DATA CLEANING GUIDANCE

# 

CHILDREN AND YOUNG PEOPLE’S PATIENT EXPERIENCE SURVEY 2018

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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 e-mail all trust contacts and contractors directly to inform them of the change.

This document is available from the Survey Coordination Centre website here: [www.nhssurveys.org/](http://www.nhssurveys.org/survey/1974)

## 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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## Introduction

At the end of fieldwork for the Children and Young People’s Patient Experience Survey 2018, participating trusts and contractors will be required to submit data to the Survey Coordination Centre in a raw (‘uncleaned’) format. Once the Survey Coordination Centre has received data from all participating trusts, the data must be cleaned. To ensure that the cleaning process is comparable across NHS trusts, data for all trusts in the survey are collated and cleaning is carried out on the full collated dataset.

This document provides a description and specification of the processes that will be used by the Survey Coordination Centre to clean and standardise data submitted by contractors and trusts as part of the 2018 survey. By following the guidance contained in this document, it should be possible to recreate this cleaning process.

If you have any comments or queries regarding this document please contact the Survey Coordination Centre on 01865 208127, or e-mail us at [cyp@surveycoordination.com](mailto:cyp@surveycoordination.com)

## Scope of this cleaning guide

For the 2018 survey, all trusts have to submit data for all three questionnaires: the 54 questions for the 0-7 age group questionnaire, 62 questions for the 8-11 age group questionnaire and 63 questions for the 12-15 age group questionnaire. All cleaning undertaken by SCC will include only these data.

## Definition of key terms

Definitions of terms commonly used in this document, as they apply to the 2018 survey are as follows:

Raw/uncleaned data: ‘Raw’ or ‘uncleaned’ data are data that have been entered verbatim from completed questionnaires without any editing taking place to remove contradictory or inappropriate responses; thus, all response boxes crossed on the questionnaire should be included in the data entry spreadsheet (see the survey’s instruction manual on creating raw data). The requirement for raw/uncleaned data does not, however, preclude the checking of data for errors resulting from problems with data entry or similar. Ensuring high data quality is paramount and errors resulting from data entry problems can and should be corrected by checking against the appropriate completed questionnaire.

Data cleaning: The Survey Coordination Centre uses the term ‘data cleaning’ to refer to all editing processes undertaken upon survey data once the survey has been completed and the data has been entered and collated.

Routing questions: These are questionnaire items that instruct respondents to either continue on to the next question or to skip past irrelevant questions depending on their response to the routing question. For the 2018 survey, the routing questions are:

0-7 questionnaire: Q2, Q17, Q30, Q33, and Q51.

8-11 questionnaire: Q8, Q14, Q32, Q43, Q46, and Q60.

12-15 questionnaire: Q8, Q15, Q33, Q44, Q47, and Q61.

Filtered questions: Questionnaire items that are not intended to be answered by all respondents are referred to as filtered questions. Whether individual respondents are expected to answer filtered questions depends on their responses to preceding routing questions. For the 2018 survey, the filtered questions in the questionnaire are:

0-7 questionnaire: Q3, Q4, Q18, Q31, Q34, Q35, Q36, Q37, Q52 and Q53.

8-11 questionnaire: Q9, Q15, Q16, Q33, Q44, Q47, Q48, Q49, Q50, Q61 and Q62.

12-15 questionnaire: Q9, Q16, Q17, Q34, Q45, Q48, Q49, Q50, Q51, Q62 and Q63.

Non-filtered questions: Questionnaire items that are not subject to any filtering and which should therefore be answered by all respondents. For the 2018 survey, the non-filtered questions are:

0-7 questionnaire: Q1, Q2, Q5-Q17, Q19- Q30, Q32, Q33, Q38-Q51 and Q54.

8-11 questionnaire: Q1-Q8, Q10-Q14, Q17-Q32, Q34- Q43, Q45, Q46 and Q51- Q60.

12-15 questionnaire: Q1- Q8, Q10- Q15, Q18- Q33, Q35- Q44, Q46, Q47, Q52- Q61.

Out-of-range data: This refers to instances where data within a variable has a value that is not permissible. For categorical data, as in the case of the majority of variables in this survey, this could be a value of ‘3’ being entered for a variable that has only two response options (‘1’ or ‘2’). For scale data (e.g. year of birth) data is considered to be out-of-range if it specifies a value that is not possible (for instance, year of birth as 983 or 2983). Out-of-range responses entered into the dataset should not be automatically (e.g. algorithmically) removed prior to submitting the data to the Survey Coordination Centre (see Section 2).

Non-specific responses: This is a loose term for response options that can be considered as not being applicable to the respondent in terms of directly answering the specific question to which they are linked. Most commonly, these are responses such as “Don’t know / can’t remember”, which indicate a failure to recall the issue in question. Likewise, responses that indicate the question is not applicable to the respondent are considered ‘non-specific’ – for example, responses such as “My child did not have hospital food”. A full list of such responses for the 2018 children’s survey can be found in Appendix B. Please note: non-specific responses are set to user missing in the final respondent level dataset. This doesn’t delete the data in any way but alters how that data is used in analysis.

‘Missing’ responses: This term is used to describe data which are not stored as a valid response for a question or variable in a dataset. There can be a number of different types of missing data, with the most common being classed as ‘user missing’ data. Within the data cleaning process, a number of different missing response codes are used to identify how data for a particular respondent has been handled. These codes are as follows:

* 999: this code is used when someone should have answered a question, but didn’t.
* 998: this code is used when someone answered a question but shouldn’t have. For example, filtered questions.

## Entering and coding data prior to submission

For the 2018 survey, trusts and contractors are required to submit raw (‘uncleaned’) data to the Survey Coordination Centre. For clarification, raw data is created as follows:

* All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (e.g. where patients answer questions that they have been directed to skip past, these responses should still be entered).
* Where a respondent has selected more than one response category on a question, this question should be set to ‘missing’ for that person in the data (i.e. left blank, or coded as a full stop (.)). The exception to this is for the ‘multiple response’ questions, where respondents may select more than one response option (See Section 3.3 below for details about how to enter responses to these types of questions).
* Where a respondent has crossed out a response, this should not be entered in the data (the response should be left blank, or coded as a full stop (.)). Where a respondent has crossed out a response and instead selected a second response option, the second choice should be entered into the data.
* Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous upon inspection of the completed questionnaire, then the respondent’s intended response should be entered. For example, where a parent / carer has written their child’s date of birth in the boxes for Q49 of the 0-7 questionnaire (“What is your child’s year of birth?”), but written their year of birth in at the side of this, then the child’s year of birth should be entered.
* For the year of birth / age questions, unrealistic responses should still be entered except following the rule above. For example, if a respondent enters ‘2020’ in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.
* Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the patient’s intended response has not been captured. This includes ‘out-of-range’ responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Survey Coordination Centre where they are found to have been entered inconsistently with the respondent’s intended response.

## Editing/cleaning data after submission

### Approach and rationale

When cleaning submitted data, the Survey Coordination Centre aims to ensure an optimal balance between data quality and completeness. Thus, we seek to remove responses that are known to be erroneous or inappropriate, but to do so in a relatively permissive way to enable as many responses as possible to contribute to the overall survey results.

Dealing with filtered questions

Some of the questions included in the survey are only relevant to a subset of respondents, and in these cases filter instructions are included in the questionnaire to route respondents past questions that are not applicable to them. For example, people who select “Yes” to Q30 in the 0-7 questionnaire (“Did you ever stay overnight in hospital with your child?”) are instructed to go to Q31, whereas those that selected all other options skip Q32.

It is necessary to clean the data to recode responses where filter instructions have been incorrectly followed. In such cases, participants’ responses to questions that were not relevant to them are recoded in the dataset. Responses are only recoded where respondents have answered filtered questions despite selecting an earlier response on a routing question instructing them to skip these questions. For example, if a respondent selects “No” to Q30 (i.e. they did not stay in hospital overnight), but then answers the subsequent question about staying in hospital overnight.

Responses to filtered questions are not recoded, however, where the response to the routing question is missing. For example, Q31 is applicable to those who stayed in hospital overnight and are filtered by the response to Q30 (e.g. they are answered if Q30=1). If a respondent does not answer Q30, or if the response to Q30 is missing for any reason, then responses to Q31 should not be recoded

The tables below show a summary of all routing questions, and the filtered questions they relate to, that are included in the 2018 survey. Please note that these instructions should be followed sequentially in order to be consistent with the procedures applied by the Survey Coordination Centre.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Table 1. Cleaning instructions for filtered questions: 0-7 Questionnaire** | | | | | |
| **Routing Question** | |  | **Response Option** | | **Filter Question** |
| if | Q2 | = | 1 | then recode responses to: | Q3- Q4 |
| if | Q17 | = | 4 | then recode responses to: | Q18 |
| if | Q30 | = | 2 or 3 | then recode responses to: | Q31 |
| if | Q33 | = | 2 | then recode responses to: | Q34- Q37 |
| if | Q51 | = | 2 | then recode responses to: | Q52- Q53 |

Please note that the instructions in the above table should be followed sequentially in the order shown above.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Table 2. Cleaning instructions for filtered questions: 8-11 Questionnaire** | | | | | |
| **Routing Question** | |  | **Response Option** | | **Filter Question** |
| if | Q8 | = | 2 or 3 | then recode responses to: | Q9 |
| if | Q14 | = | 2 | then recode responses to: | Q15- Q16 |
| if | Q32 | = | 4 | then recode responses to: | Q33 |
| if | Q43 | = | 2 or 3 | then recode responses to: | Q44 |
| if | Q46 | = | 2 | then recode responses to: | Q47-Q50 |
| if | Q60 | = | 2 | then recode responses to: | Q61- Q62 |

Please note that the instructions in the above table should be followed sequentially in the order shown above.

| **Table 3. Cleaning instructions for filtered questions: 12-15 Questionnaire** | | | | | |
| --- | --- | --- | --- | --- | --- |
| Routing Question | |  | Response Option | | Filter Question |
| if | Q8 | = | 2 or 3 | then recode responses to: | Q9 |
| if | Q15 | = | 2 | then recode responses to: | Q16-Q17 |
| if | Q33 | = | 4 | then recode responses to: | Q34 |
| if | Q44 | = | 2 or 3 | then recode responses to: | Q45 |
| if | Q47 | = | 2 | then recode responses to: | Q48-Q51 |
| if | Q61 | = | 2 | then recode responses to: | Q62- Q63 |

Please note that the instructions in the above table should be followed sequentially in the order shown above.

A worked example of the cleaning process for removing unexpected responses to filtered questions is included in Appendix A.

## Dealing with multiple response questions

For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For multiple response questions; Q28 and Q52 (0-7 questionnaire); Q41 and Q61 (8-11 questionnaire); and Q42 and Q62 (12-15 questionnaire) that give the instruction “(**Cross ALL that apply**)”, each response option is treated as a separate question in the respondent level data.

## Cleaning Special Cases

### Cleaning of the long-term condition questions

The long-term condition questions refer to **Q51, Q52** and **Q53** in the **0-7** questionnaire, **Q60**, **Q61** and **Q62** in the **8-11** questionnaire, and **Q61, Q62** and **Q63** in the **12-15** questionnaire. The cleaning rules are the same for all three questionnaires, although the **0-7** question numbers are referred to in the following instructions.

**Q51** 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?

**Q52** Does your child have any of the following? (**Select ALL conditions that have lasted or are expected to last for 12 months or more**)

**Q53** Do any of these reduce your child’s ability to carry out day-to-day activities?

Although **Q51** is a routing question and **Q52** and **Q53** are the corresponding filtered questions, these three questions are cleaned differently due to the nature of the questions.

When a respondent has answered “*No*” to **Q51** but has answered **Q52** by selecting one or more long term condition, their response to **Q51** is cleaned by setting it to missing (code ‘999’). This is because their response to **Q52** indicates that they do in fact consider their child to have a long-standing condition. Instead of changing the response to **Q51** to an answer the patient did not select (i.e. *“Yes”*), we set it to missing so that it is no longer inconsistent with their response to **Q52.**

However, when a respondent has answered “*No*” to **Q51** and has not selected any long-term conditions in **Q52** but has answered **Q53** then their response to **Q53** is cleaned by setting it to not-applicable (code ‘998’). As they have indicated that they do not have a long-term condition and have also skipped **Q52**, this would suggest that **Q54** was not applicable to them. See table 3 for a summary of how **Q51**, **Q52** and **Q53** in the 0-7 questionnaire are cleaned, table 4 for a summary of how **Q60**, **Q61** and **Q62** in the 8-11 questionnaire are cleaned, and table 5 for a summary of how **Q61**, **Q62** and **Q63** in the 12-15 questionnaire are cleaned.

Table 3. Cleaning for Q51, Q52 and Q53 in the 0-7 questionnaire

|  |  |  |  |
| --- | --- | --- | --- |
| **Q51 response** | **Q52 response** | **Q53 response** | **Cleaning** |
| Ticked option 2 (no) | Ticked one or more options | No response | Q51 is set to missing – ‘999’. |
| Ticked option 2 (no) | Ticked one or more options | Ticked any option | Q51 is set to missing – ‘999’. |
| Ticked option 2 (no) | No response | Ticked any option | Q53 is set to not-applicable – ‘998’. |

Table 4. Cleaning for Q60, Q61 and Q62 in the 8-11 questionnaire

|  |  |  |  |
| --- | --- | --- | --- |
| **Q60response** | **Q61 response** | **Q62 response** | **Cleaning** |
| Ticked option 2 (no) | Ticked one or more options | No response | Q60 is set to missing – ‘999’. |
| Ticked option 2 (no) | Ticked one or more options | Ticked any option | Q60 is set to missing – ‘999’. |
| Ticked option 2 (no) | No response | Ticked any option | Q62 is set to not-applicable – ‘998’. |

Table 5. Cleaning for Q61, Q62 and Q63 in the 12-15 questionnaire

|  |  |  |  |
| --- | --- | --- | --- |
| **Q61 response** | **Q62 response** | **Q63 response** | **Cleaning** |
| Ticked option 2 (no) | Ticked one or more options | No response | Q61 is set to missing – ‘999’. |
| Ticked option 2 (no) | Ticked one or more options | Ticked any option | Q61 is set to missing – ‘999’. |
| Ticked option 2 (no) | No response | Ticked any option | Q63 is set to not-applicable – ‘998’. |

## Dealing with demographics

Although basic demographic information, including age, sex and ethnicity of patients, are included in the sample data, the ‘About you’/‘About your child’ sections of the questionnaire also ask respondents to provide this information. In a minority of cases, the information provided from the sample frame and by the respondents does not correspond – for example, the sample may identify an individual as male only for them to report being female (i.e. 12-15 questionnaire, Q23=2).

Because of this, and because questions about demographics tend to produce relatively high item non-response rates, it is not appropriate to rely on either source of data alone for any kind of sub-group analyses (for example, if you wanted to examine the response to a particular question by age or ethnic group).

Where responses to demographic questions (age and sex) are present, it is assumed these are more likely to be accurate than sample frame information (since it is assumed that respondents are best placed to know their own sex and age). Where responses to demographic questions are missing, however, sample data are used in their place[[1]](#footnote-1). To do this, we first copy all valid responses to survey demographic questions into a new variable. Where responses are missing we then copy in the relevant sample information (note that for a very small number of patients demographic information may be missing in both the sample and response sections; in such cases data must necessarily be left missing in the new variable).

## Age

A common error when completing the year of birth question is for respondents to accidentally write in the current year. Such responses will be set to missing during cleaning. Out-of-range responses will also be set to missing[[2]](#footnote-2). For the 2018 survey, out of range responses to the year of birth question are defined as ≤ 2001 or ≥ 2018.

For the age questions (Q49 in the 0-7 questionnaire, Q23 in the 8-11 questionnaire and Q24 in the 12-15 questionnaire) responses are regarded as out-of-range if the responses given are not possible based on the questionnaire’s target population. For example, self-reported age ranges for the 8-11 questionnaire can only be between 8 and 12 years old. Self-reported responses of 12 are valid as the sampling period for most trusts in the 2018 survey ran from November to December 2018 however fieldwork was not concluded until 14th June 2019. This means respondents who were 11 during the sampling period but have a birthday in the first quarter of the year are likely to be 12 when completing the questionnaire.

## Usability and eligibility

Sometimes questionnaires are returned with only a very small number of questions completed. For the 2018 survey, questionnaires where fewer than five questions have been answered are considered ‘unusable’. In such cases, the responses to the few questions that have been answered will be deleted and the outcome codes will be changed from a code of 1 (‘returned useable questionnaire’) to a code of 6 (‘questionnaire not returned’). Please note that the number of responses per questionnaire is counted after all other cleaning[[3]](#footnote-3). This process should only affect a very limited number of cases, and so should not have a significant impact on response rates.

Outcome codes for respondents will also be changed if respondents are believed to be over the age of fifteen when they were in hospital and therefore ineligible for participation. Since the sample files for the survey are checked by the Survey Coordination Centre prior to mailing, this is unlikely to affect more than a handful of cases throughout the survey, as patients coded as being aged over 15 will be identified and removed from the sample before the start of the survey. However, in situations where sample information on a respondent’s year of birth is missing in the final data file and their response indicates that they *are over* *16* then the outcome code for that patient should be recoded from 1 (‘returned completed questionnaire’) to 5 (‘ineligible for participation in the survey’). *Please note: this cut off is set at age 16 rather than 15 because some patients will have been 15 when they were in hospital but 16 when completing the questionnaire, and in such cases they would still be eligible for inclusion in the survey.*

If data on an individual’s year of birth is missing from the sampling frame, but their responses to year of birth questions indicates the respondent under 17, outcome codes should remain as 1. If sample information indicates a patient was aged 15 or under at the time they were in hospital, but this is contradicted by the patient’s response, then the patient’s survey outcome should also remain as 1. This is to avoid removing legitimate responses because of an overly conservative approach to assessing eligibility; in other words, where the patient’s age is uncertain (because sample and response information contradict each other and in different instances either of these may be accurate or inaccurate) the benefit of the doubt is given in any assessment of eligibility.

## Missing responses

It is useful to be able to see the numbers of missing responses to each question. Responses are considered to be missing when a respondent is expected to answer a question but no response is present. For non-filtered questions, responses are expected from all respondents – thus any instance of missing data constitutes a missing response. For filtered questions, only respondents who have answered a previous routing question instructing them to go on to that filtered question or set of filtered questions are expected to give answers. Where respondents to the survey have missed a routing question, they are not expected to answer subsequent ‘filtered’ questions; thus only where respondents were explicitly instructed to answer filtered questions should such blank cells be coded as missing responses.

The Survey Coordination Centre codes missing responses in the data with the value ‘999’. For results to be consistent with those produced by the Survey Coordination Centre, missing responses should be presented but should not be included in the base number of respondents for percentages.

For the 2018 survey, the Survey Coordination Centre suppresses question data at two levels, dependent on the requirements for particular outputs; i) questions with fewer than 20 responses and ii) questions with fewer than 30 responses. The lower suppression threshold, though not desirable, is necessary so that trusts have usable results from the smaller survey version 8-11 and 12-15 sub-sets.

## Non-specific responses

As well as excluding missing responses from results, the Survey Coordination Centre also removes non-specific responses from base numbers for percentages. The rationale for this is to facilitate easy comparison between institutions by presenting only results from those patients who felt able to give an evaluative response to questions. For Q47 in the 0-7 questionnaire, Q56 in the 8-11 questionnaire and Q57 in the 12-15 questionnaire when multiple numbers have been selected (i.e. multicode) or a non-integer has been selected (i.e. circled between two numbers) this should be coded as ‘98’. For a full listing of ‘non-specific’ responses in the 2018 survey, please see Appendix B.

## Appendix A: Example of cleaning

### Incorrectly followed routing

Table 4 below shows hypothetical raw/uncleaned data for eight sample members, five of whom have responded to the survey (Outcome = 1).

| **Table 4. Example of ‘raw’/‘uncleaned’ data for the 0-7 questionnaire** | | | | | |
| --- | --- | --- | --- | --- | --- |
| Record |  | Outcome | Q2 | Q3 | Q4 |
| Patient Record Number |  | Outcome of sending questionnaire (N) | Was your child’s visit to hospital planned or an emergency? | Did the hospital give you a choice of admission dates? | Did the hospital change your child’s admission date at all? |
| CYP...0001 |  | 6 |  |  |  |
| CYP...0002 |  | 1 | 2 | 1 | 2 |
| CYP...0003 |  | 1 | 1 | 1 | 1 |
| CYP...0004 |  | 4 |  |  |  |
| CYP...0005 |  | 1 | 2 | 2 | . |
| CYP...0006 |  | 6 |  |  |  |
| CYP...0007 |  | 1 | 2 | 1 | 2 |
| CYP...0008 |  | 1 | 1 | 3 | 4 |

It can be seen from the data shown in Table 4 that some of the respondents have followed filter instructions from routing questions incorrectly:

Respondents ‘CYP...0003’ and ‘CYP...0008’ have reported that their child’s admission to hospital was an emergency (Q2=1), but have both responded to subsequent filtered questions which are only applicable to waiting list or planned patients.

By following the cleaning instructions detailed above in Section 3.2, these inappropriate responses will be recoded. Firstly, the filter instructions listed in Table 1 specify that:

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| if | Q2 | = | 1 | then recode responses to: | Q3-Q4 |

In accordance with this, all responses for Q3, and Q4 must be recoded in cases where the respondent has crossed Q2=1 (‘emergency’). Looking in column Q2 of Table 4 we can see that respondents ‘CYP...0003’ and ‘CYP...0008’ have responded Q2=1, so any responses they gave to Q3 and Q4 need to be recoded. This will lead to two responses being recoded for these respondents. Table 5 (below) shows how the data would look following cleaning by the Survey Coordination Centre to recode responses to filtered questions that should have been skipped (shaded cells represent cases where responses have been recoded).

| **Table 5. Example of cleaned data for the 0-7 questionnaire** | | | | | |
| --- | --- | --- | --- | --- | --- |
| Record |  | Outcome | Q2 | Q3 | Q4 |
| Patient Record Number |  | Outcome of sending questionnaire (N) | Was your child’s visit to hospital planned or an emergency? | Did the hospital give you a choice of admission dates? | Did the hospital change your child’s admission date at all? |
| CYP...0001 |  | 6 |  |  |  |
| CYP...0002 |  | 1 | 2 | 1 | 1 |
| CYP...0003 |  | 1 | 1 | 998 | 998 |
| CYP...0004 |  | 4 |  |  |  |
| CYP...0005 |  | 1 | 2 | 2 | . |
| CYP...0006 |  | 6 |  |  |  |
| CYP...0007 |  | 1 | 2 | 1 | 2 |
| CYP...0008 |  | 1 | 1 | 998 | 998 |

## Appendix B: Non-specific responses

The following table lists all ‘non-specific responses’ included in the 2018 survey. Numbers in the final column indicate the response options that should be considered non-specific. Where the ‘non-specific responses’ column contains only a dash, the relevant question has no such response options.

|  |  |  |
| --- | --- | --- |
| **0-7 Questionnaire:** | | |
| **Core** | **Question** | **Non-specific responses** |
| **Q1** | Did your child stay overnight during their most recent visit to hospital? | - |
| **Q2** | Was your child’s visit to hospital planned or an emergency? | - |
| **Q3** | Did the hospital give you a choice of admission dates? | 3 |
| **Q4** | Did the hospital change your child’s admission date at all? | 4 |
| **Q5** | For most of their stay in hospital, what type of ward did your child stay on? | - |
| **Q6** | Did the ward where your child stayed have appropriate equipment or adaptations for your child’s physical or medical needs? | 4,5 |
| **Q7** | How clean do you think the hospital room or ward was that your child was in? | - |
| **Q8** | Was your child given enough privacy when receiving care and treatment? | - |
| **Q9** | Were there enough things for your child to do in the hospital? | 4 |
| **Q10** | Did staff play with your child at all while they were in hospital? | 3, 4 |
| **Q11** | If your child used the hospital Wi-Fi to entertain themselves, was it good enough to do what they wanted? | 4 |
| **Q12** | Did new members of staff treating your child introduce themselves? | - |
| **Q13** | Did members of staff treating your child give you information about their care and treatment in a way that you could understand? | - |
| **Q14** | Did members of staff treating your child communicate with them in a way that your child could understand? | - |
| **Q15** | Did a member of staff agree a plan for your child’s care with you? | 3 |
| **Q16** | Did you have confidence and trust in the members of staff treating your child? | - |
| **Q17** | Did staff involve you in decisions about your child’s care and treatment? | 4 |
| **Q18** | Were you given enough information to be involved in decisions about your child's care and treatment? | - |
| **Q19** | Did hospital staff keep you informed about what was happening whilst your child was in hospital? | 4 |
| **Q20** | Were you able to ask staff any questions you had about your child’s care? | 4, 5 |
| **Q21** | Did different staff give you conflicting information? | - |
| **Q22** | Were the different members of staff caring for and treating your child aware of their medical history? | 4 |
| **Q23** | Did you feel that staff looking after your child knew how to care for their individual or special needs? | 4 |
| **Q24** | Were members of staff available when your child needed attention? | 4 |
| **Q25** | Did the members of staff caring for your child work well together? | 4 |
| **Q26** | If you had been unhappy with your child’s care and treatment, do you feel that you could have told hospital staff? | - |
| **Q27** | Did your child like the hospital food provided? | 4 |
| **Q28** | Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply) | - |
| **Q29** | Were you able to prepare food in the hospital if you wanted to? | 4 |
| **Q30** | Did you stay overnight in hospital with your child during their most recent visit to hospital? | 3 |
| **Q31** | How would you rate the facilities for parents or carers staying overnight? | - |
| **Q32** | If your child felt pain while they were at the hospital, do you think staff did everything they could to help them? | 4 |
| **Q33** | During their stay in hospital, did your child have any operations or procedures? | - |
| **Q34** | Before your child had any operation or procedures, did a member of staff explain to you what would be done? | 4 |
| **Q35** | Before the operations or procedures, did a member of staff answer your questions in a way you could understand? | 4 |
| **Q36** | During any operations or procedures, did staff play with your child or do anything to distract them? | 4 |
| **Q37** | Afterwards, did staff explain to you how the operations or procedures had gone? | 4 |
| **Q38** | Did a member of staff give you advice about caring for your child after you went home? | 4, 5 |
| **Q39** | Did a member of staff tell you who to talk to if you were worried about your child when you got home? | 4, 5 |
| **Q40** | When you left hospital, did you know what was going to happen next with your child's care? | 4 |
| **Q41** | Were you given any written information (such as leaflets) about your child’s condition or treatment to take home with you? | 3 |
| **Q42** | Do you feel that the people looking after your child listened to you? | - |
| **Q43** | Do you feel that the people looking after your child were friendly? | - |
| **Q44** | Do you feel that your child was well looked after by the hospital staff? | - |
| **Q45** | Do you feel that you (the parent/carer) were well looked after by hospital staff? | - |
| **Q46** | Were you treated with dignity and respect by the people looking after your child? | - |
| **Q47** | 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) | - |
| **Q48** | Is your child male or female? | - |
| **Q49** | What is your child’s year of birth? | - |
| **Q50** | Including this visit, how many times has your child been to hospital in the past six months? | - |
| **Q51** | 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? | - |
| **Q52** | Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more) | - |
| **Q53** | Do any of these reduce your child’s ability to carry out day-to-day activities? | - |
| **Q54** | Which of these best describes your child’s ethnic background? (Cross ONE only) | - |

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| **8-11 Questionnaire:** | | |
| **Core** | **Question** | **Non-specific responses** |
| **Q1** | Did hospital staff play with you or do any activities with you while you were in hospital? | 4 |
| **Q2** | Were there enough things for you to do in the hospital? | - |
| **Q3** | If you used the hospital Wi-Fi, was it good enough to do what you wanted? | 4 |
| **Q4** | Did you like the hospital food? | 4 |
| **Q5** | Was it quiet enough for you to sleep when needed in the hospital? | 4 |
| **Q6** | Did hospital staff talk with you about how they were going to care for you? | 4 |
| **Q7** | When the hospital staff spoke with you, did you understand what they said? | 4 |
| **Q8** | Did you feel able to ask staff questions? | 3 |
| **Q9** | Did the hospital staff answer your questions? | - |
| **Q10** | Were you involved in decisions about your care and treatment? | 4 |
| **Q11** | If you had any worries, did a member of staff talk with you about them? | 3, 4 |
| **Q12** | Were you given enough privacy when you were receiving care and treatment? | - |
| **Q13** | If you felt pain while you were at the hospital, do you think staff did everything they could to help you? | 4 |
| **Q14** | During your time in hospital, did you have any operations or procedures? | - |
| **Q15** | Before the operations or procedures, did hospital staff explain to you what would be done? | - |
| **Q16** | Afterwards, did staff explain to you how the operations or procedures had gone? | - |
| **Q17** | Did a member of staff tell you who to talk to if you were worried about anything when you got home? | 4 |
| **Q18** | When you left hospital, did you know what was going to happen next with your care? | - |
| **Q19** | Did a member of staff give you advice on how to look after yourself after you went home? | 4 |
| **Q20** | Do you feel that the people looking after you were friendly? | - |
| **Q21** | Overall, how well do you think you were looked after in hospital? | - |
| **Q22** | Are you a boy or a girl? | - |
| **Q23** | How old are you today? | - |
| **Parent’s section** | **Parent’s section** |  |
| **Q24** | Was your child’s visit to hospital planned or an emergency? | - |
| **Q25** | Did your child stay overnight during their most recent visit to hospital? | - |
| **Q26** | For most of their stay in hospital, what type of ward did your child stay on? | - |
| **Q27** | Did the ward where your child stayed have appropriate equipment or adaptations for your child’s physical or medical needs? | 4, 5 |
| **Q28** | How clean do you think the hospital room or ward was that your child was in? | - |
| **Q29** | Did members of staﬀ treating your child give you information about their care and treatment in a way that you could understand? | - |
| **Q30** | Did a member of staff agree a plan for your child’s care with you? | 3 |
| **Q31** | Did you have conﬁdence and trust in the members of staﬀ treating your child? | - |
| **Q32** | Did staff involve you in decisions about your child’s care and treatment? | 4 |
| **Q33** | Were you given enough information to be involved in decisions about your child’s care and treatment? | - |
| **Q34** | Did hospital staff keep you informed about what was happening whilst your child was in hospital? | 4 |
| **Q35** | Were you able to ask staff any questions you had about your child’s care? | 4, 5 |
| **Q36** | Were the different members of staff caring for and treating your child aware of their medical history? | 4 |
| **Q37** | Did you feel that staff looking after your child knew how to care for their individual or special needs? | 4 |
| **Q38** | Were members of staff available when your child needed attention? | 4 |
| **Q39** | Did the members of staff caring for your child work well together? | 4 |
| **Q40** | If you had been unhappy with your child’s care and treatment, do you feel that you could have told hospital staff? | - |
| **Q41** | Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply) | - |
| **Q42** | Were you able to prepare food in the hospital if you wanted to? | 4 |
| **Q43** | Did you stay overnight with your child during their most recent visit to hospital? | 3 |
| **Q44** | How would you rate the facilities for parents or carers staying overnight? | - |
| **Q45** | If your child felt pain while they were at the hospital, do you think staff did everything they could to help them? | 4 |
| **Q46** | During their stay in hospital, did your child have any operations or procedures? | - |
| **Q47** | Before your child had any operations or procedures, did a member of staff explain to you what would be done? | 4 |
| **Q48** | Before the operations or procedures, did a member of staff answer your questions in a way you could understand? | 4 |
| **Q49** | During any operations or procedures, did staff play with your child or do anything to distract them? | 4 |
| **Q50** | Afterwards, did staff explain to you how the operations or procedures had gone? | 4 |
| **Q51** | Did a staff member give you advice about caring for your child after you went home? | 4, 5 |
| **Q52** | When you left hospital, did you know what was going to happen next with your child’s care? | 4 |
| **Q53** | Were you given any written information (such as leaflets) about your child’s condition or treatment to take home with you? | 3 |
| **Q54** | Do you feel that you (the parent/carer) were well looked after by hospital staff? | - |
| **Q55** | Were you treated with dignity and respect by the people looking after your child? | - |
| **Q56** | 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) | - |
| **Q57** | Who was the main person who answered the questions in the children’s section of the questionnaire? | - |
| **Q58** | Including this visit, how many times has your child been to hospital in the past six months? | - |
| **Q59** | Which of these best describes your child’s ethnic background? (Cross ONE only) | - |
| **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? | - |
| **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) | - |
| **Q62** | Do any of these reduce your child’s ability to carry out day-to-day activities? | - |

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| **12-15 Questionnaire:** | | |
| **CORE** | **Question** | **Non-specific responses** |
| Q1 | Was the ward suitable for someone of your age? | - |
| Q2 | Were there enough things for you to do in the hospital? | - |
| Q3 | If you used the hospital Wi-Fi, was it good enough to do what you wanted? | 4 |
| Q4 | Did you like the hospital food? | 4 |
| Q5 | Was it quiet enough for you to sleep when needed in the hospital? | 4 |
| Q6 | Did hospital staff talk with you about how they were going to care for you? | 4 |
| Q7 | When the hospital staff spoke with you, did you understand what they said? | 4 |
| Q8 | Did you feel able to ask staff questions? | 3 |
| Q9 | Did the hospital staff answer your questions? | - |
| Q10 | Were you involved in decisions about your care and treatment? | 4 |
| Q11 | If you had any worries, did a member of staff talk with you about them? | 3, 4 |
| Q12 | Were you given enough privacy when you were receiving care and treatment? | - |
| Q13 | If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there? | 3 |
| Q14 | If you felt pain while you were at the hospital, do you think staff did everything they could to help you? | 4 |
| Q15 | During your time in hospital, did you have any operations or procedures? | - |
| Q16 | Before the operations or procedures, did hospital staff explain to you what would be done? | - |
| Q17 | Afterwards, did staff explain to you how the operations or procedures had gone? | - |
| Q18 | Did a member of staff tell you who to talk to if you were worried about anything when you got home? | 4 |
| Q19 | When you left hospital, did you know what was going to happen next with your care? | - |
| Q20 | Did a member of staff give you advice on how to look after yourself after you went home? | 4 |
| Q21 | Do you feel that the people looking after you were friendly? | - |
| Q22 | Overall, how well do you think you were looked after in hospital? | - |
| Q23 | Are you male or female? | - |
| Q24 | How old are you today? | - |
| **Parent’s section** | **Parent’s section** |  |
| Q25 | Was your child’s visit to hospital planned or an emergency? | - |
| Q26 | Did your child stay overnight during their most recent visit to hospital? | - |
| Q27 | For most of their stay in hospital, what type of ward did your child stay on? | - |
| Q28 | Did the ward where your child stayed have appropriate equipment or adaptations for your child’s physical or medical needs? | 4, 5 |
| Q29 | How clean do you think the hospital room or ward was that your child was in? | - |
| Q30 | Did members of staﬀ treating your child give you information about their care and treatment in a way that you could understand? | - |
| Q31 | Did a member of staff agree a plan for your child’s care with you? | 3 |
| Q32 | Did you have conﬁdence and trust in the members of staﬀ treating your child? | - |
| Q33 | Did staff involve you in decisions about your child’s care and treatment? | 4 |
| Q34 | Were you given enough information to be involved in decisions about your child’s care and treatment? | - |
| Q35 | Did hospital staff keep you informed about what was happening whilst your child was in hospital? | 4 |
| Q36 | Were you able to ask staff any questions you had about your child’s care? | 4, 5 |
| Q37 | Were the different members of staff caring for and treating your child aware of their medical history? | 4 |
| Q38 | Did you feel that staff looking after your child knew how to care for their individual or special needs? | 4 |
| Q39 | Were members of staff available when your child needed attention? | 4 |
| Q40 | Did the members of staff caring for your child work well together? | 4 |
| Q41 | If you had been unhappy with your child’s care and treatment, do you feel that you could have told hospital staff? | - |
| Q42 | Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply) | - |
| Q43 | Were you able to prepare food in the hospital if you wanted to? | 4 |
| Q44 | Did you stay overnight with your child during their most recent visit to hospital? | 3 |
| Q45 | How would you rate the facilities for parents or carers staying overnight? | - |
| Q46 | If your child felt pain while they were at the hospital, do you think staff did everything they could to help them? | 4 |
| Q47 | During their stay in hospital, did your child have any operations or procedures? | - |
| Q48 | Before your child had any operations or procedures, did a member of staff explain to you what would be done? | 4 |
| Q49 | Before the operations or procedures, did a member of staff answer your questions in a way you could understand? | 4 |
| Q50 | During any operations or procedures, did staff play with your child or do anything to distract them? | 4 |
| Q51 | Afterwards, did staff explain to you how the operations or procedures had gone? | 4 |
| Q52 | Did a staff member give you advice about caring for your child after you went home? | 4, 5 |
| Q53 | When you left hospital, did you know what was going to happen next with your child’s care? | 4 |
| Q54 | Were you given any written information (such as leaflets) about your child’s condition or treatment to take home with you? | 3 |
| Q55 | Do you feel that you (the parent/carer) were well looked after by hospital staff? | - |
| Q56 | Were you treated with dignity and respect by the people looking after your child? | - |
| Q57 | 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) | - |
| Q58 | Who was the main person who answered the questions in the children’s section of the questionnaire? | - |
| Q59 | Including this visit, how many times has your child been to hospital in the past six months? | - |
| Q60 | Which of these best describes your child’s ethnic background? (Cross ONE only) | - |
| Q61 | 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? | - |
| Q62 | Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more) | - |
| Q63 | Do any of these reduce your child’s ability to carry out day-to-day activities? | - |

1. The exception to this is when response rates are calculated. Because response rates vary between demographic groups (for instance young males are less likely to respond to the survey than other individuals), using response and sample data to calculate response rates would create a systematic source of bias in that we are only able to amend information for the respondents. Therefore, only the sample information should be used to calculate response rates by demographic groups. [↑](#footnote-ref-1)
2. The majority of out-of-range responses present in data relating to year of birth questions result from errors in data entry (for example, not keying one of the digits – so ‘2011’ may become 011, or 201). In such cases it is important that the responses be checked against the completed questionnaire forms, and data corrected if necessary, prior to submission of data to the Survey Coordination Centre. [↑](#footnote-ref-2)
3. [↑](#footnote-ref-3)