Children and Young People's Patient Experience Survey 2018

Survey Development Report

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Updates

Before using this document, please check that you have the latest version, as small amendments are made from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will email all trust contacts and contractors directly to inform them of the change.

This document is available from the Survey Coordination Centre website at: www.nhssurveys.org/surveys/1138

Questions and comments

If you have any questions or concerns regarding this document, or if you have any specific queries regarding the submission of data, please contact the Survey Coordination Centre using the details provided at the top of this page.

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Contents

1. Introduction

The Children and Young People's Patient Experience Survey (CYP) was first undertaken in 2014. The survey captures the experiences of children and young people aged 8 to 15 years and the parents and carers of children and young people aged 0 to 15 years. The survey is set to run again in early 2019, as part of the NHS Patient Survey Programme (NPSP), with samples being drawn from patients discharged from hospital in November and December 2018[1]. The data collected will be analysed to understand children and young people's experiences of NHS acute hospital care in 2018 and used to generate information to facilitate targeted quality improvement.

The survey is coordinated by the Survey Coordination Centre at Picker. The Survey Coordination Centre has worked with the Care Quality Commission (CQC) to develop each of the questionnaires for the 2018 Children and Young People's Patient Experience Survey. The Survey Coordination Centre will also provide technical advice, support for NHS trusts implementing the survey, and produce the analysis when fieldwork is completed.

2. Summary of Development

The questionnaires for the Children and Young People's Patient Experience Survey have been redeveloped following consultation with key stakeholders, including the Care Quality Commission (CQC), NHS England, and the Children and Young People's Survey Advisory Group, which comprises representatives from the Department of Health and Social Care, several NHS trusts, CLIC Sargent (the cancer charity for children and young People), CQC experts by experience, and a member of the NHS Youth Forum. The redevelopment involved a review and analysis of item non-response rates, analysis of floor and ceiling effects for the 2016 survey, the generation of new questions to investigate key patient experience issues raised by stakeholders and amendments to questions that were asked in 2016.

All three versions of the questionnaire have been revised for the 2018 survey to make them as relevant, and as useful as possible, to both trusts and stakeholders. The questionnaires were tested thoroughly with patients, parents and carers in cognitive interviews, which were held over a period of six weeks in June, July and August 2018. After each round of interviews, changes were made to questions that were problematic. The changes were then tested in subsequent rounds of cognitive interviews. Each additional round of testing increased our confidence that the developed questions were understood by respondents and measured what they were intended to measure.

3. Survey Methodology

The sampling approach for the 2018 survey remains unchanged from the 2016 Children and Young People's Inpatient and Day Case Survey. Trusts will sample up to 1,250 admitted children and young people, aged between 15 days and 15 years, who were discharged from hospital during

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[1] A handful of trusts are expected to sample back to October due to low numbers of admitted children and young people during November and December.

the sampling period of 1 November to the 31 December 2018. This includes both patients who were admitted and stayed in hospital overnight and those who were admitted but did not stay overnight (e.g. emergency admissions and planned day cases).

The systematic stratified sampling method that was introduced in the 2016 survey will again be used for the 2018 survey. This method will enable trusts to generate a more balanced sample of respondents from each of the three age groups surveyed: (A) children aged two weeks to 7 years (questionnaire for parents only); (B) children aged 8 to 11 years (questionnaire for children and parents); (C) young people aged 12 to 15 years (questionnaire for young people and parents).

A complete sample of 1,250 children and young people would include 450 patients aged between two weeks and seven years, and 400 patients from each of the other two age groups. These quantities were chosen because the majority of patients sampled for the 2014 survey of children and young people were aged 0-7. This problematically resulted in a significant number of trusts being unable to obtain enough useable data in the 2014 survey from 8-15 year olds.

This approach was thoroughly tested in a sampling pilot held in July and August 2016 and, in the full 2016 survey, both improved the balance between the age groups sampled and substantially increased the number of trusts receiving useful data for the 8-15 year olds. In addition, the overall number of respondents increased from 18,736 in 2014 to 34,708 in 2016.

Participating trusts will draw their sample by following a detailed sampling instruction manual, which will be made available on the NHS Surveys website (www.nhssurveys.org/surveys/1241). As with the other surveys conducted as part of the NPSP, each trust will be responsible for running the survey either in-house or through an approved contractor. The Survey Coordination Centre will not receive patient identifiable data for the purposes of coordinating the survey.

Trusts may use a contractor to conduct the survey on their behalf. In these cases, the trust may pass patient identifiable information outside their organisation. To adhere to regulations on the transfer of patient identifiable information, the Survey Coordination Centre, in line with previous years, applied for section 251 support for the survey under the NHS Act 2006. Approval was granted for the survey in November 2018. A copy of the approval letter is available here: http://nhssurveys.org/survey/2269

In line with the section 251 approval, trusts will be asked to provide the following information on their sampled patients: trust code, name, address, month and year of birth, gender, ethnic group, date of admission, date of discharge, length of stay, main specialty (of consultant) on discharge, referring CCG, treatment centre admission, admission method, NHS site code of admission, NHS site code of discharge, and treatment function code.

Patients meeting the criteria listed below should be excluded from the sample:

- Patients who were not admitted (e.g. ward attendees or non-admitted outpatients)
- Deceased patients
- Patients with duplicated names
- Patients aged 16 years or older at the time of their discharge
- Babies aged between 0 and 14 days at the time of their discharge
- New-born babies where the mother was the primary patient

- Patients who were only admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU) (Treatment Function Code 422)
- Obstetrics/maternity patients, including spontaneous miscarriages
- Patients admitted for planned termination of pregnancy
- Psychiatry patients, including CAMHS
- Private patients (non-NHS)
- NHS patients treated at private hospitals
- Any patients who are known to be current inpatients
- Patients without a UK postal address
- Any patient, parents or carers known to have requested that their details are not used for any purpose other than their clinical care (but note that the NHS Patient Survey Programme is presently exempt from the national data-opt out programme and patients that have opted-out through this service should not be excluded).

4. Survey Name Change

The 2018 survey will see a name change this year from ‘Children and Young People’s Inpatient and Day Case Survey’ in 2016 to ‘Children and Young People’s Patient Experience Survey’ in 2018. The survey’s new name better reflects the diverse patient population sampled.

5. Revised Illustrations

In previous surveys, the children and young person’s section of the 8-11 and 12-15 questionnaires featured illustrations of children and young people embedded among questionnaire items. These images depicted a child with a broken leg, a child in a hospital bed, a young person on crutches, and a young person using a wheelchair. Each could be interpreted as an image of illness or injury.

These illustrations, commissioned in 2014, were included in the 2016 survey with the aim of increasing respondent engagement with and interest in the questionnaire. However, recent evidence[2] suggests that, when children and young people are asked to answer questions about the quality of their care, they neither want to be reminded of their illness, their injury, nor their time in hospital.

In light of this research, new illustrations were commissioned to replace the old illustrations. The new images depict children and young people outside of a hospital setting. They feature children and young people doing activities such as running, walking, completing a questionnaire, reading,

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[2] Wray, Hobden, Knibbs, and Oldham (2018) “*Hearing the voices of children and young people to develop and test a patient-reported experience measure in a specialist paediatric setting*”, A key finding here was that children and young people did not want the questionnaire to be visually themed around illness or the hospital. Instead, children opted for pictures of animals and young people preferred cartoons and stylistic illustrations without depictions of illness or hospital care.

and listening to music. These new images were well-received by children and young people during cognitive testing of the questionnaire.

6. Changes to Mailing Letters

Prospective respondents will be sent up to three mailing letters. For the 2018 survey, changes have been made to all three mailing letters in order to make them more engaging, with the aim of increasing response rates. This followed the work carried out during the 2017 Community Mental Health Survey, where the redesigned letters resulted in an increased response rate of 4 percentage points.

The changes to mailing letters include:

- Addition of colour to highlight key words and phrases in the letter.
- A more informal font.
- Removal of superfluous and repetitive text on the front page.
- Addition of potentially motivating and empowering messages, for example;
- "Thousands of people across England have already responded, and we would really like to hear from you too."

These changes were thoroughly tested during the three rounds of cognitive interviewing with patients. The letters received generally positive feedback and alterations were made when suitable.

Additional text was also added to the reverse side of the first and third covering letters to inform patients on how their data will be used and protected as per the requirements of the new General Data Protection Regulation (GDPR). The second covering letter does not have an FAQ section on the reverse side and therefore does not include this text. In line with other NPSP surveys, all mailing letters will feature a trust logo and signatory.

In a change from the 2016 iteration of the survey, we have Section 251 Approval to reduce the time frame between the first mailing and second mailing (first reminder letter) from 2-3 weeks to 5 working days. This follows a methodological pilot that was undertaken alongside the 2017 iteration of the Adult Inpatient Survey, which investigated the impact of reducing the time gap between the first and second mailing on overall response rate. This pilot found that there was a significant increase in response rate of 3 percentage points when the time gap was reduced to 5 working days between the first and second mailings, compared to the previous survey time of 2-3 weeks (the traditional methodological approach).

7. CYP-Facing Information Leaflet and Multilanguage Sheet

For the 2018 survey, the appearance of the flyer will change following the commissioning of new illustrations. Additionally, the word "Please" has been removed from the beginning of the title for aesthetic reasons. There remains 'Thank You' wording on the leaflet (please see appendices *Fig. 1.0* and *Fig.1.1*).

There have been no changes to the multi-language sheet which is also included in the survey packs (please see appendices *Fig. 1.2*).

8. Stakeholder Consultation

Advisory group meetings were held with key stakeholders to consider what content should be included in the questionnaires and to discuss methodological issues related to the survey. As part of the consultation, a prioritisation exercise was undertaken with advisory group members to determine which issues were considered to be the most important and to determine which questions from the 2016 questionnaires should be omitted from the 2018 questionnaires. A list of potential questions were then compiled by the Survey Coordination Centre and submitted to the advisory group for feedback. The advisory group's recommendations led to the rewording of a number of questions and to the development of the initial drafts of the three questionnaires.

9. Data Confidentiality

Approval for the CYP 2018 survey has been granted by the Confidentiality Advisory Group (CAG) under Section 251 of the NHS Act 2006 (CAG reference: 18/CAG/0150). This approval allows the common law duty of confidentiality to be put aside in order to enable the processing of patient identifiable information without consent.

10. Best Practices in CYP Research

In preparation for the 2018 Survey, a review of the literature on questionnaire design when conducting survey research with children and young people was undertaken, in order to investigate best practices and to guide the rewriting of some of the questions. The literature review builds on the significant amount of research that was conducted to support the development of the questionnaires that were used for the 2014 and 2016 CYP surveys.

Young children cannot fully apply “optimizing” strategies (there are four cognitive steps for answering a survey question: understanding and interpreting the question; retrieving information from memory; making a summarized judgment; and reporting this judgment[3]), and as such, questions asked of children and young people need to be both clear and simple and need to avoid both negative phrasing and placing excessive demands on cognition and memory. Research indicates that having short and clear questions keep children engaged and can reduce the tendency for children to interpret key words too literally (e.g. children answering “no” to “have you been on a class field trip?” because they had been on a *school* field trip).

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[3] Tourangeau, R. (1984). Cognitive sciences and survey methods. In T. Jabine, M. Straf, J. Tanur, & R. Tourangeau (Eds.), Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines, pp. 73-100. Washington, DC: National Academy Press.

Short questions can also help reduce or avoid satisficing behaviours (such as loss of concentration or motivation) that can lead respondents to pick whichever response options require the least amount of cognitive effort[4].

11. Cognitive Testing of the Questionnaires

Cognitive interviews need to be carefully conducted with children as the literature suggests that they may be inclined to think researchers are looking for the "right" answer [5]. Interviewers need to stress that there are no "right" answers and in cases where children ask, they can be told something like "if you don't know, just give me your best guess". Children and young people may need more extensive probing than adults and the introduction to the interview process may take longer as not all children know what surveys are or what they are for. The literature advises to avoid the use of paraphrasing with younger children, but that it can be good approach to use a combination of direct probes and paraphrasing with adolescents ("What do you think it means?") [6].

Following consultation with key stakeholders the 2018 survey instruments were revised and then cognitively tested with 36 volunteers (18 children or young people and 18 parent/carers) split across three rounds of interviews (as shown in Table 1 below). This represents an increase of 12 additional interviews compared to the 2016 survey. The rationale for this approach is for all questions which are common to each population being tested 6 times per round. This year, two weeks were allowed per round of cognitive interviewing to allow sufficient time for recruitment, conducting interviews, analysis and changes to be made to the questionnaires.

Table 1. Cognitive Interview Numbers

Questionnaire	Round 1		Round 2		Round 3	
	CYP	Parent/carer	CYP	Parent/carer	CYP	Parent/carer
0-7	N/A	2	N/A	2	N/A	2
8-11	3	2	3	2	3	2
12-15	3	2	3	2	3	2
Total	**6**	**6**	**6**	**6**	**6**	**6**

The objectives of cognitive testing were to ensure that the questions are clear, relevant and consistently understood. Three rounds of testing were held. Revisions were made to the questionnaires at the end of each two-week round in preparation for the interviews held in the following week.

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[4] [5] Hox, J. J., Borgers, N., & Sikkel, D. (2003). Response quality in survey research with children and adolescents: the effect of labeled response options and vague quantifiers. International Journal of Public Opinion Research, 15(1), 83-94.

[6] De Leeuw, E. D., Borgers, N., & Smits, A. (2004). Pretesting questionnaires for children and adolescents. In S. Presser, J. Rothgeb, M. Couper, J. Lesser, E. Martin, J Martin & E. Singer (Eds.), Methods for Testing and Evaluating Survey Questionnaires, pp. 409-429. Hoboken, NJ: John Wiley & Sons, Inc.

Cognitive Interview Recruitment

Adverts were placed in the Oxford-area DailyInfo weekly publication, both online at DailyInfo.com and in hard copies, and online at Gumtree.com. Additionally, adverts were shared on Picker's social media platforms and in various newsletters (for example public service newsletters and the Royal College of Paediatrics and Child Health email newsletter). However, uptake was low and resulted in cognitive interviewing being largely reliant on the cooperation of a number of external organisations.

The first round of interviews included one mother from general population recruitment (Reading), with the remaining interviews taking place at Great Ormond Street Children's Hospital (GOSH).The second round of interviews were conducted at the John Radcliffe Hospital (JR) in Oxford. The final round of interviews included one father from public recruitment (Birmingham) as well as interviews at Bristol Royal Hospital for Children and GOSH.

12. Changes to the Questionnaires

All three versions of the questionnaire have been revised for the 2018 survey. The changes have been made to ensure the survey continues to provide the most useful and relevant feedback possible, addressing both the issues of importance to patients and generating information of significance for policy evaluation and the regulation of NHS trusts. Amendments have been made on the basis of the following considerations:

- Consultation with stakeholders, including the Care Quality Commission (CQC), NHS England, as well as the CQC Children's Survey Advisory Group, which comprises representatives from the Department of Health and Social Care, several NHS Trusts, CLIC Sargent (the cancer charity for children and young people), and a member of the NHS Youth Forum.
- Analysis of the 2018 survey data to examine item non-response rates, as well as floor and ceiling effects.
- All three versions of the questionnaire were cognitively tested to ensure that the question wording and response options are both suitable and understandable to respondents.

In what follows, we divide the alterations that have been made into three categories: (1) new questions, (2) removed questions, and (3) amended questions. The numbers in the age group columns indicate the question number for that version of the questionnaire. The 0-7 questionnaire is version **A**, the 8-11 questionnaire is version **B**, and the 12-15 questionnaire is version **C**.

12.1 New Questions

The following questions have been added to the questionnaires to address issues of interest to key stakeholders and to gather information related to current policy concerns.

These questions are split into two sections: questions asked of children and young people and questions asked of parents and carers. Tables 2 and 3 display the question number for each new question within each questionnaire.

New Questions for Children and Young People

Table 2: New Questions for Children and Young People

New Question and Response Options	0-7 (A)	8-11 (B)	12-15 (C)
If you used the hospital Wi-Fi, was it good enough to do what you wanted? 1. Yes, always 2. Yes, sometimes 3. No 4. I did not use Wi-Fi	N/A	Q3	Q3

If you used the hospital Wi-Fi, was it good enough to do what you wanted?

Access to good quality Wi-Fi emerged in the advisory group as very important to young people in hospital, allowing them to connect with friends, family and play games.

During cognitive interviews children in both age groups, 8-11 and 12-15, showed a good understanding of the term ‘Wi-Fi’ and what it is used for. Most commonly, children and young people reported that they used Wi-Fi to watch YouTube videos, use social media and communicate with friends. Children and young people took a number of factors into account when assessing the quality of the Wi-Fi, including video streaming speed, the reliability of connection, the connection strength in different areas of the hospital and the ease of the sign in process.

New Questions for Parents and Carers

Table 3: New Questions for Parents and Carers

New Question and Response Options	0-7 (A)	8-11 (B)	12-15 (C)
Did your child stay overnight during their most recent visit to hospital? 1. Yes 2. No	Q1	Q25	Q26
If your child used Wi-Fi in the hospital to entertain themselves, was it good enough to do what they wanted? 1. Yes, always 2. Yes, sometimes 3. No 4. Don’t know / not applicable	Q11	N/A	N/A

If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff? 1. Yes, always 2. Yes, sometimes 3. No	Q26	Q40	Q41
Were you treated with dignity and respect by the people looking after your child? 1. Yes, always 2. Yes, sometimes 3. No	N/A	Q55	Q56
Does your child have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more? 1. Yes 2. No	Q51	Q60	Q61
Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more) 1. Blood disorder 2. Bowel condition, such as Crohn's disease 3. Breathing problem, such as asthma 4. Blindness or partial sight 5. Cancer in the last 5 years 6. Chromosomal condition, such as Down's syndrome 7. Deafness or hearing loss 8. Developmental disability, such as Autism Spectrum Disorder (ASD) 9. Diabetes 10. Heart problem 11. Joint problem 12. Kidney or liver disease 13. Learning disability 14. Mental health condition 15. Neurological condition, such as epilepsy 16. Another long-term condition	Q52	Q61	Q62

Do any of these reduce your child's ability to carry out day-to-day activities? 1. Yes, a lot 2. Yes, a little 3. No, not at all	Q53	Q62	Q63

Did your child stay overnight during their most recent visit to hospital?

Between-trust comparisons are partially standardised by length of stay (0 or 1 or more overnight stays). Although this information was derived from trust-provided sample data for CYP16, it is best practice across the NPSP for respondent data to be favoured over sample data wherever available to produce standardisation weights for between-trust comparisons. Therefore, this question was added to gather respondent data on length of stay. The question was thoroughly tested during cognitive interviews and no issues around interpretation were identified.

If your child used Wi-Fi in the hospital to entertain themselves, was it good enough to do what they wanted?

As mentioned previously, access to good quality Wi-Fi emerged in the advisory group as very important to children and young people in hospital. In order to gain insight for the youngest age group sampled in the survey (0-7), the equivalent question asked of children and young people was adapted so that it could be asked of their parent/carer instead.

The concept of Wi-Fi was universally understood by parents and carers. Initially some parents/carers considered their own Wi-Fi use, rather than evaluating their child's experience. In the second round of testing, the wording was changed to direct the parent or carer to the child or young person's experience (as in the final version, above). Following this, parents and carers exclusively thought of the child's or young person's Wi-Fi use. For example, one mother answered *"don't know / not applicable"* as her baby was too young to use screens, although she had used hospital Wi-Fi.

If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?

An open feedback environment, where parents/carers and their children feel comfortable raising concerns, was raised as an important aspect of CYP hospital experience during the advisory group. It was felt that negative wording, around raising a complaint, should be avoided. Additionally, given the relatively small number of complaints received by children's health services, it was decided the question should be hypothetical to appeal to the maximum number of respondents.[7]

Because it was felt that it was important that the patient, as well as their parent/carer, should feel able to state if they were unhappy with an element of their care and treatment, a version of this

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[7] NHS Digital (2017). Data on Written Complaints in the NHS. Workforce and Facilities, NHS Digital.

question, centred around feeling able to “speak up”, was asked of both children/young people and their parents/carers during cognitive testing.

Whereas parents understood the term “speak up” and the hypothetical proposition, children and young people had considerable difficulty understanding the question. A number of children did not understand what the phrase “speak up” meant. Other children interpreted the question in unintended ways. For example, one child interpreted “speak up” to mean being “cheeky” and another interpreted it as simply giving staff feedback (both good and bad).

The question was therefore reworded for the third round of cognitive testing. Unfortunately, there was still little evidence at this late stage of testing that children and young people understood the question as intended, or otherwise had a shared understanding of it. For these reasons, it was decided that it should only be asked of parents/carers.

Were you treated with dignity and respect by the people looking after your child?

This question was previously included in the 0-7 questionnaire only. Following completion of cognitive testing, it was noted that there was capacity to include an additional question within the parents/carers sections of the 8-11 and 12-15 questionnaires. The decision was taken to include the aforementioned question as it is an important element of parent/carer hospital experience.

Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)

Following redevelopment of the long term condition (LTC) questions for the Adult Inpatient Survey 2017, three new questions have been introduced for the 2018 survey following their adoption across the NPSP. These replaced the previous two LTC questions used in the 2016 iteration. In adapting the revised LTC questions for the CYP survey, references to ‘your child’ were added and tested as part of their redevelopment during cognitive interviews.

Does your child have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more?

The purpose of this question is to route parents of children with LTCs to two further questions that enabled them to specify their child’s conditions and their impact day-to-day. The question was generally well understood by participants and those who indicated their child did have a LTC went on to specify one or more disabilities or illnesses.

Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)

This question was easily answered by the majority of parents. Most could easily identify the LTC which affected their child quickly, with many selecting more than one condition. Some long term conditions mentioned by parents, but not found in the list, included autoimmune disease, allergies and communication difficulties. Parents/carers in these cases selected ‘another long term condition’. One parent was unable to answer this question because her child was currently awaiting an LTC diagnosis.

Following feedback from the advisory group, several new response options appropriate to a CYP population were also added, they were as follows:

- Bowel conditions, such as Crohn's Disease
- Chromosomal condition, such as Downs Syndrome
- Developmental disorder, such as Autism Spectrum Disorder.

An example was added also added for clarification to one response option:

- Neurological condition, such as epilepsy.

During cognitive testing some additional LTCs were considered for inclusion, including the following:

- Mobility issues
- Autoimmune disorder (lupus)
- Communication difficulties (stammer)
- Birth defect (cleft palate).

However, due to low prevalence of these conditions within the wider population, or the possibility of fitting into another category, these were not included in the final version of the question.

Do any of these reduce your child's ability to carry out day-to-day activities?

This question assesses the everyday impact of any long term conditions indicated in the previous question.

This question was answered well during all 3 rounds of cognitive testing. The factors taken into account when thinking of 'ability to carry out day-to-day activities' were wide ranging. These included the child's ability to regularly attend school, play with friends, play sports, and mobility issues.

12.2 Removed Questions

The questions below have been removed from the parents/carer's survey due to ceiling effects, or because they have been replaced by more effective questions in line with other national surveys.

Table 4 gives the question number for each question removed as it appeared in the 2016 questionnaires.

Table 4: Removed Questions for Parents and Carers*

Removed Question and Response Options	0-7 (A)	8-11 (B)	12-15 (C)
Were you given any new medicines to take home with you for your child that they had not had before (including tablets and creams)? 1. Yes 2. No	Q35	Q48	Q49

Were you given enough information about how your child should use the medicine(s) (e.g. when to take it, or whether it should be taken with food)? 1. Yes, enough information 2. Some, but not enough 3. No information at all	Q36	Q49	Q50
Does your child have any of the following long-standing conditions? (Cross ALL that apply) 1. Deafness or severe hearing impairment 2. Blindness or partially sighted 3. Any other long-standing physical disability 4. A learning disability 5. A mental health condition 6. Another long-standing condition (e.g. cancer, diabetes, epilepsy) 7. No long-standing condition	Q50	Q58	Q59
Does this condition(s) cause your child difficulty with any of the following? (Cross ALL that apply) 1. Everyday activities that people his/ her age can usually do 2. In education or training 3. Access to buildings, streets or vehicles 4. Reading or writing 5. People's attitude to your child because of their condition 6. Communicating, mixing with others or socialising 7. Any other activity 8. No difficulty with any of these	Q51	Q59	Q60

*Question number references are in relation to the 2016 iteration versions of the questionnaires.

Were you given any new medicines to take home with you for your child that they had not had before (including tablets and creams)?

This question was primarily used as a filter question to the one which follows *(Were you given enough information about how your child should use the medicine(s) (e.g. when to take it, or whether it should be taken with food?),* and was unscored.

Review of the 2016 survey data showed that a high proportion of respondents were routed past the question that addressed whether they had been given enough information on how to take their new medicines (i.e. the question was not applicable to the experiences of the majority of respondents). As a result, there was a problematically small number of respondents per trust, resulting in the many trusts not receiving data for this question.

This evidence was presented at the initial advisory group. Stakeholders were in agreement that this question should be removed to provide questionnaire space for a different question that would like apply to the care experiences of a greater number of children and young people.

Were you given enough information about how your child should use the medicine(s) (e.g. when to take it, or whether it should be taken with food)?

In addition to the above information on the medicines routing question, analysis of the 2016 data found a ceiling effect for this question. When applicable, the vast majority of respondents reported that they were given enough information about their medication. The advisory group agreed again that this question should be removed to allow another question to be included.

Does your child have any of the following long-standing conditions? (Cross ALL that apply)

This question has been removed and replaced by a new LTC question which provides more specific response options.

Does this condition(s) cause your child difficulty with any of the following? (Cross ALL that apply)

These questions were replaced by the new LTC questions described in the '12.1 New Questions' section above, which have been rolled out across the NPSP.

12.3 Amended Questions

A number of amendments have been made to the 2018 questionnaire. The reasons for changes are outlined below.

Hospital ward question

This question appears as Q5 in questionnaire A, Q26 in questionnaire B and Q27 in questionnaire C.

A comma was added between 'hospital' and 'what'.

Previous version: For most of their stay in hospital what type of ward did your child stay on?

Revised version: For most of their stay in hospital, what type of ward did your child stay on?

CYP worries question

This question appears as Q11 in questionnaire B and Q11 in questionnaire C.

2016/2018 version: If you had any worries, did a member of staff talk with you about them?

Response options for this question were altered to allow the possibility that the child or young person did not have worries while in hospital. Previously the response options for this question made the presumption that a CYP had worries, although the question did not. The 'Sort of' option was removed to make space for the new option and to limit non-specific answering.

Previous response options:

1 ☐ Yes

2 ☐ Sort of

3 ☐ No

4 ☐ I did not want to talk to staff about any worries

Revised response options:

1 ☐ Yes

2 ☐ No

3 ☐ I did not have any worries
4 ☐ I did not want to talk to staff

Frequency of hospital visit question

Previous version: Including this visit, how many times has your child stayed in hospital on a ward in the past six months?

Revised version: Including this visit, how many times has your child been to hospital in the past six months?

This question appears as Q50 in questionnaire A, Q57 in questionnaire B and Q58 in questionnaire C.

This question was amended because it was felt that, in its previous form that included the phrase "stayed in hospital on a ward", the question may have only been answered positively—with "Yes"—by the parents of children and young people who had additional *overnight* stays over the past six months. During cognitive interviewing parents understood this question correctly, drawing on consultations after operations, longer hospital stays, day procedures and initial consultations, in addition to overnight stays.

Operations or procedures question

Previous version: During your time in hospital, did you have any operations or procedures? (For example having your tonsils removed)

Revised version: During your time in hospital, did you have any operations or procedures?

This question appears as Q14 in questionnaire B and Q15 in questionnaire C.

The example given for this question was removed after cognitive testing found it to be confusing for children and young people. A number of respondents in both the 8-11 and 12-15 age group did not know what tonsils were, or thought that the question was asking specifically whether they had had their tonsils removed. As the example was found to hinder response, it has been removed from the 2018 questionnaire.

Parent/carer's length of stay question

Previous version: Did you ever stay overnight in hospital with your child?

Revised version: Did you stay overnight in hospital with your child during their most recent visit to hospital?

This question appears as Q30 in questionnaire A, Q43 in questionnaire B and as Q44 in questionnaire C.

During the analysis of the 2016 CYP survey it was found that, contrary to expectations, a high proportion of respondents whose child had visited hospital but did not stay overnight (according to sample data) ticked the "Yes" response option to "Did you ever stay overnight in hospital with your child?". It is believed that the main driver for this anomaly was the inclusion of the word "ever" within the question text, which caused respondents to think about their child's entire life course when they responded. Although respondents are advised multiple times before answering questions to refer to their child's most recent stay in hospital when answering, these prompts effectiveness likely diminish as the questionnaire is completed.

To counter misinterpretations of the question in the 2018 survey, the term "ever" was removed from the question text and explicit wording directing respondents to think about their child's most recent stay in hospital was added. This change tested well during cognitive interviews, with parents thinking of only their most recent hospital stay as intended. Parents spoke of previous stays in hospital but answered accurately after realising that this question did not refer to their child's most recent visit.

During cognitive testing the response options for this question were also altered.

Previous response options:

1 ☐ Yes

2 ☐ No, but I wanted to

3 ☐ No, but I did not want or need to

4 ☐ My child did not stay overnight

Revised response options:

1 ☐ Yes

2 ☐ No

3 ☐ My child did not stay overnight

It was found that multiple negative responses were confusing for respondents. Moreover, because a parent or carer may want to stay with their child, but be unable to due to forces outside of a trusts control—such as the care of another child—it is unclear whether the response option "No, but I wanted to" provides trusts or other stakeholders with useful information.

In addition to changes in the questions detailed above, a section title was also amended in all three questionnaire versions.

Previous section title: Facilities for parents & carers

Revised section title: Facilities

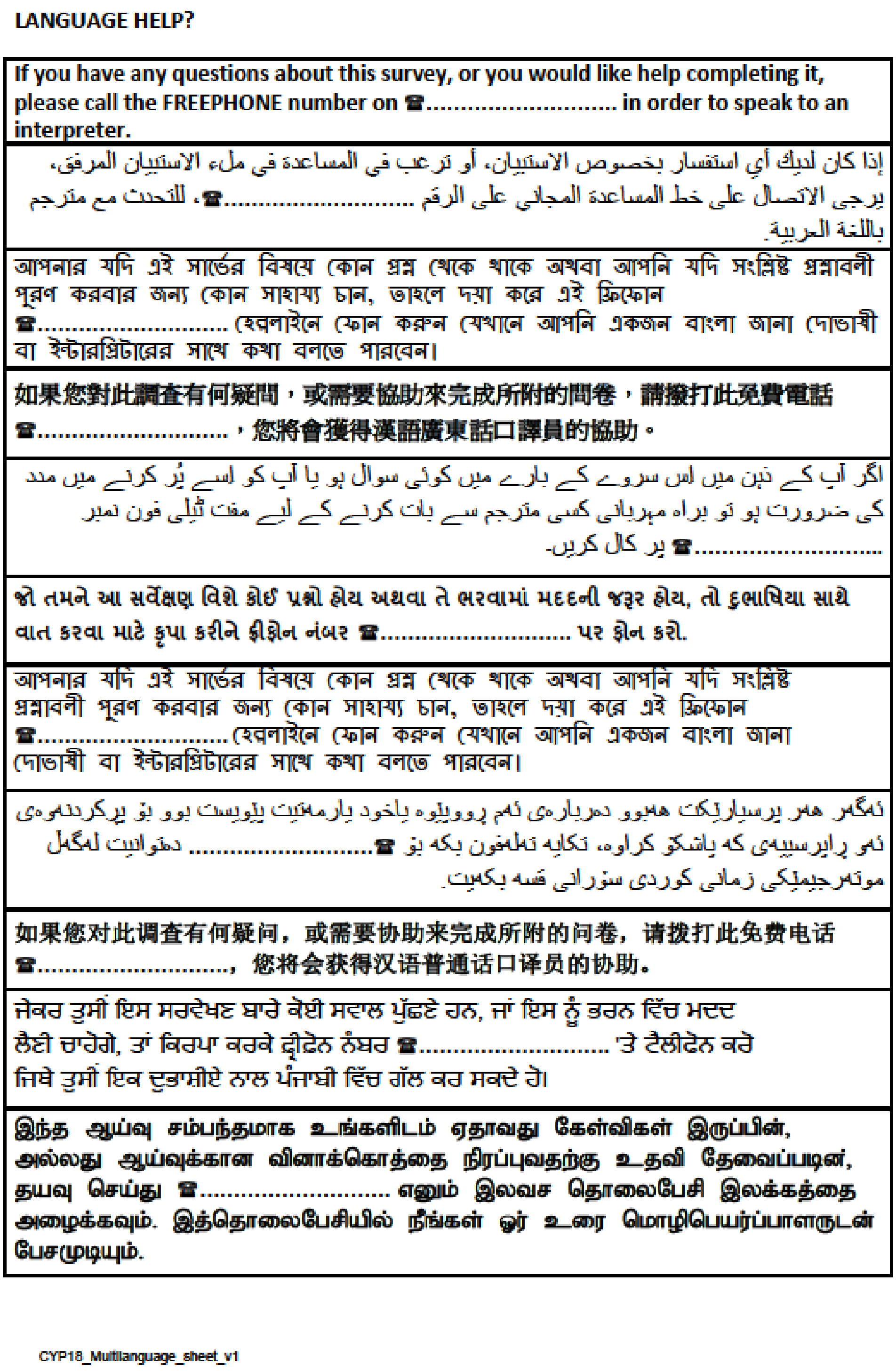
Reducing the section title allowed more space to include new questions. The change was reviewed during cognitive testing with no adverse effects identified**.**

13. Appendices

Fig. 1.0 CYP18 information leaflet for 8-to-11-year olds

Fig. 1.1 CYP18 information leaflet for 12-to-15-year olds

Fig. 1.2 Multi-language sheet.



LANGUAGE HELP?

If you have any questions about this survey, or you would like help completing it, please call the FREEPHONE number on ☎........................... in order to speak to an interpreter.

إذا كان لديك أي استفسار بخصوص الاستبيان، أو ترغب في المساعدة في ملء الاستبيان المرفق، يرجى الاتصال على خط المساعدة المجاني على الرقم .... ☎، للتحدث مع مترجم باللغة العربية.

আপনার যদি এই সার্ভের বিষয়ে কোন প্রশ্ন থেকে থাকে অথবা আপনি যদি সংশ্লিষ্ট প্রশ্নাবলী পূরণ করবার জন্য কোন সাহায্য চান, তাহলে দয়া করে এই ফ্রিফোন ☎........................... হেল্পলাইনে ফোন করুন যেখানে আপনি একজন বাংলা জানা দোভাষী বা ইন্টারপ্রিটারের সাথে কথা বলতে পারবেন।

如果您對此調查有何疑問，或需要協助來完成所附的問卷，請撥打此免費電話☎...........................，您將會獲得漢語廣東話口譯員的協助。

اگر آپ کے ذہن میں اس سروے کے بارے میں کوئی سوال ہو یا آپ کو اسے پُر کرنے میں مدد کی ضرورت ہو تو براہ مہربانی کسی مترجم سے بات کرنے کے لیے مفت ٹیلی فون نمبر ☎........................... پر کال کریں۔

જો તમને આ સર્વેક્ષણ વિશે કોઈ પ્રશ્નો હોય અથવા તે ભરવામાં મદદની જરૂર હોય, તો દુભાષિયા સાથે વાત કરવા માટે કૃપા કરીને ફ્રીફોન નંબર ☎........................... પર ફોન કરો.

আপনার যদি এই সার্ভের বিষয়ে কোন প্রশ্ন থেকে থাকে অথবা আপনি যদি সংশ্লিষ্ট প্রশ্নাবলী পূরণ করবার জন্য কোন সাহায্য চান, তাহলে দয়া করে এই ফ্রিফোন ☎...........................হেল্পলাইনে ফোন করুন যেখানে আপনি একজন বাংলা জানা দোভাষী বা ইন্টারপ্রিটারের সাথে কথা বলতে পারবেন।

ئەگەر هەر پرسیارێکت هەبوو دەربارەی ئەم ڕووپێوە یاخود یارمەتیت پێویست بوو بۆ پڕکردنەوەی ئەو ڕاپرسییەی کە پاشکۆ کراوە، تکایە تەلەفون بکە بۆ ☎........................... دەتوانیت لەگەڵ موتەرجیمێکی زمانی کوردی سۆرانی قسە بکەیت.

如果您对此调查有何疑问，或需要协助来完成所附的问卷，请拨打此免费电话☎...........................，您将会获得汉语普通话口译员的协助。

ਜੇਕਰ ਤੁਸੀਂ ਇਸ ਸਰਵੇਖਣ ਬਾਰੇ ਕੋਈ ਸਵਾਲ ਪੁੱਛਣੇ ਹਨ, ਜਾਂ ਇਸ ਨੂੰ ਭਰਨ ਵਿੱਚ ਮਦਦ ਲੈਣੀ ਚਾਹੋਗੇ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਫ੍ਰੀਫੋਨ ਨੰਬਰ ☎........................... 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ ਜਿਥੇ ਤੁਸੀਂ ਇਕ ਦੁਭਾਸ਼ੀਏ ਨਾਲ ਪੰਜਾਬੀ ਵਿੱਚ ਗੱਲ ਕਰ ਸਕਦੇ ਹੋ।

இந்த ஆய்வு சம்பந்தமாக உங்களிடம் ஏதாவது கேள்விகள் இருப்பின், அல்லது ஆய்வுக்கான வினாக்கொத்தை நிரப்புவதற்கு உதவி தேவைப்படின், தயவு செய்து ☎........................... எனும் இலவச தொலைபேசி இலக்கத்தை அழைக்கவும். இத்தொலைபேசியில் நீங்கள் ஓர் உரை மொழிபெயர்ப்பாளருடன் பேசமுடியும்.

CYP18_Multilanguage_sheet_v1

Table 4. *Questionnaire A: 0-7 parents and carers*

Question	Question number 2016	Question number 2018	Comments and notes
Did your child stay overnight during their most recent visit to hospital?	N/A	Q1	New question
Was your child's visit to hospital planned or an emergency?	Q1	Q2	
Did the hospital give you a choice of admission dates?	Q2	Q3	
Did the hospital change your child's admission date at all?	Q3	Q4	
For most of their stay in hospital, what type of ward did your child stay on?	Q4	Q5	Amended question
Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Q5	Q6	
How clean do you think the hospital room or ward was that your child was in?	Q6	Q7	
Was your child given enough privacy when receiving care and treatment?	Q7	Q8	
Were there enough things for your child to do in the hospital?	Q8	Q9	
Did staff play with your child at all while they were in hospital?	Q9	Q10	
If your child used the hospital Wi-Fi to entertain themselves, was it good	N/A	Q11	New question

enough to do what they wanted?			
Did new members of staff treating your child introduce themselves?	Q10	Q12	
Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	Q11	Q13	
Did members of staff treating your child communicate with them in a way that your child could understand?	Q12	Q14	
Did a member of staff agree a plan for your child's care with you?	Q13	Q15	
Did you have confidence and trust in the members of staff treating your child?	Q14	Q16	
Did staff involve you in decisions about your child's care and treatment?	Q15	Q17	
Were you given enough information to be involved in decisions about your child's care and treatment?	Q16	Q18	
Did hospital staff keep you informed about what was happening whilst your child was in hospital?	Q17	Q19	
Were you able to ask staff any questions you had about your child's care?	Q18	Q20	
Did different staff give you conflicting information?	Q19	Q21	
Were the different members of staff caring for and	Q20	Q22	

treating your child aware of their medical history?			
Did you feel that staff looking after your child knew how to care for their individual or special needs?	Q21	Q23	
Were members of staff available when your child needed attention?	Q22	Q24	
Did the members of staff caring for your child work well together?	Q23	Q25	
If you had been unhappy with your child’s care and treatment, do you feel that you could have told hospital staff?	N/A	Q26	New question
Did your child like the hospital food provided?	Q24	Q27	
Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	Q25	Q28	
Were you able to prepare food in the hospital if you wanted to?	Q26	Q29	
Did you stay overnight in hospital with your child during their most recent visit to hospital?	Q27	Q30	Amended question – non-comparable to previous iteration due to amendments.
How would you rate the facilities for parents or carers staying overnight?	Q28	Q31	Question non-comparable to previous iteration due to change in previous routing question.

If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Q29	Q32	
During their stay in hospital, did your child have any operations or procedures?	Q30	Q33	
Before your child had any operation or procedures, did a member of staff explain to you what would be done?	Q31	Q34	
Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Q32	Q35	
During any operations or procedures, did staff play with your child or do anything to distract them?	Q33	Q36	
Afterwards, did staff explain to you how the operations or procedures had gone?	Q34	Q37	
Did a member of staff give you advice about caring for your child after you went home?	Q37	Q38	
Did a member of staff tell you who to talk to if you were worried about your child when you got home?	Q38	Q39	
When you left hospital, did you know what was going to happen next with your child's care?	Q39	Q40	
Were you given any written information (such as leaflets) about your child’s condition	Q40	Q41	

or treatment to take home with you?			
Do you feel that the people looking after your child listened to you?	Q41	Q42	
Do you feel that the people looking after your child were friendly?	Q42	Q43	
Do you feel that your child was well looked after by the hospital staff?	Q43	Q44	
Do you feel that you (the parent/carer) were well looked after by hospital staff?	Q44	Q45	
Were you treated with dignity and respect by the people looking after your child?	Q45	Q46	
Overall… I felt that my child had a very poor experience (0) to I felt that my child had a very good experience (10) (please circle a number)	Q46	Q47	
Is your child male or female?	Q47	Q48	
What is your child's year of birth?	Q48	Q49	Example amended
Including this visit, how many times has your child been to hospital in the past six months?	Q49	Q50	Amended question – non-comparable to previous iteration due to amendments.
Does your child have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more?	N/A	Q51	New question

Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	N/A	Q52	New question
Do any of these reduce your child's ability to carry out day-to-day activities?	N/A	Q53	New question
Which of these best describes your child's ethnic background? (Cross ONE only)	Q52	Q54	

Table 5. *Questionnaire B: 8-11 children's questionnaire*

Question	Question number 2016	Question number 2018	Comments and notes
Did hospital staff play with you or do any activities with you while you were in hospital?	Q1	Q1	
Were there enough things for you to do in the hospital?	Q2	Q2	
If you used the hospital Wi-Fi, was it good enough to do what you wanted?	N/A	Q3	New question
Did you like the hospital food?	Q3	Q4	
Was it quiet enough for you to sleep when needed in the hospital?	Q4	Q5	
Did hospital staff talk with you about how they were going to care for you?	Q5	Q6	
When the hospital staff spoke with you, did you understand what they said?	Q6	Q7	
Did you feel able to ask staff questions?	Q7	Q8	
Did the hospital staff answer your questions?	Q8	Q9	
Were you involved in decisions about your care and treatment?	Q9	Q10	
If you had any worries, did a member of staff talk with you about them?	Q10	Q11	Amended question – non-comparable to previous iteration due to amendments.
Were you given enough privacy when you were	Q11	Q12	

receiving care and treatment?			
If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	Q12	Q13	
During your time in hospital, did you have any operations or procedures?	Q13	Q14	Amended question
Before the operations or procedures, did hospital staff explain to you what would be done?	Q14	Q15	
Afterwards, did staff explain to you how the operations or procedures had gone?	Q15	Q16	
Did a member of staff tell you who to talk to if you were worried about anything when you got home?	Q16	Q17	
When you left hospital, did you know what was going to happen next with your care?	Q17	Q18	
Did a member of staff give you advice on how to look after yourself after you went home?	Q18	Q19	
Do you feel that the people looking after you were friendly?	Q19	Q20	
Overall, how well do you think you were looked after in hospital?	Q20	Q21	
Are you a boy or a girl?	Q21	Q22	
How old are you today?	Q22	Q23	
Parent's section			

Was your child's visit to hospital planned or an emergency?	Q23	Q24	
Did your child stay overnight during their most recent visit to hospital?	N/A	Q25	New question
For most of their stay in hospital, what type of ward did your child stay on?	Q24	Q26	Amended question
Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Q25	Q27	
How clean do you think the hospital room or ward was that your child was in?	Q26	Q28	
Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	Q27	Q29	
Did a member of staff agree a plan for your child's care with you?	Q28	Q30	
Did you have confidence and trust in the members of staff treating your child?	Q29	Q31	
Did staff involve you in decisions about your child's care and treatment?	Q30	Q32	
Were you given enough information to be involved in decisions about your child's care and treatment?	Q31	Q33	
Did hospital staff keep you informed about what was	Q32	Q34	

happening whilst your child was in hospital?			
Were you able to ask staff any questions you had about your child’s care?	Q33	Q35	
Were the different members of staff caring for and treating your child aware of their medical history?	Q34	Q36	
Did you feel that staff looking after your child knew how to care for their individual or special needs?	Q35	Q37	
Were members of staff available when your child needed attention?	Q36	Q38	
Did the members of staff caring for your child work well together?	Q37	Q39	
If you had been unhappy with your child’s care and treatment, do you feel that you could have told hospital staff?	N/A	Q40	New question
Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	Q38	Q41	
Were you able to prepare food in the hospital if you wanted to?	Q39	Q42	
Did you stay overnight with your child during their most recent visit to hospital?	Q40	Q43	Amended question – non-comparable to previous iteration due to amendments.
How would you rate the facilities for parents or carers staying overnight?	Q41	Q44	

If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Q42	Q45	
During their stay in hospital, did your child have any operations or procedures?	Q43	Q46	
Before your child had any operations or procedures, did a member of staff explain to you what would be done?	Q44	Q47	
Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Q45	Q48	
During any operations or procedures, did staff play with your child or do anything to distract them?	Q46	Q49	
Afterwards, did staff explain to you how the operations or procedures had gone?	Q47	Q50	
Did a staff member give you advice about caring for your child after you went home?	Q50	Q51	
When you left hospital, did you know what was going to happen next with your child's care?	Q51	Q52	
Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	Q52	Q53	
Do you feel that you (the parent/carer) were well	Q53	Q54	

looked after by hospital staff?			
Were you treated with dignity and respect by the people looking after your child?	N/A	Q55	New question (added to parent's section of 8-11 questionnaire for the first time)
Overall… I felt that my child had a very poor experience (0) to I felt that my child had a very good experience (10) (please circle a number)	Q54	Q56	
Who was the main person who answered the questions in the children's section of the questionnaire?	Q55	Q57	Amended question
Including this visit, how many times has your child been to hospital in the past six months?	Q56	Q58	Amended question – non-comparable to previous iteration due to amendments.
Which of these best describes your child's ethnic background? (Cross ONE only)	Q57	Q59	
Does your child have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?	N/A	Q60	New question
Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	N/A	Q61	New question
Do any of these reduce your child's ability to carry out day-to-day activities?	N/A	Q62	New question

Table 6. *Questionnaire C: 12-15 young people's questionnaire*

Question	Question number 2016	Question number 2018	Comment
Was the ward suitable for someone of your age?	Q1	Q1	
Were there enough things for you to do in the hospital?	Q2	Q2	
If you used the hospital Wi-Fi, was it good enough to do what you wanted?	N/A	Q3	New question
Did you like the hospital food?	Q3	Q4	
Was it quiet enough for you to sleep when needed in the hospital?	Q4	Q5	
Did hospital staff talk with you about how they were going to care for you?	Q5	Q6	
When the hospital staff spoke with you, did you understand what they said?	Q6	Q7	
Did you feel able to ask staff questions?	Q7	Q8	
Did the hospital staff answer your questions?	Q8	Q9	
Were you involved in decisions about your care and treatment?	Q9	Q10	
If you had any worries, did a member of staff talk with you about them?	Q10	Q11	Amended question – non-comparable to previous iteration due to amendments.
Were you given enough privacy when you were receiving care and treatment?	Q11	Q12	

If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?	Q12	Q13	
If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	Q13	Q14	
During your time in hospital, did you have any operations or procedures?	Q14	Q15	Amended question
Before the operations or procedures, did hospital staff explain to you what would be done?	Q15	Q16	
Afterwards, did staff explain to you how the operations or procedures had gone?	Q16	Q17	
Did a member of staff tell you who to talk to if you were worried about anything when you got home?	Q17	Q18	
When you left hospital, did you know what was going to happen next with your care?	Q18	Q19	
Did a member of staff give you advice on how to look after yourself after you went home?	Q19	Q20	
Do you feel that the people looking after you were friendly?	Q20	Q21	
Overall, how well do you think you were looked after in hospital?	Q21	Q22	
Are you male or female?	Q22	Q23	
How old are you today?	Q23	Q24	

Parent's section			
Was your child's visit to hospital planned or an emergency?	Q24	Q25	
Did your child stay overnight during their most recent visit to hospital?	N/A	Q26	New question
For most of their stay in hospital, what type of ward did your child stay on?	Q25	Q27	Amended question.
Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Q26	Q28	
How clean do you think the hospital room or ward was that your child was in?	Q27	Q29	
Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	Q28	Q30	
Did a member of staff agree a plan for your child's care with you?	Q29	Q31	
Did you have confidence and trust in the members of staff treating your child?	Q30	Q32	
Did staff involve you in decisions about your child's care and treatment?	Q31	Q33	
Were you given enough information to be involved in decisions about your child's care and treatment?	Q32	Q34	
Did hospital staff keep you informed about what was	Q33	Q35	

happening whilst your child was in hospital?			
Were you able to ask staff any questions you had about your child's care?	Q34	Q36	
Were the different members of staff caring for and treating your child aware of their medical history?	Q35	Q37	
Did you feel that staff looking after your child knew how to care for their individual or special needs?	Q36	Q38	
Were members of staff available when your child needed attention?	Q37	Q39	
Did the members of staff caring for your child work well together?	Q38	Q40	
If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	N/A	Q41	New question
Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	Q39	Q42	
Were you able to prepare food in the hospital if you wanted to?	Q40	Q43	
Did you stay overnight with your child during their most recent visit to hospital?	Q41	Q44	Amended question – non-comparable to previous iteration due to amendments.

How would you rate the facilities for parents or carers staying overnight?	Q42	Q45	
If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Q43	Q46	
During their stay in hospital, did your child have any operations or procedures?	Q44	Q47	
Before your child had any operations or procedures, did a member of staff explain to you what would be done?	Q45	Q48	
Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Q46	Q49	
During any operations or procedures, did staff play with your child or do anything to distract them?	Q47	Q50	
Afterwards, did staff explain to you how the operations or procedures had gone?	Q48	Q51	
Did a staff member give you advice about caring for your child after you went home?	Q51	Q52	
When you left hospital, did you know what was going to happen next with your child's care?	Q52	Q53	
Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	Q53	Q54	

Do you feel that you (the parent/carer) were well looked after by hospital staff?	Q54	Q55	
Were you treated with dignity and respect by the people looking after your child?	N/A	Q56	New question (added to parent's section of 12-15 questionnaire for the first time)
Overall… I felt that my child had a very poor experience (0) to I felt that my child had a very good experience (10) (please circle a number)	Q55	Q57	
Who was the main person who answered the questions in the children's section of the questionnaire?	Q56	Q58	Amended question
Including this visit, how many times has your child been to hospital in the past six months?	Q57	Q59	Amended question – non-comparable to previous iteration due to amendments.
Which of these best describes your child's ethnic background? (Cross ONE only)	Q58	Q60	
Does your child have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?	N/A	Q61	New question
Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	N/A	Q62	New question

Do any of these reduce your child’s ability to carry out day-to-day activities?	N/A	Q63	New question