INSTRUCTION MANUAL FOR THE NHS MATERNITY SURVEY 2017

FOR TRUSTS USING A CONTRACTOR

THE CO-ORDINATION CENTRE FOR THE NHS PATIENT SURVEY PROGRAMME

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Contacts

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

Tel: 01865 208 127
Fax: 01865 208 101
E-mail: mat.cc@pickereurope.ac.uk
Website: www.nhssurveys.org

Key personnel

Chris Graham (Director)

Lewys Brace
Carolina Casañas i Comabella
Rory Corbett
Tiffany Gooden
John Latham-Mollart
Nick Pothecary
Firona Roth
Steve Sizmur
Eliza Swinn
Lizzie Thwaites
Alison Wright

Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in this manual, for example by offering financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages within the 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 (CQC) assessments for that trust. If trusts want to make any adjustments to the method or materials set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability or impact on Research Ethics Committee or Section 251 approvals (see *Sections 4 & 5*).

Data from the patient surveys are used in an increasing number of outcomes frameworks and indicators. If the sampling guidance issued for the survey is not adhered to and errors are detected too late for remedial action to be taken, this will impact on the use that can be made of data. CQC use patient survey data for purposes of risk monitoring. If data are excluded because sampling errors are detected, this will impact on the assurances CQC can have about the experiences of your patients.

Updates

Before you start work on your survey, check that you have the latest version of this document, as there might be some small amendments from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will e-mail all trust contacts and contractors directly to inform them of the change.

This document is available from: http://www.nhssurveys.org/survey/1943.

Contents

1 Introduction: The importance of patient feedback

1.1 The Care Quality Commission

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

As set out in the public engagement strategy[1], 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 CQC's work: it is the aim of the CQC and the Co-ordination Centre to make sure 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 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 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 the 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 Maternity Survey is part, is based at Picker Institute Europe and works under contract to the CQC to design, test, and co-ordinate the patient survey programme.

1.3 Why we need patient feedback

Quality in health and medical care has two distinct dimensions. One has to do with the quality of care from the perspective of professional, technical standards, and the other 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 Maternity Survey. It also provides guidance 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.

[1] http://www.cqc.org.uk/content/our-plan-engaging-public-our-work-2015-16

1.4 Patient feedback and the NHS Constitution

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

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

- Providing information to support local quality improvement initiatives.
- Tracking changes in patient experience locally over time.
- Providing information for active performance management.
- Providing information to support public and parliamentary accountability.
- Providing information for the CQC's programme of reviews and inspections.

1.5 CQC assessments

Information drawn from the questions in the survey will be used by the CQC in its assessment of acute and specialist trusts in England. Questions from the survey will be used within CQC's monitoring tools and within CQC's inspections of maternity services. More information is available on the CQC website at: http://www.cqc.org.uk/content/how-we-inspect.

1.6 Measuring performance across trusts

In addition to the performance assessment, the CQC will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves and national benchmarks based on reliable data. Asking each hospital trust to carry out the Maternity Survey in a consistent way builds a detailed picture of women's experiences in NHS hospital trusts.

Information collected in a nationally consistent way is also essential to support public and parliamentary accountability. The results are also used by NHS England and the Department of Health for performance assessment, improvement and regulatory purposes. These include the NHS Outcomes Framework (Domain 4.5: 'Improving women and their families' experience of maternity services' – this indicator is based on national survey data), the DH overall patient experience measure, the NHS Performance Framework, the cross-Whitehall Public Services Transparency Framework and NICE Quality Standards.

The CQC intends to archive the survey data with the UK Data Archive after the analysis is completed and published. This will be done with appropriate safeguards that ensure patient confidentiality.

1.7 Basic requirements for the Maternity Survey

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

- You should already have contacted the Co-ordination Centre to provide contact details (job titles, phone numbers and email addresses) of the two key trust contacts to allow us to

communicate vital information about the Maternity Survey 2017. If you have not already done so, please email these details to mat.cc@pickereurope.ac.uk.

- You should already have contacted the Co-ordination Centre to confirm your choice of approved contractor. If you have not already done so, please send this confirmation to mat.cc@pickereurope.ac.uk. If you are not intending to appoint an approved contractor, please refer to the manual for trusts conducting the survey in-house instead of this one.

- The sampling procedure set out in this guidance **must** be followed. To do this, you will need to work closely with the person who draws the sample, and check carefully that the instructions have been adhered to. For further details see *Section 7.*

- The sample must consist of all women who gave birth during **February 2017** as outlined in *Section 7* [If your trust had fewer than 300 births in February, please consult the additional guidance document at: http://www.nhssurveys.org/survey/1956. This document contains instructions for including January births in the sample].

- Your Caldicott Guardian must sign off the sample declaration form by completing the 'Declaration Agreement' tab in the Excel template. You will need to send the completed declaration form to your contractor for approval **before** you submit your sample for checking. The sample declaration form can be downloaded from here: http://www.nhssurveys.org/surveys/1074.

- Trusts should facilitate higher response rates by commencing work as soon as possible and publicising the survey to staff, patients and the community.

- Your contractor will be responsible for printing out and sending all of the required survey documents; however, you can access these for information on the NHS Surveys website here: http://www.nhssurveys.org/surveys/1056.

- 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 people confusion. However, trusts can start using their results internally to identify areas for quality improvement.

1.8 Why you need this guide

This instruction manual explains what your trust needs to do to prepare for and implement the survey, when 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.

You must be familiar with all aspects of this guidance, but in particular, the sections on drawing the sample, and data protection requirements.

It is a requirement of the Section 251 approval received for the survey that trusts must use a contractor that has received confirmation from the Health and Social Care Information Centre of suitable security arrangement via Information Governance Toolkit (IGT) submission. Contact information for the approved contractors for the 2017 Maternity Survey is available on the NHS Surveys website at: http://www.nhssurveys.org/approvedcontractors.

2 Setting up a project team

We recommend you set up a project team to assist you in running the survey. 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 women's 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, midwives, nurses and other health care staff
  - Managers
  - Medical records personnel or Patient Administration System (PAS) staff
  - Recent mothers and their partners
  - Members of patient groups with a special interest in the trust
  - Staff or directors responsible for:
    - Midwifery
    - Clinical governance
    - Patient advice and liaison service (PALS)
    - Quality improvement
    - Strategic planning

- **Involving the people responsible for drawing and checking the patient sample in planning meetings.** It is essential that they, and their line managers, understand the purpose of the survey and the importance of drawing the sample correctly.

- **Keeping everyone informed.** Notify as many people as possible about ideas and activities. All departments in the trust should be made aware when a survey is being conducted, in case patients contact the trust asking questions about the survey they have received.

- **Not overlooking front-line staff.** These people have the most frequent direct impact on patients' experiences.

3 What's new for 2017?

Questionnaire: There have been some question changes to the questionnaire, and the CQC helpline number has been added to the last page. A survey development report has been published on the NHS Surveys website detailing the changes and the specific reasoning behind these changes: http://www.nhssurveys.org/survey/1922. The questionnaire itself is available here: http://www.nhssurveys.org/surveys/1065.

Sample declaration form: This year, the sample declaration form is in Excel rather than Word and therefore can be signed off electronically rather than in hard copy. Both the person drawing the sample and the Caldicott Guardian will need to sign off the form. When the form is complete, it needs to be sent to your approved contractor for approval before you can send your sample file to them. The form must be sent from the work email of the Caldicott Guardian or by the person drawing the sample with the Caldicott Guardian copied into the email. The sample declaration can be downloaded from the NHS Surveys website at: http://www.nhssurveys.org/surveys/1074. See *Section 7.9* for further information.

Single sample and mailing file: To reduce error, this year trusts will only send one file to their contractor which will contain both the sample and mailing information. The contractor will then separate the files and send only the sample file to the Co-ordination Centre. More details on this are in *Section 7*.

Submission of files: The combined sample and mailing file must be sent to the contractor via their FTP. Trusts will **not** have the option to submit files via email as in previous years. Files will still need to be password protected and encrypted.

Ethnic coding: In previous surveys, ethnicity was coded as 'Z' when a patient had been asked for their ethnic category and had declined either because of refusal or genuine inability to choose. In contrast, ethnicity was left blank where ethnic category was unknown, i.e. where women had not been asked or were not in a condition to be asked (e.g. unconscious). For the 2017 survey, trusts will be asked to code **both** 'Z' and 'blanks' as 'Z' in the sample file they submit to their contractor because the distinction between codes is not useful for data analysis purposes, and is often not applied correctly or consistently across trusts. However, trusts are still able to choose whether or not to distinguish between the codes when collecting ethnicity information for their own records. Further information on ethnic coding can be found in *Section 7.6.*

CQC Intelligence Model: CQC is redeveloping its method of monitoring trust performance. Where trusts fail to submit a sample for the Maternity Survey, or if it becomes evident at a later date that an error has been made in drawing the sample that renders the data unusable, this will be flagged as a concern within the CQC monitoring tools, which may in turn have an adverse effect on the conclusions CQC draw based on the lack of patient experience data.

Errors in drawing the sample may be 'minor' or 'major'. A **minor error** means that data is still able to be used despite that error. A **major error** is so serious that data for a trust is unusable and would be excluded from CQC publications and national statistics. Making errors in drawing the sample, such as neglecting to include a core group of eligible service users, effectively biases the sample. This means that an individual trust's results are not comparable to other trusts. If major errors are spotted during the sample checking phase, the Co-ordination Centre will request that a fresh sample be drawn. However, errors are not always easy to spot in an anonymised file. If it only later becomes evident that a major error has been made and there is no time to submit a new sample for inclusion in the survey, **the survey response data will be excluded from the CQC dataset and will negatively impact on CQC assessment of your performance for this survey**.

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 2015 survey which highlights the errors that were made in compiling and submitting samples. It can be found here: http://www.nhssurveys.org/survey/1727.

There are no other changes to either the methodology or the survey materials for the 2017 survey, however some important notes are highlighted below:

3.1 Important information to remember

Providing explanations to 16 and 17 year old mothers: To meet the requirements for support under Section 251, it is necessary that midwives or other staff provide all younger mothers (aged 16 and 17 years at the time of their baby's birth) with an approved information sheet and discuss the requirements of the survey with them. The information sheet and a briefing for trusts on informing young mothers about the survey are available here: http://www.nhssurveys.org/surveys/1058. Any requests from these women to opt out of the survey must be logged at the trust and referred to when drawing the sample.

Posters: Throughout the February (and for some trusts, January) sampling period, the approved poster should be displayed to publicise the survey. The poster is available to download from the NHS Surveys website here: http://www.nhssurveys.org/survey/1876. There is space at the bottom of the poster for trusts to insert a contact telephone number for people to call should they wish to opt out. Please be aware that no other changes to the poster are permitted as the content and format has been approved as part of the Section 251 application.

Recording dissent: An essential requirement to meet the conditions of the Section 251 approval for this survey is that any patient who has previously indicated dissent must be removed from the eligible survey population prior to sending the sample to an approved contractor. If your trust has a mechanism in place to flag patients who do not wish their data to be used for secondary purposes, we advise that you refer to this when drawing your sample as these patients will need to be removed. You also must log any requests to opt out of the survey from women as a result of the posters displayed or from 16 and 17 year olds who have discussed the survey with staff (see above). The sample declaration form (see below) will ask for the number of dissenters to be logged. Please also refer to *Section 4.1*.

Embargo on results: Trust-level findings for the national Maternity Survey 2017 **must not** be released outside of the trust until the national results are published by the CQC. Please continue to use the results from your in-house survey teams, but wait until the survey results for all trusts are published by the CQC 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.

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), which incorporates the Caldicott principles[2].

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. 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 CQC and the Co-ordination Centre for the 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 Market Research Society's *Guidelines for social research* (2005). They have implications for approved contractors and for NHS trusts conducting the survey in-house.

The website below has further information:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253.

Information about the Data Protection Act 1998 can be found at the ICO – Information Commissioner's Office: https://www.ico.org.uk.

Further guidance can be found in the Market Research Society document at:
http://www.mrs.org.uk/pdf/data_protection_social.pdf.

4.1 Approval under Section 251 of the NHS Act 2006

Approval has been granted for the Maternity Survey 2017 under Section 251 of the NHS Act 2006. The survey methodology was reviewed by the Confidentiality Advisory Group at the Health Research Authority for approval. The letter of approval is available on the website here:
http://www.nhssurveys.org/survey/1929.

However, the Section 251 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

[2] 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.
- **Principle 7** – The duty to share information can be as important as the duty to protect patient confidentiality.

You should take particular care to ensure that your use of patient data in carrying out the survey complies with these seven principles. In particular, you should be aware of the flows of patient data, and the issues which these present. The Caldicott guidance and principles were incorporated into the NHS code of practice on confidentiality.

explicitly 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), these patients must be excluded from your sample.

This should be done using your local records and also with the Personal Demographics Service (PDS) if your system is compliant (i.e. those patients listed through the PDS service as having an S flag which restricts the patient's location details from being shown in PAS). We understand that some records are S-flagged for data quality reasons and some because of concerns about their contact details being available for wider research or similar uses. We expect that these flagged patients may not eventually be included in the sample drawn from the trust as the address fields will be incomplete.

Please discuss this issue with your Caldicott Guardian to ensure that any women 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.

For more information on the fair processing of data, please see the FAQs at: http://www.nhssurveys.org/Filestore/documents/20120704_FAQs_on_fair_data_processing_draft4.pdf.

It is very important that you follow the instructions set out in this 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 inform the Confidentiality Advisory Group and 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.

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

Please note that the application for Section 251 approval has been made 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 guidance, it is important to note that this is **not covered by the Section 251 approval. You must consult your trust's 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 CQC. 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 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.

For more information on conducting local surveys please refer to the NHS website here: http://nhssurveys.org/localsurveys.

4.3 Keeping patient mailing and sample data separate

You will submit one file containing the mailing information and sample information to your contractor for checking. **Before** sample and mailing data is sent to contractors, it is essential that each patient is provided with a unique Record Number. Once contractors separate the files, the unique Record Number must be available and correctly matched on both the mailing file and the sample file. Contractors will then forward the sample file only to the Co-ordination Centre for checking and approval.

It will be the responsibility of contractors to ensure that patients' names and addresses are stored separately. Keeping names and addresses separate from both sample information and respondent data is the best way to ensure that survey responses cannot be matched to the women who made them. 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 have access to the mailing file.

Applying the unique 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 (from the post-DBS list) for trusts – this will be considered a breach of the survey's Section 251 approval and action taken against both the trust and approved contractor will follow.

You should only send your approved contractor your sample and mailing data file once they have confirmed to you that your sample declaration form has been completed satisfactorily. This is to help prevent breaches of the Section 251 approval and related data protection requirements.

Where identifiable data is inadvertently transferred, the trust will be required to review the severity of the data breach using the Serious Incident Requiring Investigation (SIRI) guidance, which forms part of Information Governance Toolkit Approval. Breaches are reviewed by CQC and the Confidentiality Advisory Group also.

4.4 Mailing questionnaires

There are two methods available to trusts for mailing out questionnaires:

1. **The contractor mails out the questionnaires.** With the agreement of the trust's Caldicott Guardian, you may set up a written agreement between the trust and the external contractor. The CQC 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. The service contract can be found here: http://www.nhssurveys.org/surveys/1076. *Section 4.7* below provides more information.

2. **The trust mails out the questionnaires.** If a trust is unwillingly to share names and addresses with a contractor, despite the Section 251 approval, the contractor could deliver pre-packed record-numbered envelopes containing questionnaires, covering letters and freepost envelopes to the trust. The trust then would attach number-matched address labels to the envelopes and send them out to patients. Completed questionnaires can then be returned to the contractor and, by checking the Record Numbers on returned questionnaires, they can inform the trust which patients need to be sent reminders.

4.5 Patients' names and addresses

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

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

- All data files must be sent by trusts to contractors securely, i.e. using the agreed FTP sites, with files encrypted and password protected.

- Please ensure that the sample drawer and Caldicott Guardian have completed the sample declaration form and signed it electronically. This form is to be sent to your approved contractor before you are able to submit your sample. Once your approved contractor has checked your sample, both the sample declaration form and the anonymised sample file will be submitted to the Co-ordination Centre by your approved contractor. Sample files will not be accepted before the completed sample declaration form has been approved. The completed form can be sent to your contractor from (a) the email address of the Caldicott Guardian, or (b) the email address of the person who drew the sample if the Caldicott Guardian is copied into the email. The Co-ordination Centre will use these documents to help check your sample file.

4.6 Encryption of personal data

Any patient identifiable information sent between trusts and contractors must be in an encrypted format with password protection to help ensure good standards of information security. When sending data electronically, an encrypted session based on the Transport Layer Security (TLS) or Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP) must be used. A key size of 256 bits or greater should be used. This is to ensure a high level of security, to protect against any accidental or intentional interception during the transfer of patients' details.

Many different encryption algorithms exist and not all of these are suitable, so both the Co-ordination Centre and the CQC 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). Approved contractors should be able to provide guidance to trusts on the use of an encrypted session.

4.7 Contractor responsibilities (service contract)

A service contract has been drafted by the CQC. This is an agreement between the approved contractor and the trust contracting them. By signing it, the approved contractor is obliged to keep the information confidential at all times, and to comply with the Data Protection Act 1998. 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 service contract. The service contract is set up between the trust and the approved contractor who will have access to women's information. The service contract describes how women's personal data will be sent to the approved contractor, and how the data can be used. The CQC strongly recommend that the clauses contained in the template service contract are reviewed by qualified staff at each trust to ensure they are appropriate.

The service contract in is available here: http://www.nhssurveys.org/surveys/1076. It is designed to be used as a template contract; trusts and approved contractors may agree on amendments to the wording and content, and we recommend that Caldicott Guardians are involved in this process.

4.8 Patient anonymity

Patient anonymity can be achieved if there is a clear separation between the information seen by an approved contractor and the information held by the trust. Women's 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 women's responses. As long as the response data supplied to trusts do not include unique Record Numbers or any other detail that allows individuals to be identified or linked, it can reasonably be claimed, with regard to the trust and trust staff, that women's responses are anonymous.

4.9 Patient confidentiality

It is essential that any patient survey is conducted in such a way that patient confidentiality is respected and given a high priority. The covering letters that accompany the mailed questionnaires inform women that their name and address will never be linked to their responses. Furthermore, women's responses must not be presented to anyone in a way that allows individuals to be identified. For example, if an individual is known to have stayed on a particular ward, and 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 requirements are made:

1) Approved contractors will **not** provide raw data to the trust as a matter of course.

2) If the trust has a particular need for the raw data from the survey from the approved contractor, 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 will delete the variable pertaining to **date of delivery**.

b. The contractor will delete the two variables pertaining to **ethnicity** (i.e. both sample variable and response variable – **G7**).

c. The contractor will delete the responses to question **A1** on whether the woman gave birth to a single baby or more.

d. The contractor will delete the responses to questions **G2 and G3** on the woman's reproductive history.

e. The contractor will delete the responses to question **G5 and G6** pertaining to the respondent's religion and sexual orientation.

f. The contractor will **band the mother's year of birth** into five age groups (16-19, 20-24, 25-29, 30-34, 35+). This process should be repeated separately for both sample and response variables (**G1**). The original mother's year of birth variables (i.e. those specifying an exact year rather than age group) must then be deleted.

g. If you are publishing any **free text comments**, they must have any identifiable information removed such as people's names and ethnicity.

h. Prior to releasing the raw data, your approved contractor will ask for confirmation that you have destroyed the names and addresses of the sampled women, otherwise you will potentially be able to identify women by matching up the patient Record Number/serial numbers on the name and address list to those in the raw data file.

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 (such as by ethnic group or maternity unit), 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' and 'Asian' ethnic groups are suppressed (though other sub-group totals are shown):

	E3. Did you ever try to breastfeed your baby (even if it was only once)?		
Ethnic group	**Yes**	**No**	**Total responses**
	%	**%**	N
White	38	62	261
Mixed	-	-	8
Asian	-	-	18
Black	41	59	52
Chinese or other	85	15	36

4) Do not present response information (including comments) in a form that allows an individual woman to be identified by the group receiving the information. For example, if you are presenting the results of a small number of women, make sure that it will not be possible for the reader/audience to identify individual women from their responses, and pay particular attention to the women's free text comments in this context.

4.10 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 receive 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.

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 Maternity Survey

Research Ethics Committee (REC) approval has been obtained for the 2017 Maternity Survey and a substantial amendment submitted for changes regarding the questionnaire and covering letters, all of which will be published on the NHS Surveys website: http://www.nhssurveys.org/surveys/1056. **In order to comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document.**

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

Your trust should notify the relevant Research and Development (R&D) office that ethical approval has been obtained for the 2017 Maternity Survey. The REC letter of approval can be downloaded from the NHS Surveys website at: http://www.nhssurveys.org/survey/1924.

Further information on the ethical approval process can be found at the Health Research Authority website http://www.hra.nhs.uk/ or by emailing hra.queries@nhs.net.

5.2 Research governance requirements

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

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

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

See Appendix 1 for more details on the responsibilities of NHS organisations that are carrying out research.

6 Timetable

The fieldwork period for the Maternity Survey is 18 weeks. We recommend making full use of this time to maximise responses from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond[3]. If your trust's population has high proportions of either group, it is especially vital that you allow enough fieldwork time to capture responses from these people. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly which will enable your approved contractor to mail out your questionnaire packs promptly.

As you are using an approved contractor, much of the work will be done by them, but you will still have to be involved in some of the stages of the process. The approved contractor may provide you with a timetable that differs slightly to the one below.

Week	Task	See Section
-	Inform the Co-ordination Centre which contractor will be conducting the survey on your behalf, and provide names and contact details of two key contacts who will manage the survey on behalf of your trust.	1.7
1	Draw sample of women to be included in the survey.	7
1	Check sample for deceased women and infants using hospital records.	7.2
1	Depending on the accuracy of your hospital information systems, check sample with member(s) of the clinical midwifery team to ensure all women are eligible to participate in survey.	7.3
1	Submit sample list to DBS to check for deceased women AND infants.	7.4
1-4	Have sample declaration form signed off and send to your survey contractor, before submitting the combined sample and mailing file.	7.9
1	Supply approved contractor with trust headed paper and a signature of a senior executive and, if appropriate, ensure that the service contract is signed.	4.7
2-6	Check your trust records again for any maternal or infant deaths.	7.2
2-6	Stick labels on pre-packed numbered questionnaires and reminders supplied by approved contractor (if NOT using service contract).	4.4
8	Send data indicating whether women in your sample received their antenatal and postnatal care from the trust (**26th May 2017**). The Co-ordination centre will provide additional guidance to help trusts carry out this process.	To follow in separate guidance
5-8	Prior to first reminder mailing, submit sample again to DBS and check trust records for any deceased mothers or infants, then inform your contractor.	7.4

[3] 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.

7-10	Prior to second reminder mailing, submit sample again to DBS and check trust records for any deceased mothers or infants, then inform your contractor.	7.4
22+	Review results and / or report provided by your approved contractor but please do not release outside of the trust until published by CQC.	3.1
-	Disseminate results to staff and patients, once published by CQC.	-

Key dates

Draw sample	13th March – 14th April 2017
Submit sample to contractor	13th March – 14th April 2017
Sample checking by Co-ordination Centre	3rd – 28th April 2017
Fieldwork starts	24th April 2017
Submit data indicating which women received their antenatal and postnatal care from the trust	26th May 2017
Fieldwork closes	25th August 2017
Contractors send final data to Co-ordination Centre	1st September 2017

7 Drawing a sample

This section explains how to draw a sample of women. This task will need to be carried out by a member of staff at your trust. The sample will normally be drawn from the Patient Administration System (PAS). Depending on your trust's hospital information systems, it may be that sample information will need to be linked between the Patient Administration System (PAS) and the clinical maternity databases. In addition, maternal records will need to be linked to infants' records to apply some of the exclusion criteria, in which case support from an IT specialist may be required. The sample list will also need to be checked to make sure that the necessary exclusions have been applied, and will also need to be checked by the Demographic Batch Service (DBS) to identify deceased women and infants.

Please follow the instructions below carefully and allocate sufficient work time to check the sample with DBS and within the trust prior to each mailing.

It is essential that the person who draws the sample understands the importance of following these instructions carefully. Also, this person's line manager must give them the time and support they need to do the task properly. An incorrectly drawn sample can delay the start of the survey or can result in the questionnaires being sent to the wrong patients, both of which can have serious implications.

If an error in a sample is discovered at the close of fieldwork, data for the trust may not be suitable for inclusion in the survey publication, and, as discussed in *Section 3* of this manual, may incur penalties in the CQC's Intelligence Model.

Please read all of this section before you start to compile your list of women.

Please note: your sample should only be used for the purposes of distributing the Maternity Survey 2017 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.

Please note: 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 Compile a list of eligible women

Compile a consecutive list of all women **aged 16 years or over** at the time of delivery who had a live birth between **1st February and 28th February 2017.**

Note: If there are **fewer than 300 eligible women** who had a live birth in February, please consult the additional guidance document at: http://www.nhssurveys.org/survey/1956. This document contains instructions for including January births in the sample.

The information you obtain about each woman will be used both for administering the survey and for sending to the DBS to check for any deaths. It saves time and effort if all the information is gathered at the same time (See *Section 7.6* for a list of the data fields that you will need to include in your sample file for the survey).

Who to include

- **Women who delivered at any unit managed by the trust.** Women who gave birth at a separate maternity unit should still be included in the sample, as long as it is managed by the trust.

- **Women who delivered at home.** If home births are not recorded on the hospital information system, it will require a manual check of the records held by midwives.

- **All types of deliveries.** It is important that all women who had a baby in the time period are included in the survey, not just the ones with normal vaginal deliveries with no complications.

- **Multiparous and primiparous women.** Your sample should include both first-time mothers and women who have previously had a baby.

- Include women even if their addresses are incomplete but still useable (e.g. no postcode).

Who to exclude

The following women are **not** eligible to participate in the survey and should be **excluded** from your sample list:

- Women who are under 16 years of age at the time of delivery.

- Women who had any of the following ICD10 delivery outcomes **or their equivalents**[4]:

    - Z37.1 Single stillbirth
    - Z37.3 Twins, one live; one stillbirth
    - Z37.4 Twins, both stillbirths
    - Z37.6 Other multiple births; some live; some stillbirths
    - Z37.7 Other multiple births, all stillbirths

- Women whose baby has died since delivery[5].

- Women who have died during, or since, delivery.

- Women who are in hospital, or whose baby is in hospital, at the time of drawing the sample.

- Where possible, women who had a concealed pregnancy[6].

- Where possible, women whose baby was taken into care (i.e. foster care, adopted)[7].

- Women who gave birth in a private maternity unit or wing.

- Women who gave birth in a maternity unit managed by another provider.

[4] If you do not use ICD10 codes in your systems, please use the appropriate equivalents to the codes listed above.

[5] In order to apply this criterion, it is essential that maternal and infant records are linked. Death checks for infants will need to be run within the trust and by the DBS to ensure that deaths occurring both within the trust and outside trusts are detected.

[6] If you do not record this information in your electronic systems, these women should be removed from the sample when the list is validated by member(s) of the midwifery team.

[7] If you do not record this information in your electronic systems, these women should be removed from the sample when the list is validated by member(s) of the midwifery team.

- Women without a UK postal address (but do not exclude if addresses are incomplete e.g. no postcode)[8].

- Any patient known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those patients from your sample list at this stage).

Note on patients with safeguarding concerns: In general, patients with safeguarding concerns should be **included** in your list, unless they meet any of the other exclusion criteria. You may want to consider whether certain patients might be placed at risk by being sent a patient survey and discuss with your trust's safeguarding lead whether any of these patients should be removed from your list of eligible patients.

Patients should **only** be removed from the list of eligible patients in extreme circumstances, where the delivery of the questionnaire itself is likely to increase the risk of harm to the individual. We would expect only a very small number of patients to be removed, if any. If you expect to remove more than a handful of patients in these circumstances, please ensure you discuss this with the Co-ordination Centre first.

If you have any queries about the inclusion or exclusion criteria, please contact the Co-ordination centre for advice: mat.cc@pickereurope.ac.uk or 01865 208 127.

Data fields to include in the list of patients

Note: Not all of these fields are required by DBS but it will save time and effort if all the information is gathered at the same time.

You will need to keep the list in an electronic file in a programme such as Microsoft Excel or Access. The list should contain the following information (more detail can be found in *Section 7.6*).

- Unique Record Number
- Title
- Initials/First name
- Surname
- Address fields
- Postcode
- Year of birth
- Ethnic group
- Day of delivery
- Month of delivery
- Year of delivery
- Actual delivery place
- NHS site code
- CCG code
- Postcode sector

7.2 Check the list of women

Once you have compiled your list of women, you should carry out the following checks before you send the list to the DBS to carry out a further check for deceased women or infants.

[8] Women whose address is in the British Islands (Isle of Man, the Channel Islands) are eligible for inclusion in the survey.

- **Delivery outcome.** Check that all women in the sample had a live birth.

- **Deceased mothers or infants.** Check that all women and their infants were discharged from the trust alive and that the trust does not have a record of either person's death from a subsequent admission or visit to the hospital. **This is an essential step to ensure that women and/or their families are not further traumatised by receiving a questionnaire asking about their pregnancy.**

Checks for deceased women and infants

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 woman or her baby 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, women or their baby may also have died at home or while under the care of another trust, so you still need to check with DBS as well.

The methodology for this survey requires three stages of checks for deceased women/infants 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 women or infants who may have died in hospital after submission of the sample to DBS)

Please note: Due to the sensitivity of the Maternity Survey, **you must repeat these checks before the second and third mailings**, and ensure that approved contractors are advised immediately if any women in the sample, or their baby, die during the survey period.

- **Women's ages.** Check that all women are aged 16 or over at the time of delivery.

- **Concealed pregnancy**. Exclude any women who are known to have had a concealed pregnancy.

- **Babies taken into care**. Exclude any women who are known to have had their baby taken into care.

- **Private maternity care**. Remove any women treated as private patients from the sample.

- **Postal addresses.** Exclude any women with addresses that are outside the UK.

- **Incomplete information.** Check for any records with incomplete information on key fields (such as surname and address) and remove those women. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a woman if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered.

- **Duplicates.** Check that the same woman has not been included more than once.

- **Dissent.** Any patient known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those patients from your sample list at this stage).

- **Opt-out following publicity / contact with 16 and 17 year olds.** Any women that were recorded by staff members to have decided to opt out after seeing the publicity poster and/or the information sheet given to women aged 16 and 17 years old by midwives.

7.3 Validate the sample

There is always a possibility that a patient's record has been incorrectly coded on the hospital's information system. To ensure that all women in the sample are eligible to participate in the survey, we recommend that once the list is drawn it is given to member(s) of the clinical midwifery team to check that the following women are not included: women who had a stillbirth; women whose baby has died following the birth; women who had a concealed pregnancy and/or women whose baby was taken into care.

7.4 Submit the patient list to the Demographics Batch Service

Before sending out the questionnaires and reminders, the list of **women and their infants** 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).[9]

Please note: a unique Record Number should be assigned to each woman in your sample **before** you submit your list to DBS. See *Section 7.6* for details on Record Numbers.

Create a trace request file

Using your list of women and infants, you need to create a correctly-formatted batch trace request file to send to DBS. You should take advice from your local Trust PAS team on the correct format to submit files. Technical details on the file format are available from: http://systems.hscic.gov.uk/demographics.

For each woman and their infant(s) 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.

> **Note**
>
> Infant details should be recorded on separate rows on the file that is submitted to DBS. If a woman gave birth to more than one baby (i.e. twins or more), then the details of each baby should be given on a separate row. The number of rows in the spreadsheet will therefore be at least double the number of women in the sample.

[9] The PDS is a national electronic database of NHS patient demographic details. The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

Submit the trace request file

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

If you have been set up to use DBS, 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 file was received. DBS processes the file overnight and it should be ready the following morning. You will be notified by email when the file has been processed. During periods of high demand for DBS service, it may take 48 hours for your file to be returned.

The response file

DBS will return a header row, response body and trailer row. The response 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 on this additional response column that patients found to be deceased will be indicated.

Further information is available from: http://systems.hscic.gov.uk/demographics.

Note

Please be aware that tracing services are not foolproof and even after your patient list has been checked for deaths, and despite the checks also carried out by your trust, some mothers and/or babies may die in the period between running the check and the questionnaire being delivered. You may find that some recently deceased mothers and/or infants remain in your sample. If this happens you may receive some calls from bereaved relatives, so you need to be prepared for this. Special sensitivity is required when dealing with these calls.

7.5 When the patient file is returned from DBS

The trace response file returned from DBS can be used to identify any women and/or babies that have died (indicated by a letter 'D') and therefore need to be deleted from the sample file. **If an infant has died but their mother is still alive, that record must be removed from the list.** This may reduce the numbers in your sample list slightly.

Important note: Due to the sensitivity of the Maternity Survey, please **exclude** any women from the sample if they (or their baby) could not be traced. If there are more than 5 records which are untraced, and therefore need to be removed from the sample, please contact the Co-ordination Centre for advice (mat.cc@pickereurope.ac.uk or 01865 208 127).

7.6 Create the sample file

The spreadsheet you should use to create your sample file is available to download from: http://www.nhssurveys.org/surveys/1074. An example of how the spreadsheet should be filled out has been included below in Table 1. Save this file as **'MAT17_samplefile_XXX'** (where XXX is the trust code for your organisation).

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

Table 1 – Example: Sample construction spreadsheet

Trust code	Record number	Title	Initials (or first name)	Surname	Address 1	Address 5	Full Postcode	Mother's year of birth	Mother's ethnic group	Day of delivery	Month of delivery	Year of delivery	Actual delivery place	Place of birth: NHS Site code	CCG code	Postcode sector	Day of questionnaire being received	Month of questionnaire being received	Year of questionnaire being received	Outcome	Comments
RNH	MAT17RNH0001	Miss	AM	Abbot			AB1 1YZ	1969	A	1	2	2017	2	RNH15	03S	AB1 1				3	Informed that woman's baby had died
RNH	MAT17RNH0002	Ms	EC	Ahmed			AB2 6XZ	1978	J	3	2	2017	0	RNH03	03T	AB2 6	14	05	2017	1	
RNH	MAT17RNH0003		P	Lane			AB3 8PL	1989	B	3	2	2017	2	RNH15		AB3 8				4	
RNH	MAT17RNH0339	Mrs	K	Yoo			AB4 7MX	1982	R	27	2	2017	1		03T	AB4 7					

Important note about Table 1

The headings of Table 1 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 should be submitted to your contractor along with the information from the red headings.
Red headings: these columns should be completed during the sampling phase and submitted to your contractor who will check them and then submit them to the Co-ordination Centre for final inspection prior to mailing.
Green headings: these columns will be completed by your contractor during fieldwork.

Please follow the additional instructions in the Sample Construction Spreadsheet file.

The following information is compiled using hospital records:

- **Trust code** (the three character code of your organisation e.g. RNH[10])
- **Title** (Ms, Mrs, Miss, etc.)
- **Initials** (or first name)
- **Surname**
- **Address** fields[11]
- **Postcode**
- The mother's **Year of birth** should be included in the form NNNN
- The mother's **Ethnic group**[12] as reported by the mother should be coded using the 17 item alphabetical coding specified by NHS Digital[13]. The codes are as follows:

<u>White</u>
A British
B Irish
C Any other White background

<u>Mixed</u>
D White and Black Caribbean
E White and Black African
F White and Asian
G Any other mixed background

<u>Asian or Asian British</u>
H Indian
J Pakistani
K Bangladeshi
L Any other Asian background

<u>Black or Black British</u>
M Caribbean
N African
P Any other Black background

[10] A data file of NHS Organisation Codes can be downloaded from: https://digital.nhs.uk/organisation-data-service/data-downloads/other-nhs.

[11] The address should be held as separate fields (e.g. street, area, town, and county), consistent with the address format required by the DBS.

[12] It is acknowledged that hospital records might not always contain complete data on women's ethnic category. However, this field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic categories. This is in keeping with the aims of the CQC and Department of Health to be more responsive to all ethnic groups and to ensure all groups are appropriately represented in their assessments.

[13] These codes can be found in the NHS Data Dictionary on the following website: http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/end/ethnic_category_code_de.asp.

Other Ethnic Groups

R Chinese

S Any other ethnic group

Z Not stated

Please note: 'Z' codes should be used when a woman refuses to provide her ethnicity **AND** when ethnicity is unknown (previously recorded as blanks). See *Section 3* for details.

- **Day of delivery** (1 or 2 digits, e.g. 7 or 26)
- **Month of delivery** (1 digit, i.e. 1 or 2)
- **Year of delivery** (4 digits, i.e. 2017)
- **Actual delivery place** should be coded using the National Codes[14]:

  1 At a domestic address
  2 In NHS hospital - delivery facilities associated with CONSULTANT ward
  3 In NHS hospital - delivery facilities associated with GENERAL MEDICAL PRACTITIONER ward
  0 In NHS hospital - delivery facilities associated with MIDWIFE ward
  4 In NHS hospital - delivery facilities associated with CONSULTANT/ GENERAL MEDICAL PRACTITIONER/ MIDWIFE ward inclusive of any combination of two of the professionals mentioned
  7 In NHS hospital - ward or unit without delivery facilities
  6 In other hospital or institution
  8 None of the above
  9 Not known

- **NHS Site Code** of where the baby was delivered (i.e. to identify which hospital or maternity unit) should be coded using the five character NHS Trust Site Codes[15]. This cell should be left blank for any deliveries that were not in hospital (i.e. where the 'actual delivery place' is coded 1 or 8). NHS Site Code should be left blank if 'actual delivery place' is coded 9, unless it is known that the delivery took place in hospital.
- **CCG code** should be three characters. This should be the CCG which will be billed for the care of the person using service. Please see: https://digital.nhs.uk/organisation-data-service/data-downloads/other-nhs.
- **Postcode sector** is the first part of the mother's postcode (i.e. the postcode 'area' and 'district' e.g. MK18) and just the number in the second part of the postcode (e.g. MK18 4). Please **do not include** the two alpha characters in the second part of the postcode.

The following additional information should also be entered into the spreadsheet:

1) The **Record number (RN)** is a unique serial number which must be allocated to each woman by the trust. It should take the following format: **MAT17XXXNNNN** where XXX is your trust's three digit trust code and NNNN is the unique four digit number assigned to each of your sampled women, e.g. 0001, 0002 etc.

[14] The 'Actual place of delivery' codes can be found in the NHS Data Dictionary on the following website: http://www.datadictionary.nhs.uk/data_dictionary/attributes/a/acc/actual_delivery_place_de.asp?shownav=1.

[15] A data file of NHS Trust Site Codes can be downloaded from: https://digital.nhs.uk/organisation-data-service/data-downloads/other-nhs.

Please note: Record Numbers should be assigned **before** the sample is submitted to DBS.

The RN will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), your contractor will be able to use these numbers to monitor which women have returned their questionnaires and to identify any non-responders, who will need to be sent reminders.

2) **Day/Month/Year of questionnaire being received**. These columns can only be completed by your contractor if and when they receive a questionnaire.

3) The **Outcome** field will be used by your contractor to record which questionnaires are returned to the freepost address, or are returned undelivered, or which women opt out of the survey, etc.

    1 = Returned useable questionnaire
    2 = Returned undelivered by the mail service or woman moved house
    3 = Woman or baby died after fieldwork commenced
    4 = Woman reported too ill to complete questionnaire, opted out or returned blank questionnaire
    5 = Woman was not eligible to fill in questionnaire
    6 = Questionnaire not returned (reason not known)
    7 = Woman or baby died prior to fieldwork commencing

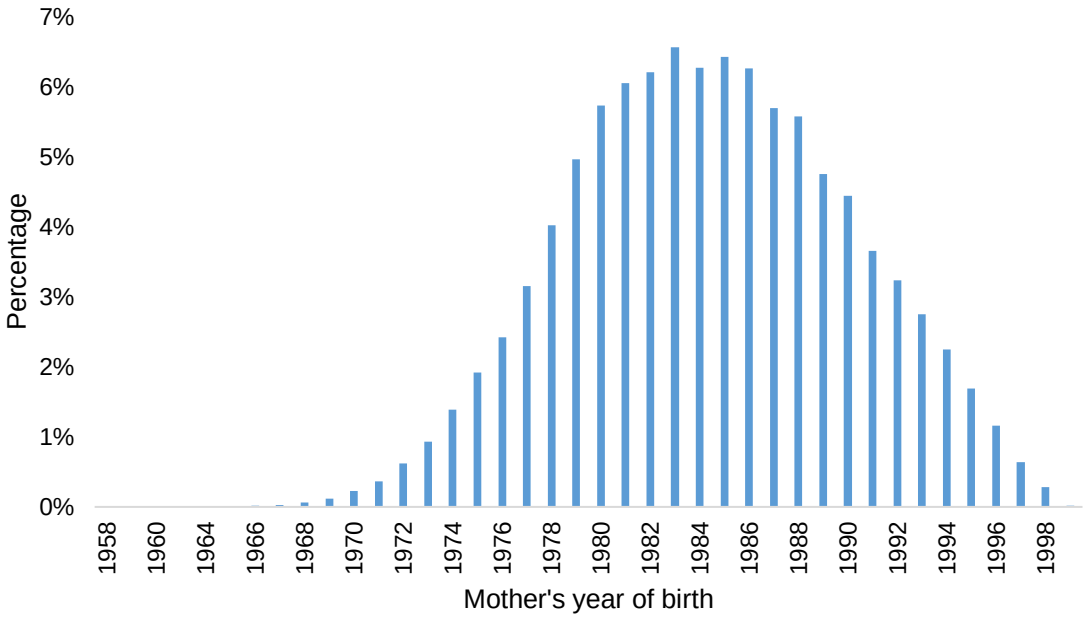
4) The **Comments** column is useful for recording any additional information that may be provided when someone calls the helpline, for example to inform you that the respondent has died or is no longer living at the address.

7.7 Check the distribution of ages

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

Check that your sampled women's ages cover the full range of expected ages. Ideally, you should do this by checking the distribution of ages on a histogram (see Figure 1). For most trusts the histogram is likely to start with a relatively small number of women aged under 20 years, and then rise steeply and form a plateau (representing a large number of women aged between 25 and 35 years) before entering a fairly gradual decline, with a small number of women aged over 40 years.

Figure 1 - Age Histogram for 2015 Maternity Survey



7.8 Check for other sampling errors

The most common sampling errors made in previous Maternity Surveys resulted from trusts:

- Excluding women aged 16-17 years
- Excluding women who had a home birth
- Coding ethnicity incorrectly
- Missing some sample information, such as year of birth data
- Entering postcode in incorrect format or with too many digits
- Submitting incorrect site codes

Using the guidance correctly will prevent any errors and reduce delays caused by mis- sampling.

7.9 Submit the sample declaration form

Before a trust submits their sample to the contractor for checking, there is a sample declaration form with a number of compliance statements that needs to be completed by the person drawing the sample and the Caldicott Guardian. The completed form can be sent to your contractor from (a) the email address of the Caldicott Guardian, or (b) the email address of the person who drew the sample if the Caldicott Guardian is copied into the email. **Do not send your sample file until your contractor has confirmed that the form has been completed satisfactorily**. The sample declaration form is available on the NHS Surveys website to download: http://www.nhssurveys.org/survey/1958.

7.10 Submit the sample file to your contractor

Once you have received confirmation that your sample declaration form has been approved, you will need to submit your sample file to your contractor. **This must be sent to the contractor as a password protected file in encrypted format via their FTP.**

In previous years, it has been a requirement for trusts to separate the mailing and sample information prior to sending to their contractor. As this led to a number of errors in trust data, it has now been agreed with the Confidentiality Advisory Group that this separation of mailing and sample data will be done by the contractor rather than the trust. This means that **you will send your contractor a single file containing all the mailing and sample information** – this will be the file called 'MAT17_samplefile_XXX' where XXX is the trust code for your organisation.

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

7.11 Deadline for submitting sample files

Contractors will set deadlines for when they will need your sample file by, however, the Co-ordination Centre will be checking these files between **3rd April and 28th April so we must have received your file from your contractor within this time frame.**

Trusts which have not submitted their sample for checking by **28th April 2017** will be contacted by the Co-ordination Centre directly to discuss any problems you are having and how we can help with the process. However, if samples are not received by **12th May 2017**, then we are required to notify the CQC of this and they will contact you to discuss any implications for inclusion in CQC produced data.

7.12 Respond to any queries

Once you have submitted your sample file to your contractor, they will undertake their own internal checks on the data. You may well get some queries from your contractor so please respond to these quickly as they cannot submit the sample file to us in the Co-ordination Centre until they have resolved those queries with you.

The Co-ordination Centre will then check the sample file, sent to us by your contractor, and we will respond to them with any queries. They may come back to you for clarification, and please respond quickly to those queries so the sample can be approved and mailing can begin.

8 Publicising the survey

The following measures will help to increase response rates and reduce the number of questions and any complaints that you or your contractor may receive about a survey, and some will help address the fair processing principle of the Data Protection Act.

8.1 Pre-survey communication with staff

Notify as many staff members as possible about the survey, in case women contact the trust asking questions about the questionnaire they have received, or who have seen the pre-survey publicity and would like to opt out of receiving a questionnaire. Women can be expected to ask midwives, 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)

A template letter which includes information which you can tailor for publicising the survey to staff can be found on the survey website at http://www.nhssurveys.org/survey/1938.

8.2 Publicising the survey externally

To help promote involvement, maximise response rates, and to offer the opportunity to opt out, the survey can be publicised to new mothers and the public in 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 available on the website: http://www.nhssurveys.org/survey/1937. Talk to your hospital's press office for more ways in which you can gain publicity locally.

- Put up posters which show the importance the trust places on gathering feedback. To be most effective at increasing your response rate, posters should be put up during the fieldwork period. A poster is available on the NHS surveys website at: http://www.nhssurveys.org/survey/1876.

- Consider using social media such as Twitter or Facebook or other local social media to publicise the survey. The official Twitter hashtag for the survey is #maternity2017.

We also recommend that posters publicising the survey should allow women to **opt out** if they do not wish to take part by providing a survey helpline phone number they can call. You can then remove any women who wish to opt out of the survey.

To encourage women to respond, we recommend you illustrate how the trust has acted on the results of the previous Maternity Survey (2015) carried out by the trust. Women are likely to be more motivated to take part in the survey if they can see tangible outcomes from a previous survey.

A document containing 'top tips' for publicising the survey is available from: http://www.nhssurveys.org/survey/1921.

9 Survey materials

9.1 Questionnaire and covering letters

The questionnaire has been rigorously tested in the format on the website at: http://www.nhssurveys.org/surveys/1065. Your contractor will be responsible for printing your questionnaires for you, but please note, **there are to be no additional questions added to the survey or layout changes. The questionnaire is also copyrighted and therefore no logos are to be added.**

The covering letters are also available for information: http://www.nhssurveys.org/surveys/1066. Please note that your contractor will be responsible for printing these but you will need to provide your contractor with your trust letter head and CEO signature. No deviation from the wording in these letters is possible due to the ethical approval given to the survey materials.

9.2 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 mothers and infants 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.**

Appendix 1: Responsibilities of NHS organisations that are carrying out research

The following table has been prepared by the CQC and is taken from Section 3.10 of the *Research Governance Framework for health and social care (2005).* The left-hand column sets out the responsibilities of organisations providing care and the right-hand column sets out the arrangements made by the CQC 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.

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 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 guidance is 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 a REC. 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.	*The Care Quality Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in Section 3.8 of the Research Governance Framework are followed thoroughly.*
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 guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.*
Maintain the necessary links with clinical governance and/or best value processes.	*The guidance notes very strongly recommend that trusts maintain these links and follow best practice evidence.*

Research Governance Framework	Care Quality Commission sponsored patient surveys
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities.[16]	*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 honorary contract with the trust. These procedures are specifically detailed in the guidance notes.*
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 the 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.*

[16] 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, Professor Sir Brian Follett and Michael Paulson-Ellis, September 2001 (The Follett Report).