



Ipsos
Social Research Institute

Development Report:

2014 Admitted Children and Young Patients Survey

A report prepared for the Bureau of Health Information

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TABLE OF CONTENTS

1. Introduction	1
2. Methodology	3
3. Findings	11
3.1 Rapid review of key literature	11
3.2 Children and young patient focus groups	22
3.3 Stakeholder engagement	34
3.4 Statistical analysis of previous surveys	49
4. Questionnaire development	55

1. INTRODUCTION

The NSW Patient Survey Program (the Survey Program) is a suite of surveys that collects information on the experiences of patients receiving care in public hospitals and other public healthcare facilities across New South Wales (NSW). The purpose of the Survey Program, which commenced in 2007, is to report on patients' experiences and perceptions of care in NSW public hospitals and public healthcare facilities so that:

- Hospital performances are readily available to the general public; and
- Health services and policy makers can identify strengths and opportunities for improvement, to assist them to provide safe, quality care.

The following principles underpin the Survey Program:

- Participation is voluntary
- Confidentiality of patients' personal information is assured
- Questionnaires are informed by evidence
- Information collected is reliable, comparable and relevant
- Reporting methods are open and transparent
- Information reported is impartial, easily understood and useful.

The Bureau of Health Information (BHI) currently manages the Survey Program. 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. In 2012, Ipsos Social Research Institute (Ipsos SRI) was contracted by NSW Health to develop and administer a new suite of surveys for the Survey Program.

The redevelopment was designed to ensure that the content of the survey and any new surveys are specifically tailored to the NSW healthcare environment (the surveys used from 2007-2011 were originally developed by NRC Picker for use in the United States). Where relevant, the surveys include a set of core, common questions. These core questions have been tested in the Adult Admitted Patient Survey, the first of the suite to be redeveloped, on behalf of the National Health Information Standards and Statistics Committee's Patient Experience Information Development Working Group (PEIDWG).

A program of research informed the development of the Admitted Children and Young Patients Survey (CYPS). The aims and objectives of the research were to ensure that the CYPS adequately captures and provides feedback on the aspects of care that:

- Are relevant to the current policy context
- Are important to NSW patients
- Will be useful to NSW health services and policy makers

This report describes the research process undertaken to develop the CYPS. The first chapters of this report summarise the information collated at each stage of the developmental process, resulting in a list of potential question areas. The final chapter documents how these potential question areas were prioritised and translated into the final surveys. The developmental process coincided with the first review of the Adult Admitted Patient Survey (AAPS) and the results of this are also reflected in the questionnaire design.

The results of the survey will be fed back to the NSW Government and public healthcare facilities to inform service improvement, and released to the public.

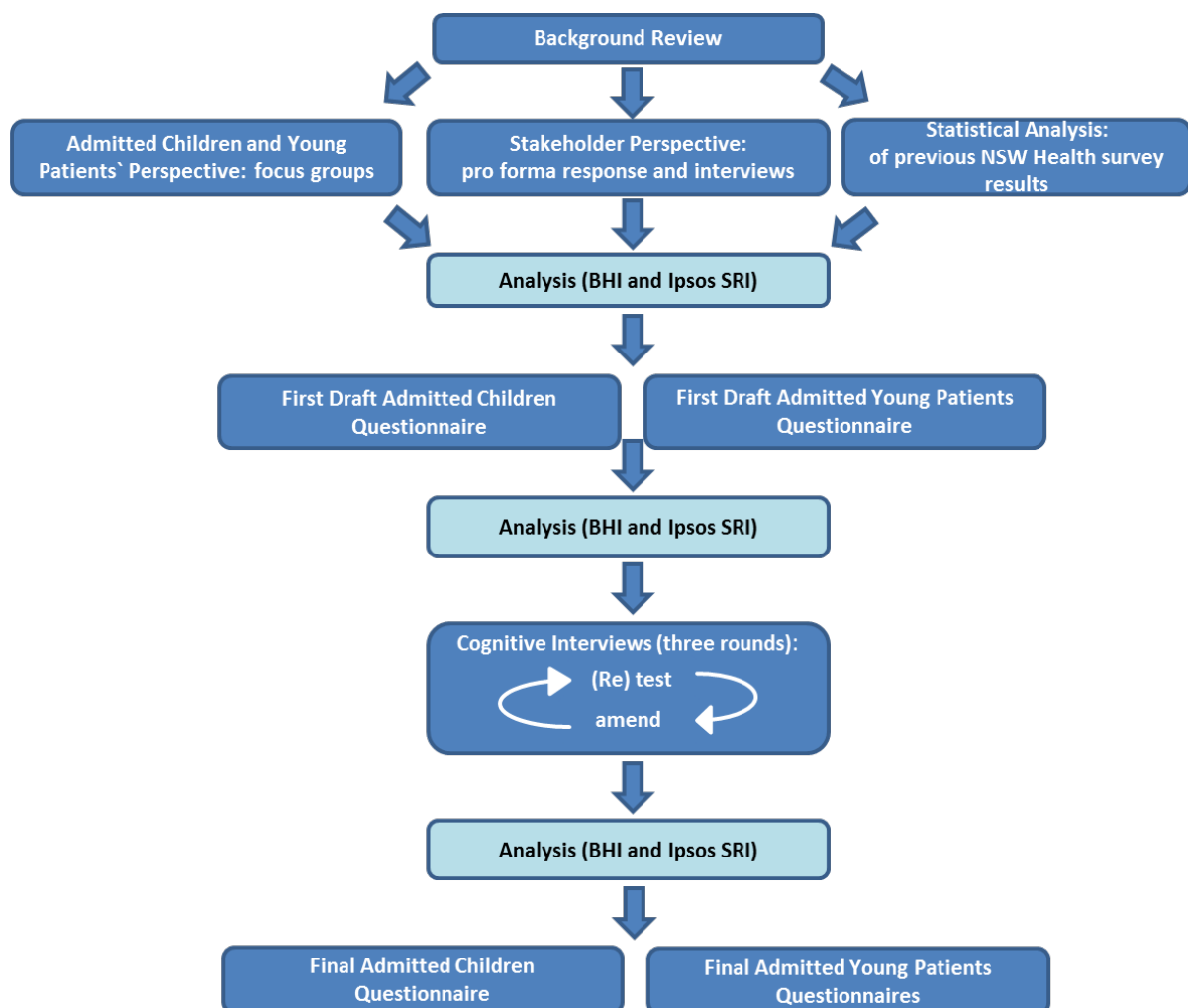
2. METHODOLOGY

The development process comprised:

1. A rapid review of key literature (including policy documents and quality standards)
2. Focus groups with parents of child and young patients
3. Stakeholder engagement
4. Statistical analysis of the 2007-2011 NSW Paediatric Patient Surveys
5. Three rounds of cognitive testing
6. Extensive discussion between the development teams at BHI and Ipsos Social Research Institute (Ipsos SRI).

The following diagram illustrates the questionnaire development process (Figure 1).

Figure 1: Questionnaire development process



Rapid literature review

The rapid literature review was performed to provide context and to broadly inform the content of the CYPS. The aims of the review were as follows:

- 1) Identify and compare the core domains of treatment and care for children and young people;
- 2) Identify the most important current policies and quality standards relevant to the CYPS (taking into account the suitability of the survey as a vehicle for assessment against these policies or standards).
- 3) Briefly describe and compare the format, content and questionnaire-related methodological issues associated with other jurisdictions' child and young patient survey instruments.

In performing this review, the following research questions were addressed.

- What do we know about the child and young person patient experience that may be relevant to developing the CYPS?
- What are the key drivers of the child and young person patient experience identified within other jurisdictions' surveys?
- What are the most important current policies and quality standards relevant to the CYPS?
- What are the core domains of care that are used in other jurisdictions' child and young person surveys?
- What are the key learnings from the literature/other jurisdictions' child and young person surveys in terms of the questionnaire design/format (for example, length or demographic questions included for standardisation purposes)?

In order to achieve the aims of the review and answer these research questions, a search of literature was completed by BHI in order to identify relevant research papers and grey literature. This search was performed on the NSW Health CIAP database. Search terms included combinations of synonyms of three phrases using the Boolean operator "and". Specifically:

- 1) 'patient satisfaction', 'patient experience', 'patient experience surveys', 'child survey', 'questionnaire', 'quality improvement', 'patient views', 'quality of patient care'.

AND

- 2) 'hospital performance', 'hospital benchmarking', 'hospital profiling', 'hospital care'

AND

- 3) 'children', 'p(a)ediatric', 'child'.

The search was restricted to original English-language papers, articles and reviews published in the last decade. Furthermore, BHI provided Ipsos SRI with key NSW and National policy documents and standards for healthcare for inclusion in the review.

These sources were synthesised to form the basis for the rapid literature review.

Patient focus groups

Patient focus groups were conducted in order to understand the range of experience of admitted children and young patients in NSW and, in particular, the aspects that were most important in creating a positive or negative hospital experience from the patient perspective. These topics were then collated with the findings from other phases of the research before being reviewed by BHI and Ipsos SRI for inclusion in the survey.

Four focus group discussions were conducted with parents of children who had been admitted to a NSW public hospital within the previous 12 months (40 in total), using a quota controlled sampling strategy to allow for a range of patients' views. Two of these groups (groups 1 and 2) were conducted as part of the development work for the Emergency Department Patient Survey (EDPS) and a further two (groups 3 and 4) were conducted specifically for the CYPS. The focus group composition consisted of a mix of metropolitan and non-metropolitan areas, parent and child age groups and planned and emergency admissions. More information about the composition of the groups is appended (Appendix A). The groups among parents of children attending the Emergency Department were conducted between 23 January and 24 January 2013, and those among parents of non-emergency admitted children were conducted between 16 July and 17 July 2013.

In addition to the focus groups, six in-depth interviews were conducted with young people aged between 14 and 17, living in Sydney, who had been admitted to hospital in the previous 12 months. These interviews were conducted between 16-18 July 2013. Where a parent was present during the interview, they occasionally offered their own perspective or additional details, but the discussions were primarily focused on the experience of the young person themselves.

A discussion guide was developed to ensure that key stages in the patient journey were discussed; from the mode of arrival, through treatment, to discharge. Following a discussion around the stages of the patient experience, participants were asked to develop a set of cards, each describing an aspect of hospital patient care, and, as a group, rank them in order of importance. The main purpose of this exercise was to observe the discussion and debate during and after this exercise to help understand what was important to patients, and why. Both the discussion guide used in the focus groups with parents of children attending the Emergency Department, and that used in the focus groups among parents of non-emergency admitted children are appended (Appendices B and C). Each group was audio recorded and transcribed in order to facilitate analysis and to provide verbatim comments.

An analysis session, involving all of the Ipsos SRI group moderators, was conducted to establish common themes and points of difference between the four groups and six in-depth interviews. This was followed by further analysis of moderator notes to provide a summary of the elements of the patient experience considered most important from the patient perspective.

Stakeholder engagement

A range of key stakeholders were consulted on topics for inclusion in the CYPS. This included issues such as informing service improvement and providing supporting evidence of compliance with quality standards and guidelines.

The key stakeholder distribution list was compiled by BHI and included representatives from 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).

These stakeholders were invited by BHI to suggest areas for inclusion in the CYPS by submitting a pro forma response. The pro forma contained the following fields: aspect of care or question topic; reason for interest in this area; whether the question applied to a sub-set of patients; how the data would be used; and suggested question phrasing (see Appendix D). The pro forma was distributed in June 2013 and was completed by 22 contributors.

A smaller subset of stakeholders was then selected to take part in a follow-up telephone interview. These stakeholders were selected because: further detail/clarification of their responses to the pro-forma was required; a new/unexpected area was suggested; they did not return a pro forma; or their area of specialisation was of particular relevance. A total of seven interviews were conducted by Ipsos SRI, involving 12 participants. The interviews were structured around a discussion guide, designed in close consultation with BHI (the guide can be found in Appendix E). Interviews were audio recorded (with participants' permission), and summary notes were written up for each. The contact email is appended (Appendix F).

Ipsos SRI reviewed the interview notes and conducted an analysis session to identify common themes and points of difference across interviews. The findings were then analysed alongside pro forma responses. Relevance to patients and information on how the data would be used were both taken into account during the subsequent prioritisation process and questionnaire design.

The question areas indicated by the stakeholder consultation were eventually collated with those identified from the other developmental phases of the research to create a comprehensive list of

potential question areas for the CYPS, which took into account the perspective of both patients, parents/carers of patients and stakeholders.

References to stakeholders within this report refer to ideas and comments put forward by one or more of the consulted stakeholders, but are not necessarily the views of all, or a majority, of stakeholders.

Statistical analysis of previous surveys

Survey results from the 2007-2011 NSW Paediatric Patient Surveys (when the survey was run by the NSW Ministry of Health), were analysed using:

- Factor and reliability analysis, to identify which factors accounted for much of the variance across the patient groups, again indicating that these areas should be prioritised for inclusion in the survey. This analysis was also used to establish whether certain factors were of more or less significance to particular groups. The reliability analysis involved the identification of highly correlated questions, to indicate where two questions were likely to be measuring the same underlying issue and could therefore be combined or removed.
- Analysis of non-response and possible ceiling and floor effects, to suggest question areas that may be less useful for informing service improvement and/or where particularly careful consideration should be given to questionnaire routing, question wording and response scales.
- Analysis of respondent comments relating to the survey itself, taken from the free-text survey question, to identify any issues that should be addressed in the new survey.

Further details are provided below and full technical details can be found in Appendix G.

Factor and reliability analysis

Filters were created for each patient group to ensure that each round of factor analysis only comprised a homogenous group of patients who had filled out the same sections of the Paediatric Patient surveys.

Consequently, the groups included in analysis comprised:

- 'general' patients (i.e. those who had filled out the 'pain' or 'test' sections);
- 'pain' pain (i.e. those who had filled out the 'pain' section but not the 'test' section); and
- 'test' patients (i.e. those who had filled out the 'test' section but not the 'pain' section).

Missing values were identified and populated for each of the patient groups using either modes (for scales with few response options) or means (for scales with more response options, or for scales

where variance in responses was greater). Question scales were then standardized by allocating each response option a value between zero and 100 in equal increments, where zero represented the poorest level of performance and 100 represented the highest level of performance.

Principal Components Analyses were performed for each of the filtered participant groups using Varimax rotation to maximise the differences between factors. Questions that contributed to the variance of several factors were removed from the analyses to ensure meaningful factors. Factors were then analysed and named to represent the range of questions that they encompassed.

Following the identification of factors, the reliability and the pattern of inter-item association of their components were examined using Cronbach's alpha and correlation matrices.

Non-response analysis

The survey results from the 2007-2011 Paediatric Patient Surveys were analysed to identify patterns of non-response in the data. These data were analysed using the filters for each question to identify the valid rates of non-response.

Ceiling and floor effects

The 2007-2011 Paediatric Patient Surveys were also analysed to identify questions that identified possible ceiling and floor effects.

A ceiling effect is present for a measurement variable when the majority of scores are at or close to the highest possible score, indicating a loss of sensitivity in the upper register. Conversely, a floor effect is present when the majority of scores are at or close to the lowest possible score.

In order to determine the occurrence of true ceiling or floor effects, several criteria were used. These criteria comprised: a sufficiently small standard deviation (25 or less), a skewness statistic exceeding 1.5 or below -1.5, and a mean greater than 85 or less than 15. These criteria represent characteristics of a probability distribution that exhibits a ceiling or floor effect. The skewness statistic, in particular, has been demonstrated as a robust measure of test score ceiling and floor severity.

Dichotomous variables were excluded from the analysis because of the inherent response constraints of these questions.

Patient comment analysis

The Paediatric Patient Surveys included a free-text question – "If you could change one thing about the hospital, what would it be?"

Comments made by survey respondents were entered into a data file and coded into themes. This analysis was used as an additional indicator of the aspects of the paediatric patient experience that were most important to respondents. More importantly, all comments coded as 'other mentions' and/or containing the keyword 'survey' were manually reviewed for content relating to the conduct of the survey.

Cognitive interviews

Three rounds of cognitive interviews were conducted with NSW paediatric patients and/or their parents/carers in order to investigate how they interpreted and responded to the survey questions. This was performed to: ensure questionnaire validity (i.e. that questions were understood, consistently interpreted and measured what they were intended to measure); ensure that respondents were able to follow the questionnaire routing instructions; ensure that they understood the cover letter; and as a final opportunity to confirm that individual questions were relevant to the respondents and that no crucial question areas were missing (from the respondent's perspective).

The first two rounds of interviews were conducted to test the questionnaire content. Questions were identified as problematic in these interviews were redrafted and presented to patients in the subsequent round of the cognitive interviews, or removed altogether. The final round of cognitive interviews was conducted primarily to test the layout of the printed survey and other materials to be sent with the survey (i.e. accompanying letter and language information sheet).

The interviews were conducted among a wide range of paediatric patients and their parents/carers from across the greater Sydney area. Quotas were set to ensure representation of a range of participants in terms of age, gender, background (including culturally and linguistically diverse patients), and hospital stay (admission type and length of stay).

A total of 30 cognitive interviews were conducted. The first round took place between 9-10 October 2013; the second round between 18 November – 3 December 2013; and the third round between 14-28 March 2014. The profile of participants in each round can be found in Appendix H.

Each interview was audio recorded and cover notes were prepared by Ipsos SRI consultants to facilitate analysis. The discussion guides used in the cognitive interviews can be found in Appendix I.

Analysis sessions involving Ipsos SRI and BHI

Throughout the development process, BHI and Ipsos teams were in regular contact. This involved ad-hoc discussions, as well as series of meetings held at the key stages of the development, including after:

- Completion of the patient focus groups and stakeholder interviews
- Each round of cognitive testing
- Each substantial redraft of the survey

At each meeting, survey inclusions and exclusions were discussed, with decisions made in light of the results of the development components, BHI's expert knowledge of the NSW healthcare system, data analysis and reporting needs and Ipsos SRI's research expertise. Further, upon the drafting of the penultimate version of the survey, the survey was presented to BHI's Strategic Advisory Committee for final review. Feedback from the committee was subsequently incorporated into the final version of the survey.

3. FINDINGS

3.1 Rapid review of key literature

Health systems across the world are widely integrating 'patient-centred' approaches into their delivery of care. 'Patient-centred' approaches are aimed at providing care that is suited to (and based around) the needs, values and priorities of the variety of patients that present at hospitals and health facilities.⁽¹⁾ Inherent in this definition of 'patient-centred care' is the necessity for dialogue between hospitals and patients: it is impossible to understand and subsequently respond to the needs of patients without first being able to define them. One of the components of this dialogue is often patient surveys (encompassing both patient experience and patient satisfaction surveys), which are used in combination with other supplementary sources of data, such as complaint receipt mechanisms and qualitative methods such as focus groups and/or interviews.^(2, 3) These methods are primarily used to gauge patients' level of satisfaction with their hospital care; measure hospital quality; provide feedback to facilities on the quality of care from the patients' perspectives; and clarify areas in which health care can be improved both in a specific facility or a wider geographic area.^(4, 5)

However, the views of children and young people have not been exclusively sought in national health surveys in a comprehensive manner.⁽⁶⁾ This is important as young people have been shown to rate their inpatient care significantly lower than adults across several domains of care and often their perceptions differ to that of their parents.^(7, 8) Hence studies have supported directly surveying children with the appropriate tool.^(7, 9)

Child and young person's perception and experience of care

Not only do children and young people experience illness and hospitalisation differently to adults, but they are also more vulnerable, due to their developmental immaturity, which leaves them disempowered and relatively dependant on their parents/carers. This level of dependence alters as emotional and developmental maturity progresses. Nevertheless, parents or carers are involved in the decision making for those in their care. However, it is commonly recognised that children and young people need to be more involved in decision making concerning their healthcare – according to their developmental capabilities and maturity. In recent years there has been an emphasis placed on children and young people to be included in patient experience surveys, in order to improve the health outcomes of this population.^(6, 10-12) The following areas of this review identify key aspects of care that may be appropriate to explore in the CYPS.

Age-appropriateness

Levels of communication by health care professionals to the child must be suited to the developmental age of the patient. Younger patients (generally 12 years and younger) have differing needs to adolescents and young patients and prefer their parents to communicate to health care professionals on their behalf.⁽¹³⁾ Contrasting with this, teenagers prefer to communicate their needs and options to health care professionals themselves.

Differences between developmental age-groups are also apparent regarding the availability of age-appropriate activities for the patient to complete when in hospital. Whereas younger patients reported favourably upon the hospital facilities available to them, such as a play room, school activities and computers, 10-12 year olds reported that they were bored.^(14, 15)

As part of the care provided, consideration should also be given to placing similarly aged patients together and to provide adolescents / young patients with specific areas for privacy or social networking.⁽¹⁶⁾ Food and noisiness on the ward were also reported by young patients to be important issues to them whilst in hospital.

Family-centred care

Family-centred care (FCC) is viewed as a partnership approach to health care, where health care providers see the family of the patient as partners-in-their-care.⁽¹⁷⁾ Hence the consideration of the care and the outcomes are given to the entire family not just the child under care. Aspects of FCC include:

- *Information sharing;*
- *Respecting differences (cultural, linguistic, diversity);*
- *Collaboration between health care providers and family;*
- *Negotiation and*
- *Care in context of child's family and community (school, education, social activity groups).*

Parents report that FCC works optimally when a nurse is present during the doctor's rounds and when the family is introduced and involved in all discussions concerning the child's care. It is further enhanced where medical terminology is avoided or alternatively, where it is comprehensively explained.

Therefore, even though the presence of parents or carers near the child is viewed as an important aspect of care to the child, particularly with younger children,⁽¹³⁻¹⁵⁾ comprehensive patient-centred care is enhanced where the patient and their family are involved in the care decisions made.

Parents report being satisfied with the nursing care provided to their child but the nurses were limited in time to answer all of their questions.⁽¹⁴⁾ Other negatives reported by parents in having a

child hospitalised included the financial costs of staying in hospital with the child – such as for meals, transport or parking, telephone calls, purchasing items to keep the child occupied; the noisiness of the ward affecting sleep; waiting time for child’s medication; and not being provided with enough information about the child’s condition and diagnosis.^(14, 16)

Transitional Care

The medical, psychosocial and educational needs of adolescents as they move from child to adult care also require attention.⁽¹⁸⁻²⁰⁾ Coordination and communication between providers in the transitional care process requires improvement with requirement for health care professionals to be honest, respectful, provide information and attention.⁽²⁰⁻²²⁾ Adolescents were also more critical of their health care professional than their parents.⁽²⁰⁾

The physical environment (decorating, furnishings) of general (non-paediatric) waiting areas and wards are also viewed as more threatening by adolescents.^(22, 23) Adolescents with chronic conditions also rely heavily on parents for their care management – such as for scheduling appointments and contacting practitioners⁽²³⁾ and often responsibility for self-care by the adolescent is lacking with parents also having difficulty letting children take control of their care.

Paediatric ED and outpatient experience

The importance of family centred care in the emergency department (ED) has also been reported, with particular attention required for patient respect and dignity, effective communication, the involvement of the family for their best interests and collaboration in the delivery of care.⁽²⁴⁾ The authors stated the importance of having a family member present with the child in the waiting and treatment areas of the ED. This is especially true for children with special needs or chronic conditions in order to reduce the amount of stress felt by the child or young patient in such an environment.

Further emphasis was placed on the need for the information provided to the patient to be adequate for the child’s and parents’ needs, as this is a significant factor correlated to both child and parent satisfaction.⁽²⁵⁾ For parents, a high-level of physician interaction with them was also related to their level of satisfaction with the ED.

In the paediatric outpatient setting, positive reports have been given for the cleanliness of the clinics and the overall ratings of care.⁽²⁶⁾ However, information provision about the waiting times and pre-appointment were poor, with information concerning medication and their potential side-effects lacking. Nearly double the proportion of children (63%) compared to their parents (35%) reported that there were not enough age-appropriate activities to keep them occupied whilst waiting. Similarly, double the proportion of children (25%) compared with their parents reported that they were not given enough privacy during their examination. One-third of children responded

that they did not understand the information provided by their doctor and a third felt that they were not fully involved in decisions made about their care during their appointment.

Quick word on Vulnerable Groups

Special attention on patient- and family-centred care must be paid to children and young people who are considered vulnerable either due to disability, learning difficulties, chronic illness, those in care, young offenders or asylum seekers.⁽¹⁰⁾

Children with speech, language or communication deficits are particularly prone to having limited understanding of their treatment and may suffer from a lack of communication with health care professionals.

Additional stress may be felt by children and young people with chronic illness due to the length of time spent in hospital, extra time spent away from family, friends and social networks, limited recreational opportunities and pain and anxiety caused from their illness. Transition planning into adult care also appears to be lacking in this group of children and adolescents.⁽²²⁾ Similar to their less-vulnerable peers, this often leaves the young person unsure of whom to seek for assistance and how to access care in this 'different world' which is often viewed by them as threatening and gloomy in comparison to the children's ward.

Key drivers of paediatric patient experience

Empirical research also often examines the key drivers of patient satisfaction. Key drivers are questions or question areas that are the most highly associated with, or have the largest effect upon, patients' satisfaction with their care and therefore should be included in the CYPS.

From the academic literature in this review, the demonstrated key drivers of paediatric patient experience were as follows:

- Child and parent / carer being informed
- Given information and explanations in a way which is understood (i.e. health literacy with precautions as appropriate for CALD patients and lower socio-economic status groups). Special consideration should be given to children who are vulnerable to ensure their care needs are understood, particularly if they lack an advocate
- Child and parent / carer being involved in decision making
- Having family present, and appropriate facilities available to them
- Age-relevant activities (for recreation and education) being available
- Privacy (for adolescents / young people)
- Food – appeal to different age-groups; nutritional
- Noise levels on the wards
- Transitional care, for young people in particular as they move towards adult care.

Policy and standards documents related to the development of the CYPS

Patient surveys are also increasingly becoming embedded in legislation and government policy both in Australia and overseas⁽²⁷⁾, and are often used to ensure that standards of care – including adherence to clinical guidelines⁽²⁸⁾ - are being met over time. In order to confirm that the CYPS includes questions relevant to Australian and NSW policy and standards documents, the documentation around the following were consulted.

Standards for the care of children and adolescents in health services⁽²⁹⁾

These standards were developed with the primary goal of ensuring that quality care is provided to a child or adolescent in an environment that is safe and appropriate to their age.⁽²⁹⁾ They were developed by an expert multidisciplinary group under the auspices of the Royal Australasian College of Physicians - Paediatrics and Child Health Division, the Association of the Wellbeing of Children in Healthcare and the Children's Hospital Australasia.

Specifically the Standards cover:

The Rights of children and adolescents:

Essentially the rights of children and adolescents must be upheld at all times and children and their families must be treated with respect and dignity, and be shown sensitivity. This includes respect for culturally and linguistically diverse populations and maintaining patient privacy. Special needs of patients must be respected and patients and their families must be consulted and kept informed about the care received. Patients and their parents / carers must be involved in the decision making concerning the health of the child. Adolescents who are mature enough have the right to make decisions regarding their own health and to have their privacy protected from their own parents / carers.

The Facilities (physical environment) in which care takes place:

Care must take place in a safe and physically appropriate environment, including design, furnishings and decoration that meet the needs of the patient and their developmental age. Hence needs of younger and older children and adolescents should be met with age-appropriateness for safety, sound, bathroom, play and education facilities, social networking and entertainment.

Facilities for parents / carers must also be provided, as having a parent close by reduces stress for both the child and the parent/carer. Such facilities may include a lounge or fold out bed in the ward, kitchenette facilities, family room or accommodation for the family unit.

Adult patients should not be accommodated in child / adolescent areas and vice versa. Ideally adolescents should be accommodated with adolescents.

The Equipment utilised in care:

Equipment used for children and adolescents must be designed to meet their needs for size and developmental age. This includes medical, resuscitation and diagnostic equipment and bedding, play and entertainment equipment.

The Staff attending to the healthcare of the child / adolescent:

Staff must be specially trained to meet the physical, psychosocial, developmental, cultural and communication needs of children and adolescents. All staff must also pass a 'working with children' check and be trained in paediatric life support and additionally clinical staff must be trained in paediatric pain management.

Charter on the rights of children and young people in healthcare services in Australia

The Charter was developed by Children's Hospital Australasia and the Association for the Wellbeing of Children in Healthcare, and sought to find positive approaches in the implementation of rights of children and young people in healthcare services.⁽³⁰⁾

The Charter reflects the rights of children and adolescents as described in the Standards (below). Every child and young person has a right to:

- *consideration of their best interests as the primary concern of all involved*
- *express their views and to be heard and taken seriously*
- *the highest attainable standard of health care*
- *respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and contexts*
- *be nurtured by their parents and family and to have family relationships supported by the (health) service in which the child or young person is receiving healthcare*
- *information, in a form that is understandable to them*
- *participate in decision-making and as appropriate to their capabilities, to make decisions about their care*
- *be kept safe from all forms of harm*
- *have their privacy respected*
- *participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability*
- *continuity of healthcare, including well-planned care that takes them beyond the paediatric context.*

Caring Together – the Health Action Plan for NSW

The Health Action Plan for NSW is another prominent document that seeks to ensure patient-centred care in NSW. The plan was created in response to the recommendations made by the Inquiry into Acute Care Services in NSW Hospitals (also known as the Garling Report⁽³¹⁾), and was informed by an extensive consultation process with key stakeholders. In order to facilitate better experience of care for patients, the report outlines six strategies for improving healthcare. The strategies relevant to the formulation of survey questions include:

- Creating better experiences for patients (including establishing the new role of nurse/midwife in charge; familiarising patients with staff names; protecting patient dignity; hygiene; patient transport; and improving the emergency experience)
- Safety (enhancing ward handovers; improving transfer of care; proactive response to patients' deterioration; supervision of junior staff)⁽³²⁾

Independent Panel – Final Progress Report on the Implementation of the Government's Response to the Special Commission of Inquiry into Acute Care Services in NSW Hospitals (the Progress Report)

Due to the imperative nature of the recommendations outlined in the Garling Report, an independent panel was contracted to investigate the progress and development of hospitals in NSW following the dissemination of the Plan. The Independent Final Progress Report documents action taken to address the concerns and recommendations articulated in the Garling Report. In addition, achievements and recommendations for the future are outlined. Amongst these recommendations are actions and procedures to be performed by medical staff that could be observed by children, young people and their families in their care. Specifically:

- Patient safety and quality (including medication safety and hand hygiene/infection prevention)
- Communication and patient experience (bedside handover, staff identification, dissemination of discharge information forms, compliance with communications mechanisms such as name badges and single-gender wards).⁽³³⁾

Other policy and standard documents

The development process also consulted other relevant policy and standards documents including the National Safety and Quality Health Service Standards and the Australian Safety and Quality Framework for Health Care. These documents contributed to the complete list of potential question areas to be assembled prior to the drafting of the survey. For clarification on the question areas derived from these documents, please refer to the Adult Admitted Patient Survey Development Report (http://www.bhi.nsw.gov.au/nsw_patient_survey_program).

Core domains of care in other jurisdictions' paediatric surveys

As previously mentioned the views from patients aged 16 years and under themselves have not extensively been sought but have been recommended for future processes. The NHS provide separate surveys for admitted patients aged <8 years (for parents / carers to complete on behalf of the child) and those aged 8-17 years to complete (with assistance from their parents / carers if required). Although the contexts of the surveys are the same, the language is slightly different with the questionnaire for the older cohort also employing pictorial prompts.

One of the few jurisdictions to specifically ask the patient experience views of the child themselves was the Urgent and Emergency Care survey produced by the Royal College of Paediatrics and Child Health in partnership with the Picker Institute Europe. This was developed using a robust method of conducting a full literature review, children and parent focus groups and cognitive testing of the draft survey before piloting commenced.⁽³⁴⁾ Children 8 years of age and older completed the survey themselves (with help if necessary); children younger than 8 years was slightly different in format and parents or carers completed.

Similarly, the Cincinnati Children's hospital developed the Child Well-Being Survey to measure patient experience of care provided during the overnight hospital stay at Cincinnati Children's (via CATI). Views on outpatient experience from a young patient and parent perspective have also been developed, tested and mailed-out by the NHS.⁽²⁶⁾

The previous NSW Paediatric Survey used the NRC Picker Paediatric tool where the questions are formulated as to seek parents / carers responses on behalf of the child.

Table 1: Domains of care covered in Paediatric Surveys:

	NRC Picker Survey	NHS Parents (for patients 0-7 years) Survey	NHS Young Patients 8-17yrs	Cincinnati Children's	PIE - Child/Parent ED Survey
Planned visit	✓✓	✓	✓		
Hospital ward	✓	✓✓	✓✓	✓	✓
Hospital food	✓	✓✓	✓✓		
Doctors	✓✓	✓✓	✓✓	✓✓	✓✓
Nurses	✓✓	✓✓	✓✓	✓✓	✓
Care and treatment	✓✓	✓✓	✓✓	✓	✓
Facilities for parents		✓✓			
Pain	✓✓	✓✓	✓✓		
Operations	✓✓	✓✓	✓✓		
Leaving hospital	✓✓	✓✓	✓✓	✓	✓
Demographics of child	✓✓	✓✓	✓✓		✓



Addressed in a domain



Addressed partially

Key learnings from research and other jurisdictions' paediatric surveys

Aside from questions and question areas, research into patient satisfaction and the use of surveys has yielded other findings useful for the: design of the Survey; distribution of the survey; collation of findings; and presentation of results.

Design of survey

The following design approaches and/or recommendations from the research literature were taken into consideration in the design of the survey.

Statistical analysis performed on the Picker Patient Experience questionnaire (for adults) - as well as its abridged version, the PPE-15 - has yielded results that indicate that the length of survey (up to 12 pages) does not impact upon patients' response rate.⁽³⁵⁾ Further, this research suggests that the quality of the data (in terms of item completion, patient attrition and internal consistency) is not compromised by the length of an instrument. No research has been provided regarding participation rates and survey length in the paediatric setting.

However questions in the Survey should primarily seek to examine patients' experiences, rather than their satisfaction or perception of performance. The rationale for this approach is that questions that ask patients about their level of satisfaction with their care tend to elicit positive responses, and are consequently unable to adequately distinguish between variable clinician and

practice performance.^(36, 37) Such responses are not useful for the generation of actionable plans aimed at improving hospitals' services and patient satisfaction. However, despite the general use of experience questions, the Survey should include one or more overarching questions examining the extent of patients' satisfaction with their care, or aspects of their care. The inclusion of these satisfaction questions is recommended by the Care Quality Commission because of these questions' amenability to key driver analysis.⁽³⁸⁾

If separate surveys are to be distributed to those aged <8 years and 8 years and over, the design of the survey for young children may also wish to add characters, pictures or faces (such as using a visual analogue scale) to help communicate with and relate to children.

Distribution of the survey

Research has demonstrated that consideration of the timing of the distribution of patient surveys is important to their success. According to Bjertnaes, a level of bias is introduced when patients are distributed surveys long after their discharge, with ratings on certain scales decreasing over time.⁽³⁹⁾ However, evidence for the effect of delays on patients' responses to satisfaction/experience surveys is far from unequivocal: other research has indicated that responses are more positive as time elapses in patients whose acute problem has resolved.⁽⁴⁰⁾ Hence, it is recommended that the timing of survey distribution is considered by the survey sampling methods working group to be between one and three months post-discharge. Further consideration should be given to the design and distribution of separate surveys for those aged <8 years and those aged 8-17 years (similar to that undertaken by the NHS).

It is also important to be aware of any effects of survey medium upon patient responses. Until recently, it was thought that mail surveys introduce an element of non-response bias into survey results, because only those patients who have had a particularly bad or good experience tend to respond.⁽⁴¹⁾ However, research performed by the NHS has indicated that this may not be the case, as patients' results of national web-based surveys were highly correlated with results on more traditional paper based surveys.⁽⁴²⁾

Collation and presentation

The literature also provides insights on what to expect in the collation of responses, and methods for the presentation of data.

According to research, the response rates for general mailed surveys range between 25-40%.^(41, 43) Typically, response rates for internet patient experience surveys are lower⁽⁴⁴⁾; however, when used in conjunction with mail surveys, evidence suggests that the response rate may be augmented.⁽⁴⁵⁾ Hence, for the CYPS the approach will be a combination of mail and internet surveys.

Research also provides guidance with regard to the presentation of survey results. The Care Quality Commission/NHS in the United Kingdom collates and disseminates results at a trust level (the UK equivalent of Local Health Districts).⁽⁴⁶⁾ This mode of presentation allows comparison between different regions in order to highlight their areas of strengths and weaknesses. Hence, the survey should be designed to allow reporting at LHD level (or by facility where permissible).

Summary – implications for the design of the CYPs

In addition to the key factors for consideration as highlighted by the rapid literature review, the development of the CYPs reflects the standards for the care of children and adolescents in health services, the Charter on the rights of children and young people in healthcare services and the Health Action Plan. For reiteration, this includes the:

- Rights of the patient and family to be upheld, including patient privacy being maintained, patients and their families being well-informed and involved in decision-making processes and patients and their families being treated with respect and dignity with appropriateness given to cultural or linguistic diversity
- Physical environment of care is age-appropriate for the patient and sufficient facilities are provided to parents / carers
- Patient's views and that of their family are heard and taken seriously
- Patient's safety is upheld at all times.

3.2 Admitted Children and Admitted Young Patient Focus Groups

This section summarises the aspects of the patient experience that were most important to the parents and young people who took part in the focus groups and in-depth interviews, and indicates the potential areas for inclusion in the survey.

Key themes were waiting times, communication about processes and next-steps, the availability of age-appropriate activities, the ability of staff to communicate with and reassure nervous children and parents, pain management, the outcome of treatment, staffing levels and a child-friendly environment.

Parents felt that from the perspective of their children the two primary emotions experienced during their visit were fear and boredom, so the provision of activities, a welcoming environment and positive interactions with staff were particularly important to them.

The emergency department

For the parents of children admitted to hospital as an emergency, the time they spent in the ED tended to be particularly prominent in their memory, especially if their child went on to be admitted for only a short period of time.

Upon arrival at the hospital, finding a parking space was problematic; designated spaces were unavailable, a long way from the emergency department, poorly lit, or required payment (when they didn't necessarily have change to hand). Where two parents had accompanied their child, the driver was able to make a drop off outside the ED and then proceed to find a space, but for parents on their own with a sick child, parking was a very stressful experience. Some were prepared to park illegally and risk suffering the consequences later. The cost of parking became a more prominent issue once patients had been admitted.

Patients who arrive at hospital by ambulance are generally very complimentary about the ambulance service, but the parent of one of the young people interviewed recalled that it took a number of hours for their child to arrive at hospital after being picked up by ambulance because he was initially taken to two different facilities. They were anxious during this time because the ambulance service could only tell them that he was in transit during this period.

Parents explained that their child was fearful when they arrived at the ED and that they, as parents, were also worried and trying not to show this for the sake of their child. Ideally, they would have liked some reassurance from the staff upon arrival, but a number found the receptionist, the first person they spoke to, brusque and unfriendly. Participants who had not been to the ED before would also have liked the process explained to them by the receptionist, but the only information they received was where to sit and wait.

Although one of the young people interviewed reported having to wait for around 45 mins to be triaged others were seen immediately, or after only a short wait. A swift assessment was important for parents who did not know how serious their child's condition might be. Some found the triage nurses calm, friendly and reassuring, but others felt that they too were a little 'cold' or 'business-like'. There was agreement that a more empathetic attitude by staff in the ED could help to reduce their child's fear and their own anxiety.

"I thought the nurse in triage was quite business-like, my daughter was very scared, so a bit more of a human approach would have been nice." (parent)

"You don't know what's wrong with your child, they haven't been assessed yet. I felt like throwing up, but you're trying to be strong for your child, so you need them to have a bit of a sense of humour and to be warm...[but] it's because they're tired and over worked, so it's the whole system." (parent)

After triage, some children were taken straight through to the ED treatment area, while others had to wait for a number of hours. The ED waiting room was viewed as an unpleasant and uncomfortable place, and not at all child-friendly. These areas were criticised for being uncomfortable, with no facility for sick children to lie down, and in some cases the room was dirty, smelly or run-down. There was very little in the way of entertainment, perhaps just a single TV and some toys. Opinion was split on the provision of a play area and toys; some parents welcomed this, while others expressed concern that they would be a breeding ground for germs.

Some children had been upset by seeing other patients in obvious pain or with bloody injuries. Parents were also uneasy about their child waiting or being treated in the same area as people who were drunk, on drugs, violent or mentally ill; a particular problem late at night. They felt that a single security guard did not offer adequate protection and that such a tense environment was not appropriate for already frightened children. They would ideally have liked a separate ED waiting and treatment area for children.

*"There were only two shower curtains between this **** and my child". (parent)*

Parents who had to wait for a number of hours sometimes felt a sense of abandonment and would have appreciated updates on how long they might be waiting (even though they understood this would just be an estimate) and for staff to re-asses their child's condition every so often. Where this had happened it made the waiting a little easier.

"Even though they had us waiting for quite a while, they did keep checking up on my daughter, which was extremely important." (parent)

Participants tended to be positive about the doctors and nurses in the ED treatment area in terms of their competence and their communication with parents and children, although parents in one

focus group felt that the doctors could have asked them more questions about their child, as they were most familiar with their child and their symptoms.

Planned admissions

Prior to a planned admission there were frustrations for some in relation to long waiting lists and fees for seeing a specialist, but otherwise the referral process seemed straightforward.

Some of the young people interviewed were nervous about going to hospital, especially for surgery, so they had valued the opportunity to speak to a specialist first about what to expect. One recalled that she had phoned the hospital, to chase the letter confirming the details of her admission. This gave her the chance to ask questions of one of the nurses who ended up caring for her on the ward, which she found reassuring.

One of the young people interviewed was asked to arrive at hospital early in the morning for her procedure, but then had to wait a number of hours in a waiting room – uncertainty about the likely wait time, as well as uncomfortable chairs, nerves and the requirement not to eat or drink made this unpleasant for both her and her parents.

The ward and facilities

The hospital environment seemed particularly important for children and young people adjusting to a new and potentially frightening situation. Some facilities were described by parents in the focus groups and the young people interviewed as modern, airy and attractive, while others were seen as clinical, run-down, morbid and intimidating.

“it was much less advanced than [more modern hospital], everything was rickety and shaky and there was water stained signs in plastic sleeves thumb tacked up on the wall. Hospitals generally have this kind of stark feeling about them. The other hospital is newer and doesn't feel like a hospital, whereas this place I walked in and was like 'oh yes, this is a hospital', it was very clinical and not a very inviting place, there was that kind of box in the corner with the chewed up children toys and a TV in the waiting room not quite loud enough. There was a sense of hostility.” (young person)

It seemed children's hospitals and wards were more likely to be reassuring and welcoming places for children. Participants tend to describe them as bright, light and colourful, with pictures on the walls, toys and staff in colourful uniforms, although this wasn't always the case.

“It was very clean, and very white, I was very impressed – pretty much perfect condition...the children's room had a bit of colour in it, which was nice.” (young person)

On arrival at the ward, the parents of children who had been admitted through the ED felt a sense of certainty that their issue would now be dealt with and relief at having reached a place of relative calm. They also described how their children began to relax upon entering the more child-friendly environment.

"She was happy because there were paintings and it's a kid friendly environment, so she was looking around, and away from all that madness downstairs." (parent)

However, parents also felt that their child's emotions inevitably shifted from fear to boredom during their stay. It seemed a children's ward typically provided bedside TVs, games consoles and some sort of play area with toys. Parents would have ideally liked there to be more 'non-screen' and sociable activities available for stays longer than a few hours. Some had been to facilities with an on-site school or activities provided, which was cited as a great idea, although they were not always available, for example during school holidays.

Parents and young people also suggested that there was a shortage of age-appropriate entertainment facilities for older children and teenagers in particular. For example, the available TV programs, films, computer games and toys tended to be aimed at younger children.

"Perhaps for the adolescent kids a section on the DVD players for older kids' movies, like MA15+, maybe a central room with a games console for older children and younger children to play different things." (young person)

The young people interviewed, described feeling a little out of place on a ward with childish toys and pictures, especially if most of the other children were much younger than them. A couple of the older teenagers thought an adult ward would have been more suitable, while others were happy enough to be on the children's ward, even if they did feel a bit 'silly'.

"I felt almost silly being there [in the children's ward], but [still] felt better to be there than in a room full of adults and older people ... the colour scheme was a little bit childish maybe, there were toys and things that were for children that were 8 years old and under, there wasn't really anything for me to do, the TV was fine, but could only get 3 channels, one was a pregnancy channel and I just remember turning it off in the end..." (young person)

"Above the age of maybe even 15 it's too old to be in the kids ward, which is for babies and the young kids that have fallen, so it's really noisy and when you get a bit older, it's a bit like 'what am I doing here'. I was the oldest by about 4 years'. The adult ward would have been fine and opened up a bed in a ward for a kid." (young person)

The parents of children of all ages were quite adamant that they were better off on the children's ward, where staff were used to caring for children and there was perceived to be slightly higher staff to patient ratios.

"The staff at the children's hospital are different, they've got a different mentality about dealing with children I suppose." (parent)

"I guess they're used to dealing with kids being scared, and they have to help them and tell them it won't be that bad." (young person)

Privacy did not seem to be a crucial issue for younger children, but this became more important for older children. Noisy children and visitors sometimes annoyed parents and older children, especially when they were admitted during the night. Parents felt the number of visitors at any one time should be limited.

Although the quality of food provided to children in hospital was not regarded as crucial in comparison to some of the other issues, especially as parents seemed to have the option to purchase food for their children elsewhere, participants pointed out that the food tended to be unappealing and that an appetising meal can provide something to look forward to when in hospital, so the quality of food would likely become more important the longer the stay.

"Every night I had to have soup, jelly and juice. I didn't want to have that stuff. It was boring...it didn't even taste nice." (Young person)

Cleanliness and hygiene practices such as hand-washing were also not generally raised as key issues in the interviews or focus groups. However, upon prompting it became clear that cleanliness was expected and to some extent taken for granted.

Interaction with staff

Interactions with hospital staff were absolutely fundamental to the experience of being in hospital, for both parents and young people.

Staff working on children's wards or in children's hospitals were, on the whole, praised for understanding the needs of children and young people. They were described as friendly, caring and patient. They tried to put children at ease by talking to them and letting them adjust to their new surroundings, rather than rushing into treating or examining them. For example, one parent described how impressed he had been that staff had recognised that his young child would be distressed by being made to sit on a bed or in a chair, so they worked around this, with her remaining sat on his lap. They also let her play with the stethoscope and other equipment.

"My little one was quite nervous and she would actively snuggle in and cling to us, and he (the Doctor) was happy to look at her and treat her while she was

there and it was really helpful ... so he went about his business did it at a pace that she could manage ... he was accommodating, he let her play with his stethoscope ... he was really able to deal with her nerves, and make her comfortable." (parent)

"I'd say I was quite well looked after, because it felt like they were caring about everything rather than just wanting to get it over and done with." (young person)

Some found doctors, specialists and surgeons less approachable, but others were equally positive about them as they were about the nurses.

"The information back from the doctors; they were very informative, they let us know step by step exactly what was going on, where they thought it would end up and they would only release her when they were 100% sure she was ok to go. I was very impressed with the doctors." (parent)

"[The doctor] was really lovely, explained who she was, what kind of work she did, explained that she was the doctor, explained that she would look after me...first she asked me how I was feeling, rather than getting straight into it, or telling me what I had to do, so it was quite calming." (young person)

It was important for children to be asked about their worries and fears, and for them to feel comfortable enough to discuss them. Some were very concerned about particular issues, a number of which may not have been anticipated by adults. Examples included being worried about taking 'drugs' (pain medication) and being afraid of what wounds would look like once the dressing was removed.

"You always feel more content and at ease if someone's told you exactly what's going to happen, what's happened to you, if you're going to be ok, you want some reassurance, that reassurance was really nice, I think that's quite important for people my age, you get quite worried and flustered, so that was really nice that they were very reassuring." (young person)

"When you're a young person the prospect of somebody putting you unconscious and cutting you open is very daunting." (young person)

Participants were often very positive about the ability of staff to communicate effectively with children and young people, as well as parents. They seemed skilled at engaging children of all ages, making sure they understood as much as possible about what was happening to them and what would happen next, even when most of the detailed information was necessarily directed at the parents of younger children.

"They were reassuring for my daughter and informative for us." (parent)

However, some doctors' and nurses' inability to speak fluent English was raised as an issue by participants in one group.

The young people interviewed appreciated staff speaking directly to them, as well as their parents, giving them the chance to ask questions and making sure they were actively involved in decisions about their care.

"...they were asking me questions, like whether I'd prefer local or general anaesthetic, and I didn't want to have local anaesthetic." (young person).

"They even told me the flavour of the anaesthetic I would be under!" (young person)

"...them putting it into more simple language, less medical language, that was nice of her to speak directly to me rather than a parent because she could tell that I was old enough to understand, it wasn't like I was 4 years old." (young person)

On the occasions where staff communication was not so effective it clearly stood out in the minds of young patients.

"The surgeon didn't really tell me much information about what was going to happen and when I asked questions they were a little bit shut down. He just said not to worry about it and that he was going to sort it out." (young person)

"I remember one morning being surprised that they said "you're going to get your cast on", and I was like 'OK!'" (young person)

The ability of staff to communicate and put children at ease is likely to be important for patient outcomes, as well as their experience of being in hospital, by ensuring that staff have as much information as possible about their condition.

"If someone's cold and disinterested, you might not want to tell them the full truth about what happened or if you've seen that they might just brush your problems aside, or anything that you're feeling..." (young person)

Treatment

Most parents who participated in the focus groups believed that their child's medical condition would be appropriately dealt with under the Australian health care system. They felt that children in particular are given a high standard of treatment. Similarly, they tended to implicitly trust the

competence of medical staff. This view was reinforced when doctors and nurses were decisive and seemed confident in their decisions, but was shaken if they received conflicting information or an uncertain diagnosis.

"The people that made the decisions were definitive; 'this is what's going to happen, and that's what happened.'" (parent)

"[The specialist] seemed to have more idea [about what the x-ray meant] than the doctors, but there were a few sketchy bits about it." (young person)

"they seemed to know exactly what they were talking about, exactly what they were doing...they seemed very sure about what they were saying, how to go about it, how long I would be there." (young person)

"I had such faith in their skills, so I didn't even think about that, what resonated was that they were really nice people..." (young person)

Although the parents and young people who participated in this research were predominantly positive about the staff in terms of their attitude and abilities they felt that understaffing impacted on their ability to respond to patient needs. Some parents recalled assisting other children as well as their own child, for example by helping them to eat at meal times, because staff simply could not keep up. Parents in the focus groups who stayed overnight with their child, did so primarily to reassure them, but also because of serious concerns about staffing levels. Some of the older teenagers interviewed were equally worried by this issue and what it might mean for their care and the care of younger patients.

"I needed to stay with her overnight to give her eye drops every hour – the nurses didn't have time to do that." (parent)

"The most important thing for me being a young person was being in the hospital by myself and knowing there was an understaffing issue - because I was one of the older kids, maybe I would be left if something went wrong, so there was a concern about that." (young person)

"It was hard to find [a nurse] if you needed one, especially at night...so you've got to be there, there's no option." (parent)

Related to this, some patients had to wait longer than they would have liked for pain relief. Others felt that the pain medication provided was simply inadequate. One young person said he was not offered any pain medication after surgery and was not even asked about his pain levels.

"I remember being in pain and pressing the button to get some morphine or something and it took about half an hour for anyone to get to me because they were completely rushed off their feet." (young person)

In addition, there were some areas where communication failed. There were times when parents and young people felt a little unsure about whether they were in the right place, what they should do, or how long they might be waiting for the next test or step in their treatment. Better communication about processes and time frames would have helped to reduce this low level anxiety. In addition, parents sometimes had to request the results of tests, or never received these at all (although they tended to assume this meant there was nothing to worry about). Having to give information already provided also seemed unnecessary and was tiresome when it occurred repeatedly.

"I find I'm always repeating myself. Three different doctors will come and I find I'm just repeating myself, repeating myself." (parent)

"a nurse came over and asked for my story and I explained it, then another one so I explained it again, so I was like, OK, I'm kind of sick of explaining this to be honest, I just want to do something about it..." (young person)

Facilities and support for parents

Parents were stressed and concerned for their children, especially if it was their first hospital visit. They appreciated it when staff were empathetic and friendly towards them, as well as their child, and seemingly small gestures made a huge difference to their overall experience. One parent recounted the person who delivered the meals asking them how they were feeling each day, another how a volunteer had guided them through the hospital and sat with them in the waiting room, making a very anxious time a little more bearable. Some parents felt that nurses probably wanted to provide more of this kind of support, but simply did not have the time because they were 'run off their feet'.

"The volunteer was fantastic – really compassionate. She was reassuring all the sick kids. Just great." (parent)

"The people who serve the food, and the cleaning staff, that's what I remember, they were comforting and asked 'how are you today?' and remembered what you'd told them yesterday, that was important...but then they're not under the pump [like the nurses]." (parent)

"When I was doing the graveyard shift [overnight], there was one nurse in particular who'd just come down and sit with me for 10 or 15 minutes." (parent)

Parents recounted a wide range of experiences regarding overnight stays, from those who had an uncomfortable and cold night on a bedside chair without even a blanket, to those who had been able to hire an overnight parents room in the hospital, for a modest fee (\$10), where they could get a good night's rest but still be on hand if their child needed them.

The provision of a kitchen area for parents offered the chance not only to make a much needed hot drink, but also to have a little respite and talk more freely with other parents than on the ward. However, in one focus group some of the parents who had apparently visited the same hospital were unaware that various facilities existed, including a canteen, overnight rooms for parents and a kitchen area, prompting the suggestion that hospitals could provide parents with a facilities information sheet.

While parents had high expectations about the quality of the treatment offered to children in public hospital, their expectations about facilities were much lower, especially in relation to those for parents or adult patients.

"We don't have very high expectations of public hospitals, so we're kind of thankful for what we get." (parent)

Discharge

The main issue raised about the discharge process was delays, which were frustrating for parents, particularly as their children became unsettled by being told they were ready to leave but then having to wait for an often unspecified length of time. At the other extreme, some felt under pressure to leave more quickly than they would have liked to free up beds, including one of the young people interviewed, who was discharged early in the morning before her parents had arrived to pick her up, so she ended up waiting for them downstairs alone, even though she was still feeling the effects of the anaesthetic/pain killers.

Parents and older children seemed to feel sufficiently informed to be able to continue care at home and had details for follow-up appointments etc., but some felt a written information sheet would be useful and others would have liked greater opportunity to ask questions. A couple of the young people also left hospital with unanswered concerns about their recovery, which they then went on to worry about at home.

"I was a bit worried about what it would look like when I took the bandage off...I was told beforehand, what was going to be happening, but not really, so from then I just had an image, the imagination is strange. When I took it off it wasn't too bad anyway." (young person)

"The guy who was my surgeon's apprentice or intern came to speak to me and he was very cold and my questions went very unanswered and he just dumped a

package on my desk which said it's going to get worse before it gets better and stuff like that, just the typical information and that was about it ... I would have liked a bit more of a talk, covering the key stages of recovery." (young person)

List of potential question areas from patient focus groups

Based on the findings outlined above, the following areas were identified for potential inclusion in the CYPS, alongside those indicated from the other stages of the development process.

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
- 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 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 ward/room

- In a room/area with children of a similar age
- Reassuring/child-friendly environment
- Privacy considerations
- Hygiene and cleanliness
- Appetising food (suitable for children/young people)
- Whether there was disturbance from other patients/their visitors.

Treatment and pain management

- Effective pain management
- 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
- Tests results provided to patients.

Interaction with staff

- Staff skilled in communicating with children
- Staff try to address children's worries and fears
- Staff behave in a patient, friendly and caring way towards children and parents
- Staff answer questions, explain condition, next steps, reasons for tests/procedures, results etc. to children and parents
- Staff ask children about their concerns and try to address these
- Children and parents involved in decisions about care.

Facilities for parents

- 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 parents away from the ward.

Discharge

- Waiting time for discharge
- Readiness for discharge
- 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
- Sufficient opportunity to ask questions
- Whether patients felt they received the treatment/outcome they required.

3.3 Stakeholder engagement

To ensure the CYPS meets the needs of key stakeholders who will use the results to monitor and improve patient services, a range of stakeholders were invited by BHI to suggest areas for inclusion in the questionnaire by completing a pro forma and/or participating in a telephone interview.

Stakeholders expressed interest in a wide range of question areas. Areas of particular interest included: staff communication; provision of information; waiting times; characteristics of treatment and care; pain relief; characteristics and the role of medical staff; facilities; levels of privacy; food and nutrition; consent and decision making; hygiene; adverse events; family involvement; special patients; discharge; and demographics.

Reasons for the recommendation of specific questions or question areas by stakeholders were similarly varied. Commonly listed reasons for recommendation included: patient empowerment; presence in policy documents and patient standards; performance improvement; staff training; informing future initiatives; and to reduce discrepancies in performance in facilities all across the state.

Suggestions made by stakeholders have been consolidated into a list of question areas, which can be seen in the 'List of potential question areas from stakeholder engagement' section of this chapter. More information about this process can be found in Appendices D, E and F.

Findings

Staff Communication

Several stakeholders indicated the need for the inclusion of questions relating to staff communication in the CYPS. Specific areas of interest for these stakeholders included: the level of courtesy of staff; approachability of staff; clarity of staff communication (particularly the use of medical terminology and jargon); whether parents/guardians were informed about any changes made to their child's care; whether staff asked patients about other aspects of their life besides the reason for presentation; whether patient or parent/guardian fears about the treatment were discussed and questions were properly answered; and whether the members of staff introduced themselves and explained their roles prior to the inception of any treatment.

The primary reasons given by stakeholders for the inclusion of these sorts of questions related to the fact that effective communication: is demonstrative of respect for the patient; can help to facilitate holistic, well-rounded care; can help young patients navigate through the health system; and can also lead to less anxiety surrounding treatment and patient complaints. Further, good

communication is a fundamental part of patient-centred care, a foundation for the treatment provided by hospitals state-wide. As one stakeholder mentioned:

"We preach family-centred care, but are we doing it?"

Provision of information

One of the most salient question areas recommended by stakeholders for inclusion in the Survey was the provision of information to patients at all stages of the paediatric patient journey. One stakeholder mentioned that there should be questions regarding the preparation for hospitalisation provided to planned paediatric patients, including the sorts of materials that were made available to the patient and their family:

"Did you get an information pack around your child coming into hospital? What sort of information did you get around what to tell your child and how to prepare them?"

The majority of stakeholders emphasised the need for questions relating to the provision of information during patients' stays in the hospital. Specific question areas of particular interest to the stakeholders included: whether information regarding treatment (including information on the diagnosis, course of treatment, medications used, waits) was provided in a timely, clear manner; whether information regarding the rights of the patient (including how to complain) was provided; and whether any questions posed by the patient or the parent/guardian were answered with clarity by medical staff.

The primary reasons for the inclusion of these question areas given by stakeholders related to the fact that clear communication by medical staff is integral in increasing the health literacy of patients, consequently helping to empower the patient in their care. Further, the provision of understandable information to patients can help to dispel any concerns or anxiety that they might have about their condition or care in hospital. Stakeholders also recognised the importance of including these question areas due to their presence in prominent health documents, including the National Safety and Quality Health Service Standards and the NSW Youth Health Policy 2011-2016 charter.

Other question areas suggested by stakeholders pertained to information provided at or prior to discharge, including: whether adequate information on how to care for one's child was provided to parents; whether young carers and other patient groups were made aware of any support services that are available to them; whether patients and parents/guardians were informed about when they should be presenting at a hospital (or tertiary centre); and whether older children were provided information regarding the prevention of sexually transmitted infections (STIs).

The rationale for including these question areas was to generate data that could assist in formulating approaches to care which could help prevent the readmission of patients who do not suffer from chronic illnesses. Further, as one stakeholder stated, one of the characteristics of NSW hospital audits is the examination of 24 hour readmission and 28 day readmission. The incorporation of these sorts of questions could be used as evidence to help maintain the level of information provision in hospitals between audits.

Waiting times

Stakeholders also expressed interest in the inclusion of questions pertaining to the length of time that paediatric patients (including mental health patients) waited during their stay in hospital. These questions included: the time that they waited before they saw a doctor or nurse in hospital; whether a doctor or nurse re-evaluated the patient's condition during this wait; and whether there were any delays in procedures or operations.

Reasons provided for the addition of these questions included the collection of data to investigate whether specific patient types (for example, young children and mental health patients) are being admitted as soon as they should be, to inform future service improvement and to aid facilities in meeting Australian Government targets for the timeliness of admission such as the National Emergency Access Target.

Treatment and Care

Another of the most prominent potential question areas of interest to stakeholders related to the characteristics of paediatric patients' treatment and care. The first area of interest for stakeholders with regard to treatment and care was patients' level of satisfaction with different aspects of their care. Topics suggested included: patients' overall level of satisfaction with the care; whether the patient felt that all the medical staff worked well together; the best aspects of the patient's care; and what could have been done to improve the patient's stay in hospital.

The second area of interest for stakeholders related to more specific aspects of paediatric hospital care. These included: the perceived timeliness of the provision of medication to the patient; whether health workers collaborated with the patient in suggesting and implementing a range of medical supports; whether staff collaborated with each other in the treatment of the patient (using multidisciplinary care); whether the patient felt well prepared to leave the children's hospital and move to an adult health service (wherever applicable); and any perceived "gaps" in community health or outpatient services that render home care difficult.

Stakeholders indicated that these sorts of questions should be included in the survey in order to examine if different types of patients have differing levels of satisfaction with their care, and if so, clarify what drives these differences. Further, stakeholders perceived the inclusion of these questions as a method through which hospital performance could be improved by additional

service planning (including staffing) or staff education on a state-wide scale. One stakeholder also identified that the inclusion of these questions would serve as another source of evidence for quantifying the performance of facilities state-wide against the goals listed in the NSW Youth Health Policy 2011-2016.

One stakeholder also expressed interest in the inclusion of a question relating to the observation of any differences in care and staff performance in hours and out of hours. This stakeholder noted that while there are audits performed in order to measure staff performance in hours, there are no measures for out of hour care, which could possibly result in lower standards of care at these times.

“Help is 24/7, 365 days of the year. We’ve got to capture what our standard is like 24/7, 365 days of the year.”

Pain relief

Several stakeholders mentioned the need for a series of questions asking paediatric patients or the parents/guardians about the pain management that they received in hospital. Specific topics included: patients’ perceptions of the adequacy of the assessment of their level of pain; patients’ perceptions of the adequacy of the pain relief provided to them; the use of sedation or anaesthesia prior to their procedure or operation; the ways in which the pain management could have been improved; and whether the parents/guardians were able to be present during sedation.

“As a parent, were they able to be present during anaesthesia induction and recovery?”

Reasons provided for the inclusion of this topic area in the Survey generally pertained to data collection. Stakeholders indicated that data from these questions could serve as evidence needed to help improve pain management - in terms of education of staff or training - provided by hospitals, both during waiting in the Emergency Department and on the ward.

Characteristics and role of medical staff

Another salient area of stakeholder interest related to the characteristics and role of the hospital medical staff. Broadly speaking, this question topic comprised features of staff service not associated with communication or provision of information. Specific question areas included: level of friendliness and empathy of staff; responsiveness of staff; level of dignity and respect shown to patients of different cultural backgrounds; whether staff introduced themselves to patients and their parents/guardians; and whether staff enquired about how patients were going in the different parts of their life.

The reasons provided for the incorporation of these questions in the survey generally included improving support services for patients and to help advance practice in patient support by identifying shortcomings that may exist, thereby improving patient experience. Stakeholders also emphasised the need to include such topics in the questionnaire due to their prominence in documents such as the NSW Youth Health Policy 2011-2016 charter.

Stakeholders further highlighted the need to include questions regarding the performance of other staff such as allied health professionals. According to these stakeholders, there is something of a deficit in data relating to patients' perceptions of allied health professionals, and in order to properly reflect the performance of hospitals with regard to paediatric care, stakeholders felt that surveys should include questions relating to the performance of allied health professionals.

"[Allied health workers] are part of the team, because that's part of your follow-up with so many kids. Unless you look at the whole picture, you're not going to get a snapshot of what the journey for a family actually is."

Facilities

Stakeholders were interested in perceptions of the suitability of hospital facilities for child patients. Specific topics for questions included: overall perception of whether the facility was child-friendly or not; whether there was a waiting area for children in the Emergency Department; whether there was a play area and/or designated adolescent space in the hospital; whether child siblings of the patient were able to stay on the ward throughout treatment; and whether the patient was treated in a paediatric, adolescent or adult ward.

"You have adults being shipped into children's wards... they're very often non-separated. [This area] is about supporting children and families better, so that the hospitalisation of these children is not a traumatic event; so that down the track there aren't any residual experiences as a result of their hospitalisation"

As for the other question areas, the primary reasons for the inclusion of these questions included to inform policy and improve practice on a state-wide scale. Stakeholders indicated that these facets of care have a bearing on the psychosocial wellbeing of the patient and their family, and noted the significant influence that the hospital environment can have on patients' medical journey and recovery.

Stakeholders also noted that data generated by the inclusion of these questions would ensure that the Guidelines for the Care of Children and Adolescents in Acute Care Settings and the Standards for the Care of Children and Adolescents in Health Services are being upheld or even exceeded, as well as helping to measure the performance of hospitals against the priorities listed in the NSW Youth Health Policy 2011-2016.

One stakeholder also identified the need for questions relating to the provision of Wi-Fi to patients. This stakeholder highlighted the importance of Wi-Fi to paediatric patients, both in terms of facilitating education throughout the patient's stay in hospital, as well as being able to maintain contact with their peers and family.

Another stakeholder mentioned that a question asking patients whether they had access to an Aboriginal liaison officer should be included in the Survey. While this stakeholder recognised that data pertaining to the prevalence of the provision of Aboriginal liaison officers exists in the Association for the Welfare of Child Health's national survey report 'The Psychosocial Care of Children and their Families in Hospital', they noted that these data are from 2005, and more recent information is needed.

Privacy

On a related note, stakeholders emphasised the need for the inclusion of questions relating to whether hospital facilities allowed patients privacy in the Survey. In particular, stakeholders suggested that questions relating to patients' perceptions of whether inpatient areas allowed privacy during medical review and, more generally, whether hospital staff explained and upheld patients' rights in terms of privacy and confidentiality.

Stakeholders indicated that privacy should be an imperative, fundamental part of care received in hospital, and therefore should be included in patient surveys. Further, they identified the presence of standards for privacy in key policy documents such as the NSW Youth Health Policy 2011-2016 charter.

Food and nutrition

Questions relating to food and nutrition were also recommended for inclusion in the Survey. Specific suggestions made by stakeholders included: whether patients were given a choice of meal; patients' perception of the nutritional value of the hospital food; patients' perception of the taste of the hospital food; whether patients received the meal that they requested; and whether the patients were provided with assistance with eating (if necessary).

The primary justification for inclusion of these questions in the Survey was to provide feedback to the dietitians, kitchen and nutrition working party and to review the nutritional components of meals. This data could subsequently be used to address what one stakeholder perceived as being a problem at their facility:

"We're not really meeting the calorie intake of children – only because we're providing adult-oriented meals... things like a five year old getting chicken cacciatore or stew."

Consent and decision making

Many of the stakeholders interviewed mentioned the need to include questions relating to consent and/or decision making in the Survey. The primary questions of interest included: whether young patients (particularly those around 14 years of age) were aware that they could provide consent themselves; whether patients were involved in the care process, including in discussions about treatment options and overall decision-making; whether staff asked patients about their views on the treatment; and whether patients or their parents/guardians actually provided consent in their treatment.

These areas were of interest to stakeholders because of the negative effect that a lack of patient or parental involvement in decision making can have on the morale of patients and their families. Stakeholders felt that these questions could generate evidence of partnerships in care between patients and the medical staff. If the data indicated that patients did not feel properly involved in their care, it could further inform Clinical Excellence Commission initiatives and the Partnering with Patients program. Further, stakeholders noted that these questions should be included in the Survey because of the presence of related concepts (“involvement in decision making”¹) in the Standards for the Care of Children and Adolescents in Health Services and the National Safety and Quality Health Service Standards.

Hygiene

Stakeholders also suggested that questions relating to the hand hygiene practices of the medical staff should be incorporated in the Survey. In particular, stakeholders were interested in whether staff washed their hands or used hand sanitizers prior to caring for the patient, both in hours and out of hours.

This question area was deemed integral for inclusion by stakeholders because of the prominence of hygiene principles in the National Safety and Quality Health Service Standards. Further, stakeholders remarked that while audit data on hand hygiene is available, patients’ perceptions are important as a supplementary source of information. One stakeholder also noted that the inclusion of this question in previous iterations of the patient experience survey had proved invaluable for hospital accreditation in NSW.

Adverse events

Patients’ perceptions of the occurrence of adverse events during treatment were also of interest to stakeholders. In particular, stakeholders suggested the inclusion of questions such as: whether patients felt that their treatment resulted in a negative outcome; whether the patient felt that they

¹ The Royal Australasian College of Physicians (2008). *Standards for the care of Children and adolescents in health services*. Accessed 5/8/2013 from http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0010/155737/RCP_Standards_of_Care.pdf

became more ill or experienced harm during their stay; and patients' perceptions of whether the staff were open about anything that went wrong in their care.

Stakeholders indicated that they felt that children and young people should be engaged openly about any errors made in their treatment. Consequently, stakeholders deemed these questions crucial inclusions in the Survey in order to clarify if patients perceived that this was happening at the hospital that they attended. Further, stakeholders recognised the lack of data sources available with regard to paediatric patients' perceptions of their safety in hospital. One stakeholder also mentioned that data from these questions could inform future Clinical Excellence Commission initiatives as well as the Partnering with Patients program.

Special populations

Some of the stakeholders mentioned that they thought the Survey should include questions related to two paediatric patient groups with particularly unique experiences: mental health paediatric patients and rural paediatric patients.

Mental Health patients

Questions relating to the suitability of mental health facilities for a paediatric population were recommended for inclusion in the Survey. Specifically, stakeholders suggested topics including: whether patients and their parents/guardians felt that the intake system was user-friendly and whether patients felt the waiting area and rooms were suitable for children. Also of interest to stakeholders were questions relating to the perceived efficacy of mental health treatment and patients' perceptions of their readiness to exit the mental health facility. One other question that stakeholders suggested for incorporation in the Survey was regarding the services accessible to parents/guardians of children and young people with autism spectrum disorders.

All of the questions above were deemed integral for inclusion in the Survey in order to promote the issues that confront the paediatric patients in the Children and Adolescent Mental Health System, evaluate the performance of this system, and if necessary, enhance its performance.

Rural patients

Stakeholders also expressed the need for the questions relating to the experiences of children and young people from rural areas in the Survey. Questions recommended by stakeholders included: whether the patient was treated in a rural area; whether anybody had discussed the transition of care from paediatric to adult services with the rural patient; rural patients' opinions on the use of videoconferencing in the care; and rural patients' perceptions of what could be done better to assist them in managing their illness.

The primary justification provided by stakeholders for the inclusion of these questions was to enable service planning and consequently help address the perceived disparity in the quality of care between rural and urban services.

Family involvement

In line with the stakeholders' emphasis on the inclusion of questions relating to consent and patients' involvement in treatment and care, stakeholders were also interested in the level of family involvement in patients' care. Particular questions of interest encompassed issues such as: whether the family of the patient were involved in the care and decision making associated with treatment, including whether they were asked their thoughts; whether the family of the patient were informed about what was happening in the patient's treatment; whether there were adequate facilities catering to the needs of the family; and whether sibling care services were available at the hospital.

One of the primary reasons for the suggestion of these questions for inclusion in the Survey was the recognition of the stress that hospitalisation can have on the patient, their parents, and their family more generally. As one stakeholder put it:

"It's parents having a part in the care of that child - I don't want to see a tube shoved down my child's throat. Yes, it's consent, but it's so much more [than that]. What does the patient want, what does the family want?"

Stakeholders also noted that hospitalisation of a child does not only affect families emotionally, and that it can often be difficult for parents to care for their other children at this time. For this reason, one stakeholder deemed it necessary to include a question relating to care services, and if care facilities were available for families at hospitals state-wide.

Further, stakeholders commented that the inclusion of these questions would help to ensure that related standards – such as those listed in the Standards for the Care of Children and Adolescents in Health Services – are being adhered to or exceeded.

Discharge

The final aspect of patient care that stakeholders were interested in incorporating in the Survey related to hospital procedures at patient discharge. Stakeholders were interested in questions relating to the on-going care to be provided by patients' families post-discharge, specifically: whether patients were aware that they were about to be discharged; and whether adequate medical information was provided to parents/guardians on how to care for their child at home prior to discharge. Further, stakeholders were interested in discharge procedures relating to ensuring on-going care of the patients by medical practitioners, including: whether the hospital made arrangements for follow-up appointments (for hospital specialists, mental health facilities, etc.);

whether patients were provided with a printed copy of their discharge summary; and whether patients' GPs received a copy of their discharge summary.

Stakeholders indicated that they were interested in this question area for several reasons. Firstly, as one stakeholder mentioned, inadequate information provision and procedures at discharge can lead to unnecessary re-presentation at hospitals by patients. Secondly, arrangements made by hospitals for follow-up appointments at discharge can facilitate patients' access of services outside the acute area. Thirdly, the inclusion of these sorts of questions would aid in the evaluation of all the aforementioned aspects of discharge, help identify any gaps in care at this stage of the patient journey, and, if necessary, improve policy and practice at a state-wide level.

Demographics

Some stakeholders mentioned that they would like the particular demographic variables to be included in the Survey. These questions included: the religion of the patient; and whether the patient has used recreational drugs.

The rationale for the incorporation of the former question into the survey was to determine if equitable care is provided to patients with differing cultural and religious backgrounds. In terms of the latter question, one stakeholder was interesting in using such a question as a screening tool which would help delineate the prevalence of drug use amongst young adults in the community.

List of potential question areas from stakeholder engagement

The potential Children and Young Person Survey question areas that were generated by stakeholder feedback are as follows.

Communication

- Whether staff communication was appropriate for both the patients and their parents/guardians
- Whether the parent/guardian were informed about all the changes to the patient's care;
- Whether staff were approachable
- The level of courtesy of staff
- Whether staff asked patients about other aspects of their life besides the reason for presentation
- 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 introduced themselves to patients and their parents/guardians (including their position).

Provision of information

- The extent of the information (regarding treatment) provided to planned patients prior to their admission
- Whether patients and their parents/guardians were provided with adequate information relating to the diagnosis and the illness
- 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 doctors and nurses answered patients' questions adequately
- 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).

Waiting times

- The length of time that the patient waited in the Emergency Department before assessment
- Whether there were any delays
- Whether a doctor or nurse re-evaluated the patients' condition during any delay

Treatment and Care

- 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
- Whether staff collaborated with each other in the treatment of the patient (using multidisciplinary care)
- Patients' overall level of satisfaction with the treatment and care they received
- What was provided to the patient in order to prepare them for any operation/procedure that they undertook
- The best aspects of patients' care
- The aspect of care that requires the most improvement
- Any perceived "gaps" in community health or outpatient services that make it difficult to care for the patient at home
- Whether health workers collaborated with the patient in suggesting and implementing a range of medical supports
- Whether the patient felt well prepared to leave the children's service and move to an adult health service
 - Whether the patient felt that all the medical staff worked well together
 - 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
- Whether the parent/guardian took their child after leaving the GP.

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.

Characteristics and role of medical staff

- The friendliness of members of staff
- The level of empathy of staff
- 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
- The responsiveness of staff

- The frequency of interruptions to meals
- Whether staff enquired about how patients were going in different parts of their life
- Whether staff showed respect to patients from culturally diverse backgrounds including consideration of their cultural beliefs and practices
- Whether the patient observed a range of health workers in the hospital.

Facilities

- Whether there was a waiting area for children in the Emergency Department;
- Perception of whether the treatment facility was child-friendly
- Whether the patient was treated in an adolescent or paediatric ward
- Whether there was a designated treatment area attended by specialist paediatric staff
- Whether there was a play area in the hospital
- Whether access to Wi-Fi was provided to patients in the hospital
- Whether the patient's educational needs were met
- Whether there were designated adolescent spaces in the hospital
- Whether there was an Aboriginal liaison officer
- Whether child siblings of the patient were able to stay on the ward.

Privacy

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

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.

Consent and decision making

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

Hygiene

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

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.

Family involvement

- Whether the family of the patient were informed about what was happening in the treatment of the patient
- Whether the family of the patient were involved in the care and decision-making associated with treatment
- Whether there were proper facilities to cater for the needs of the patient's family
- Whether there were sibling care services provided in the hospital.

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

- 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 patients were made aware that they were to be discharged from hospital

- Whether arrangements were made for follow-up appointments (including those with specialists, mental health facilities, etc.) prior to discharge
- Whether patients were provided with a printed copy of their discharge summary
- Whether patients' general practitioners received a copy of the discharge summary
- Whether patients knew who to contact if they had any questions following discharge.

Demographics

- Religion of the patient
- Whether the patient has used recreational drugs.

3.4 Statistical analysis of previous surveys

Survey results from the 2007-2011 NSW Paediatric Patient Surveys were analysed using factor and reliability analysis, analysis of respondent comments relating to the survey itself, and analysis of non-response and possible ceiling and floor effects. Although a new survey is being developed, this analysis is useful to provide an additional indication of the question areas likely to be most important for inclusion, question areas where particularly careful consideration should be given to the wording/response scales and question areas that could potentially be removed. The results of these analyses are highlighted below. More details on the analytical process can be found in Appendix G.

Factor analysis

The factor analyses provided generally consistent results across the range of paediatric patients (general paediatric patients, paediatric patients who experienced pain, paediatric surgical patients and Intensive Care Unit (ICU) paediatric patients). For three of the four groups (excluding pain-experiencing paediatric patients), the factor that accounted for the highest amount of the variance was the heterogeneous *Facilities and Food* factor (ranging from 19-23% of the total variance). This factor comprised questions relating to characteristics of the food as well as cleanliness and characteristics of facilities. While the reliability for this factor was consistently excellent (alpha value of .90), this may be due to the fact that these questions are positioned next to each other and share the same scale rather than because these questions are measuring the same latent construct. Other factors that were consistent across patient groups included *Doctors*, *Nurses* and *Discharge Information* (ranging from 8-14% of the total variance). These factors all generally comprised similar questions and had similar levels of reliability, apart from the ICU paediatric groups. For this patient group, the lower levels of reliability (alpha ranging between 0.48 and 0.75) may reflect a different latent construct compared with other patient groups— possibly due to ICU doctors and nurses.

Despite the general consistency between patient groups, there were also some differences observed. For paediatric patients who experienced pain, there were several unique factors. Firstly, the *Food* (accounting for 5.74% of total variance) and *Facilities* (accounting for 9.81% of total variance) factors were separate for this group, indicating that patients who experience pain perceive these characteristics of treatment in a fundamentally different way to the other patient groups. Secondly, the analysis yielded a *Communication* factor that grouped questions relating to the provision of information, test results, and comfort of the patient in asking questions (accounting for 10.31% of the total variance). This suggests that for paediatric patients who experience pain, communication during treatment and upon discharge holds a fundamentally different value than it does for other patient groups.

For paediatric patients who visited the ICU, there were two factors associated with nurses: one specifically related to *ICU nurses* (incorporating Q20. Did you have confidence and trust in the nurses caring for your child?; accounting for 12.46% of the total variance), and one more general overarching *Nurse* factor (accounting for 12.76% of the total variance). This result suggests that those who visit the ICU may perceive the care of nurses slightly differently to other patients and require an additional section to properly elucidate their thoughts and feelings regarding the care of nurses in hospital.

High correlations between variables

As part of the reliability analysis, inter-item correlation matrices were produced for each factor. These matrices were examined to identify redundant questions within factors. Follow-up Pearson correlations were conducted to check the correlation across patient groups. It is important to note that high correlations between variables can be an artefact of participants' response patterns. Therefore, the questions mentioned below are questions that possess strong correlationsⁱⁱ with each other as well as similarity in question wording or topic.

In the 2007-2011 Paediatric Patient Surveys six pairs of questions fulfilled the aforementioned criteria:

- Q90. Accuracy of receiving food items that were ordered for your child & Q89 Courtesy and helpfulness of the staff that served your child's food
- Q76. Would you have liked a nurse to have spent more time with you discussing how to care for your child at home? & Q75. Would you have liked a doctor to have spent more time with you discussing how to care for your child at home?
- Q83. Would you recommend this hospital to your family and friends? & Q80. What number would you use to rate this hospital during your child's stay?
- Q17. How would you rate the courtesy of the doctors? Q13. Were the doctors available to answer your questions or concerns when you needed them?
- Q91 Taste of the food & Q92. Temperature of the food
- Q87. Cleanliness of the facility & Q88. Cleanliness of the room

The analysis suggests that these question pairs could potentially be redeveloped as a single question (or only one of the two questions could be used), without significantly reducing insight into paediatric patient' experience.

ⁱⁱ Pearson correlations of more than 0.7

Other questions with slightly lower correlationsⁱⁱⁱ included:

- Q92. Temperature of the food & Q90. Accuracy of receiving food items that were ordered for your child
- Q83. Would you recommend this hospital to your family and friends? & Q79. Overall, how would you rate the care your child received at the hospital?
- Q38. Did someone explain to your child the tests that were being done in a way he or she could understand? & Q36. Was the information about his or her condition discussed with your child in a way he or she could understand?
- Q71. Were you told about what danger signals about your child's illness or surgery or procedure to watch out for after he or she got home? & 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?
- Q90. Accuracy of receiving food items that were ordered for your child & Q92. Temperature of the food
- Q18. How would you rate the availability of the doctors? & Q13. Were the doctors available to answer your questions or concerns when you needed them?
- Q19. Were the nurses available to answer your questions or concerns when you needed them? & Q24. How would you rate the availability of the nurses?

The above questions' position in the survey should be considered. While they may not be measuring the same construct, they appear to be measuring similar constructs (for example, cleanliness of the facility and cleanliness of the room). If additional succinctness is needed, these questions could possibly be redeveloped or combined.

Missing response analysis

Analysis of missing response was performed on the 2007-2011 Paediatric Patient Surveys to determine whether particular questions in the survey were prone to participants' non-response (see Appendix G).

The two experiential questions in the 2007-2011 surveys that exhibited the highest rates of non-response were Q91 'taste of the food' and Q92 'temperature of the food'. Both had rates of non-response that were around 10%. One possible explanation for these elevated rates is that there was not a filter question asking participants if they had food in the hospital and no response option through which they could 'opt out' of these questions. Given that the preceding two food-related questions (Q89 and Q90) also had slightly elevated rates of non-response (6.4% and 9.6% respectively), this explanation seems likely.

ⁱⁱⁱ Pearson correlations from 0.6 to 0.7

As a set, ICU questions in the 2007-2011 Paediatric Patient Surveys (Questions 59 to 66) also exhibited relatively high rates of non-response (between 5.1% and 8.6%). This may particularly result from patients failing to tick the 'Child not admitted to any intensive care unit' option in Q58.

Ceiling and floor effects

The questions from the 2007-2011 Paediatric Patient Surveys with a ceiling effect (i.e. indicating that the majority of patients gave a positive rating), according to the ceiling and floor effect criteria (see Methodology Section 2) were as follows (no floor effects were identified):

- Q5. Was your child's admission date changed by the hospital?
- Q30. How much did you participate in your child's care, such as feeding or bathing?
- Q73. Did someone on the hospital staff tell you when your child should see a doctor for a follow-up visit?
- Q41. Did you feel like your child was treated with respect and dignity while he/she was in the hospital?
- Q64. Did the ICU staff let you stay with your child as much as you wanted?
- Q46. Overall, how much pain medicine did your child get?
- 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?
- Q49. Did your healthcare providers/staff wash or clean their hands before providing care for your child?
- Q20. Did you have confidence and trust in the nurses caring for your child?
- Q61. Did you have confidence and trust in the doctors in the ICU?
- Q63. Did you have confidence and trust in your child's nurses in the ICU?
- Q39. Did you feel comfortable asking medical staff questions about your child's condition or treatment?
- Q53. Before your child's surgery or procedure, did anyone talk with you about the risks, benefits and alternatives of the surgery?

The identification of ceiling effects for these questions indicates that they might be less useful in terms of informing service improvement, which should be one consideration when prioritising potential question areas. However, they should not be automatically excluded from the Survey because: while the overall picture is positive, there may be problems with some of these aspects of care at the individual hospital or LHD level; patients should feel the Survey covers areas of importance to them; positive feedback is likely to be important for staff morale; and the survey is one avenue for facilities to provide evidence of compliance with standards and for accreditation.

Patient comment analysis

The Paediatric Patient Surveys included an open question, which asked 'If you could change one thing about the hospital what would it be?'. Comments made by survey respondents in 2010 were coded into categories. All comments coded as 'other mentions' and/or containing the keyword 'survey' were manually reviewed for content relating to the actual conduct of the survey. Examples of these comments can be found in Appendix G.

Recommendations based on the analysis include:

- Consideration should be given to the date at which the survey is sent out to patients (as some respondents mentioned that they had difficulty answering survey questions due to time that had elapsed between their discharge from hospital and the receipt of the survey)
- The sample frame should be examined to ensure that the survey is only sent to children with relevant paediatric ward and hospital experiences (as some respondents mentioned that the survey content was not applicable to their hospital experiences)
- The Survey should include a question that establishes if it was completed by the patient or the child who received care (as some respondents indicated that they completed the survey for their child)
- The survey length should be given careful consideration (as number of respondents made comments suggesting they felt the survey was too long)
- The information accompanying the survey should clearly explain which specific visit to the hospital the patient should be basing their survey responses on (as some respondents' comments indicated that their responses were based on their experiences in a different hospital visit to the one that they were sampled for)
- Additional information should be provided with the survey, including what is done with the results of the survey
- Consideration should be given to the schedule of reminder letters sent after the survey has been sent out.

Summary of implications for the design of the CYPs

- Key factors (question areas) in the Survey should include: facilities, food, nurses, ICU nurses, doctors, discharge information, discharge conversations, communication, hygiene, family involvement and provision of information to the child patient
- Pairs of questions that correlate highly should be amalgamated (or one removed) to ensure that redundancy of questions is minimised. Specifically:
 - Q90. Accuracy of receiving food items that were ordered for your child & Q89 Courtesy and helpfulness of the staff that served your child's food

- Q76. Would you have liked a nurse to have spent more time with you discussing how to care for your child at home? & Q75. Would you have liked a doctor to have spent more time with you discussing how to care for your child at home?
- Q83. Would you recommend this hospital to your family and friends? & Q80. What number would you use to rate this hospital during your child's stay?
- Q17. How would you rate the courtesy of the doctors? Q13. Were the doctors available to answer your questions or concerns when you needed them?
- Q91. Taste of the food & Q92. Temperature of the food
- Q87. Cleanliness of the facility & Q88. Cleanliness of the room
- Question areas with high rates of non-response (hygiene, for example) should have less questions dedicated to them
- The presence of ceiling effects should be taken into consideration when prioritising question areas for the Survey
- Consideration should be given to the date at which the survey is sent out to patients, with a preference for a closer proximity to the date of discharge
- The sample frame should be examined to ensure that the survey is sent to patients with experiences relevant to the paediatric survey content
- A balance must be sought between ensuring the Survey provides sufficiently detailed feedback and minimising the burden on respondents in terms of survey length
- The information accompanying the survey should clearly explain which specific visit to the ED the patient should be basing their survey responses on, and what is going to be done with the data generated by the survey
- The Paediatric Survey should include a question that establishes if the survey was completed by the patient or by their parent or guardian
- Consideration for two survey instruments, one for those under 8 years of age and one for those 8 years of age and older.

4. QUESTIONNAIRE DEVELOPMENT

This section summarises how the various stages of the development process were brought together – the rapid literature review, the statistical analysis, the stakeholder consultation and patient focus groups.

This included:

- Applying parameters/rules to guide the questionnaire development
- Creating a list of potential question areas for inclusion in the survey instrument
- Consideration of other implications arising from each stage of the development
- Applying amendments arising from the Adult Admitted Patient Survey review
- Extensive consultation between BHI and Ipsos
- Extensive cognitive testing.

Potential question areas

The potential question areas indicated by each stage of the development research were brought together to create a comprehensive list of possible topics. This included a range of issues relating to:

- Means and experience of arrival at the ED
- Availability and cost of parking
- Waiting times and delays (between arrival, triage, treatment and discharge)
- Attitude of staff
- Responsiveness of staff
- Organisation and communication of staff
- Information provision and communication with parents and patients, and efficiency of handovers
- Privacy
- Complaints
- Pain relief
- Cleanliness and hygiene
- Food/diet
- Availability of age appropriate activities and environment
- Availability of facilities for parents
- Competency of staff and quality of treatment
- Discharge/care transition
- Overall ratings of care
- Patient suggestions for improvements

- Demographics and health status information (including questions required for standardisation purposes)
- Data linkage permission.

The full list of potential question areas can be found in Appendix J.

This comprehensive list, drawn from all developmental stages, was used as the basis of the initial questionnaire design, and then refined through consultation and testing.

Development of rules/design parameters for the questionnaire design

The design of the CYPS built on the rules and design parameters established in the development of the Adult Admitted Patient Survey (AAPS) and the Emergency Department Patient Survey (EDPS). The same planned approach – of consultation with patients and stakeholders, and review of ‘best practice’ patient surveys – was adopted. ‘Tried and tested’ questions as a design starting point were also used where appropriate. Similarly, the design was a process of extensive discussion between BHI and Ipsos, and finalised through cognitive testing.

These common rules and design parameters included: that the primary focus should be the patient’s experience of care and factual rather than judgemental assessment; inclusion of an overall rating question; use of balanced rating scaled; avoidance of double-barrelled questions (wherever possible); avoidance of leading or biased wording; using a limited suite of question formats and response options for ease of completion; using plain English throughout; and providing ‘don’t know’ and ‘not applicable’ options only where essential.

To align with and allow comparison with the AAPS and EDPS, the questionnaire includes the set of national core, common patient experience questions, on behalf of Patient Experience Information Development Working Group (PEIDWG). This meant that these questions could only be amended if agreed by PEIDWG, resulting in some inconsistency in relation to the design parameters outlined above.

Cognitive testing

An essential part of the development process was the undertaking of cognitive testing to ensure the validity of the questionnaire. As with the AAPS and EDPS, the aim of this is to ensure that participants were able to understand and answer the survey questions and that they were consistently interpreted in the way intended. This stage of development was particularly valuable given the large variety in patient experience and pathways that it highlighted.

The cognitive interviews were conducted in three rounds. The first two rounds provided an opportunity to assess whether the instrument successfully captured the full range of CYPS patient experiences. This was an iterative process with the findings from the first round informing the

subsequent draft, and being tested in the second round until a final draft was achieved. This was then graphically designed and tested in the final round, to ensure that the layout of the questionnaire encouraged participation and supported successful completion of the survey.

A summary of the edits made as a result of the cognitive testing phase and subsequent discussion between BHI and Ipsos SRI, follows below:

- The questionnaire was developed as two separate surveys; 'Admitted Children' was designed for completion by the parents of patients aged under 8 years old, and 'Admitted Young Patients' was designed for completion by parents and patients aged 8 and over
- 'Admitted Young Patients' includes a distinct section for completion by the young patient. These two pages are shaded pale blue to distinguish them from the remainder of the document. The questions included in this section are simplified for ease of comprehension:
 - the phrase 'health professionals' was changed to 'doctors and nurses' (AYPQ85, AYPQ88, AYPQ89, AYPQ90)
 - the five-point rating scale was changed from good/poor, to good/bad, with a mid-point of 'not good or bad' (AYPQ91, AYPQ97)
 - the overall rating question (AYPQ97) included the use of icons to aid response
 - the wording of the open-ended questions as changed to use less formal language that was more accessible to young patients (AYPQ98, AYPQ99)
- 'Social worker' was added to the list of 'other health professionals' to reflect the range of individuals a paediatric patient was likely to encounter (ACQ31/AYPQ24)
- The question addressing 'worries and fears' was revised to separately ask about the concerns of the parent/carer (ACQ39/AYPQ30), and the concerns of the patient (ACQ41/AYPQ89), as it became clear that these may be very different in terms of whether they were experienced and whether they were expressed
- A question was added to address whether or not parent/carers were able to remain with the child throughout treatment (ACQ44/AYPQ33)
- A number of questions were designed to measure the provision and use of hospital facilities for parent/carers, and whether parent/carers were informed about what was available to them (ACQ52-ACQ55/AYPQ41-AYPQ44)

- The answer categories for the long-standing conditions question (ACQ90/AYPQ78) was amended to reflect the younger age profile of patients being surveyed
- The question wording was amended to clarify whether it was the parent/carer, patient, or parent/carer and patient together who had completed the survey (ACQ93/AYPQ81/AYPQ100).

Appendix K details the development process for every individual question in the final surveys, including the primary reason for inclusion, the source question (where applicable) and changes made to the question during the development process (as a result of cognitive testing and discussion between BHI and Ipsos SRI).

Appendix L outlines which questions in the final surveys are relevant to the National Safety and Quality Service Standards and the Charter on the Rights of Children and Young People in Healthcare Services in Australia.

The final Admitted Children's questionnaire is included in Appendix M and the final Admitted Young Patients questionnaire is included in Appendix N. The cover letter for those Admitted Young Patients aged 16 and 17 is included in Appendix O.

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