

DATA CLEANING GUIDANCE

NHS CHILDREN AND YOUNG PEOPLE'S SURVEY 2016

THE SURVEY COORDINATION CENTRE FOR THE NHS PATIENT
SURVEY PROGRAMME

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Contacts

The Survey Coordination Centre for the NHS Patient Survey Programme
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0BJ

Tel: 01865 208127
Fax: 01865 208101
E-mail: cyp@surveycoordination.com
Website: www.nhssurveys.org

Authors

The Patient Survey Coordination Centre

Updates

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This document is available from the Survey Coordination Centre website here:
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.

Contents

Introduction	4
Scope of this cleaning guide.....	4
Definition of key terms	4
Entering and coding data prior to submission	6
Editing/cleaning data after submission	7
Dealing with multiple response questions	8
Dealing with demographics.....	12
Age (Q48 in the 0-7 questionnaire, Q22 in the 8-11 questionnaire and Q23 in the 12-15 questionnaire).....	13
Usability and eligibility	13
Missing responses.....	14
Non-specific responses	15
Appendix A: Example of cleaning	16
Appendix B: Non-specific responses	18

Introduction

At the end of fieldwork for the NHS Children and Young People's Inpatient and Day Case Survey 2016, 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 2016 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

Scope of this cleaning guide

For the 2016 survey, all trusts have to submit data for all three questionnaires: the 52 questions for the 0-7 age group questionnaire, 59 questions for the 8-11 age group questionnaire and 60 questions for the 12-15 age group questionnaire. All cleaning undertaken by ourselves will include only this data.

Definition of key terms

Definitions of terms commonly used in this document, as they apply to the 2016 survey are as follows:

Raw/uncleaned data: 'Raw' or 'uncleaned' data is data that has 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 items on the questionnaire which 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 2016 survey, the routing questions in the questionnaires are:

0-7 questionnaire: Q1, Q15, Q27, Q30, Q35, and Q50.

8-11 questionnaire: Q7, Q13, Q30, Q40, Q43, Q48 and Q58.

12-15 questionnaire: Q7, Q14, Q31, Q41, Q44, Q49 and Q59.

Filtered questions: Items on the questionnaire 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 2016 survey, the filtered questions in the questionnaire are:

0-7 questionnaire: Q2, Q3, Q16, Q28, Q31-Q34, Q36, and Q51.

8-11 questionnaire: Q8, Q14, Q15, Q31, Q41, Q44-Q47, Q49 and Q59.

12-15 questionnaire: Q8, Q15, Q16, Q32, Q42, Q45-Q48, Q50 and Q60.

Non-filtered questions: These are items in the questionnaire which are not subject to any filtering and which should therefore be answered by all respondents. For the 2016 survey, the non-filtered questions are:

0-7 questionnaire: Q1, Q4-Q15, Q17-Q27, Q29, Q30, Q35, Q37-Q50, and Q52.

8-11 questionnaire: Q1-Q7, Q9-Q13, Q16-Q30, Q32-Q40, Q42, Q43, Q48, Q50-Q58.

12-15 questionnaire: Q1-Q7, Q9-Q14, Q17-Q31, Q33-Q41, Q43, Q44, Q49, Q51-Q59.

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 2016 children's survey can be found in Appendix B.

Entering and coding data prior to submission

For the 2016 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 Q48 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 '2017' 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

The aim of the Survey Coordination Centre in cleaning the data submitted to us is 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 do this in a relatively permissive way so as 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 Q27 in the 0-7 questionnaire (“Did you ever stay overnight in hospital with your child?”) are instructed to go to Q28, whereas those that selected all other options skip Q29.

It is necessary to clean the data to remove responses where filter instructions have been incorrectly followed. In such cases, participants’ responses to questions that were not relevant to them are removed from the dataset. Responses are only removed 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 Q27 (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 removed, however, where the response to the routing question is missing. For example, Q28 is applicable to those who stayed in hospital overnight and are filtered by the response to Q27 (e.g. they are answered if Q27=1). If a respondent does not answer Q27, or if the response to Q27 is missing for any reason, then responses to Q28 should not be removed.

The tables below show a summary of all routing questions, and the filtered questions they relate to, that are included in the 2016 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 Q1	=	1	then delete responses to: Q2-Q3
if Q15	=	4	then delete responses to: Q16
if Q27	=	2, 3 or 4	then delete responses to: Q28
if Q30	=	2	then delete responses to: Q31-34
if Q35	=	2	then delete responses to: Q36
if Q50	=	7	see specific instructions below Q51

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 Q7	=	2 or 3	then delete responses to: Q8
if Q13	=	2	then delete responses to: Q14-Q15
if Q30	=	4	then delete responses to: Q31
if Q40	=	2, 3 or 4	then delete responses to: Q41
if Q43	=	2	then delete responses to: Q44-Q47
if Q48	=	2	then delete responses to: Q49
if Q58	=	7	see specific instructions below Q59

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 Q7	=	2 or 3	then delete responses to: Q8
if Q13	=	2	then delete responses to: Q14-Q15
if Q30	=	4	then delete responses to: Q31
if Q40	=	2, 3 or 4	then delete responses to: Q41
if Q43	=	2	then delete responses to: Q44-Q47
if Q49	=	2	then delete responses to: Q50
if Q59	=	7	see specific instructions below Q60

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; Q25, Q50 and Q51 (0-7 questionnaire); Q38, Q58 and Q59 (8-11 questionnaire); and Q39, Q59 and Q60 (12-15 questionnaire) that give the instruction “(Cross ALL that apply)”, each response option is treated as a separate question.

Example:

Q50. Does your child have any of the following long-standing conditions? (**Cross ALL that apply**)

- 1 Deafness or severe hearing impairment
- 2 Blindness or partially sighted
- 3 Any other long-standing physical disability
- 4 A learning disability
- 5 A mental health condition
- 6 Another long-standing condition (eg. cancer, diabetes, epilepsy)
- 7 No long-standing condition

Responses to each part of this question are coded: **1 if the box is crossed**
0 if the box is not crossed

Q50 takes up seven columns in the data file, labelled as follows:

Column headings	Q50_1	Q50_2	Q50_3	Q50_4	Q50_5	Q50_6	Q50_7
Codings for this example	1	0	0	0	1	0	0

For Q25 of the 0-7 question, Q38 of the 8-11 questionnaire and Q39 of the 12-15, no cleaning is applied beyond removing out-of-range responses. For the long-term condition questions, however, the last response to each of these questions is an exclusive option – respondents should not have selected Q50_7 ('No long-standing condition') as well as any of Q50_1-6. If this is the case, the cleaning of Q50 takes into account the response to Q51 when deciding which options to retain, as detailed below. **It is essential that each step outlined below is carried out sequentially, exactly in the order specified, or the cleaning will not be correct.**

When a respondent has crossed any of options Q50_1-6 as well as Q50_7:

- o If they **have also crossed any of Q51_1-7 and have also crossed Q51_8** then Q50_1-7 and Q51_1-8 (i.e. all responses to Q50 & Q51) are removed (set to blank or full stop), because it is unclear which options are most likely to be correct for the respondent.
- o If they **have also crossed any of Q51_1-7 and have not crossed Q51_8** then Q50_7 is recoded to 0 (and options Q50_1-6 remain as selected by the respondent), because their response to Q51 suggests they do in fact have a long-standing condition.
- o If they **have not crossed any of Q51_1-7 and have not crossed Q51_8** then Q50_1-6 are recoded to 0 and option Q50_7 remains crossed, because their lack of response to Q51 suggests that they have correctly followed the routing from Q50_7, and therefore do not have a long-standing condition.

- If they **have not crossed any of Q51_1-7 and have crossed Q51_8** then Q50_1-7 and Q51_1-8 (i.e. all responses to Q50 & Q51) are removed (set to blank or full stop), because it is unclear which options are most likely to be correct for the respondent.

Similarly, a respondent should not have selected Q51_8 ('No difficulty with any of these') as well as any of Q51_1-7, and in these cases the cleaning of Q51 takes into account responses to Q50, as detailed below.

When a respondent has crossed any of options Q51_1-7 as well as Q51_8:

- If they **have also crossed any of Q50_1-6** then Q51_8 is recoded to 0 (and options Q51_1-7 remain as selected by the respondent), because their response to Q50 indicates that they do have a long-standing condition and therefore their Q51 responses about difficulties caused are likely to be correct.
- If they **have not crossed any of Q50_1-6** then all responses to Q51_1-8 are removed (set to blank or full stop) as the respondent should not have completed this filtered question.

After the above cleaning has taken place:

- If Q50_7 is selected, any responses to Q51_1-8 are removed (set to blank or full stop), as respondents who do not have a long-standing condition should not have answered Q51.
- If any of Q50_1-6 are selected and no response has been given to Q51, then Q51_1-8 are set to missing, as Q51 should have been answered by all respondents who selected at least one of Q50_1-6.
- If no responses have been given to Q50, Q50_1-7 are set to missing and Q51_1-8 are removed (set to blank or full stop), as Q51 is a filtered question which should only have been answered by respondents selecting at least one of Q50_1-6.

Several examples of the cleaning undertaken for Q50 and Q51 are provided below.

Example 1

Q50. Does your child have any of the following long-standing conditions? (**Cross ALL that apply**)

- 1 Deafness or severe hearing impairment
- 2 Blindness or partially sighted
- 3 Any other long-standing physical disability
- 4 A learning disability
- 5 A mental health condition
- 6 Another long-standing condition
- 7 No long-standing condition

Q51. Does this condition(s) cause your child difficulty with any of the following? (**Cross ALL that apply**)

- 1 Everyday activities that people his/her age can usually do
- 2 In education or training
- 3 Access to buildings, streets or vehicles
- 4 Reading or writing
- 5 People's attitudes to your child because of his/ her condition
- 6 Communicating, mixing with others and socialising
- 7 Any other activity
- 8 No difficulty with any of these

BEFORE CLEANING:

Q50 is coded as follows:

Column headings	Q50_1	Q50_2	Q50_3	Q50_4	Q50_5	Q50_6	Q50_7
Coding for this example	1	0	0	0	1	0	1

Q51 is coded as follows:

Column headings	Q51_1	Q51_2	Q51_3	Q51_4	Q51_5	Q51_6	Q51_7	Q51_8
Coding for this example	0	0	0	0	0	0	0	0

AFTER CLEANING:

Q50 is coded as follows:

Column headings	Q50_1	Q50_2	Q50_3	Q50_4	Q50_5	Q50_6	Q50_7
Coding for this example	0	0	0	0	0	0	1

Q51 is coded as follows:

Column headings	Q51_1	Q51_2	Q51_3	Q51_4	Q51_5	Q51_6	Q51_7	Q51_8
Coding for this example	0	0	0	0	0	0	0	0

When the data is cleaned, Q50_1-6 are recoded to 0 and option Q50_7 remains crossed, because their lack of response to Q51 suggests that they have correctly followed the routing from Q50_7, and therefore do not have a long-standing condition.

Example 2

Q50. Does your child have any of the following long-standing conditions? (**Cross ALL that apply**)

- 1 Deafness or severe hearing impairment
- 2 Blindness or partially sighted
- 3 Any other long-standing physical disability
- 4 A learning disability
- 5 A mental health condition
- 6 Any other long-standing condition
- 7 No long-standing condition

Q51. Does this condition(s) cause your child difficulty with any of the following? (**Cross ALL that apply**)

- 1 Everyday activities that people his/ her age can usually do
- 2 In education or training
- 3 Access to buildings, streets or vehicles
- 4 Reading or writing
- 5 People's attitudes to your child because of his/ her condition
- 6 Communicating, mixing with others and socialising
- 7 Any other activity
- 8 No difficulty with any of these

BEFORE CLEANING:

Q50 is coded as follows:

Column headings	Q50_1	Q50_2	Q50_3	Q50_4	Q50_5	Q50_6	Q50_7
Coding for this example	0	0	0	0	0	0	1

Q51 is coded as follows:

Column headings	Q51_1	Q51_2	Q51_3	Q51_4	Q51_5	Q51_6	Q51_7	Q51_8
Coding for this example	0	1	0	0	1	0	0	1

AFTER CLEANING:

Q50 is coded as follows:

Column headings	Q50_1	Q50_2	Q50_3	Q50_4	Q50_5	Q50_6	Q50_7
Coding for this example	0	0	0	0	0	0	1

Q51 is coded as follows:

Column headings	Q51_1	Q51_2	Q51_3	Q51_4	Q51_5	Q51_6	Q51_7	Q51_8
Coding for this example

When the data are cleaned, the responses to Q51 are removed (set to blank or full stop) as the respondent indicated they do not have a long-standing condition and therefore should not have completed Q51.

Dealing with demographics

Basic demographic information, including age, sex and ethnicity of patients, are included in the sample section of the data but 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, Q22=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 place¹. 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 (Q48 in the 0-7 questionnaire, Q22 in the 8-11 questionnaire and Q23 in the 12-15 questionnaire)

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 missing². For the 2016 survey, out of range responses to the year of birth question (Q48 in the 0-7 questionnaire) are defined as ≤ 1999 or ≥ 2017 .

For the Age questions (Q22 in the 8-11 questionnaire and Q23 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 2016 survey ran from November to December 2016 however fieldwork was not concluded until early June 2017. 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 a 12 when completing the questionnaire.

Usability and eligibility

Sometimes questionnaires are returned with only a very small number of questions completed. For the 2016 survey, questionnaires where fewer than five questions have been answered are

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.

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 '1984' may become 984, 184, 194, or 198). 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.

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 cleaning³. 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

³ Please note that the multiple choice questions, Q50 and Q51 are only counted once. So for example, even if Q51_1 and Q51_4 are crossed, this would count as only one response for the purpose of determining if a questionnaire is usable.

responses should be presented but should not be included in the base number of respondents for percentages.

For the 2016 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 Q46 in the 0-7 questionnaire, Q54 in the 8-11 questionnaire and Q55 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 2016 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	Q1	Q2	Q3
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	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 (Q1=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 removed. Firstly, the filter instructions listed in Table 1 specify that:

if	Q1 = 1	then delete responses to:	Q2-Q3
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In accordance with this, all responses for Q2, and Q3 must be removed in cases where the respondent has crossed Q1=1 ('emergency'). Looking in column Q1 of Table 4 we can see that respondents 'CYP...0003' and 'CYP...0008' have responded Q1=1, so any responses they gave to Q2 and Q3 need to be removed. This will lead to two responses being removed for these respondents. Table 5 (below) shows how the data would look following cleaning by the Survey Coordination Centre to remove responses to filtered questions that should have been skipped (shaded cells represent cases where responses have been removed).

Table 5. Example of cleaned data for the 0-7 questionnaire

Record	Outcome	Q1	Q2	Q3
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	.	.
CYP...0004	4			
CYP...0005	1	2	2	.
CYP...0006	6			
CYP...0007	1	2	1	2
CYP...0008	1	1	.	.

Appendix B: Non-specific responses

The following table lists all 'non-specific responses' included in the 2016 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	Was your child's visit to hospital planned or an emergency?	-
Q2	Did the hospital give you a choice of admission dates?	3
Q3	Did the hospital change your child's admission date at all?	4
Q4	For most of their stay in hospital what type of ward did your child stay on?	-
Q5	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	4,5
Q6	How clean do you think the hospital room or ward was that your child was in?	-
Q7	Was your child given enough privacy when receiving care and treatment?	-
Q8	Were there enough things for your child to do in the hospital?	4
Q9	Did staff play with your child at all while they were in hospital?	3,4
Q10	Did new members of staff treating your child introduce themselves?	-
Q11	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	-
Q12	Did members of staff treating your child communicate with them in a way that your child could understand?	-
Q13	Did a member of staff agree a plan for your child's care with you ?	3
Q14	Did you have confidence and trust in the members of staff treating your child?	-
Q15	Did staff involve you in decisions about your child's care and treatment?	4
Q16	Were you given enough information to be involved in decisions about your child's care and treatment?	-

Q17	Did hospital staff keep you informed about what was happening whilst your child was in hospital?	4
Q18	Were you able to ask staff any questions you had about your child's care?	4,5
Q19	Did different staff give you conflicting information?	-
Q20	Were the different members of staff caring for and treating your child aware of their medical history?	4
Q21	Did you feel that staff looking after your child knew how to care for their individual or special needs?	4
Q22	Were members of staff available when your child needed attention?	4
Q23	Did the members of staff caring for your child work well together?	4
Q24	Did your child like the hospital food provided?	4
Q25	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	-
Q26	Were you able to prepare food in the hospital if you wanted to?	4
Q27	Did you ever stay overnight in hospital with your child?	4
Q28	How would you rate the facilities for parents or carers staying overnight?	-
Q29	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	4
Q30	During their stay in hospital, did your child have any operations or procedures ?	-
Q31	Before your child had any operations or procedures did a member of staff explain to you what would be done ?	4
Q32	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	4
Q33	During any operations or procedures, did staff play with your child or do anything to distract them?	4
Q34	Afterwards , did staff explain to you how the operations or procedures had gone ?	4
Q35	Were you given any new medicines to take home with you for your child that they had not had before (including tablets and creams)?	-
Q36	Were you given enough information about how your child should use the medicine(s) (e.g. when to take it, or whether it should be taken with food)?	-
Q37	Did a member of staff give you advice about caring for your child after you went home?	4,5

Q38	Did a member of staff tell you who to talk to if you were worried about your child when you got home?	4,5
Q39	When you left hospital, did you know what was going to happen next with your child's care?	4
Q40	Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	3
Q41	Do you feel that the people looking after your child listened to you?	-
Q42	Do you feel that the people looking after your child were friendly?	-
Q43	Do you feel that your child was well looked after by the hospital staff?	-
Q44	Do you feel that you (the parent/carer) were well looked after by hospital staff?	-
Q45	Were you treated with dignity and respect by the people looking after your child?	-
Q46	Overall... (please circle a number)	-
Q47	Is your child male or female?	-
Q48	What is your child's year of birth?	-
Q49	Including this visit , how many times has your child stayed in hospital on a ward in the past six months?	-
Q50	Does your child have any of the following long-standing conditions? (Cross ALL that apply)	-
Q51	Does this condition(s) cause your child difficulty with any of the following? (Cross ALL that apply)	-
Q52	Which of these best describes your child's ethnic background? (Cross ONE only)	-

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	Did you like the hospital food?	4
Q4	Was it quiet enough for you to sleep when needed in the hospital?	4
Q5	Did hospital staff talk with you about how they were going to care for you?	4
Q6	When the hospital staff spoke with you , did you understand what they said?	4
Q7	Did you feel able to ask staff questions?	3
Q8	Did the hospital staff answer your questions?	-
Q9	Were you involved in decisions about your care and treatment?	4
Q10	If you had any worries, did a member of staff talk with you about them?	4
Q11	Were you given enough privacy when you were receiving care and treatment?	-
Q12	If you felt pain while you were at the hospital, do you think staff did everything they could to help you?	4
Q13	During your time in hospital, did you have any operations or procedures (such as having your tonsils taken out)?	-
Q14	Before the operations or procedures, did hospital staff explain to you what would be done ?	-
Q15	Afterwards , did staff explain to you how the operations or procedures had gone ?	-
Q16	Did a member of staff tell you who to talk to if you were worried about anything when you got home?	4
Q17	When you left hospital, did you know what was going to happen next with your care?	-
Q18	Did a member of staff give you advice on how to look after yourself after you went home?	4
Q19	Do you feel that the people looking after you were friendly?	-
Q20	Overall, how well do you think you were looked after in hospital?	-

Q21	Are you a boy or a girl?	-
Q22	How old are you today?	-
Q23	Was your child's visit to hospital planned or an emergency?	-
Q24	For most of their stay in hospital what type of ward did your child stay on?	-
Q25	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	4,5
Q26	How clean do you think the hospital room or ward was that your child was in?	-
Q27	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	-
Q28	Did a member of staff agree a plan for your child's care with you ?	3
Q29	Did you have confidence and trust in the members of staff treating your child?	-
Q30	Did staff involve you in decisions about your child's care and treatment?	4
Q31	Were you given enough information to be involved in decisions about your child's care and treatment?	-
Q32	Did hospital staff keep you informed about what was happening whilst your child was in hospital?	4
Q33	Were you able to ask staff any questions you had about your child's care?	4,5
Q34	Were the different members of staff caring for and treating your child aware of their medical history?	4
Q35	Did you feel that staff looking after your child knew how to care for their individual or special needs?	4
Q36	Were members of staff available when your child needed attention?	4
Q37	Did the members of staff caring for your child work well together?	4
Q38	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	-
Q39	Were you able to prepare food in the hospital if you wanted to?	4
Q40	Did you ever stay overnight in hospital with your child?	4
Q41	How would you rate the facilities for parents or carers staying overnight?	-
Q42	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	4

Q43	During their stay in hospital, did your child have any operations or procedures ?	-
Q44	Before your child had any operations or procedures, did a member of staff explain to you what would be done ?	4
Q45	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	4
Q46	During any operations or procedures, did staff play with your child or do anything to distract them?	4
Q47	Afterwards , did staff explain to you how the operations or procedures had gone ?	4
Q48	Were you given any new medicines to take home with you for your child that they had not had before (including tablets and creams)?	-
Q49	Were you given enough information about how your child should use the medicine(s) (e.g. when to take it, or whether it should be taken with food)?	-
Q50	Did a member of staff give you advice about caring for your child after you went home?	4,5
Q51	When you left hospital, did you know what was going to happen next with your child's care?	4
Q52	Were you given any written information (such as leaflets) about your child's condition or treatment to take home with you?	3
Q53	Do you feel that you (the parent/carer) were well looked after by hospital staff?	-
Q54	Overall... (please circle a number)	-
Q55	Who was the main person who answered the questions in the children's section of the questionnaire?	-
Q56	Including this visit , how many times has your child stayed in hospital on a ward in the past six months?	-
Q57	Which of these best describes your child's ethnic background? (Cross ONE only)	-
Q58	Does your child have any of the following long-standing conditions? (Cross ALL that apply)	-
Q59	Does this condition(s) cause your child difficulty with any of the following? (Cross ALL that apply)	-

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	Did you like the hospital food?	4
Q4	Was it quiet enough for you to sleep when needed in the hospital?	4
Q5	Did hospital staff talk with you about how they were going to care for you?	4
Q6	When the hospital staff spoke with you , did you understand what they said?	4
Q7	Did you feel able to ask staff questions?	3
Q8	Did the hospital staff answer your questions?	-
Q9	Were you involved in decisions about your care and treatment?	4
Q10	If you had any worries, did a member of staff talk with you about them?	4
Q11	Were you given enough privacy when you were receiving care and treatment?	-
Q12	If you wanted, were you able to talk to a doctor or nurse without your parent or carer being there?	3
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 (such as having your tonsils taken out)?	-
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 male or female?	-
Q23	How old are you today?	-
Q24	Was your child's visit to hospital planned or an emergency?	-
Q25	For most of their stay in hospital what type of ward did your child stay on?	-
Q26	Did the ward where your child stayed have appropriate equipment or adaptations for your child's physical or medical needs?	4,5
Q27	How clean do you think the hospital room or ward was that your child was in?	-
Q28	Did members of staff treating your child give you information about their care and treatment in a way that you could understand?	-
Q29	Did a member of staff agree a plan for your child's care with you ?	3
Q30	Did you have confidence and trust in the members of staff treating your child?	-
Q31	Did staff involve you in decisions about your child's care and treatment?	4
Q32	Were you given enough information to be involved in decisions about your child's care and treatment?	-
Q33	Did hospital staff keep you informed about what was happening whilst your child was in hospital?	4
Q34	Were you able to ask staff any questions you had about your child's care?	4,5
Q35	Were the different members of staff caring for and treating your child aware of their medical history?	4
Q36	Did you feel that staff looking after your child knew how to care for their individual or special needs?	4
Q37	Were members of staff available when your child needed attention?	4
Q38	Did the members of staff caring for your child work well together?	4
Q39	Did you have access to hot drinks facilities in the hospital? (Cross ALL that apply)	-
Q40	Were you able to prepare food in the hospital if you wanted to?	4
Q41	Did you ever stay overnight in hospital with your child?	4
Q42	How would you rate the facilities for parents or carers staying overnight?	-

Q43	If your child felt pain while they were at the hospital, do you think staff did everything they could to help them?	4
Q44	During their stay in hospital, did your child have any operations or procedures ?	-
Q45	Before your child had any operations or procedures, did a member of staff explain to you what would be done ?	4
Q46	Before the operations or procedures, did a member of staff answer your questions in a way you could understand?	4
Q47	During any operations or procedures, did staff play with your child or do anything to distract them?	4
Q48	Afterwards , did staff explain to you how the operations or procedures had gone ?	4
Q49	Were you given any new medicines to take home with you for your child that they had not had before (including tablets and creams)?	-
Q50	Were you given enough information about how your child should use the medicine(s) (e.g. when to take it, or whether it should be taken with food)?	-
Q51	Did a member of staff 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	Overall... (please circle a number)	-
Q56	Who was the main person who answered the questions in the children's section of the questionnaire?	-
Q57	Including this visit , how many times has your child stayed in hospital on a ward in the past six months?	-
Q58	Which of these best describes your child's ethnic background? (Cross ONE only)	-
Q59	Does your child have any of the following long-standing conditions? (Cross ALL that apply)	-
Q60	Does this condition(s) cause your child difficulty with any of the following? (Cross ALL that apply)	-