INSTRUCTION MANUAL FOR THE NATIONAL CHILDREN AND YOUNG PEOPLE'S INPATIENT AND DAY CASE SURVEY 2016

FOR TRUSTS CONDUCTING THE SURVEY IN-HOUSE

THE CO-ORDINATION CENTRE FOR THE NHS PATIENT SURVEY PROGRAMME

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Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in this guidance manual, for example, by offering financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages within the survey. The terms of the ethical approval do not permit these types of alteration. Furthermore, such alterations might mean that the comparability of the survey would be compromised and such results may not be acceptable for computation of the relevant measures within the CQC assessments for that trust. If trusts want to make any adjustments to the method or materials set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability or impact on Research Ethics Committee or Section 251 approvals.

Data from the patient surveys are used in an increasing number of outcomes frameworks and indicators. If the sampling guidance issued for the survey is not adhered to and errors are detected too late for remedial action to be taken, this will impact on the use that can be made of data. CQC use patient survey data for purposes of risk monitoring. If data are excluded because sampling errors are detected, this will impact on the assurances CQC can have about the experiences of your patients.

Updates

Before you start work on your survey, check that you have the latest version of this document, as there might be some small amendments 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 Co-ordination Centre website at:
www.nhssurveys.org

Contents

1 Introduction: The importance of patient feedback

1.1. The Care Quality Commission

The NHS Patient Survey Programme was established by the Department of Health and has been operating since 2002. The Care Quality Commission took over from its predecessor, the Healthcare Commission, in April 2009 and is responsible for administering the programme. The Care Quality Commission (CQC) is the independent regulator of health and adult social care in England. CQC regulates care provided by the NHS, private companies and voluntary organisations. CQC aims to ensure that better care is provided for everyone – in hospitals, care homes and people's own homes.

CQC is committed to involving people who use services in all its work and ensuring that the providers of care services themselves involve people and respond to their views. The experiences of patients, people who use services, their carers and families are at the heart of the Care Quality Commission's work.

By ensuring that organisations carry out these surveys in a consistent and systematic way it is possible to build up a picture of people's experience across England and to compare the performance of different organisations, monitor change over time and identify variations between different patient groups. The surveys are expected to inform local improvement activity; they are seen as an important source of information for people to help them choose between providers and for informing commissioners of services. As well as supplying NHS England and the Department of Health with data to assess performance against national targets on patient experience, the survey programme provides an important source of data for CQC's assessments.

1.2. The Co-ordination Centre for patient surveys

The Co-ordination Centre for the Patient Survey Programme is based at the Picker Institute and works under contract to the CQC to design, test and co-ordinate the patient survey programme.

1.3. Why we need patient feedback

Quality in health and medical care has two distinct dimensions. One has to do with the quality of care from the perspective of professional, technical standards; and the other concerns the quality of care from the perspective of patients. Understanding the way patients experience the care they receive is essential to a complete assessment of the quality of healthcare and this can only be obtained by asking the patients themselves.

It is important to adopt systematic, appropriate and effective ways to ask patients about their experiences, and use this information to shape and improve the way healthcare is delivered. This instruction manual is designed to help NHS hospital trusts to obtain patient feedback through the patient survey. By following this guidance, you will also help to ensure that the survey results from all trusts are comparable.

1.4. Patient feedback and the NHS Constitution

Improving the experience of each individual patient is at the centre of the NHS Constitution. Obtaining feedback from patients and taking account of their views and priorities are vital for the delivery of high quality services and for driving real service improvements.

The NHS Constitution requires that NHS services reflect the needs and preferences of patients, their families and their carers. It is therefore important that all NHS trusts carry out local surveys asking patients their views on the services they have received. It is intended that measuring patients' experiences in a structured way will act as an incentive to make patient experience a real and central priority for the NHS. The NHS Patient Survey Programme is an important mechanism for making the NHS more patient-focused and provides a quantifiable way of achieving this by:

- providing information to support local quality improvement initiatives
- tracking changes in patient experience locally over time
- providing information for active performance management
- providing information to support public and parliamentary accountability
- providing information for the CQC to inspect and regulate services

1.5. CQC assessments

Information drawn from the questions in the National Children and Young People's Inpatient and Day Case Survey will be used by the CQC in its assessment of trusts in England. Questions from the survey will be used within CQC's monitoring tools and within CQC's inspections of hospital services.

1.6. Measuring performance over time

In addition to performance assessment, the CQC will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data, while providing a detailed picture of patients' experiences. Information collected nationally in a consistent way is also essential to support public and parliamentary accountability.

The CQC intends to archive the survey data with the UK Data Archive after the analysis is completed and published. This will be done with appropriate safeguards that ensure patient confidentiality.

1.7. Embargo on results

Trust-level findings for the 2016 National Children and Young People's Inpatient and Day Case Survey should not be released outside of the trust until the national results are published by the Care Quality Commission.

Trusts and contractors must wait until the survey results for all trusts are published by the CQC before promoting results in any way (either on their website, in press releases or any other external publicity) to the local community and media. Trusts will receive advance notice of the publication date and will have time to prepare for their local announcements once the embargo is lifted.

1.8. Basic requirements for the National Children and Young People's Inpatient and Day Case Survey

For comparisons between and within trusts to be accurate, fair and effective, it is essential that the surveys are carried out using a standard procedure in all NHS trusts. Furthermore, this is essential in order to comply with the procedures and standards covered by the Research Ethics Committee and Section 251 approvals. Those standards are set out in detail later in this document. In summary, they are as follows:

- If you have not done already, you must contact the Co-ordination Centre to tell us the contact details of at least two staff members of your trust who are responsible for the survey (email: cyp.cc@PickerEurope.ac.uk).

- The survey must be carried out using a postal questionnaire.

- There are 3 core questionnaires for this survey: 0-7 year olds (parent's survey), 8-11 year olds (child and parent's survey), and 12-15 year olds (child and parent's survey).

- The sampling procedure set out in this instruction manual **must** be followed. To do this you will need to work closely with the person who draws the sample and check carefully that these instructions have been followed. **Please note that a new sampling method is being implemented for the 2016 Survey, so please read the instructions very carefully.** For further details see Section 8 ***Compiling your patient sample***.

- Sample data must be submitted to the Co-ordination Centre for final checks before mailing, as outlined in Section 9 ***Final sampling inspection by the Co-ordination Centre***. Sample files should be submitted to us between **Monday 16th January and Friday 27th January 2017.** Submitting at the start of this period will allow sufficient fieldwork period to maximise your response rates.

- Your Caldicott Guardian must sign off the sample.

- You must submit a Sampling Declaration Form before your sample is submitted to the Co-ordination Centre. It can be downloaded from here: http://www.nhssurveys.org/surveys/1004.

- Trusts running the survey in house must send signed copies of the data protection declaration forms to the Co-ordination Centre before mailing out.

- You should aim to obtain the highest response rate possible. Trusts should facilitate higher response rates through maximising their collection period by commencing work as soon as possible and by publicising the survey to staff, patients and the community.

- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **Thursday 9th February 2017**. A spreadsheet has been created for this purpose. For further details see Section 10 ***Weekly monitoring***.

- Changes to the official questionnaire are not allowed. See Section 11 **Materials**

- The standard covering letters and reminder letters (which can be found at http://www.nhssurveys.org/surveys/1010) must be used as outlined in Section 11 ***Materials***

- Two reminders must be sent to non-responders. These procedures are outlined in Sections 11.7 and 11.8.

- A paper copy of the questionnaire and covering letters you used must be submitted to the Co-ordination Centre by **20th January 2017**. See Section 11.10 ***Submitting hard copies of the questionnaire and cover letters***.

- The data from the questionnaire, including the free text comments and the required information about the patient sample, must be submitted to the Co-ordination Centre in the

form outlined in Section 13.3 ***Submitting data to the Co-ordination Centre*** - by **Friday 9th June 2017**.

- The data must be checked carefully for errors before submitting it to the Co-ordination Centre. Specific advice on how to carry this out is included in Section 13 ***Entering data and submission to the Co-ordination Centre.***

- You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until **Friday 8th December 2017** but please do **not** send these to the Co-ordination Centre. These returned questionnaires may be needed to audit the data sent to the Co-ordination Centre.

- You must not delete the sample file from your records until **Friday 8th December 2017** in case there are any queries from the Co-ordination Centre.

- Trusts are not permitted to publish their survey results prior to the official release of CQC results for England and trust level results as there might be differences which could cause confusion. However, trusts can start using their results internally to identify areas for quality improvement.

1.9. Why you need these instructions

This guide is designed for trusts wishing to conduct the survey in-house. **You must be familiar with all aspects of this guide, but in particular, the sections on drawing the sample, data protection requirements, the practicalities of mailing out the survey, and the processing and submission of data to the Co-ordination Centre.**

2 Setting up a Project Team

We recommend you set up a project team to assist you. The best way to ensure that your survey is a success is to work hard *in the beginning* to involve those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey.

We suggest:

- **Establishing a workgroup.** Put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:
    - Board members
    - Doctors, nurses and other health care staff
    - Managers
    - Medical records personnel or Patient Administration System (PAS) staff
    - Patients and carers
    - Members of patient groups with a special interest in the trust
    - Caldicott Guardian
    - Staff or directors responsible for:
        - Clinical governance
        - Patient advice and liaison service (PALS)
        - Quality improvement
        - Strategic planning

- **Involving the person responsible for drawing the patient sample in planning meetings.** It is essential that this person, and their line manager, understand the purpose of the survey and the importance of drawing the sample correctly. You must share these survey instructions with them.

- **Keeping everyone informed.** Notify as many people as possible about ideas and activities. All departments in the trust should be made aware when a survey is being conducted, in case patients contact the trust asking questions about the survey they have received.

- **Not overlooking front-line staff.** These people have the most direct impact on patients' experiences.

3 What's new for 2016?

3.1. Sampling months for 2016 survey

The sampling months for the National Children and Young People's Inpatient and Day Case Survey will be **November and December** 2016.

The change in the sampling period (and the sampling method) means that **historical comparisons will not be possible** for the 2016 National Children and Young People's Inpatient and Day Case Survey.

3.2. Increase in sample size to 1250 patients per trust

The sample size was 850 patients per trust in the 2014 survey. The survey was not implemented in 2015. In 2016, all participating trusts are required to draw a sample of 1250 patients. This change is in line with the approach followed in the Inpatient Survey since 2015, and is designed to protect data reliability and allow more useful granular analysis.

3.3. Systematic stratified sample

A systematic stratified sampling method is being introduced to enable trusts to generate a balanced sample of respondents from each of the three age groups being surveyed: (A) children aged two weeks to 7 years (questionnaire for parents only); (B) children aged 8 to 11 years (questionnaire for children and parents); (C) young people aged 12 to 15 years (questionnaire for young people and parents).

The approach requires trusts to divide the population of eligible patients that attended hospital during the sampling period into three groups based on three age brackets and to then sort the patient list by date of birth and by gender. Trusts then draw a sample systematically from these three groups.

A complete sample of 1250 would include 450 patients aged between two weeks and seven years, and 400 patients from each of the other two age groups. These quantities have been chosen because the average response rate to the 0-7 questionnaire in 2014 was slightly lower than it was for the other two age groups. The larger sample size for this group should lead to a more balanced number of responses across the three groups if the response rates in 2016 are the same as they were in 2014.

In cases where a trust has fewer than the target for one or two of the age groups, and where there are more patients than the target in one or two of the other age groups, the spreadsheet that trusts will use to draw their sample will automatically add patients to the sample from the group(s) with an excess of patients. Additional patients are drawn in cases where there is a possibility to increase the size of a trust's sample, so that a trust's total sample is as close to the target of 1250 patients as possible.

3.4. Changes to the questionnaires

All three versions of the questionnaire have been revised for the 2016 survey in order to make them as useful as possible for trusts and stakeholders. Amendments have been made on the basis of the following considerations:

- Consultation with stakeholders, including the Care Quality Commission (CQC) and NHS England, as well as the National Children and Young People's Inpatient and Day Case Survey Advisory Group, which comprises representatives from the Department of Health, several NHS Trusts, CLIC Sargent (the cancer charity for Children and Young People), and a number of young patients.
- Analysis of the 2014 survey data to examine item non-response rates and floor / ceiling effects.
- Feedback obtained from children and parents, with whom the questionnaires were cognitively tested to ensure that the question wording and response options are both suitable and understandable to respondents.

The alterations that have been made fall into three categories: (1) new questions, (2) removed questions, and (3) amended questions. A survey development report will be published on the NHS Surveys website (http://www.nhssurveys.org/surveys/1005) detailing the changes that have been made and the specific reasons for these changes.

3.5. CQC Intelligence Model

CQC is redeveloping its method of monitoring trust performance. Where trusts fail to submit a sample for the National Children and Young People's Inpatient and Day Case Survey, or if it becomes evident at a later date that an error has been made in drawing the sample that renders the data unusable, this will be flagged as a concern within the CQC monitoring tools, which may in turn have an adverse effect on the conclusions CQC draw based on the lack of patient experience data.

Errors that impact on CQC's use of data may be 'minor' or 'major':

- A **minor error** means that data are still able to be used despite the error.
- A **major error** is so serious that data for a trust are unable to be used, and would be excluded from the CQC publication and all other uses, such as in CQC's monitoring tools.

Making errors in drawing the sample, for example, neglecting to include a core group of eligible patients, effectively biases the sample, meaning an individual trust's results are not comparable to other trusts. If major errors are spotted during the sample checking phase then the Co-ordination Centre will request that a fresh sample be drawn, however, errors are not always easy to spot in an anonymised file. If it only later becomes evident that a major error has been made and there is no time to submit a new sample for inclusion in the survey, the survey response data **will be excluded from the CQC dataset and will negatively impact on CQC assessment of your performance for this survey.**

4 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. **If you have not already done so, please ensure that you add research to your Data Protection Act registration, as one of the purposes for processing personal data supplied by data subjects.** You will also need to comply with the NHS Code of Practice on Confidentiality (2003)[1], which incorporates the Caldicott principles. You should take particular care to ensure that your use of patient data in carrying out the survey complies with these six principles. In particular, you should be aware of the flows of patient data and the issues which these present.

The Caldicott Principles

Each NHS trust has a Caldicott Guardian who is responsible for overseeing proper use of patient data. They have to ensure that any use of patient data conforms to the following principles:

- **Principle 1**: Individuals, departments and organisations must justify the purpose(s) for which information is required
- **Principle 2**: Don't use patient-identifiable information unless it is absolutely necessary
- **Principle 3**: Use the minimum necessary patient-identifiable information
- **Principle 4**: Access to patient-identifiable information should be on a strict need-to-know basis
- **Principle 5**: Everyone should be aware of their responsibilities
- **Principle 6**: Understand and comply with the law

It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire

Guidelines on the use and security of the data collected have been agreed by the CQC and Co-ordination Centre. These guidelines will help to ensure that data are handled in a manner most in keeping with the spirit of the Data Protection Act 1998 and the Market Research Society's *Guidelines for Social Research* (2005)[2]. They have implications for approved contractors and for NHS trusts conducting surveys in-house.

Information about the Data Protection Act 1998 can be found at the ICO – Information Commissioner's Office (http://www.ico.gov.uk)

Further guidance can be found in the Market Research Society document at https://www.mrs.org.uk/standards/data_protection.

[1] https://www.gov.uk/government/publications/confidentiality-nhs-code-of-practice and https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf

[2] http://the-sra.org.uk/wp-content/uploads/sra_data_protection.pdf

4.1. Statements of Compliance with Data Protection

Each NHS trust has a Caldicott Guardian responsible for overseeing proper use of patient data. If you are conducting the survey in-house then you must submit a formal declaration to the Co-ordination Centre before mailing out the sample. This declaration will be signed by the Caldicott Guardian and survey lead(s) for the trust and will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines. Templates for these declarations are available on the NHS Surveys website: http://www.nhssurveys.org/surveys/1004.

You must wait for specific approval from the Co-ordination Centre before mailing out your sample.

If the Caldicott Guardian is unable to make such a declaration, then the trust must use an approved contractor to ensure that appropriate standards of confidentiality data protection are maintained.

4.2. Approval under Section 251 of the NHS Act of 2006

Approval for the National Children and Young People's Inpatient and Day Case Survey 2016 was sought under Section 251 of the NHS Act 2006. This approval allows the common law duty of confidentiality to be put aside in order to enable the processing of patient identifiable information without consent. The survey methodology was reviewed by the Health Research Authority (HRA), and the Confidentiality Advisory Group (CAG) of the Health Research Authority (previously NIGB) has granted a recommendation of support. **Please note that any deviation from the procedures described here may lead to breaches in patient confidentiality, or could have implications for the comparability of data and its use by CQC and others and would lead to action being taken against an NHS trust.**

The recommendation of support does not cover the transfer of patient identifiable information where a patient has indicated dissent - by this we mean instances where a patient has indicated that they do not want their information to be shared for purposes such as patient surveys, or specifically stated that they do not want their details shared outside of the trust. It is strongly advised that in-house trusts follow the same procedures as outlined in the recommendation for support from the HRA.

Consequently, if any patients have indicated that they do not want their records used for secondary purposes (e.g. they have asked to be excluded from all surveys or they do not want their address details shared for any reason other than clinical care), please ensure that these patients are excluded from your sample. This should be done using your local records.

There is, however, evidence available from research to suggest that a considerable degree of bias is likely to be introduced depending on the stage at which dissent is recorded, the severity of patients' conditions, and their understanding of the aim and purpose of the research or evaluation. Such bias would negatively impact on the results for a trust.

Trusts must process any opt outs received during the course of the survey in the following way:

1. Any objection is to be recorded immediately and checks made to determine whether a mailing is underway. If a mailing is underway the caller will need to be advised that it might not be possible to prevent this mailing but assured that they will receive no future mailings.
2. People wishing to receive no further questionnaires can be identified with a flag/code/number on the mailing file.
3. When speaking to callers wishing to opt-out of future survey mailings, it is **not appropriate to try and dissuade them from their intent**. There is a risk that even well intentioned

discussion around the benefits of the survey could be perceived as applying pressure to participate. The benefits of the survey should only be mentioned by call-takers in response to queries from callers. If someone feels strongly enough about the survey that they initiate contact to object, this needs to be respected and acted upon immediately to avoid upset and misunderstanding.

4. Callers are advised they are being removed from the mailing list for this survey only and that if they wish to register their dissent against wider research participation at their trust, they need to speak to their trust (via PALS or the trust Information Governance Team) to do this.

Please discuss this issue with your Caldicott Guardian to ensure that any patients who have indicated that they do not wish to have their details shared for purposes such as this survey, yet may have sufficient address details visible in PAS, are not included in the sample that is submitted to the Co-ordination Centre.

For more information on the fair processing of data, please see the Q&A on the NHS surveys website at:

http://www.nhssurveys.org/Filestore/documents/20120704_FAQs_on_fair_data_processing_draft4.pdf.

4.3. Keeping patient mailing data and response data separate

For patient confidentiality reasons, patient responses must never be matched to the patients that made them. The best way to ensure this is to store patient names and address details separately from sample information or survey response data. **For this reason, we strongly recommend that once the sample has been returned from DBS and the 1250 patients are finalised, patient names, addresses and postcodes are removed from the sample file to a 'mailing file'.**

Before this is done, it is essential each patient is provided with a unique number (a patient record number (PRN) and that this number is available and correctly matched on both the 'mailing file' and the sample information file (the 'sample file') (see Section 8.10). Note the PRN must be in the format: CYP16XXXNNNNN where XXX is your trust's 3 digit trust code and NNNNN is the 5 digit number relating to your sampled patients.

It is fundamentally important to remove all patient identifiable data (patient names and addresses) from the sample file submitted to the Co-ordination Centre.

4.4. Mailing questionnaires to patients

Another important issue regarding mailing questionnaires and data protection relates to the envelopes used to mail out questionnaires to patients. Some patients may not have told family or friends that they have gone to hospital and, under data protection regulations, it is important that this information remains confidential to the patient. Therefore it is important that the envelope(s) used to mail out your survey materials to patients does not show any indication of the NHS Trust name.

4.5. Assurances of patient anonymity

It is important to ensure that any claims you make about patient anonymity are accurate; you are obliged by law to honour any statements that you make.

In most cases where a survey is carried out in-house, it is not accurate to tell patients that their responses will be anonymous. The person who receives the completed questionnaires is usually able to match these responses to patient names and addresses.

4.6. Patient confidentiality

It is essential that any patient survey is conducted in such a way that patient confidentiality is respected and given a high priority. The covering letters that accompany the mailed questionnaires inform patients that their name and address will never be linked to their responses. Furthermore, patients' responses must not be presented to anyone in a way that allows individuals to be identified. For example, if a patient attended on a particular date and his or her year of birth, sex and ethnic category are known from their survey responses, it might be possible to use this information to identify them. It would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

1) The raw data set should not be provided to any member of staff at the trust who does not need to view it, i.e. those who are not directly working on the project.

2) If data are to be presented to other trust staff only the aggregated totals for each question should be provided. If analysis by subgroup is carried out the results for any group consisting of fewer than 30 respondents should be suppressed (replaced by a dash). The data should be presented as in the following example. In this case, responses for the 'Mixed/Multiple' and 'Asian' ethnic categories are suppressed (though the subgroup totals are shown):

Ethnic category	**Q13. Were the different members of staff caring for and treating your child aware of their medical history?**				
	Yes, definitely	**Yes, to some extent**	**No**	**Don't know / not applicable**	**Total responses**
	%	**%**	**%**	**%**	**n**
White	70	10	10	10	261
Mixed / Multiple	-	-	-	-	8
Asian	-	-	-	-	18
Black / African / Caribbean	59	31	14	6	52
Other	80	12	5	3	36

3) Do not present response information (including comments) in a form that allows an individual patient to be identified by the group receiving the information. For example, if you are presenting the results for a small number of patients, make sure that it will not be possible for the reader/audience to identify individual patients from their responses.

4) Free text comments do not need to be anonymised. A statement has been added to the questionnaire stating that any information provided in the free text box will be shared. **PLEASE NOTE**: This does not apply if you are publishing the comments. Any comments that are published must have any identifiable information removed such as a patients' or staff members' names, ethnicity, condition or health details.

5) The electronic file containing the patients' names and addresses should be stored securely (i.e. password protected). Access to the file should be given only to those individuals who have signed the declaration of compliance.

4.7. Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of patients' names, and the questionnaires kept until **Friday 8th December 2017.** All mailing lists of patients' names and addresses should be stored on a separate computer to that containing survey data. Mailing lists of patients' names and addresses should be destroyed when the mailing process is complete. The final sample should be kept until **Friday 8th December 2017**, when it can be deleted.

4.8. Encryption of Personal Data

Any patient identifiable information sent between trusts and third parties must be in an encrypted format with password protection to help ensure good standards of information security. When sending data electronically an encrypted session based on the Transport Layer Security (TLS) or Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP) must be used. A key size of 256 bits or greater should be used. This is to ensure a high level of security, to protect against any accidental or intentional interception during the transfer of patients' details.

Many different encryption algorithms exist and not all of these are suitable, so both the Co-ordination Centre and the Care Quality Commission very strongly recommend the use of the **256-bit AES** (Advanced Encryption Standard) algorithm. There are several software tools that can be used to encrypt data in this way, the most commonly available of these being WinZip® (v9 and above).

5 Ethical Issues, Ethics Committees and Research Governance

5.1. Ethical approval for the National Children and Young People's Inpatient and Day Case Survey

Research Ethics Committee (REC) approval has been obtained for the National Children and Young People's Inpatient and Day Case Survey questionnaires and the covering and reminder letters, all of which can be downloaded from the NHS Surveys website (http://www.nhssurveys.org/surveys/1010). In order to comply with the ethical approval, the survey must be carried out according to the instructions set out in this document.

Trusts do not, therefore, need to seek individual ethical approval for this survey. If you wish, you can send your Local Research Ethics Committee(s) (LREC) a copy of the REC approval letter, but you are not required to do this and you do not need to wait for confirmation or approval from the LREC before starting your survey. Trusts should notify the relevant R&D office that ethical approval has been obtained for the National Children and Young People's Inpatient and Day Case Survey 2016. The REC letter can be downloaded from the NHS Surveys website http://www.nhssurveys.org/surveys/1006.

Further information on the ethical approval process can be found on the NHS Health Research Authority website: http://www.hra.nhs.uk/ or by e-mailing HRA.Queries@nhs.net.

5.2. Research Governance Requirements

The *Research Governance Framework* (2002, 2003, 2005) aims to ensure that health and social care research is conducted to high scientific and ethical standards. It spells out standards and the responsibilities of various parties involved in the research. One of the main purposes of the framework is to reduce unacceptable variations in research practice.

The Care Quality Commission, as sponsor of this national survey, has taken steps to ensure that principles of research governance and ethics are followed thoroughly. A standard questionnaire and guidance notes are an important step in ensuring that the survey is carried out by all trusts in the same way without any variations.

The Department of Health has confirmed to the CQC that it would be inappropriate for individual trusts to follow the same local research governance processes as they would if the survey were a study the trust is sponsoring. As this national patient survey has multi-centre research ethics committee approval and the CQC takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.

See Appendix 1 for more details on the responsibilities of NHS organisations that are carrying out research.

6 Collecting data from non-English-speaking populations

The patients who respond to your survey should be representative of all of the patients who use the trust, so it is important that groups with limited understanding of English are not excluded. The questionnaire has been written in as **plain language** as possible to facilitate optimum understanding by all respondents.

For this survey, translated questionnaires are not being used since it is not possible to identify non-English-speaking patients, or their specific language, from patient records before questionnaires are sent out because language spoken is not usually included on patient administrative systems. Therefore, the first contact with them will have to be in English.

There are a number of strategies you can adopt to facilitate the process of collecting the views of people with a limited understanding of English within this survey:

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of whom offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the patient and the interpreter (note that trusts may already have arrangements with such a service). Please contact the Co-ordination Centre for further advice if you need to do this.

- A multi-language leaflet template is available on our site, and this can be included with your first and third mailings. Trusts can use this leaflet by inserting their appropriate helpline number. This gives directions in the 20 most common non-English languages spoken in England and also in EasyRead (routed to a separate number run by Mencap to help those with learning disabilities).

- Many households include at least one **competent English speaker** who can help the patient to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from non-English-speakers, although it is not ideal, as there is no control over the way in which a patient's family or friends translate questions or interpret their responses, and it does not allow the patient to answer the questions directly.

7 Timetable

The survey fieldwork period for the 2016 survey is 18 weeks. We strongly recommend making full use of this time to maximise response from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond. If your patient population has high proportions of either group, it is especially vital you allow enough fieldwork time to capture responses from these patients. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. and have this sent to the Co-ordination Centre for checking between 16th January and 27th January 2017) and mail out your questionnaire packs promptly once permission has been received. Ensuring your survey results are representative of your patients will create more value for the survey.

Please ensure the full fieldwork period is used to optimise response rates. The data should be submitted to the Co-ordination Centre no later than the **9th June 2017.**

7.1. Key Dates

Inform Co-ordination Centre who is carrying out survey	16th December 2016
Draw your sample (you should begin as soon as data from the previous month become available)	9th - 20th January 2017
Submission of sample data	16th Jan – 27th Jan 2017
Fieldwork starts	30th January 2017
Close of fieldwork	2nd June 2017
Submission of data to the Co-ordination Centre	9th June 2017

Please remember to leave no more than 2- 3 weeks between each mailing

8 Compiling your patient sample

This section explains how to draw a sample of patients. This task will need to be carried out by a member of staff at the NHS Trust. In hospital trusts, the sample will normally be drawn from the Patient Administration System (PAS). Prior to sending out questionnaires, the list will also have to be checked by the Demographics Batch Service (DBS) to identify deceased patients.

Please follow the instructions below carefully and allocate sufficient work time to check the sample with DBS before the first mailing and within the trust prior to each mailing.

It is essential that the person who draws the sample understands the importance of following these instructions carefully. Also, this person's line manager must give them the time and support they need to do the task properly. An incorrectly drawn sample can delay the start of the survey or can result in the questionnaires being sent to the wrong patients, both of which can have serious implications.

The sampling process for the National Children and Young People's Inpatient and Day Case Survey 2016 is different to that used in 2014, and is also different to that used in the other patient surveys.

We strongly advise that you read <u>all</u> of this section BEFORE you start to compile your patient list.

It is vital that you use the correct template workbooks provided for each stage of the process.

Please note: The sample should only be used for the purposes of distributing the National Children and Young People's Inpatient and Day Case Survey 2016 and up to two reminder letters. This is because the precise use of the sample collated for the survey is described in the survey protocol that forms part of the ethical approval for the survey and any additional use of the sample would therefore require a separate ethics application. For example, it would not be appropriate to send additional reminder letters to people in the sample nor to contact them as a group either before or after the survey.

8.1. Compile a full list of patients discharged in November and December 2016 (workbook 1)

1) Download "**CYP16 Sampling workbook 1**' from http://www.nhssurveys.org/surveys/1002

2) In tab 1 '*Full list'* in that template, compile a list of all children and young people that were admitted patients, discharged from your trust in line with the eligibility criteria below.

The list should **include**:

- **ALL** eligible **admitted patients** discharged from your Trust between **1st November 2016 and 31st December 2016**, who were aged **between 15 days and 15 years** (inclusive) at the time of their discharge.

N.B. Patients are considered eligible if they have been **admitted** (i.e. have an admission method code: www.datadictionary.nhs.uk/data_dictionary/attributes/a/add/admission_method_de.asp) and fulfil all other eligibility criteria. Eligible patients include:

- Admitted patients who did not stay overnight (e.g. emergency admissions and planned day cases)
- Admitted patients who did stay overnight.

The list should **exclude**:

- Patients who were not admitted (e.g. ward attendees or patients who attended an outpatient appointment, but were not admitted)
- Deceased patients
- Patients aged 16 years or older at the time of their discharge
- Babies aged between 0 and 14 days at the time of their discharge
- Newborn babies where the mother is the primary patient (ie: well babies, treatment function code 424)
- Patients who were only admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU) (treatment function code 422)
- Obstetrics/maternity patients, including spontaneous miscarriages
- Patients admitted for planned termination of pregnancy
- Psychiatry patients, including CAMHS
- Private patients (non-NHS)
- NHS patients treated at private hospitals
- Any patients who are known to be current inpatients
- Patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode)
    - Please note: patients should be *included* if they have an address in any part of the UK, including those not in England (Wales, Scotland, Northern Ireland, Isle of Man, Channel Islands, etc.). Equally, patients whose address is a military base, care home or prison establishment are also eligible
- Any patient, parents or carers known to have requested their details are not used for any purpose other than their clinical care. Under the conditions of the survey's Section 251 approval from the Confidentiality Advisory Groups, **trusts must also consult their**

dissent logs from the 2014 CYP survey and exclude any patients who asked to be removed from that survey.

Please note:

- **Exclusions should only be made based on the criteria listed in the sampling instructions.** In general, patients with safeguarding concerns should be included in your list, unless they meet any of the other exclusion criteria. You may want to consider whether certain patients might be placed at risk by being sent a patient survey and discuss with your Trust Safeguarding Lead whether any of these patients should be removed from your list of eligible patients.

  Patients should only be removed from the list of eligible patients in extreme circumstances, where the delivery of the questionnaire itself is likely to increase the risk of harm to the individual. We would expect only a very small number of patients to be removed, if any. If you expect to remove more than a handful of patients in these circumstances, please ensure you discuss this with the Coordination Centre first.

- It is not a problem your sample does not contain 1250 patients as long as you include in your sample all eligible admitted patients that were discharged from hospital during the two sampling months.

- Your patient list should be a list of **unique patients.** If a patient has attended more than once during the sampling period, please remove the earlier attendance(s) and leave the **most recent attendance** for that patient.
  - If you are unable to remove duplicates when drawing the patient list from your patient administration system, you can include duplicate attendances at this stage, and remove them from your full list as outlined in section **Error! eference source not found.**, below.

If you are have questions about the inclusion/exclusion criteria, please contact the Co-ordination Centre on 01865 208127 or at cyp.cc@pickereurope.ac.uk.

3) When you put your data into '**CYP16 Sampling workbook 1**', you should include the following information:

- NHS number
  - Please note, this will be used for removing duplicates and for DBS checks - it **must not** be submitted to your contractor. If you are missing the NHS number for any patients who are otherwise eligible, please still include these patients in your list.
- Patient initials or first name
- Patient surname
- Address, including postcode
- NHS Trust Code
- Month of Birth
- Year of Birth

- Gender (numeric: male coded as 1, female coded as 2)

- Ethnicity is required in order to evaluate non-response from different ethnic categories. The ethnicity of a person is specified by that person and should be coded using the 17 item alphabetical coding specified by the Health and Social Care Information Centre (HSCIC). Further information is available at: www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp?query=ethnicity&rank=70&shownav=1.

  Some trust systems no longer accept missing ethnic data, so please note that any patient whose ethnic category is unknown may be coded as "Z" or left blank; Ethnic codes are as follows:

  White

A	British
B	Irish
C	Any other White background

  Mixed

D	White and Black Caribbean
E	White and Black African
F	White and Asian
G	Any other mixed background

  Asian or Asian British

H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background

  Black or Black British

M	Caribbean
N	African
P	Any other Black background

  Other Ethnic Groups

R	Chinese
S	Any other ethnic group
Z	Not stated or unknown

- Date of admission (separate columns for day, month and year)

- Date of discharge (separate columns for day, month and year)

- Length of stay. (Number of days. For example, if the admission date was 15/11/2016 and the discharge date was 16/11/2016, the Length of Stay = 1. If the child did not stay overnight, Length of Stay = 0.)

- Main specialty (of consultant) code on discharge (using numeric codes)

- Treatment function code

- CCG code. This should be the CCG which will be billed for the care of the patient. Please see: http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs

- Treatment centre admission
- Route of admission. Please see: http://www.datadictionary.nhs.uk/data_dictionary/attributes/a/add/admission_method_de.asp?shownav=1
- NHS Site Code on admission
- NHS Site Code on discharge

There is also a column for record number (column K), please leave this blank at this stage. Instructions on how to construct this later are provided below.

If you have **more than 10,000** records at this stage, **please contact the Co-ordination Centre on 01865 208 127 or cyp.cc@pickereurope.ac.uk**

8.2. Removing duplicates: Tab 1

➔ **If you have already removed duplicate patients from your patient list, please skip to the following section, 8.3 'Submit the patient list to the Demographic Batch Service'**

The sample that you will submit to the Co-ordination Centre will consist of a list of unique patients. Some patients may have attended hospital more than once during the sampling months; in these cases, you may have duplicate patients in the initial selected sample you have just put into tab *1. Full List*. You need to remove those, so that you have only unique patients.

If you have not already removed duplicates, you should be able to use the NHS number to identify such patients. When removing duplicates, you should remove the earlier attendances and leave **the most recent attendance** for that patient. When removing duplicate records, please ensure that you do not leave blank rows.

The following instructions explain one of the ways you can remove duplicate patients, based on NHS number:

1) Sort your patient list by NHS number. To do this, select **all** your data starting on row 3 – please **ensure you are not selecting the two header rows**. Click on the data menu, then click 'sort'. Select to sort by column A (NHS Number), then click ok.

Please note, it is vital that you **select <u>all</u> your data (all columns and rows) except for the header rows (1 and 2) before** sorting, as otherwise the file can become mis-sorted. If the data is mis-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

2) Now select all the values in column A 'NHS number', then click on 'conditional formatting', 'highlight cell rules' then 'duplicate values'. This will colour all duplicate values in that column.

3) Go through the list looking at the coloured values to identify duplicate patients. You can filter the records to show only highlighted cases by clicking the filter arrow on column A, then selecting 'filter by colour' then clicking the cell colour listed.

4) When removing duplicates, you should remove the earlier attendances and **leave the most recent attendance for that patient**.

5) When you remove duplicate records, you should also ensure that you **do not leave blank rows**.

6) If you are missing NHS number for any patients in your list, please use their name and address information to check that they appear only once in your list and remove any duplicates.

8.3. Submit the patient list to the Demographics Batch Service

Your **full list** of eligible patients should now be checked for any deaths by the Demographics Batch Service (DBS). The DBS enables users to submit and receive a file containing relevant patient records electronically using dedicated client software. The patient records in the file are matched against the NHS Spine Personal Demographics Service (PDS)[3].

Create a trace request file

Using your list of patients, you need to create a correctly formatted batch trace request file to send to DBS. You should take advice from your local Trust PAS team on the correct format to submit files. Technical details on the file format are available from http://www.hscic.gov.uk/demographics/.

For each patient you will need to include as a minimum:

- NHS number and full date of birth (yyyymmdd) – this is the recommended approach

  OR

- Surname, first name, gender, date of birth and postcode (can be wildcarded e.g. LS1*)

Although residential postcode is not mandatory it is highly recommended to include it to avoid incorrect matches. Due to the way addresses are recorded throughout the NHS, it is very difficult to get an exact match on address lines. For this reason, **do not** include address lines in the trace request file.

Submitting the trace request file

Please note that the DBS does **not** accept the transfer of files by encrypted emails or on physical media. Instead, **request and response files must be transferred electronically using the dedicated DBS client software**. The DBS client software should have already been installed on a server within your trust. Please speak to a member of your IT department or PAS team if you do not know how to access and use the application. If your IT department cannot help, contact the DBS implementation team at: demographics@nhs.net and they should be able to advise you.

If you have been set up to use DBS, then once you have created the request file, it should be placed in the client in-box. The DBS client will then send the file to the Spine and, if you are registered, you will receive an email to say that the file was received. The DBS processes the file overnight and it should be ready the following morning. You will be notified by email when the file has been processed. During periods of high demand for DBS service, it may take 48 hours for your file to be returned.

The response file

[3] The PDS is a national electronic database of NHS patient demographic details. The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

The DBS will return a header row, response body and trailer row. The response row will be in two parts:

- The response containing all the data supplied in the request record, together with a trace outcome indicator. The main record is returned in all cases.
- An additional response column, which is returned only when there is a single unique match. It is on this additional response column that patients found to be deceased will be indicated (by a letter 'D').

Further information is available from www.hscic.gov.uk/demographics/

Please be aware that tracing services are not infallible and even after your patient list has been checked for deaths, some patients may die in the period between running the check and the questionnaire being delivered. You may find that some recently deceased patients remain in your sample. You need to be prepared for this. Special sensitivity is required when dealing with telephone calls from bereaved relatives.

8.4. When the patient file is returned from DBS

1) The trace response file returned from DBS can be used to identify any patients that have died (indicated by a letter 'D') and therefore need to be deleted from the sample file. You should remove these patients from tab *1. Full list* in 'CYP16 Sampling workbook 1'.

You should not exclude patients just because it was not possible for DBS to match them on their records. If you did this, you would bias the sample.

When removing deceased patients from tab *1. Full List* in 'CYP16 Sampling workbook 1', please make sure you **do not leave blank rows**.

8.5. Checks to be carried out by the trust

Once you have compiled your full list of unique eligible patients, have removed duplicates if necessary, and have removed any patients identified as deceased through the DBS check, please carry out the following checks before continuing to section 8.6.

- **Deceased patients**. Check hospital records do not have a record of a patient's death from a subsequent admission or visit to hospital. More information on checking for deceased patients is shown in the text box below.

Checks for deceased patients

One of the most reliable and up-to-date sources of information on patient deaths is your own trust's records. **It is essential that you check that your trust has no record of a patient selected for the survey having died at your trust.** Relatives are likely to be particularly upset if they receive a questionnaire or reminder from the trust where their relative died. Clearly, patients may also have died at home or while under the care of another trust, so you still need to check with the tracing service (DBS) as well.

The methodology for this survey requires three stages of checks for deceased patients before the first mailing is sent out. The checks are carried out sequentially by:

1) the trust

2) DBS

3) again by the trust (for patients who may have died in hospital after submission of the sample to DBS).

You are also advised to check your hospital records for any further deaths prior to each mailing.

- **Current inpatients**. Check that none of the patients are known to be current inpatients in your trust (or elsewhere, if possible). This should be the only time current inpatients are excluded from the survey process. When checks for deceased patients are carried out immediately prior to each mailing, do not check for, or exclude, current inpatients at these times. This improves the comparability of samples between trusts and thus reduces bias.
- **Patient ages**. Check that all patients are aged 15 days to 15 years old (inclusive) at the time of their discharge in November or December 2016.
- **Postal addresses**. Exclude any addresses that are outside the UK. Patients whose address is in the British Islands (Isle of Man, the Channel Islands) are eligible. Equally patients whose address is a military base, care home or prison establishment are also eligible.
- **Incomplete information**. Check for any records with incomplete information on key fields (such as surname and address) and remove those patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a patient if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias.
- **Duplications**. Check that the same patient has not been included more than once.
- **Community Hospitals**. As a general rule, patients who have only spent time in a community hospital should not be included in the sample. Patients who have spent time in both a community hospital and an acute hospital can be included depending on circumstance - please contact the Co-ordination Centre for further advice.
- **Obstetrics/maternity service user**. Check that the list does not include maternity service users. Please ensure that no episode of a patient's care has a maternity specialty code and that there are no route of admission codes indicating a maternity admission. You should not include patients with a Route of Admission code of 31 (ante-partum) or 32 (post-partum). There should also be no patients included who have a Treatment Function code of 501 (obstetrics) or 560 (midwife). If codes of 500 (obstetrics and gynaecology) are included, please ensure any included patients have been treated for gynaecology and not obstetrics. Please note, gynaecology patients *should* be included if their visit was unrelated to pregnancy.
- Check again that none of the patients were admitted for a **termination of pregnancy**.
- **Psychiatry patients**. Check Treatment Function codes and ensure that the list does not include psychiatry patients.
- **Private patients**. Remove any private patients from the sample.
- **Patients treated at private hospitals**. Remove any patients who were treated by the trust as NHS patients in private hospitals.
- **Dissent**. Any patient known to have requested their details are not used for any purpose other than their clinical care including requests made following sight of survey pre-publicity (you must ensure that you remove these patients from your sample list at this stage). **You should also consult your dissent log from the 2014 CYP survey and exclude any patients who asked to be removed from that survey.**

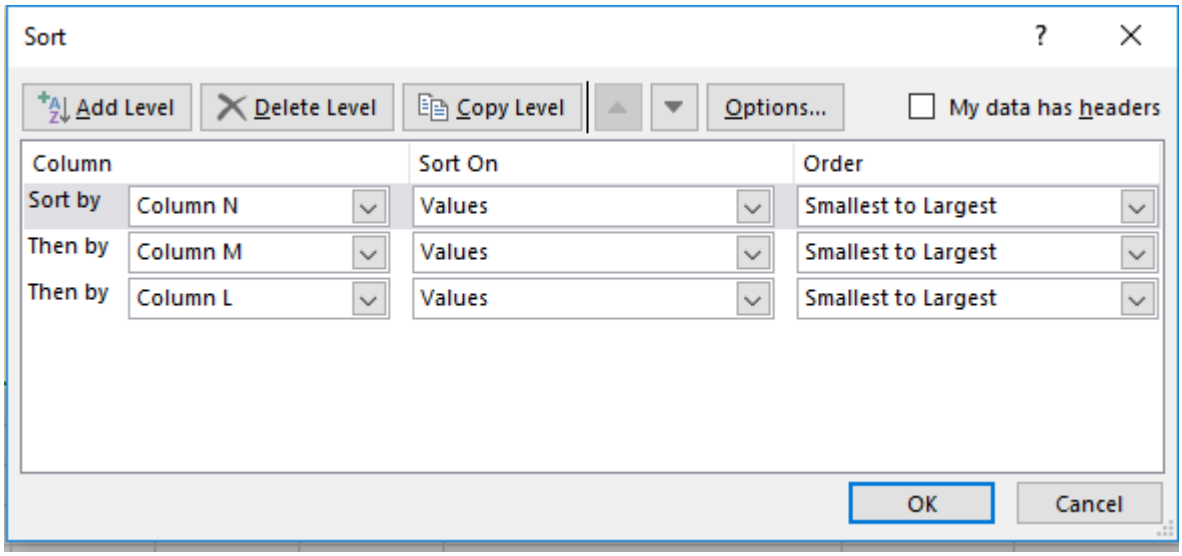
8.6. Sorting and cleaning your eligible patient list in Workbook 1: Tab 1

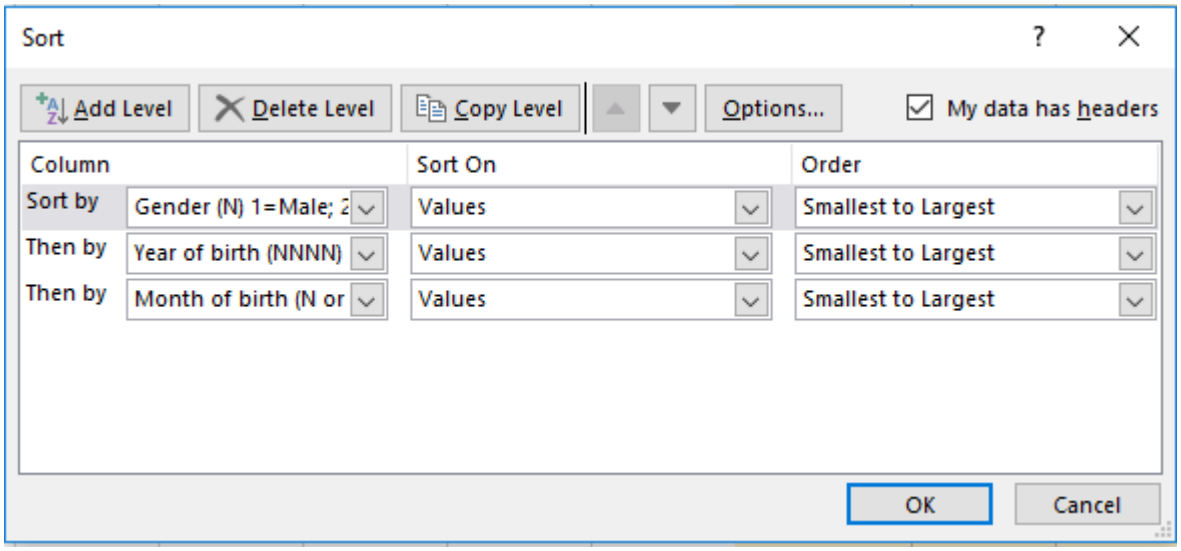
Once you have compiled and checked your full eligible patient list in 'CYP16 Sampling workbook 1', tab '1. Full List', you will need to follow the process below to sort and label your eligible patient list, prior to drawing the sample.

To sort the data in '**CYP16 Sampling workbook 1**', please complete the following steps:

1) Sort by gender (**column N**), then by year of birth (**column M**), and then by month of birth (**column L**).

To do this, select **all** your data starting on row 3 – please **ensure you are not selecting the two header rows**. Click on the data menu, then click 'sort'. Then create three sorting levels to include column N (gender), column M (year of birth), and column L (month of birth), **in that order**. It should look like one of the images below. Click 'OK' to sort your data.





Please note, it is vital that you **select <u>all</u> your data (all columns and rows) except for the header rows (1 and 2) before sorting**, as otherwise the file can become mis-sorted. If the data

are mis-sorted, this could result in a major sampling error, which could invalidate your sample or your survey data.

2) Now add a **record number** in the correct column. The record number should be in the following format: CYP16XXXNNNNN where “CYP16” is the survey code, “XXX” is your trust code, and “NNNNN” is the number.
At this stage, record numbers will run consecutively from CYP16XXX00001 to CYP16XXXNNNNN, where NNNNN should match the total number of records you have in your list of attendances. You should not have any duplicate record numbers.

3) Please check that there are no blank rows in your data.

8.7. Creating the sample: Tab 2

Once your data is sorted correctly and you have added record numbers you need to use workbook 1 tab 2 ‘Sample selection’ to calculate the survey versions and draw your sample, as detailed in the following instructions.

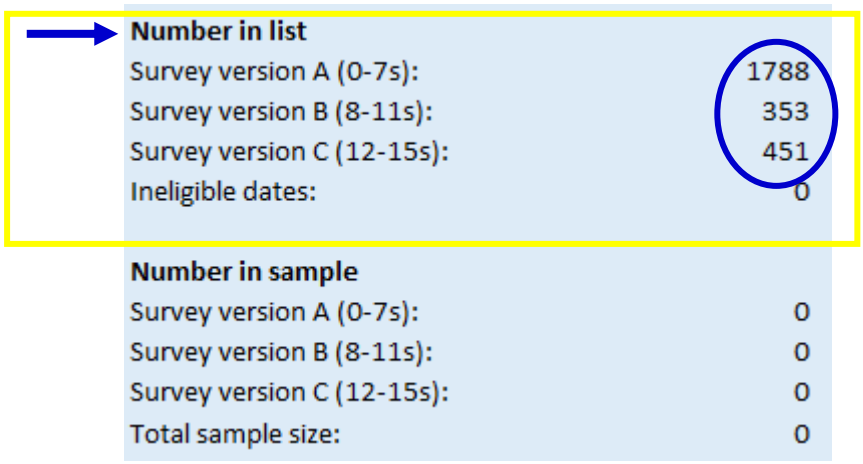
1) Please select all your data in workbook 1, tab ‘1. Full List, **except for column A, ‘NHS number’,** then copy and paste this into the corresponding columns in tab ‘2. Sample selection’ of ‘CYP16 Sampling workbook 1’. (Do not copy the two header rows).

Please note that once the data is pasted, it may take time for Microsoft Excel to load it into the file. Wait for the program to finish processing before going onto the next step. Closing any other programs you have running in the background may speed up this processing.

2) Check the “Number in list” section (see example image below), which is located in columns AF and AG, to see if the template has loaded your data properly. This section will show you how many records you have for each age group: double-check to be sure these figures are in line with what you know about your trust.

Please note: survey version is calculated automatically by the workbook based on patient month and year of birth. The survey version sent to each patient is based on their age at the very end of the sampling period, rather than their age when they were in hospital. This is to avoid patients of the same age receiving different versions of the survey. All patients born 2009 or later will be counted as version A, all patients born between 2005 and 2008 will be counted as version B, and all patients born in 2004 or earlier will be counted as version C.

EXAMPLE



Number in list	
Survey version A (0-7s):	1788
Survey version B (8-11s):	353
Survey version C (12-15s):	451
Ineligible dates:	0
Number in sample	
Survey version A (0-7s):	0
Survey version B (8-11s):	0
Survey version C (12-15s):	0
Total sample size:	0

The “Ineligible dates” count should be zero, and you should not have any records marked ‘Ineligible’ in column B.

EXAMPLE

A	B
In sample? (1 if included in sample, 0 if not)	Survey version
0	Ineligible
0	
0	
0	

If you do have any records marked as ‘Ineligible’ in column B, please look at them and check the following:

- there are no missing birth or discharge dates;
- all birth dates are between November 2000 and December 2016;
- all discharge dates are November or December 2016;
- all patients were aged 15 or below on the date of their discharge;
- all the above numbers are entered as integers (whole numbers with no decimal places).

If you have checked all the above and still have records marked ineligible, please contact the Co-ordination Centre on 01865 208127.

3) Now you need to enter a random start number in the orange boxes in column AG for each of the three survey versions A, B and C. This must be a whole number (i.e. not have a decimal place). The red text will give you a number range that you can choose from – for instance, if it says “Version A: Enter random start between 1 and 2” you can put a 1 or 2 in the orange box next to it. (If the red text says to enter a number ‘between 1 and 1’, you must enter the number 1 in the orange box).

EXAMPLE

Version A: Enter random start between 1 and 2:	1
Version B: Enter random start between 1 and 1:	1
Version C: Enter random start between 1 and 3:	3

Please allow time for Microsoft Excel to finish processing after you enter a number in each of the orange boxes. This may take some time.

4) After doing this, a random sample of records will be selected and column A and column B of the spreadsheet will automatically update. **Please allow time for Microsoft Excel to do this.** Records that have been randomly selected will be denoted by a '1'; those that have not been selected will be indicated by a '0'.

EXAMPLE

A	B
In sample? (1 if included in sample, 0 if not)	Survey version
1	C
0	
1	B
0	
0	
1	B
0	
0	

5) The "Number in sample" section in columns AE-AF will automatically update.

A sample of 1250 will be drawn if there are enough eligible patients. The target sample sizes for each survey version are:

- Version A: 450
- Version B: 400
- Version C: 400

You should check the "numbers in sample" listed in columns AE-AF are in line with the instructions below. If your numbers do not match what you would expect from the instructions below, please contact the Co-ordination Centre for advice.

- **If your trust has enough eligible cases for all three survey versions:**
  - The total sample size will be 1250, made of 450 cases for version A, 400 for version B, and 400 for version C. For example:

Number in list	
Survey version A (0-7s):	824
Survey version B (8-11s):	583
Survey version C (12-15s):	649
Ineligible dates:	0
Number in sample	
Survey version A (0-7s):	450
Survey version B (8-11s):	400
Survey version C (12-15s):	400
Total sample size:	1250

- **If your trust has fewer than or exactly 1250 eligible cases in total:**
  - All cases should be included in your sample, meaning the 'number in sample' section will match the 'number in list' section. For example:

Number in list	
Survey version A (0-7s):	516
Survey version B (8-11s):	269
Survey version C (12-15s):	141
Ineligible dates:	0
Number in sample	
Survey version A (0-7s):	516
Survey version B (8-11s):	269
Survey version C (12-15s):	141
Total sample size:	926

- **If your trust has more than 1250 eligible cases in total, but less than the target sample size for one or two of the survey versions:**
  - All patients from the survey version(s) with less than the target number of cases will be included.
  - The workbook will automatically increase the number of cases from the survey version(s) with excess patients, selecting a total sample size of 1250 cases. For example:

Number in list	
Survey version A (0-7s):	229
Survey version B (8-11s):	285
Survey version C (12-15s):	1108
Ineligible dates:	0
Number in sample	
Survey version A (0-7s):	229
Survey version B (8-11s):	285
Survey version C (12-15s):	736
Total sample size:	1250

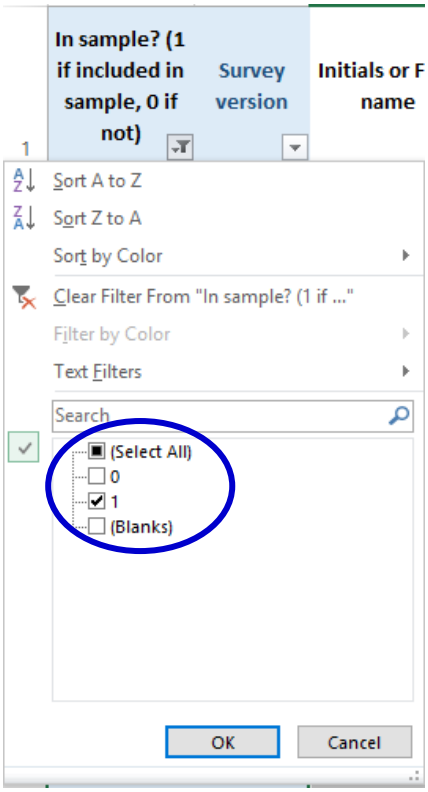
6) Now **save this file** for future reference. Note that you will **not send 'CYP16 Sampling workbook 1''** to the Co-ordination Centre, but you will use it to create the final sample file and may need to refer back to the file in the next few months if the Co-ordination Centre have any queries, so please make sure that the person that will deal with it in the next few months is aware of its location.

8.8. Creating your final sample file in Workbook 2

1) Download 'CYP16 Sampling workbook 2' from http://www.nhssurveys.org/surveys/1002

2) In **'CYP16 Sampling workbook 1'**, in tab *2. Sample selection*, filter by column A so that only cases with a "1" in the column are shown. These are the cases that will be included in your

sample. You can filter this column by clicking the grey arrow in cell A1 and making sure only "1" is selected, as shown below, then clicking 'OK'. Once you have applied the filter, you should only see "1" in column A, and no blanks in column B.



3) **With the filter still on**, select all data from **column B "Survey version"** through to column **AD "NHS Site Code on discharge"** (but do not select the header row 1), right click, and press copy. **Please ensure you select your entire sample (all records with a '1' in column A).**

4) Now paste this data into the corresponding columns (A to AC) in the tab named "*Sample"* of **workbook 2.**

5) Check that the number of records you have pasted into the tab named *"Sample"* of **workbook 2** matches the total number of records in your sample indicated in **workbook 1** tab '*2*. Sample Selection' in the 'Number in sample' section (the total sample size is in cell AF18).

   (Please note that the column titles are in the first row, so the total number of records in the workbook 2 "sample" tab will be the number of rows minus 1).

6) Finally, you need to complete the population numbers information in the 'population numbers' tab of **workbook 2**. This information must be taken from the '**Number in List'** cells in **workbook 1**, tab 2 (cells AF9-AF11). Please enter the 'number in list' for each of the three survey versions.

   It is very important you enter these numbers accurately, as they will be used in the analysis of your survey response data.

7) **Save the workbook as 'CYP16_< trust code >_sample'**

This workbook has three main purposes:

1. It will be used to keep a record of which patients have not returned questionnaires so that reminders can be sent to them.
2. It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from 9th February 2017 until the closing date of the survey.
3. The anonymous data in this file (i.e. all the data **except** patient name and address information) will form part of the file that you will submit to the Co-ordination Centre when the survey is completed.

Additional information should also be entered on this spreadsheet. The details of this information are indicated below.

1) **Day of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trust. It should be a one or two digit numerical response **not** a date format, e.g. N or NN not 20/02/17.

2) **Month of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trusts. It should be a one or two digit numerical response, **not** a date format.

3) **Year of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trusts. It should be a four digit numerical response, **not** a date format.

4) **Outcome**. This field will be used to record which questionnaires are returned to the freepost address, or are returned undelivered, or which patients opt out of the survey, etc.
   1 = Returned useable questionnaire
   2 = Returned undelivered by the mail service or patient moved house
   3 = Patient died (after fieldwork had commenced)
   4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire
   5 = Patient was not eligible to fill in questionnaire
   6 = Questionnaire not returned (reason not known)
   7 = Patient deceased prior to fieldwork

   The outcome column is left blank at first if the survey has not been returned (in table 1 you can see that K Yoo has not yet returned their questionnaire).

5) **Comments**. This column is useful for recording any additional information that may be provided when someone calls the helpline – for example, to inform you that the respondent has died or is no longer living at this address.

An example of the sample worksheet you will complete has been included below:

Table 1 – Sample Excel file of patient details

Initials or first name	Surname	Address1		Address5	Postcode	*Trust Code*	*Record number*	*Month of Birth*	*Year of birth*	*Gender*	*Ethnicity*	*Day of admission*	*Month of admission*	*Year of admission*	*Day of Discharge*	*Month of Discharge*	*Year of Discharge*	*Length of Stay*	*Main Speciality on Discharge*	*Treatment function code*	*CCG code*	*Treatment Centre Admission*	Route of Admission	NHS Site code on Admission	NHS Site code on Discharge	*Day of questionnaire being received*	*Month of questionnaire being received*	*Year of questionnaire being received*	*Outcome*	Comments
AM	Abbot		--		AB1 1YZ	R1X	CYP16 R1X10 0001	1	2004	2	A	5	11	2016	11	11	2016	6	120	220	10Q	0		RR115	RR115		2	2017	1	Informed that patient had died
EC	Ahmed		--		AB2 6XZ	R1X	CYP16 R1X00 005	1	2009	1	J	1	11	2016	12	11	2016	10	101	215	10Q	1	11	RTE03	RTE03	24	2	2017	6	
			--																										
K	Yoo		--		AB4 7MX	R1X	CYP16 R1X 02655	3	2012	2	R	5	11	2016	11	11	2016	6	110	215	10Q	1		RR115	RR115	28	2	2017		
F	You Ng		--		AB9 5ZX	R1X	CYP16 R1X 02658	1	2006	2	A	2	11	2016	12	12	2016	10	420	219	10Q	0	22	RR117	RR117	01	3	2017	1	

The headings of Table 1 are in three different colours:

Bold black headings: These columns contain information on patients' names, addresses and comments that may allow them to be identified. This information should be DELETED from all files sent to the Co-ordination Centre.

Red italic headings: These columns should be completed during the sampling phase and submitted to the Co-ordination Centre for final inspection prior to mailing (see the Instruction Manual) and at the conclusion of the survey.

Green italic headings: These columns should be completed after a patient has responded to the survey. If you are working with an approved contractor they will complete these columns on your behalf.

8.9. Checking for sample errors

Distribution of patient gender
Your sample will probably have similar proportions of boys and girls - unless your trust treats boys or girls only. You should check both of these genders are included and that you can explain if the sample is skewed toward male or female patients.

Distribution of patient ages
You should check that patients of all ages are included in your sample. A good way to check that your sampled patients' ages cover the full range of expected ages is to examine the distribution of ages on a histogram.

Checking the distribution of patient route of admission and episode type
Please also check that the split of patients is roughly as you would expect – for example between emergency versus planned admissions, and the proportion of inpatients versus day case patients. This is essential as it helps you to discover any errors that might have occurred when the sample was drawn. The split across groups is unlikely to *exactly* match any data you have on the proportions across all patients, as it is a sample survey. However, looking at the data this way will help you spot problems.

Checking for other sample errors
Please also ensure you have checked the following:

- No patients aged 0-14 days at the time of discharge should be included
- No patients aged 16 or over at the time of discharge should be included
- Correct ethnicity coding
- Gender coding should be numeric (male = 1, female = 2)
- Only unique patients should be included (no duplicates)
- The sample should have been drawn from the full sampling period (November 1st to December 31st 2016).

Please also check to ensure your data has not become mis-sorted. Mis-sorting can occur if data has been sorted while only part of the data has been selected (e.g. if some columns were not selected). To check this, please look at several patient records spread throughout your data and ensure the data in every column is correct for these patients.

8.10. Separating mailing details from sample information

Once you are confident your sample is correct, please follow the below instructions to split the file in two separate Excel files: one for you to use for your mailing, another one for you to submit to the Co-ordination Centre.

Sample file – for submission to the Co-ordination Centre

1) Open your saved version of workbook 2, and save a **new version** of this file by going to 'file' > 'save as' and then saving as: **'CYP16_<trust code>_sampledata'** (e.g. CYP16_RTH_sampledata).

2) In this sample data file, **delete the mailing data columns**. To do this, in the 'sample' tab, select from column B 'Initials or First name' through to column I 'Postcode' by clicking on the 'B' at the top of the column and then sliding the mouse over to the 'I'. Then right click and press delete.

Initials or First name	Surname	Address 1	Address 2	Address 3	Address 4	Address 5	Postcode
Initials or first name of patient	Last name of patient	First line of patient's UK address	Second line of patient's UK address	Third line of patient's UK address	Fourth line of patient's UK address	Fifth line of patient's UK address	Patient's postcode

3) Please do not add any extra levels of protection to the workbook. In particular, the workbook should not be made 'read only'.

4) Save your sample data file, and double check that it **does not contain any of the mailing data columns (Initials, name, address, postcode)**.

Mailing file

1) Rename your **original** saved version of **workbook 2** to: **'CYP16_mailingdata'**.

2) Now **delete the sample data**, **keeping only the mailing data and patient record number**. To do this, in the 'sample' tab, select column J 'Trust code' by clicking on the 'J' at the top of the column. Then right click and press delete. Then do the same to delete from the column 'Month of birth' (now column K) through to the column 'Comments (now column AG).

3) Save the mailing data file and check it **only** contains the survey version column, the mailing information columns and the patient record number column, as shown below. It is essential that the patient record number matches that used in the sample file as this is used to link the two datasets.

A	B	C	D	E	F	G	H	I	J
Survey version	Initials or First name	Surname	Address 1	Address 2	Address 3	Address 4	Address 5	Postcode	Record number

Your 'CY16_mailingdata' file should be used for mailing purposes: it will be used to check for deceased service users prior to reminder mailings and will be cross-referenced with the sample file ('CYP16_<trust code>_sampledata') to identify service users who will need to be sent reminders.

As this "CYP2016_mailing data" file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing data file should be destroyed when the survey is complete, along with all other files created for the survey (aside from the survey response data files http://www.nhssurveys.org/surveys/1008).

For patient confidentiality reasons, **it is essential that you do not keep patient name and address details in the same file as their survey response data**.

8.11. Sample declaration form

Before a trust submits their sample for checking, there is a sample declaration form with a number of compliance statements that needs to be completed by both the person drawing the sample and the Caldicott Guardian. They complete the form by indicating their agreement with the statements on the form. The completed form must then be (1) sent to the Co-ordination Centre from the email address of the Caldicott Guardian or (2) from the email address of the person who drew the sample if the Caldicott Guardian is cc'd into the email.

The sample declaration form is available on the NHS Surveys website to download at http://www.nhssurveys.org/surveys/1004.

The form covers a number of purposes:

- Reminds trusts of the key steps in sampling
- Ensures that the Caldicott Guardian is content with the sample and mailing information leaving the trust.

The form **must** be completed and submitted to the Co-ordination Centre **prior to submitting your** anonymised sample file for checking. You will receive notification when you are permitted to submit your data. The form has a separate compliance statement where you must indicate that you confirm that there are no patient identifiable data (names and addresses) in the sample file before it is submitted to the Co-ordination Centre. This is a key element of the survey methodology as approved under section 251, and must be followed in order to minimise the risk of any data breaches occurring.

Trusts must submit the sample data to the Co-ordination Centre for checking no later than **Friday 27th January 2017**. If you do not meet this deadline, there is a risk your trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may result in the data from the trust being excluded from the relevant CQC assessments.

Samples that have not been submitted for checking by the **27th January 2017** will be followed up by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **Friday 3rd February 2017**, then we are required to notify the CQC of this and they will contact you to discuss any implications for inclusion in CQC produced data.

Please see section 9, below, for further details on how to submit your sample to the Co-ordination Centre for checking.

8.12. Making more use of the survey locally

Up to this point, this section of the instruction manual has described in detail how sampling must be undertaken to provide the basic required sample of 1250 patients for the 2016 Children's and Young People's Inpatient and Day Case Survey. However, in addition to this minimum requirement, your trust may wish to use this survey as an opportunity to gather further data beyond that required by the CQC. Increasing the sample size is a good way to do this.

Increasing the sample size for the survey may be helpful if, for example, you wish to analyse or compare results for specific subgroups (for example, patients treated at different sites or patients of different ethnicities) in more detail than would be possible from a sample of 1250 patients. By increasing the sample size you can ensure that you have a large enough sample of patients from each group.

Alternatively, if your trust regularly treats very large numbers of patients, you may wish to draw an extra sample of patients to survey additionally to those included in the main survey. For example, you could select patients discharged in a different time period from those in the national survey and send them questionnaires either at the same time as or at some point after the national survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out a children and young people's survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of patients which do not overlap. Guidance for carrying out a local survey is available at http://www.nhssurveys.org/localsurveys.

However, before you decide to do this, there are some important points to consider:

- Please note that the section 251 approval obtained for the 2016 Children's and Young People's Inpatient and Day Case Survey only covers the national standardised survey. If you wish to collect any additional sample information please contact your trust's Caldicott Guardian for advice as to whether it is appropriate to contact the Health Research Authority for further approval.

- The core sample for the 2016 National Children and Young People's Inpatient and Day Case Survey **must** be drawn as specified in this instruction manual; any deviation from the instructions may make it impossible for the CQC to use the data that you collect. It is therefore essential that any additional sample drawn can be easily distinguished from the core sample, and that it is drawn in such a way as to not interfere with selection of the core sample.

- If you are planning to undertake surveys more frequently than the NHS patient survey programme, then you should consider how any increased sample here will fit with the additional surveys you will be undertaking.

8.13. Summary of steps

Before submitting your sample to the Co-ordination Centre, please ensure you followed the instructions in this section:

1. Compiled a list of eligible patients (Section 8.1).
2. Removed duplicates (section 8.2).
3. Sent the list to the DBS to check for deceased patients and removed these patients from your list (Section 8.3 and Section 8.4).
4. Checked your patient list to make sure it meets requirements and only includes eligible patients (Section 8.5).
5. Sorted and cleaned the eligible patient list (Section 8.6).
6. Selected a patient sample, closely following the instructions in sections 8.7.
7. Created the final sample file (Section 8.8).
8. Checked the distribution of gender in your sample file (Section 8.9).
9. Checked for other errors that may have occurred when drawing your sample (Section 8.9).
10. Removed personal data from the sample file and created a mailing file (Section 8.10).
11. **Complete the sample declaration form** (see section 8.11) and send this to the Co-ordination Centre **before** sending them your sample file. **Do not send the sample file before your sample declaration form has been approved.**

12. Now your sample is ready to be submitted to the Co-ordination Centre. See section 9 for further details.

PLEASE NOTE: trusts will NOT be permitted to submit any files to the Co-ordination Centre with more than 1250 records (maximum), from which the Co-ordination Centre would draw the sample on behalf of the trust. If trusts do this, it will be considered a breach of the Section 251 Approval for the survey, resulting in follow up action being taken. It is not permissible for the Co-ordination Centre to draw the post DBS sample on behalf of the trust

9 Final sampling inspection by the Co-ordination Centre

Trust data should be checked for errors and received back from DBS before being forwarded to the Co-ordination Centre. Your anonymised sample file ('CYP16_<trust code>_sampledata' – created following the instructions in section 8.13), which **does not contain** patients' names or addresses **must** be submitted to the Co-ordination Centre **prior** to the first mailing. This is to allow us to make final quality control checks.

9.1 Sample declaration form

As discussed above, there is a sample declaration form that needs to be completed by the person preparing the sample. The form must be completed and submitted to the Co-ordination Centre prior to submitting your anonymised sample file. When the Co-ordination Centre has confirmed with you that they have received a completed sample declaration, you will be permitted to submit your anonymised sample file to the Co-ordination Centre for checking. The aim of this is to minimise the risk of any data breaches occurring and so it is worthwhile ensuring that this stage is followed correctly. Please see section 8.11 for further details**.**

9.2 Submitting your sample to the Co-ordination Centre

Once the Co-ordination Centre has approved your sample declaration form, you will be provided with details on how to submit your sample to the Co-ordination Centre via the secure FTP server.

E-mails discussing any sample anomalies will be returned to the trust within four working days of receiving the sample.

Important note
Your first mailing should take place as soon as possible after your sample has been approved by the Co-ordination Centre and certainly **no later than seven days** after this. A large time lag increases the likelihood of patients having died between the sample file being received back from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to your trust.

9.3 Making the most of the fieldwork period

Because certain demographic groups (specifically younger patients and those from black and minority ethnic categories) have been shown to take longer to respond to patient surveys, we strongly recommend that files are submitted within the four weeks specified for sample checking. The best way to ensure you can do this is to prepare before the start date of the survey (30th January 2017). You can do this by:

1) Allocating sufficient time to the individual who will generate your sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by the Co-ordination Centre.

2) Discuss the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey.

3) Ensure your trust is registered with DBS and that the person who submits your sample to them understands their requirements – problems with data submitted to tracing services is one of the most significant obstacles in mailing out your survey in good time. Also, do not assume you are registered – please check this ahead of time.

4) Printing of questionnaires and assembly of mailing packs can take place before the sample is signed off. Please ensure that the envelopes are left open though so that you can check the correct label is applied to the correct questionnaire.

10 Weekly monitoring

The Co-ordination Centre requires weekly submissions of data on response rates and helpline calls. The first submission of data must be made on **9th February 2017**[4], and every Thursday thereafter until the final date of submission. An Excel spreadsheet for trusts conducting the survey in-house is available at http://www.nhssurveys.org/surveys/1007 which **must** be used to return this information to the Co-ordination Centre.

This information should be emailed to the Co-ordination Centre (cyp.cc@pickereurope.ac.uk) by the end of the workday every Thursday throughout the survey.

Important notes:

Weekly submissions only apply to the core sample of patients

Please do not alter the structure of the Excel weekly monitoring spreadsheet.

File name **must** be in the following format:

CYP16_<trust code>_<week of submission>.xls

e.g. CYP16_RAC_1.xls (first submission of monitoring data on 9th February 2017)
CYP16_RY2_5.xls (fifth submission of monitoring data on 9th March 2017)

10.1 Monitoring response rate

The information submitted should contain the following data:

- The total number of patients in your sample, i.e. the total number of all those included in the first mailing.
- The number of patients in each outcome field.

This will allow the Co-ordination Centre to monitor progress at a trust level and to identify trusts that may need assistance. It will also allow us to provide the CQC with regular updates on response rate at trust level.

10.2 Helpline monitoring

The information you submit should contain the following data for each trust:

- The overall total number of calls received by the helpline for this survey.
- A breakdown of this overall total number, into:
    - The total number of calls that led to completion of the questionnaire using the helpline (this should include completions via translation services).
    - The total number of calls seeking assistance with language and translation (this should include completions via translation services).

[4] This submission must be made regardless of whether mailing has commenced.

- The total number of calls that led to completion of the questionnaire using translation services.

Examples: how to record calls

If a caller rang the helpline and completed the questionnaire over the phone using translation services, then this call should be recorded in all four 'categories'.

If a caller rang the helpline to opt out of the survey (and did not require translation services), this call should just be recorded in the 'overall total' number of calls' (i.e. first category).

If a caller completed the questionnaire over the phone (and did not require translation services) this call should be recorded in the 'overall total' and the 'total number of calls that led to completion' (i.e. first and second categories).

This information allows the Co-ordination Centre to identify areas of concern to patients and to improve future surveys.

11 Materials

11.1. The Questionnaires

Each trust must use the core questionnaires as provided by the Co-ordination Centre. There are three versions of the questionnaire to cater for the different age groups of children and young people that we are gathering data from. These are:

- A survey for children aged 0-7 years old to be completed by the parent/ carer
- A survey for children aged 8-11 years old with a section to be completed by the child and a section for the parent/carer to complete
- A survey for young people aged 12-15 years old with a section to be completed by the young person and a section for the parent/ carer to complete

All three pre-designed core questionnaires are available on the NHS Surveys website and must be used by all NHS trusts participating in this survey. **The questionnaires are copyrighted and therefore no trust logos are to appear on the questionnaire versions.**

The parents' questionnaire (for children aged 0-7)

The parents' paper questionnaire consists of 52 questions on 8 pages. These questions cover the issues that have been found to be most important to parents/ carers and those interested in delivering high quality children's services. The front page of the questionnaire explains the purpose of the survey and gives instructions on how to fill it in. In the pages that follow, the survey questions are divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the parent or carer. The questionnaire can be downloaded from the NHS Surveys website: http://www.nhssurveys.org/surveys/1009

The front page must be printed in colour as this will have the colour CQC and Picker Institute logos; all other pages can be in black and white.

The 8 - 11 year olds questionnaire

The 8 - 11 year olds paper questionnaire consists of 59 questions on 8 pages: the first section is for the child and contains 22 questions over 3 pages. These questions cover the issues that have been found to be most important to patients of this age group. This questionnaire also includes a section for parents/ carers to complete, as well as the child. Note that the section for the child to complete has been limited to 3 pages - this is to prevent attrition and reduce burden on the child whilst allowing us to gather data on the most important aspects of care. The covering letter explains the purpose of the survey and gives instructions on how to fill it in. There are additional survey information leaflets specifically for children and young people which must accompany the covering letter and questionnaire. The parents and carers section follows the section for the 8-11 year olds and is divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the parent or carer. The questionnaire can be downloaded from the NHS Surveys website: http://www.nhssurveys.org/surveys/1009

This questionnaire must be printed in colour throughout.

The 12 - 15 year olds questionnaire

The 12-15 years old questionnaire consists of 60 questions on 8 pages: the first section is for the child and contains 23 questions over 3 pages. These questions cover the issues that have been found to be most important to patients of this age group. This questionnaire also includes a section for parents/ carers to complete, as well as the child/ young person. The covering letter explains the purpose of the survey and gives instructions on how to fill it in. The parents and carers section

follows the section for the 12-15 year olds and is divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the parent or carer. The questionnaire can be downloaded from the NHS Surveys website: http://www.nhssurveys.org/surveys/1009

This questionnaire must be printed in colour throughout.

11.2. Printing questionnaires

Questionnaire layout

The questionnaire is rigorously tested in the current format. All questionnaires used by trusts must replicate this format because any differences can impact on the responses patients give. The format should be comprised of the following:

- Two columns of questions on each page
- Questions should be presented with a consecutive question number, followed by the exact question wording used in the questionnaire, and then each of the response options presented on a separate line beneath the question, for example:

  Q4. Was it quiet enough for you to sleep when needed in the hospital?

  1 ☐ Yes, always

  2 ☐ Yes, sometimes

  3 ☐ No

  4 ☐ I did not sleep in the hospital

- Please do not arrange the response options horizontally across the page, rearrange the question options, or change the order of the questions in the questionnaire.
- Please ensure all routing instructions are accurate as any errors might impact on the use of ensuing data.

Number of pages

It is practical to ensure that the number of pages in a questionnaire is a multiple of four so that sheets can be printed double-sided on A3 paper and folded to make an A4 booklet, stapled in the middle. If pages are stapled at the corner, there is a greater chance that some pages will become detached and get lost. The questionnaires, available in PDF format on the NHS Surveys website, are designed to fit onto 8 sides of A4 paper (http://www.nhssurveys.org/surveys/1009).

Number of questionnaires

When calculating the number of questionnaires to be printed, you will need to allow for sending out duplicate questionnaires with second reminders. Printing costs can be unnecessarily high if a second print-run is required, so it is worth ensuring that the first print-run is sufficiently large to allow for contingencies. As a rule of thumb, multiply the number of patients in each group of the sample by 1.8 to obtain the total number of questionnaires required; you may need to use a slightly larger number for 0-7 year olds, due to lower response rates amongst this group. So, if the number of first mailing questionnaires you intend to send out is 1250 (450 to 0-7 year olds, and 400 to both 8-11 year olds and 12-15 year olds), then you might want to print 1.85 x 450 questionnaires for 0-7 year olds (830), 1.8 x 400 questionnaires for 8-11 year olds (680), and 1.8 x 400 questionnaires for 12-15 year olds (680). A total of approximately 2,190 questionnaires.

11.3. Covering letters and Information leaflet

Trusts should only use their sample information to mail out the three official survey mailings. The sample list should not be used for any other type of mailing i.e. Trusts must not mail their own letter to the sample list prior to the first mailing being despatched.

Furthermore, only the materials described below should be included in the mailings because of the unmeasurable impact upon response rates to the survey.

For this survey there are three covering letters, to be printed on A4 paper. The first letter is to be sent in the first mailing pack. It contains some background information about the survey, and a page of Q&A. The second letter is to be sent as a reminder to respondents, to ask them to complete and return the questionnaire. The final letter reiterates the purpose and the importance of the study, as well as requesting recipients again to return the questionnaire. It also repeats the Q&A that were included in the first mailing letter.

It is vitally important that the covering letters are mailed in the correct order. The three letters can be downloaded from the NHS Surveys website: http://www.nhssurveys.org/surveys/1012

There are two different 1 page A4 information leaflets. One for children aged 8-11 years and one for young people aged 12-15 years. Contractors will need to print these out and include them in the relevant survey packs. The leaflets can be downloaded from the NHS Surveys website: http://www.nhssurveys.org/surveys/1012

11.4. Trust headed paper

You will need headed paper from the trust for all three letters to comply with section 251. Therefore, depending on your response to the initial mailings and trust sample size, you will need approximately up to around 3,300 sheets of trust headed notepaper.

11.5. Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to patients does not show any indication of the NHS Trust. Some patients may not have told family or friends that they have gone to hospital and, under data protection regulations, it is important that this information remains confidential to the patient. We would therefore recommend that the return address used on any mail out envelope(s) does not indicate Trust name or address. It is, however, important that we record questionnaires which are returned undelivered as this affects response rate. We would therefore advise that, where necessary, a PO Box address is set up for envelopes which are returned undelivered.

Please note that the above does not apply to the address on the reply paid envelope (which can be a hospital address) as we assume that the patient (or their parent/carer) is responsible for opening his or her own mail.

11.6. First mailing

If you have a full sample, you will need 1250 of each of the following items:

- Printed questionnaires
- Large envelopes for mailing questionnaires to patient
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address if necessary)

- FREEPOST envelopes for return of questionnaires
- Covering letters using the trust's letterhead
- Multi-language helpline sheet (recommended)[5]
- Information leaflet

11.7. Second mailing (first reminder)

First reminders are sent to all patients who do not respond to the first mailing (except, of course, those who withdraw). Usually you will need to send first reminders to around 85-95% of the original patient sample. The following items are needed:

- Reminder letters using the trust's letterhead
- Envelopes
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house Trusts)

11.8. Third mailing (second reminder)

The second reminder should replicate the first mailing, and you will need to send this to around 75-85% of the original sample, depending on the number of responses to the previous two mailings. The following items are needed:

- Printed questionnaires
- Large envelopes for mailing questionnaires to patient
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes
- FREEPOST envelopes for returning questionnaires
- Reminder letters using the trust's letterhead
- Multi-language helpline sheet (if used in first mailing).
- Information leaflet

11.9. Other mailings and inclusion of other information in mailing packs

Trusts should only use their sample information to mail out the three official survey mailings. The sample list should not be used for any other type of mailing, i.e. trusts should not mail their own letter to the sample list prior to the first mailing being dispatched.

Furthermore, no other material should be included in the questionnaire packs because of the immeasurable impact upon response rates to the survey. Additionally, the multi-region ethics board judged that inclusion of additional material that they had not viewed would invalidate the ethical approval they have given and the survey would therefore not be able to proceed.

11.10. Submitting hard copies of the questionnaire and cover letters

Hard copies of the questionnaire and cover letters must be submitted to the Co-ordination Centre by **Friday 20th January 2017**. As standard, please submit:

- Two paper copies of the questionnaire
- Two paper copies of the first mailing covering letter

[5] This document can be found on our website alongside the cover letters. The languages covered by this document are: Arabic, Bengali, Chinese (Cantonese), Farsi /Persian, Guajarati, Hindi, Kurdish, Chinese (Mandarin), Punjabi, Tamil, Thai, Turkish, Urdu, French, Italian, Polish, Portuguese, Russian, Somali, Spanish.

- Two paper copies of the first reminder letter
- Two paper copies of the second reminder letter

Please ensure that you completely redact any patient names and/or addresses from hard copies of covering letters; failure to do so will constitute a breach of patient confidentiality.

These must be sent to:

National Children and Young People's Inpatient and Day Case Survey 2016
Patient Survey Co-ordination Centre
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0JB

12 Implementing the survey - practicalities

12.1 Setting up a FREEPOST address

A FREEPOST address allows patients to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the envelopes you send out with the questionnaires. Printed envelopes must comply with Royal Mail guidelines. Details of how to apply for a FREEPOST licence can be found at the Royal Mail website: http://www.royalmail.com. Alternatively, you can call your local Sales Centre on 0845 7950 950.

12.2 Setting up a PO Box

This is recommended for in-house trusts to ensure that the mail out envelope(s) does not include any indication of the hospital address. Information on setting up a PO address can be found at http://www2.royalmail.com/delivery/inbound-mail/po-box.

12.3 Setting up a FREEPHONE line

The covering letter to patients should include a telephone number for patients to call if they have any questions or complaints about the survey. All staff who are likely to take calls should be properly briefed about the details of the survey, and be aware of the questions or complaints they are likely to receive. You might want to set up a FREEPHONE line for this purpose.

12.4 Managing calls to the FREEPHONE line

Where appropriate, ask the patients who calls to tell you their patient record number, which should be on the address label of the envelope they received, and on the questionnaire itself. You can then use this number to identify people who do not want to receive any further reminders.

Below are some questions and comments commonly asked by patients and some advice on how they can be managed:

My child has had two or more hospital admissions or attendances as a day case - which one should I refer to?

Parents / carers should be advised to refer to their child's **most recent** hospital inpatient admission or day case attendance. Usually, this is the admission or attendance covered by your sampling period but, for the few patients who have been re-admitted since you drew the sample, it is simpler to tell them to refer to their most recent stay. It will not make the results invalid if a few of the patients refer to a more recent episode than the others.

I have a specific comment, complaint or question about my child's care or treatment. Who can I contact at the trust?

Patients can be referred to the trust's PALS, the complaints manager or patient services manager.

The person to whom the questionnaire is addressed is unable to understand the questionnaire.

Relatives or carers may call to pass on this information. In some cases, if the child would like to complete the questionnaire with assistance, or the parent/ carer would like to complete it on their behalf, this is permissible. Parents/ carers can offer to complete the questionnaire for the patient, but this is only advisable if there is a good chance that the responses are a true reflection of the patients' views.

The person to whom the questionnaire is addressed has died.

Even with the use of a deceased patients tracing service, it may not be possible to identify all deceased patients, particularly those who have died most recently. It is very important that staff who take the calls are aware of this possibility and are prepared to respond sensitively to such calls. These patients should be recorded as outcome = 3 (patient deceased) in the sample file.

I would like to take part but English is not my first language.

If a patient's spoken English is better than their written English, they may be willing to have someone, such as a family member, fill in a form on their behalf. It is also strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. A multi-language sheet in the twenty most commonly spoken languages in England is available on the NHS Surveys website, and trusts can make use of this by inserting the appropriate number for their helpline and/or translation service.

I do not wish to participate in this survey.

A few patients might call to say that they do not want to be involved in the survey, and fewer still may object to being sent the questionnaire in the first place. Staff should apologise to the patient and reiterate the statement in the covering letter - that taking part in the survey is voluntary, and that the patient's care will not be affected in any way if they do not respond. There are a number of requirements for this survey for recording this information:

A few additional instructions for handling patients who do not want to participate in the survey:

- Any objection is to be recorded immediately and checks made to determine whether a mailing is underway. If a mailing is underway the caller will need to be advised that it might not be possible to prevent this mailing but assured that they will receive no future mailings.
- People wishing to receive no further questionnaires can be identified with a flag/code/number on the mailing file.

When speaking to callers wishing to opt-out of future survey mailings, **it is not appropriate to try and dissuade them from their intent**. There is a risk that even well intentioned discussion around the benefits of the survey could be perceived as applying pressure to participate. The benefits of the survey should only be mentioned by call-takers in response to queries from callers. If someone feels strongly enough about the survey that they initiate contact to object, callers are advised they are being removed from the mailing list for this survey only and that if they wish to register their dissent against wider research participation at their trust, they need to speak to their trust (via PALS or the trust Information Governance Team to do this).

It is also advisable to ask the patient to ignore any future reminders that they might receive. These patients should be recorded as outcome = 4 (opt out) in the sample file (see sampling handbook).

Making a record of the calls

It is important to keep a record of the reasons patients called, as this can help to make improvements to future surveys and can provide useful additional information on patients' concerns. A standard form should be produced for completion by those taking the calls. The relevant details of each call can be recorded so that survey organisers can monitor any problems and remove patients who wish to be excluded from the mailing list.

We are also asking for weekly submissions of helpline use for each trust to the Co-ordination Centre. This is discussed in detail in Section 10.2.

12.5 Covering letters

The standard letters for all mailings are available in Microsoft Word format on the Children and Young People's Survey section of the NHS Surveys website for you to download and add your own trust's details (http://www.nhssurveys.org/surveys/1010). These letters have been given ethical approval for use in the National Children and Young People's Inpatient and Day Case Survey 2016 and changes are **not** permissible. The covering letters must be printed on the trust's letterhead paper. Two paper copies of the letters that you use must be sent to the Co-ordination Centre by 20th January 2017.

Please note that for all mailing letters there is the option to include patient name. If patient name is used, please take great care that each letter is correctly matched to its corresponding questionnaire.

12.6 Sending out questionnaires

Address labels

Three address labels are needed for each patient: one set of labels will be used for the first mailing, one for the first reminder, and one for the second reminder.

We recommend using the mail merge feature in a word processing package to create the mailing labels from the database of patient names and addresses. **It is essential that the patient record number is on each address label,** as this has to be matched with the number on the front of the questionnaire. The label should not include any other information except the patients' name, address and postcode details, and the patient record number.

Note on the patient record number (PRN)

The patient record number is a unique number allocated to all patients at the start of the survey that allows their responses to be kept separate from their name and address, but allows matching up of the response data with the sample data. It also allows them to identify themselves if they contact the trust or contactor without needing to provide name and address information. This should be centrally placed and large enough to be visible to all patients. The Royal National Institute of the Blind recommends the number be printed in size 14 font and located inside the box on the lower half of the front page of the questionnaire.

If patients delete this number from the cover page and then return the questionnaire, please add their response information in an additional row to the bottom of the data file before submitting it to the Co-ordination Centre. Please do not attempt to match this data to a non-responder of similar demographics, but instead inform the Co-ordination Centre about this respondent and they will be treated as an additional patient to the sample.

Questionnaire packs

The envelope sent to each patient at the first mailing should include the following:

1) A questionnaire **numbered with the patient record number**. The number must match the number on the address label, and the number on the list of patient details.
2) A covering letter.
3) The information leaflet.
4) The multi-language helpline sheet (recommended).
5) A large envelope, labelled with the FREEPOST address on it.
6) These items should be packed into an envelope that has a return address on the outside. (PO Box recommended for in-house Trusts). This should be the contact at the NHS trust.

Postage

The postage may exceed the standard letter rate. It is essential that the appropriate postage rate is paid.

12.7 Booking in questionnaires

When questionnaires are received, match up the patient record numbers against the list of patients, so that you can record (in the *outcome* column) which patients have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until **Friday 8th December 2017**, but please **do not** send these to the Co-ordination Centre.

12.8 Sending out reminders

For results to be representative, it is essential to get a good response rate. To achieve this, you must send out two reminders to non-responders. **Remember, it is essential that you send out both reminders.** Depending on the time that has elapsed since you first checked your patient list for deaths, it might be necessary to send your list back to the tracing service for a further check before you send out reminders.

The first reminder should be sent to patients who have not responded after **one to two weeks**. We recommend approximately **ten** days between the mailing day of the first questionnaire and the

mailing day of the first reminder. The first reminder should reach the participant while they are still in possession of the first questionnaire, and the optimal time for this will vary between trusts.

Second reminders should be sent out approximately two to three weeks after the first reminder to patients who have not yet responded. Again the optimal time will vary between trusts and experience is the best guide for choosing mailing dates.

Remember that you should check your trust's own records for deaths before sending out reminders.

While trusts should choose the most suitable time to send out reminder mailings to achieve the optimal response rate, **please do not leave more than 3 weeks between each mailing.**

13 Entering data and submission to the Co-ordination Centre

The data should be entered into the pre-designed Excel files, which can be found in the National Children and Young People's Inpatient and Day Case Survey section of the NHS Surveys website http://www.nhssurveys.org/surveys/1008).

There are three data entry spreadsheets. The first one should be used to enter data from the parent's survey (0-7 year olds), the second should be used to enter data from the child survey (8-11 year olds) and the third should be used to enter data from the young person survey (12-15 year olds).

You will see that at the bottom of the Excel screen for each spreadsheet there are labelled tabs for each of the worksheets. The second of these tabs in the first spreadsheet is labelled "Data_0-7" and should be used to enter the data from the parent's survey (aged 0-7 years old). Click on this tab to show the data entry window. Data should be entered using the following guidelines:

- Each row records one patient's responses to the survey.
- Patients who are missing their patient record numbers should be added to the bottom of the list, and not matched to patients with similar demographics.
- For each question, the small number next to the box crossed by the patient should be entered as the response.
- If a response is missing for any reason, it should be coded as a full stop (.).
- If two boxes are crossed (where only one should be crossed), the response should be coded as a full stop (.).
- For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For the multiple response questions in the ABOUT YOUR CHILD section that give the instruction "Cross all that apply", each response option is treated as a separate question.

In the second workbook: the second tab is labelled "Data_8-11", which should be used to enter data from the child survey (8-11 year olds). In the third spreadsheet the second tab is labelled "Data_12-15", which should be used to enter data from the young person survey (12-15 year olds).

The three complete workbooks should be submitted to the Co-ordination Centre. Please don't submit any other worksheets as part of the workbook, such as those with formulas in, as the Co-ordination Centre will not need that information for analysis.

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 e.g. 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[6]

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**
Codes for this example	1	0	0	0	1	1	0

13.1 Entering the patients' written comments ("free text")

The CQC has asked the Co-ordination Centre to request all free text comments provided by respondents to the survey. Any analysis of these free text comments will be conducted in a way that would not allow individuals to be identified.

The questionnaires include a note to respondents to inform them that the comments will **not** be anonymised, to ensure that full use can be made of the detailed feedback. You may want to exercise discretion if a particular trust staff member is named in the comments, though we request that all patient feedback is respected and noted accordingly.

The comments should be entered in the main data file alongside the responses to all the questions and submitted to the Co-ordination Centre by **Friday 9th June 2017**.

[6] Please note: if a respondent does not answer any part of a multiple response question, (i.e. does not cross any of the response options) then it should be coded as a full stop (.)

13.2 Coding data

For the National Children and Young People's Inpatient and Day Case Survey 2016, raw ('uncleaned') data is to be submitted to the Co-ordination Centre. For clarification, raw data is created by the following:

1) 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).

2) Where a respondent has crossed more than one response category on a question, this should be set to missing in the data. The **exception** to this is for the 'multiple response' questions, where respondents may cross more than one response option.

3) Where a respondent has crossed out a response, this should not be entered in the data. Where a respondent has crossed out a response and instead crossed a second response option, this second choice should be entered into the data.

4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered.

5) Once the data have 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 Co-ordination Centre where they are found to have been entered inconsistently with the respondent's intended response.

A data cleaning document will be made available on our website (http://www.nhssurveys.org/surveys/1008) which documents all filtering and cleaning that will be carried out on the collated dataset by the Co-ordination Centre so that trusts can duplicate this process after submitting the raw data to the Co-ordination Centre.

13.3 Submitting data to the Co-ordination Centre

The data from the National Children and Young People's Inpatient and Day Case Survey 2016 must be supplied to the Co-ordination Centre via FTPs as anonymised, password protected Excel files that include information about the patient sample and responses. To comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre.

Required file format

Please submit the file to the following specifications:

- Use Microsoft Excel Worksheet (not Workbook). Any version of Excel is acceptable.
- The file names must be in the form <NHStrustName>_<SurveyVersion>_CYP2016.xls
- Use one row of data for each patient in the sample.
- Use one column of data for each item of patient information or response.
- Patients who are missing their Patient Record Numbers should be added to the bottom of the list, and not matched to patients with similar demographics.

- Missing data should be coded as a full stop (.). [7]

Table 2 shows the information that must be provided for each of the 1250 patients in the original sample.

Table 2: Data fields to be included in file submitted to Co-ordination Centre

Field	Format	Data codes	Comments
Survey Version	N	A= Parents Questionnaire (0-7yrs), B= Children's questionnaire (8-11yrs) , C= Young people's questionnaire (12-15yrs)	3 character trust code
NHS Trust code	NNN		
Patient record number	CYP16XXXNNNNN		The unique serial number allocated to each patient by the trust administering the survey.
Month of birth	NN		Format this simply as a number, not in date format.
Year of birth	NNNN		Format this simply as a number, not in date format.
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.).
Ethnic category	N	**National Codes:** **White** A British B Irish C Any other White background **Mixed** D White and Black Caribbean E White and Black African F White and Asian G Any other mixed background **Asian or Asian British** H Indian J Pakistani K Bangladeshi L Any other Asian background **Black or Black British** M Caribbean N African P Any other Black background **Other Ethnic Groups** R Chinese S Any other ethnic group Z Not stated	Ethnic category should be included if the information is available.

[7] Data may be missing for a number of reasons. The patient may have skipped a question or a set of questions by following instructions; a patient may have not answered for some other reason. However, all missing data should be coded as a full stop (.), regardless of the reason for the omission.

Field	Format	Data codes	Comments
Day of admission	N or NN	Format this field as a number, not a date	For example, if the patient was admitted on 14th November 2016, this column should read '14'.
Month of admission	N or NN	Format this field as a number, not a date	For example, if the patient was admitted on 14th November 2016, this column should read '11'.
Year of admission	NNNN	Format this field as a number, not a date	For example, if the patient was admitted on 14th November 2016, this column should read '2016'.
Day of discharge	N or NN	Format this field as a number, not a date	For example, if the patient was discharged on 29th November 2016, this column should read '29'.
Month of discharge	N	Format this field as a number, not a date	For example, if the patient was discharged on 29th November 2016, this column should read '11'.
Year of discharge	NNNN	Format this field as a number, not a date	For example, if the patient was discharged on 29th November 2016, this column should read '2016'.
Length of Stay	N to NNNN		For example, if the admission date was 15/11/2016 and the discharge date was 16/11/2016, the Length of Stay = 1.If the child is a day case patient, Length of Stay = 0.
Main Specialty of consultant on Discharge	NNN	Use the codes as provided by HSCIC to complete this field.	Only supply the 'Main specialty' (of consultant) for each patient on their DISCHARGE.
Treatment function code	NNN	Use the codes as provided by HSCIC to complete this field.	Use the three digit Treatment Function code.
CCG	NNN	Use the character codes provided by HSCIC to complete this field	Use the three characters of the CCG.
Treatment centre admission	N (0 or 1)	This flags whether the patient spent time in a NHS treatment centre at the trust.	If the patient spent any time as an inpatient in a treatment centre, this should be recorded as '1'; if they did not then it should be recorded as '0'.
Route of admission	NN	Please use the two-digit descriptive code provided by HSCIC to complete this data.	A blank or full-stop should be used if this information cannot be obtained for a patient.

Field	Format	Data codes	Comments
NHS Site Code on admission	NNNNN	Use the character codes provided by HSCIC to complete this field.	Use the five characters of the NHS site code.
NHS Site Code on discharge	NNNNN	Use the character codes provided by HSCIC to complete this field.	Use the five characters of the NHS site code.
Day of receiving questionnaire	N or NN	This is the day you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out).	For example, if the questionnaire was received on 15th February 2017, this column should read '15'.
Month of receiving questionnaire	N or NN	This is the month you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out).	For example, if the questionnaire was received on 15th February 2017, this column should read '2'.
Year of receiving questionnaire	NNNN	This is the year you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out).	For example, if the questionnaire was received on 15th February 2017, this column should read '2017.
Outcome of sending questionnaire	N	1 = Returned useable **paper** questionnaire 2 = Returned undelivered by the mail service or patient moved house 3 = Patient died after fieldwork had commenced 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire 5 = Patient was ineligible to fill in questionnaire 6 = Questionnaire not returned (reason not known) 7 = Patient deceased prior to fieldwork	Remember to fill in all the blank cells with the number 6 when the survey is complete.
Responses to each of the survey questions	N or NN or NNNN		Each column must be clearly headed with the core questionnaire question number. Data should be coded using the numbers next to the response boxes on the printed surveys.
Patients' free text comments:	Text		

To comply with the Data Protection Act,
the name and address details must NOT be sent to the Co-ordination Centre.

Table 3 below is an example of the columns of data to be included in the file. Your file should have up to 1250 rows (one for each patient included in your sample) spread out over the three tabs. You will notice that there are several blank cells in the response section of the file. This is because the file includes a row for every patient in the sample, but you will only have responses from patients who have returned a completed questionnaire, and who will therefore have an outcome code "1").

Additional information required

The following information should also be included when submitting the final data file to the Co-ordination Centre:

- **Contact details** (telephone numbers and e-mail addresses) of at least two members of staff (usually the main and secondary contacts) who will be available to answer any queries about the data.
- A completed copy of the **checklist** (see Section 13.4 below).

Delivery

Data must be sent via our secure File Transfer Protocol (FTP) facility. Please contact us directly in order to set up your access to the secure FTP by telephone on 01865 208127.

Hard copy documents should be posted to the address below:

2016 National Children and Young People's Inpatient and Day Case Survey
The Patient Survey Co-ordination Centre
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0JB

E-mail: cyp.cc@PickerEurope.ac.uk

Deadline for submission

The data must be supplied by **9th June 2017.**

Table 3 – Example of data file to be submitted to Co-ordination Centre

Patient Sample Information | **Patient Response Information**

Survey Version	NHS Trust Code	Patient record number	Month of birth	Year of birth	Gender	Ethnic category	Day of admission	Month of Admission	Year of Admission	Day of discharge	Month of discharge	Year of discharge	Length of Stay	Main Specialty of consultant discharge	Treatment function code	CCG code	Treatment centre admission	Route of admission	NHS Site code on admission	NHS Site code on discharge	Day of questionnaire being received	Month of questionnaire being received	Year of questionnaire being received	Outcome	Q1	Q2	.....	Q53	Was there anything particularly good about your hospital care?
B	RT5	CYP16ABC00001	6	2006	2	A	5	11	2016	11	11	2016	6	120	254	10Q	0	12	RR115	RR115				3			-		
B	RT5	CYP16ABC00005	8	2006	1	J	1	11	2016	12	11	2016	11	101	256	10Q	1	11	RTE03	RTE03	22	2	2017	1	1	1	-	1	I was seen straight away
B	RT5	CYP16ABC00020	1	2006	2	C	5	11	2016	11	11	2016	6	110	213	09Y	0	21	RR115	RR115				3			-		
B	RT5	CYP16ABC00065	11	2006	1	Z	2	11	2016	12	11	201	10	420	211	08L	1	11	RTE03	RTE03	22	2	2017	1	2	1	-	1	The nurses were very helpful
																											-		
B	RT5	CYP16ABC00849	5	2006	2	R	17	11	2016	30	11	201	13	130	218	08L	0	11	RR115	RR115				6			-		
B	RT5	CYP16ABC00920	7	2006	2	A	30	11	2016	30	11	2016	0	120	220	09Y	0	22	RR120	RR117	6	2	2017	1	2		-	2	The staff were great!

13.4 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below in Table 4, and include this checklist when you submit your final data file (the checklist can be found on the NHS Surveys website at: http://www.nhssurveys.org/surveys/1061

It is essential that these checks are carried out thoroughly. The Co-ordination Centre is not obliged to make any corrections to data supplied.

If incorrect data are submitted, it is possible that the data will be considered unreliable and will not be used by the Care Quality Commission in its assessment for the trust. We cannot accept re-submissions of data after the deadline, and likewise data are unlikely to then be included in the Care Quality Commission assessments.

Table 4: Checklist

Check	Done?
1) Check that your file names follows the naming convention: <Trust name>_SurveyVersion_CYP2016.xls)	
2) Check that you have saved the data sheet only as an Excel worksheet, rather than a workbook. (The frequency and percentage counts on the other pages of the workbook on the website are intended for your use only)	
3) Check that you have included data columns for **all questions from each survey** and **patient written comments**	
4) Check that all data are correct, and that all values are in range	
5) Send data only for the **1250 patients** sampled from the trust	
6) Check that all the data (excluding written comments) are in **NUMERIC** format only, including dates, which should be entered as separate numeric fields for day, month and year.	
7) Check that you have completed the columns for the day, month and year you received the questionnaire back from patients	
8) To comply with Data Protection regulations, any patient name and address details must be removed before the file is sent to the Co-ordination Centre	
9) Zip, encrypt and password protect your data before uploading it to the Co-ordination Centre **secure FTP site** (please contact the Co-ordination Centre if you need help doing this).	
10) Notify the Co-ordination Centre of the **password separately** from the data file	
11) Include **telephone and e-mail contact** details of two people who will be available to respond to any queries about the data	

14 Making sense of the data

The usefulness of your survey data will depend on how well you plan the survey process and on how effectively you analyse the data. Standard data analysis usually involves examination of the frequency of responses to each question and some cross-tabulation of responses against demographic and other information.

14.1 Suggestions on data analysis

The following suggestions may help you make the data analysis more useful and focused.

Use the data to help pinpoint problems

It is often tempting to focus on organisational strengths. This may be important for public relations and employee morale. However, if you emphasise only the positive, you may miss a critical opportunity to use the data to spur improvement.

One way to focus attention on where improvements are needed is to analyse responses in terms of the proportion of answers that suggest a problem with care. Try to maintain high standards in determining what constitutes a problem For example, if questions allow respondents moderate response categories (such as "to some extent" or "sometimes"), in addition to more extreme ones ("always" or "never"), your analysis will be more powerful if you identify these moderate responses, as also indicating a problem.

"Drill down" into the data

It is impossible to analyse absolutely every issue a patient survey raises. One reasonable way to control the number of analytical questions is to conduct a staged analysis.

The **first** level of analysis should be the most general - for example, summary measures or measures of overall performance. The next level should delve into particular issues that underlie the summary measures - performance along particular dimensions of care, for example, or of particular units or staff. The final level should entail statistical or cross-tab analysis to get at the causes of the particular issues.

Group similar questions together to provide summary analysis

Analysing questions and presenting findings in a way that is comprehensive, logical and not overwhelming is a significant challenge. To make the data more compelling for others, and to speed up the analysis, we suggest:

- Linking questions that cover similar topics or processes
- Combining several questions into a single composite measure (by averaging responses, for example)

Use statistical tests to make comparisons and subgroup analyses

Statistical tests can be used to examine relationships and associations between groups (for example age, sex or ethnic categories). These tests take into account the number of responses, the variation in responses, and values of the items you are comparing (such as average responses). If tests show that the differences between two groups are not statistically significant, you should view the patterns of responses as only suggestive[8].

Calculate confidence intervals to give an indication of the uncertainty surrounding your results

Although there are many methods of describing uncertainty, confidence intervals[9] are used most often. By taking into account the number of responses, the variation in response, and the magnitude and direction of the estimate, the confidence interval describes the range of plausible values within which the "true" value for the population is likely to fall. Remember that the estimate itself is the most likely result, and this is therefore your best estimate, not the limits of the confidence interval.

Make use of the free text

Patients' comments on the questionnaire can provide valuable feedback about their experiences. Such data illustrate responses to closed questions and allow respondents to identify new issues not captured elsewhere in the questionnaire. It can be effective to group comments made about similar topics to identify themes in patients' experiences.

Any information that could allow respondents to be identified, such as patient and staff names should be removed.

Use patient feedback data with other data

Patient feedback data provides one valuable source of information about how patients experience and feel about the health services they receive. Linking feedback data with clinical data, outcomes data, and routinely collected data, when done appropriately, can provide useful insights.

Perform analysis by sub-groups

You may want to compare the answer to a survey question between two different groups to see if the differences are significantly different (e.g. the answers for men versus women). However, comparing results *within* your trust considerably reduces the number of responses in each group. This will impact upon the level of confidence you have in the results and, therefore, your ability to accurately detect differences between these groups.

[8] **Statistical significance** is the degree to which a result is substantially different than would be expected by chance alone. For example, if the difference in data for a question from two survey years is statistically significant, this means that there has been a true change in the results that cannot be attributed solely to chance.

[9] A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the trust mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made

Table 5 (below) shows the level of confidence you would achieve for various numbers of respondents.

Table 5: Confidence intervals*

Number of respondents	Widest Confidence Interval (+/-)[10]
50	13.9%
100	9.8%
200	6.9%
300	5.7%
400	4.9%
500	4.4%
600	4.0%

*at a 95% confidence level

If you are interested in looking at different sub-groups within your trust population (for example, different ethnic groups), you will need to think about the number of respondents you need in each group, and how this will impact on the confidence you can have in the results. The Co-ordination Centre recommends a minimum of 100 respondents per group for comparison between sub-groups. Confidence intervals for analysis with groups of fewer than 100 respondents will be so large that there would be little certainty of detecting reliable statistical differences.[11]

Example: How confident you can be in your results?

For a trust, 400 patients responded in total. Taking a particular question, of which 50% of respondents answered '*Yes*', from the table we can see that the widest confidence interval for 400 respondents would be +/- 4.9%. We would therefore be 95% confident that the true results would be between 45.1% and 54.9% - that is, if you had surveyed the entire population of attendances at a trust.

However, if we are looking at the results for this particular question *by eight different groups of patients* (assuming an equal number of respondents in each region), there would only be 50 respondents in each group. If there are 50 respondents and 50% answered '*Yes*', the confidence interval would be +/- 13.9%, so the true results could be between 36.1% and 63.9%.

[10] This column (the widest confidence interval) shows the **maximum** margin of error for binomial estimates of proportions

[11] A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the trust mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made.

15 Reporting results

15.1 Prioritising your findings

Patient surveys can raise many compelling and important issues. To help you decide which issues to focus on first, you may like to consider the following suggestions:

Rank results by their magnitude

The most straightforward method of prioritising is to rank issues in order of the size of the problem and to focus first on those that are the greatest.

Compare your results against outside norms or benchmarks

A common method of prioritising is to select issues that compare unfavourably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Compare your trust's results with the benchmarks on the NHS Surveys website (www.nhssurveys.org) to find out where your trust performs better or worse than other trusts. These will be available when the survey is published by CQC.

Compare results within your organisation

Comparisons within organisations can facilitate networking among units or departments and the sharing of information about effective practices. Internal 'competitiveness' may also fuel improvement efforts. You will need to ensure that you have collected this information in your sample fame.

Comparison with predefined goals

Another way to identify priorities is to set threshold or target goals prior to the survey. You would then focus on issues where performance does not meet these goals. This method is particularly effective when there is clear consensus on what those goals should be.

Correlation with overall measures

Correlating patient responses to specific questions with responses to the question about overall quality of care can help focus attention on issues that are important for patients.

Predictive value on overall measures (regression analysis)

Similar to correlation, regression analysis also gives a sense of the issues that most sharply affect patients' overall assessments of care. Regression analysis is superior to simple correlation, in that it can adjust for other things that have an impact on the overall measure, and it provides more precise estimates of how overall measures will change in response to improvement on individual items. Regression analysis is also more complex but in essence, it allows for a more level 'playing field'. There are limits to a univariate (crude) analysis and so regression analysis is an attractive option.

Ease of action

Many organisations focus initially on the issues that are easiest to improve. By demonstrating successful interventions, this prioritisation method can rally support for more difficult improvement efforts later on.

Areas of excellence

An organisation may also want to maintain excellence in areas where it is already perceived to be doing well. This approach can provide a clear and positive focus for clinical and administrative staff.

15.2 Writing the report

User-friendly reports that enable readers to understand and begin to take action on key issues are critical to the success of any survey project. The following suggestions will help you produce useful reports:

Tailor the document to the audience

- Use brief, succinct summaries for executive audiences.
- Use comprehensive summaries for those who will implement improvements. They will help achieve buy-in and generate action.
- A separate resource booklet or data disks/CD-ROMs with full details may be important if staff or researchers have questions.

Use graphics

- Data that are displayed visually can be easier to interpret.
- Display trends or comparisons in bar charts, pie charts, and line charts.
- Remember that colours don't photocopy or fax very well.

Keep the format succinct and consistent

- Graphics, bullets, tables, and other visuals help guide the reader.
- Choose a few of these elements and use them consistently.
- Too many types of visual elements can detract from the message.
- Be consistent in the use and appearance of headers, fonts, graphic styles and placement of information.

Emphasise priorities clearly

- Emphasise the highest priority items for action or commendation in executive summaries and major findings sections.
- Highlight the most important items - for example, use bold type.

Appendix 1

Table 6: Responsibilities of NHS organisations that are carrying out research

Research Governance Framework	**Care Quality Commission sponsored patient surveys**
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	*The survey is carried out on the experiences of patients after they have received the care so this does not apply.*
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	*All Chief Executives are informed of the proposals of the survey. Trusts should notify their Research and Development Managers of the survey.*
Ensure patients or users and carers are provided with information on research that may affect their care.	*The survey does not adversely affect the care of individual patients. Anonymised results are used by the Care Quality Commission, the Department of Health and NHS England for performance assessment purposes, and for local quality improvement initiatives. Detailed guidance is issued to survey leads regarding the publicity of the results and its impact on patient care.*
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	*This requirement is not specific to this survey.*
Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	*The Care Quality Commission as sponsors of the study have sought ethics approval from MREC. There is a designated lead for each survey who is appointed by the Chief Executive.*
Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	*The Care Quality Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in Section 3.8 of the Research Governance Framework are followed thoroughly.*
Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	*Detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.*
Maintain the necessary links with clinical governance and/or best value processes.	*The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.*

Continued...

Research Governance Framework	Care Quality Commission sponsored patient surveys
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities.[12]	*In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an appropriate contract with the trust. These procedures are specifically detailed in the guidance notes.*
Put and keep in place systems to identify and learn from errors and failures.	*The Care Quality Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Care Quality Commission. The survey programme is constantly evaluated and reviewed in light of these.*
Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	*This requirement is not specific to this survey.*
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	*The Care Quality Commission maintains a helpline facility, which can be used by patients or trusts to report any complaints. Similar arrangements are in place with the Co-ordination Centre who are commissioned by the Care Quality Commission to co-ordinate the patient surveys.*
Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	*Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.*
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	*The results of the surveys are used for monitoring of trusts performance by the Care Quality Commission*

[12] When universities and hospitals employ staff on joint or dual contracts, they are expected to make joint arrangements for accountability and management. See: *A Review of Appraisal, Disciplinary and Reporting Arrangements for Senior NHS and University Staff with Academic and Clinical Duties*, a report to the Secretary of State for Education and Skills by Professor Sir Brian Follett and Michael Paulson-Ellis, September 2001 (The Follett Report).