

GUIDANCE MANUAL FOR THE 2014 NATIONAL NHS CHILDREN'S INPATIENT AND DAY CASE SURVEY

THE CO-ORDINATION CENTRE FOR THE
NHS PATIENT SURVEY PROGRAMME

Guidance for trusts using a contractor

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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. Please note that trusts using a contractor which deviate from the guidance will no longer be covered by Section 251 approval which has been sought for this project. For example, trusts must not send patient identifiable data such as patient names and/or addresses to the Co-ordination Centre. It is also not permitted to offer financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages within the national survey. More guidance on how to reach ethnic minority groups can be found in Section 8. 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 Care Quality Commission 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.

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 email 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 (CQC) is the independent regulator of health and adult social care in England and is responsible for administering the programme. CQC regulates care provided by the NHS, private companies and voluntary organisations. We aim to ensure that better care is provided for everyone . in hospitals, care homes and people's own homes.

As set out in our statement of involvement, Putting people first¹, 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 CQC's work: CQC and the Co-ordination Centre for this survey both aim to make sure that better care is provided for everyone.

By ensuring that organisations carry out these surveys in a consistent and systematic way it is possible to build up a national picture of people's experience and, *with care*, 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 NHS Patient Survey Programme, of which the 2014 National NHS Children's Inpatient and Day Case Survey (2014 Children's Survey) is part, is based at Picker Institute Europe and works under contract to the Care Quality Commission to design, test, and co-ordinate the surveys in the NHS 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 dimension 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 manual is designed to help staff in NHS hospital trusts to obtain patient feedback through the 2014

¹ http://www.cqc.org.uk/sites/default/files/documents/cqc_putting_people_first_tagged.pdf

National NHS Children's Inpatient and Day Case Survey. It also provides guidance on how you may use the information you gather in quality improvement programmes and for monitoring performance. By following this guidance, you will also help to ensure that the survey results from your trust are comparable with other trusts, and with national benchmarks.

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. 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 Care Quality Commission's programme of reviews and inspections.

By ensuring that organisations carry out the survey in a consistent and systematic way it will be possible to build up a national picture of children's experience and, with care, to compare the performance of different organisations, monitor change over time, and identify variations between different patient groups. This will in turn lead to improvements in overall child and younger patient experience.

1.5 Care Quality Commission assessments

Information drawn from the questions in the 2014 National NHS Children's Inpatient and Day Case Survey (2014 Children's Survey) will be used by the Care Quality Commission (CQC) in its assessment of trusts in England. Questions from the survey will be used within CQC's Intelligent Monitoring system¹ and within CQC's inspections of children's services.

1.6 Measuring performance over time

In addition to the performance assessment, the Care Quality Commission will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data. Asking each hospital trust to carry out the survey in a consistent way builds a detailed picture of patients' experiences in NHS hospital trusts. Information collected nationally in a consistent way is also essential to support public and Parliamentary accountability. The results are also used by NHS England and the Department of Health (DH) for performance assessment, improvement and regulatory purposes.

¹ <http://www.cqc.org.uk/public/hospital-intelligent-monitoring>

The Care Quality Commission intends to archive the survey data with the UK Data Service 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 2014 Children's Survey should not be released outside of the trust until the national results are published by the Care Quality Commission.

1.8 Basic requirements for the CYP 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:

- Let the Co-ordination Centre know your two trust contacts, their job titles, phone numbers and email addresses as soon as possible, and no later than **22nd August 2014** to allow us to communicate vital information about the 2014 Children's survey to you (e-mail: CYP.data@pickereurope.ac.uk). Please also ensure that you tell the Co-ordination Centre which contractor is running the survey on your behalf.
- The survey must be carried out using postal questionnaires - however you will also have the option of being able to offer an online version of the survey online alongside the postal version.
- There are 3 core questionnaires for this survey: 0-7 year olds (parents survey), 8-11 year olds (child and parents survey), and 12- 15 year olds (child and parents survey).
- The samples of patients must consist of the most recent consecutive discharges up to the last day of **August 2014** as outlined in *Section 9 – Compiling a list of patients*.
- The sampling procedure set out in this guidance must be followed. To do this, you will need to work closely with the person who draws the sample, and check carefully that this guidance has been adhered to. For further details see *Section 9 – Compiling a list of patients*.
- It is important that you liaise with your PALS department, who were contacted over the collection of notifications of dissent i.e. patients, parents and carers that have asked to **not** be sent a questionnaire for the survey. Those children should be removed from the sample before it is sent to the survey contractor.
- A new sampling checklist and declaration have been provided, for the member of staff drawing your sample and your Caldicott Guardian to sign. This declaration should be sent before you send the separate mailing file and sample files to your contractor. The contractor will not be able to receive your mailing file or sample file until you have sent the declaration confirming that no patient identifiable data is within the **sample file**. This is important in order to follow the requirements from the ~~Section~~ **Section 251 Approval**.
- Your contractor will submit your sample file (your anonymised ~~sample file~~ to the Co-ordination Centre for final checks before mailing as outlined in *Section 10 – Final sampling inspection by the Co-ordination Centre*. You should aim to submit your sample file to your contractor **between 15th September and 3rd October 2014** to allow sufficient fieldwork period to maximise your response rates.
- Contractors should aim to obtain the highest response rate possible. Three mailings will be necessary for most trusts to achieve a high response rate. 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.

- Contractors will submit details of response rates and helpline calls to the Co-ordination Centre, on a weekly basis, from **16th October 2014**. A spreadsheet has been created for this purpose.
- Contractors will use the questionnaire versions issued by the Co-ordination Centre. See *Section 13 - The questionnaires and covering letters*.
- Contractors will also use the standard covering letters and reminder letters (which can be found in the Children and Young People's survey section of the NHS Surveys website) as outlined in *Section 14 – Materials*.
- Contractors will send two reminders to non-responders, even if a high response rate is already achieved. These procedures are outlined in *Section 15.7 – Sending out reminders*.
- A paper copy of the questionnaire and covering letters will be submitted by your contractor to the Co-ordination Centre by **24th October 2014**.

1.9 Why you need this guide

This guide explains what your trust needs to do for the preparation and implementation of the survey, when you are using an approved contractor. This guidance 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.

2 Setting up a project team

Even if you are using an approved contractor, 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:
 - Caldicott Guardian
 - Board members
 - Doctors, nurses and other health care staff
 - Members of patient groups with a special interest in the trust
 - Patients and parents/ carers
 - Medical records personnel or Patient Administration System (PAS) staff
 - Managers
 - 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, particularly the implications of any data breaches.
- **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 questionnaire they have received. For more information on publicising the survey see Section 12.
- **Not overlooking front-line staff.** These people have the most direct impact on patients' experiences.

3 Commissioning a survey from an approved contractor

This guidance manual is for use by trusts who have appointed an approved contractor to manage the survey on their behalf.

The framework agreement set up by the Care Quality Commission covers the core survey process. Approved contractors are expected to provide the following services:

- Advising on sampling, providing support to trusts for sampling
- Printing questionnaires, covering letters, reminders and providing consumables
- Online questionnaire set up and management of responses
- Handling receipt of questionnaires, liaising with trusts regarding non-responses and reminders
- Support to ensure good response rates, e.g. FREEPHONE line
- Data entry, cleaning data and providing data to the Co-ordination Centre by the deadline
- Preparing standard reports for trusts.

Four organisations have been approved by the Care Quality Commission to carry out surveys for the 2014 Children's Survey (see below). Trusts may commission any one of these contractors without further tendering the survey work. Before committing to a contractor, you are advised to **check exactly what is covered** within the cost quoted.

3.1 List of approved contractors

The following contractors have approved status for work on the 2014 Children's survey. If a trust chooses to use a contractor, it is a requirement of the survey that one of the following approved contractors is used.

Capita Surveys and Research

Contacts: Cheryl Kershaw and Aimi Blueman
Spa House
Hookstone Park
Harrogate
HG2 7DB

Tel: 01423 818700
E-mail: Cheryl.kershaw@capita.co.uk; Aimi.blueman@capita.co.uk
Website: www.capitasurveys.co.uk

Patient Perspective

Contacts: Stephen Bruster, Chris Henderson
Standingford House
26 Cave Street
Oxford
OX4 1BA

Tel: 01865 205100
Fax: 01865 205111

E-mail: stephen.bruster@patientperspective.org; chris.henderson@patientperspective.org
Website: www.patientperspective.org

Picker Institute Europe

Contacts: Tim Markham, Amy Tallett, Sarah-Ann Burger and Tamara Van Doorn

Buxton Court
3 West Way
Oxford
OX2 0JB

Tel: 01865 208100
Fax: 01865 208101
E-mail: surveys.team@pickereurope.ac.uk
Website: www.pickereurope.org

Quality Health

Contacts: Dr Reg Race, Kerry Hibberd, and Lucinda Phillips

Unit 1 Holmewood Business Park
Chesterfield Road
Holmewood
Chesterfield
Derbyshire
S42 5US

Tel: 01246 856263
Fax: 01246 855897
Email: reg.race@quality-health.co.uk; kerry.hibberd@quality-health.co.uk; lucinda.phillips@quality-health.co.uk
Website: www.quality-health.co.uk

3.2 Contracts with survey contractors

CQC has produced a document that we shall refer to as the ~~service contract~~for NHS trusts to use as a template agreement when providing sampling details to their approved contractor. CQC strongly recommends that the contract template is reviewed by your trust and legal advice is obtained to ensure each clause is relevant and accepted by the trust. Further details on this document in relation to data protection issues are available in Section 5.

We suggest that the service contract is used as either an arrangement separate to the financial agreement made between a trust and an approved contractor when commissioning that contractor, or combined with the financial agreement to minimise the administrative burden. In either case, trusts should specify the following when confirming the requirements of the contractor:

- The groups, and numbers, of patients to be surveyed
- The survey methodology i.e. postal questionnaire with two reminders to non-responders, alongside the use of an online questionnaire (online version is optional)
- Exactly what the contractor and the trust are responsible for in carrying out the survey project (division of responsibilities)
- The main contact at the contractor and the individual at the trust responsible for managing the project
- A timetable showing the dates when each task is to be carried out and by whom

- The outputs of the project. That is, the types of and numbers of reports to be delivered and details of any presentations to be carried out by approved contractors
- The costs and a payment schedule.

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 (see text box below). You should take particular care to ensure that your use of patient data in carrying out the survey complies with these 6 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 form. It will also be necessary to establish appropriate contractual arrangements with any contractors (see Section 5.2). Your trust's Caldicott Guardian and legal advisors should advise you on these matters.

Guidelines on the use and security of the data collected have been agreed by the Care Quality Commission and the Co-ordination Centre for the NHS Patient Survey Programme. 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 Social Research Association and Market Research Society's *Guidelines for social research* (2005)². They have implications for approved contractors and for NHS trusts conducting surveys in-house.

Information about the Data Protection Act 1998 can be found at the ICO . Information Commissioner's Office: <http://ico.org.uk/>

Further guidance can be found on the Market Research Society website: http://www.mrs.org.uk/standards/data_protection/

¹ 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 for a trust working with 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 Confidentiality Advisory Group at the Health Research Authority (HRA). This includes ensuring each have completed the relevant sections of the Information Governance Toolkit to a sufficient standard.³

4.2 Approval under Section 251 of the NHS Act 2006

Approval for the survey was sought this year 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 Confidentiality Advisory Group (CAG) of the Health Research Authority (previously NIGB), covering trusts using an approved survey contractor (those listed in Section 3 of this guidance) and the CAG has granted a recommendation of support. **Please note that any deviation from the methodology outlined in this guidance manual may render the approval invalid.**

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.

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 mailing list. This should be done using your local records.

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

Please note that contractors will be required to deal with calls to their helpline in a consistent manner- they have been briefed and provided with information about how they are to do this. If you would like more information about this, please speak to your contractor. This has been introduced as a requirement of the survey's Section 251 Approval. Please ensure you record all requests made from patients or parents/carers as a direct result of your pre-survey publicity (such as the information flyers given out during your sampling period) and refer to those records to remove individuals from the sample file drawn at your trust. A dissent record log was produced and provided on the NHS Surveys website to explicitly record this information (<http://www.nhssurveys.org/survey/1401>) and PALS teams were the contact point for patients.

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

³ <https://www.igt.connectingforhealth.nhs.uk/>

survey, yet may have sufficient address details visible in PAS, are not included in the sample that is submitted to contractors/the Co-ordination Centre.

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

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

4.3 Keeping patient mailing data and sample data separate

For patient confidentiality reasons, survey responses must never be matched to the contact details of the patients that made them. The best way to ensure this is to store patient names and address details separately from sample information or survey response data. **For this reason, once the sample has been returned from DBS and the number of patients is finalised, patient names, addresses and postcodes must be removed from the sample file to a 'mailing file'.** Before this is done, it is essential each patient is provided with a unique number (a patient record number (PRN)) and that this number is available and correctly matched on both the mailing file and the sample information file (the sample file) (see Section 8.9). Note the PRN must be in the format: CYP14XXXNNNN where XXX is your trust's 3 digit trust code and NNNN is the 4 digit number relating to your sampled patients, e.g., 0001-0850.

Please note that the signed sample declaration form and the checklist includes the separation of the mailing file from the sample file. **By signing the declaration form and checklist you are confirming that no patient identifiable data is included in the anonymised sample file.** You must ensure that there is no patient identifiable data in the sample file that is sent to your approved contractor. The patient names and addresses must be held in a separate mailing file only.

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. This approach has received support from the Confidentiality Advisory Group at the Health Research Authority, under section 251 of the NHS Act 2006.
- 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.

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](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).
- As the owners of the data, the method for transferring patient samples is ultimately the trust's decision because the trust remains legally responsible for the security and processing of the information it shares. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption is available from NHS Connecting for Health see: <http://systems.hscic.gov.uk/infogov/security/infrasec/gpg/acs.pdf>
- 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. Samples files will not be accepted without the signed sample declaration form. 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 should 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)⁴. Approved contractors should be able to provide guidance on the use of an encrypted session to trusts.

4.7 Contractor responsibilities (service contract)

As mentioned in Section 5.2, a service contract has been drafted by the Care Quality Commission for use in the NHS Patient Survey Programme. By signing it, in addition to the points mentioned in Section 5.2, 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/789>

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

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. Patients' names and addresses will be seen by trust staff when generating the sample, while contractor staff will usually possess both patient details and patient responses. As long as the response data supplied to trusts do not include patient record numbers or any other detail that allows individuals to be identified or linked, it can reasonably be claimed that, with regard to the trust and trust staff, the 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 is known to have stayed on a particular ward, and his or her year of birth, sex and ethnic category are known from their survey responses, it might be possible to use this information to identify them. It would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

- 1) Approved contractors will not provide raw data to the trust as a matter of course.
- 2) If the trust has 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:

⁴ <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 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 original year of birth variables (e.g. those specifying an exact year rather than age group) must then be deleted.
 - c. Additional information specific to a survey that can be used to identify individual patients must be removed. For example main specialty, Clinical Commissioning Group (CCG), and NHS site code of admission and discharge must be removed.
 - d. 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 admitted for an emergency or urgent admission, or from a waiting list or planned admission.
- 3) Free text comments will not be anonymised, so that they can be looked at in full by trusts, the CQC and researchers. The CQC felt that the uncensored comments would provide valuable feedback. Comments will, however, be anonymised prior to any publication of results.
 - 4) Children will also be able to provide their feedback by drawing a picture instead of writing comments. These will not be anonymised.

The contractor must have received confirmation from the trust that the names and addresses of the sampled patients have been destroyed before they provide any data to you; 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 data to trusts. This is to prevent the disclosure of a patients' identity by specific demographic factors. The response data will be anonymous when passed to the Co-ordination Centre and Care Quality Commission, and all published and archived results will not identify patients.

- 5) If data are to be presented to 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. The data should be presented as in the following example. In this case responses for the ~~Mixed / Multiple~~ and ~~Asian~~ ethnic categories are suppressed (though sub-group totals are shown):

Ethnic category	Q13. Were there enough things for someone of your age to do on the ward?				
	Yes, a lot	Yes, a little	No	I did not want or need them	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
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- 1) 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.
- 2) The electronic file containing the patientsnames and addresses should be stored securely (i.e. password protected). Access to the file should be given only to those individuals who have signed the service contract.

4.10 Storing mailing data

All mailing lists of patientsnames and addresses should be stored on a separate computer to that containing survey data. Mailing lists of patientsnames and addresses should be destroyed when the mailing process is complete.

5 Ethical issues, ethics committees and research governance

Research Ethics Committees provide independent advice to participants, researchers, care organisations and professionals on the extent to which proposals for research studies comply with recognised ethical standards. The purpose of Research Ethics Committees in reviewing a proposed study is to protect the dignity, rights, safety and well-being of all actual or potential research participants. They will also seek reassurances regarding issues such as data protection, confidentiality and patient anonymity, and they will want to check that proposed research projects will not cause physical or mental harm to patients.

5.1 Ethical approval

Research Ethics Committee (REC) approval has been obtained for the 2014 National NHS children& inpatient and day case survey (January 2014) and a substantial amendment submitted for changes regarding the survey, all of which can be downloaded from the NHS Surveys website: <http://www.nhssurveys.org/surveys/788>. In order to comply with the ethical approval, the survey must be carried out according to the guidelines 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.

Your trust should notify the relevant Research and Development (R&D) office that ethical approval has been obtained for the 2014 Children& Survey. The REC letter of approval can be found on the NHS Surveys website (see link above).

Further information on the ethical approval process can be found on the National Research Ethics Service website: <http://www.nres.nhs.uk/home/> or by e-mailing nres.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 core 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 Care Quality Commission 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 inpatient survey has research ethics committee approval and the Care Quality Commission takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.

The following table (Table 1, below) has been prepared by the Care Quality Commission and is taken from Section 3.10 of the *Research Governance Framework for health and social care (2005)*. The left-hand column sets out the responsibilities of organisations providing care and the right-hand column sets out the arrangements made by the Care Quality Commission for patient surveys. If you are required to seek approval from your research governance lead, you are advised to present this information to your Research and Development Manager in support of your request.

Table 1 – Responsibilities of NHS organisations who 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. ¹	<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>

¹ 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).

6 Collecting data from non-English-speaking populations

The patients, parents and carers who respond to your survey should be representative of all of the patients who use the trust, so it is important that groups with limited understanding of English are not excluded. Questions in the core questionnaires have been written in as **plain language** as possible to facilitate optimum understanding by all respondents. The questions have also been tested with children and their parents and carers to ensure they are easy to understand.

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

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

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of which offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the patient and the interpreter. Your trust may already have arrangements with such a service. A multi-language leaflet template is available on the NHS Surveys website, and this can be included with your first and third mailings. Approved contractors can use this leaflet by inserting their appropriate helpline number (see Section 15.3 for details on setting up a helpline). This gives directions in the 20 most common non-English languages spoken in England and also in easy read (routed to a separate number run by Mencap to help those with learning disabilities).
- Many households include at least one **competent English speaker** who can help the patient to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from non-English-speakers, although it is not ideal, as there is no control over the way in which a patient's family or friends translate questions or interpret their responses, and it does not allow the patient to answer the questions directly.

7 Timetable

The survey fieldwork period is 18 weeks. Previous research shows that younger respondents and those from black and minority ethnic (BME) groups tend to take longer to respond to the survey². As the survey focuses on younger people, it is important that you make full use of the 18 week fieldwork period to maximise your response rate.

The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. within the recommended three week sample checking period . see key dates below). Dissemination of the results to all staff, and to the local community and media, can only start after the survey has been completed so this will take additional time to complete.

If you commission an approved contractor, much of the work will be done by them, but you will still have to be involved in some of the stages of the process. If you are using an approved contractor for the survey, they will provide you with a timetable that might differ slightly to the suggested time periods below.

Table 2 – Children’s Survey timetable

Week	Task	See Section
0	Inform Co-ordination Centre of trust contacts and who is carrying out your survey by 22nd August 2014 (in-house or using an approved contractor)	4 & 5
0	Check your DBS licence is valid and your software for submitting to DBS is up to date	
1	Draw sample of patients to be included in the survey	9
1	Check sample for deceased patients using hospital records	9.2
1	Submit sample list to DBS to check for deceased patients and remove deceased patients from your sample list	9.3 & 9.4
1 - 4	Send your separate mailing file and sample file to your approved contractor for checking	4.1
1	Supply your contractor with trust headed paper and a signature of a senior executive and, if appropriate, ensure that the service contract is signed	5.2 & 15.2
3	Check your own trusts records again for any patient deaths	9.2
6-9	For reminders, check your own trusts records again for any patient deaths	9.2
9-12	For the final mailing, check your own trusts records for any patient deaths	9.2
18	Your contractor sends survey data to Co-ordination Centre (by 20th February 2014 at the latest)	16

Key dates

Inform Co-ordination Centre of your approved contractor

ASAP and no later than **22nd August 2014**

Submission of sample data and mailing data to your contractor(in separate files)

15th September – 3rd October 2014

² For details of this research carried out by the Picker Institute Europe see:

http://www.nhssurveys.org/Filestore/documents/Extension_of_fieldwork_for_inpatient_survey_2007.pdf

Approval of sample data

From **15th September 2014**

Start of fieldwork

6th October 2014

Close of fieldwork

13th February 2015

8 Compiling a list of patients

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, a number of important checks must be carried out on the sample, including a check 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 for deceased patients with DBS before the first mailing and within the trust prior to each mailing.

Before compiling your patient list

We strongly advise that you read all of Section 9 BEFORE you start to compile your patient list.

8.1 Compile a list of eligible patients

- 1) Select the month of paediatric inpatient and day case discharges in which your survey sample will end. **NOTE: This should be August 2014.** You should start counting back from the last day of **August 2014.**
- 2) Compile a list of a **maximum** of 900 eligible patients (**aged 0-15 years old**) inpatients and day case patients consecutively discharged alive from your trust working back from the **31st August 2014.** That is, you should count back through the list of patients discharged live from the trust, including all eligible patients, until you have a maximum of 900, or until you reach 1st August 2014 (whichever occurs first). The minimum sample size for this survey is 300 patients. **With the exclusions that will be made as a result of deceased checks, removing duplicate records etc, you are advised to have a minimum pre-DBS sample size of 380 patients.** If you have sampled back from 31st August 2014 and have not reached 380 patients, you may sample back into July 2014 until you reach the minimum sample size. The reason for including a minimum of 380 patients and maximum of 900 patients at this stage is to allow for the removal of some patients following checks (for example deceased patients will need to be removed following DBS checks) to achieve to minimum sample size of 300 and maximum of 850.

Note

Some trusts have a much lower discharge rate than others. If necessary, a trust can include all patients discharged back as far as the **1st July 2014** to generate their sample of eligible patients submitted to DBS. The minimum sample size drawn required is 380 prior to DBS, therefore if July and August discharges does not generate a large enough sample, then the sample should include inpatients and day cases from September. If you wish to sample September please contact the Co-ordination Centre to discuss.

The information you obtain about each patient will be used both for administering the survey and for sending to the tracing service to check for deceased patients. It saves time and effort if all the information is gathered at the same time.

The list should **include**:

- **ALL** eligible inpatients and planned day cases aged 0-15 years at the time of their discharge. This should **NOT** include any patients who were aged 16 years or older at the time of discharge.

The list should **exclude**:

- deceased patients
- patients **aged 16 years or older** at the time of their discharge
- obstetrics/maternity patients, including spontaneous miscarriages
- newborn babies where the mother is the primary patient (ie: *well babies*, specialty code 424)
- patients who were **only admitted to a Neonatal Intensive Care Unit (NICU) or a Special Care Baby Unit (SCBU)** ie: specialty code 422.
- 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
- ward attendees- exclude those patients who visited the ward (eg: for a blood test) but were **not** admitted as a day case or did not have an overnight stay as an inpatient.
- patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode).
- Any patient, parents or carers known to have requested their details are not used for any purpose other than their clinical care (if this information is collected by your trust you should ensure that you remove these patients from your sample list at this stage).

Treatment Centres

If there are any instances where young patients stayed as an inpatient or received day case services from an NHS treatment centre at the trust, they are eligible for inclusion in the sample for the 2014 Children's survey, provided they meet the criteria above. These patients should be flagged up by inserting a '1' in the appropriate column in the sample file (see the example sample file in Table 3, in Section 8.5).

8.2 Checks carried out by the trust

Once you have compiled your list of 900 patients, you should carry out the following checks *before* you send the list to the DBS (who will carry out a further check for deceased patients):

- **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.
- **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 0-15 years old at the time of their discharge in August 2014 (and July 2014 if you are also including that month in your sampling period).

- **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 Main Specialty 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.
- Check again that none of the patients were admitted for a **termination of pregnancy**.
- **Psychiatry patients.** Check Main Specialty codes and ensure that the list does not include psychiatry patients i.e. patients with the following Main Speciality codes should be excluded:
 - 700 learning disability
 - 710 adult mental illness
 - 711 child and adolescent psychiatry
 - 712 forensic psychiatry
 - 713 psychotherapy
- **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. Your trust will have been asked to administer survey flyers on discharge to the eligible patient population during the sampling period. The flyer will have advised patients to contact the PALS team at your trust to indicate dissent. The PALS team will have been provided with a dissent log, and you should cross check your sample with this log to make sure any patients who have indicated dissent are removed.

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 child 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 posting the second and third mailings, and to ensure that approved contractors are advised immediately if any patients in the sample die during the survey period.

8.3 Submitting your patient list to the Demographics Batch Service (DBS)

Before sending out the questionnaires, the list of patients should 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). The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

Please ensure that you have checked that your DBS licence is up to date and that you have updated your software (which changed as of July 2014). Please make sure that you have done this well in advance of when you need to draw your sample and submit this to the Co-ordination Centre.

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 wild carded 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@hscic.gov.uk 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.

8.4 Identifying deceased patients when the patient file is returned from DBS

The trace response file returned from DBS can be used to identify any patients who have died and therefore need to be deleted from the sample file (see below). This will reduce the numbers in your sample list slightly. **Please note that 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.**

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.
- An additional response column, which is returned only when there is a single unique match. It is in this additional response column that patients found to be deceased will be indicated (by a letter \pounds).

For further information see: <http://www.hscic.gov.uk/demographics/>

Note

Please be aware that tracing services are not fool proof 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. We recommend that you take all possible measures to avoid this occurring in the first instance.

What to do if you have more than 850 patients remaining on your list

When your patient list is returned by DBS, and you have removed all deceased patients, there should still be more than 850 patients in the list. You will need to remove the **least recent** patients from your sample so that only the 850 most recent patients remain.

What to do if you have fewer than 300 patients remaining on your list

If your patient list has fewer than 300 patients after deceased patients have been removed, you **MUST** contact the Co-ordination Centre on 01865 208127 or email CYP.data@pickereurope.ac.uk. If possible, the next most recently discharged patients after the sample will need to be added to create a sample of 300 patients, although these must also be checked by DBS.

Important note

You are aiming for a **high response rate for this survey**. You will be able to maximise your response rate by following this guidance carefully. It is **not** acceptable to try to boost the number of responses you receive by including more patients when compiling your sample for the survey as this would bias the survey. The Co-ordination Centre will only be able to accept responses from the patients in your list that have been correctly sampled and mailed.

8.5 Create the sample file

Information relating to your sample of patients should be entered into an Excel file which should resemble Table 3 below. A pre-designed spreadsheet including all the required column headings can be downloaded from the NHS Surveys website (<http://www.nhssurveys.org/surveys/787>) and is entitled 'Sample construction spreadsheet'. The column headings in this spreadsheet are identical to those supplied in the validated spreadsheet produced by the Co-ordination Centre for final submission of data (the 'Data entry spreadsheet') and so it will be advantageous for you to use the sample construction spreadsheet at this stage, rather than to create your own spreadsheet. Enter the required information and save this file as <NHStrustname>_CYPInpatients2014.

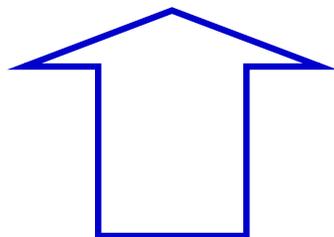
This file has three purposes:

- 1) It will be used to keep a record of which patients have not returned questionnaires so that reminders can be sent to them.
- 2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from **16th October 2014** until the closing date of the survey.
- 3) The anonymous data in this file (i.e. all the data **except** patient name and address information) will form part of the file that your contractor will submit to the Co-ordination Centre when the survey is completed.

More details about the information required in this file are provided below.

Table 3 – Sample construction spreadsheet of patient details

<i>NHS Trust Code</i>	<i>Patient record number</i>	<i>First name</i>	<i>Surname</i>	<i>Address1</i>	<i>Address5</i>	<i>Postcode</i>	<i>Month of birth</i>	<i>Year of birth</i>	<i>Gender</i>	<i>Ethnic category</i>	<i>Day of admission</i>	<i>Month of Admission</i>	<i>Year of Admission</i>	<i>Day of discharge</i>	<i>Month of discharge</i>	<i>Year of discharge</i>	<i>Length of Stay</i>	<i>Main Speciality on discharge</i>	<i>CCG code</i>	<i>Treatment centre admission</i>	<i>Route of admission</i>	<i>NHS Site code on admission</i>	<i>NHS Site code on discharge</i>	<i>Day of questionnaire being received</i>	<i>Month of questionnaire being received</i>	<i>Year of questionnaire being received</i>	<i>Outcome</i>	<i>Comments</i>
RT5	CYP14RX 10001	Annie	Shaw	-	-	AB1 1YZ	2	2005	2	A	5	6	2014	11	8	2014	6	100	12H	0		RR115	RR115				3	Informed that patient had died
RT5	CYP14RX 10002	Jatish	Ahmed	-	-	AB2 6XZ	11	2000	1	J	20	6	2014	30	8	2014	10	101	10Q	1	11	RTE03	RTE03	22	10	2014	1	
RT5	CYP14RX 10849	Katherine	Yoo	-	-	AB4 7MX	10	2000	2	R	17	6	2014	17	7	2014	0	300	09Y	0		RR115	RR115					
RT5	CYP14RX 10850	Ruby	Young	-	-	AB9 5ZX	08	2013	2	A	14	6	2014	14	8	2014	0	100	08L	0	22	RR120	RR117	6	11	2014	1	



FIRST NAME, SURNAME, ADDRESS1...ADDRESS5 and POSTCODE columns are PATIENT IDENTIFIABLE DATA.

MUST NOT BE INCLUDED IN THE ANONYMISED SAMPLE FILE.

Important note about Table 3

The headings are in three different colours:

Black headings: these columns contain information on patients' names, addresses and comments that may allow them to be identified. This information must not appear in **any files** sent to the Co-ordination Centre. This mailing information, along with a copy of the patient record number should be removed from the sample file as soon as your sample is finalised and saved to a new file (your %mailing data+file - see Section 8.9). Please note that no patient identifiable data (names and addresses) should appear in the same file as the sample information when you send this to your contractor. All information MUST be kept separate.

Red italic headings: these columns should be completed during the sampling phase and submitted to your approved contractor, who will then submit the anonymised sample file to the Co-ordination Centre prior to mailing and at the conclusion of the survey.

Green italic headings: these columns should be completed when the patient responds to the survey (e.g. by returning a completed questionnaire), or when the approved contractor is notified the patient will not be participating (patient deceased, moved address, too ill, or called to opt out). The approved contractor will provide this information to the Co-ordination Centre.

The information that must be entered into this spreadsheet will come from a number of different sources:

Information from hospital records

The following information can be compiled from hospital records:

- **First name** ensure that the first name is present rather than ~~baby~~ ~~boy~~ ~~girl~~ etc OR **Initials:** trusts have the option of mailing to either first name or initials- please discuss this with your contractor
- **Surname**
- **Address Fields:** This should be held as separate fields (e.g. street, area, town and county)
- **Postcode**

Note

The **Patient Record Number** (see ~~Additional information~~ section below), **First name/ initials, Surname, Address Fields** and **Postcode** are used for printing out address labels. You (or your contractor) can use the mail merge function in a word processing package for this purpose. (See Section 16.5)

- **Month of birth** should be included in the form of N or NN: eg. June=6 or November=11.
- **Year of Birth** should be included in the form NNNN, eg: 2011.
- **Gender** should be coded in numeric form: 1 = male, 2 = female.
- **Ethnic Category** 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:
http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp?query=ethnicity&rank=70&shownav=1

Please note that only patients who refuse to provide ethnic category should be coded as %Z+ (not stated). If this code is missing for any other reason, ethnic category should be left blank in the sample information. 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

- **Day** of the month of admission (1 or 2 digits; e.g. 7 or 26)*
- **Month** of admission (1 or 2 digits; e.g. June = 6 or November = 11)*
- **Year** of admission (4 digits; e.g. 2014)*
- **Day** of the month of discharge (1 or 2 digits; e.g. 2 or 30)*
- **Month** of discharge (1 digit; e.g. August = 8)*
- **Year** of discharge (4 digits; e.g. 2014)*
- **Length of stay** (Units = Days). Calculate this by subtracting the admission date (day/month/year) from the discharge date (day/month/year). For example, if discharge date = 15/8/2014 and admission date = 14/8/2014, the length of stay = 1. Do not use any other type of unit to calculate length of stay (i.e. do not use hours/minutes/seconds).
- **Main Specialty (of consultant) code on discharge.** It is recorded in the form NNN as outlined by the Health and Social Care Information Centre (HSCIC). Please see: http://www.datadictionary.nhs.uk/data_dictionary/attributes/m/main_specialty_code_de.asp
- **CCG code:** please provide the 3 character 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** should be coded as 1q for patients who spent any part of their inpatient stay at an NHS treatment centre within the trust, and coded as 0q if they did not.
- **Route of Admission:** Please include the two-digit descriptive code as used within the NHS Commissioning Data Sets. A blank or full-stop should be used if this information cannot be obtained for a patient. Please see: http://www.datadictionary.nhs.uk/data_dictionary/attributes/a/add/admission_method_de.asp?shownav=1
- **Hospital Site Code on Admission:** Please record the site of admission of the patient using the five character NHS Trust Site Codes (maintained by HSCIC). Please see: <http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs>
- **Hospital Site Code on Discharge:** Please record the site from which the patient was discharged using the five character NHS Trust Site Codes (maintained by HSCIC). Please see: <http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs>

Additional information

A number of additional pieces of information should also be entered into this spreadsheet:

* Date fields must be supplied in separate columns (e.g. date, month, and year).

- 1) **NHS Trust Code.** Enter your 3-character Trust Code against all records in the first column.
- 2) **Patient record number (PRN).** This is a unique serial number which must be allocated to each patient by the trust. It should take the following format: CYP14XXXNNNN where XXX is your trust's 3-digit trust code and NNNN is the 4-digit number relating to your sampled patients, e.g., 0001-0850. The PRN will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), the approved contractor will be able to use these numbers to monitor which patients, parents and carers have returned their questionnaires and to identify any non-responders, who will need to be sent reminders. **Please note: this number should be available in, and correctly referenced for, every patient dataset for this survey (e.g. sample file, mailing file, final data).** Note that the PRN is a unique number assigned to each patient record and the PRN will be the same regardless of whether the survey was completed on paper or online.
- 3) **Day of questionnaire being received.** This will only be completed if and when a questionnaire is received by the approved contractor.
- 4) **Month of questionnaire being received.** This will only be completed if and when a questionnaire is received by the approved contractor.
- 5) **Year of questionnaire being received.** This will only be completed if and when a questionnaire is received by the approved contractor.
- 6) The **Outcome** field will be used to record which questionnaires are returned to the freepost address, or are returned undelivered, or which patients opt out of the survey, etc.
 - 1 = Returned useable **paper** questionnaire
 - 2 = Returned undelivered by the mail service or patient moved house
 - 3 = Patient died
 - 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire
 - 5 = Patient was not eligible to fill in questionnaire
 - 6 = Questionnaire not returned (reason not known)
 - 7 = Returned useable **online** questionnaire
- 7) The **Comments** column is useful for recording any additional information that may be provided when someone calls the helpline. For example, to inform the contractor that the respondent has died or is no longer living at this address.

8.6 Checking the distribution of patient ages in your sample

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.

8.7 Checking the distribution of patient gender

With the exception of hospitals specialising in one gender, your sample will probably have similar proportions of boys and girls. You should check that both boys and girls are included and that you can explain if the sample is skewed toward male or female patients.

8.8 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 any apparent problems.

8.9 Separating mailing details from sample information

At this point you should transfer the names, address and postcode for each patient in the sample to a new file . your mailing fileq The patient record number (PRN) for each patient should be copied to the new file, so that the two datasets are connected using the unique PRN. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as <YPIPandDC2014_mailing dataq It should resemble Table 4 below.

This file should be used for mailing purposes: it will be used to check for deceased patients prior to reminder mailings and will be cross-referenced with the sample file (<NHStrustname>_CYP2014) to identify patients who will need to be sent reminders.¹

As this mailing file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing file should be destroyed when the survey is complete. This should be done by both the trust and the approved contractor, along with all other files created for the survey (aside from the survey response file).

Remember

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

Table 4 – Example mailing file

NHS Trust Code	Patient record number	First name	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
RT5	CYP14RX10001	Annie	Abbot	14 Station Road	London				AB1 1YZ

¹ As shown in Table 3 (see section 9.5), the <outcomeqfield in the sample file is used to record which questionnaires are returned completed (and whether paper or online), or are returned undelivered, or which patients opt out etc...

RT5	CYP14RX10002	Jatish	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
RT5	CYP14RX10849	Katherine	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4
RT5	CYP14RX10850	Ruby	Young	634 Tyne	Newcastle-Upon-Tyne	Tyne and Wear			AB9

8.10 Sample declaration form

For this survey, there is a sample declaration form that needs to be completed by the person preparing the sample. This form has a number of compliance statements which both the person drawing the sample and also the Caldicott Guardian must sign.

The form must be completed and sent to your approved contractor prior to submitting your separate mailing file and anonymised sample file to them. The form will be provided to the Co-ordination Centre alongside your sample file, as it will be used for assisting with sample checking for both the contractor and Co-ordination Centre.

8.11 Sharing the patient sample file with an approved contractor

If you have a contract in place, with your approved contractor, relating to the transfer of patient identifiable information (i.e. names and addresses) which allows the contractor to carry out the mailing of the questionnaires for you, both the sample file (<NHStrustname>_CYP2014) **and** the mailing file (CYP2014_mailing data) should be sent to the contractor staff in encrypted format (see Section 4.6).

You must submit your completed sample declaration form to your contractor first before you send any files to them. The contractor will then confirm they are happy to receive both the separate mailing file and anonymised sample file.

Whilst your contractor has approval to receive patient identifiable data, this must be received by them in a separate file to the anonymised sample information. Files that contain both the sample information and mailing information will be considered a breach of the surveys Section 251 Approval. Breaches of this nature will be reported to the CQC and follow up action will be taken.

If you are working with an approved contractor, but have chosen to mail out the questionnaires yourself, in-house, you should supply them with just the sample file (<NHStrustname>_CYP). 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.

Trusts which have not submitted their sample for checking by the **3rd October 2014** will be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **8th October 2014**, then we are required to notify the Care Quality Commission of this and they will contact you to discuss any implications for inclusion in Care Quality Commission produced data.

8.12 Summary of key steps

By following the guidance in this section you should have completed all of the tasks set out below:

1. Compiled a list of eligible patients (Section 8.1)
2. Checked your patient list to make sure it meets requirements and only includes eligible patients (Section 8.2)
3. Sent the list to the DBS to check for deceased patients and removed these patients from your list (Section 8.3 and 8.4)
4. Created a sample file (Section 8.5)
5. Checked the distribution of patient age, gender and route of admission (planned versus emergency) in your sample file (Section 8.6, 8.7 and 8.8)
6. Checked for other errors that may have occurred when drawing your sample.
7. Removed personal data from the sample file and created a mailing file (Section 8.9)
8. Share the sample file (and possibly the mailing file) with an approved contractor (Section 8.11)

8.13 Making the most of the fieldwork period

Because certain demographic groups and those from non-white ethnic backgrounds have been shown to take longer to respond to patient surveys, we strongly recommend that files are submitted within the four weeks specified for sample checking detailed above. The best way to ensure you are able to do this is to prepare before the start date of the survey (**15th September 2014**). **There are several ways you can do this:**

- 1) Check that your DBS software and licence are up to date- issues with submitting your sample to DBS will introduce delays into the sampling process meaning that you may end up delaying when your mailings are sent out and how long you have in the fieldwork period.
- 2) Allocate sufficient time to the individual who will generate your sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by your contractor or the Co-ordination Centre.
- 3) Discuss the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey.
- 4) Ensure your trust is registered with DBS and that the person who submits your sample to them understands their requirements . problems with data submitted to tracing services is one of the most significant obstacles in mailing out your survey in good time. Also, do not assume you are registered . please check this ahead of time.

PLEASE NOTE: Your contractor only has approval to receive information relating to the patients that will be in your sample. Therefore, you are not permitted (under any circumstances) to send more than 850 records to your contractor. Your contractor will not be able to draw the sample for you from the returned list of records from DBS.

9 Publicising the survey

9.1 Pre-survey communication with staff

As highlighted in Section 2, the best way to ensure 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.

Setting up a project team

We suggest you put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:

- Caldicott Guardian
- Board members
- Doctors, nurses and other health care staff
- Members of patient groups with a special interest in the trust
- Patients and carers
- Medical records personnel or Patient Administration System (PAS) staff
- Managers
- Staff or directors responsible for:
 - Clinical governance
 - Patient advice and liaison service (PALS)
 - Quality improvement
 - Strategic planning

Keeping everyone informed

Notify as many staff members as possible about the survey in case patients contact the trust asking questions about the questionnaire they have received. Patients can be expected to ask receptionists, doctors, nurses, patient liaison officers, or the Chief Executive's office about the survey, even when your covering letters give contact details for the survey manager(s) and the dedicated helpline. Notify front line staff and executive offices that a survey is being conducted, and give them the name and number of a contact person. Survey manager(s) should be prepared to respond to these calls quickly.

Staff could be notified of the survey through a variety of methods:

- Electronic (e.g. e-bulletins, website, intranet)
- Paper-based (e.g. staff briefings, newsletters, flyers, posters)
- Face-to-face (e.g. meetings, presentations and events)

Appendix 1 includes information which you can tailor for publicising the survey to staff.

9.2 Publicising the survey externally

To help promote involvement and maximise response rates, and to give the opportunity to opt out, the survey can be publicised to patients and the public through a number of ways, for example:

- Send a press release to the local media to raise awareness of the survey and gain publicity just before the survey takes place. Information to help you draft a press release is shown in Appendix 2 and can be found on the NHS surveys website: <http://www.nhssurveys.org/surveys/792>. Talk to your hospital's press office for more ways in which you can gain publicity locally.

- Put up posters around the hospital which show the importance the trust places on gathering patient feedback. To be most effective at increasing your response rate, posters should be put up in the hospital during the sampling period (i.e. during the month(s) from which your sample of inpatients will be drawn). A poster is available on the NHS surveys website at: <http://www.nhssurveys.org/surveys/774>

10 The questionnaires and covering letters

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

All 3 pre-designed core questionnaires are available on the NHS Surveys website and must be used by all NHS trusts participating in this survey. Your contractor will be organising the production and printing of all survey materials for you.

Trusts will also be able to offer the 8-11 and 12- 15 year olds questionnaires as online surveys to respondents. This option will be available to trusts to take up voluntarily, meaning that it is not a requirement of the survey. If the online versions are offered by trusts, there is space on the covering letters to add text regarding the online option including details of the URL to access the online versions and details of logins required.

If you are using an approved contractor, they will have set up the different online versions of the survey. **Please discuss the online option with your contractor who be able to explain how the process will work in practice.**

10.1 The parents questionnaire

The parents paper questionnaire consists of 48 questions on 8 pages. These questions cover the issues that have been found to be most important to parents/ carers and those interested in delivering high quality children's services. The front page of the questionnaire explains the purpose of the survey and gives instructions on how to fill it in. In the pages that follow, the survey questions are divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the parent or carer. The three questionnaires can be downloaded from the NHS Surveys website: <http://www.nhssurveys.org/surveys/778>

10.2 The 8 - 11 year olds questionnaire

The 8 - 11 year olds paper questionnaire consists of 53 questions on 8 pages: the first section is for the child and contains 18 questions over 3 pages. These questions cover the issues that have been found to be most important to patients of this age group. This questionnaire also includes a section for parents/ carers to complete, as well as the child/ young person. Note that the section for the child/ young person to complete has been limited to 3 pages- this is to prevent attrition and reduce burden on the child whilst allowing us to gather data on the most important aspects of care. The covering letter explains the purpose of the survey and gives instructions on how to fill it in. The parents and carers section follows the section for the 8-11 year olds and is divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the

parent or carer. The three questionnaires can be downloaded from the NHS Surveys website:
<http://www.nhssurveys.org/surveys/778>

10.3 The 12 - 15 year olds questionnaire

The 12. 15 years old questionnaire consists of 57 questions on 8 pages: the first section is for the child and contains 22 questions over 3 pages. These questions cover the issues that have been found to be most important to patients of this age group. This questionnaire also includes a section for parents/ carers to complete, as well as the child/ young person. The covering letter explains the purpose of the survey and gives instructions on how to fill it in. The parents and carers section follows the section for the 8-12 year olds and is divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the parent or carer. The three questionnaires can be downloaded from the NHS Surveys website:
<http://www.nhssurveys.org/surveys/778>

10.1 The covering letters

For this survey there are 2 covering letters:

- **0-7 year olds version:** addressed to the parent/ carer of the child which will accompany the parents questionnaire
- **8-15 year olds version:** addressed to the parent/ carer of the child which will accompany the children's 8-11 year olds and the 12-15 year olds questionnaires. There will also be an information leaflet for the child to read through.

The different covering letters can be downloaded from the NHS Surveys website:
<http://www.nhssurveys.org/surveys/783>. Your contractor will be responsible for producing these documents for you.

As mentioned in Section 8.5, your trust has the option of using either the child's FIRST name OR INITIALS to address the letter to, for example: To the Parent or carer of Annie Abbott or To the parent or carer of A Abbott. If you decide to use the initials and not first name of the child (patient) then there will be a slight change to the information in the covering letter- an extra line will be added to the letter advising parents to think of the child with the most recent discharge. Please discuss this with your contractor.

11 Materials

11.1 Trust headed paper

You will need headed paper from your trust for covering letters for the first and third mailing. A reminder letter is used for the second mailing. Therefore, depending on your response to the initial mailings, you will need approximately 1,200 to 1,600 sheets of trust headed notepaper. If an approved contractor is being used to carry out the survey work, 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.

11.2 Flyer

For this survey, a survey flyer has been produced by the CQC (this is in addition to the patient information flyer already sent to you to provide to patients/ carers at discharge). This flyer explains who the CQC are, the importance of gathering patient feedback and what will be done with the data collected. The flyer will be included in both the first and third mailings. It is hoped that it will highlight the importance and purpose of the survey to patients and provide evidence of how their feedback contributes to monitoring the performance of the NHS.

For trusts using a contractor, sufficient numbers of flyers will be provided to each contractor to cover the different mailings.

11.3 Sending out reminders

For results to be representative, it is essential to get a good response rate. To achieve this, two reminders must be sent out to non-responders. **This is essential, even if your trust has already have achieved a high response rate.**

Depending on the time that has elapsed since you first checked your patient list for deaths, it might be necessary to send your list back to the Demographic Batch Service for a further check before your contractor sends out reminders. You must provide this information back to your approved contractor prior to the reminders being sent out.

If a trust is using an approved contractor but is carrying out the survey mailing in-house, the approved contractors should send the pre-packed envelopes bearing the patient record numbers of the non-responders to the acute trust. Again, the envelopes should be clearly marked with the patient record number so that those carrying out the mailing can correctly attach address labels by matching up patient record numbers.

First reminders

The first reminder should be sent to patients who have not responded after **one to two weeks**. We recommend approximately **ten** days between the mailing day of the first questionnaire and the mailing day of the first reminder. The first reminder should reach the participant while they are still in possession of the first questionnaire, and the optimal time for this will vary between trusts.

The standard first reminder letter is available in Microsoft Word format on the NHS Surveys website for you to download (see <http://www.nhssurveys.org/surveys/783>). It can be printed on A5. It has been given ethical approval so no changes are permitted.

Your approved contractor will manage this process for you.

Second reminders

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

The envelopes should include the following:

- 1) A questionnaire numbered with the patient record number. The number must match (or correspond to) the number on the address label and the number on the list of patient details.
- 2) A covering letter.
- 3) A multi-language helpline sheet (if used in first mailing)
- 4) A large envelope, labelled with the FREEPOST address on it.

The standard second reminder letters are available in Microsoft Word format on the NHS Surveys website for you to download and add your trust's details (<http://www.nhssurveys.org/surveys/783>). These have been given ethical approval so no changes are permitted. A paper copy of the second reminder letter you use must be sent to the Co-ordination Centre accompanying the hard copies of the questionnaire.

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

12 Making sense of the data

Standard data analysis usually involves examination of the frequency of responses to each question and some cross-tabulation of responses against demographic and other information. Your contractor will also provide you with some analysis of your results- you will need to speak to them directly about this to confirm what analysis will be done.

12.1 Suggestions for data analysis

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

Use the data to help pinpoint problems

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

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

"Drill down" into the data

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

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

Group similar questions together to provide summary analysis

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

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

Use statistical tests to make comparisons and analyse subgroups

Statistical tests can be used to examine relationships and associations between groups (for example age, sex or ethnic categories). These tests take into account the number of responses, the variation in responses, and values of the items you are comparing (such as average responses). If tests show that the differences between two groups are not statistically significant², you should view the patterns of responses as only suggestive.

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

Although there are many methods of describing uncertainty, confidence intervals³ are used most often. By taking into account the number of responses, the variation in response, and the magnitude and direction of the estimate, the confidence interval describes the range of plausible values within which the "true" value for the population is likely to fall. Remember that the estimate itself is the most likely result, and this is therefore your best estimate, not the limits of the confidence interval.

Make use of the free text

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

Any information that could allow respondents to be identified, such as patient and staff names should be removed. See Section **Error! Reference source not found.** for further information regarding anonymising patientsqcomments.

As this survey allows children to provide their feedback via drawings, you can also use these in the same way as the free-text comments to look for any valuable feedback within the drawings. You may also want to display some of these drawings on the wards, if they do not include identifiable data.

² **Statistical significance** is the degree to which a result is substantially different than would be expected by chance alone. For example, if the difference in data for a question from two survey years is statistically significant, this means that there has been a true change in the results that cannot be attributed solely to chance.

³ A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the trust mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made.

Use patient feedback data with other data

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

Perform analysis by sub-groups

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

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

Table 5 – Confidence intervals* for different numbers of respondents

Number of respondents	Widest Confidence Interval (+/-) ¹
50	13.9%
100	9.8%
200	6.9%
300	5.7%
400	4.9%
500	4.4%
600	4.0%

*at a 95% confidence level

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

Example: How confident you can be in your results?

For a trust, 400 patients responded in total. Taking a particular question, of which 50% of respondents answered *Yes*, from Table 9 we can see that the widest confidence interval for 400 respondents would be +/- 4.9%. We would therefore be 95% confident that the true results would be between 45.1% and 54.9% - that is, if you had surveyed the entire population of inpatients at a trust.

¹ This column (the widest confidence interval) shows the **maximum** margin of error for binomial estimates of proportions

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

If you are using a survey contractor to help you carry out your survey, they should be able to advise you on the minimum sample size for comparisons by particular sub-groups

13 Reporting results

13.1 Prioritising your findings

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

Rank results by their magnitude

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

Compare your results against outside norms or benchmarks

A common method of prioritising is to select issues that compare unfavourably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Compare your trust's results with the benchmarks on the Care Quality Commission website to find out where your trust performs better or worse than other trusts.

Compare results within your organisation

Comparisons within organisations can facilitate networking among units or departments and the sharing of information about effective practices. Internal competitiveness may also fuel improvement efforts.

Comparison with predefined goals

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

Correlation with overall measures

Correlating patient responses to specific questions with their response to the question about their overall experience can help focus attention on issues that are important for patients.

Predictive value on overall measures (regression analysis)

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

Ease of action

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

Areas of excellence

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

13.2 Writing the report

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

Tailor the document to the audience

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

Remember that if you are planning on presenting the findings back to children and parents/ carers, make sure that you use lots of colour, graphics, easy to understand language and focus on the most important or interesting feedback.

Use graphics

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

Keep the format succinct and consistent

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

Emphasise priorities clearly

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

14 Using results for quality improvement

Arguably the most important aspect of the survey process is making use of the results to bring about improvements. It is essential that this patient feedback is used to set priorities for quality improvement programmes and to create a more responsive, patient-centred service. It should then be possible to measure progress when the survey is repeated.

14.1 Prepare in advance

The most important way to ensure that the survey will result in improvement is to plan for improvement work before the survey is conducted.

- We recommend the survey lead/team take responsibility for developing a dissemination strategy to inform all of the relevant stakeholders about the survey findings.
- Publicise the survey before it happens. Engaging staff from the start will help to ensure their support later on with any improvement initiatives. Involving the local media and informing the public may encourage a good response rate from patients.

14.2 Dissemination of survey results

Engage key stakeholders

Raising awareness of the survey programme in your organisation is vital. Publication is an excellent way to inspire staff to take patient feedback seriously. By communicating your survey results to key stakeholders you will help to ensure they are used effectively and not forgotten. Consider the following groups:

- Staff throughout the trust as they will be responsible for tackling any problems identified by patients.
- Board members as they are involved in prioritising areas for improvement and shaping action plans. Their support is often crucial for the successful implementation of change.
- Patients have taken time to report their experiences so it is important they are informed of the results via local meetings, newsletters and articles in the local press.
- Patient groups with special interest in the trust who may have a key role to play in initiating discussions with the board about priorities for improvement and be keen to monitor progress as it occurs.
- When reporting the results it is a good idea to also invite people to contribute their ideas on how services could be improved and to suggest ways in which they can become involved if they wish to.

Spread the Word

Disseminating survey results entails far more than producing and photocopying a report. Consider how to share the survey results in training sessions, staff and public meetings, employee newsletters, executive communications, process improvement teams, patient care conferences, and other communication channels. You may wish to consider the following:

- Determine whether information should be shared initially with only senior-level people, or whether (and when) it should be spread further afield
- Make presentations to your trust board and to as many groups of staff as possible, each tailored appropriately for the audience

- Organise a high profile event to publicise the results and invite staff and patients and parents/ carers to contribute to improvement plans
- Encourage staff at all levels in the organisation to contribute their ideas for improving patients' experience
- Publish the survey results on your website, including any intranet site and give readers the opportunity to feed back their ideas
- Email staff to tell them about the survey results and the action plan
- Share information with other NHS organisations in your area and other partner organisations including local authorities
- Give the results to community organisations and ask them for their views and suggestions
- Publicise results via local press, radio and community newsletters
- Publish results in your trust newsletter along with details of improvement plans

Promote understanding

To assist others in understanding the results, we recommend the following:

- Present results in user-friendly formats. Remember not everyone will be an expert in reading graphs and deciphering data
- Communicate information in a visual way, perhaps in the form of posters which can be displayed around your organisation.
- Focus on key messages arising from the results and emphasise both the positive and negative themes
- Illustrate themes with relevant patient comments or other forms of patient feedback to put the results in context

14.3 Identify key "change agents"

The people who can motivate others to bring about change and who hold the keys to improvement in the organisation are not necessarily the most senior people. Identify these individuals and involve them as "change agents" early in the survey process.

14.4 Prioritising areas for improvement

Compare with other trusts

Compare your trust's results with the benchmarks on the Care Quality Commission website to find out where your trust performs better or worse than other trusts.

Compare departments within your trust

If your data allow it, further analysis of your results by sites or departments will provide a more detailed breakdown of performance. You may be able to identify examples of good practice within your trust which can be applied to other areas requiring improvement.

Identify where patients report most room for improvement

Issues can be ranked according to the size of the problem. Look at questions where more patients indicate that their care was not perfect and could be improved. Select the questions where most problems are reported and focus on the issues that are a priority for your organisation.

Focus on areas where work is already underway and solutions can be easily identified

Focusing on issues that present solutions (e.g. improving information provided to patients about medications they are given when they leave hospital) and choosing topics currently being considered by existing groups in your trust (e.g. the Clinical Governance Group) will help to gain the ownership and involvement of staff and patients and avoid duplication of effort.

Identify problems surrounding particular aspects of the patient experience

There may be particular aspects of care or elements of the patient experience where more problems are reported than others. For example:

- Carers being involved in making decisions about care
- Having appropriate equipment and adaptations for children
- Hospital food

14.5 Develop an action plan

Having used your survey results to identify areas for improvement, we recommend you work with staff and patients to identify and prioritise the actions required. Decide on achievable timescales and on the individuals who will be responsible for taking this work forward. This will form the basis of an action plan which can be updated on a regular basis.

Wherever possible, link the information from the patient survey results with other activities in the trust. You can also use other sources of patient feedback from:

- Patient Advice and Liaison Service (PALS)
- Complaints
- Service Improvement/Modernisation Teams

Initially it is a good idea to focus on one or two key areas for improvement and not to attempt to tackle all of the issues at once. Publishing regular progress reports widely throughout your trust and the local area will help to enlist ongoing support. Repeat surveys can then be used to monitor any improvements.

14.6 Use small follow-up surveys or focus groups to delve deeper

Your initial survey can help you identify areas in need of improvement, but you might need more detailed information to focus your improvement effort. It can be time-consuming and expensive to gather this information on a large scale. Small follow-up surveys focusing on selected groups of patients can provide valuable information and faster feedback.

14.7 Use already existing resources

The Department of Health has published the guide [Understanding what matters: A guide to using patient feedback to transform care](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780) which can be found on their website at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780. This guide may help you to get the most from your survey results.

15 Glossary

Inpatient

The definition of an inpatient admission can be found within the description of the NHS Data Model and Dictionary attribute Patient Classification:

'A patient not admitted electively, and any patient admitted electively with the expectation that they will remain in hospital for at least one night, including a patient admitted with this intention who leaves hospital for any reason without staying overnight.'

Day case

The definition of a Day Case admission can be found within the description of the NHS Data Model and Dictionary attribute Patient Classification:

'A patient admitted electively during the course of a day with the intention of receiving care who does not require the use of a hospital bed overnight and who returns home as scheduled. If this original intention is not fulfilled and the patient stays overnight, such a patient should be counted as an ordinary admission.'

It follows from this and other related NHS Data Model and Dictionary definitions that:

- A Day Case admission must be an elective admission, for which a Decision To Admit has been made by someone with the Right Of Admission

Current inpatient

For the purposes of this survey, we define a current inpatient as a participant who meets the inclusion criteria for the survey, but is a current inpatient at any hospital in England. Please check your own trust records for any current inpatients during sampling and exclude these people from the sample during the sampling phase only. If you are aware that a patient is a current inpatient at another trust, also exclude these people. When checks for deceased patients are carried out prior to subsequent mailings, do not check for, or exclude, current inpatients.

Research Ethics Committee (REC)

The purpose of Research Ethics Committees in reviewing a proposed study is to protect the dignity, rights, safety, and well-being of all actual or potential research participants. A favourable ethical opinion from the committee implies that the research does protect the participants' aforementioned rights. A REC can grant a favourable ethical opinion for studies carried out in multiple regions of England. The inpatient survey is operated under approval from the North West REC. Prior to each survey a substantial amendment is applied for to cover any changes in questionnaire content or wording in the cover letters. The favourable ethical opinion for the study covers all NHS hospital trusts in England.

Section 251 Approval and Confidentiality Advisory Group (CAG)

The purpose of CAG in reviewing a proposed studies application for Section 251 Approval is to ensure that the request for the transfer of patient identifiable data (patient names and addresses) by a trust to a third party, without consent from the patient for research purposes, is valid. A favourable opinion from the committee implies that there is a valid and public need for the survey

to proceed and that data can be transferred without consent for this purpose only. CQC completes the application process for each survey and approval has been given for this survey.

Obstetrics/Maternity patients

Any patients with route of admission codes of 31 or 32 and/or coded with a main specialty of 501 (obstetrics) or 560 (midwife) admitted for management of pregnancy and childbirth, including miscarriages, should be excluded from the sample.

Psychiatry patients

Patients admitted as an inpatient to hospital for primarily psychiatry reasons should not be included in the sample. This will include all those with main specialties of:

- 700 learning disability
- 710 adult mental illness
- 711 child and adolescent psychiatry
- 712 forensic psychiatry
- 713 psychotherapy
- 715 old age psychiatry

Research Governance Framework

This outlines the principles of good research practice and is key to ensuring that health and social care research is conducted to high scientific and ethical standards.

Appendix 1: Suggested text for pre-survey communication with staff

Example titles:

What do our young patients think about the [trust name]?

Getting young patients' views on the quality of care in [trust name]

Understanding young patients' experiences in [trust name]

Children's views vital to drive service improvements in [trust name]

We [or NHS Trust name / Hospital name] are carrying out a survey to find out what children and their parents or carers think about the care they receive.

Why are we doing another patient survey?

A new national Children's inpatients and day case survey is being carried out as part of the NHS patient survey programme.

Obtaining feedback from young patients and their parents and carers, and taking account of their views and priorities is vital for bringing about improvements in the quality of care.

When is the survey taking place?

Questionnaires will be posted to a sample of patients during [month].

This national survey will seek to gather patient experience data from parents of children aged 0-15 years old and for children aged 8-15 years old they will have a chance to complete their own questionnaires also.

Reminders will be sent to those who have not responded during [month(s)].

Patients are being asked about various aspects of their care, including [how well they were treated by hospital staff, how involved they were in decisions about their care and how well staff worked together].

Who is the survey being sent to?

The survey will be sent to a sample of [number] patients, aged 15 years and under, who either spent at least one night in hospital during [month] or spent time at the hospital as a day case patient during the same month. [An external survey contractor, {name}, is administering the survey so that patients' responses are anonymous].

When will the results of this survey be available?

The results of this survey will be available in [month/date] in [location of where results will be published or shared with staff]. The survey findings will be reported in [format, e.g. a summary report, at a meeting etc.]. By working with both staff and patients we will use the feedback from this survey to further help improve patients' experiences at the trust.

Where can I find out more?

For more information about the survey, please contact [lead survey name and contact details].

Appendix 2: Suggested template text for pre-survey article for external media

Title: [\[NHS Trust name\] seeks young patient views or
Children's views vital to drive service improvements in \[NHS
Trust name\]
Your chance to tell \[NHS Trust name\] about quality of care](#)

[NHS Trust name] is carrying out a survey to find out what young patients and their parents and carers think about the care they receive. The trust plans to use this feedback to improve patients' experiences. The results will be used to help [NHS Trust name] highlight areas where they perform well and to identify the areas where there is most room for improvement.

Patients who have recently been an inpatient or day case patient at [Hospital A and Hospital B] may receive a questionnaire in [month], asking about their experiences. They will be asked about various aspects of their care, including [how well they were treated by hospital staff, how involved they were in decisions about their care and how well staff worked together](#).

Obtaining feedback from patients and their carers and taking account of their views and priorities is vital for bringing about improvements in the quality of care. Results from the survey will be used to [\[insert purpose of survey here\]](#)

The results of the survey will be presented in a form that does not allow any individual's answers to be identified. The results will be published by [NHS Trust name] in [month and year].

[\[A senior executive at the trust\] says %We hope that our younger patients and their parents and carers will take the time to help us with this survey. Their views are vital in helping us to find out how we are doing and how we can improve. This is an excellent way for patients to help shape the services we provide in the future.+](#)

