



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

FOR TRUSTS USING AN APPROVED
CONTRACTOR

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 is 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

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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 approved contractor organisations 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. Please also note that any results you receive from an approved contractor are valid results and can be used to improve services. However, they are not the official survey results for your trust which will be published by the CQC. Any comparisons included in the report from your approved contractor have not been made against all other trusts that took part in the survey nationally, but only against those trusts that used that particular contractor.

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

1.8. Basic requirements for the National Children and Young Survey 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:

- You should already have contacted the Co-ordination Centre to tell them who is carrying out your survey (i.e. whether it will be carried out by an approved contractor and, if so, which contractor). Please do this by e-mail: 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 7](#) **Compiling your patient sample**
- 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 the person drawing the sample and the Caldicott Guardian. The completed form can be (1) sent to your contractor 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 contractor must confirm that the form has been completed satisfactorily before a trust can submit their sample. **Please note**, sample data does not need to be split in two (sample file and mailing file) but can be sent to your contractor as one single file containing both sample and mailing data).
- Sample data - your anonymised 'sample file' will be submitted to the Co-ordination Centre for final checks before mailing by your survey contractor. Sample files should be submitted **to your contractor between Tuesday 16th January and Friday 27th January 2017**. Submitting near the start of this period will allow sufficient fieldwork period to maximise your response rates.
- You should aim to obtain the highest response rate possible. However, 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.
- Your contractor will be responsible for using all the required survey documents, however, you can access these for information on the NHS Surveys website here: <http://www.nhssurveys.org/surveys/953>
- 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 instruction manual explains what your trust needs to do for the preparation and implementation of the survey, when you are using an approved contractor. This manual only covers the parts of the survey process that your trust is involved in. Your contractor will have additional information to make sure that they fulfil the requirements of the survey, such as submitting sample files to the Co-ordination Centre, survey mailings and coding the data.

Please ensure you are familiar with all aspects of this instruction manual, but in particular, the sections on drawing the sample, on data protection and on section 251 requirements.

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 month (and the sampling method) means that **historical comparisons will not be possible** for this year's 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 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 less 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 of 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 is still able to be used despite the error
- A **major error** is so serious that data for a trust is 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. It will also be necessary to establish appropriate contractual arrangements with any contractors. Your trust's Caldicott Guardian and legal advisors should be able to advise you on these matters.

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 <https://ico.org.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](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

The framework agreement between the approved contractors and the Care Quality Commission contains clauses stating that the approved contractor will comply with the Data Protection Act so no declaration is required if a trust appoints a contractor. The contractors' procedures and policies have also been reviewed as part of the recommendation for support under Section 251 of the NHS Act 2006, granted by the Health Research Authority (HRA) Confidentiality Advisory Group. This includes ensuring each have completed the relevant sections of the Information Governance Toolkit.

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

Approval for the NHS 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.

Due to the requirements of this survey's Section 251 Approval, contractors will be required to 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.

It is very important that you follow the instructions set out in the survey instruction manual so as not to breach this approval, or related data protection requirements. If CQC become aware of a breach of the section 251 approval they are obliged to take the following steps:

- Inform the Confidentiality Advisory Group of the breach;
- Inform the relevant CQC Inspector. All breaches will be considered by inspectors as a breach of regulation 20 (Records) and inspectors will make a decision as to whether enforcement activity is required.

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. Extending your sample and / or collecting additional sample variables and Section 251

Please note that the application for Section 251 approval has been made by the CQC on behalf of all trusts for a **standardised survey only**. If your trust would like to do anything in addition to this, such as increasing their sample size, or including extra sample variables outside of the requirements specified in this instruction manual, it is important to note that this is **not covered by the section 251 approval. You must consult the Caldicott Guardian at your trust for advice as to whether it is appropriate to contact the Health Research Authority for further section 251 approval.** You should also ensure that you have appropriate contractual arrangements in place to ensure the secure transfer of additional data.

4.4. Mailing questionnaires to patients

When working with approved contractors, trusts must be aware of any implications for data protection when deciding who should mail out the questionnaires. There are two common methods practised by trusts, and advised by the Care Quality Commission, when working with approved contractors:

1. **The contractor mails out the questionnaires.** If a contractor is going to be mailing out questionnaires on behalf of a trust, this will require the trust to share patient name and address details with their approved contractor. This method is only possible if the contractor is carrying out the work under a service contract, which can be set up with the agreement of the trust's Caldicott Guardian. The Care Quality Commission has provided the template service contract for trusts and approved contractors carrying out the survey, to avoid the need for each trust to develop its own arrangements. It is strongly recommended that these documents are reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required. When personal data is shared with contractors, trusts must adhere to the

principles outlined in Sections 4.5 and 4.6 below. When the patient details are shared with the contractor the instructions regarding how to share this data must be followed at all times.

2. **The trust mails out the questionnaires.** If a trust has not signed a service contract with a contractor then they will have no recourse if any breach of the contract were to occur. In this case the trust must conduct the survey mailing in-house. The contractor will deliver pre-packed envelopes (clearly marked with the patient record number) containing questionnaires, covering letters and FREEPOST envelopes to the trust. The trust must then attach number-matched address labels to the envelopes and send them out to patients. Completed questionnaires can then be returned to the contractor and, by checking the record numbers on returned questionnaires, they can inform the trust which patients need to be sent reminders.

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. Sharing personal data (patients' names and addresses)

Please note that under the data protection guidelines for patient surveys, the following principles must be followed:

- Trusts/contractors must undertake to keep their products up to date to ensure that security is effective and must strictly observe the following guidance. The requirements that dictate the guidelines include the Data Protection Act 1998, the Health and Social Care Act (Community Health and Standards) Act 2003 and the NHS confidentiality code of practice 2003 (which incorporates the Caldicott principles), see: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf.
- Personal data such as names and addresses must be sent by trusts to contractors securely (please see further details below).

Trusts transferring files must use the agreed FTP sites, with files encrypted. Please ensure that the relevant members of staff at your trust have completed the sampling declaration and checklist, and signed them. These documents are to be sent to your approved contractor before you are able to submit your sample. Once your approved contractor has checked your sample, both the sample declaration form and the anonymised sample file will be submitted to the Co-ordination Centre by your approved contractor. Sample files will not be accepted before the signed sample declaration form has been approved. The completed form can be (1) sent to your contractor 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 Co-ordination Centre will use these documents to help check your sample file.

4.6. Encryption of personal data

Any patient identifiable information sent between trusts and contractors 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)³. Approved contractors should be able to provide guidance to trusts on the use of an encrypted session.

4.7. Contractor responsibilities (service contract)

A service contract has been drafted by the Care Quality Commission for use in the NHS Patient Survey Programme. By signing it, the approved contractor is obliged to keep information confidential at all times and to comply with the Data Protection Act 1998. The contract describes how patients' personal data will be sent to the approved contractor and how the data can be used. It provides the trust with some recourse if any breach of the Data Protection Act were to occur, as a result of the actions of the approved contractor. The document also ensures that approved contractor staff members sign and abide by the contract.

The service contract in Word format is available on the NHS Surveys website:
<http://www.nhssurveys.org/surveys/1011>.

The service contract is designed to be used as a template contract; trusts and approved contractors may agree on amendments to the wording and content when using them.

4.8. 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.

Patient anonymity can be achieved if there is a clear separation between the information seen by an approved contractor and the information held by the trust. Patient names and full addresses will be seen by trust staff when generating the sample, while contractor staff will usually possess both sample member details and patient responses. As long as the response data supplied to trusts do not include unique record numbers or any other detail that allows patients to be identified or linked, it can reasonably be claimed, with regard to the trust and trust staff, that patients responses are anonymous.

4.9. 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's 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) Approved contractors must not provide raw data to the trust as a matter of course.
- 2) If you have a particular need for the raw data collected by the survey, the contractor may provide an abridged version of this dataset to the trust upon request, providing that the steps below are undertaken first:

³ <http://www.winzip.com/>

- a. The contractor must delete the two variables pertaining to ethnicity (e.g. both sample and response variables).
- b. The contractor must delete the responses to the questions in the 'ABOUT YOUR CHILD' section of the questionnaires pertaining to the respondents' religion.
- c. The contractor must band year of birth into three age groups (0-7, 8-11, 12-15). This process should be repeated separately for both sample and response variables. The date and year of birth variables (e.g. those specifying an exact birth date and year rather than age group) must then be deleted
- d. Additional information specific to a survey that can be used to identify individual patients must be removed. For example, department type, CCG, NHS site code, treatment function code must be removed.
- e. Free text comments do not need to be anonymised, as a statement in the questionnaire states that any information provided in the free text box will be looked at by trusts, the CQC and researchers. If you are publishing the comments, any comments that are published must have any identifiable information removed such as a patients or members of staff names, ethnicity, condition or health details.
- f. Admission and discharge dates in the survey must be removed, but length of stay can be calculated from the admission and discharge dates and provided to trusts. Route of admission to hospital does not need to be excluded unless the trust had fewer than 30 respondents.
- g. The contractor must have received confirmation from the trust that the names and addresses of the sampled patients have been destroyed; otherwise they will be able to identify individual patients by matching up the patient record numbers on the name and address list to those in the raw data file.

These steps MUST be followed before supplying raw data to trusts. This is to prevent the disclosure of a patients' identity by specific demographic factors. Different arrangements govern the supply of raw data to the Co-ordination Centre. The arrangements are described in full in the sampling handbook. The response data will be anonymous when passed to the Co-ordination Centre and Care Quality Commission, and published and archived results will not identify patients.

- 3) 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 example in Table 1. In this case, responses for the 'Mixed' and 'Asian' ethnic categories are suppressed (though the subgroup totals are shown)
- 4) Do not present response information 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 of a small number of patients, make sure that it will not be possible for the reader/audience to identify individual patients from their responses.

Table 1: Suppressing Data

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

- 5) The electronic file containing the patients' names and addresses should be stored securely (i.e. password protected).

Sharing of survey data between contractors

If a trust will be using a different approved contractor than in the last survey year, contractors are permitted to transfer an unabridged version of the data set if there is a clear need to use the data from the previous year's surveys to allow year-on-year comparison. You will need to give your new contractor written permission to request this data from the Co-ordination Centre.

Storing sample and mailing information

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.

5 Ethical Issues, Ethics Committees and Research Governance

5.1. Ethical Approval

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/953>). 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 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 (and send this to your contractor for checking between 16th January and 27th January 2017) and ensure your questionnaire packs are mailed out promptly once permission has been received. Ensuring your survey results are representative of your patients will create more value for the survey.

The approved contractor will carry out many stages in the process but you will still have to be involved in some of them. Your approved contractor for the survey will provide you with a timetable that might differ slightly to the suggested time periods below. As long as the specified three mailings take place and data is submitted to the Co-ordination Centre no later than the **2nd June 2017** the timetable provided by the contractor should take precedence over the below.

6.1. Key Dates

Inform Co-ordination Centre who is carrying out survey	16 th December 2016
Draw your sample (you should begin as soon as data from the previous month become available)	9 th - 20 th January 2017
Submit sample to contractor and respond to queries	16 th – 27 th January
Contractor submit sample to Co-ordination Centre	16 th Jan – 3 rd Feb 2017
Fieldwork starts	30 th January 2017
Close of fieldwork	2 nd June 2017
Submission of data to the Co-ordination Centre	9 th June 2017

7 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 all 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.

7.1. 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 7.2, below.

If you 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 is a day case patient, 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**

7.2. Removing duplicates: Tab 1

➔ **If you have already removed duplicate patients from your patient list, please skip to the following section, 7.3 ‘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 month; 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 all 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.

7.3. 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)⁴.

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

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.

⁴ 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.

- 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.

7.4. 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**.

7.5. 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 7.6

- **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 mailings, and to ensure that approved contractors are advised immediately if any patients in the sample die during the survey period.

- **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.** 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.**

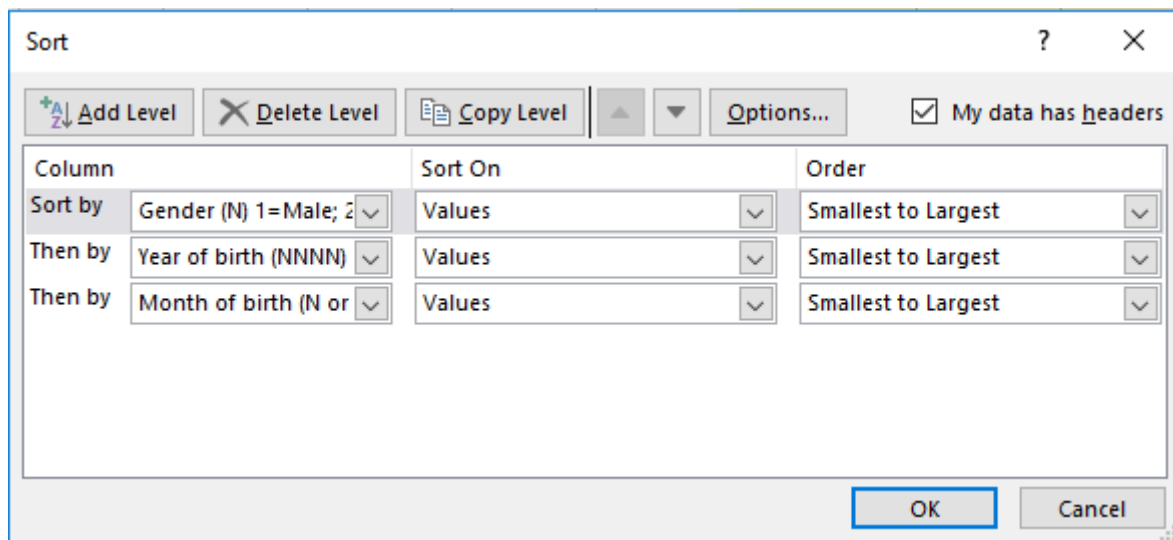
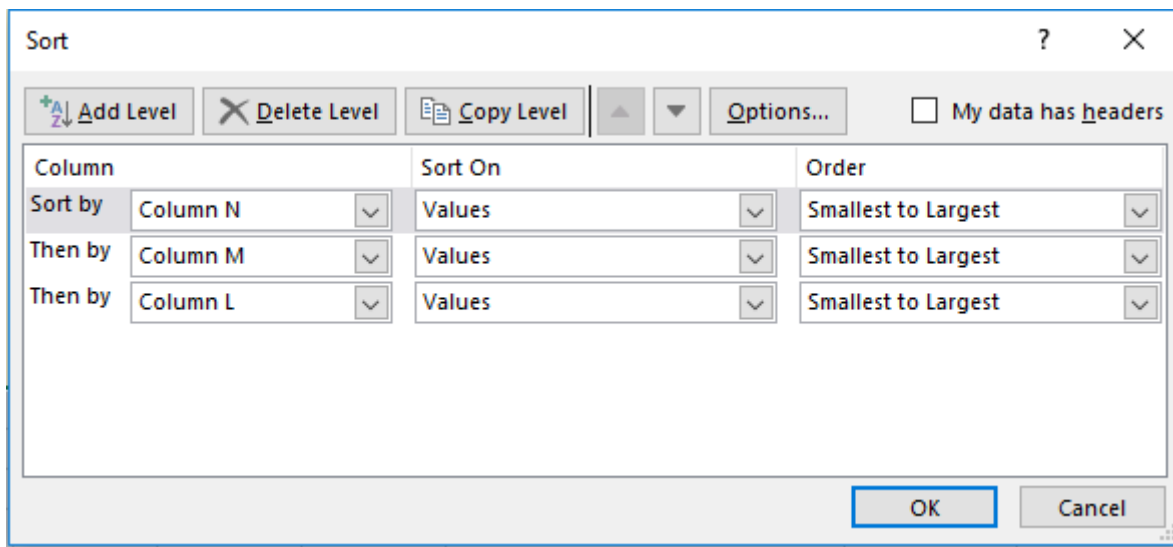
7.6. Sorting and numbering your eligible patient list in Workbook 1: Tab 1

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 all 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 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.

7.7. Creating the sample in Workbook 1: 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 is based on each patient’s 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 counted as version A, all patients born between 2005 and 2008 will be counted as version B, and all patients 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 yellow 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
<input type="checkbox"/>	<input type="checkbox"/>
	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

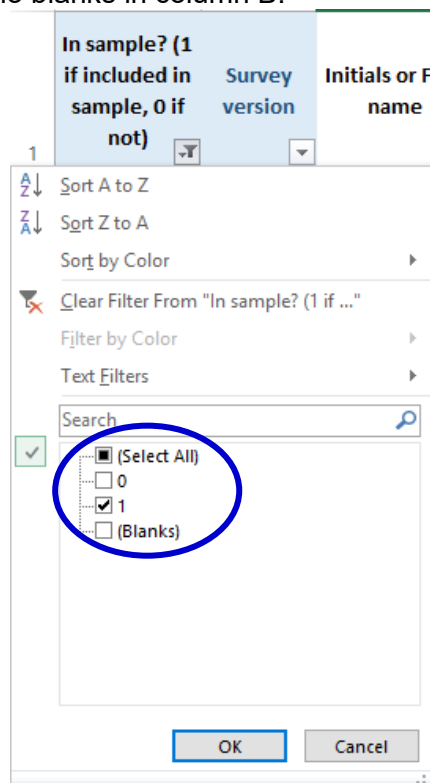
- **If your trust has more than 1250 eligible cases in total, but less than the target sample size for one or two of the survey versions:**
 - All patients from the survey version(s) with less than the target number of cases will be included.
 - The workbook will automatically increase the number of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

7.8. 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’**, then follow the steps below to complete the final checks on your sample.

7.9. Checking for sampling 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 help 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.

7.10. 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 the person drawing the sample and the Caldicott Guardian. The completed form can be (1) sent to your contractor 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 contractor must confirm that the form has been completed satisfactorily before a trust can submit their sample. 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.

7.11. Sharing the patient sample file with an approved contractor

Once you have received confirmation that your sample declaration form is approved, you will need to submit your sample file to your contractor. This **must be sent to the contractor staff in encrypted format via their FTP**.

In previous years, it has been a requirement for trusts to separate the mailing and sample information before sending this to their contractor. As this led to a number of errors in trust data, it has now been agreed with the Confidentiality Advisory Group that this separation of mailing and sample data will be done by the contractor rather than the trust. This means that **you will send your contractor a single file containing all the mailing and sample information** – this file will be the one called 'CYP16_< trust code>_sample' created in section 7.8 above.

However, if you are working with an approved contractor but have chosen to mail out the questionnaires yourself, in-house, you should supply them with a copy of this sample file with all personal data (names, surnames, addresses) **removed**. If you are doing this, please ensure the record number is kept the same in both versions of the file. The contractor can use this file to record the outcome codes, but you should ensure that the contractor is kept up to date with any information that comes directly to the trust about patient deaths, etc.

Please note: trusts must only send the sample and mailing data for their final sample to their contractor. Approved contractors are not permitted to draw the sample for trusts - this will be considered a breach of the survey's Section 251 approval and action taken against both the trust and approved contractor will follow.

If records need to be replaced following contractor checks

If any records need to be replaced following contractor checks (before the sample has been submitted by the contractor to the Co-ordination Centre), for instance, if the contractor notices any records with insufficient address details, the trust should follow the below process to identify the replacement record:

- 1) Look at their saved version of workbook 1 tab 2
- 2) If this tab has a filter applied to column A, change this so that all records are visible (both 1s and 0s in column A)
- 3) Locate the record that has to be removed from their sample
- 4) Find the next record down the list from this that has a 0 in column A (i.e. was not included in the sample the first time around) and is the same survey version as the record that needs to be removed (i.e. if the record being removed is survey version B, another version B record should be added).
- 5) Add this record into their sample file to replace the one they needed to remove.

Sample submission deadline

Contractors need to have submitted the sample data to the Co-ordination Centre no later than **Friday 27th January 2017**. If they 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.

If your sample is late to be submitted, you may be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. If samples are not received within a reasonable timeframe, we will need to notify CQC of this, and they may contact you/the contractor to discuss any implications for inclusion in CQC produced data.

7.12. 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. 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.

7.13. Summary of steps

By following the instructions above, you should have completed all of the tasks set out below:

1. Compiled a list of eligible patients (Section 7.1).
2. Removed duplicates (Section 7.2)
3. Sent the list to the DBS to check for deceased patients and removed these patients from your list (Section 7.3 and 7.4)
4. Checked your patient list to make sure it meets requirements and only includes eligible patients (Section 7.5).
5. Sorted the eligible patient list and added record numbers (Section 7.6)
6. Selected a patient sample, closely following the instructions (section 7.7)
7. Created the final sample file (Section 7.8)
8. Checked the final sample for errors (Section 7.9).
9. **Completed the sample declaration form** (see section 7.10) and received approval **before** sending your contractor your sample file. **Do not send the sample file before your sample declaration form has been approved.**
10. Shared the sample file with your approved contractor (section 7.11).

Remember: trusts will NOT be permitted to submit any files to an approved contractor with more than 1250 records (maximum), from which the contractor 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 contractor to draw the post DBS sample on behalf of the trust.

8 Materials

8.1. Questionnaires, covering letters, and information leaflets

Your contractor will produce all the survey materials for you using the standard templates. They will discuss any concerns with the Co-ordination Centre.

Questionnaires

Each trust must use the core questionnaires as provided by the Co-ordination Centre. There are 3 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/young person 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 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 contractor or trust logos are to appear on the questionnaire versions.

Covering letters and information leaflet

The covering letters and information leaflets can be downloaded from the NHS Surveys website. Your contractor will be responsible for producing these documents for you.

8.2. Trust headed paper

You will need to use headed paper from the trust for covering letters for all three mailings. Therefore, depending on your sample size and response to the initial mailings, you will need up to around 3300 sheets of trust headed paper. It is preferable that the paper does not include a telephone number for the trust, as patients should call the contractor's FREEPHONE line, rather than the trust.

You will need to provide the headed paper to your contractor so they can complete the mailings for you. No deviation from the wording in these letters is possible due to the ethical approval given to the survey materials.

8.3. Reminders

As per the standard methodology for this survey, two reminders will be sent to non-responders throughout the course of fieldwork. Your contractor will manage this process for you but you will need to check your sample list against local records for deceased patients before each of these reminder mailings, your contractor will advise you when to do this.

As standard, before the second and third mailings are sent out, you should **check the sample list for any further deceased records**. It is likely that your approved contractor will inform you of the mailing dates for your trust: you must send the full sample list to DBS prior to the second and third mailings and inform your approved contractor of any deceased records. Please ensure that you allow sufficient time to provide this information to your contractor otherwise the mailings for your trust may be delayed.

9 Appendix 1:

Table 2: 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.	<i>The survey is carried out on the experiences of patients after they have received the care so this does not apply.</i>
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.	<i>All Chief Executives are informed of the proposals of the survey. Trusts should notify their Research and Development Managers of the survey.</i>
Ensure patients or users and carers are provided with information on research that may affect their care.	<i>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.</i>
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	<i>This requirement is not specific to this survey.</i>
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.	<i>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.</i>
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.	<i>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.</i>
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.	<i>Detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.</i>
Maintain the necessary links with clinical governance and/or best value processes.	<i>The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.</i>

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. ⁵	<i>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.</i>
Put and keep in place systems to identify and learn from errors and failures.	<i>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.</i>
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.	<i>This requirement is not specific to this survey.</i>
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	<i>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.</i>
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.	<i>Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.</i>
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	<i>The results of the surveys are used for monitoring of trusts performance by the Care Quality Commission</i>

⁵ 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).