

DEVELOPMENT REPORT FOR THE 2016 CHILDREN'S INPATIENT AND DAY CASE SURVEY

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NHS PATIENT SURVEY PROGRAMME

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1. Introduction

The National Children and Young People's Inpatient and Day Case (CYP) survey was first run in 2014. The data collected in July and August 2014 captured the experiences of children and young people aged 8 to 15 years and the parents and carers of children and young people aged 0-15 years. The survey is set to run again in early 2017 as part of the NHS Patient Survey Programme, with the sample being drawn from patients discharged from hospital in November and December 2016. The data collected will be used to analyse children and young people's experiences of care in 2016 and to generate information to facilitate targeted quality improvement.

The survey is coordinated by the Patient Survey Co-ordination Centre at Picker Institute Europe. The Co-ordination Centre has worked with the Care Quality Commission (CQC) to develop each of the questionnaires that are being used for the 2016 Children and Young People's Inpatient and Day Case survey. The Co-ordination Centre will also provide technical advice and support to NHS trusts implementing the survey and will produce the analysis on completion of the survey.

Summary of development

The questionnaires for the National Children and Young People's Inpatient and Day Case survey have been redeveloped following consultation with key stakeholders, including CQC, NHS England and the Department of Health. The process of redevelopment involved a review and analysis of item non-response rates and floor / ceiling effects from 2014, the generation of new questions to investigate key patient experience issues raised by stakeholders and amendments to a number of questions that were asked in 2014.

All three versions of the questionnaire have been revised for the 2016 survey to make them as relevant and as useful as possible for trusts and stakeholders. The questionnaires have been tested thoroughly with patients and parents through the use of cognitive interviews that were held over a period of three weeks in July and August 2016. After each week of interviews, changes were made to any questions that prompted interviewees to suggest that amendments may be necessary. Changes were then tested in further interviews. Each additional round of testing enabled us to increase our confidence that the questions that have been developed are understood by patients and are measuring what is intended.

A systematic stratified sample will be used for the 2016 Children's and Young People's Survey, with samples being drawn from a list of day case and inpatients that attend hospital in November and December 2016. Trusts will be issued with instruction manuals that explain how to apply the sampling method and which outline the criteria for determining eligibility.

2. Survey Methodology

For the 2014 survey, each trust compiled a list with a maximum of 900 eligible (aged 0-15 years old) inpatients and day case patients that were consecutively discharged alive from their trust, working back from August 31st 2014. Trusts included patients from July only if they did not reach the minimum requirement of 380 patients during the month of August alone. The samples were then decreased to 850 patients following DBS checks. The majority of patients treated in these trusts during the sampling period were aged 0-7 years, which meant that the consecutive, non-stratified sampling method that was used in 2014 resulted in the generation of samples (and therefore the response population) that were largely populated by 0-7 year olds. This was problematic as it led to a significant number of trusts being unable to obtain enough usable data from 8-15 year olds.

In response to this the problem, the Co-ordination Centre ran a pilot in July and August 2016 to investigate if the use of a systematic stratified sample would increase the number of responses that trusts would likely receive from 8-15 year olds. The approach required trusts to divide their population of patients into three groups based on the three age brackets being surveyed and to then sort the patient list by date of birth and by gender. Trusts were then instructed to draw a sample systematically from each of the groups.

The decision to adopt the method was taken following an analysis of the sample data that was submitted to the Co-ordination Centre from 113 Trusts. The analysis found that (1) the method sufficiently increased the number of responses that trusts could expect to receive from 8-15 years old, (2) that significantly more trusts should receive enough responses for the Co-ordination Centre to provide them with useful data than did so in 2014, and (3) that trusts did not have any significant problems in accurately implementing the more complex sampling approach. A small number of errors were found in the samples submitted by trusts, as detailed in table 1, below. The instruction manuals that will be used by trusts and contractors when drawing their samples for the 2016 survey will include information that explains how these errors can be avoided.

Table 1: Errors in Submitted Samples

Error
Did not input the necessary random start numbers, which meant that the automatic sampling could not take place.
Failed to copy and paste the entire data set when transferring it from one excel sheet to another
Mistakenly included only the most recent 1250 patients. Trust did not select all eligible patients that had been discharged during the sampling period.
Coded 'gender' using text (males/females) instead of using numeric 1s and 2s. Coded 'main speciality' using text (Anaesthetics, Paediatrics etc.) instead of using numeric codes.
Used the trust's patient ID instead of Trust code (patient ID being a unique identifier added by the trust and not the same as their NHS number).

The sample size that each trust will draw has also been increased from 850 to 1250 patients. This is in line with changes to the national Inpatients and Emergency Department surveys, and takes account of both sample power calculations and cost-effectiveness considerations. A complete sample would contain 1250 patients. This would consist of 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 average response rate to the 0-7 questionnaire in 2014 was slightly lower than it was for the other two age groups. Having a larger sample size for the youngest group for the 2016 survey should lead to a balanced number of responses across the three groups if the response rates to the questionnaires are the same as they were in 2014.

Of the 113 trusts that submitted pilot data, only a small minority of trusts were able to generate a full sample of 1250 patients. This was in many cases due to trusts having too few patients in one or two of the age groups. However, many of these trusts had more than the target number in one or two of the other groups, and as such, they would be able to increase the size of their sample if these 'excess' patients were included. The analysis of the sample pilot data also found that the method caused five trusts to generate a sample that was smaller than if they used the method that was used in 2014. This occurred because the

systematic stratified sampling method put a limit on the maximum number of patients that could be included in the sample from each of the groups.

In response to these findings, it has been decided that when trusts draw their sample in early 2017, they will be enabled to increase the size of their sample by including any excess patients from any group(s) with more patients than the target number. The sample construction spreadsheet that trusts will use to draw their sample will automatically determine if this is possible, and if so, it will also automatically calculate how many patients to include and from which group(s) to include them from.

For the 2014 survey, the questionnaires were made available to be completed online. It has been decided not to re-run the survey online for the 2016 survey as not enough responses were generated - only 147 online responses (<1%) were received nationally.

3. Changes to the mailing letters and information leaflet

Some minor alterations have been made to the text of the cover letters in order to make them shorter and to make the language more accessible. Text has been included to inform recipients about the quantity of people who returned the questionnaire in 2014, to tell them that their answers will help hospitals improve the care that they provide to other children, and to inform them that there is a section for children to complete. Colour has also been added to the mailing letters to make them more appealing.

Changes have been made to the children's information leaflet (which is included in the mailing packs) in order to make it both shorter and more engaging for children. It now uses less text and more colour. It has been redesigned to increase the likelihood that children will read it.

4. 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 decide which questions that appeared in the 2014 questionnaires should be omitted from the 2016 questionnaires. A list of potential questions were then drafted by the Co-ordination Centre and submitted to the advisory group for feedback. Their comments and recommendations led to the rewording of a number of questions and to the development of the initial first drafts of the three questionnaires.

5. Data confidentiality

Approval for the National Children and Young People's Inpatient and Day Case Survey 2016 was sought and obtained under Section 251 of the NHS Act 2006. 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.

The way in which data is transferred between trusts and their contractors has been changed in order to reduce the possibility of data breaches. Previously NHS trusts split patient name and address details out into a 'mailing file' and the demographic information of the patients into a 'sample file'. Following a serious error in the use of this approach in another survey, it

has been decided that trusts will no longer separate the two types of information before sending it to their approved contractor. This change will ensure that the integrity of the dataset is maintained as it reduces the chance of sampling and mailing files becoming desynchronised due to changes inadvertently made to one file and not the other.

6. Best practices in CYP research and the use of 'Easy Read' questionnaires

In preparation for the 2016 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 Children and Young People's Inpatient and Day Case Survey.

Young children can't 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), and as such, questions asked to 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'd been on a *school* field trip). 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. For example, Q5 in the 8-11 year olds questionnaire from 2014 '*Did hospital staff talk to you about how they were going to care for you, in a way that you could understand?*' was reduced in length in order to reduce its complexity by removing the unnecessary text '*in a way that you could understand*'. The literature suggests that having four response options per question is optimal when considering the trade-off between having more response options against question response rates. Generally speaking, offering clear and unambiguous response options produces the best data when conducting questionnaire research with children.

As part of the development process, the viability and the practicality of using 'Easy Read' questionnaires was investigated. Easy Read refers to text that is presented in an accessible, easy to understand format. It is used when presenting information to people with learning disabilities or to those that have less capacity or ability to process information.

The decision was taken not to use Easy Read questionnaires for a number of reasons. The main concern was that using Easy Read versions of the questionnaires would have a negative effect on the amount of useable data that would be collected from individual trusts. This is because having two versions of each questionnaire would reduce the number of responses to the full survey, thereby negatively impacting on the amount of usable data trusts would receive (which was already limited in 2014 for some trusts due to low response rates). It is extremely unlikely that enough responses would be received to the Easy Read survey to provide any trust level data, so there is the potential that there would not be enough data collected (from either version of the survey) to provide feedback to some trusts. Added to this, is the fact that if there were two versions of the questionnaires they would not produce comparable data.

At a national level we would not anticipate receiving a large amount of data from an Easy Read version of the CYP survey. In 2014, of those respondents in the 8-11 and 12-15 categories who were identified as having a learning disability, slightly under half (237 respondents) had the child's section completed by the parent or carer. Whilst there may be some cases where the introduction of an Easy Read version would lead to new people responding, we would expect some of these parents would still choose to complete the main survey rather than requesting the Easy Read version, and as such, the numbers are unlikely to be large.

There is also the possibility that making Easy Read questionnaires available would lead some people to opt to complete the Easy Read versions who would have otherwise completed the main version.

There are also a number of other issues that complicate the use of Easy Read versions of the questionnaires. Children with learning disabilities are not a homogenous group, meaning that children with different types of learning disabilities would likely require different survey instruments - different language/pictures/content. The challenge of designing effective Easy Read questionnaires would therefore be significant. Not only would the language need to be rigorously tested, but the images would also have to be tested to ensure that they are understood and responded to in a consistent way by a variety of different types of children (with different disabilities and from different cultural and family backgrounds). This is unlikely to be completely possible in a single version.

The use of Easy Read questionnaires would also require undertaking a significant amount of cognitive testing to ensure that children with different types of learning disabilities interpret the questionnaire(s) in the way that they are intended to be understood. If a questionnaire could be developed following that, it would then need to be piloted in order to assess its viability and impact upon response rates.

Parents and carers of children with learning disabilities have the best understanding of how to work with their child's communication needs and, as such, they are the people best placed to help their child complete a survey. Even if an Easy Read survey were to be developed, it is highly likely that parents and carers would still need to be involved in many cases, in order for a child to complete it.

7. Cognitive testing of the questionnaires

Cognitive interviews conducted with children need to be approached in a careful way as the literature suggests that children may be inclined to think researchers are looking for the "right" answer. 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?").

Following consultation with key stakeholders the 2014 survey instruments were revised and then cognitively tested with 24 volunteers. The objectives of cognitive testing were to ensure that the questions are clear, relevant and consistently understood. Three rounds of testing were held, each over a period of one week. Revisions were made to the questionnaires at

the end of each of the first two weeks of testing in preparation for the interviews held in the following week.

Recruitment was challenging and required the use of a number of different approaches. The help provided by Great Ormond Street Hospital (GOSH) enabled recruitment of more volunteers than any other approach. GOSH advertised our search for volunteers using their Facebook and Twitter accounts. They recruited eight volunteers in week one of testing and four volunteers in week three of testing.

Oxford University hospital helped by recruiting two volunteers. The remaining volunteers responded to an advert placed on DailyInfo.com. Physical adverts placed in various locations around Oxford (noticeboards in supermarkets, GP offices, local community centres etc.), as well as adverts placed on Mumsnet and Gumtree did not lead to the recruitment of any volunteers. The quantity and the spread of the ages of the 24 volunteers are outlined in the table below.

Table 2: Cognitive Interviewees

Age group	CYP required	Parents required
0-7	0	4
8-11	6	3
12-15	7	4

8. Changes to Questionnaires

All three versions of the questionnaire have been revised for the 2016 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 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, and the Department of Health.
- Analysis of the 2014 survey data to examine item non-response rates and floor / 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**.

8.1 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.

Table 3: New Questions in Children's Section

New Question Reference	8-11 (B)	12-15 (C)	Question
N1		1	Was the ward suitable for someone of your age?
N2	2		Were there enough things for you to do in the hospital?
N3	4	4	Was it quiet enough for you to sleep when needed in the hospital
N4	6	6	When the hospital staff spoke with you, did you understand what they said?
N5	7	7	Did you feel able to ask staff questions?
N6	8	8	Did the hospital staff answer your questions?
N7		12	If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?
N8	9		Were you involved in decisions about your care and treatment?
N9	17		When you left hospital, did you know what was going to happen next with your care?
N10	18		Did a member of staff give you advice on how to look after yourself after you went home?

Children N1 (C) - No problems with this question. Respondents either named things to play with in the ward that they deemed age appropriate or mentioned the age range of the other children in the ward.

Children N2 (B) - No major problems with this question. One child thought 'things' was too vague. Children mentioned the availability of PlayStations, films and games.

Children N3 (B, C) - No problems with this question. Understood question as referring to both night time sleeping and daytime sleeping. Some children mentioned noisy machines.

Children N4 (B, C) - One child mentioned that their mother spoke with the staff. One respondent found it difficult to differentiate between always and sometimes. A number of respondents mentioned that some of the staff used 'scientific' words that they didn't understand.

Children N5 (B, C) - The word 'staff' was added to the question after the first round of testing to ensure children weren't thinking about their parents or someone else not responsible for their medical care. A few children didn't understand the routing until it was explained to them. Respondents mentioned they spoke with nurses, doctors or surgeons.

Children N6 (B, C) - No problems with this question.

Children N7 (C) - After the first round of testing 'without anyone else being there?' was changed to "without your parent or carer being there?" as some children did not interpret the question as intended. There was no issues when the revised question was tested.

Children N8 (B) – Respondents understood involvement as meaning being asked to make choices or to participate in discussions about what would be done about their care or treatment. During the first week of testing, one child did not understand the question until it was explained to them. During weeks two and three this question was tested more closely and all children offered valid explanations for what involved meant.

Children N9 (B) - 'what would happen' was changed to 'what was going to happen' after the first round of testing because the former was perceived as being less definitive than the latter. Question was then understood by all respondents as intended.

Children N10 (B) - Response option 'I did not need any advice' was added after first round of testing in response to children reporting that they did not need advice. Children mentioned that medical advice was communicated verbally to either them or to their parent by the hospital staff.

Table 4: New Questions in Adult's Section

New Question Reference	0-7 (A)	8-11 (B)	12-15 (C)	Question
N12	16	31	32	Were you given enough information to be involved in decisions about your child's care and treatment?
N13	26	39	40	Were you able to prepare food in the hospital if you wanted to?
N14	33	46	47	During any operations or procedures, did staff play with your child or do anything to distract them?
N15	44	53	54	Do you feel that you (the parent/carer) were well looked after by hospital staff?

Adults N12 (A, B, C) - Parents reported that information was mostly communicated to them verbally. They mentioned that they had discussed with staff how long their child would need to stay in hospital, how they would need to care for their child at home, and the reasons for doing particular tests. The response option "I did not want to be involved" was removed after the first round of testing because all parents/carers are involved to some degree in their child's care.

Adults N13 (A, B, C) - No problems with this question. A few parents/carers reported that there was a microwave available, but the majority of the parents/carers stated that they did not want to prepare food.

Adults N14 (A, B, C) - Parents mentioned that staff chatted with the children or used toys to distract them. One parent noted that it was a 'bizarre' question and that it was 'not appropriate for an adolescent. The word 'tests' was removed after cognitive testing from all question in the 'operations & procedures' section as there was a concern that respondents would think about test results rather than whether or not the test had been performed successfully. See **Children A7** below for more details

Adults N15 (A, B, C) - The words in brackets "(parent/carer)" were added to the question after the first round of testing as some parents referred to how their child was looked after by the hospital rather than how they (the parent/carer) were looked after when answering the question. Question performed as intended after the change, with parents mentioning staff helping them with their bed, with making coffee, and with taking the responsibility for caring for their child while they took a break.

8.2 Removed Questions

The questions below have been removed (1) due to ceiling effects and lack of variation at the trust level, (2) because of the addition of new questions which make the old question redundant, or (3) as a consequence of amendments that have been made to other questions in the questionnaires.

Table 5: Questions Removed from Children's Section (2014 question numbers)

Removed Question Reference	8-11 (B)	12-15 (C)	Question
R1	1	1	When you first arrived at hospital, did people working at the hospital tell you what was going to happen to you while you were there?
R2	2	2	Did you feel safe on the hospital ward?
R3		8	Did staff talk to each other about you as if you weren't there?
R4	8	10	Did your condition ever cause you pain while you were in hospital?
R5	14	18	Do you feel that the people looking after you listened to you?

Table 6: Questions Removed from Adult's Section (2014 question numbers)

Removed Question Reference	0-7 (A)	8-11 (B)	12-15 (C)	Question
R5	7			Did you feel that your child was safe on the hospital ward?
R6	4	20	24	Did hospital staff tell you what was going to happen to your child while they were in hospital?
R7	28	36	40	Did your child's condition cause them any pain while they were in hospital?

8.3 List of Amendments

There have been amendments to a significant number of questions in each of the questionnaires. The amendments that have been made and the reason for the changes are outlined below.

Each of the amendments are referenced using a code with three parts. The first part indicates if the amendment is in the children's section or in the adult's section, the second part refers to the amendment reference number (see table 7 and table 8 following the list of amendments), and the third part indicates the versions in which the question has been amended. The 0-7 questionnaire is version **A**, the 8-11 questionnaire is version **B**, and the 12-15 questionnaire is version **C**. Table 8 and Table 9 in the appendix below show which amendments correspond with which question numbers for each of the three versions of the questionnaire. For the questions where there have only been amendments to the response options, there is an asterisk next to the reference code in the table.

Children A1 (C)

Previous: Were there enough things for someone of your age to do on the ward?

New: Were there enough things for you to do in the hospital?

- This was changed as there can be a disassociation between what a respondent considers age appropriate and what they are happy to play with or to do to keep themselves entertained while in hospital.

Cognitive testing: see notes for **Children N2** above.

Children A2 (B, C)

Previous: Did hospital staff talk to you about how they were going to care for you, in a way that you could understand?

New: Did hospital staff talk with you about how they were going to care for you?

- '*in a way that you could understand?*' was removed to avoid asking respondents two questions at once i.e. 1) did they talk, and 2) was it understandable.

Cognitive testing: Respondents mentioned nurses, doctors, consultants and play specialists. Respondents interpreted question as asking them about how staff would help them get better.

Children A3 (B, C)

Previous: If you had any worries, did someone at the hospital talk with you about them?

New: If you had any worries, did a member of staff talk with you about them?

- Question amended to ensure respondents are thinking about hospital staff, rather than a parent, a carer or some other non-medical professional.
- Response option has also been amended. "I did not have any worries" has been changed to "I did not want to talk to staff about any worries". This change was made to ensure respondents are thinking about staff rather than their parent or guardian.

Cognitive testing: This question was seen as tricky, because parents are often used as a conduit and it would be more usual for a child to raise any concerns with a parent, who would then pass it on. One respondent mentioned they had no worries, but that if they did they would have spoken with their mother. Most children said that they had no worries. Respondents mentioned play specialists and nurses as the staff members they spoke with.

Children A4 (B, C)

Previous: Do you think the hospital staff did everything they could to help your pain?

New: If you felt pain while you were at the hospital, do you think staff did everything they could to help you?

- Two questions turned into one in order to remove a routing question
- Response options now include. 'I did not feel any pain while in hospital'. The inclusion of this option addresses the lack of routing and frees up space for other questions

Cognitive testing: No problems with this question. Most children answered yes without elaborating. One respondent said that staff would check up on them and give them a painkiller if they felt pain. Another child stated "Yes, but sometimes there isn't anything they can do".

Children A5 (B, C)

Previous: During your time in hospital, did you have an operation or procedure (such as having your tonsils taken out)?

New: During your time in hospital, did you have any operations or procedures (such as having your tonsils taken out)?

- The words operation or procedure have been made plural. This is to account for patients who have had more than one operation or procedure

Cognitive testing: This question was not tested in 2016. The question that will be asked is a slightly amended version of the question that was asked in 2014.

Children A6 (B, C)

Previous: Before the operation or procedure, did hospital staff tell you what would be done?

New: Before the operations or procedures, did hospital staff explain to you what would be done?

- The words operation or procedure have been made plural. This is to account for patients who have had more than one operation or procedure
- 'tell you' has been changed to 'explain to you' to match the text used for the same question asked to parents and carers

Cognitive testing: Respondents found it easy to answer this question. See **Children A7** below for more details about the comments made during cognitive testing.

Children A7 (B, C)

Previous: Afterwards, did someone from the hospital explain to you how the operation or procedure had gone in a way you could understand?

New: Afterwards, did staff explain to you how the operations or procedures had gone?

- The words operation or procedure have been made plural. This is to account for patients who have had more than one operation or procedure.
- *'in a way you could understand'* was removed to avoid asking respondents two questions at once i.e. 1) did they talk and 2) was it understandable.

Cognitive testing: The section on Operations and Procedures for both the children's (A5-A7 above) and the adult's sections (A23 –A26 below) of the questionnaires went through a number of changes during cognitive testing. An alternative to the routing question was tested and all of the questions in the sections were tested with the inclusion of the word 'tests'. It was ultimately decided to reuse the questions that were used in 2014, albeit with very minor changes.

In the first two weeks of cognitive interviewees, the question 'Before you had any operations, procedures or tests, did a member of staff explain to you what would be done?' was tested with the response option 'I did not have any operations, procedures or tests'. The objective of this was to see if it was possible to remove the routing question. In week 2 of cognitive testing, interviewees suggested adding a 'don't know/can't remember' response option to this question, which meant that there were five response options to the question in week 3 of cognitive testing. In order to avoid having five responses options, it was decided to include the routing question that was used in the 2014 survey.

The word 'tests' was removed from all of the Operations and Procedures questions as there was a concern that respondents would think about test results when they were asked 'Afterwards, did staff explain to you how the operations, procedures or tests had gone?' This was seen as being problematic for two reasons (1) because test results may not be available immediately, and (2) because the objective of the question is to ask patients if staff had explained how any operations, procedures or tests had gone. For example, if the child had had a blood test, the answer to the question should be about whether or not blood had been drawn successfully, and not about the result of the blood test.

Children A8 (B, C)

Previous: Did someone from the hospital tell you what to do or who to talk to if you were worried about anything when you got home?

New: Did a member of staff tell you who to talk to if you were worried about anything when you got home?

- 'what to do or' has been removed from the middle of question. This change was made so that respondents are now only being asked one question.

Cognitive testing: No problems with this question. Respondents mentioned being told to speak with their parents or that they couldn't remember if they were told anything.

Children A9 (C)

Previous: Did a member of staff tell you what would happen after you left hospital?

New: When you left hospital, did you know what was going to happen next with your care?

- This was changed to ensure children think about what will happen next with their care, rather than think about what would happen when they left hospital in a general sense. Using the first option could lead some children to interpret the questions as asking to what they will do in a general sense, e.g. go to the shops etc.
- The response option 'Yes, completely' was changed to 'Yes' to standardise the response options across the section.

Cognitive testing: See '**Children N9**' above for more details about the comments made during cognitive testing.

Children A10 (C)

Question unchanged: Did a member of staff give you advice on how to look after yourself after you went home?

- 'Yes, definitely' response option shortened to just 'Yes' to standardise the response options across the section
- 'I did not need any advice option' has been added in response to feedback obtained during cognitive interviews

Cognitive testing: See '**Children N10**' above for more details about the comments made during cognitive testing.

Children A11 (B, C)

Previous: Overall... (please circle a number)

New: Overall, how well do you think you were looked after in hospital?

- The text of the question was expanded to ensure respondents knew what they were rating
 - Response option is no longer a 1-10 scale. This change was made because there was a concern that children were rating their experience with the number of their age. It was decided to use the Likert scale below as it is less complicated and more easily understood by children.
1. Very good
 2. Quite good
 3. OK
 4. Quite bad
 5. Very bad

Cognitive interviews: One parent felt that this was a 'very weird question' because if you've been unwell then it's miserable. In week two of testing the possibility that respondents were using the number of their age to rate their experience was observed, which prompted the decision to try a new format of question.

The question '*Overall, how would you describe your hospital experience?*' was tested in week three of cognitive interviews. The answers given to the question were very similar to those given to the "Overall" question that will be asked. It was decided to use the question above as it better addresses the objective of the question, which is to find out how the patient was looked after in the hospital.

Children A12 (B)

Previous: How old are you?

New: How old are you today?

- The word 'today' was added at the end of the question to make it clear to children we are not referring to their age when they were in hospital, but on the day they complete the questionnaire

Cognitive interviews: One girl gave her age at the time of attending hospital. She was admitted for one night, two days before her birthday. She found this question confusing because she wasn't sure if it was asking her present age or her age when she was at the hospital. She felt we should add "now" or clarify what age we mean. No other issues

Children A13 (C)

Previous: What is your year of birth?

New: How old are you today?

- Question changed to match the question in the 8-11 questionnaire

Cognitive interviews: See '**Children A12**' above for more details about the comments made during cognitive testing.

Adult A14 (A, B, C)

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

- This question was moved from 'About your child' section to "The hospital ward" section because the question asks about the ward the child stays in.

Cognitive interviews: '*During their stay in hospital, was your child on a ward appropriate for their age?*' was tested in week 1 of cognitive interviews as an alternative to the question above. Respondents focused on the age of the children in the ward so it was decided to add "situation" to the question to capture more information - '*During their stay in hospital, was your child on a ward appropriate for their age and situation?*' This question was tested in weeks two and three of cognitive interviews. One respondent thought "situation" was good, and that it meant that "they weren't planned or booked it", as they came via emergency. She commented that the response options did not capture her experience and that she wanted the opportunity to say more: "Appropriate for age and the fact that we turned up in an 'emergency'... but not a particularly 'ideal' or comfortable place to be." Another respondent liked that the question asks "age and situation", because age may be different to situation. In her daughter's case, the age is the biological age, but the situation is her mental age. It was decided to revert to the use of the original question as the questions tested here are similar to question **Children N1** above.

Adult A15 (A, B, C)

Previous: Did the ward where your child stayed have appropriate equipment or adaptations for your child?

New: Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?

- The words 'physical or medical' added to ensure consistent interpretation of the question, and to ensure respondents aren't thinking about non-health related equipment or adaptations.

Cognitive interviews: During cognitive testing a number of interviewees mentioned non-medical related equipment or adaptations, such as, clothes, play areas, games etc. After the final week of testing, it was decided to add the word 'physical' to the question to address the concern that when answering the question, respondents may only think about the case in hand rather than about their child's routine needs. We were unable to re-test the question with the word 'physical' included due to time constraints. However, as its inclusion does not change the logic of the question this was not considered to be an issue.

Adult A16 (A)

Previous: Did you think there were appropriate things for your child to play with on the ward?

New: Were there enough things for your child to do in the hospital?

- This question was amended so that it is similar to the related question in the children's sections of the other two questionnaires.

Cognitive interviews: No problems with this question. Parents interpreted the question as referring to recreational activities. They mentioned toys, a play room and books as things available to keep children entertained. One parent mentioned that there was nothing for a baby, but that there were things available to keep older children entertained.

Adult A17 (A, B, C)

Previous: Were you encouraged to be involved in decisions about your child's care and treatment?

New: Did staff involve you in decisions about your child's care and treatment?

- Question re-written following cognitive interviews. It now more directly asks if the parent was involved
- Response option added - 'I did not want to be involved' - to route past next question

Cognitive interviews: This question was changed in response to a comment in week one of testing where an interviewee suggested that being encouraged to be involved is not the same as actually being listened to and involved. Interviewees in later rounds responded well to the change, stating that they understood the question to be about either participating in the discussion about the choices available to them or about being able to make decisions.

Adult A18 (A, B, C)

Previous: Did staff ask you if you had any questions about your child's care?

New: Were you able to ask staff any questions you had about your child's care?

- This was changed in response to cognitive interviews, where volunteers suggested that being asked if they had any questions wasn't as important as being able to ask questions.

Cognitive interviews: One interviewee pointed out that some parents may find it difficult to challenge the authority of medical professionals, even when they are asked if they have any questions. The question was therefore reworded in such a way as to find out if parents were both given an opportunity to ask questions and were able to take the opportunity if they had wanted to.

Adult A19 (A)

Previous: Were you told different things by different people, which left you feeling confused?

New: Did different staff give you conflicting information?

- The complexity of this question has been reduced in response to concerns raised by the advisory group. As previously the question asked about two things at once 1) did staff say different things, and 2) did this confuse them

Cognitive interviews: No problems with this question. Respondents understood 'conflicting' correctly - that different people give different information.

Adult A20 (A, B, C)

Question unchanged: Were the different members of staff caring for and treating your child aware of their medical history?

- The last response option has been amended. It has been changed from 'Don't know / can't remember' to 'Don't know / not applicable' in response to feedback obtained during cognitive interviews.

Cognitive interviews: One respondent did not answer because she wasn't sure what was meant by "medical history". She suggested using "underlying conditions" or "health problems". All other respondents understood the question as intended.

Adult A21 (A, B, C)

Question unchanged: Were members of staff available when your child needed attention?

- Response options now include a 'Don't know / not applicable' option. This option was included in response to requests for its inclusion during cognitive interviews.

Cognitive interviews: No problems with this question. One parent thought about when their child might be in discomfort or about when staff might play with their child when they were bored. Another respondent said that the question made them think about whether or not staff were available to help the child immediately if something serious/dangerous were to happen.

Adult A22 (A, B, C)

Previous: Do you think the hospital staff did everything they could to help ease your child's pain?

New: If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?

- Two questions turned into one in order to remove a routing question
- Response options now include. 'I did not feel any pain while in hospital'. This change addresses the lack of routing.

Cognitive interviews: No problems with this question. Respondents mentioned staff providing medication, offering comfort, engaging in conversation and using distraction techniques in order to alleviate pain.

Adult A23 (A, B, C)

Previous: During their stay in hospital, did your child have an operation or procedure?

New: During their stay in hospital, did your child have any operations or procedures?

- The words 'operation or procedure' have been made plural. This is to account for patients who have had more than one operation or procedure

Cognitive interviews: See '**Children A7**' above for more details about the testing of this question

Adult A24 (A, B, C)

Previous: Before the operation or procedure, did a member of staff explain to you what would be done during the operation/procedure?

New: Before your child had any operations or procedures, did a member of staff explain to you what would be done?

- 'during the operation/procedure' removed from the end of question as the text is redundant. The text of the question also now matches the wording in the children's section.
- The words 'operation or procedure' have been made plural. This is to account for patients who have had more than one operation or procedure.

Cognitive interviews: See '**Children A7**' above for more details about the testing of this question

Adult A25 (A, B, C)

Previous: Before the operation or procedure, did a member of staff answer your questions about the operation or procedure in a way you could understand?

New: Before the operations or procedures, did a member of staff answer your questions in a way you could understand?

- The words operation or procedure have been made plural. This is to account for patients who have had more than one operation or procedure.

Cognitive interviews: See 'Children A7' above for more details about the testing of this question

Adult A26 (A, B, C)

Previous: After the operation or procedure, did someone explain to you how the operation or procedure had gone in a way you could understand?

New: Afterwards, did staff explain to you how the operations or procedures had gone?

- The question has been amended so that it now uses the same text as the children's section.

Cognitive interviews: See 'Children A7' above for more details about the testing of this question.

Adult A27 (A)

Previous: Did a member of staff tell you what to do or who to talk to if you were worried about your child when you got home?

New: Did a member of staff tell you who to talk to if you were worried about your child when you got home?

- 'what to do or' has been removed from the middle of the question. This change was made so that respondents are now only being asked one question. The question is also now the same as the question in the children's section.

Cognitive interviews: No problem with this question. Respondents said that they were given a contact number for the outpatients ward or for the ICU.

Adult A28 (A, B, C)

Previous: Did a member of staff tell you what would happen next after your child left hospital?

New: When you left hospital, did you know what was going to happen next with your child's care?

- This question was changed to ensure respondents think of what will happen next with their care, rather than just generally what would happen when they left hospital.

Cognitive interviews: No problem with this question. Respondents mentioned future appointments or when they were instructed to contact the hospital again for an update on their care.

Adult A29 (A, B, C)

Same Question: Does your child have any of the following long-standing conditions? (Cross all that apply)

- The box for text below "Another long-standing condition" has been removed as this data is not used for analysis

Cognitive interviews: No significant problems with this question. However, one respondent did feel that the response options did not capture her daughter's condition (autism). She noted it is not a mental health condition and that it's not covered by any of the categories.

8.4 Unchanged Questions

There are three questions that were previously tested in 2014 for which respondents gave some feedback of value.

Children CT1 (A) Did hospital staff play with you or do any activities with you while you were in hospital?

Cognitive interviews: This question tested well with 8-11 year olds, with children mentioning games, computers, and the work of a play specialist. The question tested badly with 12-15 year olds, with one person stating that "I don't need someone to play with me." Consequently, it was decided not to use this question in the 12-15 questionnaire.

Children CT2 (A, B) Were you given enough privacy when you were receiving care and treatment?

Cognitive interviews: This question was understood by the majority of respondents. There was one girl with autism who had difficulty understanding the meaning of 'privacy.'

Adult AT1 (A, B, C) Did a member of staff agree a plan for your child's care with you?

Cognitive interviews: One respondent mentioned that "plan" needed to be more specific - does it mean a short-term plan i.e. the operation and procedures, or a long-term plan i.e. follow-up appointments and physio.

Table 7: Additional feedback for questions that were previously tested in 2014

	0-7 (A)	8-11 (B)	12-15 (C)
Children CT1		1	
Children CT2		11	11
Adult AT1	13	27	28

8.5 Amended explanatory information

- a. The image of a notebook on page 2 of the 8-11 questionnaire has been removed to create additional space.
- b. On page 8 the following text has been added *"If you have any concerns about the care you or others have received please contact CQC on 0300 61 61 61"*
- c. The following text has been amended on page 1: "We want to **hear about your experiences** at the hospital. For each question please cross clearly inside one box using a black or blue pen. If you have any questions, please ask your parent or carer or call the helpline number given in the letter enclosed with this questionnaire."
 - The words 'hear about your experiences' have been changed to 'hear about your most recent experience'
 - The box with the x inside has been added
- d. The following text has been amended on page 3: "Was there anything else you wanted to tell us about your time in hospital (anything particularly good, or anything that could have been better)? **Write or draw a picture here...**"
 - The words 'Write or draw a picture here...' from the 8-11 questionnaire have been removed as the request for pictures was not found to be helpful in 2014, as

the data collected was very limited and not useable for quality improvement or regulatory purposes.

- e. The following text has been amended on page 3: “Whatever you write **or draw** in the box above will be seen by the hospital, the Care Quality Commission and researchers working with the data. We will remove any information that means someone might recognise you before publishing any of your feedback.”
- The words ‘or draw’ have been removed from the 8-11 questionnaire, in line with the change above.
- f. The following text has been amended on page 8: “Please note that the comments you provide in the box above will be looked at in full by the NHS Trust, Care Quality Commission and researchers **analysing the data**. We will remove any information that could identify you before publishing any of your feedback.”
- The words ‘analysing the data’ have been changed to ‘working with the data’ in all versions.

8.6 Appendix

Table 8: Questions Amended in Children’s Section

Amendment reference number	8-11 (B)	12-15 (C)	New Question	Old Question
A1		2	Were there enough things for you to do in the hospital?	Were there enough things for someone of your age to do on the ward?
A2	5	5	Did hospital staff talk with you about how they were going to care for you?	Did hospital staff talk to you about how they were going to care for you, in a way that you could understand?
A3	10	10	If you had any worries, did a member of staff talk with you about them?	If you had any worries, did someone at the hospital talk with you about them?
A4	12	13	If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	Do you think the hospital staff did everything they could to help your pain?
A5	13	14	During your time in hospital, did you have any operations or procedures (such as having your tonsils taken out)?	During your time in hospital, did you have an operation or procedure (such as having your tonsils taken out)?
A6	14	15	Before the operations or procedures, did hospital staff explain to you what would be done?	Before the operation or procedure, did hospital staff tell you what would be done?
A7	15	16	Afterwards, did staff explain to you how the operations or procedures had gone?	Afterwards, did someone from the hospital explain to you how the operation or procedure had gone in a way you could understand?
A8	16	17	Did a member of staff tell you who to talk to if you were	Did someone from the hospital tell you what to do or who to talk

			worried about anything when you got home?	to if you were worried about anything when you got home?
A9		18	When you left hospital, did you know what was going to happen next with your care?	Did a member of staff tell you what would happen after you left hospital?
A10*		19	Did a member of staff give you advice on how to look after yourself after you went home?	Did a member of staff give you advice on how to look after yourself after you went home?
A11	20	21	Overall, how well do you think you were looked after in hospital?	Overall... (please circle a number)
A12	22		How old are you today?	How old are you?
A13		23	How old are you today?	What is your year of birth?

Table 9: Questions Amended in Adult's Section

Amendment reference number	0-7 (A)	8-11 (B)	12-15 (C)	New Question	Old Question
A14	4	24	25	For most of their stay in hospital what type of ward did your child stay on?	For most of their stay in hospital what type of ward did your child stay on?
A15	5	25	26	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	Did the ward where your child stayed have appropriate equipment or adaptations for your child?
A16	8			Were there enough things for your child to do in the hospital?	Did you think there were appropriate things for your child to play with on the ward?
A17	15	30	31	Did staff involve you in decisions about your child's care and treatment?	Were you encouraged to be involved in decisions about your child's care and treatment?
A18	18	33	34	Were you able to ask staff any questions you had about your child's care?	Did staff ask you if you had any questions about your child's care?
A19	19			Did different staff give you conflicting information?	Were you told different things by different people, which left you feeling confused?
A20*	20	34	35	Were the different members of staff caring for and treating your child aware of their medical history?	Were the different members of staff caring for and treating your child aware of their medical history?
A21*	22	36	37	Were members of staff available when your child needed attention?	Were members of staff available when your child needed attention?

A22	29	42	43	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	Do you think the hospital staff did everything they could to help ease your child's pain?
A23	30	43	44	During their stay in hospital, did your child have any operations or procedures?	During their stay in hospital, did your child have an operation or procedure?
A24	31	44	45	Before your child had any operations or procedures, did a member of staff explain to you what would be done?	Before the operation or procedure, did a member of staff explain to you what would be done during the operation/procedure?
A25	32	45	46	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	Before the operation or procedure, did a member of staff answer your questions about the operation or procedure in a way you could understand?
A26	34	47	48	Afterwards, did staff explain to you how the operations or procedures had gone?	After the operation or procedure, did someone explain to you how the operation or procedure had gone in a way you could understand?
A27	38			Did a member of staff tell you who to talk to if you were worried about your child when you got home?	Did a member of staff tell you what to do or who to talk to if you were worried about your child when you got home?
A28	39	51	52	When you left hospital, did you know what was going to happen next with your child's care?	Did a member of staff tell you what would happen next after your child left hospital?
A29	50	58	59	Does your child have any of the following long-standing conditions? (Cross all that apply)	Does your child have any of the following long-standing conditions? (Cross all that apply)