



# INSTRUCTION MANUAL FOR THE NHS ADULT INPATIENT SURVEY 2016

# TRUSTS USING A CONTRACTOR

THE CO-ORDINATION CENTRE FOR THE NHS PATIENT SURVEY PROGRAMME

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#### Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as Section 251 approval has been granted for this project to provide a legal basis for trusts using a contractor to provide names and addresses to them. Any breach of the conditions of the support will be reported to the CQC and the Confidentiality Advisory Group at the Health Research Authority.

It is also not permissible 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.

Data from the inpatient survey are used in an increasing number of outcomes frameworks and indicators and have now achieved National Statistics status. If the sampling guidance issued for the survey is not adhered to, and errors are detected too late for remedial action to be taken, this will impact on the use that can be made of data. CQC use patient survey data for purposes of risk monitoring, and data is also used by NHS England and the Department of Health for Patient Experience Outcome Measures and the NHS Outcomes Framework. If data is excluded because sampling errors are detected, this will impact on the assurances these organisations can have about the experiences of your patients.

#### **Updates**

Before you start work on your survey, check that you have the **latest version** of this document, as there might be some small amendments from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will e-mail all trust contacts and contractors directly to inform them of the change. This document is available from the Co-ordination Centre website at: <a href="https://www.nhssurveys.org">www.nhssurveys.org</a>

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# 1 Introduction: The importance of patient feedback

#### 1.1 The Care Quality Commission

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

As set out in CQC's statement of involvement, Putting people first, Voices into action<sup>1</sup>, the statement on involving people, CQC is committed to involving people who use services in all its work, and ensuring that the providers of care services themselves involve people and respond to their views. The experiences of patients, people who use services, their carers and families are at the heart of the Care Quality Commission's work: 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 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 NHS adult inpatient 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 inpatient survey. It also provides instructions on how you may use the information you gather in quality improvement programmes and for monitoring performance. By following these instructions, you will also help to ensure that the survey results from your trust are comparable with other trusts, and with national benchmarks.

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

#### 1.4 Patient feedback and the NHS Constitution

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

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

- providing information to support local quality improvement initiatives
- tracking changes in patient experience locally over time
- providing information for active performance management
- providing information to support public and parliamentary accountability
- providing information for the Care Quality Commission's programme of reviews and inspections.

#### 1.5 Care Quality Commission assessments

Information drawn from the questions in the 2016 Adult Inpatient 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 risk monitoring tools and within CQC's inspections of acute services.

More information on CQC's role in regulating, checking and inspecting services is available on the CQC website:

http://www.cqc.org.uk/content/monitoring-nhs-acute-hospitals

#### 1.6 Measuring performance over time

In addition to the performance assessment, the Care Quality Commission will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data. Asking each hospital trust to carry out an Inpatient 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.

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 2016 NHS Adult Inpatient survey should not be released outside of the trust until the national results are published by the Care Quality Commission. Please also note that any results you receive from an approved contractor are valid results and can be used to improve

services. However, they are not the official survey results for your trust which will be published by the CQC. Any comparisons included in the report from your approved contractor have not been made against all other trusts that took part in the survey nationally, but only against those trusts that used that particular contractor.

Please 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 NHS Adult Inpatient survey

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

- You must let the Co-ordination Centre know your two trust contacts, their job titles, phone
  numbers and email addresses as soon as possible, and no later than 15<sup>th</sup> July to allow us
  to communicate vital information about the 2016 Inpatient survey to you (e-mail:
  ip.cc@PickerEurope.ac.uk).
- You must contact the Co-ordination Centre, as soon as possible, and no later than 1<sup>st</sup>
   August to tell us which contractor is carrying out your survey (e-mail: ip.cc@PickerEurope.ac.uk).
- The survey must be carried out using a postal guestionnaire.
- This year, the sample month for the adult inpatient survey has been fixed to July. You must start counting back from the last day of July 2016 as outlined in the sampling chapter of this document and in the separate sampling handbook.
- The sampling procedure set out in this instruction manual must be followed. To do this, you
  will need to work closely with the person who draws the sample and check carefully that
  these instructions have been followed. For further details see <a href="Section 7 Compiling a list">Section 7 Compiling a list
  of patients</a>
- Your Caldicott Guardian must sign off the sample. You will need to complete the sample declaration form which needs to be sent to your approved contractor and approved by them before you send your anonymised sample file and mailing file (See Section 11 Appendix 1: Inpatient survey 2016 sampling declaration: trusts using a contractor). Alternatively, sample declaration forms can be completed online. Trusts wishing to complete the declaration online will need to provide the Co-ordination Centre with the names and email addresses for the person drawing their sample and the trust's Caldicott Guardian. Unique links will be sent to these named individuals by email.
- Sample data your anonymised 'sample file' will be submitted to the Co-ordination Centre
  for final checks before mailing by your survey contractor. You should aim to submit the
  sample files to your contractor between 8<sup>th</sup> August and 26<sup>th</sup> August to allow a sufficient
  fieldwork period that maximises your response rates.

You should aim to obtain the highest response rate possible, three mailings will be necessary for trusts to achieve this. However, trusts should facilitate higher response rates through maximising their collection period by commencing work as soon as possible, and by publicising the survey to staff, patients and the community.

- Your contractor will be responsible for using all the required survey documents, however, you can access these for information on the NHS Surveys website here: <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>
- Trusts are not permitted to publish their survey results prior to the official release of CQC national and trust level results as there might be differences which could cause confusion for people. However, trusts can start using their results internally to identify areas for quality improvement.

#### 1.9 Why you need these instructions

This instruction manual explains what your trust needs to do for the preparation and implementation of the survey, when you are using an approved contractor. This manual only covers the parts of the survey process that your trust is involved in. Your contractor will have additional information to make sure that they fulfil the requirements of the survey, such as submitting sample files to the Co-ordination Centre, survey mailings and coding the data.

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

# 2 Setting up a project team

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

#### We suggest:

- **Establishing a workgroup.** Put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:
  - Caldicott Guardian
  - Board members
  - Doctors, nurses and other health care staff
  - Members of patient groups with a special interest in the trust
  - Patients and carers
  - Medical records personnel or Patient Administration System (PAS) staff
  - Managers
  - Staff or directors responsible for:
    - Clinical governance
    - Patient advice and liaison service (PALS)
    - Quality improvement
    - Strategic planning
- Involving the person responsible for drawing the patient sample in planning meetings. It is essential that this person, and their line manager, understand the purpose of the survey and the importance of drawing the sample correctly. You must share these survey instructions with them.
- Keeping everyone informed. Notify as many people as possible about ideas and
  activities. All departments in the trust should be made aware when a survey is being
  conducted in case patients contact the trust asking questions about the questionnaire they
  have received. For more information on publicising the survey see <a href="Section 8">Section 8</a>.
- Not overlooking front-line staff. These people have the most direct impact on patients' experiences.

# **3** What's new for 2016?

#### 3.1 Changes for the 2016 Inpatient survey

#### **CQC Intelligence Model**

Trusts will be flagged as a risk within the appropriate survey data indicators if they either fail to submit a sample for the adult inpatient survey or if it becomes evident at a later date that an error has been made in drawing the sample that renders the data unusable.

Errors considered in the indicator may be 'minor' or 'major'. A minor error means that data is still able to be used despite the error. A 'major' error is so serious that data for a trust is unable to be used, and would be excluded from the CQC publication and all other uses, such as in CQC's risk monitoring tools, as well as by other organisations such as NHS England for use in their national statistics.

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

Ultimately, it is the trust's responsibility to ensure that the sample is drawn correctly. To help avoid making such errors, ensure that you follow the instructions very carefully when drawing your sample. You should also read the 'Sampling Errors Report' for the previous year's survey which highlights the errors that were made in compiling and submitting samples – it can be found here <a href="http://nhssurveys.org/survey/1731">http://nhssurveys.org/survey/1731</a>.

#### **Treatment Function Codes**

This year we will be collecting treatment function codes for each patient in the sample. This data will allow trusts to more accurately identify patients who are ineligible, particularly patients who have been treated for planned termination of pregnancy. In previous surveys, trusts have used main specialty to identify these patients but in certain cases there are problems with the accuracy of these codes in terms of the actual treatment received. The treatment function data will also allow more accurate sub-group analysis of results than main specialty. For 2016, we will be collecting both main specialty codes and treatment function codes. For more information please see: <a href="http://www.datadictionary.nhs.uk/data\_dictionary/attributes/t/tran/treatment\_function\_code\_de.asp">http://www.datadictionary.nhs.uk/data\_dictionary/attributes/t/tran/treatment\_function\_code\_de.asp</a>

#### **Outcome Code**

A new code has been added to the 'Outcome' field to indicate patients who have been traced as being deceased after the sample file has been signed off by the persons who drew and checked the sample within your organisation and your Caldicott Guardian, and submitted to the Coordination Centre (via your contractor), but before any mailings have been sent out. In these instances, records are not to be removed from either the sample or mailing files. Instead the new code of '7- service user deceased prior to fieldwork' will be applied by your contractor.

Note that in instances where the first mailing has been sent out and a service user is subsequently identified as having died, then the outcome code of '3 – service user died' should be used.

Your contractor will assign these codes; they will be used in the weekly monitoring updates they send us and the final data file that is submitted once fieldwork has completed.

#### **ICD-10 Chapter Code Data Submission and Mapping Tool**

As in 2015, we will be collecting ICD-10 chapter codes. In a change to last year's methodology, trusts that are unable to submit ICD-10 codes with their initial data submission can submit these data to their contractor during fieldwork, using the contractor's secure FTP site. This year we are also providing a mapping tool for assigning ICD-10 chapter codes. This tool allows trusts to enter detailed ICD-10 codes (as they are held on trust databases) and convert them into the broad chapter codes. We anticipate that this will allow more trusts to submit their ICD-10 chapter codes with their initial data submission.

#### Changes to the questionnaire – questions added, modified and removed

The 2016 Inpatient questionnaire has been kept as similar as possible to the 2015 Inpatient questionnaire to allow comparisons to be made between survey years. There are <u>84</u> core questions, one more than last year. When published, the development report will contain complete documentation about any changes made to the questionnaire and can be found on the NHS Surveys website at <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>. A summary of the changes made to the core questionnaire are listed below:

One question carried in the 2015 Inpatient questionnaire has been removed for the 2016 survey:

Were hand-wash gels available for patients and visitors to use?

One question new to the 2015 Inpatient questionnaire has been redeveloped and modified from:

 When you transferred to another hospital or went to a nursing or residential home, was there a plan in place for continuing your care?

To:

Q60. When you left hospital, did you know what would happen next with your care?

Three new questions have been added for the 2016 survey:

- Q20. Did you get enough help from staff to wash or keep yourself clean?
- Q21. If you brought your own medication with you to hospital, were you able to take it when you needed to?
- Q32. Did you know which nurse was in charge of looking after you? (this would have been a different person after each shift change)

# 4 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. If you have not already done so, please ensure that you add research to your Data Protection Act registration, as one of the purposes for processing personal data supplied by data subjects. You will also need to comply with the NHS Code of Practice on Confidentiality (2003)<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. 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/

#### 4.1 Statements of compliance with data protection

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

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/200146/Confidentiality\_-NHS\_Code\_of\_Practice.pdf

<sup>&</sup>lt;sup>2</sup> http://the-sra.org.uk/wp-content/uploads/sra\_data\_protection.pdf

includes ensuring each have completed the relevant sections of the Information Governance Toolkit.<sup>1</sup>

#### 4.2 Approval under section 251 of the NHS Act 2006

Approval for the NHS Adult Inpatient Survey 2016 was sought this year, as it was last 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 Health Research Authority (HRA), and the Confidentiality Advisory Group (CAG) of the Health Research Authority (previously NIGB) has granted a recommendation of support. Please note that any deviation from the methodology outlined in this instruction manual may render the approval invalid and would lead to action being taken against an NHS trust.

The recommendation of support does not cover the transfer of patient identifiable information where a patient has previously indicated dissent - by this we mean instances where a patient has indicated that they do not want their information to be shared for purposes such as patient surveys, or specifically stated that they do not want their details shared outside of the trust.

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

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

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).

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<sup>1</sup> https://www.igt.hscic.gov.uk/

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.

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

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

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

at: <a href="http://www.nhssurveys.org/Filestore/documents/20120704\_FAQs\_on\_fair\_data\_processing\_dra">http://www.nhssurveys.org/Filestore/documents/20120704\_FAQs\_on\_fair\_data\_processing\_dra</a> ft4.pdf

# 4.3 Extending your sample and / or collecting additional sample variables and Section 251

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

In addition to the minimum sample requirement for this survey, you may wish to use this survey as an opportunity to gather further data beyond that required by the Care Quality Commission. Increasing the sample size could be a good way to do this.

If you wish to survey a larger sample of people or collect additional information then we recommend that **you** as data controller must consider the purpose of the data collection and any release of identifiable data. Your Caldicott Guardian should be consulted and will be able to offer advice on whether adequate provisions are in place to permit release of data outside of the national survey programme. You must also ensure that you have appropriate contractual arrangements in place to ensure the secure transfer of additional data.

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

Alternatively, if your trust regularly treats very large numbers of people, you may wish to draw an extra sample to survey in addition to those included in the main survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out a survey locally at the same time as the national survey you will need to ensure that you sample two distinct and separate groups of people which do not overlap.

If you decide to collect additional data outside of the national survey, this must not under any circumstances be sent by trusts or contractors to the Survey Co-ordination Centre, as it would constitute a breach of the section 251 approval and action would be taken accordingly.

#### 4.4 Keeping patient mailing data and sample data separate

For patient confidentiality reasons, patient responses must never be matched to the patients that made them. The best way to ensure this is to store patient names and address details separately from sample information or survey response data. For this reason once the sample has been returned from DBS and the 1250 patients are finalised, patient names, addresses and postcodes must be removed from the sample file to a 'mailing file'. Keeping the two sets of information separate reduces the amount of information disclosed if either file were to be lost or shared with unauthorised individuals. It also means that only the necessary information is shared with those who need it – for example staff members who deal solely with the mailing need only the 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 sampling handbook). Note the PRN must be in the format: IP16XXXNNNN where XXX is your trust's 3 digit trust code and NNNN is the 4 digit number relating to your sampled patients, e.g., 0001-1250. Please ensure the files are separated and that no patient identifiable information is on your sample file before you send them to your contractor.

Applying this record number is the responsibility of the trust - approved contractors must not do this for trusts. Approved contractors will also not be permitted to draw the sample for trusts - this will be considered a breach of the surveys Section 251 approval and action taken against both the trust and approved contractor will follow.

Please note that the signed sample declaration form that you must fill in includes the separation of the mailing file from the sample file. By signing the Declaration Form the trust is confirming that no identifiable data is included in the anonymised sample file. You should only send your approved contractor your sample file and mailing file once they have confirmed to you that they have determined that your form has been completed satisfactorily. This is to help prevent breaches of the section 251 approval and related data protection requirements.

#### 4.5 Mailing questionnaires to patients

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

1. The contractor mails out the questionnaires. If a contractor is going to be mailing out questionnaires on behalf of a trust, this will require the trust to share patient name and address details with their approved contractor. This method is only possible if the contractor is carrying out the work under a service contract, which can be set up with the agreement of the trust's Caldicott Guardian. The Care Quality Commission has provided the template service contract for trusts and approved contractors carrying out the survey, to avoid the need for each trust to develop its own arrangements. It is strongly recommended that these documents are reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required. When personal data is shared with contractors, trusts must adhere to the principles outlined in <a href="Sections 4.6">Sections 4.6</a> and <a href="4.7">4.7</a> below. When the patient details are shared with the contractor the instructions regarding how to share this data must be followed at all times.

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

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

#### 4.6 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:
   <a href="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</a>
- Personal data such as names and addresses must be sent by trusts to contractors securely (please see further details below). These must be sent as separate files.
- 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:
  <a href="http://systems.hscic.gov.uk/infogov/security/infrasec/gpg/acs.pdf">http://systems.hscic.gov.uk/infogov/security/infrasec/gpg/acs.pdf</a>
- Please ensure that the relevant members of staff at your trust have completed the sampling declaration and checklist, and signed them. These documents are to be sent to your approved contractor before you are able to submit your sample. Once your approved contractor has checked your sample, both the sample declaration form and the anonymised sample file will be submitted to the Co-ordination Centre by your approved contractor. Samples files will not be accepted without the signed sample declaration form. The Co-ordination Centre will use these documents to help check your sample file. Trusts wishing to complete the declaration online will need to provide the Co-ordination Centre with the names and email addresses for the person drawing their sample and the trust's Caldicott Guardian. Unique links will be sent to these named individuals by email.

#### 4.7 Encryption of personal data

Any patient identifiable information sent between trusts and contractors must be in an encrypted format with password protection to help ensure good standards of information security. When sending data electronically an encrypted session based on the Transport Layer Security (TLS) or

Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP) must be used. A key size of 256 bits or greater should be used. This is to ensure a high level of security, to protect against any accidental or intentional interception during the transfer of patients' details.

Many different encryption algorithms exist and not all of these are suitable, so both the Coordination Centre and the Care Quality Commission very strongly recommend the use of the **256-bit AES** (Advanced Encryption Standard) algorithm. There are several software tools that can be used to encrypt data in this way, the most commonly available of these being WinZip® (v9 and above)¹. Approved contractors should be able to provide guidance to trusts on the use of an encrypted session.

#### 4.8 Contractor responsibilities (service contract)

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

The service contract in Word format is available on the NHS Surveys website: http://www.nhssurveys.org/surveys/935

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

#### 4.9 Assurances of patient anonymity

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

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

#### 4.10 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:

<sup>&</sup>lt;sup>1</sup> http://www.winzip.com/

#### **Approved contractor**

- 1. Approved contractors must not provide raw data to the trust as a matter of course.
- 2. If you have a particular need for the raw data collected by the survey, the contractor may provide an abridged version of this dataset to the trust upon request, providing that the steps below are undertaken first:
  - a. The contractor must delete the two variables pertaining to ethnicity (e.g. both sample and response variables).
  - b. The contractor must delete the responses to questions Q82 and Q83 pertaining to the respondents' religion and sexual orientation.
  - c. The contractor must band year of birth into five age groups (16-35, 36-50, 51-65, 66-80, 81+). This process should be repeated separately for both sample and response variables. The original year of birth variables (e.g. those specifying an exact year rather than age group) must then be deleted.
  - d. Additional information specific to a survey that can be used to identify individual patients must be removed. For example main specialty, CCG, treatment centre, ICD10 code and NHS site code of admission and discharge must be removed.
  - e. Admission and discharge dates in the NHS Adult Inpatient survey must be removed, but length of stay can be calculated from the admission and discharge dates and provided to trusts. Route of admission to hospital does not need to be excluded unless the trust had fewer than 30 respondents admitted for an emergency or urgent admission, or from a waiting list or planned admission.
  - f. The contractor must have received confirmation from the trust that the names and addresses of the sampled patients have been destroyed; otherwise they will be able to identify individual patients by matching up the patient record numbers on the name and address list to those in the raw data file.

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

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

	Q16. Were you ever bothered by noise at night from hospital staff?											
Ethnic category	Yes	No	Total responses									
	%	%	n									
White	81	19	261									
Mixed / Multiple	-	-	8									
Asian	-	-	18									
Black / African / Caribbean	79	21	52									
Other	85	15	36									

- 4. Do not present response information (including comments) in a form that allows an individual patient to be identified by the group receiving the information. For example, if you are presenting the results 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.
- 5. The electronic file containing the patients' names and addresses should be stored securely (i.e. password protected). Access to the file should be given only to those individuals who have signed the service contract.

#### 4.11 Sharing of survey data between contractors

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

#### 4.12 Storing sample and mailing information

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

# 5 Ethical issues, ethics committees and research governance

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

#### 5.1 Ethical approval for the Inpatient survey

Research Ethics Committee (REC) approval has been obtained for the NHS Adult Inpatient Survey 2016 and a substantial amendment submitted for changes regarding the survey, all of which can be downloaded from the NHS Surveys website: <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>. In order to comply with the ethical approval, the survey must be carried out according to the instructions set out in this document.

Trusts do not, therefore, need to seek individual ethical approval for this survey. If you wish, you can send your Local Research Ethics Committee(s) (LREC) a copy of the REC approval letter but you are not required to do this and you do not need to wait for confirmation or approval from the LREC before starting your survey.

Your trust should notify the relevant Research and Development (R&D) office that ethical approval has been obtained for the 2016 Inpatient Survey. The REC letter of approval can be found on the NHS Surveys website (see link above).

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

#### 5.2 Research governance requirements

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

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

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

The Care Quality Commission has produced a table with information taken from the Research Governance Framework for health and social care (2005), which can be found in **Appendix 4** of this instruction manual. The table's left-hand column sets out the responsibilities of organisations providing care and the right-hand column sets out the arrangements made by the Care Quality Commission for patient surveys. If you are required to seek approval from your research

governance lead, you are advised to present this information to your Research and Development Manager in support of your request.

### 6 Timetable

The survey fieldwork period for 2016 is 19 weeks. We strongly recommend making full use of this to maximise response from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond<sup>1</sup>. If your patient population has high proportions of either group, it is especially vital you allow enough fieldwork time to capture responses from these patients. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. within the recommended three week sample checking period – see key dates below) and if applicable, mail out your questionnaire packs promptly once permission has been received. Dissemination of the results to all staff, to the local community and media can only start after the survey has been completed.

The approved contractor will carry out many stages in the process but you will still have to be involved in some of them. Your approved contractor for the survey will provide you with a timetable that might differ slightly to the suggested time periods below. This year there is an additional week between the end of fieldwork and the submission of data to the Co-ordination centre. Ensure the full fieldwork period is used to optimise response rates. As long as the specified three mailings take place and data is submitted to the Co-ordination Centre no later than the 13<sup>th</sup> January 2017, the timetable provided by the contractor should take precedence over the suggested intervals below.

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<sup>&</sup>lt;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

Table 1 Inpatient Survey timetable

Week	Task	See
0	Inform Co-ordination Centre of trust contacts and who is carrying out your survey by 3 <sup>rd</sup> August 2016 (which contractor)	-
1	Trust draws sample of patients to be included in the survey	<u>7</u>
1	Check sample for deceased patients using hospital records	<u>7.2</u>
1	Submit sample list to DBS to check for deceased patients and remove deceased patients from your sample list	<u>7.3</u> & <u>7.4</u>
	Have the sample declaration form signed off and sent to your survey contractor before submitting the sample file to your contractor	•
1 - 4	Submit anonymised sample file and separate mailing file to your contractor before starting mailing process	<u>7.5</u>
1	Supply contractor with trust headed paper and a signature of a senior executive and ensure that the service contract is signed	9.3
3	Prior to the first mailing, check your records again for any patient deaths and inform your contractor	<u>7.2</u>
6-9	Prior to the first reminder, check trust's records again for any patient deaths and inform your contractor	7.2, 7.3 & 7.4
9-12	Prior to the final mailing, check trust's records for any patient deaths and inform your contractor	7.2, 7.3 & 7.4
19	Contractor to send data to Co-ordination Centre (by 13th January 2017)	-

#### **Key dates**

Inform Co-ordination Centre who is carrying out survey ASAP and no later than 1st August 2016
Submission of sample data to contractor 8th August – 26th August 2016
Start of fieldwork 29th August 2016
Approval of sample data from 8th August 2016
Close of fieldwork 6th January 2017
Contractor to send data to Co-ordination Centre 13th January 2017

# 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.

Please note: Data from the inpatient survey are used in an increasing number of outcomes frameworks and indicators and have now achieved National Statistics status. If the sampling guidance issued for the survey is not adhered to and errors are detected too late for remedial action to be taken, this will impact on the use that can be made of data. CQC use patient survey data for purposes of risk monitoring and data is also used by NHS England and the Department of Health for Patient Experience Outcome Measures and the NHS Outcomes Framework. If data is excluded because sampling errors are detected this will impact on the assurances these organisations can have about the experiences of your patients.

We have recently encountered incidences of historical errors having been made in previous surveys and unfortunately we have to respond to these errors by, for example, removing trust results. We request that all trust staff involved in drawing samples are made aware of the importance of checking previously written codes and other historical arrangements, to minimise the risk of future cases being discovered and the risk that your trust's survey results cannot be used. It is essential that the person who draws the sample understands the importance of following these instructions carefully. Also, this person's line manager must give them the time and support they need to do the task properly. An incorrectly drawn sample can delay the start of the survey or can result in the questionnaires being sent to the wrong patients, both of which can have serious implications.

#### Before compiling your patient list

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

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

Approved contractors are not permitted to draw the sample for trusts, this is the responsibility of the trust. If a contractor draws the sample on behalf of the trust it will be considered a breach of the survey's Section 251 approval and action taken against both the trust and approved contractor will follow.

#### 7.1 Compiling a list of patients

1. As in 2015, the sample month for the adult inpatient survey has been fixed to July. You must start counting back from the last day of **July 2016**. If you are unable to sample enough patients from July alone then you will have to include patients discharged in previous months. However, posters **must** be displayed for your chosen sample month(s) to attain compliance with section 251- patients must have the chance to dissent.

2. Compile a list of 1350 adult (aged 16 and over) inpatients consecutively discharged alive from your trust working back from the last day of the sampling month. You must count back through the list of patients discharged alive from the trust, including all eligible patients, until you have 1350 patients. The reason for including 1350 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).

#### 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> January 2016 to generate their sample of 1350 adult inpatients submitted to DBS.

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 adult patients, who have had at least one overnight stay within the trust.

#### The list should exclude:

- deceased patients
- children or young persons under 16 years old at the time of sampling
- obstetrics/maternity service users, including spontaneous miscarriages
- patients admitted for planned termination of pregnancy
- psychiatry patients
- day case patients (i.e. patients who arrive and leave on the same day. If the patient stays
  overnight and is occupying a bed, then they should be included in the sample.)
- private patients (non-NHS)
- NHS patients treated at private hospitals
- any patients who are known to be current inpatients
- patients without a UK postal address (but do not exclude if addresses are incomplete but useable, e.g. no postcode)
- Any patient known to have requested their details are not used for any purpose other than
  their clinical care, including requests made following sight of survey pre-publicity; 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**

Patients who stayed as an inpatient at an NHS treatment centre at the trust are eligible for inclusion in the sample for the 2016 Inpatient 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 2, in <u>Section 7.5</u>).

#### 7.2 Checks carried out by the trust

Once you have compiled your list of 1350 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.
- Overnight stay. Check that patients had at least one overnight stay in hospital. Patients
  are considered to have had an overnight stay if they were admitted as an inpatient and
  occupying a bed at midnight, e.g. patients who are admitted as an inpatient on Day 1 and
  discharged on Day 2 are considered to have had a single overnight stay regardless of their
  admission time or discharge time. Day cases and outpatients are not included in this
  survey.
- 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 16 or over at the time of sampling (i.e. on the day you draw your sample the patient must be aged 16 or over). Please do not exclude patients treated at children's hospitals as such sites do treat patients who are 16 years and over.
- 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 treatment function code, that there are no route of admission codes indicating a maternity admission and no ICD-10 chapter codes of XV (if ICD-10 codes are available). You should not include patients with a Route of Admission code of 31 (ante-partum) or 32 (post-partum). There should also be no patients included who have a treatment function code of 501 (obstetrics) or 560 (midwife). If codes of 500 (obstetrics and gynaecology) are included, please ensure any included patients have been treated for gynaecology and not obstetrics.
- Check again that none of the patients were admitted for a termination of pregnancy.
- Psychiatry patients. Check Main Specialty and Treatment Function codes and ensure that
  the list does not include psychiatry patients i.e. patients with the following Treatment
  Function codes should be excluded (a more complete list can be found in <u>Section 10</u> –
  Glossary):
  - o 700 learning disability
  - o 710 adult mental illness

- 711 child and adolescent psychiatry
- 712 forensic psychiatry
- o 713 psychotherapy
- o 715 old age 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 including requests made following sight of survey pre-publicity (you must ensure that you remove these patients from your sample list at this stage).

#### Checks for deceased patients

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

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

- 1) The trust
- 2) DBS
- 3) Again by the trust (for patients who may have died in hospital after submission of the sample to DBS).

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

#### 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 <a href="http://www.hscic.gov.uk/demographics/">http://www.hscic.gov.uk/demographics/</a>

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

- NHS number and full date of birth (yyyymmdd) this is the recommended approach OR
- Surname, first name, gender, date of birth and postcode (can be wildcarded e.g. LS1\*)

Although residential postcode is not mandatory it is highly recommended to include it to avoid incorrect matches. Due to the way addresses are recorded throughout the NHS, it is very difficult to

get an exact match on address lines. For this reason, **do not** include address lines in the trace request file.

#### Submitting the trace request file

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

#### Note

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

#### What to do if you have more than 1250 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 1250 patients in the list. You will need to remove the **least recently discharged** patients from your sample so that only the 1250 most recent patients remain.

#### What to do if you have fewer than 1250 patients remaining on your list

If your patient list has fewer than 1250 patients after deceased patients have been removed, you **MUST** contact the Co-ordination Centre on 01865 208127 or email <u>ip.cc@pickereurope.ac.uk</u>. If

possible, the next most recently discharged patients after the sample will need to be added to create a sample of 1250 patients, although these must also be checked by DBS.

#### Important note

You will be able to maximise your response rate by following these instructions carefully, drawing your sample and contractors sending your mailing out as soon as possible, and your contractor 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 the sample of 1250 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 1250 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 2 below. A pre-designed spreadsheet including all the required column headings can be downloaded from the NHS Surveys website (<a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>) 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>\_Inpatients2016.

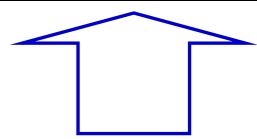
This file has three purposes:

- 1) It will be used by your contractor to keep a record of which patients have not returned questionnaires so that reminders can be sent to them.
- It will be used by your contractor to generate weekly response rates, which must be forwarded to the Co-ordination Centre every Thursday from 1<sup>st</sup> September 2016 until the closing date of the survey.
- 3) The anonymous data in this file (i.e. all the data except patient name and address information) will form part of the file that your contractor will submit to the Co-ordination Centre when the survey is completed.

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

 Table 2
 Sample construction spreadsheet of patient details

Patient record number	Title	Initials	Surname	Address1	Address5	Postcode	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	Treatment Function code	ICD 10 (Chapter Code)	epoo 900	Treatment centre admission	Route of admission	NHS Site code on admission	NHS Site code on discharge	Day of questionnaire being	Month of questionnaire being	Year of questionnaire being received	Outcome	Comments
IP16RX10001	Mrs	Α	Abbot	-	ł	AB1 1YZ	1934	2	Α	5	8	2016	11	8	2016	6	100	102	ΧI	12H	0	12	RR115	RR115				3	Informe d that patient had died
IP16RX10002	Mr	Е	Ahmed	-		AB2 6XZ	1970	1	J	20	7	2016	12	8	2016	23	101	101	IX	10Q	1	11	RTE03	RTE03	22	10	2016	1	
IP16RX11249	Ms	K	Yoo	-		AB4 7MX	1950	2	R	17	6	2016	31	8	2016	75	300	306	IV	09Y	0	21	RR115	RR115					
IP16RX11250	Ms	F	Young	-		AB9 5ZX	1946	2	Α	14	8	2016	31	8	2016	17	100	107	VII	08L	0	22	RR120	RR117	6	11	2016	1	1



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

PATIENT IDENTIFIABLE DATA MUST NOT BE INCLUDED IN THE ANONYMISED SAMPLE FILE.

#### Important note about Table 2

The headings are in three different colours:

**Black** headings: these columns contain information on patients' names, addresses and comments that may allow them to be identified. This information must not appear in any files sent to the Co-ordination Centre. This information should be removed from the sample file as soon as your sample is finalised and saved to a new file (your "mailing data" file). The patient record number must be retained in both files, in order to be able to link the data.

Red italic headings: these columns should be completed during the sampling phase and submitted to your contractor who will submit them to the Coordination Centre prior to mailing (to allow for final inspection by the Co-ordination Centre.

*Green italic* headings: these columns will be completed when the patient responds to the survey by your contractor (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:

- **Title** (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- 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), **Title**, **Initials**, **Surname**, **Address Fields** and **Postcode** are used for printing out address labels. You (or your contractor) can use the mail merge function in a word processing package for this purpose.

- Year of Birth should be included in the form NNNN.
- **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: <a href="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</a>. 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
  - 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. March = 3 or October = 10)\*
- Year of admission (4 digits; e.g. 2016)\*
- Day of the month of discharge (1 or 2 digits; e.g. 2 or 30)\*
- Month of discharge (1 digit; e.g. June = 6 or July = 7)\*
- Year of discharge (4 digits; e.g. 2016)\*
- 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 = 15/7/2016 and admission date = 14/7/2016, 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). All patients in the sample should have a length of stay greater than or equal to 1 day.
- 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: <a href="http://www.datadictionary.nhs.uk/datadictionary/attributes/m/main\_specialty\_code\_de.asp">http://www.datadictionary.nhs.uk/datadictionary/attributes/m/main\_specialty\_code\_de.asp</a>
- Treatment Function Code. It is recorded in the form NNN as outlined by the Health and Social Care Information Centre (HSCIC). Please see: <a href="http://www.datadictionary.nhs.uk/data\_dictionary/attributes/t/tran/treatment\_function\_code\_de.asp">http://www.datadictionary.nhs.uk/data\_dictionary/attributes/t/tran/treatment\_function\_code\_de.asp</a>
- 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: <a href="http://www.datadictionary.nhs.uk/data\_dictionary/attributes/a/add/admission\_method\_de.asp?shownay=1">http://www.datadictionary.nhs.uk/data\_dictionary/attributes/a/add/admission\_method\_de.asp?shownay=1</a>
- Hospital Site Code on Admission: Please record the site of admission of the patient
  using the five character NHS Trust Site Codes (maintained by HSCIC). Please see:
  http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs
- Hospital Site Code on Discharge: Please record the site from which the patient was
  discharged using the five character NHS Trust Site Codes (maintained by HSCIC). Please
  see: <a href="http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs">http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs</a>
- ICD 10 (Chapter Code): Please enter the ICD10 (4<sup>th</sup> Edition) chapter code in Roman Numerals (i.e. III, VI, IX etc.) Please note: This should be based on the primary diagnosis at discharge. For a list of the chapter codes please see: <a href="http://apps.who.int/classifications/icd10/browse/2016/en">http://apps.who.int/classifications/icd10/browse/2016/en</a>. We have produced a mapping tool for assigning ICD-10 chapter codes. This tool allows trusts to enter detailed ICD-10 codes (as they are held on trust databases) and converts them into the broad chapter codes. The tool is available on the NHS surveys website at: <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>. If ICD-10 codes are not available when you draw your sample, you will be able to submit these to your contractor during fieldwork.

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

#### **Information**

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

- 1) Patient record number (PRN). This is a unique serial number which must be allocated to each patient by the trust. It should take the following format: IP16XXXNNNN where XXX is your trust's 3-digit trust code and NNNN is the 4-digit number relating to your sampled patients, e.g., 0001-1250. The PRN will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), the approved contractor will be able to use these numbers to monitor which patients have returned their questionnaires and to identify any non-responders, who will need to be sent reminders. You will need to agree with your approved contractor 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).
- 2) **Day of questionnaire being received**. This will only be completed if and when a questionnaire is received by the approved contractor.
- 3) **Month of questionnaire being received**. This will only be completed if and when a questionnaire is received by the approved contractor.
- 4) **Year of questionnaire being received**. This will only be completed if and when a questionnaire is received by the approved contractor.
- 5) 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 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 = Service user deceased prior to fieldwork.

The outcome column is left blank at first if the questionnaire has not been returned (in Table 2 you can see that Ms Yoo has not yet returned her questionnaire).

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

#### 7.6 Checking the distribution of patient ages in your sample

You should check that patients of all ages are included in your sample, paying particular attention to those aged 16, 17 or 18 years and those over 75 years. We have found these age groups are the most likely to be excluded due to poor sampling. It is possible there may not be any young adults or very old adults in your sample, but this should be confirmed by checking your original sample (before exclusion criteria were applied) and your sampling techniques.

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 (See Figure 1). The histogram for your trust should resemble the shape of the histogram below.

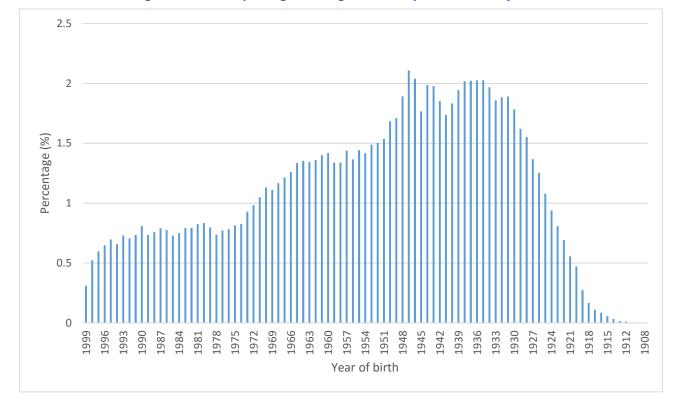


Figure 1 – Example Age Histogram for Inpatient Survey 2015

#### 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 men and women. You should check that both men and women 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

Please also check that the split of patients between emergency versus planned admissions is similar to the proportions that were in your sample last year. If there is a substantial change there should be an explanation. For example, if your hospital is now conducting more day case surgery this year than last you may expect to see an increase in the proportion of emergency admissions in your patient sample.

#### 7.9 Checking for other errors with your sample

Information on the errors made when samples were drawn for the 2015 Inpatient survey can be found on the following webpage: <a href="http://nhssurveys.org/survey/1731">http://nhssurveys.org/survey/1731</a>. Using this document to check for any errors may reduce delays caused by incorrect sampling and consequentially improve your response rate to this survey.

#### 7.10 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 'Inpatients2016\_mailing data'. It should resemble Table 3 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>\_Inpatients2016) 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).

#### 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.

Patient record number	Title	Initials	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
IP16RX10001	Mrs	AM	Abbot	14 Station Road	London				AB1 1YZ
IP16RX10002	Mr	EC	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
IP16RX11249	Ms	K	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4 7MX
IP16RX11250	Ms	F	Young	634 Tyne Road	Newcastle-Upon-Tyne	Tyne and Wear			AB9 5ZX

Table 3 Example mailing file

## 7.11 Sharing the patient sample file with an approved contractor

Both the sample file (<NHStrustname>\_Inpatients2016) **and** the mailing file (Inpatients2016\_mailing data) must be sent to the contractor staff in encrypted format.

If you are working with an approved contractor, but have chosen to mail out the questionnaires yourself, in-house, you should only supply them with the sample file (<NHStrustname>\_Inpatients2016). The contractor can use this file to record the outcome codes, but you should ensure that the contractor is kept up to date with any information that comes directly to the trust about patient deaths, etc.

## 7.12 Sample declaration form

For this survey, there is a sample declaration form that needs to be completed by the person preparing the sample (see appendix 1). The sample declaration form is available on the NHS Surveys website to download at <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>. The form has a number of compliance statements that both the person drawing the sample and also the Caldicott Guardian must sign. An online version of the sample declaration form is available.

<sup>&</sup>lt;sup>1</sup> As shown in Table 2 (<u>see section 7.5</u>), the 'outcome' field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which patients opt out etc.

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

Contractors need to have submitted the sample data to the Co-ordination Centre no later than **26**<sup>th</sup> **August 2016**. If they do not meet this deadline, there is a risk your trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may result in the data from the trust being excluded from the relevant Care Quality Commission assessments.

Samples that have not been submitted for checking by the **2**<sup>nd</sup> **September 2016** will be followed up by the Co-ordination Centre to discuss any problems you or the contractor are having and how we can help with the process. However, if samples are not received by the **9**<sup>th</sup> **September 2016**, then we are required to notify the Care Quality Commission of this and they will contact you/ the contractor to discuss any implications for inclusion in Care Quality Commission produced data.

## 7.13 Making more use of the survey locally

Up to this point, this section of the guidance has described in detail how sampling must be undertaken to provide the basic required sample of 1250 patients for the NHS Adult Inpatient survey. In addition to this minimum requirement, though, your trust may wish to use the National Inpatient survey as an opportunity to gather further data beyond that required by the Care Quality Commission. A good way to do this would be to increase your sample size.

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

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

If you are using an approved contractor for the national survey they will be able to advise you on the best way to increase your sample size to achieve your specific goals.

Please note that the application for Section 251 approval has been made by the CQC on behalf of all trusts for a national standardised survey. **Therefore Section 251 approval covers the national surveys only, and will not apply to any local surveys.** Please contact your trust's Caldicott Guardian for advice as to whether it is appropriate to contact the Health Research Authority for further approval.

### Important points to consider

Before you decide whether to gather additional patient feedback (e.g. by increasing your sample size), there are some important points to consider:

- The core sample for the 2016 Inpatient survey must be drawn as specified in this sampling instruction manual; any deviation from these instructions may make it impossible for the Care Quality Commission to use the data that you collect. It is therefore essential that any additional sample drawn can be easily distinguished from the core sample, and that it is drawn in such a way as to not interfere with selection of the core sample.
- If you are planning to undertake surveys more frequently than the national programme, then you should consider how any increased sample here will fit with the additional surveys you will be undertaking.

## Remember

If you do choose to increase your sample size, it is essential that you ensure that the sample of patients you draw according to the requirements for the national survey can be easily distinguished from any additional patients you include in the sample. Your approved survey contractor or the Coordination Centre will be able to advise you on this.

If you decide to carry out an Inpatient survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of patients which do not overlap.

## 7.14 Summary of key steps

By following the instructions 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 (<u>Section 7.6, 7.7</u> and <u>7.8</u>)
- 6. Checked for other errors that may have occurred when drawing your sample (Section 7.9)
- 7. Removed personal data from the sample file and created a mailing file (Section 7.10)
- 8. Complete the sample declaration form (<u>see appendix 1</u>) and send this to your contractor **before** sending them your sample file and separate mailing file. **Do not send your contractor these files before they have approved the sample declaration form.**
- 9. Share the sample file (and possibly the mailing file, depending on the model you are using as described in the instruction manual) with your contractor.

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

## 8 Publicising the survey

## 8.1 Pre-survey communication with staff

As highlighted in <u>Section 2</u>, the best way to ensure your survey is a success is to work hard in the beginning to involve those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey.

### Keeping everyone informed

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

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

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

Appendix 2 includes information which you can tailor for publicising the survey to staff.

## 8.2 Publicising the survey externally

It is important that the national surveys are publicised and responses encouraged so that as many patients' voices are heard as possible. To help promote involvement and maximise response rates, and to give the opportunity to opt out, the survey can be publicised to patients and the public through a number of ways, for example:

- Send a press release to the local media to raise awareness of the survey and gain publicity just before the survey takes place. Information to help you draft a press release is shown in Appendix 3 and can be found on the NHS surveys website:
   <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>. Talk to your hospital's press office for more ways in which you can gain publicity locally.
- Put up posters around the hospital which show the importance the trust places on gathering
  patient feedback. To be most effective at increasing your response rate, posters should be
  put up in the hospital during the sampling period (i.e. during the month(s) from which your
  sample of inpatients will be drawn). A poster is available on the NHS surveys website
  at: http://www.nhssurveys.org/surveys/936
- Consider using social media such as twitter or other local social media to publicise the survey.

## 9 The questionnaire and mailing letters

## 9.1 The questionnaire

The questionnaire consists of 84 questions on 12 pages. The questions cover the issues that have been found to be most important to patients and **must** be included in your survey. 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 patient's experience. The questionnaire can be downloaded from the NHS Surveys website: <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>

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

## 9.2 Mailing Letters

The covering letters can be downloaded from the NHS Surveys website: <a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>. Your contractor will be responsible for producing these documents for you.

## 9.3 Trust headed paper

You will need headed paper from your trust and CEO signature for covering letters for the first and third mailing. A reminder letter is used for the second mailing. It is preferable that the paper does not include a telephone number for the trust, as patients should call the contractor's FREEPHONE line, rather than the trust. You will need to provide the headed paper to your contractor so they can complete the mailings for you. No deviation from the wording in these letters is possible due to the ethical approval given to the survey materials.

## 9.4 Mailing packs and reminders

Your contractor will prepare the mailing packs but these will typically include (first and third mailing) the following items:

- Questionnaire:
- Covering letter;
- Multi language sheet;
- Freepost envelope;
- CQC flyer.

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

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

## 10 Glossary

## **Adult inpatient**

Any person having at least one overnight stay (see below) and aged 16 years or over.

### **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 you should also exclude this person. When checks for deceased patients are carried out prior to subsequent mailings do not check for, or exclude, current inpatients.

### **Research Ethics Committee (REC)**

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

## **Section 251 Approval and Confidentiality Advisory Group (CAG)**

The purpose of CAG in reviewing a proposed studies application for Section 251 Approval is to ensure that the request for the transfer of patient identifiable data (patient names and addresses) by a trust to a third party is valid, without specific consent from the patient. 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. The Co-ordination Centre completes the application process for each survey and approval has been given for this survey.

#### **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.

## **Overnight stay**

Patients are considered to have had an overnight stay if they were admitted as an inpatient and occupying a bed at midnight, i.e. patients who are admitted as an inpatient on Day 1 and discharged on Day 2 are considered to have had a single overnight stay regardless of their admission time or discharge time.

## **Obstetrics/Maternity patients**

Any patients with route of admission codes of 31 or 32 and/or coded with a treatment function code of 501 (obstetrics) or 560 (midwife) admitted for management of pregnancy and childbirth, including miscarriages and/or coded with an ICD-10 chapter code of XV (if ICD-10 codes are available) should be excluded from the sample. If codes of 500 (obstetrics and gynaecology) are included, please ensure any included patients have been treated for gynaecology and not obstetrics.

## **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 treatment function codes of:

700	learning disability
710	adult mental illness
711	child and adolescent psychiatry
712	forensic psychiatry
713	psychotherapy
715	old age psychiatry
720	eating disorders
721	addiction services
722	liaison psychiatry
723	psychiatric intensive care
724	perinatal psychiatry
725	mental health recovery and rehabilitation service
726	mental health dual diagnosis service
727	dementia assessment service.

## 11 Appendices

# Appendix 1 Inpatient survey 2016 sampling declaration: trusts using a contractor

This declaration is to be signed by your trust's Caldicott Guardian and the member of staff responsible for drawing the sample of patients as set out in the 'Inpatient Survey Instruction Manual'. This checklist will be used for audit purposes to ensure that the sample conforms to the instructions and if all steps are completed will greatly help avoid any breaches of confidentiality occurring.

This declaration is also available to complete online. Trusts wishing to complete the declaration online will need to provide the Co-ordination Centre with the names and email addresses for the person drawing their sample and the trust's Caldicott Guardian. Unique links will be sent to these named individuals by email.

The national survey has received 'section 251 approval' from the Health Research Authority to enable data to be transferred to survey contractors for the purposes of this survey only. In order to be operating under that approval, you must follow the steps outlined below, otherwise the 'approval' will not apply. For more information on the approval requirements and confidentiality, please refer to the survey instruction manual (<a href="http://www.nhssurveys.org/surveys/935">http://www.nhssurveys.org/surveys/935</a>).

#### For staff drawing the sample:

Please complete this form once you have drawn your sample of patients. You must send this form to your approved contractor **before** you send your anonymised sample file and separate mailing file. Your approved contractor will check the form and confirm that you can submit your samples to them. Following checking of your sample file, your contractor will complete the final two questions on the form (titled "section for approved contractors"), and will send both the form and sample file to the Co-ordination Centre on your behalf.

Please confirm that the following tasks have been completed on behalf of your NHS trust by **initialling and ticking the boxes** and **signing the declaration**:

A sample of up to 1250 inpatients who attended in July 2016 has been drawn according to the instructions in this sampling instruction manual.	Initials
Have you <b>excluded</b> the following groups?	Confirmed
Patients who did not stay overnight	
Deceased patients	
Patients known to be current inpatients	
Patients under the age of 16 at the time of sampling	
Obstetrics/Maternity service users	
Patients admitted for planned termination of pregnancy	
Psychiatry patients	
Private patients or NHS patients treated at private hospitals	
Patients without a UK postal address	
Any patient known to have requested their details are not used for any purpose other than their clinical care, including requests made following sight of survey pre-publicity	
Have you <b>included</b> the following groups?	Confirmed
All eligible patients who had at least one overnight stay	
Patients born in 2000 who were 16 at the time of sampling	
Patients treated by a consultant with main specialty 500 or 501, who were not actually treated for obstetrics and maternity	
Patients whose address is incomplete, but contains enough information to have a reasonable chance of being delivered	
Patients with an address in the UK, but not England (Wales, Scotland, Northern Ireland, Isle of Man, Channel Islands, etc.), including military personnel	
Please check your extraction code/data logic, to ensure you do not exclude ANY patients simply because they are missing an item of data or are NULL for a sample data field.	Initials

Please check your extraction code/data logic again, to ensure you have not accidentally excluded any eligible patient groups, or any other patient groups not specified in the sampling instructions.	Initials
Please check that your sample consists of the most recently discharged, eligible patients, counting back from the 31st July (inclusive): You must not use admission dates, or a random number generator, or any other criteria to select which eligible patients you include in your sample.	Initials
Patients who indicated dissent have been removed from the sample (PALS team and Survey Lead to check records).	Initials
Please record how many dissenting patients were removed: (If none were removed, please record as 0)	Initials
The sample has been checked by the Demographic Batch Service (DBS)	Initials & Date
How many records were <b>submitted to DBS</b> for checking, in total?	Initials
How many records <b>could not be matched</b> by DBS?	Initials
The sample has been checked by Trust staff as outlined in the instruction manual.	Initials & Date
The sample and mailing files have been separated, with no identifiable information (patient name and address) in the sample file.	Initials
The sample file has been prepared and is ready to send to the Coordination Centre alongside this form for the sample checking, and no name or address details are contained within the sample file.  The only fields within the sample file are:	Initials
NHS trust code Patient record number (THIS IS NOT THE NHS NUMBER – it is a unique reference for this survey only) Year of birth Gender Ethnic category Day, month, and year of admission Day, month, and year of discharge Length of stay Main specialty on discharge Treatment Function Code ICD10 chapter code Treatment centre admission Route of admission NHS site code on admission NHS site code on discharge CCG code	

**Please note** you will be required to amend or update the sample and mailing files if any errors or deviations are identified during the sample check conducted by your approved contractor and then by the Survey Co-ordination Centre.

You will also be sending a separate mailing file to your contractor- that file will contain the names and addresses. If sample files are sent to your approved contractor mistakenly containing patients' names and addresses, or any other directly identifiable data, your contractor is obliged to report this to the Care Quality Commission. Your trust will have to consider logging the incident as a serious incident on the Information Governance Toolkit - see the 'Guidance for Reporting, Managing and Investigation Information Governance Serious Incidents Requiring Investigation'. The Confidentiality Advisory Group at the Heath Research Authority will also be notified by CQC.

## **Declaration by trust staff drawing the sample**

I understand that any errors with the way the sample has been drawn may limit, or prevent, the use of the survey data. Where data cannot be used, this would mean survey results would not be available for my trust in 2016 and may increase my trust's level of risk within CQC's risk monitoring tools. I confirm that the above steps have been completed and that the sample has been drawn in accordance with the survey instructions.

Trust name.				
Contact name				
Contact signature				
Contact email address	Contact phone number			
Declaration by Caldicott Guardian I confirm that the above steps have been completed and all steps have been followed.				
Name				
Signature				
Contact email address	Contact phone number			
Section for <b>approved contractors</b> : Please write in how many patients in the samp	le were replaced:			

Please note the reason(s) for these replacements:

## Appendix 2 Suggested text for pre-survey communication with staff

## **Example titles:**

What do our patients think about us?

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

Understanding patients' experiences in [trust name]

Patient views vital to drive service improvements in [trust name]

We [or NHS Trust name / Hospital name] will soon be carrying out a survey to find out what patients think about the care that we provide. The survey of adult inpatients is part of the national NHS patient survey programme.

#### Why are we doing another patient survey?

The survey needs to be run every year using the same method and asking the same (or similar) questions so that we can see any changes in patients' experiences over time. This enables us to make improvements in a specific area if people's responses show a poor experience. It also helps us to evaluate the success of quality improvement initiatives implemented since the last survey.

It's vital to gather feedback from patients and take their views and priorities into account to improve the quality of care.

## When is the survey happening?

Questionnaires will be posted to a sample of patients during [month]. A reminder will then be sent during [month] to those who have not responded.

Patients are being asked about various aspects of their care, including [arrival at hospital, the quality of care and treatment, pain management, communication with doctors and nurses, information, and the hospital environment.]

#### Who is the questionnaire being sent to?

The questionnaire will be sent to a sample of [number] patients, aged 16 years and over, who spent at least one night in hospital during [month]. [An external survey contractor, {name}, is administering the survey so that patients' responses are anonymous].

#### How have we used the results from previous survey?

Results from the 2015 inpatient survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here].

#### When will the results of this survey be available?

The results of the 2016 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...]. We will work with our staff and patients to use the feedback from this survey to help improve patient's experiences at the trust.

#### Where can I find out more?

Please contact [lead survey name and contact details].

# Appendix 3 Suggested template text for pre-survey article for external media

### **Example titles:**

[NHS Trust name] seeks patient views
Patient views vital to drive service improvements in [NHS Trust name]
Your chance to tell [NHS Trust name] about quality of care
We [NHS trust name] want to hear about your care

[NHS Trust name] is carrying out a survey to find out what patients think about the care they received when they were in hospital. The trust plans to use this feedback to improve patients' experiences. [NHS Trust name] will use the results of the survey to highlight areas where they perform well and to identify the areas where they need to improve.

Patients who have recently stayed in hospital as an inpatient 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 [arrival at hospital, the quality of care and treatment, communication with doctors and nurses, information, and the hospital environment.]

Obtaining feedback from patients and taking account of their views is really important for bringing about improvements in the quality of care. Results from the survey will be used to [insert purpose of survey here, e.g. to track patients' experiences of care received at the trust since the last survey was undertaken in [2015] / or to measure the impact of changes made at the trust based on feedback from the 2015 survey / or to find out if recent changes made to the service has led to an improvement in patients' experiences.]

Results from the 2015 adult inpatient survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here.]

People's responses are anonymous and 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 patients 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 4 Responsibilities of NHS organisations who are carrying out research

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

Continued...

Research Governance Framework	Care Quality Commission sponsored patient surveys
Maintain the necessary links with clinical governance and/or best value processes.	The instruction manual very strongly recommends that the trusts maintain these links and follow best practice evidence.
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities. <sup>1</sup>	In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an appropriate contract with the trust. These procedures are specifically detailed in the instruction manual.
Put and keep in place systems to identify and learn from errors and failures.	The Care Quality Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Care Quality Commission. The survey programme is constantly evaluated and reviewed in light of these.
Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	This requirement is not specific to this survey.
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	The Care Quality Commission maintains a helpline facility, which can be used by patients or trusts to report any complaints. Similar arrangements are in place with the Co-ordination Centre who are commissioned by the Care Quality Commission to co-ordinate the patient surveys.
Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	The results of the surveys are used for monitoring of trusts performance by the Care Quality Commission.

<sup>1</sup> When universities and hospitals employ staff on joint or dual contracts, they are expected to make joint arrangements for accountability and management. See: *A Review of Appraisal, Disciplinary and Reporting Arrangements for Senior NHS and University Staff with Academic and Clinical Duties*, a report to the Secretary of State for Education and Skills by Professor Sir Brian Follett and Michael Paulson-Ellis, September 2001 (The Follett Report).