#### Questions and Answers for NHS trusts Information on data uses and fair processing

When undertaking surveys as part of the National Patient Survey Programme Trusts may choose to carry out their surveys in-house or to commission an approved contractor to carry out the work for them.

The below provides some information to help trusts make this decision and provides information on the fair processing of data for surveys in the National Patient Survey Programme. This is important for trusts to be aware of, regardless of whether a contractor is involved in running the survey. It is a requirement of the Data Protection Act 1998 that the processing of personal data is fair and lawful. The following has been provided by the Care Quality Commission (CQC) to set out best practice (as detailed in full in the relevant survey guidance manual available on the NHS surveys website) but does not constitute legal advice.

Survey Contractors	2
Why should we use an approved survey contractor rather than doing the	
survey in house?	2
What is an approved survey contractor?	
How do we decide on a contractor to use?	
What sort of mistakes can be made if we decide to undertake the survey i	in-
house?	
Data Checking	4
The sample for our trust survey is checked by the Approved Contractor ar	nd
the Co-ordination Centre so why do I need to check it?	4
Information Governance	4
What is section 251 approval?	4
Does the section 251 approval cover any 'local' surveys that my trust	
chooses to undertake?	4
What are fair processing requirements?	4
How do I know when there will be a survey?	5
How should we notify our patients about the surveys?	5
Should we remove patients who have already opted out of research?	5
How should I transfer data to our approved contractor?	6
What should I do with the mailing list and the completed questionnaires	
when the survey has finished?	6
Where can I find more information?	6

### **Survey Contractors**

# Why should we use an approved survey contractor rather than doing the survey in house?

It is very strongly recommended that you employ the services of an approved contractor to undertake the survey on your behalf as they have the specialist expertise, knowledge and resources to undertake a survey. Planning, undertaking and reporting surveys is an administratively complex task requiring dedicated resources for several months, and it is easy to underestimate the skills, money, resources and staff time required. Previous surveys within the programme have shown that more <a href="mistakes">mistakes</a> are made by trusts undertaking the survey in-house, and in-house trusts account for a higher proportion of the more serious errors. If the survey is not undertaken in accordance with the guidance manual, the results for your trust might not be eligible for inclusion in the CQC publication, the QRP and for use by others such as NHS Choices and the Department of Health for their performance assessment, improvement and regulatory purposes.

The section in the guidance manual on *deciding whether to use an approved contractor or carry out the survey in house* details the sorts of issues you should consider. The services provided by an approved contractor will vary depending on what you commission them for, but at a minimum they will include sample checking, mailing and data entry, and may also include report writing, advice on areas to target for quality improvement and different types of analyses etc. Before committing to a contractor, you are advised to check exactly what is covered within the cost quoted, and to consider exactly what you might need.

#### What is an approved survey contractor?

If you decide to use a survey contractor, it is a requirement to use one that is currently approved by the CQC. These are organisations which have been assessed on a number of criteria including their capability to undertake surveys, their data protection requirements and their value for money. To undertake a survey on behalf of a trust these organisations will have submitted a System Level Security Policy (SLSP) which is reviewed by NIGB as part of a survey's section 251 approval. An SLSP covers the security and confidentiality measures that the company has in place for all stages of the survey. The approved contractors which have submitted an SLSP as part of the section 251 application will be listed in the survey guidance manual.

#### How do we decide on a contractor to use?

A list of contractors approved to undertake surveys for the patient survey programme may be found at: <a href="http://www.nhssurveys.org/approvedcontractors">http://www.nhssurveys.org/approvedcontractors</a>

Before committing to a contractor, you are advised to check exactly what is covered within the cost quoted, and to consider exactly what you might need. You will also need to confirm with the survey Co-ordination Centre, or refer to

the guidance manual, to ensure that the contractor has been included in the section 251 approval.

### What sort of mistakes can be made if we decide to undertake the survey in-house?

Please remember that if the survey is not undertaken in accordance with the guidance manual, the results for your trust might not be eligible for inclusion in the CQC publication, the QRP and for use by others such as NHS Choices and the Department of Health for their performance assessment, improvement and regulatory purposes. This means that the data will be far less useful for you, and may not be available on the CQC website to be viewed by the public.

Planning, undertaking and reporting surveys is an administratively complex task and errors can occur at any stage from creating the questionnaire to sampling, mailing or data entry.

#### Common sampling errors include:

- Inclusion of ineligible patients
- Exclusion of eligible patients
- Not taking the correct type of sample as specified in the survey guidance (for example, taking a random sample instead of a sample of consecutive discharges)
- Excluding hospital sites

The Co-ordination Centre publishes a report for each survey detailing the sampling errors undertaken and these are available in the relevant survey folder on the NHS survey website. These reports detail major errors (which require re-sampling) and minor errors (which require correction). More major errors are made by trusts who decide to undertake the survey in-house.

#### Common questionnaire errors include:

- Incorrect questionnaire filtering or 'go to' instruction: Inserting or removing a question will affect the 'go to' or routing instructions in a questionnaire. If these are incorrect, a respondent may incorrectly miss out a series of questions applicable to them, or answer questions that are not relevant to them.
- Missing out a question or questions
- Including the wrong response categories for a question

Questionnaire errors can result in the data for the affected questions(s) being ineligible for inclusion in the trusts published results. **We very strongly recommend that you do not reformat the questionnaire** in any way and use the Question Bank Tool to generate a questionnaire on the NHS surveys website.

### **Data Checking**

# The sample for our trust survey is checked by the Approved Contractor and the Co-ordination Centre so why do I need to check it?

We strongly advise you to ensure that thorough checks are carried out at every stage of the sampling process. The Co-ordination Centre's role is to check for extraordinary errors which are more visible from looking at the samples of many trusts at once. Please remember that some errors cannot be identified by the Co-ordination Centre until the data has been collated at the end of the fieldwork period. It would then be too late to rectify such errors, and if the data is deemed to be affected by this, it will not be used for the CQC and other purposes. Ultimately, you have the best knowledge of the data for your trust.

#### **Information Governance**

#### What is section 251 Approval?

Section 251 of the NHS Act 2006 allows the Secretary of State for Health to set aside the common law duty of confidentiality so that service user information can be disclosed for a range of secondary healthcare purposes.

All surveys developed since August 2011 have received section 251 approval from the National Information Governance Board. This means that trusts taking part in the National Patient Survey Programme have approval to pass certain information about patients who have been selected for inclusion in a survey to their approved contractor, provided they follow the recommendations for data transfer as set out in the relevant survey guidance.

# Does the section 251 approval cover any 'local' surveys that my trust chooses to undertake?

The approval covers the national surveys only, and **will not** apply to any local surveys as the application has been made by CQC on behalf of all trusts, for a national standardised survey. Please contact your trusts Caldicott Guardian for advice as to whether it is appropriate to contact the National Information Governance Board for approval.

### What are fair processing requirements?

The first principle of the Data Protection Act 1998 (DPA) requires that all processing of personal data is 'fair and lawful'.

One of the specific requirements of the DPA is that, in order to make processing fair, you must take reasonable steps to let people know about the purposes for which their information may be used (such as surveys) and to whom the information will be disclosed (such as approved survey contractors).

A useful guide detailing requirements in full may be found at: <a href="https://www.nigb.nhs.uk/advice/guideinfomaterial">www.nigb.nhs.uk/advice/guideinfomaterial</a>

In terms of the National Patient Survey Programme, this means that in order to satisfy fair processing requirements you need to:

- take steps to ensure that patients or service users are informed about use of data
- ensure that when sharing data with your approved contractor, this is done
  in a safe and secure way.

Both of the above can be achieved by following the best practice recommendations as summarised in this Q&A section, and as set out in detail in the relevant survey guidance.

#### How do I know when there will be a survey?

We will aim to notify all organisations that a survey is to be run before the actual sampling frame period, so that all organisations can assess their fair processing responsibilities and alert their patients or service users that their data may be shared with researchers.

Please also see the forward planner available on the surveys section of the CQC website at: <a href="https://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys">www.cqc.org.uk/public/reports-surveys-and-reviews/surveys</a>

#### How should we notify our patients about the surveys?

Ways of notifying patients about a survey include pre survey publicity. One means of doing this is to publicise the survey during the sampling period. For example, if you usually undertake an inpatient survey drawing a sample from people who had an inpatient stay during August, you should put up posters where they will be seen by patients during the month of August. A template poster will be provided to help with the preparation on <a href="www.nhssurveys.org">www.nhssurveys.org</a>, though NHS organisations are expected to also make any other arrangements in order to be satisfied that they fulfil their responsibilities as data controller.

The survey guidance manual suggests other ways in which you can keep patients / services users and staff informed, for example, on your trust's website, or in local newsletters or local or hospital radio.

Ideally, any information – such as leaflets – that you give to your patients when collecting their data in the course of your normal service provision should mention the possibility that data may be shared for the purpose of sampling for surveys.

## Should we remove patients who have already opted out of research?

Section 251 approval can not be used to override any instances where patients or service users have previously requested that their data is not shared outside the trust, or that their information is not used for any purpose other than their clinical care. NHS trusts will be asked to remove these patients from their samples, as detailed in the guidance documents for each survey. However, there is considerable 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.

In order to keep the potential for bias to a minimum, we request that trusts ensure that where any opportunity is provided for patients to opt out, they are made aware of the purpose of this specific use of the data, including the aim of the national survey programme and how data will be used by the Care Quality Commission (and others) to assess and improve the care that is provided in the future. Information on the National Patient Survey Programme is available on the CQC website here: <a href="https://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys">www.cqc.org.uk/public/reports-surveys-and-reviews/surveys</a>

#### How should I transfer data to our approved contractor?

The guidance manual for each survey sets out in detail our recommendations for the secure transfer of data.

The CQC has provided template service contracts to cover the transfer of sample data from each NHS organisation to the survey company, for the purposes of mailing out questionnaires. It is strongly recommended that these are used by all parties, and reviewed by all to ensure agreement on the proposed arrangements. The survey companies have submitted details of their information security arrangements to the CQC, and abide by market research regulations. Various other safeguards are in place to protect the confidentiality of patient data, including guidance on secure transmission of data and encryption methods.

# What should I do with the mailing list and the completed questionnaires when the survey has finished?

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 must be destroyed when the survey is complete. This must be done by both the trust and the approved contractor. The original lists may need to be referred to if any errors are identified part of the way through a survey, though are to be destroyed once it is apparent that no further checks would be necessary.

The completed questionnaires should be retained until the date specified in the relevant survey guidance manual available on the NHS survey website. Again, this is to ensure that they are available should there be any queries with the data which require going back to the original questionnaires to resolve (for example, a data entry error).

#### Where can I find more information?

The websites below are some further sources of further information. However, you should also consult your Caldicott Guardian and / or Information Governance Department for advice if required.

The individual survey guidance manuals provide detailed descriptions of the necessary processes for undertaking patient surveys, and are available at: www.nhssurveys.org

Information about the Data Protection Act 1998 can be found at the Information Commissioner's Office: <a href="www.ico.gov.uk">www.ico.gov.uk</a>

Further guidance can be found in the Market Research Society at: <a href="https://www.mrs.org.uk/standards/data">www.mrs.org.uk/standards/data</a> protection/

The website for the National Information Governance Board is: <a href="https://www.nigb.nhs.uk">www.nigb.nhs.uk</a>