (wherever appropriate)

Consent and decision making

- whether staff asked the patient and their parent/carer about their views on the treatment
- whether patients were involved in the care process, including in discussions about treatment options and overall decision-making
- whether the family of the patient were involved in the care and decision-making associated with treatment
- whether patients and their parents/guardians provided consent in their treatment
- whether young patients (14 years old or above) were aware that they could provide consent

Food and nutrition

- patients' perception of the nutritional value of the hospital food
- patients' opinion on the taste of the hospital food
- whether patients were given a choice of meal
- whether patients received the meal that they requested
- whether patients were provided with assistance when eating (if necessary)
- whether the mother of a new-born patient was provided with food
- the frequency of interruptions to meals

Special patients

- Mental Health patients
 - what services were accessible to parents/guardians of children and young people with autism spectrum disorders
 - whether the patient and/or their parent/guardian found the mental health intake system user-friendly
 - patients' perception of how child-friendly the waiting area and rooms were
 - patients' perception of the effectiveness of their mental health treatment

- patients' perception of their readiness to exit the mental health facility
- Rural patients
 - whether the patient was treated in a rural area
 - rural patients' perceptions of what could be done better to assist them in managing their illness
 - patients' opinions on the use of videoconferencing in their care
 - if patients presented at an ED and did not wait for care

Discharge

- waiting time for discharge
- readiness for discharge
- whether patients were made aware that they were to be discharged from hospital
- whether patients were provided with a printed copy of their discharge summary
- whether patients' general practitioners received a copy of the discharge summary
- provision of information on self-care at home, including medication and what to watch out for, what to expect during each recovery phase and follow-up appointments
- whether adequate information (regarding their child's condition and how to care for them at home) was provided to parents/guardians prior to discharge
- whether arrangements were made for follow-up appointments (including those with specialists, mental health facilities, etc.) prior to discharge
- whether the patient felt well prepared to leave the children's hospital and move to an adult health service
- any perceived "gaps" in community health or outpatient services that make it difficult to care for the patient at home
- sufficient opportunity to ask questions
- whether patients knew who to contact if they had any questions following discharge
- whether patients felt they received the treatment/outcome they required

Demographics

- religion of the patient
- whether the patient has used recreational drugs.

APPENDIX K: CYPS DEVELOPMENT TABLE

The following table outlines the process of development for each question of the Admitted Children (AC) and Admitted Young Patients (AYP) Surveys. Included in the table is: the final question; the main reasons for the question's inclusion; the source questionnaire or survey and original source question; and any changes made to the question in development, either as a result of the three rounds of cognitive interviews and/or discussions between BHI and Ipsos SRI. Where there are no development notes it is an indication that the question tested well and did not require any significant amendments.

The following acronyms used in the table to denote source of the question:

- **NHS** - NHS Inpatient Question Bank 2011
- **NHS NPS** – NHS National Patient Survey 'Young Patient Parent or Guardian' questionnaire (0-11) 2004
- **NCCQ** - National Set of Core, Common Patient Experience Questions
- **CF** – the Commonwealth Fund International Health Policy Survey of Sicker Adults 2008
- **CQI** - the 'Consumer Quality Index (CQ-Index) in an accident and emergency department: development and first evaluation' BMC Health Services Research 2012
- **AAPS** – the NSW Patient Experience Survey Adult Admitted Patient Survey
- **AAPS 2014** – the NSW Patient Experience Survey Adult Admitted Patient Survey, Reviewed 2014
- **EDPS** – the NSW Emergency Department Patient Survey
- **RCPCH** – Picker Institute Europe/Royal College of Paediatrics and Child Health emergency care survey
- **NSWAPS** – 2010 NSW Overnight Patient Survey/2010 NSW Day Patient Survey

Table 12: Survey development table

Question wording	Reason(s) for inclusion	Source question	Development notes
<p>ACQ1 / AYPQ1</p> <p>Was your child's stay in hospital planned in advance or an emergency?</p> <p><i>An emergency</i></p> <p><i>Planned in advance</i></p> <p><i>Something else</i></p>	<p>This question was included to route respondents, according to their type of hospital visit.</p>	<p>Was your visit to hospital planned in advance or an emergency?</p> <p><i>Emergency or urgent</i></p> <p><i>Waiting list or planned in advance</i></p> <p><i>Something else</i></p> <p>NSWAPS, subsequently adapted for AAPS</p>	<p>The question wording was altered to reflect the fact that the survey was focusing on the child – not the adult respondent's – time in hospital.</p> <p>The word 'visit' was also amended to 'stay' as the survey was only including admitted patients.</p>

<p>ACQ2 / AYPQ2</p> <p>From the time a doctor said your child would need to go to hospital, how long did they have to wait to be admitted?</p> <p><i>Less than 1 month</i></p> <p><i>1 to 3 months</i></p> <p><i>4 to 6 months</i></p> <p><i>7 to 12 months</i></p> <p><i>More than 1 year</i></p> <p><i>Don't know / can't remember</i></p>	<p>The length of waiting time for planned admissions was raised as an issue by parents/carers of paediatric patients in the focus groups.</p>	<p>From the time a doctor said you would need to go to hospital, how long did you have to wait to be admitted?</p> <p><i>Less than 1 month</i></p> <p><i>1 to 3 months</i></p> <p><i>4 to 6 months</i></p> <p><i>7 to 12 months</i></p> <p><i>More than 1 year</i></p> <p><i>Don't know/can't remember</i></p> <p>AAPS</p>	<p>The question wording was altered to reflect the fact that the survey was focusing on the child's time in hospital, not an adult's.</p> <p>The phrasing was also broadened to encompass any need to go to hospital, not just those needing operations or surgical procedures.</p>
<p>ACQ3 / AYPQ3</p> <p>Do you think the amount of time your child waited to go to hospital was ... ?</p> <p><i>About right</i></p> <p><i>Slightly too long</i></p> <p><i>Much too long</i></p> <p><i>Don't know / can't remember</i></p>	<p>Waiting lists for admission to hospital were raised as an issue by focus group participants and stakeholders. Questions relating to waiting lists/pre-admission were commonly included in other prominent admitted patient surveys.</p>	<p>Do you think the amount of time you waited was ...?</p> <p><i>About right</i></p> <p><i>Slightly too long</i></p> <p><i>Much too long</i></p> <p><i>Don't know/can't remember</i></p> <p>AAPS</p>	<p>The word 'admitted' was changed to 'waited to go' to hospital to reflect feedback from cognitive interviews suggesting patients more easily comprehend the meaning of this phrase.</p>

<p>ACQ4 / AYPQ4</p> <p>Before your child's arrival, how much information about their hospital stay was given to you?</p> <p><i>Not enough</i></p> <p><i>The right amount</i></p> <p><i>Too much</i></p> <p><i>Don't know / can't remember</i></p>	<p>Parents/carers considered provision of pre-admission information as important in terms of practicalities, such as knowing where to go, when, and what to expect. Also relevant to Stakeholders, who felt that lack of sufficient information sometimes lead to incorrect preparation and potential cancellation of procedures.</p>	<p>Before your arrival to hospital, how much information about your hospital stay was given to you?</p> <p><i>Not enough</i></p> <p><i>The right amount</i></p> <p><i>Too much</i></p> <p><i>Don't know/can't remember</i></p> <p>AAPS</p>	<p>The question was amended to reflect the change from an adult admitted patient filling in the survey on their own behalf, to a child or young patient where an adult may be filling the survey in for them.</p>
<p>ACQ5 / AYPQ5</p> <p>When your child arrived in hospital did they spend time in the emergency department?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>This question was included as an essential routing question to disaggregate planned and emergency admissions.</p>	<p>When you arrived in hospital did you spend time in the Emergency Department?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p> <p>AAPS</p>	<p>The question was amended to reflect the change from adult admitted patient filling in the survey on their own behalf, to a child, or young, patient where an adult may be filling the survey in for them.</p>

<p>ACQ6 / AYPQ6</p> <p>Were the emergency department staff polite and courteous?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>Behaviour of Emergency Department staff was an issue raised by parents in the focus groups. It was also in-keeping with this nature of question being asked of the range of health professionals encountered.</p>	<p>How would you rate the courtesy of your doctors?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>EDPS</p>	<p>Discussions with the Bureau led to the decision to move from a rating scale to a short frequency scale.</p> <p>The phrase 'Emergency Department staff' was used to be sufficiently broad to encompass the full range of health professionals encountered by patients at this stage of their hospital experience.</p>
<p>ACQ7 / AYPQ7</p> <p>Do you think the amount of time your child spent in the emergency department was ... ?</p> <p><i>About right</i></p> <p><i>Slightly too long</i></p> <p><i>Much too long</i></p> <p><i>Don't know/can't remember</i></p>	<p>This question was included to better understand patient perspective on the process and potential delays and waiting times they experienced, which were raised as issues by patients' parents/carers.</p>	<p>ORIGINAL QUESTION</p>	<p>This question was designed to be in keeping with ACQ3/AYPQ3, but referring specifically the period of time in ED prior to admission.</p>

<p>ACQ8 / AYPQ8</p> <p>Were the staff you saw on your arrival to hospital polite and courteous?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Behaviour of admissions staff was an issue raised by parents/carers in the focus groups. It was also in-keeping with this nature of question being asked of the range of health professionals encountered.</p>	<p>How would you rate the courtesy of your doctors?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>EDPS</p>	<p>Discussions with the Bureau led to the decision to move from a rating scale to a short frequency scale.</p> <p>The phrase 'staff' was used to be sufficiently broad to encompass the full range of health professionals encountered by patients on arrival in hospital.</p>
<p>ACQ9 / AYPQ9</p> <p>Do you think the time your child had to wait from arrival at hospital until they were taken to their room or ward was ... ?</p> <p><i>About right</i></p> <p><i>Slightly too long</i></p> <p><i>Much too long</i></p> <p><i>Don't know/can't remember</i></p>	<p>This question was included to better understand patient perspective on the process and potential delays and waiting times they experienced, which were raised as issues by patients' parents/carers.</p>	<p>ORIGINAL QUESTION</p>	

<p>ACQ10 / AYPQ10</p> <p>For <u>most</u> of your child's stay in hospital, what type of room or ward were they in?</p> <p><i>A children's room or ward</i></p> <p><i>An adolescent's/teenager's room or ward</i></p> <p><i>An adult's room or ward</i></p> <p><i>Don't know/can't remember</i></p>	<p>The parent/carer focus groups highlighted this as an important consideration and area of concern.</p>	<p>For most of your stay in hospital, what type of ward were you on?</p> <p><i>A children's ward</i></p> <p><i>An adult ward</i></p> <p><i>An adolescent or teenager ward</i></p> <p><i>Other</i></p> <p>NHS NPS</p>	<p>The final word 'on' was changed to 'in', as being more appropriate. The wording was also altered to refer specifically to 'your child's stay'. 'Most' was underlined for emphasis.</p>
<p>ACQ11 Was the room or ward suitable for someone your child's age?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p>	<p>Parents/carers and stakeholders raised the appropriateness of rooms and wards to children.</p>	<p>Was the area in which your child was treated suitable for someone of their age group?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>EDPS</p>	<p>The question was amended to reflect a planned admission, not an emergency admission. The phrase 'the area' was replaced with 'the room or ward'.</p>
<p>AYPQ92 Did the hospital room suit someone your age?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, sort of</i></p> <p><i>No</i></p>	<p>Parents/carers and stakeholders raised the appropriateness of rooms and wards to children.</p>	<p>ORIGINAL QUESTION</p>	<p>Cognitive testing suggested the need to simplify the self-completion question wording for young patients.</p>

<p>ACQ12 Were there things for your child to do (such as books, games and toys)?</p> <p><i>There were plenty of things for my child to do</i></p> <p><i>There were some things, but not enough</i></p> <p><i>There was nothing for my child's age group</i></p> <p><i>There was nothing for children to do</i></p> <p><i>Not applicable to my child's stay</i></p> <p><i>Don't know/can't remember</i></p>	<p>Patients and stakeholders raised the issue of whether or not there were appropriate things for children to do, to occupy their time, while staying in hospital</p>	<p>Was there enough for your child to do when you were waiting to be seen (such as toys, games and books)?</p> <p><i>Yes, lots to do</i></p> <p><i>Yes, some things but not enough</i></p> <p><i>There were things, but not for my age group</i></p> <p><i>No</i></p> <p><i>Can't remember/Did not notice</i></p> <p><i>I had my own things to do</i></p> <p>RCPCH, adapted for EDPS</p>	<p>The question was developed through cognitive testing to clarify the distinction on whether or not toys, games and books were available, and whether or not they were age appropriate.</p>
--	---	---	--

<p>AYPQ93 Were there things for you to do (such as books, games and toys)?</p> <p><i>There were plenty of things for me to do</i></p> <p><i>There were some things, but not enough</i></p> <p><i>There was nothing for my age group</i></p> <p><i>There was nothing for children to do</i></p> <p><i>Don't know/can't remember</i></p>	<p>Patients and stakeholders raised the issue of whether or not there were appropriate things for children to do, to occupy their time, while staying in hospital</p>	<p>Was there enough for your child to do when you were waiting to be seen (such as toys, games and books)?</p> <p><i>Yes, lots to do</i></p> <p><i>Yes, some things but not enough</i></p> <p><i>There were things, but not for my age group</i></p> <p><i>No</i></p> <p><i>Can't remember/Did not notice</i></p> <p><i>I had my own things to do</i></p> <p>RCPCH, adapted for EDPS</p>	<p>The question was developed through cognitive testing to clarify the distinction on whether or not toys, games and books were available, and whether or not they were age appropriate.</p> <p>The phrasing was altered for self-completion by the patient, not their parent/carer.</p>
<p>ACQ13 / AYPQ11</p> <p>How clean were the wards or rooms your child stayed in while in hospital?</p> <p><i>Very clean</i></p> <p><i>Fairly clean</i></p> <p><i>Not very clean</i></p> <p><i>Not at all clean</i></p> <p><i>Don't know/can't remember</i></p>	<p>Cleanliness was an issue raised by parents/carers in the focus groups, and also emerged from the analysis of previous data as a key factor.</p>	<p>How clean were the wards or rooms you stayed in while in hospital?</p> <p><i>Very clean</i></p> <p><i>Fairly clean</i></p> <p><i>Not very clean</i></p> <p><i>Not at all clean</i></p> <p>AAPS</p>	<p>The question wording was altered to refer to 'your child'.</p>

<p>ACQ14 / AYPQ12</p> <p>How clean were the toilets and bathrooms that your child used while in hospital?</p> <p><i>Very clean</i></p> <p><i>Fairly clean</i></p> <p><i>Not very clean</i></p> <p><i>Not at all clean</i></p> <p><i>Don't know/can't remember</i></p>	<p>Cleanliness was an issue raised by parents/carers in the focus groups, and also emerged from the analysis of previous data as a key factor.</p>	<p>How clean were the toilets and bathrooms that you used while in hospital?</p> <p><i>Very clean</i></p> <p><i>Fairly clean</i></p> <p><i>Not very clean</i></p> <p><i>Not at all clean</i></p> <p>NCCQ, subsequently adapted for AAPS</p>	<p>The question wording was altered to refer to 'your child'.</p>
<p>ACQ15 / AYPQ13</p> <p>Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No, I did not see this</i></p> <p><i>Can't remember</i></p>	<p>Hygiene and the issue of hospital acquired infections were raised in the patient discussion groups.</p>	<p>Did you see <u>doctors</u> wash their hands, use hand gel to clean their hands or put on clean gloves before touching you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p> <p>AAPS, subsequently adapted for EDPS</p>	<p>The question wording was adapted to refer to 'health professionals', not 'doctors', and also 'touching you' was changed to 'touching your child'.</p>

<p>ACQ16 /AYPQ14</p> <p>Was your child given enough privacy during their hospital stay?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>The issue of privacy was raised by both patients and their parents/carers and by stakeholders. It emerged as an issue in the literature review, and is also included in compliance with national standards.</p>	<p>Were you given enough privacy when being examined or treated in the A&E Department?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>Don't know/Can't remember</i></p> <p>NHS</p>	<p>The question was revised to include the phrase 'during their hospital stay' to encompass both admission and possible time spent in the ED, and also 'your child' replaced 'you'.</p>
<p>AYPQ94 Were you given enough privacy during your hospital stay?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>The issue of privacy was raised by both patients and their parents/carers and by stakeholders. It emerged as an issue in the literature review, and is also included in compliance with national standards.</p>	<p>Were you given enough privacy when being examined or treated in the A&E Department?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>Don't know/Can't remember</i></p> <p>NHS</p>	<p>The phrasing was altered for self-completion by the patient, not their parent/carer.</p>

<p>ACQ17 Was your child ever bothered by noise in the hospital?</p> <p>Yes</p> <p>No</p>	<p>Noise in hospital was raised as an issue by parents/carers.</p>	<p>Was your child ever bothered by noise from other patients?</p> <p>Yes</p> <p>No</p> <p>Was your child ever bothered by noise from hospital staff?</p> <p>Yes</p> <p>No</p> <p>NHS NPS</p>	<p>The question was broadened to be a generic noise question as not considered a sufficiently high priority to warrant the greater detail, and space required in the questionnaire.</p>
<p>AYPQ95 Were you ever bothered by noise in the hospital?</p> <p>Yes</p> <p>No</p>	<p>Noise in hospital was raised as an issue by parents/carers.</p>	<p>Was your child ever bothered by noise from other patients?</p> <p>Yes</p> <p>No</p> <p>Was your child ever bothered by noise from hospital staff?</p> <p>Yes</p> <p>No</p> <p>NHS NPS</p>	<p>The phrasing was altered for self-completion by the patient, not their parent/carer.</p>

<p>ACQ18 Did your child have any hospital food during this visit?</p> <p>Yes</p> <p>No</p>	<p>Required for routing purposes.</p>	<p>Did you have any hospital food during this visit?</p> <p>Yes</p> <p>No</p> <p>AAPS</p>	<p>The question was altered to refer to 'your child', rather than 'you'.</p>
<p>ACQ19</p> <p>How would you rate the hospital food?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Neither good nor poor</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p>	<p>The issue of quality, both in taste and nutrition, of hospital food was raised by patients and their parents/carers. The issue was also raised in the literature review, and emerged as a key factor in the analysis of past data.</p>	<p>How would you rate the hospital food?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Neither good nor poor</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p> <p><i>I did not have any hospital food</i></p> <p>NHS</p>	<p>The addition of the filter question (ACQ18) meant that the last answer category, 'I did not have any hospital food', was not needed.</p>

<p>AYPQ91</p> <p>How would you rate the hospital food?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Not good nor bad</i></p> <p><i>Bad</i></p> <p><i>Very bad</i></p> <p><i>I did not have any hospital food</i></p>	<p>The issue of quality, both in taste and nutrition, of hospital food was raised by patients and their parents/carers. The issue was also raised in the literature review, and emerged as a key factor in the analysis of past data.</p>	<p>How would you rate the hospital food?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Neither good nor poor</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p> <p><i>I did not have any hospital food</i></p> <p>NHS</p>	<p>Through cognitive testing, and discussion between Ipsos and BHI, 'poor' and 'very poor' were changed to 'bad' and 'very bad' as this was seen as more readily understood by this age group, and 'good' and 'bad' more easily seen as opposite positions. The mid-point was also changed to 'not good or bad', rather than 'neither good nor poor' as cognitive testing showed that this simplified phrasing was less confusing for respondents.</p>
<p>ACQ20 /AYPQ15</p> <p>Did your child have any special dietary needs (e.g. vegetarian, diabetic, food allergies, religious, cultural or related to their treatment)?</p> <p><i>Yes</i></p> <p><i>No</i></p>	<p>Required for routing purposes.</p>	<p>Do you have any special dietary requirements (e.g. vegetarian, diabetic, food allergies)?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Don't know</i></p> <p>NHS</p>	<p>The NHS question was broadened to include examples relating different cultural and religious beliefs or treatment needs, following consultation between the Bureau and Ipsos SRI.</p>

<p>ACQ21</p> <p>Was the hospital food suitable for their dietary needs?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>The issue of quality, both in taste and nutrition, of hospital food was raised by patients and their parents/carers. The issue was also raised in the literature review, and emerged as a key factor in the analysis of past data.</p>	<p>Was the hospital food suitable for your dietary needs?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p> <p>NHS</p>	<p>The question was re-phrased to refer to 'their dietary needs', rather than 'your dietary needs'.</p>
<p>ACQ21 / AYPQ16</p> <p>Was the hospital food suitable for their dietary needs?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>My child didn't have hospital food</i></p>	<p>The issue of quality, both in taste and nutrition, of hospital food was raised by patients and their parents/carers. The issue was also raised in the literature review, and emerged as a key factor in the analysis of past data.</p>	<p>Was the hospital food suitable for your dietary needs?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p> <p>NHS</p>	<p>The question was re-phrased to refer to 'their dietary needs', rather than 'your dietary needs'.</p> <p>The last answer category was changed to 'My child didn't have hospital food' as the filter question (ACQ18) was not asked of parents/carers in AYP.</p>

<p>ACQ22 /AYPQ17</p> <p>If you needed to talk to a doctor, did you get the opportunity to do so?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No, I did not get the opportunity</i></p> <p><i>I had no need to talk to a doctor</i></p>	<p>The importance of access to doctors and having time to talk with them was raised as an issue by both parents/carers and stakeholders. It was also highlighted in the literature review and in the analysis of previous data.</p>	<p>If you ever needed to talk to a doctor, did you get the opportunity to do so?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>I had no need to talk to a doctor</i></p> <p>NHS</p>	
---	---	--	--

<p>ACQ23 /AYPQ18</p> <p>In your opinion, did the doctors who treated your child know enough about their medical history?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Doctors' knowledge of the patient's medical history was an important issue for patients and their parents/carers, and emerged as a key issue in the analysis of previous data.</p>	<p>In your opinion, did the doctors who treated you know enough about your condition or treatment?</p> <p><i>All the doctors knew enough</i></p> <p><i>Most of the doctors knew enough</i></p> <p><i>Only some of the doctors knew enough</i></p> <p><i>None of the doctors knew enough</i></p> <p><i>Can't say</i></p> <p>AAPS</p>	<p>The question was re-phrased to ask about 'your child', not 'you'.</p>
<p>ACQ24 /AYPQ19</p> <p>Did you have confidence and trust in the doctors treating your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Confidence and trust in doctors was salient to participants in the focus groups and also mentioned by stakeholders.</p>	<p>Did you have confidence and trust in the doctors treating you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>NHS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p>

<p>ACQ25 /AYPQ20</p> <p>Were the doctors polite and courteous?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>The courtesy and politeness of the doctors was raised as an important issue by patients, their parents/carers and stakeholders.</p> <p>The analysis of previous survey data highlighted this as an important question.</p>	<p>How would you rate the courtesy of your doctors?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>AAPS</p>	<p>The answer scale was revised so that it was no longer a rating scale, and became a frequency scale.</p>
<p>ACQ26 Were the doctors kind and caring towards your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Patients' parents/carers in the focus groups emphasised that care provided by staff should transcend courtesy to encompass a degree of empathy and care.</p>	<p>Were the doctors kind and caring towards you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p>
<p>AYPQ86 Were the <u>doctors</u> kind and caring?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Patients' parents/carers in the focus groups emphasised that care provided by staff should transcend courtesy to encompass a degree of empathy and care.</p>	<p>Were the doctors kind and caring towards you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>The phrasing was simplified for self-completion by the patient, not their parent/carers.</p> <p>'Doctors' underlined for clarity and emphasis due to proximity of similar question for nurses.</p>

<p>ACQ27 /AYPQ21</p> <p>In your opinion, did the nurses who treated your child know enough about their care and treatment?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Some patients' parents/carers in the focus groups perceived inadequate communication between staff in the handover of patients/reading of notes, resulting in insufficient knowledge of their care needs and the apparently needless repetition of questions.</p>	<p>In your opinion, did the nurses who treated you know enough about your condition or treatment?</p> <p><i>All of the nurses knew enough</i></p> <p><i>Most of the nurses knew enough</i></p> <p><i>Only some of the nurses knew enough</i></p> <p><i>None of the nurses knew enough</i></p> <p><i>Can't say</i></p> <p>AAPS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p>
<p>ACQ28 /AYPQ22</p> <p>Did you have confidence and trust in the nurses treating your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Confidence and trust in nurses was salient to participants in the focus groups and also mentioned by stakeholders.</p>	<p>Did you have confidence and trust in the nurses treating you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>NHS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p>

<p>ACQ29 /AYPQ23</p> <p>Were the nurses polite and courteous?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>The courtesy and politeness of the nurses was raised as an important issue by patients, their parents/carers and stakeholders.</p> <p>The analysis of previous survey data highlighted this as an important question.</p>	<p>How would you rate the courtesy of your nurses?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>AAPS</p>	<p>The answer scale was revised so that it was no longer a rating scale, and became a frequency scale.</p>
<p>ACQ30 Were the nurses kind and caring towards your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Patients' parents/carers in the focus groups emphasised that care provided by staff should transcend courtesy to encompass a degree of empathy and care.</p>	<p>Were the nurses kind and caring towards you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p>
<p>AYPQ87 Were the <u>nurses</u> kind and caring?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Patients' parents/carers in the focus groups emphasised that care provided by staff should transcend courtesy to encompass a degree of empathy and care.</p>	<p>Were the nurses kind and caring towards you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>The phrasing was simplified for self-completion by the patient, not their parent/carers.</p> <p>'Nurses' underlined for clarity and emphasis due to proximity of similar question for doctors.</p>

<p>ACQ31 /AYPQ24</p> <p>Which, if any, of the following <u>other</u> health professionals did your child receive care or treatment from during this hospital stay?</p> <p><i>Dietician</i></p> <p><i>Occupational therapist</i></p> <p><i>Pharmacist</i></p> <p><i>Physiotherapist</i></p> <p><i>Psychologist</i></p> <p><i>Radiographer (X-ray, ultrasound, MRI)</i></p> <p><i>Social worker</i></p> <p><i>Speech pathologist</i></p> <p><i>Other</i></p> <p><u><i>None</i></u> of these</p>	<p>Stakeholders indicated that they were keen that the survey captures findings relating to other health professionals, to allow feedback to these groups and in recognition of their role. This also emerged as important in the analysis of previous survey data.</p>	<p>Which, if any of the following other healthcare professionals did you receive care or treatment from during this hospital stay?</p> <p><i>Dietician</i></p> <p><i>Occupational therapist</i></p> <p><i>Pharmacist</i></p> <p><i>Physiotherapist</i></p> <p><i>Psychologist</i></p> <p><i>Radiographer (X-ray, ultrasound, MRI)</i></p> <p><i>Social worker</i></p> <p><i>Speech pathologist</i></p> <p><i>Any other health care professional</i></p> <p><i>None of these</i></p> <p>AAPS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p> <p>The answer category 'Any other health professional' was shortened to 'Other' for brevity.</p>
---	---	--	---

<p>ACQ32 /AYPQ25</p> <p>Were these <u>other</u> health professionals polite and courteous?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>The courtesy and politeness of the all health professionals was raised as an important issue by patients, their parents/carers and stakeholders. The analysis of previous survey data highlighted this as an important question.</p>	<p>How would you rate the courtesy of your doctors?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>AAPS</p>	<p>The answer scale was revised so that it was no longer a rating scale, and became a frequency scale.</p> <p>The question wording was re-phrased to refer to 'other health professionals', rather than 'doctors'.</p>
<p>ACQ33 /AYPQ26</p> <p>Did you have confidence and trust in these <u>other</u> health professionals treating your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Confidence and trust in all health professionals was salient to participants in the focus groups and also mentioned by stakeholders.</p>	<p>Did you have confidence and trust in the doctors treating you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>NHS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p> <p>The question wording was re-phrased to refer to 'other health professionals', rather than 'doctors'.</p>

<p>ACQ34 Did the health professionals introduce themselves <u>to your child</u>?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Not applicable as my child is too young</i></p> <p><i>Don't know/can't remember</i></p>	<p>Staff introducing themselves to patients is a health service standard, and, as such, a question was designed to address this issue.</p>	<p>Did the Emergency Department health professionals caring for you introduce themselves to you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>EDPS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you'.</p> <p>It was also altered to 'health professionals' rather than 'Emergency Department health professionals', to be less specific but simpler. The phrase 'caring for you' was cut as unnecessary.</p> <p>The answer category 'Not applicable as my child is too young' was added for those parents/carers attending with very young children. 'Don't know/can't remember' was also added as an answer category.</p>
<p>AYPQ85 Did the doctors and nurses introduce themselves to you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Staff introducing themselves to patients is a health service standard, and, as such, a question was designed to address this issue.</p>	<p>Did the Emergency Department health professionals caring for you introduce themselves to you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>EDPS</p>	<p>The phrasing was simplified for self-completion by the patient, not their parent/carers.</p> <p>It was also altered to 'doctors and nurses' for ease of comprehension by young patients. The phrase 'caring for you' was cut as unnecessary.</p>

<p>ACQ35 Did the health professionals explain things in a way <u>your child</u> could understand?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Not applicable as my child is too young</i></p> <p><i>Don't know/can't remember</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>Also an easily comprehensible reason for patient's attendance, or condition, was highlighted as being important to patients.</p>	<p>During your most recent hospital stay, how often did the doctors, nurses and other health professionals caring for you explain things in a way you could understand?</p> <p><i>All of the time</i></p> <p><i>Most of the time</i></p> <p><i>Some of the time</i></p> <p><i>Rarely</i></p> <p><i>Never</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The question was revised to refer to 'health professionals' to be consistent with other questions asked about all staff in the survey.</p> <p>The question was re-phrased to ask about 'your child', rather than 'you'.</p> <p>The answer categories were changed to use the shorter frequency scale used widely throughout the survey.</p> <p>The answer category 'Not applicable as my child is too young' was added for those parents/carers attending with very young children. 'Don't know/can't remember' was also added as an answer category.</p>
---	---	---	--

<p>AYPQ88 Did the doctors and nurses explain things in a way you could understand?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>Also an easily comprehensible reason for patient's attendance, or condition, was highlighted as being important to patients.</p>	<p>During your most recent hospital stay, how often did the doctors, nurses and other health professionals caring for you explain things in a way you could understand?</p> <p><i>All of the time</i></p> <p><i>Most of the time</i></p> <p><i>Some of the time</i></p> <p><i>Rarely</i></p> <p><i>Never</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The phrasing was simplified for self-completion by the patient, not their parent/carer.</p> <p>It was also altered to 'doctors and nurses' for ease of comprehension by young patients.</p> <p>The answer categories were changed to use the shorter frequency scale used widely throughout the survey.</p>
--	---	---	--

<p>ACQ36 /AYPQ27</p> <p>Did the health professionals explain things in a way you could understand?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>Also an easily comprehensible reason for patient's attendance, or condition, was highlighted as being important to patients' parents/carers.</p>	<p>During your most recent hospital stay, how often did the doctors, nurses and other health professionals caring for you explain things in a way you could understand?</p> <p><i>All of the time</i></p> <p><i>Most of the time</i></p> <p><i>Some of the time</i></p> <p><i>Rarely</i></p> <p><i>Never</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The question was revised to refer to 'health professionals' to be consistent with other questions asked about all staff in the survey.</p> <p>The answer categories were changed to use the shorter frequency scale used widely throughout the survey.</p>
--	---	---	---

<p>ACQ37 / AYPQ28</p> <p>During your child's stay in hospital, how much information about their condition or treatment was given to you?</p> <p><i>Not enough</i></p> <p><i>The right amount</i></p> <p><i>Too much</i></p> <p><i>Not applicable to our situation</i></p>	<p>The discussion groups highlighted the importance of information provision to patients' parents/carers.</p>	<p>How much information about your condition or treatment was given to your family, carer or someone close to you?</p> <p><i>Not enough</i></p> <p><i>Right amount</i></p> <p><i>Too much</i></p> <p><i>No family, carer or friends were involved</i></p> <p><i>They did not want or need information</i></p> <p><i>I did not want them to have any information</i></p> <p><i>Don't know/Can't say</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The question was revised as the respondent is the parent – i.e. the family or carer – and so the previous wording was not an effective way of approaching this question. The phrase 'During your child's stay in hospital' was added to clarify the period of the care episode referred to.</p> <p>The answer categories were also simplified.</p>
---	---	---	---

<p>ACQ38 / AYPQ29</p> <p>Did you receive contradictory information from health professionals in the hospital – for example, different opinions on your child’s treatment?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p>	<p>The patient discussion groups and stakeholder feedback raised contradictory information as an aspect of poor handover between staff, and possible cause of unreliable diagnoses.</p>	<p>Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you in the A&E Department?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>EDPS</p>	<p>The question was revised to refer to ‘health professionals’, so as to be in keeping with the other questions in this survey. It was also changed to refer to ‘your child’s treatment’.</p>
<p>ACQ39 / AYPQ30</p> <p>Did you have worries or fears about your child’s condition or treatment while in hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions. The issue of emotional support was also raised by patients’ parents/carers and stakeholders.</p>	<p>Did you have worries or fears about your condition or treatment while in hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p>NCCQ, subsequently for AAPS and EDPS</p>	<p>The question was re-phrased to ask about ‘your child’s’, rather than ‘your’.</p>

<p>ACQ40 / AYPQ31</p> <p>Did a health professional discuss your worries or fears about your child with you?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions, as above.</p>	<p>Did a health care professional discuss your worries or fears with you?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>NCCQ, subsequently for AAPS and EDPS</p>	<p>The question was re-phrased to include 'about your child'.</p>
<p>ACQ41 Did <u>your child</u> have worries or fears about their condition or treatment while in hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Not applicable as my child is too young</i></p> <p><i>Don't know/can't remember</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions. The issue of emotional support was also raised by patients' parents/carers and stakeholders.</p>	<p>Did you have worries or fears about your condition or treatment while in hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p>NCCQ, subsequently for AAPS and EDPS</p>	<p>The question was re-phrased to refer to 'your child's' worries or fears.</p> <p>'Your child' underlined for clarity between this question and the previous similar question about the parent/carer's worries or fears.</p>

<p>ACQ42 Did a health professional <u>discuss your child's</u> worries or fears with them?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions, as above.</p>	<p>Did a health care professional discuss your worries or fears with you?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>NCCQ, subsequently for AAPS and EDPS</p>	<p>The question was re-phrased to refer to 'your child's' worries or fears.</p> <p>'Don't know/can't remember' was added as parents/carers may not know if this has taken place.</p> <p>'Your child' underlined for clarity between this question and the previous similar question about the parent/carer's worries or fears.</p>
<p>AYPO89 Did a doctor or nurse discuss your worries or fears with you?</p> <p><i>Yes, completely</i></p> <p><i>Yes, sort of</i></p> <p><i>No, no-one discussed my worries and fears with me</i></p> <p><i>I did not have any worries or fears</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions, as above.</p>	<p>Did a health care professional discuss your worries or fears with you?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>NCCQ, subsequently for AAPS and EDPS</p>	<p>The phrasing was simplified for self-completion by the patient, not their parent/carer.</p> <p>It was also altered to 'doctors and nurses' for ease of comprehension by young patients.</p> <p>The answer category 'No' was extended to 'No, no-one discussed my worries and fears with me' for clarification. The answer category 'I did not have any worries or fears' was added as this question was asked of patients without the filter question asked of parents/carers (ACQ41).</p>

<p>ACQ43 / AYPQ32</p> <p>Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>I did not want or need to be involved</i></p> <p><i>Not applicable to our situation</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>The discussion groups also demonstrated the importance of the patient and parent/carer involvement in the decision-making process.</p>	<p>Were you involved, as much as you wanted to be, in decisions about your care and treatment?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>I was not well enough or did not want to be involved in decisions about my care or treatment</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The question was re-phrased to refer to 'your child's' care and treatment.</p>
<p>AYPQ96</p> <p>Were you involved, as much as you wanted to be, in decisions about your care and treatment?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, sort of</i></p> <p><i>No</i></p> <p><i>I did not want or need to be involved</i></p> <p><i>I was not well enough</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>The discussion groups also demonstrated the importance of the patient and parent/carer involvement in the decision-making process.</p>	<p>Were you involved, as much as you wanted to be, in decisions about your care and treatment?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>I was not well enough or did not want to be involved in decisions about my care or treatment</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The last answer category was divided into two separate responses; 'I did not want or need to be involved' and 'I was not well enough'. This was done for clarity and ease of response.</p>

<p>ACQ44 / AYPQ33</p> <p>Were you allowed to remain with your child when they were being treated (excluding surgery)?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>This issue emerged from the literature review as being salient for parents.</p>	<p>ORIGINAL QUESTION</p>	
<p>ACQ45 / AYPQ34</p> <p>How would you rate how well the health professionals worked together?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Neither good nor poor</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>This was raised as an issue by stakeholders.</p>	<p>How would you rate how well the doctors and nurses worked together?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>NCCQ, subsequently adapted for AAPS and EDPS</p>	<p>The response options were adapted to be in line with those adopted for overall rating questions in AAPS, and also with best practice guidelines (ensuring a neutral midpoint, with a balance positive and negative scale).</p> <p>'Doctors and nurses' was replaced with 'health professionals' to be in keeping with the majority of questions in CYPS.</p>

<p>ACQ46 / AYPQ35</p> <p>Did you feel your child was treated with respect and dignity while they were in the hospital?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p>	<p>Part of the suite of proposed National Set of Core, Common Patient Experience questions.</p> <p>The importance of this factor was raised by parents/carers and by stakeholders. It emerged as a key factor in the analysis of previous survey data, and its inclusion meets the requirements of national standards.</p>	<p>Did you feel you were treated with respect and dignity while in hospital?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>NCO</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you', and also 'while they were in hospital'.</p>
<p>ACQ47 / AYPQ36</p> <p>Were your child's cultural or religious beliefs respected by the hospital staff?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No, my child's beliefs were not respected</i></p> <p><i>My child's beliefs were not an issue</i></p>	<p>Raised by stakeholders to ensure patients cultural and religious beliefs and preferences were being respected. (These questions relate to the Multicultural Health: Policy and Implementation Plan for Healthy Culturally Diverse Communities 2012-2016).</p>	<p>Were your religious beliefs respected by the hospital staff?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p><i>My beliefs were not an issue during my hospital stay</i></p> <p>NHS, subsequently adapted for AAPS and EDPS</p>	<p>The question wording was amended to refer to 'your child'.</p> <p>The question was broadened to include 'cultural' as well as 'religious' beliefs, and presented in this order to discourage respondents from immediately distancing themselves from identifying as 'religious'.</p>

<p>ACQ48 / AYPQ37</p> <p>While in hospital, did you receive, or see, any information about patient's rights, including how to comment or complain?</p> <p>Yes</p> <p>No</p> <p><i>Don't know/can't remember</i></p>	<p>Stakeholders mentioned the need for a question asking whether patients were made aware of their rights as a patient.</p> <p>This question will provide evidence of compliance with this aspect of the National Standards.</p>	<p>While in hospital, did you ever see any posters or leaflets explaining how to complain about the care you received?</p> <p>Yes</p> <p>No</p> <p><i>Don't know / Can't remember</i></p> <p>NHS, subsequently adapted for AAPS and EDPS</p>	<p>The question was revised to widen its scope (i.e. not just restricted to posters or leaflets) to include any information.</p>
---	--	---	--

<p>ACQ49 / AYPQ38</p> <p>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?</p> <p><i>An infection</i></p> <p><i>Uncontrolled bleeding</i></p> <p><i>A negative reaction to medication</i></p> <p><i>Complications as a result of surgery</i></p> <p><i>Complications as a result of tests or procedures</i></p> <p><i>A blood clot</i></p> <p><i>A pressure wound or bed sore</i></p> <p><i>A fall</i></p> <p><i>Any other complication or problem</i></p> <p><u><i>None of these</i></u></p>	<p>Stakeholders raised the issue of adverse events, and mentioned that there is a lack of data pertaining to the prevalence of these events.</p>	<p>Not including the reason you came to hospital, during your hospital stay, or soon afterwards, did you experience any of the following complications or negative effects?</p> <p><i>An infection</i></p> <p><i>Uncontrolled bleeding</i></p> <p><i>A negative reaction to medication</i></p> <p><i>Complications as a result of surgery</i></p> <p><i>Complications as a result of tests of procedures</i></p> <p><i>A blood clot</i></p> <p><i>A pressure wound or bed sore</i></p> <p><i>A fall</i></p> <p><i>Any other complication or negative effect</i></p> <p><i>None of these</i></p> <p>AAPS</p>	<p>The question was re-phrased to ask about 'your child', rather than 'you', and 'they' rather than 'you'.</p> <p>The phrase 'negative effects' in both the question wording and the answer category was replaced with 'problems' which was more readily understood by respondents.</p>
---	--	--	---

<p>ACQ50 / AYPQ39</p> <p>Was the impact of this complication or problem ... ?</p> <p><i>Very serious</i></p> <p><i>Fairly serious</i></p> <p><i>Not very serious</i></p> <p><i>Not at all serious</i></p>	<p>Stakeholders raised the issue of adverse events, and mentioned that there is a lack of data pertaining to the prevalence these events.</p>	<p>Was the impact of this complication or negative effect...?</p> <p><i>Very serious</i></p> <p><i>Fairly serious</i></p> <p><i>Not very serious</i></p> <p><i>Not at all serious</i></p> <p>AAPS</p>	<p>The phrase 'negative effect' in the question wording was replaced with 'problem' which was more readily understood by respondents.</p>
<p>ACQ51 / AYPQ40</p> <p>In your opinion, were members of the hospital staff open with you about this complication or problem?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p>	<p>In addition to providing an indication of prevalence, stakeholders also indicated that it was important to assess whether adverse events were appropriately addressed. Patients in the focus groups also emphasised the importance of staff openness.</p>	<p>In your opinion, were members of the hospital staff open with you about this complication, condition or negative effect?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>The phrase 'condition or negative effect' in the question wording was replaced with 'problem' which was more readily understood by respondents.</p>

<p>ACQ52 / AYPQ41</p> <p>How much information were you given about the hospital facilities available to you and your child?</p> <p><i>Not enough</i></p> <p><i>The right amount</i></p> <p><i>Too much</i></p> <p><i>Not applicable to our situation</i></p>	<p>The focus groups with parents/carers highlighted the need to provide timely, sufficient information about the process of a child's admission, and illustrated that some parents/carers were not aware of what was available to them and their child while in hospital.</p>	<p>ORIGINAL QUESTION</p>	
<p>ACQ53 / AYPQ42</p> <p>Did you (the patient's parent or carer) make use of the overnight facilities at the hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>There were no overnight facilities available</i></p> <p><i>Not applicable to our situation</i></p>	<p>The question was included as this aspect of the parents/carers experience was raised in the focus groups.</p>	<p>ORIGINAL QUESTION</p>	

<p>ACQ54 / AYPQ43</p> <p>How would you rate the overnight facilities for parents or carers at the hospital?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Neither good nor poor</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p>	<p>The question was included as this aspect of the parents experience was raised in the focus groups.</p>	<p>ORIGINAL QUESTION</p>	<p>A standard rating scale was used, in keeping with that used elsewhere in the suite of NSW surveys.</p>
<p>ACQ55 / AYPQ44</p> <p>Were facilities available for parents and carers to make drinks or food?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>Focus groups with parents/carers raised the lengthy period they may be in hospital and the need for food and drink during this period.</p>	<p>ORIGINAL QUESTION</p>	

<p>ACQ56 / AYPQ45</p> <p>Was there a problem finding parking near the hospital?</p> <p><i>Yes, a big problem</i></p> <p><i>Yes, a small problem</i></p> <p><i>No problem</i></p> <p><i>Not applicable – did not need parking</i></p>	<p>Parking remains a concern for parents/carers (although less so for planned admissions, than for those being admitted via the Emergency Department).</p>	<p>Was there a problem in finding a parking place near to the A&E?</p> <p><i>A big problem</i></p> <p><i>A small problem</i></p> <p><i>No problem</i></p> <p><i>N/A (came by public transport, taxi, walking or on a bike)</i></p> <p>CQI, subsequently adapted for EDPS</p>	<p>The question was amended to be appropriate for planned admission, as well as those going to the Emergency Department.</p> <p>The last answer category was simplified.</p>
<p>ACQ57 If your child was in pain, did the doctors and nurses do everything they could to help with their pain?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>My child was not in pain</i></p>	<p>The pain management question is part of the set of Core Common questions.</p> <p>The effective management of pain was raised by both parents/carers of patients and stakeholders.</p>	<p>Do you think hospital staff did everything they could to help manage your pain?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>NCQ, subsequently adapted for AAPS and EDPS</p>	<p>The phrase 'If your child was in pain' was added so that a filter question was not needed. As a consequence, the answer category 'My child was not in pain' was added.</p> <p>'Hospital staff' was changed to 'doctors and nurses' following cognitive testing, and the emphasis on simplifying language that flowed from designing for young patients to potentially complete the survey themselves.</p>

<p>AYPQ90 If you were in pain, did the doctors and nurses do everything they could to help with your pain?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, sort of</i></p> <p><i>No</i></p> <p><i>I was not in any pain</i></p>	<p>As above.</p>	<p>Do you think hospital staff did everything they could to help manage your pain?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p>NCQ, subsequently adapted for AAPS and EDPS</p>	<p>The phrase 'If you were in pain' was added so that a filter question was not needed. As a consequence, the answer category 'I was not in any pain' was added.</p> <p>The cognitive testing with young patients introduced the preference for saying 'doctors and nurses' not 'hospital staff', as this was seen as clearer.</p> <p>The cognitive testing also suggested the use of 'sort of' as an answer category, as 'to some extent' was less clearly understood.</p>
<p>ACQ58 / AYPQ46</p> <p>During your child's stay in hospital, did they have any tests, X-rays or scans?</p> <p><i>Yes</i></p> <p><i>No</i></p>	<p>The question was included for routing purposes.</p>	<p>During your stay in hospital, did you have any tests, X-rays or scans other than blood or urine tests?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p>NHS, subsequently adapted for AAPS</p>	<p>The question was amended to refer to 'your child's stay'.</p>

<p>ACQ59 / AYPQ47</p> <p>Did a health professional discuss the purpose with you and/or your child?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No, did not discuss with me and/or my child</i></p> <p><i>Don't know/can't remember</i></p>	<p>This question was included because of the importance of patient involvement in care-related decisions, as raised by stakeholders.</p> <p>Questions relating to communication between patients and staff are commonly included in other prominent admitted patient surveys.</p>	<p>Did a doctor, nurse or other health professional discuss the purpose of these tests, X-rays or scans with you?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>In line with other questions, the wording was simplified to only refer to 'health professionals'. It was also amended to refer to 'your child'.</p>
<p>ACQ60 / AYPQ48</p> <p>Did your child receive text, X-ray or scan <u>results</u> while they were still in hospital?</p> <p>Yes</p> <p>No</p>	<p>The question was required for routing purposes.</p>	<p>Did you receive test, X-ray or scan results while you were still in hospital?</p> <p>Yes</p> <p>No</p> <p>AAPS</p>	<p>The question was amended to refer to 'your child'.</p>

<p>ACQ61 / AYPQ49</p> <p>Did a health professional explain the test, X-ray or scan results in a way that you could understand?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p>	<p>Parents/carers and stakeholders both stressed the importance of effective communication and understandable explanations throughout the patient journey.</p> <p>Questions relating to staff communication with patients are commonly included in other prominent admitted patient surveys.</p>	<p>Did a doctor or nurse explain the results of the tests in a way that you could understand?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>Not sure/can't remember</i></p> <p><i>I was told I would get the results at a later date</i></p> <p><i>I was never told the results of the tests</i></p> <p>AAPS</p>	<p>The question wording was amended to refer to 'health professional' rather than 'doctor or nurse' in line with the consistent use of this phrase throughout the questionnaire.</p>
<p>ACQ62 / AYPQ50</p> <p>Did you feel involved in decisions about your child's discharge from hospital?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No, I did not feel involved</i></p> <p><i>I did not want or need to be involved</i></p>	<p>Stakeholders emphasised the importance of patient involvement in discharge planning.</p> <p>Some parents/carers in the focus groups were unsure whether their child was ready to be discharged.</p>	<p>Did you feel you were involved in decisions about your discharge from hospital?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>I did not need to be involved</i></p> <p>NHS</p>	<p>The question was amended to refer to 'your child', and the phrase 'you were' was cut for brevity.</p>

<p>ACQ63 / AYPQ51</p> <p>At the time your child was discharged, did you feel that they were well enough to leave the hospital?</p> <p>Yes</p> <p>No</p>	<p>Some parents/carers in the focus groups were unsure whether their child was ready to be discharged.</p>	<p>At the time you were discharged, did you feel that you were well enough to leave the hospital?</p> <p>Yes</p> <p>No</p> <p>AAPS</p>	<p>The question was amended to refer to 'your child' and 'they'.</p>
<p>ACQ64 / AYPQ52</p> <p>Thinking about when your child left hospital, were you given enough information about how to manage their care at home?</p> <p>Yes, completely</p> <p>Yes, to some extent</p> <p>No, I was not given enough</p> <p>I did not need this type of information</p>	<p>This question is part of the suite of National Set of Core, Common Patient Experience questions.</p> <p>Stakeholders raised the importance of good communication around on-going care, specifically in relation to readmissions.</p> <p>Parents/carers in the focus group were also keen to be well informed, and able to successfully manage the child's on-going care.</p>	<p>Thinking about when you left hospital, were you given enough information about how to manage your care at home?</p> <p>Yes, completely</p> <p>Yes, to some extent</p> <p>No</p> <p>I did not need this type of information</p> <p>NCCQ</p>	<p>The question was amended to refer to 'your child' and 'their care', not 'you' and 'your care'.</p> <p>Cognitive testing also suggested that the 'No' answer category needed clarification, and was amended to 'No, I was not given enough'.</p>

<p>ACQ65 / AYPQ53</p> <p>Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No, arrangements were not adequate</i></p> <p><i>It was not necessary</i></p>	<p>This question is part of the suite of National Set of Core, Common Patient Experience questions.</p>	<p>Thinking about when you left hospital, were adequate arrangements made by the hospital for any services you needed?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No</i></p> <p><i>I did not need any services</i></p> <p>NCCQ</p>	<p>The question was amended to refer to 'your child' and 'they', rather than 'you'.</p> <p>Cognitive testing also suggested that the 'No' answer category needed clarification, and was amended to 'No, arrangements were not adequate'.</p>
<p>ACQ66 / AYPQ54</p> <p>Did hospital staff tell you who to contact if you were worried about your child's condition or treatment after they left hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Don't know/can't remember</i></p>	<p>Patients felt it was important to know what to do/who to contact if their condition deteriorated.</p>	<p>Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p><i>Don't know / Can't remember</i></p> <p>NHS</p>	<p>The question was amended to refer to 'your child' and 'they', rather than 'your' and 'you'.</p>

<p>ACQ67 / AYPQ55</p> <p>Was your child given or prescribed medication to take at home?</p> <p>Yes</p> <p>No</p> <p><i>Don't know/can't remember</i></p>	<p>This question was included for routing purposes.</p>	<p>Were you given medication to take at home?</p> <p>Yes</p> <p>No</p> <p>AAPS</p>	<p>The question was amended to refer to 'your child', rather than 'you'.</p> <p>'Don't know/can't remember' was added as an answer category.</p>
<p>ACQ68 / AYPQ56</p> <p>Did a health professional in the hospital explain the purpose of this medication in a way you could understand?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p>No</p>	<p>An important area raised in patient discussion groups, the literature review and the analysis of previous survey data. It is also designed to assess compliance with national standards.</p>	<p>Did a member of staff explain the purpose of the medications you were to take at home in a way you could understand?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p>No</p> <p>NHS A&E</p>	<p>The question wording was adapted to refer to 'a health professional in the hospital', rather than 'a member of staff'.</p>
<p>ACQ69 / AYPQ57</p> <p>Did a health professional in the hospital tell you about medication side effects to watch for?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p>No</p>	<p>Patients' parents/carers raised the importance of adequate information provision relating to the transition to self-care.</p>	<p>Did a member of staff tell you about medication side effects to watch for?</p> <p><i>Yes, completely</i></p> <p><i>Yes, to some extent</i></p> <p>No</p> <p>NHS A&E</p>	<p>The question was revised to include 'health professionals' to be consistent with the phrasing used throughout the survey.</p>

<p>ACQ70 / AYPQ58</p> <p>Did you receive a copy of a letter from the hospital doctors to your family doctor (GP)?</p> <p>Yes</p> <p>No</p> <p><i>Don't know/can't remember</i></p>	<p>This question is included to establish whether patients are provided with the information required for a complete discharge.</p>	<p>Did you receive a copy of a letter from the hospital doctors to your family GP?</p> <p>Yes</p> <p>No</p> <p><i>Not sure/don't know</i></p> <p>AAPS</p>	<p>'Family GP' was re-phrased to 'family doctor (GP)' for clarification.</p>
<p>ACQ71 / AYPQ59</p> <p>On the day your child left hospital, was their discharge delayed?</p> <p>Yes</p> <p>No</p>	<p>Some parents/carers in the focus groups complained of delays at this stage of the hospital journey.</p> <p>The question was also required for routing purposes.</p> <p>Questions relating to efficacy of discharge were commonly included in other prominent admitted patient surveys.</p>	<p>On the day you left hospital, was your discharge delayed for any reason?</p> <p>Yes</p> <p>No</p> <p>NHS</p>	<p>The question was re-phrased to refer to 'your child'.</p>

<p>ACQ72 / AYPQ60</p> <p>How long was the delay?</p> <p><i>Less than 1 hour</i></p> <p><i>At least 1 hour but less than 2 hours</i></p> <p><i>At least 2 hours but less than 4 hours</i></p> <p><i>4 hours or longer</i></p> <p><i>Don't know/can't remember</i></p>	<p>Inclusion of this question will provide information, not currently available, on the extent of delays during the discharge process.</p>	<p>How long was the delay?</p> <p><i>Up to 1 hour</i></p> <p><i>Longer than 1 hour but no longer than 2 hours</i></p> <p><i>Longer than 2 hours but no longer than 4 hours</i></p> <p><i>Longer than 4 hours</i></p> <p>NHS</p>	<p>Ranges changed to ensure no overlap and enhance comprehension.</p>
<p>ACQ73 / AYPQ61</p> <p>Did a member of staff explain the reason for the delay?</p> <p><i>Yes</i></p> <p><i>No</i></p>	<p>Communication around waiting times, or delays, was important for patient and parent/carer understanding and acceptance.</p>	<p>Did a member of staff explain the reason for the delay?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p>NHS</p>	

<p>ACQ74 / AYPQ62</p> <p>What were the main reasons for the delay?</p> <p><i>They had to wait for medicines</i></p> <p><i>They had to wait to see the doctor</i></p> <p><i>They had to wait for an ambulance/transport</i></p> <p><i>They had to wait for the letter for the GP</i></p> <p><i>They were not well enough</i></p> <p><i>Some other reason</i></p> <p><i>Don't know/can't remember</i></p>	<p>The question was included to understand the most common reasons for delay to inform service improvement.</p>	<p>What was the MAIN reason for the delay? (Tick ONE only)</p> <p><i>I had to wait for medicines</i></p> <p><i>I had to wait to see the doctor</i></p> <p><i>I had to wait for an ambulance</i></p> <p><i>Something else</i></p> <p>AAPS</p>	<p>The question was amended to refer to 'they', rather than 'I' to reflect that we are asking about the child's delay.</p> <p>The answer category 'They were not well enough' was also added to reflect patient experience highlighted in the cognitive testing.</p>
<p>ACQ75 / AYPQ63</p> <p>Overall, how would you rate the care your child received while in hospital?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Neither good nor poor</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p>	<p>Part of the suite of National Set of Core, Common Patient Experience questions.</p>	<p>Overall, how would you rate the care you received while in hospital?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Adequate</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p> <p>NCCQ, subsequently adapted for EDPS</p>	<p>The question was re-phrased to refer to 'your child', rather than 'you'.</p> <p>The mid-point answer category was amended from 'Adequate' to 'Neither good nor poor' as this was felt to be a more balanced scale, and one more readily understood by respondents.</p>

<p>AYPQ97 Overall, how would you rate the care you received while in hospital?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Not good or bad</i></p> <p><i>Bad</i></p> <p><i>Very bad</i></p>	<p>Part of the suite of National Set of Core, Common Patient Experience questions.</p>	<p>Overall, how would you rate the care you received while in hospital?</p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Adequate</i></p> <p><i>Poor</i></p> <p><i>Very poor</i></p> <p>NCCQ, subsequently adapted for EDPS</p>	<p>The answer categories were further amended for the self-completion section for young patients.</p> <p>Through cognitive testing, and discussion between Ipsos and BHI, 'poor' and 'very poor' were changed to 'bad' and 'very bad' as this was seen as more readily understood by this age group, and 'good' and 'bad' more easily seen as opposite positions. The mid-point was also changed to 'not good or bad', rather than 'neither good nor poor' as cognitive testing showed that this simplified phrasing was less confusing for respondents.</p>
<p>ACQ76 / AYPQ64</p> <p>How well organised was the care your child received in hospital?</p> <p><i>Very well organised</i></p> <p><i>Fairly well organised</i></p> <p><i>Not well organised</i></p>	<p>Analysis highlighted the importance of well organised hospital care as a key driver for admitted patients. The efficiency of the care process was also an issue for parents and carers.</p>	<p>How well organised was the care you received in hospital?</p> <p><i>Very well organised</i></p> <p><i>Fairly well organised</i></p> <p><i>Not well organised</i></p> <p>AAPS</p>	<p>The question wording was amended to say 'your child' rather than 'you'.</p>

<p>ACQ77 / AYPQ65</p> <p>If asked about your child's hospital experience by friends and family how would you respond?</p> <p><i>I would speak highly of the hospital</i></p> <p><i>I would neither speak highly nor be critical</i></p> <p><i>I would be critical of the hospital</i></p>	<p>The question was suggested by stakeholders as recommendation by family or friends is frequently a main source of information about healthcare services.</p>	<p>If asked about your hospital experience by friends and family, how would you respond?</p> <p><i>I would speak highly of the hospital</i></p> <p><i>I would neither speak highly nor be critical</i></p> <p><i>I would be critical of the hospital</i></p> <p>AAPS</p>	<p>The question was amended to refer to 'your child's hospital experience', not 'your hospital experience'.</p>
<p>ACQ78 / AYPQ66</p> <p>Did you want to make a complaint about something that happened in hospital?</p> <p><i>Yes, and I did complain</i></p> <p><i>Yes, but I did <u>not</u> complain</i></p> <p><i>No, I did not want to make a complaint</i></p>	<p>This question was included as a filter question to ACQ79/AYPQ67.</p>	<p>Did you want to make a complaint about something that happened in hospital?</p> <p><i>Yes, and I did complain</i></p> <p><i>Yes, but I did <u>not</u> complain</i></p> <p><i>No, I did not want to make a complaint</i></p> <p>AAPS 2014</p>	

<p>ACQ79 / AYPQ67</p> <p>Why didn't you make a complaint? Please x <u>all</u> the boxes that apply to you.</p> <p><i>I didn't know how to make a complaint</i></p> <p><i>I didn't know who to complain to</i></p> <p><i>I was worried it might affect my child's future care</i></p> <p><i>I didn't think it would be taken seriously</i></p> <p><i>It wasn't a serious issue</i></p> <p><i>Other reason</i></p>	<p>This question was included to provide greater insight into the barriers to making a complaint.</p>	<p>Why didn't you make a complaint?</p> <p><i>I didn't know how to make a complaint</i></p> <p><i>I didn't know who to complain to</i></p> <p><i>I was worried it might affect my child's future care</i></p> <p><i>I didn't think it would be taken seriously</i></p> <p><i>It wasn't a serious issue</i></p> <p><i>Other reason</i></p> <p>AAPS 2014</p>	<p>Changed third category to be focused on child.</p>
<p>ACQ80 / AYPQ68</p> <p>Did the care and treatment received in hospital help your child?</p> <p><i>Yes, definitely</i></p> <p><i>Yes, to some extent</i></p> <p><i>No, not at all</i></p>	<p>This question was included as a patient reported outcome measures (PROM).</p>	<p>ORIGINAL QUESTION</p>	

<p>ACQ81 / AYPQ69</p> <p>Is the problem your child went to hospital for ... ?</p> <p><i>Much better</i></p> <p><i>A little better</i></p> <p><i>About the same</i></p> <p><i>A little worse</i></p> <p><i>Much worse</i></p>	<p>This question was included as a patient reported outcome measures (PROM).</p>	<p>ORIGINAL QUESTION</p>	
<p>ACQ82 / AYPQ70</p> <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><i>Not at all difficult</i></p> <p><i>Only a little difficult</i></p> <p><i>Somewhat difficult</i></p> <p><i>Very difficult</i></p> <p><i>They were not able to at all</i></p>	<p>This question was included as a patient reported outcome measures (PROM).</p>	<p>ORIGINAL QUESTION</p>	

<p>ACQ83 / AYPQ71</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><i>Not at all difficult</i></p> <p><i>Only a little difficult</i></p> <p><i>Somewhat difficult</i></p> <p><i>Very difficult</i></p> <p><i>They were not able to at all</i></p>	<p>This question was included as a patient reported outcome measures (PROM).</p>	<p>ORIGINAL QUESTION</p>	
<p>ACQ84 / AYPQ72</p> <p>What is your gender?</p> <p><i>Male</i></p> <p><i>Female</i></p>	<p>This question is required for classification and analysis purposes, including standardisation.</p>	<p>Your gender is: (please tick the appropriate box)</p> <p><i>Male</i></p> <p><i>Female</i></p> <p>NHS</p>	<p>The question was simplified following consultation between the Bureau and Ipsos SRI.</p>

<p>ACQ85 / AYPQ73</p> <p>What is the highest level of education you (the parent/carer) have <u>completed</u>?</p> <p><i>Still at secondary school</i></p> <p><i>Less than Year 12 or equivalent</i></p> <p><i>Completed Year 12 or equivalent</i></p> <p><i>Trade or technical certificate or diploma</i></p> <p><i>University degree</i></p> <p><i>Post graduate/higher degree</i></p>	<p>This question is required for classification and analysis purposes, including standardisation.</p>	<p>What was the highest level of education you completed?</p> <p><i>Less than Year 12 at secondary school</i></p> <p><i>Completed Year 12 at secondary school</i></p> <p><i>Trade or technical certificate or diploma</i></p> <p><i>University graduate</i></p> <p><i>Post graduate / higher degree</i></p> <p>AAPS</p>	<p>The question was amended to be in the present tense – changed ‘What was ...’ to ‘What is ...’. The wording was changed to refer to the ‘parent/carer’, not the ‘patient’.</p> <p>The answer categories were also changed. The reference to ‘primary’ school was deleted as the question is being answered by parents and carers. The answer categories were changed to refer to ‘Year 12 or equivalent’ to encompass those adults educated overseas. ‘University graduate’ was amended to ‘University degree’ as more appropriate phrasing in response to the question wording and in line with ABS wording.</p>
<p>ACQ86 / AYPQ74</p> <p>Which language do you (the parent/carer) mainly speak at home?</p> <p><i>English</i></p> <p><i>A language other than English</i></p>	<p>Part of the suite of National Set of Core, Common Patient Experience questions.</p>	<p>What language do you mainly speak at home?</p> <p><i>English</i></p> <p><i>A language other than English – please specify</i></p> <p>NCCQ</p>	<p>The phrase ‘you (the parent/carer)’ was amended to clarify who this question is asking about.</p>

<p>ACQ87 / AYPQ75</p> <p>Was an interpreter provided when you (the parent/carer) or your child needed one?</p> <p><i>Yes, always</i></p> <p><i>Yes, sometimes</i></p> <p><i>No, an interpreter was needed but not provided</i></p> <p><i>No, an interpreter was not needed</i></p>	<p>The issue was raised as being important by stakeholders.</p>	<p>Did you need, or would you have liked, to use an interpreter at any stage while you were in hospital?</p> <p><i>Yes</i></p> <p><i>No</i></p> <p>AAPS</p>	<p>The question wording was amended to refer to both 'you (the parent/carer)' and 'your child'.</p>
<p>ACQ88 / AYPQ76</p> <p>What year was your child born?</p> <p><i>WRITE IN</i></p>	<p>Part of the suite of National Set of Core, Common Patient Experience questions.</p> <p>This question is required for classification and analysis purposes, including standardisation.</p>	<p>What year were you born?</p> <p><i>WRITE IN</i></p> <p>NCQ</p>	<p>The question was amended to refer to 'your child'.</p>
<p>ACQ89 / AYPQ77</p> <p>What is your child's gender?</p> <p><i>Male</i></p> <p><i>Female</i></p>	<p>This question is required for classification and analysis purposes, including standardisation.</p>	<p>Your gender is: (please tick the appropriate box)</p> <p><i>Male</i></p> <p><i>Female</i></p> <p>NHS</p>	<p>The question wording is amended to refer to 'your child'.</p>

<p>ACQ90 / AYPQ78</p> <p>Which, if any, of the following long-standing conditions does your child have?</p> <p><i>Deafness or severe hearing impairment</i></p> <p><i>Blindness or severe vision impairment</i></p> <p><i>A long-standing illness (e.g. cancer, diabetes, respiratory diseases)</i></p> <p><i>A long-standing physical condition</i></p> <p><i>A learning disability</i></p> <p><i>A mental health condition (e.g. depression, eating disorder)</i></p> <p><i>A neurological condition (e.g. ADHD)</i></p> <p><u><i>None of these</i></u></p>	<p>This question is included so that patients with long-standing conditions can be identified and the data used to identify if their needs are being met. Also a common demographic question to the suite of NSW surveys.</p>	<p>Do you have any of the following long-standing conditions?</p> <p><i>Deafness or severe hearing impairment</i></p> <p><i>Blindness or partially sighted</i></p> <p><i>A long-standing physical condition</i></p> <p><i>A learning disability</i></p> <p><i>A mental health condition</i></p> <p><i>A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy</i></p> <p><i>No, I do not have a long-standing condition</i></p> <p>NHS</p>	<p>The question wording was amended to refer to 'your child', and the reference to '(including age-related conditions)' was deleted as not being relevant to this patient group.</p> <p>The answer category examples of long-standing illnesses and mental health conditions were changed to be more child-appropriate.</p> <p>Following cognitive testing, and discussion between Ipsos and BHI, the additional category of 'A neurological condition (e.g. ADHD)' and 'A long-standing physical condition' were added to capture this aspect of paediatric patient health conditions.</p> <p>The final category, '<u>None of these</u>' was distinguished in the layout by being spaced after the main list of answer categories and also underlined. This was to help ensure this option is seen by respondents.</p>
---	---	--	---

<p>ACQ91 / AYPQ79</p> <p>In general, how would you rate your child's health?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p>	<p>Part of the suite of National Set of Core, Common Patient Experience questions. This question was also included in other prominent admitted patient surveys.</p>	<p>In general, how would you rate your health?</p> <p><i>Excellent</i></p> <p><i>Very good</i></p> <p><i>Good</i></p> <p><i>Fair</i></p> <p><i>Poor</i></p> <p>NCCQ</p>	<p>The question wording was amended to refer to 'your child's' health, rather than 'your' health.</p>
<p>ACQ92 / AYPQ80</p> <p>Is your child of Aboriginal origin, Torres Strait Islander origin, or both?</p> <p><i>Yes, Aboriginal</i></p> <p><i>Yes, Torres Strait Islander</i></p> <p><i>Yes, both Aboriginal and Torres Strait Islander</i></p> <p><i>No</i></p>	<p>Part of the suite of National Set of Core, Common Patient Experience questions. This question was also necessary for analysis purposes, to assess whether the needs of patients of Aboriginal and Torres Strait Islander origin are being met.</p>	<p>Are you of Aboriginal origin, Torres Strait Islander origin, or both?</p> <p><i>Yes, Aboriginal</i></p> <p><i>Yes, Torres Strait Islander</i></p> <p><i>Yes, both Aboriginal and Torres Strait Islander</i></p> <p><i>No</i></p> <p>NCCQ</p>	<p>The question wording was amended to refer to 'your child'.</p>

<p>ACQ93 / AYPQ81</p> <p>Who completed this questionnaire?</p> <p><i>The parent or carer of the child</i></p> <p><i>The child with help from a parent or carer</i></p> <p><i>The child</i></p>	<p>This question was requested for analysis purposes, and may also be used for standardisation at the analysis stage.</p>	<p>Who completed this questionnaire?</p> <p><i>The patient</i></p> <p><i>The patient with help from someone else</i></p> <p><i>Someone else on behalf of the patient</i></p> <p>AAPS</p>	<p>The question wording was amended to refer to 'the child'.</p>
<p>AYPQ100 Who completed this section?</p> <p><i>Me, the patient</i></p> <p><i>Me, with someone helping me</i></p> <p><i>A parent or carer of the patient</i></p>	<p>This question was requested for analysis purposes, and may also be used for standardisation at the analysis stage.</p>	<p>Who completed this questionnaire?</p> <p><i>The patient</i></p> <p><i>The patient with help from someone else</i></p> <p><i>Someone else on behalf of the patient</i></p> <p>AAPS</p>	<p>After cognitive testing with young patients filling in the self-completion survey, the wording was simplified (following discussion between BHI and Ipsos SRI) to incorporate the words and phrasing used by respondents.</p>

<p>ACQ94 / AYPQ82</p> <p>The Bureau 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>To enable data linkage.</p>	<p>The Bureau 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 by 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>The question wording was amended to refer to 'your child'.</p>
--	--------------------------------	--	---

<p>Yes</p> <p>No</p>		<p>Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you (the patient)?</p> <p>Yes</p> <p>No</p> <p>AAPS</p>	
<p>ACQ95 / AYPQ83</p> <p>What was the best part of the care your child received while in this hospital?</p>	<p>The question was included to provide patients to highlight aspects of their care in their own words.</p>	<p>What was the best part of the care you (the patient) received whilst in this Emergency Department?</p> <p>AAPS</p>	<p>The question was reworded to refer to 'your child', not 'you (the patient)'. The reference to 'Emergency Department' was also changed to 'this hospital'.</p>
<p>AYPQ98 What did you think was really good about your hospital visit?</p>	<p>The question was included to provide patients to highlight aspects of their care in their own words.</p>	<p>What was the best part of the care you (the patient) received whilst in this Emergency Department?</p> <p>AAPS</p>	<p>The question was reworded following cognitive testing, to simplify the phrasing and use phrases that were less confusing and more meaningful to young patients completing the self-completion section of the survey.</p>

<p>ACQ96 / AYPQ84</p> <p>What part of your child's care provided by this hospital most needs improving?</p>	<p>The question was included to provide patients to highlight aspects of their care in their own words.</p>	<p>What part of your (the patient's) care provided by this Emergency Department most needs improving?</p> <p>AAPS</p>	<p>The question was reworded to refer to 'your child', not 'you (the patient)'. The reference to 'Emergency Department' was also changed to 'this hospital'.</p>
<p>AYPQ99 What could have been better?</p>	<p>The question was included to provide patients to highlight aspects of their care in their own words.</p>	<p>What part of your (the patient's) care provided by this Emergency Department most needs improving?</p> <p>AAPS</p>	<p>The question was reworded following cognitive testing, to simplify the phrasing and use phrases that were less confusing and more meaningful to young patients completing the self-completion section of the survey.</p>

APPENDIX L: SURVEY QUESTIONS RELEVANT TO THE NATIONAL SAFETY AND QUALITY HEALTH SERVICE STANDARDS AND THE AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

National Safety and Quality Health Service Standards

The Admitted Children and Young Patients Survey includes a number of questions that are relevant to the implementation and achievement of the mandatory National Safety and Quality Health Service Standards that came into operation in January 2013. The ten standards aim to protect the public from harm and improve the quality of health service provision. Standard 1 ‘Governance for Safety and Quality in Health Service Organisations’ and Standard 2 ‘Partnering with Consumers’ set the overarching framework for the remaining eight standards¹. The Admitted Children and Admitted Young Patient Survey sits within the intention of Standard 2 – to create a health service that is responsive to patient, carer and consumer input and needs. The following table identifies which questions provide data relevant to specific standards.

Table 13: Questions relevant to the National Safety and Quality Health Service Standards

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
1.15 Implementing a complaints management system that includes partnership with patients and carers	<p>ACQ48/AYPQ37 While in hospital, did you receive, or see, any information about patients’ rights, including how to comment or complain?</p> <p>ACQ78/AYPQ66 Did you make a complaint about something that happened in hospital?</p> <p>ACQ79/AYPQ67 Why didn’t you make a complaint?</p>
1.16 Implementing an open disclosure process	ACQ37/AYPQ28 During your child’s stay in

¹ Australian Commission on Safety and Quality in Healthcare. *Australian Safety and Quality Framework for Health Care*. Accessed 27/11/2012 from <http://qldvoice.org.au/wp-content/uploads/2011/10/Australian-Safety-and-Quality-Framework-for-Health-Care.pdf>

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
based on the national open disclosure standard	<p>hospital, how much information about their condition or treatment was given to you?</p> <p>ACQ51/AYPQ40 In your opinion, were members of the hospital staff open with you about this complication or problems?</p> <p>ACQ52/AYPQ41 How much information were you given about the hospital facilities available to you and your child?</p>
1.17 Implementing through organisational policies and practices a patient charter of rights that is consistent with the current national charter of healthcare rights	ACQ48/AYPQ37 While in hospital, did you receive, or see, any information about patients' rights, including how to comment or complain?
1.18 Implementing processes to enable partnership with patients in decisions about their care, including informed consent to treatment	<p>ACQ35 Did the health professionals explain things in a way your child could understand?</p> <p>AYPQ88 Did the doctors and nurses explain things in a way you could understand?</p> <p>ACQ36/AYPQ27 Did the health professionals explain things in a way you could understand?</p> <p>ACQ37/AYPQ28 During your child's stay in hospital, how much information about their condition or treatment was given to you?</p> <p>ACQ40/AYPQ31 Did a health professional discuss your worries or fears about your child with you?</p> <p>ACQ42/AYPQ89 Did a health professional discuss your child's worries or fears with</p>

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
	<p>them?</p> <p>ACQ43/AYPQ32 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?</p> <p>AYPQ96 Were you involved, as much as you wanted to be, in decisions about your care and treatment?</p> <p>ACQ62/AYPQ50 Did you feel involved in decisions about your child's discharge from hospital?</p> <p>ACQ87/AYPQ75 Was an interpreter provided when you (the parent/carer) or your child needed one?</p>
<p>1.8 Adopting processes to support the early identification, early intervention and appropriate management of patients at increased risk of harm.</p> <p>1.8.1 Mechanisms are in place to identify patients at increased risk of harm</p>	<p>ACQ22/AYPQ17 If you needed to talk to a doctor, did you get the opportunity to do so?</p> <p>ACQ23/AYPQ19 In your opinion, did the doctors who treated your child know enough about their medical history?</p> <p>ACQ27/AYPQ21 In your opinion, did the nurses who treated your child know enough about their care and treatment?</p>
<p>2.2 Implementing policies, procedures and/or protocols for partnering with patients, carers and consumers in strategic and operational/services planning, decision making about safety and quality initiatives quality improvement activities.</p> <p>2.2.2 Consumers and/or carers are actively</p>	<p>ACQ40/AYPQ31 Did a health professional discuss your worries or fears about your child with you?</p> <p>ACQ42/AYPQ89 Did a health professional discuss your child's worries or fears with</p>

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
involved in decision making about safety and quality	<p>them?</p> <p>ACQ43/AYPQ32 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?</p>
<p>2.7 Informing consumers and/or carers about the organisation's safety and quality performance in a format that can be understood and interpreted independently.</p> <p>2.7.1 The community and consumers are provided with information that is meaningful and relevant on the organisation's safety and quality performance</p>	<p>ACQ4/AYPQ4 Before your child's arrival, how much information about their hospital stay was given to you?</p> <p>ACQ52/AYPQ41 How much information were you given about the hospital facilities available to you and your child?</p>
3.5 Developing, implementing and auditing hand hygiene program consistent with the current national hand hygiene initiative	ACQ15/AYPQ13 Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching your child?
3.15 Using risk management principles to implement systems that maintain a clean and hygienic environment for patients and healthcare workers	<p>ACQ13/AYPQ11 How clean were the wards or rooms your child stayed in while in hospital?</p> <p>ACQ14/AYPQ12 How clean were the toilets and bathrooms that your child used while in hospital?</p>
<p>4.4 Using a robust organisation-wide system of reporting, investigating and managing change to respond to medication incidents.</p> <p>4.4.1 Medication incidents are regularly</p>	ACQ49/AYPQ38 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?

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
monitored, reported and investigated	
4.5 Undertaking quality improvement activities to enhance the safety of medicines use	<p>ACQ67/AYPQ55 Was your child given or prescribed medication to take at home?</p> <p>ACQ68/AYPQ56 Did a health professional in the hospital explain the purpose of this medication in a way you could understand?</p> <p>ACQ69/AYPQ57 Did a health professional in the hospital tell you about medication side effects to watch for?</p> <p>ACQ49/AYPQ38 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?</p>
4.12 Developing and implementing governance arrangements and organisational policies, procedures and/or protocols for medication safety, which are consistent with national and jurisdictional legislative requirements, policies and guidelines	<p>ACQ67/AYPQ55 Was your child given or prescribed medication to take at home?</p> <p>ACQ68/AYPQ56 Did a health professional in the hospital explain the purpose of this medication in a way you could understand?</p> <p>ACQ69/AYPQ57 Did a health professional in the hospital tell you about medication side effects to watch for?</p>
4.13 The clinical workforce informing patients and carers about medication treatment options, benefits and associated risks	<p>ACQ43/AYPQ32 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?</p> <p>ACQ67/AYPQ55 Was your child given or</p>

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
	<p>prescribed medication to take at home?</p> <p>ACQ68/AYPQ56 Did a health professional in the hospital explain the purpose of this medication in a way you could understand?</p> <p>ACQ69/AYPQ57 Did a health professional in the hospital tell you about medication side effects to watch for?</p>
<p>4.15 Providing current medicines information to patients in a format that meets their needs whenever new medicines are prescribed or dispensed</p>	<p>ACQ37/AYPQ28 During your child's stay in hospital, how much information about their condition or treatment was given to you?</p> <p>ACQ67/AYPQ55 Was your child given or prescribed medication to take at home?</p> <p>ACQ68/AYPQ56 Did a health professional in the hospital explain the purpose of this medication in a way you could understand?</p> <p>ACQ69/AYPQ57 Did a health professional in the hospital tell you about medication side effects to watch for?</p>
<p>5.4 Developing, implementing and regularly reviewing the effectiveness of the patient identification and matching system at patient handover, transfer and discharge.</p> <p>5.4.1: A patient identification and matching system is implemented and regularly reviewed as part of structured clinical handover, transfer and discharge processes</p>	<p>ACQ45/AYPQ34 How would you rate how well the health professionals worked together?</p>

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
<p>5.5 Developing and implementing a documented process to match patients to their intended procedure, treatment or investigation and implementing the consistent national guidelines for patient procedure matching protocol or other relevant protocols</p>	<p>ACQ45/AYPQ34 How would you rate how well the health professionals worked together?</p> <p>ACQ23/AYPQ19 In your opinion, did the doctors who treated your child know enough about their medical history?</p> <p>ACQ27/AYPQ21 In your opinion, did the nurses who treated your child know enough about their care and treatment?</p>
<p>6.3 Monitoring and evaluating the agreed structured clinical handover processes, including:</p> <p>Regularly reviewing local processes based on current best practice in collaboration with clinicians, patients and carers</p> <p>Undertaking quality improvement activities and acting on issues identified from clinical handover reviews</p> <p>Reporting the results of clinical handover reviews at executive level of governance</p>	<p>ACQ45/AYPQ34 How would you rate how well the health professionals worked together?</p> <p>ACQ23/AYPQ19 In your opinion, did the doctors who treated your child know enough about their medical history?</p> <p>ACQ27/AYPQ21 In your opinion, did the nurses who treated your child know enough about their care and treatment?</p>
<p>6.5 Developing and implementing mechanisms to include patients and carers in the clinical handover process that are relevant to the healthcare setting.</p> <p>6.5.1 Mechanisms to involve a patient and, where relevant, their carer in clinical handover are in use</p>	<p>ACQ23/AYPQ19 In your opinion, did the doctors who treated your child know enough about their medical history?</p> <p>ACQ27/AYPQ21 In your opinion, did the nurses who treated your child know enough about their care and treatment?</p>

National Safety and Quality Health Service Standards	Relevant question from the Admitted Children and Admitted Young Patients Surveys
9.7 Ensuring patients, families and carers are informed about, and are supported so that they can participate in recognition and response systems and processes	ACQ66/AYPO54 Did hospital staff tell you who to contact if you were worried about your child's condition or treatment after they left hospital?
9.9 Enabling patients, families and carers to initiate an escalation of care response	<p>ACQ22/AYPO17 If you needed to talk to a doctor, did you get the opportunity to do so?</p> <p>ACQ37/AYPO28 During your child's stay in hospital, how much information about their condition or treatment was given to you?</p>
10.3 Undertaking quality improvement activities to address safety risks and ensure the effectiveness of the falls prevention system	<p>ACQ66/AYPO53 Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?</p> <p>ACQ49/AYPO38 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?</p>

The Australian Charter of Healthcare Rights

The Admitted Children and Admitted Young Patient Surveys includes a number of questions that are relevant to the Australian Charter of Healthcare Rights, developed by ACSQHC in 2007 and 2008. The charter was developed with extensive and widespread consultation and specifies the key rights of patients and consumers, when seeking or receiving healthcare services. The Charter highlights seven rights, underpinned by the principles of access to health care, the right to the highest possible standard of physical and mental health, and acknowledgement and respect for difference.² The following table identifies which questions provide data relevant to specific standards.

Table 10: Questions relevant to the Australian Charter of Healthcare Rights

Australian Charter of Healthcare Rights	Relevant question from the Admitted Children and Admitted Young Patients Surveys
Access: I have a right to health care	<p>ACQ/AYPO2 From the time a doctor said your child would need to go to a hospital, how long did they have to wait to be admitted?</p> <p>ACQ3/AYPO3 Do you think the amount of time your child waited to go to hospital was ...?</p> <p>ACQ7/AYPO7 Do you think the amount of time your child spent in the Emergency Department was ...?</p> <p>ACQ9/AYPO9 Do you think the time your child had to wait from arrival at hospital until they were taken to their room or ward was ...?</p>
Safety: I have a right to receive safe and high quality care	<p>ACQ24/AYPO19 Did you have confidence and trust in the doctors treating your child</p> <p>ACQ28/AYPO22 Did you have confidence and trust in the nurses treating your child?</p> <p>ACQ15/AYPO13 Did you see health professionals wash</p>

² *Australian Charter of Healthcare Rights*. Accessed from

<http://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDF.pdf>

Australian Charter of Healthcare Rights	Relevant question from the Admitted Children and Admitted Young Patients Surveys
	<p>their hands, or use hand gel to clean their hands, before touching your child?</p> <p>ACQ57 If your child was in pain, did the doctors and nurses do everything they could to help with their pain?</p> <p>AYPO90 If you were in pain, did the doctors and nurses do everything they could to help with your pain?</p> <p>ACQ13/AYPO11 How clean were the wards or rooms your child stayed in while in hospital?</p> <p>ACQ14/AYPO12 How clean were the toilets and bathrooms that your child used while in hospital?</p>
<p>Respect: I have a right to be shown respect, dignity and consideration</p>	<p>ACQ6/AYPO6 Were the Emergency Department staff polite and courteous?</p> <p>ACQ8/AYPO8 Were the staff you saw on your arrival to hospital polite and courteous?</p> <p>ACQ16/AYPO14 Was your child given enough privacy during their hospital stay?</p> <p>ACQ25/AYPO20 Were the doctors polite and courteous?</p> <p>ACQ26 Were the doctors kind and caring towards your child?</p> <p>AYPO86 Were the doctors kind and caring?</p> <p>ACQ29/AYPO23 Were the nurses polite and courteous?</p> <p>ACQ30 Were the nurses kind and caring towards your child?</p> <p>AYPO87 Were the nurses kind and caring?</p>

Australian Charter of Healthcare Rights	Relevant question from the Admitted Children and Admitted Young Patients Surveys
	<p>ACQ32/AYPQ25 Were these other health professionals polite and courteous?</p> <p>ACQ34 Did the health professionals introduce themselves to your child?</p> <p>AYPQ85 Did the doctors and nurses introduce themselves to you?</p> <p>ACQ46/AYPQ35 Did you feel your child was treated with respect and dignity while they were in the hospital?</p> <p>ACQ47/AYPQ36 Were you child's cultural or religious beliefs respected by the hospital staff?</p> <p>ACQ48/AYPQ37 While in hospital, did you receive, or see, any information about patients' rights, including how to comment or complain?</p> <p>ACQ57 If your child was in pain, did the doctors and nurses do everything they could to help with their pain?</p> <p>AYPQ90 If you were in pain, did the doctors and nurses do everything they could to help with your pain?</p>
<p>Communication: I have a right to be informed about services, treatment, options and costs in a clear and open way</p>	<p>ACQ37/AYPQ28 During your child's stay in hospital, how much information about their condition or treatment was given to you?</p> <p>ACQ43/AYPQ32 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?</p> <p>ACQ62/AYPQ50 Did you feel involved in decisions about your child's discharge from hospital?</p> <p>ACQ59/AYPQ47 Did a health professional discuss the</p>

Australian Charter of Healthcare Rights	Relevant question from the Admitted Children and Admitted Young Patients Surveys
	<p>purpose with you and/or your child?</p> <p>ACQ60/AYPQ48 Did your child receive test, X-ray or scan results while they were still in hospital?</p> <p>ACQ61/AYPQ49 Did a health professional explain the test, X-ray or scan results in a way that you could understand?</p> <p>ACQ64/AYPQ52 Thinking about when your child left hospital, were you given enough information about how to manage their care at home?</p> <p>ACQ68/AYPQ56 Did a health professional in the hospital explain the purpose of this medication in a way you could understand?</p> <p>ACQ73/AYPQ59 On the day your child left hospital, was their discharge delayed?</p> <p>ACQ87/AYP75 Was an interpreter provided when you (the parent/carer) or your child needed one?</p>
<p>Participation: I have a right to be included in decisions and choices about my care</p>	<p>ACQ22/AYPQ17 If you needed to talk to a doctor, did you get the opportunity to do so?</p> <p>ACQ37/AYPQ28 During your child's stay in hospital, how much information about their condition or treatment was given to you?</p> <p>ACQ35/AYPQ27 Did the health professionals explain things in a way your child could understand?</p> <p>ACQ36 Did the health professionals explain things in a way you could understand?</p> <p>AYPQ88 Did the doctors and nurses explain things in a way you could understand?</p>

Australian Charter of Healthcare Rights	Relevant question from the Admitted Children and Admitted Young Patients Surveys
	<p>ACQ43/AYPQ32 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?</p> <p>AYPQ96 Were you involved, as much as you wanted to be, in decisions about your care and treatment?</p>
<p>Privacy: I have a right to privacy and confidentiality of my personal information</p>	<p>ACQ16/AYPQ14 Was your child given enough privacy during their hospital stay?</p> <p>AYPQ94 Were you given enough privacy during your hospital stay?</p>
<p>Comment: I have a right to comment on my care and to have my concerns addressed.</p>	<p>ACQ48/AYPQ37 While in hospital, did you receive, or see, any information about patients' rights, including how to comment or complain?</p> <p>ACQ78/AYPQ66 Did you want to make a complaint about something that happened in hospital?</p> <p>ACQ79/AYPQ67 Why didn't you make a complaint?</p>

APPENDIX M: FINAL ADMITTED CHILDREN SURVEY



Bureau of
Health Information

NSW Patient Survey: Admitted Children

<Barcode>
Parent or Carer of <Title> <First Name> <Last Name>
<Address Line 1>
<SUBURB> <STATE> <POSTCODE>

Date

Dear Parent or Carer of <First Name> <Last Name>,

Your child's experience in hospital is very important to us

I am writing to ask you to take part in the NSW Patient Survey by telling us about your child's recent admission to [HOSPITAL NAME] during [MONTH]. Your child's experience in this hospital is important as it helps us to understand the quality of care they received and allows hospitals to see where they need to improve.

The Bureau of Health Information was established by the NSW Government to independently report on the performance of the public health system in NSW, including the healthcare experiences of patients. We are running the survey along with Ipsos Social Research Institute, who is sending you this survey on the Bureau's behalf.

The survey is easiest to complete online. Please visit the web address below and log in with the following username and password. It is possible to partially complete the survey online and then return to it later to complete the remainder.



Web address: survey.ipsos.com.au/patientsurvey

Username: [INS_UNAME]

Password: [INS_PWORD]

If you prefer to complete the attached paper survey, please use the included reply-paid envelope to mail it back to us.

Taking part in the survey is voluntary. You have been randomly selected to participate and there are many safeguards in place to protect your identity. The hospital staff who cared for your child will not know if you have returned a completed survey and will not be able to see your responses to the survey. At no point will we report any information that identifies you or your child as an individual.

If you have any queries regarding the survey, please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm).

Thank you for taking part in the survey.

Yours sincerely

Jean-Frédéric Lévesque
Chief Executive
Bureau of Health Information

How to complete the survey

This survey is about your child's recent experience as an admitted patient in the hospital named on the previous page. If your child has been an admitted patient more than once during the month specified on the previous page, please answer about their most recent experience.

For each question, please use a blue or black pen to mark the box next to the answer you choose, as shown below.

Example only

How clean were the wards or rooms your child stayed in while in hospital?

- Very clean
 Fairly clean
 Not very clean
 Not at all clean

Sometimes you will find the box you have marked has an instruction to go to another question. By following the instructions carefully you will be able to move past questions that do not apply to you.

If you would prefer not to answer individual questions, leave them blank but please complete the rest of the survey.

If you make a mistake or wish to change a response, simply fill in that box and mark the correct box like this:

If someone is helping you to complete this survey, please ensure the answers given are from your point of view, and not the opinion of the person helping you.

If you prefer a language other than English, please refer to the separate language sheet for information on the Healthcare Interpreter Service.

Please do not write your name or address on the questionnaire.

When you have finished

- ➔ Remove the covering letter by tearing along the perforated line.
- ➔ Place the completed survey in the "Reply Paid" envelope and post it. You do not have to use a stamp.
- ➔ If you have misplaced the "Reply Paid" envelope, please use a plain envelope (no stamp is necessary) and address to:

**NSW Patient Survey Program
Ipsos Social Research Institute
Reply Paid 84599
Hawthorn VIC 3122**

Some questions and answers

Why are you carrying out the survey?

The NSW Patient Survey gathers information about your child's experience of health services. By completing the survey, you are helping to improve health services in NSW.

How do I make a formal complaint about my child's experience in hospital?

Please contact the hospital directly. Alternatively, you can get more information about your options at the following website:

www.health.nsw.gov.au/patientconcerns

What happens to my survey responses?

Your survey responses will be de-identified and then processed with responses from other people who completed the survey to form a report. These reports will then be provided to NSW Health and local hospitals to help them to improve health services.

Your responses will be treated in the strictest confidence and no identifying information will be given to NSW Health, the hospital or health service your child attended, their doctor or other health provider unless required by law. Your responses will not affect any future health services that may be provided to your child.

How is my privacy protected?

Your privacy is protected by legislation. Ipsos has been provided with your name and address by NSW Health for the purpose of sending you this survey only, and will keep your contact details confidential.

After all surveys are processed, identifying information will be destroyed and Ipsos will then no longer be able to identify the responses you provided. However, for the period that identifiable details remain, you will be able to contact Ipsos through the toll-free Patient Survey Helpline to ask to see your responses, or to request that some or all of your information be deleted.

You can get more information about privacy and confidentiality by calling the toll-free Patient Survey Helpline or at the following website:

www.bhi.nsw.gov.au/nsw_patient_survey_program/privacy

How do I get more information about the survey?

Please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm, excluding public holidays).

NSW Patient Survey: Admitted Children

Q1 Was your child's stay in hospital planned in advance or an emergency?

- An emergency.....Go to Q5
- Planned in advance
- Something else



BEFORE ARRIVING AT HOSPITAL

Thinking back to before your child's hospital stay...

Q2 From the time a doctor said your child would need to go to hospital, how long did they have to wait to be admitted?

- Less than 1 month
- 1 to 3 months
- 4 to 6 months
- 7 to 12 months
- More than 1 year
- Don't know/can't remember

Q3 Do you think the amount of time your child waited to go to hospital was ...?

- About right
- Slightly too long
- Much too long
- Don't know/can't remember

Q4 Before your child's arrival, how much information about their hospital stay was given to you?

- Not enough
- The right amount
- Too much
- Don't know/can't remember

ARRIVING AT HOSPITAL

Q5 When your child arrived in hospital did they spend time in the Emergency Department?

- Yes
- NoGo to Q8
- Don't know/can't remember.....Go to Q8



THE EMERGENCY DEPARTMENT (ED)

Q6 Were the Emergency Department staff polite and courteous?

- Yes, always
- Yes, sometimes
- No
- Don't know/can't remember

Q7 Do you think the amount of time your child spent in the Emergency Department was...?

- About right
- Slightly too long
- Much too long
- Don't know/can't remember

Go to Q10

PLANNED AND OTHER TYPES OF ARRIVAL /ADMISSION

Q8 Were the staff you saw on your arrival to hospital polite and courteous?

- Yes, always
- Yes, sometimes
- No

Q9 Do you think the time your child had to wait from arrival at hospital until they were taken to their room or ward was...?

- About right
- Slightly too long
- Much too long
- Don't know/can't remember

THE HOSPITAL AND WARD

Q10 For most of your child's stay in hospital, what type of room or ward were they in?

- A children's room or ward
- An adolescent's/teenager's room or ward
- An adult's room or ward
- Don't know/can't remember

Q11 Was the room or ward suitable for someone your child's age?

- Yes, definitely
- Yes, to some extent
- No

Q12 Were there things for your child to do (such as books, games and toys)?

- There were plenty of things for my child to do
- There were some things, but not enough
- There was nothing for my child's age group
- There was nothing for children to do
- Not applicable to my child's stay
- Don't know/can't remember

Q13 How clean were the wards or rooms your child stayed in while in hospital?

- Very clean
- Fairly clean
- Not very clean
- Not at all clean
- Don't know/can't remember

Q14 How clean were the toilets and bathrooms that your child used while in hospital?

- Very clean
- Fairly clean
- Not very clean
- Not at all clean
- Don't know/can't remember

Q15 Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching your child?

- Yes, always
- Yes, sometimes
- No, I did not see this
- Can't remember

Q16 Was your child given enough privacy during their hospital stay?

- Yes, always
- Yes, sometimes
- No

Q17 Was your child ever bothered by noise in the hospital ?

- Yes
- No

FOOD

Q18 Did your child have any hospital food during this visit?

- Yes
- NoGo to Q22

Q19 How would you rate the hospital food?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q20 Did your child have any special dietary needs (e.g. vegetarian, diabetic, food allergies, religious, cultural, or related to their treatment)?

- Yes
- NoGo to Q22

Q21 Was the hospital food suitable for their dietary needs?

- Yes, always
- Yes, sometimes
- No
- Don't know/can't remember

DOCTORS

Q22 If you needed to talk to a doctor, did you get the opportunity to do so?

- Yes, always
- Yes, sometimes
- No, I did not get the opportunity
- I had no need to talk to a doctor

Q23 In your opinion, did the doctors who treated your child know enough about their medical history?

- Yes, always
- Yes, sometimes
- No

Q24 Did you have confidence and trust in the doctors treating your child?

- Yes, always
- Yes, sometimes
- No

Q25 Were the doctors polite and courteous?

- Yes, always
- Yes, sometimes
- No

Q26 Were the doctors kind and caring towards your child?

- Yes, always
- Yes, sometimes
- No

NURSES

Q27 In your opinion, did the nurses who treated your child know enough about their care and treatment?

- Yes, always
- Yes, sometimes
- No

Q28 Did you have confidence and trust in the nurses treating your child?

- Yes, always
- Yes, sometimes
- No

Q29 Were the nurses polite and courteous?

- Yes, always
- Yes, sometimes
- No

Q30 Were the nurses kind and caring towards your child?

- Yes, always
- Yes, sometimes
- No

OTHER HEALTH PROFESSIONALS

Q31 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 your child

- Dietician
- Occupational therapist
- Pharmacist
- Physiotherapist
- Psychologist
- Radiographer (X-ray, ultrasound, MRI)
- Social worker
- Speech pathologist
- Other

Go to Q32



Please write in then go to Q32

None of theseGo to Q34

Q32 Were these other health professionals polite and courteous?

- Yes, always
- Yes, sometimes
- No

Q33 Did you have confidence and trust in these other health professionals treating your child?

- Yes, always
- Yes, sometimes
- No

YOUR CHILD'S TREATMENT & CARE

For the following questions, please think about all the health professionals who treated or examined your child in the hospital, including doctors, nurses and others.

Q34 Did the health professionals introduce themselves to your child?

- Yes, always
- Yes, sometimes
- No
- Not applicable as my child is too young
- Don't know/can't remember

Q35 Did the health professionals explain things in a way your child could understand?

- Yes, always
- Yes, sometimes
- No
- Not applicable as my child is too young
- Don't know/can't remember

Q36 Did the health professionals explain things in a way you could understand?

- Yes, always
- Yes, sometimes
- No

Q37 During your child's stay in hospital, how much information about their condition or treatment was given to you?

- Not enough
- The right amount
- Too much
- Not applicable to our situation

Q38 Did you receive contradictory information from health professionals in the hospital – for example, different opinions on your child's treatment?

- Yes, definitely
- Yes, to some extent
- No

Q39 Did you have worries or fears about your child's condition or treatment while in hospital?

- Yes
- NoGo to Q41

Q40 Did a health professional discuss your worries or fears about your child with you?

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

Q41 Did your child have worries or fears about their condition or treatment while in hospital?

- Yes
- NoGo to Q43
- Not applicable as my child is too youngGo to Q43
- Don't know/can't rememberGo to Q43

Q42 Did a health professional discuss your child's worries or fears with them?

- Yes, completely
- Yes, to some extent
- No
- Don't know/can't remember

Q43 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?

- Yes, definitely
- Yes, to some extent
- No
- I did not want or need to be involved
- Not applicable to our situation

Q44 Were you allowed to remain with your child when they were being treated (excluding surgery)?

- Yes, always
- Yes, sometimes
- No
- Don't know/can't remember

Q45 How would you rate how well the health professionals worked together?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q46 Did you feel your child was treated with respect and dignity while they were in the hospital?

- Yes, always
- Yes, sometimes
- No

Q47 Were your child's cultural or religious beliefs respected by the hospital staff?

- Yes, always
- Yes, sometimes
- No, my child's beliefs were not respected
- My child's beliefs were not an issue

Q48 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

Q49 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 theseGo to Q52

Q50 Was the impact of this complication or problem ...?

- Very serious
- Fairly serious
- Not very serious
- Not at all serious

Q51 In your opinion, were members of the hospital staff open with you about this complication or problem?

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

INFORMATION AND ACCESS

Q52 How much information were you given about the hospital facilities available to you and your child?

- Not enough
- The right amount
- Too much
- Not applicable to our situation

Q53 Did you (the patient's parent or carer) make use of the overnight facilities at the hospital?

- YesGo to Q54
- NoGo to Q55
- There were no overnight facilities availableGo to Q55
- Not applicable to our situation ...Go to Q55

Q54 How would you rate the overnight facilities for parents or carers at the hospital?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q55 Were facilities available for parents and carers to make drinks or food?

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

Q56 Was there a problem finding parking near the hospital?

- Yes, a big problem
- Yes, a small problem
- No problem
- Not applicable – did not need parking

PAIN

Q57 If your child was in pain, did the doctors and nurses do everything they could to help with their pain?

- Yes, definitely
- Yes, to some extent
- No
- My child was not in pain

TESTS

Q58 During your child's stay in hospital, did they have any tests, X-rays or scans?

- Yes
- NoGo to Q62

Q59 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

Q60 Did your child receive test, X-ray or scan results while they were still in hospital?

- Yes
- NoGo to Q62

Q61 Did a health professional explain the test, X-ray or scan results in a way that you could understand?

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

LEAVING HOSPITAL (DISCHARGE)

Thinking now about when your child was discharged, that is when they left the hospital to go home or to another facility...

Q62 Did you feel involved in decisions about your child's discharge from hospital?

- Yes, definitely
- Yes, to some extent
- No, I did not feel involved
- I did not want or need to be involved

Q63 At the time your child was discharged, did you feel that they were well enough to leave the hospital?

- Yes
- No

Q64 Thinking about when your child left hospital, were you given enough information about how to manage their care at home?

- Yes, completely
- Yes, to some extent
- No, I was not given enough
- I did not need this type of information

Q65 Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?

- Yes, completely
- Yes, to some extent
- No, arrangements were not adequate
- It was not necessary

Q66 Did hospital staff tell you who to contact if you were worried about your child's condition or treatment after they left hospital?

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

Q67 Was your child given or prescribed medication to take at home?

- Yes
- NoGo to Q70
- Don't know/can't rememberGo to Q70

Q68 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

Q69 Did a health professional in the hospital tell you about medication side effects to watch for?

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

Q70 Did you receive a copy of a letter from the hospital doctors to your family doctor (GP)?

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

Q71 On the day your child left hospital, was their discharge delayed?

- Yes
- NoGo to Q75

Q72 How long was the delay?

- Less than 1 hour
- At least 1 hour but less than 2 hours
- At least 2 hours but less than 4 hours
- 4 hours or longer
- Don't know/can't remember

Q73 Did a member of staff explain the reason for the delay?

- Yes
- No

Q74 What were the main reasons for the delay? Please **x** all the boxes that apply to your child

- 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

OVERALL

Q75 Overall, how would you rate the care your child received while in hospital?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q76 How well organised was the care your child received in hospital?

- Very well organised
- Fairly well organised
- Not well organised

Q77 If asked about your child's hospital experience by friends and family how would you respond?

- I would speak highly of the hospital
- I would neither speak highly nor be critical
- I would be critical of the hospital

- Q78** Did you want to make a complaint about something that happened in hospital?
- Yes, and I did complain.....Go to Q80
 - Yes, but I did not complain
 - No, I did not want to make a complaint.....Go to Q80

- Q79** Why didn't you make a complaint?
Please **x** all the boxes that apply to you
- I didn't know how to make a complaint
 - I didn't know who to complain to
 - I was worried it might affect my child's future care
 - I didn't think it would be taken seriously
 - It wasn't a serious issue
 - Other reason

OUTCOMES

- Q80** Did the care and treatment received in hospital help your child?
- Yes, definitely
 - Yes, to some extent
 - No, not at all
- Q81** Is the problem your child went to hospital for...?
- Much better
 - A little better
 - About the same
 - A little worse
 - Much worse
- Q82** 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

- Q83** 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

**ABOUT YOU
(THE PARENT OR CARER)**

- Q84** What is your gender?
- Male
 - Female
- Q85** What is the highest level of education you (the parent/carer) have completed?
- Still at secondary school
 - Less than Year 12 or equivalent
 - Completed Year 12 or equivalent
 - Trade or technical certificate or diploma
 - University degree
 - Post graduate/higher degree
- Q86** Which language do you (the parent/carer) mainly speak at home?
- EnglishGo to Q88
 - A language other than English
- ↓
Please write in then go to Q87
-
- Q87** Was an interpreter provided when you (the parent/carer) or your child needed one?
- Yes, always
 - Yes, sometimes
 - No, an interpreter was needed but not provided
 - No, an interpreter was not needed

ABOUT YOUR CHILD

Q88 What year was your child born?

WRITE IN (YYYY)

Q89 What is your child's gender?

- Male
 Female

Q90 Which, if any, of the following long-standing conditions does your child have?

Please **x** all the boxes that apply to your child

- 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 of these

Q91 In general, how would you rate your child's health?

- Excellent
 Very good
 Good
 Fair
 Poor

Q92 Is your child of Aboriginal origin, Torres Strait Islander origin, or both?

- Yes, Aboriginal
 Yes, Torres Strait Islander
 Yes, both Aboriginal and Torres Strait Islander
 No

Q93 Who completed this questionnaire?

- The parent or carer of the child
 The child with help from a parent or carer
 The child

Q94 The Bureau 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.

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.

Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to your child?

- Yes
 No

Please go to the next page to complete the final two questions 

YOUR FINAL COMMENTS

Q95 What was the best part of the care your child received while in this hospital?

Q96 What part of your child's care provided by this hospital most needs improving?

**Thank you for your time.
Please remove the covering letter by tearing along the perforated line.
Return the survey in the reply paid envelope provided
or send it in an envelope addressed to
NSW Patient Survey, Ipsos Social Research Institute,
Reply Paid 84599, Hawthorn, VIC 3122 (no stamp is needed)**

Certain questions within this survey are drawn from: the NHS Inpatient Survey and NHS Accident & Emergency Survey (courtesy of the NHS Care Quality Commission); Picker Institute questionnaires (courtesy of National Research Corporation); the Patient Experience Information Development Working Group (PEIDWG) national set of core, common patient experience questions; the Royal College of Paediatrics and Child Health and Picker Institute Europe 'Urgent and Emergency Care PREM tools'; and (Bos N, Sturms LM, Shriver AJP and van Stel HL 'The consumer quality index (CQ-index) in an accident and emergency department: development and first evaluation' BMC Health Services Research 2012, 12:284), and are used with permission.

Barcode

APPENDIX N: FINAL ADMITTED YOUNG PATIENTS SURVEY



NSW Patient Survey: Admitted Young Patients

<Barcode>
Parent or Carer of <Title> <First Name> <Last Name>
<Address Line 1>
<SUBURB> <STATE> <POSTCODE>

Date

Dear Parent or Carer of <INS_FIRST NAME> <INS_SURNAME>,

Your child's experience in hospital is very important to us

I am writing to ask you and your child to take part in the NSW Patient Survey by telling us about your child's recent admission to [HOSPITAL NAME] during [MONTH]. Your child's experience in this hospital is important as it helps us to understand the quality of care they received and allows hospitals to see where they need to improve.

The Bureau of Health Information was established by the NSW Government to independently report on the performance of the public health system in NSW, including the healthcare experiences of patients. We are running the survey along with Ipsos Social Research Institute, who is sending you this survey on the Bureau's behalf.

The main part of the survey should be completed by a parent or carer who was present during the child's time in hospital. The final section is for your child to complete from their point of view (although younger children might need some help).

The survey is easiest to complete online. Please visit the web address below and log in with the following username and password. It is possible to partially complete the survey online and then return to it later to complete the remainder.



Web address: [INS_URL]

Username: [INS_UNAME]

Password: [INS_PWORD]

If you prefer to complete the attached paper survey, please use the included reply-paid envelope to mail it back to us.

Taking part in the survey is voluntary. Your child has been randomly selected to participate and there are many safeguards in place to protect their identity. The hospital staff who cared for your child will not know if you have returned a completed survey and will not be able to see your responses to the survey. At no point will we report any information that identifies you or your child as an individual.

If you have any queries regarding the survey, please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm).

Thank you for taking part in the survey.

Yours sincerely

Jean-Frédéric Lévesque
Chief Executive
Bureau of Health Information

How to complete the survey

This survey is about your child's recent experience as an admitted patient in the hospital named on the previous page. If your child has been an admitted patient more than once during the month specified on the previous page, please answer about their most recent experience. **The last two pages of the questionnaire are for your child to fill out themselves.**

For each question, please use a blue or black pen to mark the box next to the answer you choose, as shown below.

Example only

How clean were the wards or rooms your child stayed in while in hospital?

- Very clean
 Fairly clean
 Not very clean
 Not at all clean

Sometimes you will find the box you have marked has an instruction to go to another question. By following the instructions carefully you will be able to move past questions that do not apply to you.

If you would prefer not to answer individual questions, leave them blank but please complete the rest of the survey.

If you make a mistake or wish to change a response, simply fill in that box and mark the correct box like this:

If someone is helping you to complete this survey, please ensure the answers given are from your point of view, and not the opinion of the person helping you.

If you prefer a language other than English, please refer to the separate language sheet for information on the Healthcare Interpreter Service.

Please do not write your name or address on the questionnaire.

When you have finished

- ➔ Remove the covering letter by tearing along the perforated line.
- ➔ Place the completed survey in the "Reply Paid" envelope and post it. You do not have to use a stamp.
- ➔ If you have misplaced the "Reply Paid" envelope, please use a plain envelope (no stamp is necessary) and address to:

**NSW Patient Survey Program
Ipsos Social Research Institute
Reply Paid 84599
Hawthorn VIC 3122**

Some questions and answers

Why are you carrying out the survey?

The NSW Patient Survey gathers information about your child's experience of health services. By completing the survey, you are helping to improve health services in NSW.

How do I make a formal complaint about my child's experience in hospital?

Please contact the hospital directly.

Alternatively, you can get more information about your options at the following website:

www.health.nsw.gov.au/patientconcerns

What happens to my survey responses?

Your survey responses will be de-identified and then processed with responses from other people who completed the survey to form a report. These reports will then be provided to NSW Health and local hospitals to help them to improve health services.

Your responses will be treated in the strictest confidence and no identifying information will be given to NSW Health, the hospital or health service your child attended, their doctor or other health provider unless required by law. Your responses will not affect any future health services that may be provided to your child.

How is my privacy protected?

Your privacy is protected by legislation. Ipsos has been provided with your name and address by NSW Health for the purpose of sending you this survey only, and will keep your contact details confidential.

After all surveys are processed, identifying information will be destroyed and Ipsos will then no longer be able to identify the responses you provided. However, for the period that identifiable details remain, you will be able to contact Ipsos through the toll-free Patient Survey Helpline to ask to see your responses, or to request that some or all of your information be deleted.

You can get more information about privacy and confidentiality by calling the toll-free Patient Survey Helpline or at the following website:

www.bhi.nsw.gov.au/nsw_patient_survey_program/privacy

How do I get more information about the survey?

Please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm, excluding public holidays).

NSW Patient Survey: Admitted Young Patients

Parents and carers please start the survey here:

- Q1** Was your child's stay in hospital planned in advance or an emergency?
- An emergency.....Go to Q5
 - Planned in advance
 - Something else

BEFORE ARRIVING AT HOSPITAL

Thinking back to before your child's hospital stay...

- Q2** From the time a doctor said your child would need to go to hospital, how long did they have to wait to be admitted?
- Less than 1 month
 - 1 to 3 months
 - 4 to 6 months
 - 7 to 12 months
 - More than 1 year
 - Don't know/can't remember

- Q3** Do you think the amount of time your child waited to go to hospital was...?
- About right
 - Slightly too long
 - Much too long
 - Don't know/can't remember

- Q4** Before your child's arrival, how much information about their hospital stay was given to you?
- Not enough
 - The right amount
 - Too much
 - Don't know/can't remember

ARRIVING AT HOSPITAL

- Q5** When your child arrived in hospital did they spend time in the Emergency Department?
- YesGo to Q6
 - NoGo to Q8
 - Don't know/can't rememberGo to Q8

THE EMERGENCY DEPARTMENT (ED)

- Q6** Were the Emergency Department staff polite and courteous?
- Yes, always
 - Yes, sometimes
 - No
 - Don't know/can't remember

- Q7** Do you think the amount of time your child spent in the Emergency Department was... ?
- About right
 - Slightly too long
 - Much too long
 - Don't know/can't remember
- } Go to Q10

PLANNED AND OTHER TYPES OF ARRIVAL/ADMISSION

- Q8** Were the staff you saw on your arrival to hospital polite and courteous?
- Yes, always
 - Yes, sometimes
 - No

- Q9** Do you think the time your child had to wait from arrival at hospital until they were taken to their room or ward was...?
- About right
 - Slightly too long
 - Much too long
 - Don't know/can't remember

THE HOSPITAL AND WARD

- Q10** For most of your child's stay in hospital, what type of room or ward were they in?
- A children's room or ward
 - An adolescent's/teenager's room or ward
 - An adult's room or ward
 - Don't know/can't remember

Q11 How clean were the wards or rooms your child stayed in while in hospital?

- Very clean
- Fairly clean
- Not very clean
- Not at all clean
- Don't know/can't remember

Q12 How clean were the toilets and bathrooms that your child used while in hospital?

- Very clean
- Fairly clean
- Not very clean
- Not at all clean
- Don't know/can't remember

Q13 Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching your child?

- Yes, always
- Yes, sometimes
- No, I did not see this
- Can't remember

Q14 Was your child given enough privacy during their hospital stay?

- Yes, always
- Yes, sometimes
- No

FOOD

Q15 Did your child have any special dietary needs (e.g. vegetarian, diabetic, food allergies, religious, cultural, or related to their treatment)?

- Yes
- NoGo to Q17

Q16 Was the hospital food suitable for their dietary needs?

- Yes, always
- Yes, sometimes
- No
- My child didn't have hospital food

DOCTORS

Q17 If you needed to talk to a doctor, did you get the opportunity to do so?

- Yes, always
- Yes, sometimes
- No, I did not get the opportunity
- I had no need to talk to a doctor

Q18 In your opinion, did the doctors who treated your child know enough about their medical history?

- Yes, always
- Yes, sometimes
- No

Q19 Did you have confidence and trust in the doctors treating your child?

- Yes, always
- Yes, sometimes
- No

Q20 Were the doctors polite and courteous?

- Yes, always
- Yes, sometimes
- No

NURSES

Q21 In your opinion, did the nurses who treated your child know enough about their care and treatment?

- Yes, always
- Yes, sometimes
- No

Q22 Did you have confidence and trust in the nurses treating your child?

- Yes, always
- Yes, sometimes
- No

Q23 Were the nurses polite and courteous?

- Yes, always
- Yes, sometimes
- No

OTHER HEALTH PROFESSIONALS

Q24 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 your child

- Dietician
- Occupational therapist
- Pharmacist
- Physiotherapist
- Psychologist
- Radiographer (X-ray, ultrasound, MRI)
- Social worker
- Speech pathologist
- Other

Please write in

None of theseGo to Q27

Q25 Were these other health professionals polite and courteous?

- Yes, always
- Yes, sometimes
- No

Q26 Did you have confidence and trust in these other health professionals treating your child?

- Yes, always
- Yes, sometimes
- No

YOUR CHILD'S TREATMENT & CARE

For the following questions, please think about all the health professionals who treated or examined your child in the hospital, including doctors, nurses and others.

Q27 Did the health professionals explain things in a way you could understand?

- Yes, always
- Yes, sometimes
- No

Q28 During your child's stay in hospital, how much information about their condition or treatment was given to you?

- Not enough
- The right amount
- Too much
- Not applicable to our situation

Q29 Did you receive contradictory information from health professionals in the hospital – for example, different opinions on your child's treatment?

- Yes, definitely
- Yes, to some extent
- No

Q30 Did you have worries or fears about your child's condition or treatment while in hospital?

- Yes
- NoGo to Q32

Q31 Did a health professional discuss your worries or fears about your child with you?

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

Q32 Were you involved, as much as you wanted to be, in decisions about your child's care and treatment?

- Yes, definitely
- Yes, to some extent
- No
- I did not want or need to be involved
- Not applicable to our situation

Q33 Were you allowed to remain with your child when they were being treated (excluding surgery)?

- Yes, always
- Yes, sometimes
- No
- Don't know/can't remember

Q34 How would you rate how well the health professionals worked together?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q35 Did you feel your child was treated with respect and dignity while they were in the hospital?

- Yes, always
- Yes, sometimes
- No

Q36 Were your child's cultural or religious beliefs respected by the hospital staff?

- Yes, always
- Yes, sometimes
- No, my child's beliefs were not respected
- My child's beliefs were not an issue

Q37 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

Q38 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.....Go to Q41

Go to Q39

Q39 Was the impact of this complication or problem...?

- Very serious
- Fairly serious
- Not very serious
- Not at all serious

Q40 In your opinion, were members of the hospital staff open with you about this complication or problem?

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

INFORMATION AND ACCESS

Q41 How much information were you given about the hospital facilities available to you and your child?

- Not enough
- The right amount
- Too much
- Not applicable to our situation

Q42 Did you (the patient's parents or carers) make use of the overnight facilities at the hospital?

- Yes
- NoGo to Q44
- There were no overnight facilities available.....Go to Q44
- Not applicable to our situation.....Go to Q44

Q43 How would you rate the overnight facilities for parents or carers at the hospital?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q44 Were facilities available for parents and carers to make drinks or food?

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

Q45 Was there a problem finding parking near the hospital?

- Yes, a big problem
- Yes, a small problem
- No problem
- Not applicable – did not need parking

TESTS

Q46 During your child's stay in hospital, did they have any tests, X-rays or scans?

- Yes
- NoGo to Q50

Q47 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

Q48 Did your child receive test, X-ray or scan results while they were still in hospital?

- Yes
- NoGo to Q50

Q49 Did a health professional explain the test, X-ray or scan results in a way that you could understand?

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

LEAVING HOSPITAL (DISCHARGE)

Thinking now about when your child was discharged, that is when they left the hospital to go home or to another facility...

Q50 Did you feel involved in decisions about your child's discharge from hospital?

- Yes, definitely
- Yes, to some extent
- No, I did not feel involved
- I did not want or need to be involved

Q51 At the time your child was discharged, did you feel that they were well enough to leave the hospital?

- Yes
- No

Q52 Thinking about when your child left hospital, were you given enough information about how to manage their care at home?

- Yes, completely
- Yes, to some extent
- No, I was not given enough
- I did not need this type of information

Q53 Thinking about when your child left hospital, were adequate arrangements made by the hospital for any services they needed?

- Yes, completely
- Yes, to some extent
- No, arrangements were not adequate
- It was not necessary

Q54 Did hospital staff tell you who to contact if you were worried about your child's condition or treatment after they left hospital?

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

Q55 Was your child given or prescribed medication to take at home?

- Yes
- NoGo to Q58
- Don't know/can't rememberGo to Q58

Q56 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

Q57 Did a health professional in the hospital tell you about medication side effects to watch for?

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

Q58 Did you receive a copy of a letter from the hospital doctors to your family doctor (GP)?

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

Q59 On the day your child left hospital, was their discharge delayed?

- Yes
- NoGo to Q63

Q60 How long was the delay?

- Less than 1 hour
- At least 1 hour but less than 2 hours
- At least 2 hours but less than 4 hours
- 4 hours or longer
- Don't know/can't remember

Q61 Did a member of staff explain the reason for the delay?

- Yes
- No

Q62 What were the main reasons for the delay? Please **x** all the boxes that apply to your child

- 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

OVERALL

Q63 Overall, how would you rate the care your child received while in hospital?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q64 How well organised was the care your child received in hospital?

- Very well organised
- Fairly well organised
- Not well organised

Q65 If asked about your child's hospital experience by friends and family how would you respond?

- I would speak highly of the hospital
- I would neither speak highly nor be critical
- I would be critical of the hospital

Q66 Did you want to make a complaint about something that happened in hospital?

- Yes, and I did complain.....Go to Q68
- Yes, but I did not complain
- No, I did not want to make a complaintGo to Q68

Q67 Why didn't you make a complaint? Please **x** all the boxes that apply to you

- I didn't know how to make a complaint
- I didn't know who to complain to
- I was worried it might affect my child's future care
- I didn't think it would be taken seriously
- It wasn't a serious issue
- Other reason

OUTCOMES

Q68 Did the care and treatment received in hospital help your child?

- Yes, definitely
- Yes, to some extent
- No, not at all

Q69 Is the problem your child went to hospital for...?

- Much better
- A little better
- About the same
- A little worse
- Much worse

Q70 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

Q71 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

ABOUT YOU (THE PARENT OR CARER)

Q72 What is your gender?

- Male
- Female

Q73 What is the highest level of education you (the parent/carer) have completed?

- Still at secondary school
- Less than Year 12 or equivalent
- Completed Year 12 or equivalent
- Trade or technical certificate or diploma
- University degree
- Post graduate/higher degree

Q74 Which language do you (the parent/carer) mainly speak at home?

- EnglishGo to Q76
- A language other than English

↓
Please write in then go to Q75

Q75 Was an interpreter provided when you (the parent/carer) or your child needed one?

- Yes, always
- Yes, sometimes
- No, an interpreter was needed but not provided
- No, an interpreter was not needed

ABOUT YOUR CHILD

Q76 What year was your child born?

WRITE IN (YYYY)

Q77 What is your child's gender?

- Male
- Female

Q78 Which, if any, of the following long-standing conditions does your child have?

Please **X** all the boxes that apply to your child

- 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 of these

Q79 In general, how would you rate your child's health?

- Excellent
- Very good
- Good
- Fair
- Poor

Q80 Is your child of Aboriginal origin, Torres Strait Islander origin, or both?

- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, both Aboriginal and Torres Strait Islander
- No

Q81 Who completed the survey up to this point?

The parent or carer of the young patient

The young patient with help from a parent or carer

The young patient

Q82 The Bureau would like your permission to link you and your child's 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.

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.

Do you give permission for the Bureau of Health Information to link answers from this survey to health records related to your child?

Yes

No

YOUR FINAL COMMENTS

Q83 What was the best part of the care your child received while in this hospital?

Q84 What part of your child's care provided by this hospital most needs improving?

Please now hand the survey to your child and ask them to complete pages 11 and 12.

Once your child has also completed the survey, please remove the covering letter by tearing along the perforated line. Return the survey in the reply paid envelope provided or send it in an envelope addressed to NSW Patient Survey, Ipsos Social Research Institute, Reply Paid 84599, Hawthorn, VIC 3122 (no stamp is needed)

Certain questions within this survey are drawn from: the NHS Inpatient Survey (courtesy of the NHS Care Quality Commission); Picker Institute questionnaires (courtesy of National Research Corporation); the Patient Experience Information Development Working Group (PEIDWG) national set of core, common patient experience questions; the 2008 Commonwealth Fund International Health Policy Survey of Sicker Adults (courtesy of NRC and Picker Institute Europe); and (Bos N, Sturms LM, Shriver AJP and van Stel HL. The consumer quality index (CQ-index) in an accident and emergency department: development and first evaluation' BMC Health Services Research 2012, 12:284), and are used with permission.

YOUNG PATIENT'S SECTION

This section should be completed by the young person who was admitted to the hospital.

Please tell us about your experience in the hospital named on the front page. Your answers will help hospitals to see which things they are doing well and which things they need to improve.

For each question, please use a blue or black pen to mark the box next to the answer you choose.

Please mark just one answer for each question.

Q85 Did the doctors and nurses introduce themselves to you?

- Yes, always
- Yes, sometimes
- No

Q86 Were the doctors kind and caring?

- Yes, always
- Yes, sometimes
- No

Q87 Were the nurses kind and caring?

- Yes, always
- Yes, sometimes
- No

Q88 Did the doctors and nurses explain things in a way you could understand?

- Yes, always
- Yes, sometimes
- No

Q89 Did a doctor or nurse discuss your worries or fears with you?

- Yes, completely
- Yes, sort of
- No, no-one discussed my worries and fears with me
- I did not have any worries or fears

Q90 If you were in pain, did the doctors and nurses do everything they could to help with your pain?

- Yes, definitely
- Yes, sort of
- No
- I was not in any pain

Q91 How would you rate the hospital food?

- Very good
- Good
- Not good or bad
- Bad
- Very bad
- I did not have any hospital food

Q92 Did the hospital room suit someone your age?

- Yes, definitely
- Yes, sort of
- No

Q93 Were there things for you to do (such as books, games and toys)?

- There were plenty of things for me to do
- There were some things, but not enough
- There was nothing for my age group
- There was nothing for children to do
- Don't know/can't remember

Q94 Were you given enough privacy during your hospital stay?

- Yes, always
- Yes, sometimes
- No

Q95 Were you ever bothered by noise in the hospital?

- Yes
- No

Q96 Were you involved, as much as you wanted to be, in decisions about your care and treatment?

- Yes, definitely
- Yes, sort of
- No
- I did not want or need to be involved
- I was not well enough

Q97 Overall, how would you rate the care you received while in hospital?



- Very good
- Good
- Not good or bad
- Bad
- Very bad

Q98 What did you think was really good about your hospital visit?

Q99 What could have been better?

Q100 Who completed this section?

- Me, the patient
- Me, with someone helping me
- A parent or carer of the patient

Thank you for completing the Young Patient's Section.

Please hand the survey back to your parent or carer. Instructions for returning the completed survey are on page 10.



APPENDIX O: COVER LETTER FOR ADMITTED YOUNG PATIENTS SURVEY FOR THOSE AGED 16 AND 17



NSW Patient Survey: Admitted Young Patients

<Barcode>
<First Name> <Last Name>
<Address Line 1>
<SUBURB> <STATE> <POSTCODE>

Date

Dear <FIRST NAME> ,

Your experience in hospital is very important to us

I am writing to ask you to take part in the NSW Patient Survey by telling us about your recent admission to [HOSPITAL NAME] during [MONTH]. Your experience in this hospital is important as it helps us to understand the quality of care you received and allows hospitals to see where they need to improve.

The survey is easiest to complete online. Please visit the web address below (or scan the QR code) and log in with the following username and password. It is possible to partially complete the survey online and then return to it later to complete the remainder.



Web address: survey.ipsos.com.au/patientsurvey

Username: [INS_UNAME]

Password: [INS_PWORD]

If you prefer to complete the attached paper survey, please use the included reply-paid envelope to mail it back to us.

Taking part in the survey is voluntary. You have been randomly selected to participate and there are many safeguards in place to protect your identity. The hospital staff who cared for you will not know if you have returned a completed survey and will not be able to see your responses to the survey. At no point will we report any information that identifies you as an individual.

The Bureau of Health Information (BHI) runs the survey along with Ipsos Social Research Institute, who is sending you this survey on BHI's behalf. BHI was established by the NSW Government to independently report on the performance of the public health system in NSW, including the healthcare experiences of patients. Results for the NSW Patient Survey are reported in *Healthcare Observer*, found on our website www.bhi.nsw.gov.au

If you have any queries regarding the survey, please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm).

Thank you for taking part in the survey.

Yours sincerely

Jean-Frédéric Lévesque
Chief Executive
Bureau of Health Information

