

# DATA CLEANING GUIDANCE

## CHILDREN AND YOUNG PEOPLE'S PATIENT EXPERIENCE SURVEY 2020

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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 [NHS Surveys Website](#).

## 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 for Existing Methods (SCCEM) using the details provided at the top of this page.



### For trusts and contractors taking part in the survey:

Contractors and trusts submitting final data for the Children and Young People's Patient Experience Survey **must not** clean their data before submitting it to the Survey Coordination Centre for Existing Methods. Please refer to the [survey handbook](#) and [Entering and Submitting Final Data](#) instructions for more details.

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# Data Cleaning- An overview

## Introduction

At the end of fieldwork for the Children and Young People's Patient Experience Survey 2020, participating trusts and contractors will be required to submit data to the Survey Coordination Centre for Existing Methods (SCCEM) in a raw ('uncleaned') format. Once the SCCEM has received data from all participating trusts and contractors, data cleaning is undertaken. 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 SCCEM to clean and standardise data submitted by contractors and trusts as part of the 2020 survey. By following the guidance contained in this document, it should be possible to recreate this cleaning process. Please note that no data cleaning should be conducted in advance of the data being submitted to the SCCEM, data cleaning should only be applied once the raw data has been submitted.

## Scope of this cleaning guide

For the 2020 survey, all trusts must submit data for all three questionnaires: the 55 questions for the 0-7 age group questionnaire, 65 questions for the 8-11 age group questionnaire and 67 questions for the 12-15 age group questionnaire. All cleaning undertaken by the SCCEM will include only these data.

## Definition of key terms

Definitions of key terms used in this document, as applied to the 2020 survey, are:

### 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 selected 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 SCCEM 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 to the next question or to skip past irrelevant questions depending on their response to the routing question. For the 2020 survey, the routing questions are:

- 0-7 questionnaire: Q2, Q18, Q31, Q34 and Q52.
- 8-11 questionnaire: Q8, Q15, Q34, Q45, Q48 and Q63.
- 12-15 questionnaire: Q8, Q16, Q37, Q48, Q51 and Q65.

### 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 2020 survey, the filtered questions in the questionnaire are:

- 0-7 questionnaire: Q3, Q4, Q19, Q32, Q35, Q36, Q37, Q38, Q53 and Q54.
- 8-11 questionnaire: Q9, Q16, Q17, Q35, Q46, Q49- Q52, Q64 and Q65.
- 12-15 questionnaire: Q9, Q17, Q18, Q38, Q49, Q52 - Q55, Q66 and Q67.

### Non-filtered questions

Questionnaire items that are not subject to any filtering and which should therefore be answered by all respondents. For the 2020 survey, the non-filtered questions are:

- 0-7 questionnaire: Q1, Q2, Q5- Q18, Q20- Q31, Q33, Q34, Q39- Q52 and Q55.
- 8-11 questionnaire: Q1- Q8, Q10- Q15, Q18- Q34, Q36- Q45, Q47, Q48 and Q53- Q63.
- 12-15 questionnaire: Q1- Q8, Q10- Q16, Q19- Q37, Q39- Q48, Q50, Q51 and Q56- Q65.

### Sample data

Patient data provided from the trust as part of the sampling process are "sample data". This includes gender, month of birth, year of birth, ethnicity, patient's postcode, date of admission (day, month and year), date of discharge (day, month and year), main specialty on discharge, treatment function code, CCG code, route of admission, treatment centre admission, NHS site code (admission and discharge), COVID-19 diagnosis, COVID-19 treatment and mobile phone indicator as it is recorded on the trust's system.

### Response data

Data from the completed questionnaire provided from the patient are "response data". This includes answers to Q1 through Q55 for the 0- 7 questionnaire, Q1 through Q65 for the 8 – 11 questionnaire and Q1 to Q67 for the 12 - 15 questionnaire.

### 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 most 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 SCCEM. A full list of such responses for the 2020 Children and Young People's Patient Experience Survey can be found in [Appendix B: out of range data.](#)

### Outcome

An outcome code is given to each patient to indicate the result of their participation in the survey. These codes are used when calculating the adjusted response rate for the survey and is therefore vital to ensure all patients are coded appropriately:

- Outcome 1: Returned completed questionnaire
- Outcome 2: Undelivered / moved house
- Outcome 3: Deceased after the start of fieldwork
- Outcome 4: Too ill / opt out
- Outcome 5: Ineligible
- Outcome 6: Unknown
- Outcome 7: Deceased before the start of fieldwork
- Outcome 8: Easy Read completed questionnaire
- Outcome 9: Braille completed questionnaire
- Outcome 10: Large print completed questionnaire

### Non-specific responses

This is a term for response options 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 2020 children's survey can be found in [Appendix C: Non-specific responses.](#)

### Missing responses

This term describes data that 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 did not. For example, non-filtered questions or filtered questions where the respondent meets the filter criteria.
- 998: this code is used when someone answered a question but should not have. For example, filtered questions.
- 996: this code is used to suppress data at trust level when a question has fewer than 30 responses. These responses would also remain suppressed from the overall base at a national level.

## Entering and coding data prior to submission

For the 2020 survey, trusts and contractors are required to submit raw/ uncleaned data to the SCCEM. Raw data is created as follows:

- All responses should be entered into the dataset, regardless of whether 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 [Dealing with multiple response questions](#) 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 Q50 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 '2021' 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 SCCEM 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 SCCEM 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, 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 Q31 in the 0-7 questionnaire (“Did you ever stay overnight in hospital with your child during their most recent visit to hospital?”) are instructed to go to Q32, whereas those that selected all other options skip Q32 and are routed to Q33.

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 Q31 (i.e. they did not stay in hospital overnight), but then answers the subsequent question about staying in hospital overnight. In such cases, participants’ responses to questions that were not relevant to them are recoded to ‘998’ to indicate a non-applicable response<sup>1</sup>. Thus we conduct “forward coding, whereby the filter question is assumed to have the correct response.

Responses to filtered questions are not recoded, however, where the response to the routing question is missing. For example, Q32 is applicable to those who stayed in hospital overnight and are filtered by the response to Q31 (e.g. they are answered if Q31=1). If a respondent does not answer Q31, or if the response to Q31 is missing for any reason, then responses to Q32 should not be recoded.

Tables 1 to 3, following page, show a summary of all routing questions, and the filtered questions they relate to, that are included in the 2020 survey. Please note that these instructions should be followed sequentially in order to be consistent with the procedures applied by the Survey Coordination Centre for Existing Methods.

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<sup>1</sup> Code ‘998’ is an arbitrary value chosen because it is out of range for all other questions on the survey.

Table 1: cleaning rules for filtered questions in the 0-7 questionnaire

Routing question	Response values requiring cleaning	Filtered questions to be recoded as '998'
Q2	1	Q3 – Q4
Q18	4	Q19
Q31	2 or 3	Q32
Q34	2	Q35 - Q38
Q52	2	See <a href="#">Cleaning Special Cases</a>

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

Table 2: cleaning rules for filtered questions in the 8-11 questionnaire

Routing question	Response values requiring cleaning	Filtered questions to be recoded as '998'
Q8	2 or 3	Q9
Q15	2	Q16 – Q17
Q34	4	Q35
Q45	2 or 3	Q46
Q48	2	Q49 – Q52
Q63	2	See <a href="#">Cleaning Special Cases</a>

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

Table 3: cleaning rules for filtered questions in the 12-15 questionnaire

Routing question	Response values requiring cleaning	Filtered questions to be recoded as '998'
Q8	2 or 3	Q9
Q16	2	Q17 – Q18
Q37	4	Q38
Q48	2 or 3	Q49
Q51	2	Q52 – Q55
Q65	2	See <a href="#">Cleaning Special Cases</a>

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

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

The recoding of filtered questions into 998 only applies where the response to the routing question is not missing. Indeed, in this case, it is considered that the respondent contradicted their previous answer (example 1).

### Example 1:

#### OPERATIONS AND PROCEDURES

34. During their stay in hospital, did your child have any **operations or procedures**?

*Please do not include blood tests, scans or x-rays.*

- 1  Yes → [Go to Question 35](#)  
2  No → [Go to Question 39](#)

35. **Before** your child had any operations or procedures did a member of staff explain to you **what would be done**?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  I did not want an explanation

In example 1, the response to Q35 would be recoded to '998' because according to their answer from Q34 (the routing question), the respondent was supposed to skip Q35.

However, where the response to a routing question is missing, responses to filtered questions are not removed. It is considered that the respondent might have been unsure or missed the routing question and therefore, their responses to filtered questions are still relevant (example 2).

### Example 2:

## OPERATIONS AND PROCEDURES

34. During their stay in hospital, did your child have any operations or procedures?

*Please do not include blood tests, scans or x-rays.*

- 1  Yes → Go to Question 35  
2  No → Go to Question 39

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

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  I did not want an explanation

In example 2, Q34 would be coded as missing ('999') and the response to Q35 would remain as code 1.

## Cleaning Special Cases

### Cleaning the long-term condition questions

The long-term condition questions refer to **Q52**, **Q53** and **Q54** in the **0-7** questionnaire, **Q63**, **Q64** and **Q65** in the **8-11** questionnaire, and **Q65**, **Q66** and **Q67** 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.

**Q52** 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?

**Q53** Does your child have any of the following? (**Select ALL conditions that have lasted or are expected to last for 12 months or more**)

**Q54** Do any of these reduce your child's ability to carry out day-to-day activities?

Although **Q52** is a routing question and **Q53** and **Q54** 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 **Q52** but has answered **Q53** by selecting one or more long term condition, their response to **Q52** is cleaned by setting it to missing (code '999'). This is because their response to **Q53** indicates that they do in fact consider their child to have a long-standing condition. Instead of changing the response to **Q52** 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 **Q53**.

However, when a respondent has answered “No” to **Q52** and has not selected any long-term conditions in **Q53** but has answered **Q54** then their response to **Q54** 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 **Q53**, this would suggest that **Q53** was not applicable to them. See table 4 for a summary of how **Q52**, **Q53** and **Q54** in the 0-7 questionnaire are cleaned, table 5 for a summary of how **Q63**, **Q64** and **Q65** in the 8-11 questionnaire are cleaned, and table 6 for a summary of how **Q65**, **Q66** and **Q67** in the 12-15 questionnaire are cleaned.

Table 4. Cleaning for Q52, Q53 and Q54 in the 0-7 questionnaire

Q52 response	Q53 response	Q54 response	Cleaning
Ticked option 2 (no)	Ticked one or more options	No response	Q52 is set to missing – ‘999’ and as there was no response to Q54 this would also be set to missing (999)
Ticked option 2 (no)	Ticked one or more options	Ticked any option	Q52 is set to missing – ‘999’.
Ticked option 2 (no)	No response	Ticked any option	Q54 is set to not-applicable – ‘998’.

Table 5. Cleaning for Q63, Q64 and Q65 in the 8-11 questionnaire

Q63 response	Q64 response	Q65 response	Cleaning
Ticked option 2 (no)	Ticked one or more options	No response	Q63 is set to missing – ‘999’ and as there was no response to Q65 this would also be set to missing (999).
Ticked option 2 (no)	Ticked one or more options	Ticked any option	Q63 is set to missing – ‘999’.
Ticked option 2 (no)	No response	Ticked any option	Q65 is set to not-applicable – ‘998’.

Table 6. Cleaning for Q65, Q66 and Q67 in the 12-15 questionnaire

Q65 response	Q66 response	Q67 response	Cleaning
Ticked option 2 (no)	Ticked one or more options	No response	Q65 is set to missing – ‘999’ and as there was no response to Q67 this would also be set to missing (999).
Ticked option 2 (no)	Ticked one or more options	Ticked any option	Q65 is set to missing – ‘999’.
Ticked option 2 (no)	No response	Ticked any option	Q67 is set to not-applicable – ‘998’.

## Dealing with multiple response questions

For most questions, each column corresponds to one survey question. However, there are some exceptions. For multiple response questions; Q29 and Q53 (0-7 questionnaire); Q43 and Q64 (8-11 questionnaire); and Q46 and Q66 (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.

### Example:

## FACILITIES

29. Did you have access to hot drinks facilities in the hospital? **(Cross ALL that apply)**

- 1  Yes, I used a kitchen area / parents room attached to the ward
- 2  Yes, I used a hospital café / vending machine
- 3  I was allowed to use the staff room
- 4  I was offered drinks by members of staff
- 5  No

The above example would be coded as the following:

Column headings	Q29_1	Q29_2	Q29_3	Q29_4	Q29_5
Codings for this example	1	0	1	0	0

For Q29 above we do apply some additional cleaning rules. This question is a multiple response question however one of these options is mutually exclusive from the rest: option 5 “No”. In cases where a respondent has selected option 5 (No) and any other response (options 1-4), we clean out the data for this question completely and code the response as missing (999). We do not apply a hierarchy or priority to any of the options (ie: removing the ‘no’ answer and keeping the positive response or vice versa) as it is not possible to determine what the true response is in these cases.

## Eligibility

### Age / Year of birth

For the age questions (Q50 in the 0-7 questionnaire, Q23 in the 8-11 questionnaire and Q25 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, as self-reported responses of 12 are valid as the sampling period for most trusts in the 2020 survey ran from November 2020 to January 2021 whilst the fieldwork was not concluded until July 2021. This means respondents who were 11 during the sampling period and have a birthday in the first half of the year will be 12 when completing the questionnaire.

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 is 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.

## 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, Q26=1).

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).

The standard approach across the wider NHS Patient Survey Programme (NPSP) to deal with discrepancies between response and sample data on specific demographic characteristics (age and gender) is to prioritise a patient's response over what is indicated on the sample. 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 normally used in their place<sup>2</sup>. To do this, we first copy all valid responses to survey demographic questions into a new variable. Where responses are missing we copy in the relevant sample information. 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.

For the Children and Young People's Patient Experience Survey the gender and sex questions have been redesigned and not only vary between who is asked them (parent only, parent and child, young person only) but also vary with the response options used across the different survey versions. This, therefore, requires a potentially different approach for how the gender and sex questions are treated compared to the standard approach across the NPSP. Discussions are currently underway to consider how best to report the revised gender and sex questions for this

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<sup>2</sup> 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.



survey. Those decisions may impact how we eventually clean or reconcile data between the response and sample information, but it is not conclusive at the time of publishing this guidance. Consequently, we will be advising trusts and contractors of the outcome of those decisions to help support interpretation and analysis of the survey data when it is published.

## Usability

Sometimes questionnaires are returned with only a very small number of questions completed. For the 2020 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<sup>3</sup>. When counting the total number of responses for the purpose of determining if a questionnaire is usable, multiple choice questions are counted once. For instance, Q53 from the 0- 7 questionnaire would be counted as one response in the below scenario.

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

- 1  Blood disorder
- 2  Bowel condition, such as Crohn's disease
- 3  Breathing problem, such as asthma
- 4  Blindness or partial sight
- 5  Cancer in the last 5 years
- 6  Chromosomal condition, such as Down's syndrome
- 7  Deafness or hearing loss
- 8  Developmental disability, such as Autism Spectrum Disorder (ASD)
- 9  Diabetes
- 10  Heart problem
- 11  Joint problem
- 12  Kidney or liver disease
- 13  Learning disability
- 14  Mental health condition
- 15  Neurological condition, such as epilepsy
- 16  Another long-term condition

This process should only affect a very limited number of cases, and so should not have a significant impact on response rates.

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<sup>3</sup> The exception to this is when response rates are calculated. Because response rates vary between demographic groups, 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 data should be used to calculate response rates by demographic groups.

It is possible that a questionnaire could be considered usable because there are five or more responses, despite having an outcome code of 2, 3, 4, 6 or 7. In this case the outcome would be recoded to 1 to indicate a complete usable questionnaire and the response data kept for this patient.

## Missing responses

It is useful 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 and 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 will such blank cells be coded as missing responses.

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

For the 2020 survey, the SCCEM 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 SCCEM removes non-specific responses from base numbers for percentages. The rationale for this is to facilitate comparison between institutions by presenting only results from those patients who felt able to give an evaluative response to questions. For Q48 in the 0-7 questionnaire, Q58 in the 8-11 questionnaire and Q61 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 2020 survey, please see [Appendix C: Non-specific responses](#).

## Appendix A: Example of cleaning

### Incorrectly followed routing

Table 7 below shows hypothetical raw/uncleaned data for eight sample members, five of whom have responded to the survey (Outcome = 1).

Table 7. 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 in Table 7 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 in [Dealing with filtered questions](#), 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
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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 7 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 8 (below) shows how the data would look following cleaning by the SCCEM to recode responses to filtered questions that should have been skipped (shaded cells represent cases where responses have been recoded).

**Table 8. Example of cleaned data for the 0-7 questionnaire**

<b>Record</b>	<b>Outcome</b>	<b>Q2</b>	<b>Q3</b>	<b>Q4</b>
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: out of range data

0-7 questionnaire:

Variable	Out-of-range data
Month of birth	$\leq 0$ $> 12$
Year of birth	$< 2014$ $> 2021$
Gender	$\leq 0$ 3-8 $\geq 10$
Ethnicity	Anything except A-H, J-N, P, R, S or Z
Day of Admission	$\leq 0$ $\geq 31$
Month of Admission	$\leq 0$ $\geq 13$
Year of Admission	$< 2019$ $> 2021$
Day of Discharge	$\leq 0$ $\geq 31$
Month of Discharge	$\leq 0$ 2-9 $\geq 13$
Year of Discharge	$< 2020$ $> 2021$
DayQRec	$\leq 0$ $\geq 32$
MonthQRec	$\leq 0$ 1 $\geq 8$
YearQRec	$< 2021$ $\geq 2022$
Q1	$\leq 0$ $\geq 3$
Q2	$\leq 0$ $\geq 3$
Q3	$\leq 0$ $\geq 4$

Variable	Out-of-range data
Q4	$\leq 0$ $\geq 5$
Q5	$\leq 0$ $\geq 4$
Q6	$\leq 0$ $\geq 6$
Q7	$\leq 0$ $\geq 5$
Q8	$\leq 0$ $\geq 4$
Q9	$\leq 0$ $\geq 5$
Q10	$\leq 0$ $\geq 5$
Q11	$\leq 0$ $\geq 5$
Q12	$\leq 0$ $\geq 5$
Q13	$\leq 0$ $\geq 4$
Q14	$\leq 0$ $\geq 4$
Q15	$\leq 0$ $\geq 4$
Q16	$\leq 0$ $\geq 4$
Q17	$\leq 0$ $\geq 4$
Q18	$\leq 0$ $\geq 4$
Q19	$\leq 0$ $\geq 4$
Q20	$\leq 0$ $\geq 5$
Q21	$\leq 0$ $\geq 6$
Q22	$\leq 0$ $\geq 4$
Q23	$\leq 0$ $\geq 5$

Variable	Out-of-range data
Q24	≤ 0 ≥ 5
Q25	≤ 0 ≥ 5
Q26	≤ 0 ≥ 5
Q27	≤ 0 ≥ 4
Q28	≤ 0 ≥ 5
Q29_1	< 0 ≥ 2
Q29_2	< 0 ≥ 2
Q29_3	< 0 ≥ 2
Q29_4	< 0 ≥ 2
Q29_5	< 0 ≥ 2
Q30	≤ 0 ≥ 5
Q31	≤ 0 ≥ 4
Q32	≤ 0 ≥ 6
Q33	≤ 0 ≥ 5
Q34	≤ 0 ≥ 3
Q35	≤ 0 ≥ 5
Q36	≤ 0 ≥ 5
Q37	≤ 0 ≥ 5
Q38	≤ 0 ≥ 5
Q39	≤ 0 ≥ 6
Q40	≤ 0 ≥ 6

Variable	Out-of-range data
Q41	≤ 0 ≥ 5
Q42	≤ 0 ≥ 4
Q43	≤ 0 ≥ 4
Q44	≤ 0 ≥ 4
Q45	≤ 0 ≥ 4
Q46	≤ 0 ≥ 4
Q47	≤ 0 ≥ 4
Q48	< 0 ≥ 11
Q49	≤ 0 ≥ 5
Q50	< 2014 > 2021
Q51	≤ 0 ≥ 4
Q52	≤ 0 ≥ 3
Q53_1	< 0 ≥ 2
Q53_2	< 0 ≥ 2
Q53_3	< 0 ≥ 2
Q53_4	< 0 ≥ 2
Q53_5	< 0 ≥ 2
Q53_6	< 0 ≥ 2
Q53_7	< 0 ≥ 2
Q53_8	< 0 ≥ 2
Q53_9	< 0 ≥ 2

Variable	Out-of-range data
Q53_10	< 0 ≥ 2
Q53_11	< 0 ≥ 2
Q53_12	< 0 ≥ 2
Q53_13	< 0 ≥ 2
Q53_14	< 0 ≥ 2
Q53_15	< 0 ≥ 2
Q53_16	< 0 ≥ 2
Q54	≤ 0 ≥ 4
Q55	≤ 0 ≥ 19

### 8 - 11 questionnaire:

Variable	Out-of-range data
Month of birth	≤ 0 >12
Year of birth	< 2013 > 2010
Gender	≤ 0 3-8 ≥ 10
Ethnicity	Anything except A-H, J-N, P, R, S or Z
Day of Admission	≤ 0 ≥ 31
Month of Admission	≤ 0 ≥ 13
Year of Admission	< 2019 > 2021
Day of Discharge	≤ 0 ≥ 31
Month of Discharge	< 0 2-9 ≥ 13
Year of Discharge	< 2020 > 2021
DayQRec	≤ 0 ≥ 32
MonthQRec	≤ 0 1 ≥ 8
YearQRec	< 2021 ≥ 2022
Q1	≤ 0 ≥ 5
Q2	≤ 0 ≥ 4
Q3	≤ 0 ≥ 5
Q4	≤ 0 ≥ 5
Q5	≤ 0 ≥ 5

Variable	Out-of-range data
Q6	≤ 0 ≥ 5
Q7	≤ 0 ≥ 5
Q8	≤ 0 ≥ 4
Q9	≤ 0 ≥ 4
Q10	≤ 0 ≥ 5
Q11	≤ 0 ≥ 6
Q12	≤ 0 ≥ 5
Q13	≤ 0 ≥ 4
Q14	≤ 0 ≥ 5
Q15	≤ 0 ≥ 3
Q16	≤ 0 ≥ 4
Q17	≤ 0 ≥ 4
Q18	≤ 0 ≥ 5
Q19	≤ 0 ≥ 4
Q20	≤ 0 ≥ 5
Q21	≤ 0 ≥ 4
Q22	≤ 0 ≥ 6
Q23	< 8 > 12
Q24	≤ 0 ≥ 5
Q25	≤ 0 ≥ 3
Q26	≤ 0 ≥ 3



Variable	Out-of-range data
Q27	$\leq 0$ $\geq 4$
Q28	$\leq 0$ $\geq 6$
Q29	$\leq 0$ $\geq 5$
Q30	$\leq 0$ $\geq 5$
Q31	$\leq 0$ $\geq 4$
Q32	$\leq 0$ $\geq 4$
Q33	$\leq 0$ $\geq 4$
Q34	$\leq 0$ $\geq 5$
Q35	$\leq 0$ $\geq 4$
Q36	$\leq 0$ $\geq 5$
Q37	$\leq 0$ $\geq 6$
Q38	$\leq 0$ $\geq 5$
Q39	$\leq 0$ $\geq 5$
Q40	$\leq 0$ $\geq 5$
Q41	$\leq 0$ $\geq 5$
Q42	$\leq 0$ $\geq 4$
Q43	$\leq 0$ $\geq 6$
Q44	$\leq 0$ $\geq 5$
Q45	$\leq 0$ $\geq 4$
Q46	$\leq 0$ $\geq 6$
Q47	$\leq 0$ $\geq 5$

Variable	Out-of-range data
Q48	$\leq 0$ $\geq 3$
Q49	$\leq 0$ $\geq 5$
Q50	$\leq 0$ $\geq 5$
Q51	$\leq 0$ $\geq 5$
Q52	$\leq 0$ $\geq 5$
Q53	$\leq 0$ $\geq 6$
Q54	$\leq 0$ $\geq 5$
Q55	$\leq 0$ $\geq 4$
Q56	$\leq 0$ $\geq 4$
Q57	$\leq 0$ $\geq 4$
Q58	$< 0$ $\geq 11$
Q59	$\leq 0$ $\geq 4$
Q60	$\leq 0$ $\geq 4$
Q61	$\leq 0$ $\geq 5$
Q62	$\leq 0$ $\geq 19$
Q63	$\leq 0$ $\geq 3$
Q64_1	$< 0$ $\geq 2$
Q64_2	$< 0$ $\geq 2$
Q64_3	$< 0$ $\geq 2$
Q64_4	$< 0$ $\geq 2$
Q64_5	$< 0$ $\geq 2$

Variable	Out-of-range data
Q64_6	< 0 ≥ 2
Q64_7	< 0 ≥ 2
Q64_8	< 0 ≥ 2
Q64_9	< 0 ≥ 2
Q64_10	< 0 ≥ 2
Q64_11	< 0 ≥ 2
Q64_12	< 0 ≥ 2
Q64_13	< 0 ≥ 2
Q64_14	< 0 ≥ 2
Q64_15	< 0 ≥ 2
Q64_16	< 0 ≥ 2
Q65	≤ 0 ≥ 4

## 12 - 15 questionnaire:

Variable	Out-of-range data
Month of birth	≤ 0 >12
Year of birth	< 2006 > 2009
Gender	≤ 0 3-8 ≥ 10
Ethnicity	Anything except A-H, J-N, P, R, S or Z
Day of Admission	≤ 0 ≥ 31
Month of Admission	≤ 0 ≥ 13
Year of Admission	< 2019 > 2021
Day of Discharge	≤ 0 ≥ 32
Month of Discharge	< 0 2-9 ≥ 13
Year of Discharge	< 2020 > 2021
DayQRec	≤ 0 ≥ 32
MonthQRec	≤ 0 1 ≥ 8
YearQRec	< 2021 ≥ 2022
Q1	≤ 0 ≥ 4
Q2	≤ 0 ≥ 4
Q3	≤ 0 ≥ 5
Q4	≤ 0 ≥ 5
Q5	≤ 0 ≥ 5

Variable	Out-of-range data
Q6	≤ 0 ≥ 5
Q7	≤ 0 ≥ 5
Q8	≤ 0 ≥ 4
Q9	≤ 0 ≥ 4
Q10	≤ 0 ≥ 5
Q11	≤ 0 ≥ 6
Q12	≤ 0 ≥ 5
Q13	≤ 0 ≥ 4
Q14	≤ 0 ≥ 4
Q15	≤ 0 ≥ 5
Q16	≤ 0 ≥ 3
Q17	≤ 0 ≥ 4
Q18	≤ 0 ≥ 4
Q19	≤ 0 ≥ 5
Q20	≤ 0 ≥ 4
Q21	≤ 0 ≥ 5
Q22	≤ 0 ≥ 4
Q23	≤ 0 ≥ 6
Q24	≤ 0 ≥ 6
Q25	≤ 11 > 16
Q26	≤ 0 ≥ 7

Variable	Out-of-range data
Q27	$\leq 0$ $\geq 4$
Q28	$\leq 0$ $\geq 3$
Q29	$\leq 0$ $\geq 3$
Q30	$\leq 0$ $\geq 4$
Q31	$\leq 0$ $\geq 6$
Q32	$\leq 0$ $\geq 5$
Q33	$\leq 0$ $\geq 5$
Q34	$\leq 0$ $\geq 4$
Q35	$\leq 0$ $\geq 4$
Q36	$\leq 0$ $\geq 4$
Q37	$\leq 0$ $\geq 5$
Q38	$\leq 0$ $\geq 4$
Q39	$\leq 0$ $\geq 5$
Q40	$\leq 0$ $\geq 6$
Q41	$\leq 0$ $\geq 5$
Q42	$\leq 0$ $\geq 5$
Q43	$\leq 0$ $\geq 5$
Q44	$\leq 0$ $\geq 5$
Q45	$\leq 0$ $\geq 4$
Q46	$\leq 0$ $\geq 6$
Q47	$\leq 0$ $\geq 5$

Variable	Out-of-range data
Q48	$\leq 0$ $\geq 4$
Q49	$\leq 0$ $\geq 6$
Q50	$\leq 0$ $\geq 5$
Q51	$\leq 0$ $\geq 3$
Q52	$\leq 0$ $\geq 5$
Q53	$\leq 0$ $\geq 5$
Q54	$\leq 0$ $\geq 5$
Q55	$\leq 0$ $\geq 5$
Q56	$\leq 0$ $\geq 6$
Q57	$\leq 0$ $\geq 5$
Q58	$\leq 0$ $\geq 4$
Q59	$\leq 0$ $\geq 4$
Q60	$\leq 0$ $\geq 4$
Q61	$< 0$ $\geq 11$
Q62	$\leq 0$ $\geq 4$
Q63	$\leq 0$ $\geq 4$
Q64	$\leq 0$ $\geq 19$
Q65	$\leq 0$ $\geq 3$
Q66_1	$< 0$ $\geq 2$
Q66_2	$< 0$ $\geq 2$
Q66_3	$< 0$ $\geq 2$

Variable	Out-of-range data
Q66_4	< 0 ≥ 2
Q66_5	< 0 ≥ 2
Q66_6	< 0 ≥ 2
Q66_7	< 0 ≥ 2
Q66_8	< 0 ≥ 2
Q66_9	< 0 ≥ 2
Q66_10	< 0 ≥ 2
Q66_11	< 0 ≥ 2
Q66_12	< 0 ≥ 2
Q66_13	< 0 ≥ 2
Q66_14	< 0 ≥ 2
Q66_15	< 0 ≥ 2
Q66_16	< 0 ≥ 2
Q67	≤ 0 ≥ 4

## Appendix C: Non-specific responses

The following table lists all 'non-specific responses' included in the 2020 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	Were you able to be with your child as much as you needed to?	4
Q13	Did new members of staff treating your child introduce themselves?	-
Q14	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	-
Q15	Did members of staff treating your child communicate with them in a way that your child could understand?	-

<b>Q16</b>	Did a member of staff agree a plan for your child's care with you?	3
<b>Q17</b>	Did you have confidence and trust in the members of staff treating your child?	-
<b>Q18</b>	Did staff involve you in decisions about your child's care and treatment?	4
<b>Q19</b>	Were you given enough information to be involved in decisions about your child's care and treatment?	-
<b>Q20</b>	Did hospital staff keep you informed about what was happening whilst your child was in hospital?	4
<b>Q21</b>	Were you able to ask staff any questions you had about your child's care?	4, 5
<b>Q22</b>	Did different staff give you conflicting information?	-
<b>Q23</b>	Were the different members of staff caring for and treating your child aware of their medical history?	4
<b>Q24</b>	Did you feel that staff looking after your child knew how to care for their needs?	4
<b>Q25</b>	Were members of staff available when your child needed attention?	4
<b>Q26</b>	Did the members of staff caring for your child work well together?	4
<b>Q27</b>	If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	-
<b>Q28</b>	Did your child like the hospital food provided?	4
<b>Q29</b>	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	-
<b>Q30</b>	Were you able to prepare food in the hospital if you wanted to?	4
<b>Q31</b>	Did you stay overnight in hospital with your child during their most recent visit to hospital?	3
<b>Q32</b>	How would you rate the facilities for parents or carers staying overnight?	-
<b>Q33</b>	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	4

<b>Q34</b>	During their stay in hospital, did your child have any operations or procedures?	-
<b>Q35</b>	Before your child had any operation or procedures, did a member of staff explain to you what would be done?	4
<b>Q36</b>	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	4
<b>Q37</b>	During any operations or procedures, did staff play with your child or do anything to distract them?	4
<b>Q38</b>	Afterwards, did staff explain to you how the operations or procedures had gone?	4
<b>Q39</b>	Did a member of staff give you advice about caring for your child after you went home?	4, 5
<b>Q40</b>	Did a member of staff tell you who to talk to if you were worried about your child when you got home?	4, 5
<b>Q41</b>	When you left hospital, did you know what was going to happen next with your child's care?	4
<b>Q42</b>	Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	3
<b>Q43</b>	Do you feel that the people looking after your child listened to you?	-
<b>Q44</b>	Do you feel that the people looking after your child were friendly?	-
<b>Q45</b>	Do you feel that your child was well looked after by the hospital staff?	-
<b>Q46</b>	Do you feel that you (the parent/carer) were well looked after by hospital staff?	-
<b>Q47</b>	Were you treated with dignity and respect by the people looking after your child?	-
<b>Q48</b>	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)	-
<b>Q49</b>	What best describes your child's gender?	-
<b>Q50</b>	What is your child's year of birth?	-
<b>Q51</b>	Including this visit, how many times has your child been to hospital in the past six months?	-



<b>Q52</b>	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?	-
<b>Q53</b>	Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	-
<b>Q54</b>	Do any of these reduce your child's ability to carry out day-to-day activities?	-
<b>Q55</b>	Which of these best describes your child's ethnic background? (Cross ONE only)	-

<b>8-11 Questionnaire:</b>		
<b>Core</b>	<b>Question</b>	<b>Non-specific responses</b>
<b>Q1</b>	Did hospital staff play with you or do any activities with you while you were in hospital?	4
<b>Q2</b>	Were there enough things for you to do in the hospital?	-
<b>Q3</b>	If you used the hospital Wi-Fi, was it good enough to do what you wanted?	4
<b>Q4</b>	Did you like the hospital food?	4
<b>Q5</b>	Was it quiet enough for you to sleep when needed in the hospital?	4
<b>Q6</b>	Did hospital staff talk with you about how they were going to care for you?	4
<b>Q7</b>	When the hospital staff spoke with you, did you understand what they said?	4
<b>Q8</b>	Did you feel able to ask staff questions?	3
<b>Q9</b>	Did the hospital staff answer your questions?	-
<b>Q10</b>	Were you involved in decisions about your care and treatment?	4
<b>Q11</b>	When you spoke to hospital staff, did they listen to what you had to say?	4, 5
<b>Q12</b>	If you had any worries, did a member of staff talk with you about them?	3, 4
<b>Q13</b>	Were you given enough privacy when you were receiving care and treatment?	-
<b>Q14</b>	If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	4
<b>Q15</b>	During your time in hospital, did you have any operations or procedures?	-
<b>Q16</b>	Before the operations or procedures, did hospital staff explain to you what would be done?	-
<b>Q17</b>	Afterwards, did staff explain to you how the operations or procedures had gone?	-

<b>Q18</b>	Did a member of staff tell you who to talk to if you were worried about anything when you got home?	4
<b>Q19</b>	When you left hospital, did you know what was going to happen next with your care?	-
<b>Q20</b>	Did a member of staff give you advice on how to look after yourself after you went home?	4
<b>Q21</b>	Do you feel that the people looking after you were friendly?	-
<b>Q22</b>	Overall, how well do you think you were looked after in hospital?	-
<b>Q23</b>	How old are you today?	-
<b>Q24</b>	What best describes your gender?	-
<b>Parent's section</b>	<b>Parent's section</b>	
<b>Q25</b>	Was your child's visit to hospital planned or an emergency?	-
<b>Q26</b>	Did your child stay overnight during their most recent visit to hospital?	-
<b>Q27</b>	For most of their stay in hospital, what type of ward did your child stay on?	-
<b>Q28</b>	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	4, 5
<b>Q29</b>	How clean do you think the hospital room or ward was that your child was in?	-
<b>Q30</b>	Were you able to be with your child as much as you needed to?	4
<b>Q31</b>	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	-
<b>Q32</b>	Did a member of staff agree a plan for your child's care with you?	3
<b>Q33</b>	Did you have confidence and trust in the members of staff treating your child?	-
<b>Q34</b>	Did staff involve you in decisions about your child's care and treatment?	4

<b>Q35</b>	Were you given enough information to be involved in decisions about your child's care and treatment?	-
<b>Q36</b>	Did hospital staff keep you informed about what was happening whilst your child was in hospital?	4
<b>Q37</b>	Were you able to ask staff any questions you had about your child's care?	4, 5
<b>Q38</b>	Were the different members of staff caring for and treating your child aware of their medical history?	4
<b>Q39</b>	Did you feel that staff looking after your child knew how to care for their needs?	4
<b>Q40</b>	Were members of staff available when your child needed attention?	4
<b>Q41</b>	Did the members of staff caring for your child work well together?	4
<b>Q42</b>	If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	-
<b>Q43</b>	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	-
<b>Q44</b>	Were you able to prepare food in the hospital if you wanted to?	4
<b>Q45</b>	Did you stay overnight with your child during their most recent visit to hospital?	3
<b>Q46</b>	How would you rate the facilities for parents or carers staying overnight?	-
<b>Q47</b>	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	4
<b>Q48</b>	During their stay in hospital, did your child have any operations or procedures?	-
<b>Q49</b>	Before your child had any operations or procedures, did a member of staff explain to you what would be done?	4
<b>Q50</b>	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	4
<b>Q51</b>	During any operations or procedures, did staff play with your child or do anything to distract them?	4

<b>Q52</b>	Afterwards, did staff explain to you how the operations or procedures had gone?	4
<b>Q53</b>	Did a staff member give you advice about caring for your child after you went home?	4, 5
<b>Q54</b>	When you left hospital, did you know what was going to happen next with your child's care?	4
<b>Q55</b>	Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	3
<b>Q56</b>	Do you feel that you (the parent/carer) were well looked after by hospital staff?	-
<b>Q57</b>	Were you treated with dignity and respect by the people looking after your child?	-
<b>Q58</b>	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)	-
<b>Q59</b>	Who was the main person who answered the questions in the children's section of the questionnaire?	-
<b>Q60</b>	Including this visit, how many times has your child been to hospital in the past six months?	-
<b>Q61</b>	What sex was your child assigned at birth?	-
<b>Q62</b>	Which of these best describes your child's ethnic background? (Cross ONE only)	-
<b>Q63</b>	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?	-
<b>Q64</b>	Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	-
<b>Q65</b>	Do any of these reduce your child's ability to carry out day-to-day activities?	-

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	When you spoke to hospital staff, did they listen to what you had to say?	4, 5
Q12	If you had any worries, did a member of staff talk with you about them?	3, 4
Q13	Were you given enough privacy when you were receiving care and treatment?	-
Q14	If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?	3
Q15	If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	4
Q16	During your time in hospital, did you have any operations or procedures?	-
Q17	Before the operations or procedures, did hospital staff explain to you what would be done?	-

Q18	Afterwards, did staff explain to you how the operations or procedures had gone?	-
Q19	Did a member of staff tell you who to talk to if you were worried about anything when you got home?	4
Q20	When you left hospital, did you know what was going to happen next with your care?	-
Q21	Did a member of staff give you advice on how to look after yourself after you went home?	4
Q22	Do you feel that the people looking after you were friendly?	-
Q23	Overall, how well do you think you were looked after in hospital?	-
Q24	If you are moving to adult services, did hospital staff give you enough information about what will happen?	4, 5
Q25	How old are you today?	-
Q26	What best describes your gender?	
Q27	Is your gender the same as the sex you were given at birth?	-
<b>Parent's section</b>	<b>Parent's section</b>	
Q28	Was your child's visit to hospital planned or an emergency?	-
Q29	Did your child stay overnight during their most recent visit to hospital?	-
Q30	For most of their stay in hospital, what type of ward did your child stay on?	-
Q31	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	4, 5
Q32	How clean do you think the hospital room or ward was that your child was in?	-
Q33	Were you able to be with your child as much as you needed to?	4
Q34	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	-
Q35	Did a member of staff agree a plan for your child's care with you?	3

Q36	Did you have confidence and trust in the members of staff treating your child?	-
Q37	Did staff involve you in decisions about your child's care and treatment?	4
Q38	Were you given enough information to be involved in decisions about your child's care and treatment?	-
Q39	Did hospital staff keep you informed about what was happening whilst your child was in hospital?	4
Q40	Were you able to ask staff any questions you had about your child's care?	4, 5
Q41	Were the different members of staff caring for and treating your child aware of their medical history?	4
Q42	Did you feel that staff looking after your child knew how to care for their needs?	4
Q43	Were members of staff available when your child needed attention?	4
Q44	Did the members of staff caring for your child work well together?	4
Q45	If you had been unhappy with your child's care and treatment, do you feel that you could have told hospital staff?	-
Q46	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	-
Q47	Were you able to prepare food in the hospital if you wanted to?	4
Q48	Did you stay overnight with your child during their most recent visit to hospital?	3
Q49	How would you rate the facilities for parents or carers staying overnight?	-
Q50	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	4
Q51	During their stay in hospital, did your child have any operations or procedures?	-
Q52	Before your child had any operations or procedures, did a member of staff explain to you what would be done?	4



Q53	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	4
Q54	During any operations or procedures, did staff play with your child or do anything to distract them?	4
Q55	Afterwards, did staff explain to you how the operations or procedures had gone?	4
Q56	Did a staff member give you advice about caring for your child after you went home?	4, 5
Q57	When you left hospital, did you know what was going to happen next with your child's care?	4
Q58	Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	3
Q59	Do you feel that you (the parent/carer) were well looked after by hospital staff?	-
Q60	Were you treated with dignity and respect by the people looking after your child?	-
Q61	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)	-
Q62	Who was the main person who answered the questions in the young people's section of the questionnaire?	-
Q63	Including this visit, how many times has your child been to hospital in the past six months?	-
Q64	Which of these best describes your child's ethnic background? (Cross ONE only)	-
Q65	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?	-
Q66	Does your child have any of the following? (Select ALL conditions that have lasted or are expected to last for 12 months or more)	-
Q67	Do any of these reduce your child's ability to carry out day-to-day activities?	-

