

# 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 in house trusts

## Contacts

The Patient Survey Co-ordination Centre  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford  
OX2 0JB

Tel: 01865 208127  
Fax: 01865 208101  
E-mail: [CYP.data@pickereurope.ac.uk](mailto:CYP.data@pickereurope.ac.uk)  
Website: [www.nhssurveys.org](http://www.nhssurveys.org)

## Key personnel

Chris Graham (Director)

Hannah Atherton  
Caroline Killpack

Susie Stevenson  
Mark Waters

## 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. 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](http://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 first<sup>1</sup>, 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 (CYP 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 National NHS Children's Inpatient and Day Case Survey. It also provides guidance on how you

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<sup>1</sup> [http://www.cqc.org.uk/sites/default/files/documents/cqc\\_putting\\_people\\_first\\_tagged.pdf](http://www.cqc.org.uk/sites/default/files/documents/cqc_putting_people_first_tagged.pdf)

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 system<sup>1</sup> 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 and 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. These include the NHS Outcomes Framework (domain 4: Ensuring patients have a positive experience), the DH overall patient experience measure, the NHS Performance Framework, the cross-Whitehall Public Services Transparency Framework and NICE Quality Standards.

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<sup>1</sup> <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. Please continue to use the results from your in-house survey teams to improve services, but wait until the survey results for all trusts are published by the Care Quality Commission before promoting your results in any way (either on your website, in press releases or any other external publicity) to the local community and media. You will receive, along with communications staff in your trust, advance notice of the publication date and will have time to prepare for your local announcements once the embargo is lifted.

## 1.8 Basic requirements for the 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:

- The survey must be carried out using postal questionnaires - however trusts 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 (parent's survey), 8-11 year olds (child and parent's survey), and 12- 15 year olds (child and parent's 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 7 – Compiling a list of patients*.
- The sampling procedure set out in this guidance must be followed. For further details see *Section 7 – Compiling a list of patients*.
- It is important that your trusts liaise with the trust PALS/ patient experience 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 you submit your final anonymised sample file for checking. **This is a requirement of the Section 251 Approval given for this survey.**
- A new sampling checklist and declaration have been provided, for the member of trust staff drawing the sample and the Caldicott Guardian to sign. This declaration should be sent to the Co-ordination Centre before you send your anonymised sample file. This is important in order to follow the requirements from the 'Section 251 Approval'.
- Sample data (anonymised 'sample file') must be submitted to the Co-ordination Centre for final checks before mailing as outlined in *Section 8 – Final sampling inspection by the Co-ordination Centre*. You should aim to submit these sample files to us **between 15<sup>th</sup> September and 3rd October 2014** to allow sufficient fieldwork period to maximise response rates.
- You 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.

- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **16<sup>th</sup> October 2014**. A spreadsheet has been created for this purpose. For further details see *Section 11 – Weekly monitoring*.
- The questionnaires used for this survey must be the versions issued by the Co-ordination Centre. See *Section 10 - The questionnaires and covering letters*.
- 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) must be used as outlined in *Section 11 – Materials*.
- Two reminders must be sent to non-responders, even if a high response rate is already achieved. These procedures are outlined in *Section 12.4 – Sending out reminders*.
- A paper copy of the questionnaire and covering letters you used should be submitted to the Co-ordination Centre by **24<sup>th</sup> October 2014**.
- The final data must be entered and coded as specified in *Section 13 – Entering Data*.
- The final data from the questionnaires, and the required information about the patient sample, must be submitted to the Co-ordination Centre in the form outlined in *Section 13.5 – Submitting data to the Co-ordination Centre* by **20<sup>th</sup> February 2015**
- The free text comments must also be submitted to the Co-ordination Centre. These should be included as part of the final data file. See *Section 13.2 – Entering written comments (‘free text’) from patients*.
- Drawings from children must be submitted separately to the datafile. Each image should contain the patient record number. See *Section 13.3- Submitting drawings from patients*
- You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until **28<sup>th</sup> August 2015** but please do not send these to the Co-ordination Centre. These returned questionnaires may be needed to audit the data sent to the Co-ordination Centre.

## 2 Setting up a project team

Whether you choose to do the survey in-house, or to use 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 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)<sup>1</sup>, 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)<sup>2</sup>. 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/](http://www.mrs.org.uk/standards/data_protection/)

### 3.1 Statements of compliance with data protection

Each NHS trust has a Caldicott Guardian responsible for overseeing proper use of patient data. If you are conducting the survey in-house then, before mailing out the sample, you must submit a

<sup>1</sup> [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)

<sup>2</sup> [http://the-sra.org.uk/wp-content/uploads/sra\\_data\\_protection.pdf](http://the-sra.org.uk/wp-content/uploads/sra_data_protection.pdf)

formal declaration (see Appendices 3 and 4), signed by the Caldicott Guardian and survey lead(s) for the trust, to the Co-ordination Centre. This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the guidelines (see Section 5).

Templates for these declarations are available on the NHS Surveys website:  
<http://www.nhssurveys.org/surveys/790>.

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

**You must wait for confirmation of receipt from the Co-ordination Centre before you mail out your sample.**

### 3.2 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 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), the trust **must** ensure that these patients are excluded from the mailing list. Trusts should do this using their local records, and checking any other information sources where this data would be held.

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.

Due to the requirements of this surveys Section 251 Approval, contractors will be required to process any opt outs from parents/carers in a particular way. Contractors must confirm to the CQC that the following processes will be fulfilled:

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

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

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

Trusts have been advised to record all requests made from patients or parents/carers as a direct result of pre-survey publicity (such as the information flyers given out during the 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 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](http://www.nhssurveys.org/Filestore/documents/20120704_FAQs_on_fair_data_processing_draft4.pdf)

### 3.3 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 7.9). 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.** Where patient identifiable data is inadvertently transferred, breaches are reviewed by CQC and the Confidentiality Advisory Group also.

### 3.4 Mailing questionnaires to patients

Another important issue regarding mailing questionnaires and data protection relates to the envelopes used to mail out questionnaires. Some patients, parents and carers may not have told

family or friends that the child has gone to hospital and, under data protection regulations, it is important that this information remains confidential. Therefore it is important that the envelope(s) used to mail out your survey materials does not show any indication of the NHS Trust name.

### 3.5 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 the Co-ordination Centre before you are able to submit your sample. The Co-ordination Centre will use these documents to help check your sample file.

### 3.6 Assurances of patient anonymity

Patient anonymity can be achieved if there is a clear separation between the information used for mailing and the survey response information held by the trust. Patients' names and addresses will be seen by trust staff when generating the sample, and must be kept separate from both the anonymised sample file and the survey response file. As long as the response data held by 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.

### 3.7 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:

## Trust level

- 1) The raw data set should not be provided to any member of staff at the trust who does not need to view it, i.e. those who are not directly working on the project.
- 2) If data are to be presented to other trust staff, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than **30 respondents** should be suppressed (replaced by a dash). The data should be presented as in the following example. In this case, responses for the 'Mixed' and 'Asian' ethnic categories are suppressed (though the subgroup 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              |

- 3) 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.
- 4) 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.
- 5) Children will also be able to provide their feedback by drawing a picture instead of writing comments. Again, the pictures will not be anonymised in any way.
- 6) The electronic file containing the patients' names and addresses should be stored securely (i.e. password protected).

## 3.8 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of patients' names, and the questionnaires kept until **28th August 2015**. All mailing lists of patients' names and addresses should be stored on a separate computer to that containing survey data. Mailing lists of patients' names and addresses should be destroyed when the mailing process is complete.



## 4 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.

### 4.1 Ethical approval

Research Ethics Committee (REC) approval has been obtained for the 2014 National NHS children's 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.

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](mailto:nres.queries@nhs.net)

### 4.2 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.

## 5 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. If you are a trust that intends to conduct the survey using an in-house team, and you do not have access to such a service, please contact the Co-ordination Centre for further advice.
- A multi-language leaflet template is available on the NHS Surveys website, and this can be included with your first and third mailings. Trusts and 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.

## 6 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 survey<sup>1</sup>. 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.

### Key dates

|   |  |
|---|--|
| Trusts to inform Co-ordination Centre of survey leads                   | ASAP and no later than <b>22nd August 2014</b>       |
| Submission of sample data   | <b>15<sup>th</sup> September – 3rd October 2014</b>  |
| Approval of sample data   | From <b>15<sup>th</sup> September 2014</b>           |
| Submission of online questionnaire to Co-ordination Centre for checking | <b>22<sup>nd</sup> September 2014</b>                |
| Start of fieldwork  | <b>6<sup>th</sup> October 2014</b>                   |
| Weekly monitoring starts  | <b>16<sup>th</sup> October 2014</b>                  |
| 2 <sup>nd</sup> mailing (1 <sup>st</sup> reminder)                      | <b><u>By</u> w/e 5<sup>th</sup> December 2014</b>    |
| 3 <sup>rd</sup> mailing (2 <sup>nd</sup> reminder)                      | <b>5<sup>th</sup> - 23<sup>rd</sup> January 2015</b> |
| Close of fieldwork  | <b>13<sup>th</sup> February 2015</b>                 |

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<sup>1</sup> 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](http://www.nhssurveys.org/Filestore/documents/Extension_of_fieldwork_for_inpatient_survey_2007.pdf)

## 7 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 7 BEFORE you start to compile your patient list.

#### 7.1 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 **31<sup>st</sup> 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 1<sup>st</sup> August 2014 (whichever occurs first). The minimum pre DBS sample size for this survey is 380 patients. If you have sampled back from 31<sup>st</sup> 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 is 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 **1<sup>st</sup> July 2014** to generate their sample of eligible patients submitted to DBS. The minimum sample size drawn required is 380, 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 7.5).

## 7.2 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.

### 7.3 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 and your clients have checked that DBS licences are 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 samples are drawn 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://nww.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](mailto: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.

## 7.4 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 'D').

For further information see: <http://nww.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](mailto: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, drawing your sample and mailing out as soon as possible, and you will need to send out two reminders. 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 of that have been correctly sampled and mailed.

## 7.5 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.

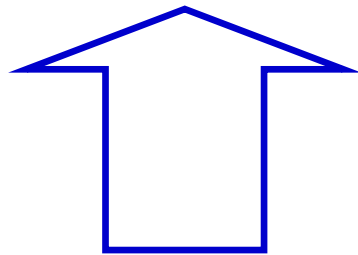
This file has three purposes:

- 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 you 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 1 – 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>Survey version</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 Specialty 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                 | B                     | 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                 | C                     | 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                 | C                     | 2             | R                      | 17                      | 6                         | 2014                     | 17                      | 7                         | 2014                     | 0                     | 300                                | 09Y             | 0                                 |                           | RR115                             | RR115                             |  |  |   |                |                                |
| RT5                   | CYP14RX 10850                | Ruby              | Young          | -               | -               | AB9 5ZX         | 08                    | 2013                 | A                     | 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 1

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.

*Red italic* headings: these columns should be completed during the sampling phase and submitted to the Co-ordination Centre prior to mailing (to allow for final inspection by the Co-ordination Centre - see Section 11) and at the conclusion of the survey (see Section 13.5).

*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 trust is notified the patient will not be participating (patient deceased, moved address, too ill, or called to opt out).

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', 'twin' etc OR **Initials:** trusts have the option of either using first name or initials for the covering letter mailing
- **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, 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). Envelopes will be addressed: 'To the parent or carer of.'

- **Month of birth** (1 or 2 digits; e.g. June = 6 or November = 11)\*
- **Year of Birth** (4 digits eg 2011)
- **Survey version:** calculate the patient's age as of **August 2014**, using the month and year of birth information above. Assign the correct questionnaire version:
  - A (0-7s) – any child with a birth date of September 2006 or later
  - B (8-11's) – any child with a birth date of September 2002 - August 2006
  - C (12-15s) – any child with a birth date of September 1998 – August 2002
- **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](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](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 '1' for patients who spent any part of their inpatient stay at an NHS treatment centre within the trust, and coded as '0' 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](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>

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

- **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:

- 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 (if the survey is being carried out in-house) or the contractor (if the survey is being carried out by an approved contractor). 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), you (or 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. If an approved contractor is used, you will need to agree with them on the range of serial numbers that will be used for your patients. 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 can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be filled in as a one or two digit numerical response which will range from 1-31, **not** a date format (e.g. N or NN **not** 22/10/14).
- 4) **Month of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be a one or two digit numerical response, ranging between 1 and 12, **not** a date format.
- 5) **Year of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be a four digit numerical response (e.g. 2014), **not** a date format.
- 6) In the event that both a paper and an online questionnaire are received with the same PRN, the version that arrives first must be the one that is logged as completed (and the data processed). Priority must not be given to either method as this would skew the response rates by method.
- 7) 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

The outcome column is left blank at first if the questionnaire has not been returned (in Table 3 you can see that Ms Yoo has not yet returned her questionnaire).

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

## 7.6 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.

## 7.7 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.

## 7.8 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.

## 7.9 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 file'. 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 'CYPIPandDC2014\_mailing data'. It should resemble Table 2 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.<sup>1</sup>

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).

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<sup>1</sup> As shown in Table 1 (see section 9.5), the 'outcome' field 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...

## 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 2 – Example mailing file*

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

### 7.10 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 is a requirement to reduce data breaches where patient identifiable data is submitted in the same file as the sample variables. The form can be downloaded from here: <http://www.nhssurveys.org/surveys/787>

The sample declaration form must be emailed to the Co-ordination Centre before you send the sample file to them. The Co-ordination Centre must confirm that they are happy to receive the sample file before it is sent to them. **You must not send the sample file to the Co-ordination Centre until the permission has been given.** The Co-ordination Centre will not be able to receive your anonymised sample file until they have received your sample declaration form and have confirmed that they are happy to receive the sample.

**Please ensure that no patient identifiable data is sent to the Co-ordination Centre. If this happens, it will be logged as a breach of the Section 251 Approval for the survey, and follow up action taken by the CQC.**

### 7.11. 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 7.1)



2. Checked your patient list to make sure it meets requirements and only includes eligible patients (Section 7.2)
3. Sent the list to the DBS to check for deceased patients and removed these patients from your list (Section 7.3 and 7.4)
4. Created a sample file (Section 7.5)
5. Checked the distribution of patient age, gender and route of admission (planned versus emergency) in your sample file (Section 7.6, 7.7 and 7.8)
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 7.9)
8. If required, shared the sample file (and possibly the mailing file) with an approved contractor (Section 7.11)

## 8 Final sampling inspection by the Co-ordination Centre

### 8.1 Procedure for submitting the anonymised sample file to the Co-ordination Centre

In order for the Co-ordination Centre to make final quality control checks, an anonymised sample file must be submitted to the Co-ordination Centre **prior** to the first mailing. This file will contain all columns *in red italics* in Table 3 – *Sample construction spreadsheet of patient details*, **but must not contain name, address and postcode details** (see Section 7.5).

#### Remember

Before submitting this data, you **must** first complete all checks described in the previous section

You must submit your sample declaration form to the Co-ordination Centre and wait for confirmation that this has been received **before** you send your anonymised sample file. **This is a requirement of the survey's Section 251 Approval and must be adhered to.**

**Please ensure the sample file does not contain patient name, address or postcode details.**

Please ensure fields are correctly formatted and contain only the data requested in the format requested e.g. year of birth field does not contain date of birth. If name, address and similar identifiable data is transferred to the Co-ordination Centre, CQC inspectors will be notified of such data breaches and will consider if enforcement action is required.

The sample construction spreadsheets will be formatted to prevent data being entered in the wrong format. It is essential that samples are submitted using the construction spreadsheets provided.

### 8.2 Timetable for submitting data to the Co-ordination Centre

The Co-ordination Centre will be checking for extraordinary errors. These are more visible when viewing data from many trusts at one time. For this reason, samples will be checked as collated files (the 'anonymised' versions of files, excluding names and addresses). Table 5, below, sets out the dates of submission and the respective date trusts can expect to receive a response back from the Co-ordination Centre.

**Table 3 – Sample submission dates**

| Date sample received  | Date of response (midday)  |
|---|----------------------------|
| 15 <sup>th</sup> September -19 <sup>th</sup> September      | 25 <sup>th</sup> September |
| 22 <sup>nd</sup> <sup>th</sup> - 24 <sup>th</sup> September | 29 <sup>th</sup> September |
| 25 <sup>th</sup> – 29 <sup>th</sup> September               | 3 <sup>rd</sup> October    |
| 29 <sup>th</sup> September – 3 <sup>rd</sup> October        | 8 <sup>th</sup> October    |

In cases where anomalies are discovered in the sample data submitted, trusts will be notified no later than midday of the day indicated in Table 3 above.

Samples should be submitted to the Co-ordination Centre no later than **3rd October 2014**. If they are not, there is a risk the trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may result in the data from the trust being excluded from CQC assessments and national level indicators.

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 **8<sup>th</sup> 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.

### Important note

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

**Remember to submit your data declaration form to the Co-ordination Centre before you start mailing out, even if your sample has been approved.**

## 8.3 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 (**15<sup>th</sup> September 2014**). **There are several ways you can do this:**

- 1) Check your DBS licence and software are up to date, ready for the sample to be submitted to check for patient deaths.
- 2) Allocate sufficient time to the individual who will generate the sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by the Co-ordination Centre.
- 3) The printing of questionnaires and assembly of mailing packs can take place before the sample is signed off. Please ensure that the envelopes are left open though so that you can check the correct label is applied to the correct questionnaire.

## 9 Weekly Monitoring

The Co-ordination Centre requires weekly submissions of data on response rates and usage of the helpline (see Sections 11.1 and 11.2 respectively). The first submission of data must be made on **16th October 2014**, regardless of whether mailing has commenced, with further submissions being made every Thursday thereafter until the final date of submission. An Excel spreadsheet is available (<http://www.nhssurveys.org/surveys/784>) which **must** be used to return this information to the Co-ordination Centre. This information should be emailed to the Co-ordination Centre ([CYP.data@pickereurope.ac.uk](mailto:CYP.data@pickereurope.ac.uk)) by the end of the workday every Thursday throughout the survey.

### Important note

It is important that the structure of the Excel weekly monitoring spreadsheet is not altered and that the correct file name is used when submitting the data.

#### For approved contractors:

When the data is submitted, the file name **must** be in the following format:

CYP14\_<Trustcode>\_<week of submission>.xls

e.g. CYP14\_R1F\_1.xls (first submission of monitoring data on **16th October 2014**)

CYP14\_R1F\_3.xls (third submission of monitoring data on **6th November 2014**)

***Each trust should use their NHS trustcode.***

### 9.1 Monitoring response rates

The information submitted to the Co-ordination Centre should contain the following data:

- The total number of patients in the sample i.e. the total number of all those included in the first mailing.
- The number of patients in each outcome field (see (5) under the 'Additional information' subheading in Section 7.5).

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

### 9.2 Helpline monitoring

It is advised that a helpline is set up to deal with calls from patients or parents/carers (Section 15.3). You must submit the following information to the Co-ordination Centre:

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

- The number of calls seeking assistance with language and translation (this should include completions via translation services)
- The number of calls that led to completion of the questionnaire using translation services

### Example: How to record calls

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

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

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

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

## 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. The questionnaires are copyrighted and therefore no trust logos are to appear on the questionnaire versions.

Trusts will also be able to offer the core 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. . **Please note that the online option will be offered to patients concurrently: this means that all patients will still receive a paper questionaire but the information about the online option will appear in the covering letter. You will not be able to offer the online option only.**

If you wish to take the online option up, you must contact the Co-ordination Centre to let them know- please do so as soon as possible. The Co-ordination Centre will check all online surveys before they go live, please contact the Co-ordination Centre on email:

[CYP.data@pickereurope.ac.uk](mailto:CYP.data@pickereurope.ac.uk). **You must submit the online questionnaires to the Co-ordination Centre for checking by 22<sup>nd</sup> September 2014.**

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

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>

The front page must be printed in colour as this will have the colour CQC and NHS logos; all other pages can be in black and white. **Trust logos are NOT to be added to this version.**

### 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. There is an additional survey information leaflet specifically for children which accompanies the covering letter and questionnaire. The parents and carers section follows the section for the 8-11 year olds and is divided into sections that broadly follow the experience of an inpatient/ day case but from the perspective of the parent or carer. The three questionnaires can be downloaded from the NHS Surveys website: <http://www.nhssurveys.org/surveys/778>

This questionnaire must be printed in colour throughout. This questionnaire is copyrighted meaning that no changes are permitted and trust logo's are not to be added.

### 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>

This questionnaire must be printed in colour throughout. This questionnaire is copyrighted meaning that no changes are permitted and trust logo's are not to be added.

### 10.4 The covering letters and leaflet

#### Covering letters

For this survey there are 2 covering letters, both are 2 sides of A4:

- **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.

#### Children's leaflet

There will also be a 1 page A4 information leaflet for the child aged 8-15 to read through. You will need to print this and include in the mailing packs.

The different covering letters and the children's leaflet can be downloaded from the NHS Surveys website: <http://www.nhssurveys.org/surveys/783>.

It is vitally important that the correct covering letter is mailed with the correct questionnaire type.

# 11 Materials

## 11.1 Paper questionnaires

### Questionnaire layout

The questionnaires are tested in the format of the templates available on the NHS Surveys website (<http://www.nhssurveys.org/surveys/778>).

## 11.2 Online questionnaire

It is up to individual trusts whether the online survey option is offered to respondents or not. If you decide to offer this option, you will need to program the online survey and provide details of the web link to patients. For those trusts who are doing the survey in-house and intend to offer the online questionnaire, it is important that the online survey mirrors the paper version as far as is possible in terms of content, format and appearance.

Though the content will remain the same, online surveys are generally less formal than paper-based surveys and so the online version needs to account for this. Additionally, some of the paper-based questionnaire content, such as the front page instructions, is not applicable to the online version.

It is important that the online questionnaire is comparable across all contractor and in-house versions. For this reason, online surveys will be checked by the Co-ordination Centre and signed off before going live.

### Questionnaire layout

The paper questionnaires should be adapted for online use accordingly:

- Respondents will log into the survey using their assigned Patient Record Number (referred to as their username) and a password (both as per their covering letter);
- The survey version will automatically be assigned based on the PRN (rather than the respondent having to select the survey version);
- Question and response code fonts should be in black on a white background;
- Question wording to be the same as in the paper questionnaire;
- If possible, question numbers should not appear on screen (as the parent / carer sections in the Children's and Young Person's Questionnaires start at Q19 / Q23 respectively so might be confusing). Questions should have the same question number assigned in the datasheet however.
- Any parts of a question in bold or underlined should be presented as such;
- If possible, scale questions should appear horizontally but must have the same anchor points;
- Response options to be the same as in the paper questionnaire and in the same order;
- Response options to appear vertically as per the paper version;
- Response options to have the same response codes assigned;
- Routing will be pre-programmed;
- Single code questions should allow a single code response; multi-code questions should allow multiple codes;



- For all questions, respondent is allowed to skip without answering (even if there's a 'don't know' or similar response listed);
- One question per screen;
- Free-text questions must have space for up to 800 characters (approximately 200 words);
- Similar section colouring should be used as in the Children's and Young Person's Questionnaires;
- The smiley faces that accompany the response codes on the Children's Questionnaire should be used;
- The illustrations used in the Children's and Young Person's Questionnaires should be used where indicated;
- Progress bars should not be used;
- 'Back' and 'next' buttons to appear on screen;
- Text in black (below) to appear on screen;
- Program instructions or information (below) in grey

## Log in screen

### Log in screen

Hello and welcome to the 2014 National NHS Children's Inpatient and Day Case Survey. Please enter your username and your password - these can be found on the letter that was sent with your questionnaire.

Username

Password

If correct, the intro screen will appear.

If incorrect, a message appears 'Sorry, we are unable to log you in, please call the helpline number given in the letter for assistance'

## 'Parent or Carer Questionnaire'

### Intro screen

This survey is about your child's most recent visit or admission to hospital named in the letter which was sent to you along with the questionnaire. Your child may have only been in hospital for a day (as a day case) or may have stayed for at least one night in hospital (inpatient).

For each question, just click the option that best applies.

Most questions will need one answer only, however some questions will allow you to choose more than one answer (these will ask you to 'choose all that apply').

Click 'next' to continue...

### Question screens

This first set of questions is about **Going to Hospital**. So...

Was your child's visit to hospital planned or an emergency?

Emergency (went to A&E / Casualty / came by ambulance etc.)

code 1

Route to Q5

Planned visit / was on the waiting list

code 2

Route to Q2

Choose the response that best applies, then click 'next' to continue...

Separate screens for each question. For questions 2-4, keep the header **Going to Hospital**, with the question beneath it.

At Q5, show the section header **The Hospital Ward** with Q5 below it.

Keep the section header for Q6, with Q6 beneath it.

Continue in the same fashion for the subsequent questions and sections.

Notes:

Q45 Remove 'please circle a number'

Q50 and Q51 Add the instruction 'Choose all that apply'

Q52 May need to present as 2 columns?

At end of survey, say **That's the end of the survey, thank you for completing it. Please click 'submit'**

## **'Children's Questionnaire'**

Intro screen 1

This survey is about your most recent stay in hospital. There are two sections - the first is about your own experience of what happened; the second section is for the parent or carer who took you to hospital to complete.

For each question, just choose the word or phrase that best matches what you think.

Click 'next' when you are ready to start...

Question screens

This first question is about **Going to Hospital**. So...

**Before** you went into hospital, did you know **what was going to happen to you** while you were there?



Yes

code 1



Yes, sort of

code 2



No

code 3

Choose the word or phrase that best matches what you think, then click 'next' to continue...

Next screen

The next section is about **The Hospital Ward**...

Show Q2 beneath this header.

Show Image  of the girl with the broken leg at the bottom of the screens for Q2- 4 in this section.

Next screen

At Q3, show as the header **The Hospital Ward – Things To Do On The Ward**

Show Q3 beneath it.

Next screen

At Q4, show as the header **The Hospital Ward – Hospital Food**

Show Q4 beneath it.

Next screen

The next section is about **Looking After You In Hospital**...

Show Q5 beneath it.

Show Image  of the boy with his arm in plaster at the bottom of the screen for this section.

Repeat in the same fashion for the subsequent sections and questions.

At 'Operations' section, show Image  of the notepad at the bottom of the screen.

At 'And Finally' section, show Image  of the stethoscope at the bottom of the screen.

Next screen

## Anything Else To Say?...

Was there anything else you wanted to tell us about your time in hospital (anything particularly good, or anything that could have been better)? Please tell us in your own words here...

Click 'Next' when you are finished.

Next screen

Please now ask your parent or carer to complete the next section.

Click 'next' to continue.

Parent's section

Intro screen 2

This survey is about your child's most recent visit or admission to hospital named in the letter which was sent to you along with the questionnaire. Your child may have only been in hospital for a day (as a day case) or may have stayed for at least one night in hospital (inpatient).

This section of the survey is about your experience of your child's stay or visit.

For each question, just click the option that best applies.

Most questions will need one answer only, however some questions will allow you to choose more than one answer (these will ask you to 'choose all that apply').

Click 'next' to continue...

Next screen

Was your child's visit to hospital planned or an emergency?

Emergency (went to A&E / Casualty / came by ambulance etc.)

code 1

Route to Q23

Planned visit / was on the waiting list

code 2

Route to Q20

Choose the response that best applies, then click 'next' to continue...

Separate screens for each question.

At Q23, show the section header **Hospital Staff** with Q23 below it.

Continue in the same fashion for the subsequent questions and sections.

Notes:

Q48 Remove 'please circle a number'

Q51 May need to present as 2 columns?

Q52 and Q53 Add the instruction 'choose all that apply'

At end of survey, say That's the end of the survey, thank you for completing it. Please click 'submit'

## 'Young Person's Questionnaire'

Intro screen 1

This survey is about your most recent stay in hospital. There are two sections - the first is about your own experience of what happened; the second section is for the parent or carer who took you to hospital to complete.

For each question, just click the option that best applies.

Click 'next' when you are ready to start...

Question screens

This first question is about **Going to Hospital**. So...

**Before** you went into hospital, did you know **what was going to happen to you** while you were there?

|              |        |
|--------------|--------|
| Yes          | code 1 |
| Yes, sort of | code 2 |
| No           | code 3 |

Choose the response that best applies, then click 'next' to continue...

Next screen

The next section is about **The Hospital Ward...**

Show Q2 beneath the header.

Show Image  of the boy with the arm in plaster at the bottom of the screens for this section.

Repeat in the same fashion for the subsequent sections and questions.

At 'Pain' section, show Image  of the stethoscope at the bottom of the screen.

At 'Leaving the Hospital' section, show Image  of the girl on crutches at the bottom of the screen.

Next screen

**Anything Else To Say?...**

Was there anything else you wanted to tell us about your time in hospital? Please tell us in your own words here...

Click 'Next' when you are finished.

Next screen

Please now ask your parent or carer to complete the next section.

Click 'Next' to continue.

Program the rest of the survey as per the parent section in the Children's Questionnaire.

### 11.3 Trust headed paper

You will need headed paper for covering letters for the first and third mailing. A reminder letter is used for the second mailing. Therefore, depending on the response to the initial mailings, you will need approximately 1,200 to 1,600 sheets of trust headed notepaper.

### 11.4 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.

CQC will supply sufficient numbers of the flyers to each in house trust. If you require more flyers during fieldwork then you need to contact the CQC team.

### 11.5 Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to patients does not show any indication of the NHS Trust name, or any other information linking it to health care.

Some patients, parents or carers may not have told family or friends that the child had gone to hospital and, under data protection regulations, it is important that this information remains confidential to the patient and their parent/carer. We would therefore recommend that the return address used on any mail out envelope(s) does not indicate trust name or address. It is, however, important that you record questionnaires which are returned undelivered as this affects response rate.

## 11.6 Materials required for first mailing

You will need 850 (or the correct number for your sample) of each of the following items:

- Printed questionnaires
- Large envelopes for mailing questionnaires to parents/ carers of the sampled patients
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes
- FREEPOST envelopes for return of questionnaires
- Covering letters using the trust's letterhead
- Children's information leaflet
- Multi-language helpline sheet (recommended)<sup>1</sup>
- Survey flyer.

## 11.7 Materials required for second mailing (first reminder)

First reminders are sent to all patients who do not respond to the first mailing (except, of course, those who withdraw). Usually you will need to send first reminders to around 55-75% of the original patient sample. The following items are needed:

- Reminder letters
- Envelopes
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house trusts)

## 11.8 Materials required for third mailing (second reminder)

The second reminder should replicate the first mailing, and you will need to send this to around 45-65% of the original sample, depending on the number of responses to the previous two mailings. The following items are needed:

- Printed questionnaires
- Large envelopes for mailing questionnaires to parents/ carers of sampled patients
- Labels for addressing envelopes

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<sup>1</sup> This document can be found on our website alongside the cover letters. The languages covered by this document are: Arabic, Bengali, Chinese (Cantonese), Farsi /Persian, Gujarati, Hindi, Kurdish, Chinese (Mandarin), Punjabi, Tamil, Thai, Turkish, Urdu, French, Italian, Polish, Portuguese, Russian, Somali, Spanish.

- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house trusts)
- FREEPOST envelopes for returning questionnaires
- Reminder letters
- Children's information leaflet
- Multi-language helpline sheet (if used in first mailing)
- Survey flyer.

## 11.9 Other mailings and inclusion of other information in the mailing packs

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

Furthermore, no other material should be included in the questionnaire packs because of the immeasurable impact upon response rates to the survey. Additionally, the NHS REC who gave the survey ethical approval will not have viewed any additional material. There is potential for the ethical approval to be invalidated if non approved materials are included for this survey.

## 12 Implementing the survey - practicalities

### 12.1 Setting up a FREEPOST address

A FREEPOST address allows patients to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the envelopes you send out with the questionnaires. Printed envelopes must comply with Royal Mail guidelines.

Details of how to apply for a FREEPOST licence can be found at the Royal Mail website: <http://www.royalmail.com/>. Alternatively, you can call your local Sales Centre on 0845 7950 950.

### 12.2 FREEPHONE line

As covered in section 11.2, it is advised that you set up a Freephone line to deal with any queries from patients about the survey. All staff who are likely to take calls should be properly briefed about the details of the survey, and be aware of the questions or complaints they are likely to receive.

#### Managing calls to the FREEPHONE line

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

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

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

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

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

Patients can be referred to the trust's PALS, the complaints manager or patient services manager. Approved contractors should be given the contact details of the PALS office or an appropriate member of trust staff so that they can refer callers to that person.

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

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

### The person to whom the questionnaire is addressed has died.

Even with the use of a deceased patients tracing service, it may not be possible to identify all deceased patients, particularly those who have died most recently. It is very important that staff who take the calls are aware of this possibility and are prepared to respond sensitively to such calls. These patients should be recorded as outcome = 3 (patient deceased) in the sample file (see (5) under 'Additional information' subheading of Section 9.5).

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

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

### I do not wish to participate in this survey.

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

5. Any objection is to be recorded immediately and checks made to determine whether a mailing is underway. If a mailing is underway the caller will need to be advised that it might not be possible to prevent this mailing but assured that they will receive no future mailings.
6. People wishing to receive no further questionnaires can be identified with a flag/ code/ number on the mailing file. Where an individual objects to their data being held by the contractor, their name and address information will be overwritten.

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

It is also advisable to ask the patient to ignore any future reminders that they might receive. These patients should be recorded as outcome = 4 (opt out) in the sample file (see (5) under 'Additional information' subheading of Section 9.5).

## Making a record of the calls

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

We also ask for weekly submissions of helpline use from each trust to the Co-ordination Centre. This is discussed in detail in Section 11.2.



## 12.3 Covering letters

The two standard covering letters and a children's information leaflet for the first and third mailings are available in Microsoft Word format on the NHS Surveys website for you to download and add your own trust's details (see <http://www.nhssurveys.org/surveys/783>). These letters have been given ethical approval for use in the 2014 National NHS Children's inpatient and day case Survey and changes are not permissible. They should be printed on the trust's letterhead paper. A paper copy of the letters you use must be sent to the Co-ordination Centre by **29th August 2014**.

**Please note that if you wish to mail to parents/ carers using the child's initials rather than first name, please contact the Co-ordination Centre. They will provide you with the covering letter template that has the additional line of text in, asking parents/ carer to answer the questionnaire based on the child most recently discharged (see Section below).**

## 12.4 Sending out questionnaires

### Address labels

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

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

Ideally, and in most cases where possible, envelopes should be addressed: **'To the parent or carer of:'** with the child's first and last name and address details underneath eg:

To the parent or carer of:  
Annie Abbot  
14 Station Road  
London  
AB1 1YZ

Please note that some trusts may prefer to address the envelope: 'To the parent or carer of A Abbot'. If trusts do use initials and surname, rather than first name and surname, a note should be added to the covering letter instructing the parent/carer to think of the child most recently discharged from hospital- please speak to the Co-ordination Centre about this..

Analysis will be done at survey close to determine the levels of mistaken completion, by comparing self-reported demographics against sample information. This information will form part of the evaluation at the end of the survey.

## Note on the patient record number (PRN)

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

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

## Questionnaire packs

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

- 1) A questionnaire **numbered with the patient record number**. The number must match the number on the address label, and the number on the list of patient details.
- 2) A covering letter.
- 3) Children's information leaflet
- 4) The multi-language helpline sheet (recommended).
- 5) A large envelope, labelled with the FREEPOST address on it.
- 6) Survey flyer
- 7) These items should be packed into an envelope that has a return address on the outside. This should be your contact details.

## Postage

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

### 12.5 Booking in questionnaires

When questionnaires are received, match up the patient record numbers against the list of patients, so that you can record (in the *outcome* column of your 'sample file') which patients have returned questionnaires and will not therefore need to be sent reminders. (See text box – 'Note on the patient record number (PRN)' – above about what to do if a questionnaire is returned without the patient record number on the front). You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until **28th August 2015**, but please **do not** send these to the Co-ordination Centre.

### 12.6 Sending out reminders

For results to be representative, it is essential to get a good response rate. To achieve this, you must send out two reminders to non-responders. **Remember, it is essential that you send out both reminders, even if you already have achieved a high response rate.**

Depending on the time that has elapsed since you first checked the patient list for deaths, it might be necessary to send the list back to the Demographic Batch Service for a further check before you send out reminders.

## 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.

As the fieldwork period extends into the Christmas and New Year holiday period (when response would be expected to be lower), you must send out the first reminder mailing by the **week ending 5<sup>th</sup> December**.

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. A paper copy of the reminder letter you use must be sent to the Co-ordination Centre accompanying the hard copies of the questionnaire.

## Second reminders

Due to the holiday period, **the second reminder must be sent out between 5<sup>th</sup> and 23<sup>rd</sup> January 2015**, after the holiday period, and giving sufficient time until the close of fieldwork for questionnaires to be returned.

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 the trust should check their own records for deaths before you send out reminders.**

## 13 Entering data

Final data must be submitted to the Co-ordination Centre in the appropriate format by the deadline of **20<sup>th</sup> February 2015**.

### 13.1 Entering data from the different questionnaires

The data should be entered into the pre-designed Excel files, called the 'Data entry spreadsheet', which can be found on the NHS Surveys website (<http://www.nhssurveys.org/surveys/816>).

Data should be entered using the following guidelines:

- There is a separate data entry spreadsheet for every questionnaire (0-7, 8-11 and 12-15)
- Each row records one patient response to the parents survey
- Patients who are missing their patient record numbers should be added to the bottom of the list, and not matched to patients with similar demographics
- For each question, the small number next to the box crossed by the patient should be entered as the response
- If a response is missing for any reason, it should be left blank, or coded as a full stop (.).<sup>1</sup>
- If two boxes are crossed (where only one should be crossed), the response should be left blank or coded as a full stop (.). The only exception to this is the 'Overall...' question, where the code 98 should be used for any incidence when a single number has not been selected, ie: a mark in between two numbers or where more than one number has been circled.
- For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For multiple response questions (e.g. in the 8-11 year olds version: Q52 and Q53 which instruct respondents to "Cross ALL boxes that apply", each response option is treated as a separate question (see example text box below)

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

#### Example: Entering data for multiple response questions

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

- 1  Deafness or severe hearing impairment
- 2  Blindness or partially sighted
- 3  A long-standing physical condition
- 4  A learning disability
- 5  A mental health condition
- 6  A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
- 7  No, I do not have a long-standing condition

If you want frequencies of missing responses by question to be displayed on the other pages of the workbook, you will need to fill in the blank cells with a full stop (.).

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

Q52 takes up seven columns in the data file, labelled as follows:

| Column headings          | Q52_1 | Q52_2 | Q52_3 | Q52_4 | Q52_5 | Q52_6 | Q52_7 |
|--------------------------|-------|-------|-------|-------|-------|-------|-------|
| Codings for this example | 1     | 0     | 0     | 0     | 1     | 0     | 0     |

## Adapting the data file for sending required data to the Co-ordination Centre

You will need to send the data from the three questionnaires to the Co-ordination Centre. To do this, you will need to transfer those columns of data that cover the responses to those questions to the pre-designed Excel files (the 'Data entry spreadsheets') available on the NHS surveys website. Within each questionnaire file (0-7, 8-11, 12-15), the columns of this pre-designed Excel file are headed with the numbers corresponding to the question numbers in the survey. They also include the wordings of the survey questions so that you can match them up.<sup>2</sup>

### 13.2 Entering written comments ('free text') from patients

The Care Quality Commission has asked the Co-ordination Centre to provide all written comments ('free text comments') in verbatim format. The CQC feels that valuable feedback will be lost if the free-text comments were anonymised, and therefore comments will be looked at in full by trusts, the CQC and researchers. However, any information that would allow an individual to be identified will be removed prior to any publication of results.

### 13.3 Submitting drawings from patients

For this survey, children will have the opportunity to provide a drawing that details their experience instead of, or as well as, free text comments. It is important that these drawings are submitted to the Co-ordination Centre alongside the data file. The drawings must be submitted in a separate file to the survey data and each image must have the patient's PRN in the file name, along with the trust code in the format CYP14XXXNNNN...where 'XXX' is the 3 character trust code and 'NNNN' is the Patient Record Number.

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<sup>1</sup> Please note: if a respondent does not answer any part of a multiple response question, (i.e. does not select any of the response options) then it should be left blank or coded as a full stop (.)

## 13.4 Coding data

For the National NHS children and young people's inpatient and day case survey 2014, contractors are required to submit raw ('uncleaned') data to the Co-ordination Centre. For clarification, raw data is created by the following:

- 1) All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (e.g. where patients answer questions that they have been directed to skip past, these responses should still be entered).
- 2) Where a respondent has selected more than one response category on a question, this question should be set to missing for that person in the data (i.e. left blank, or coded as a full stop (.)). The **exception** to this is for the 'multiple response' questions (e.g. Q52 and Q53), where respondents may select more than one response option (see Section 13.1 for details about how to enter responses to these types of questions). The **other exception** to this is for the 'Overall...' question when a code of '98' should be used for any incidences where a whole number hasn't been circled (ie: the mark falls between two numbers) or when more than one number has been circled.
- 3) Where a respondent has crossed out a response, this should not be entered in the data (the response should be left blank, or coded as a full stop (.)). Where a respondent has crossed out a response and instead selected a second response option, this second choice should be entered into the data.
- 4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a patient has written their date of birth in the boxes for the "What was your year of birth?" question, but written their year of birth in at the side of this, then the respondent's year of birth should be entered.
- 5) For the year of birth question unrealistic responses should still be entered except following rule (4) above. For example, if a respondent enters '2015' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.
- 6) Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the patient's intended response has not been captured. This includes 'out-of-range' responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Co-ordination Centre where they are found to have been entered inconsistently with the respondent's intended response.

A data cleaning document will be provided during the fieldwork that will document all filtering and cleaning carried out on the collated dataset by the Co-ordination Centre so that trusts and can duplicate this process after submitting the raw data to the Co-ordination Centre.

## 13.5 Submitting data to the Co-ordination Centre

The data from the questions of the questionnaire must be supplied to the Co-ordination Centre as anonymised Excel files that includes information about the patient sample as well as data from respondents to the survey. The easiest way to do this is to use the pre-designed Excel files available on the NHS Surveys website (the 'Data entry spreadsheet', see) as described in Section <http://www.nhssurveys.org/surveys/816> 13.1.

**Please remember, in order to comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre.**

## Required file format for final data

Please submit the file to the following specifications:

- Use Microsoft Excel Worksheets included in the template provided by the Co-ordination Centre. Any version of Excel is acceptable
- The file name must be in the form <NHSTrustcode>\_CYP2014.xls
- Use one row of data for each patient in the sample in each worksheet
- Use one column of data for each item of patient information or response in each worksheet
- Patients who are missing their patient record numbers should be added to the bottom of the list, and not matched to patients with similar demographics
- Missing data should be left blank or coded as a full stop (.).<sup>1</sup>

Table 4 details the information that must be provided for each of the 850 (or otherwise) patients in the original sample. Table 5, below, provides an example of the columns of data to be included in the file. The file should have 300-850 rows (one for each patient included in the sample) for each trust.

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<sup>1</sup> Data may be missing for a number of reasons. The patient may have skipped a question or a set of questions by following instructions; a patient may have not answered for some other reason. However, all missing data should be left blank or coded as a full stop (.), regardless of the reason for the omission.

**Table 4 – Data fields to be included in final data file submitted to Co-ordination Centre**

| Field                 | Format           | Data codes  | Comments   |
|-----------------------|------------------|---|--|
| NHS Trust code        | NNN              |   | 3 character trust code   |
| Patient record number | CYP14XXXNN<br>NN |   | The unique serial number allocated to each patient by the trust or approved contractor administering the survey. |
| Month of birth        | NN               |   | Format this simply as a number, not in date format.  |
| Year of birth         | NNNN             |   | Format this simply as a number, not in date format.  |
| Gender                | N                | 1 = male<br>2 = female  | If gender is not known or unspecified, this field should be left blank or coded as a full stop (.).              |
| Ethnic category       | N                | <p><b>National Codes:</b></p> <p><b>White</b><br/>                     A British<br/>                     B Irish<br/>                     C Any other White background</p> <p><b>Mixed</b><br/>                     D White and Black Caribbean<br/>                     E White and Black African<br/>                     F White and Asian<br/>                     G Any other mixed background</p> <p><b>Asian or Asian British</b><br/>                     H Indian<br/>                     J Pakistani<br/>                     K Bangladeshi<br/>                     L Any other Asian background</p> <p><b>Black or Black British</b><br/>                     M Caribbean<br/>                     N African<br/>                     P Any other Black background</p> <p><b>Other Ethnic Groups</b><br/>                     R Chinese<br/>                     S Any other ethnic group</p> <p>Z Not stated</p> | Ethnic category should be included if the information is available.  |
| Day of admission      | N or NN          |   | For example, if the patient was admitted on 14 <sup>th</sup> August 2014, this column should read '14'.          |
| Month of admission    | N or NN          |   | For example, if the patient was admitted on 14 <sup>th</sup> August 2014, this column should read '8'.           |
| Year of admission     | NNNN             |   | For example, if the patient was admitted on 14 <sup>th</sup> August 2014, this column should                     |



| Field                       | Format     | Data codes   | Comments   |
|-----------------------------|------------|--|--|
|                             |            |  | read '2014'.   |
| Day of discharge            | N or NN    |  | For example, if the patient was discharged on 29 <sup>th</sup> August 2014, this column should read '29'.  |
| Month of discharge          | N          |  | For example, if the patient was discharged on 29 <sup>th</sup> August 2014, this column should read '8'.   |
| Year of discharge           | NNNN       |  | For example, if the patient was discharged on 29 <sup>th</sup> August 2014, this column should read '2014'.  |
| Length of Stay              | N to NNNN  |  | For example, if the admission date was 15/8/2014 and the discharge date was 16/8/2014, the Length of Stay = 1. If the child is a day case patient, Length of Stay = 0. |
| Main Specialty on Discharge | NNN        | Use the codes as provided by HSCIC to complete this field.                         | Only supply the 'Main specialty' (of consultant) for each patient on their DISCHARGE.  |
| CCG                         | NNN        | Use the character codes provided by HSCIC to complete this field                   | Use the three characters of the CCG.   |
| Treatment centre admission  | N (0 or 1) | This flags whether the patient spent time in a NHS treatment centre at the trust.  | If the patient spent any time as an inpatient in a treatment centre, this should be recorded as '1'; if they did not then it should be recorded as '0'.                |
| Route of admission          | NN         | Please use the two-digit descriptive code provided by HSCIC to complete this data. | A blank or full-stop should be used if this information cannot be obtained for a patient.  |
| NHS Site Code on admission  | NNNNN      | Use the character codes provided by HSCIC to complete this field.                  | Use the five characters of the NHS site code.  |
| NHS Site Code on discharge  | NNNNN      | Use the character codes provided by HSCIC to complete this field.                  | Use the five characters of the NHS site code.  |

Continued...

**Table 4 continued**

| <b>Field</b>                              | <b>Format</b>   | <b>Data codes</b>  | <b>Comments</b>   |
|---|-----------------|--|---|
| Day of receiving questionnaire            | N or NN         | This is the day you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out).  | For example, if the questionnaire was received on 15 <sup>th</sup> October 2014, this column should read '15'.  |
| Month of receiving questionnaire          | N or NN         | This is the month you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out).  | For example, if the questionnaire was received on 15 <sup>th</sup> October 2014, this column should read '10'.  |
| Year of receiving questionnaire           | NNNN            | This is the year you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out).   | For example, if the questionnaire was received on 15 <sup>th</sup> October 2014, this column should read '2014'.  |
| Outcome of sending questionnaire          | N               | 1 = Returned useable <b>paper</b> questionnaire<br>2 = Returned undelivered by the mail service or patient moved house<br>3 = Patient died<br>4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire<br>5 = Patient was not eligible to fill in questionnaire<br>6 = Questionnaire not returned (reason not known)<br>7= Returned useable <b>online</b> questionnaire | Remember to fill in all the blank cells with the number 6 when the survey is complete.  |
| Responses to each of the survey questions | N or NN or NNNN |  | Each column must be clearly headed with the core questionnaire question number. Data should be coded using the numbers next to the response boxes on the printed surveys. |
| Patients' free text comments:             | Text            |  |   |

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

**Table 5– Example of data file to be submitted to Co-ordination Centre**

**Patient Sample Information**

**Patient Response Information**

| NHS Trust Code | Patient record number | Month of birth | Year of birth | Gender | Ethnic category | Day of admission | Month of Admission | Year of Admission | Day of discharge | Month of discharge | Year of discharge | Length of Stay | Main Specialty on discharge | CCG code | Treatment centre admission | Route of admission | NHS Site code on admission | NHS Site code on discharge | Day of questionnaire being received | Month of questionnaire being received | Year of questionnaire being received | Outcome | Q1 | Q2 | ..... | Q53                   | Was there anything particularly good about your hospital care? |
|----------------|-----------------------|----------------|---------------|--------|-----------------|------------------|--------------------|-------------------|------------------|--------------------|-------------------|----------------|-----------------------------|----------|----------------------------|--------------------|----------------------------|----------------------------|-------------------------------------|---------------------------------------|--------------------------------------|---------|----|----|-------|-----------------------|--|
| RT5            | CYP14ABC0001          | 6              | 1998          | 2      | A               | 5                | 6                  | 2014              | 11               | 6                  | 2014              | 6              | 100                         | 10Q      | 0                          | 12                 | RR115                      | RR115                      |                                     |                                       |                                      | 3       |    |    | -     |                       |  |
| RT5            | CYP14ABC0002          | 8              | 2001          | 1      | J               | 1                | 6                  | 2014              | 12               | 6                  | 2014              | 11             | 101                         | 10Q      | 1                          | 11                 | RTE03                      | RTE03                      | 22                                  | 10                                    | 2014                                 | 1       | 1  | 1  | -     | 1                     | I was seen straight away                                       |
| RT5            | CYP14ABC0003          | 1              | 2012          | 2      | C               | 5                | 6                  | 2014              | 11               | 6                  | 2014              | 6              | 100                         | 09Y      | 0                          | 21                 | RR115                      | RR115                      |                                     |                                       |                                      | 3       |    |    | -     |                       |  |
| RT5            | CYP14ABC0004          | 11             | 2006          | 1      | Z               | 2                | 6                  | 2014              | 12               | 6                  | 2014              | 10             | 101                         | 08L      | 1                          | 11                 | RTE03                      | RTE03                      | 22                                  | 10                                    | 2014                                 | 1       | 2  | 1  | -     | 1                     | The nurses were very helpful                                   |
| RT5            | CYP14ABC0849          | 5              | 2000          | 2      | R               | 17               | 6                  | 2014              | 30               | 6                  | 2014              | 13             | 300                         | 08L      | 0                          | 11                 | RR115                      | RR115                      |                                     |                                       |                                      | 6       |    |    | -     |                       |  |
| RT5            | CYP14ABC0850          | 7              | 2013          | 2      | A               | 30               | 6                  | 2014              | 30               | 6                  | 2014              | 0              | 100                         | 09Y      | 0                          | 22                 | RR120                      | RR117                      | 6                                   | 11                                    | 2014                                 | 1       | 2  | -  | 2     | The staff were great! |  |

You will notice that there are several blank cells in the response section of the file shown in Table 5 above. This is because the file includes a row for every patient in the sample, but you will only have responses from only those patients who have returned a completed questionnaire, and who will therefore have an outcome code “1”.

## Additional information required

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

- **Contact details** (telephone numbers and e-mail addresses) of at least two members of staff (usually the main and secondary contacts) who will be available to answer any queries about the data
- A completed copy of the **checklist** (see Section 13.6 below).

## Delivery

Data may be sent on encrypted CD-ROMs or by e-mail (see Section 3 for details on the recommended encryption and delivery methods to use). Hard copy documents should be posted to the address below:

2014 National NHS Children’s Inpatient and Day Case Survey  
The Patient Survey Co-ordination Centre  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford  
OX2 0JB

E-mail: [CYP.data@pickereurope.ac.uk](mailto:CYP.data@pickereurope.ac.uk)

## Deadline for submission

The data must be supplied by **20<sup>th</sup> February 2015**.

### 13.6 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below in Table 6, and include this checklist when you submit your final data file (the checklist can be found on the NHS Surveys website at: <http://www.nhssurveys.org/surveys/786>).

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

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

**Table 6 – Checks to be carried out on final data prior to submitting the data to the Co-ordination Centre**

| Check   | Done? |
|---|-------|
| 1) Check that your <b>file name</b> follows the naming convention: <NHSTrustcode>_CYPInpatients2014.xls)  |       |
| 2) Please send us your final data worksheet only. We do not require the frequency and percentage counts provided on the other worksheets of the data entry workbook.  |       |
| 3) Check that you have included data columns for <b>all questions from each survey</b>  |       |
| 4) Send data only for the <b>number of patients for the sampling month or months</b> consecutively discharged from the trust in August 2014 (including July if necessary).  |       |
| 5) Check that all the data (excluding written comments) are in <b>numeric format</b> only, including dates, which should be entered as separate numeric fields for day, month and year.   |       |
| 6) Check that each drawing has the trust code and patient's PRN assigned to enable the drawing to be linked to the survey response data   |       |
| 7) Check that you have completed the columns for the day, month and year you received the questionnaire back from patients.   |       |
| 8) To comply with data protection regulations, any <b>patient name and address details must be removed</b> before the file is sent to the Co-ordination Centre.   |       |
| 9) Please zip, encrypt and password protect your data before sending to the Co-ordination Centre (please contact the Co-ordination Centre if you need help doing this). And remember to inform us of the password by telephone! |       |
| 10) Include <b>telephone and e-mail contact details of two people</b> who will be available to respond to any queries about the data  |       |

# 14 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.

## 14.1 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 significant<sup>1</sup>, 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 intervals<sup>2</sup> are used most often. By taking into account the number of responses, the variation in response, and the magnitude and direction of the estimate, the confidence interval describes the range of plausible values within which the "true" value for the population is likely to fall. Remember that the estimate itself is the most likely result, and this is therefore your best estimate, not the limits of the confidence interval.

## Make use of the free text

Patients' comments on the 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 patient's experiences.

Any information that could allow respondents to be identified, such as patient and staff names should be removed. See Section 13.2 for further information regarding anonymising patients' comments.

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.

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<sup>1</sup> **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.

<sup>2</sup> 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 7 – Confidence intervals\* for different numbers of respondents**

| Number of respondents | Widest Confidence Interval<br>(+/-) <sup>1</sup> |
|-----------------------|--|
| 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.

<sup>1</sup> 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

# 15 Reporting results

## 15.1 Prioritising your findings

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

### **Rank results by their magnitude**

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

### **Compare your results against outside norms or benchmarks**

A common method of prioritising is to select issues that compare unfavourably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Compare your trust's results with the benchmarks on the 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.

### 15.2 Writing the report

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

#### Tailor the document to the audience

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

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.

# 16 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.

## 16.1 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.

## 16.2 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

### 16.3 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.

### 16.4 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

### **16.5 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.

### **16.6 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.

### **16.7 Use already existing resources**

The Department of Health has published the guide 'Understanding what matters: A guide to using patient feedback to transform care', which can be found on their website at: [http://webarhive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099780](http://webarhive.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.

# 17 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 participant's 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

## **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 patient's 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.”

## Appendix 3: Declarations of data protection compliance

### Declaration of compliance with the Data Protection Act 1998

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#### DECLARATION RELATING TO THE

#### 2014 National NHS Children's inpatient and day case Survey FOR TRUSTS USING IN-HOUSE SURVEY TEAMS

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Children's survey, all trusts need to comply with:

- the Data Protection Act 1998,
- the NHS Code of Practice on Confidentiality, and
- the Caldicott principles.

Due to the large amount of patient information requested by the NHS patient survey programme, it has become necessary to regulate which individuals at a trust are able to view the raw data and some of the processed data. Only those trust staff who have completed this declaration will be authorised to view this restricted data. As the Caldicott Guardian is the designated person within the trust to supervise access to patient identifiable information, all declarations must be co-signed by the trust's Caldicott Guardian. If the trust's Caldicott Guardian does not authorise this, the trust must carry out the survey using an approved contractor.

For further information on the guidelines, please see the "Data protection and confidentiality" section of the Guidance Manual for the 2014 National NHS **Children's inpatient and day case Survey**.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection and confidentiality" in the Guidance Manual for the 2014 National NHS **Children's inpatient and day case Survey**

Signature: ..... Date: .....

I, **[insert name of first survey lead]** the first Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2013 adult inpatient survey and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection and confidentiality" in the Guidance Manual for the 2014 National NHS **Children's inpatient and day case Survey**.

Signature: ..... Date: .....

I, **[insert name of second survey lead]** the second Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2013 adult inpatient survey and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection and confidentiality" in the Guidance Manual for the 2014 National NHS **Children's inpatient and day case Survey**.

Signature: ..... Date: .....

## Appendix 4: Declarations for additional data analysts

### Declaration of compliance with the Data Protection Act 1998

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**DECLARATION  
RELATING TO THE  
2014 National NHS Children's inpatient and day case Survey  
Additional data analysts**

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If the trust requires additional data analysts to have access to the raw data set, this form must be completed and sent to the Co-ordination Centre, and a response received before access to the data set is granted. Only those trust staff who have completed this declaration will be authorised to view this restricted data. As the Caldicott Guardian is the designated person within the trust to supervise this access, all declarations must be co-signed by the Caldicott Guardian. If the Caldicott Guardian does not authorise this, the raw data set and responses from subgroups numbering less than twenty can only be viewed by the authorised survey leads.

For further information on the guidelines, please see the "Data protection and confidentiality" section in the Guidance Manual for the **2014 National NHS Children's inpatient and day case Survey**.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection and confidentiality" in the Guidance Manual for the **2014 National NHS Children's inpatient and day case Survey**.

Signature: ..... Date: .....

I, **[first additional data analyst]** the first additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2014 Children's Survey and will conform to these requirements and the guidelines set out under the section "Data protection and confidentiality" in the Guidance Manual for the **2014 National NHS Children's inpatient and day case Survey**.

Signature: ..... Date: .....

I, **[second additional data analyst]** the second additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2014 **National NHS Children's inpatient and day case Survey** and will conform to these requirements and the guidelines set out under the section "Data protection and confidentiality" in the Guidance Manual for the **2014 National NHS Children's inpatient and day case Survey**.

Signature: ..... Date: .....