# GUIDANCE MANUAL FOR THE NHS MATERNITY SURVEY 2013

THE CO-ORDINATION CENTRE FOR THE NHS PATIENT SURVEY PROGRAMME



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

It is not permissible to deviate from the agreed protocol as set out in this guidance manual, for example, by offering financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages. More guidance on how to reach ethnic minority groups can be found in Section 8. The terms of the ethical approval do not permit these types of alteration. Furthermore, such alterations might mean that the comparability of the survey would be compromised, and such results may not be acceptable for computation of the relevant measures within the Care Quality Commission assessments for that trust. If trusts want to make any adjustments to the method set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability.

## **Updates**

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

This document is available from the Co-ordination Centre website at: http://www.nhssurveys.org/

#### Contents

Guid	lance Manual for the NHS Maternity survey 2013	1
The	Co-ordination Centre for the NHS Patient Survey programme	1
1 I	ntroduction: The importance of patient feedback	1
1.1	The Care Quality Commission	1
1.2	The Co-ordination Centre for patient surveys	1
1.3	Why we need patient feedback	1
1.4	Patient feedback and the NHS Constitution	2
1.5	Care Quality Commission assessments	2
1.6	Measuring performance	2
1.7	Basic requirements for the Maternity survey	3
1.8	Why you need this guide	4
2 5	Setting up a project team	5
3 V	What's new for 2013?	6
3.1	Changes to the questionnaire	6
3.2	Changes to the sampling and methodology	7
3.3	Mail out envelopes	8
3.4	Important information to remember	8
4 [	Deciding whether to use an approved contractor or carry out the	
surv	ey in-house	10
4.1	Costs	10
4.2	Internal resources	11
4.3	Timing	11
4.4	Quality and confidence in the findings	11
5 (	Commissioning a survey from an approved contractor	12
5.1	List of approved contractors	12
5.2	Contracts with survey contractors	13
6 [	Data protection and confidentiality	14
6.1	Statements of compliance with data protection	15
6.2	Section 251 Approval	15

6.3	Keeping patient mailing data and sample data separate	. 16
6.4	Mailing questionnaires to patients	. 16
6.5	Patients' names and addresses	. 16
6.6	Encryption of personal data	. 17
6.7	Contractor responsibilities (service contract)	. 17
6.8	Patient anonymity	. 18
6.9	Patient confidentiality	. 18
6.10	Sharing of survey data between contractors	. 20
6.11	Storing completed questionnaires	. 21
7 E	thical issues, ethics committees and research governance	. 22
7.1	Ethical approval for the maternity survey	. 22
7.2	Research governance requirements	. 22
7.3	Responsibilities of NHS organisations who are carrying out research	. 23
8 C	ollecting data from non-English-speaking populations	. 25
9 T	imetable	. 26
10	Compiling a list of women	. 29
10.1	Compile a list of eligible women	. 29
10.2	Checks carried out by the trust	. 31
10.3	Validating the sample	. 32
10.4	Submit the patient list to the Demographics Batch Service (DBS)	. 32
10.5	When the patient file is returned from DBS	. 33
10.6	Create the sample file	. 34
10.7	Distribution of ages	. 40
10.8	Check for other sample errors	. 40
10.9	Separating mailing details from sample information	. 41
10.10	Sharing the sample file with an approved contractor	. 42
10.11	Making more use of the survey locally	. 42
11	Final sampling inspection by the Co-ordination Centre	. 44
12	Weekly monitoring	. 46
12.1	Response rate	
12.2	Helpline monitoring	. 47

13	Publicising the survey48	3
13.1	Pre-survey communication with staff48	3
13.2	Publicising the survey externally48	3
14	Materials49	9
14.1	Printing questionnaires49	9
14.2	Trust headed paper50	)
14.3	Mail out envelopes50	)
14.4	First mailing50	)
14.5	Second mailing (first reminder)	l
14.6	Third mailing (second reminder)51	1
15	Implementing the survey - practicalities52	2
15.1	Setting up a FREEPOST address	2
15.2	Setting up a PO Box	2
15.3	Setting up a FREEPHONE line	2
15.4	Covering letters53	3
15.5	Sending out questionnaires54	1
15.6	Booking in questionnaires 55	5
15.7	Sending out reminders55	5
16	Entering data	7
16.1	Entering and coding data from the questionnaire 57	7
16.2	Entering the patients' written comments	3
16.3	Checking the data for errors59	)
16.4	Submitting data to the Surveys Co-ordination Centre	)
16.5	Checklist	5
17	Making sense of the data67	7
17.1	Using the data entry spreadsheet to look at your results	7
17.2	Suggested approaches to data analysis67	7
18	Reporting results	)
18.1	Prioritising your findings	)
18.2	Writing the report	1
19	Using results for quality improvement	3

19.1	Prepare in advance	73
19.2	Dissemination of survey results	73
19.3	Identify key "change agents"	74
18.4 D	evelop an action plan	74
18.5 U	se small follow-up surveys or focus groups to delve deeper	75
Apper	ndix 1: Suggested text for pre-survey communication with staff	76
Apper	ndix 2: Suggested template text for pre-survey article for externa	ı
media	l	78
Apper	ndix 3: Glossary	80

## 1 Introduction: The importance of patient feedback

#### 1.1 The Care Quality Commission

The national patient survey programme was established by the Department of Health and has been operating since 2002. The Care Quality Commission took over from its predecessor, the Healthcare Commission, in April 2009 and is responsible for administering the programme. The Care Quality Commission (CQC) is the independent regulator of health and 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 Voices Into Action<sup>1</sup>, the statement on involving people, CQC is committed to involving people who use services in all its work, and ensuring that the providers of care services themselves involve people and respond to their views. The experiences of patients, people who use services, their carers and families are at the heart of the Care Quality Commission's work: it is the aim of the Care Quality Commission 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 the Department of Health with data to assess performance against national targets on patient experience, the survey programme provides an important source of data for CQC's assessments.

## 1.2 The Co-ordination Centre for patient surveys

The Co-ordination Centre for the NHS Patient Survey Programme is based at Picker Institute Europe and works under contract to the Care Quality Commission 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 patient survey. It also provides guidance on how you may use the information you gather in quality improvement programmes and for monitoring performance. By following this guidance,

<sup>1</sup> http://archive.cqc.org.uk/\_db/\_documents/A4\_Report\_2009\_01.pdf

you will also help to ensure that the survey results from your trust are comparable with other trusts, and with national benchmarks.

#### 1.4 Patient feedback and the NHS Constitution

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

The NHS Constitution requires that NHS services reflect the needs and preferences of patients, their families and their carers. It is therefore important that all NHS trusts carry out local surveys asking patients their views on the services they have received. The national patient survey programme is an important mechanism for making the NHS more patient-focused and provides a quantifiable way of achieving this by:

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

#### 1.5 Care Quality Commission assessments

Information drawn from the core questions in the survey will be used by the Care Quality Commission in its assessment of acute and specialist trusts in England. The survey results will be used when producing the CQC quality and risk profiles (QRP) for NHS trusts. The QRP is a tool that gathers all relevant information about a trust in one place. It enables the CQC to assess where risks lie and prompt front line regulatory activity, such as inspection. The profiles support teams to make robust judgements about the quality of services and will be used in conjunction with CQC's guidance about compliance documents. Information from the survey will be mapped to relevant essential standards as described in the compliance documents. The QRPs will be shared with NHS trusts and lead Commissioners. More information is available at: http://www.cqc.org.uk/organisations-we-regulate/registered-services/guidance-meeting-standards

#### 1.6 Measuring performance

In addition to the performance assessment, the Care Quality Commission will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data and to inform the public. Asking each hospital trust to carry out a maternity survey in a consistent way builds a detailed picture of womens' experiences in NHS hospital trusts.

The results will be used by the Department of Health for performance assessment, improvement and regulatory purposes. The Government is committed to ensuring women receive excellent maternity care that focuses on the best outcomes for women and their babies and on improving women's experience of this care. This commitment has been articulated in a number of publications including the NHS Operating Framework for 2012/13, the NHS Outcomes Framework of 2012/13 (there is a specific indicator on improving women and families' experience of maternity services, based on the national survey data) and in May 2012 the Government pledged to improve maternity care. The survey results will be a key resource used by the Department of Health and Ministers to assess how well the Government's commitment and priorities to improving women's

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overall experience of maternity services are being delivered by the NHS and to help identify key areas of concern for women (and their families) that could be improved through policy initiatives. This information will be used to inform future policy development, and future refreshes of the NHS and public health outcome frameworks and the Mandate to the NHS Commissioning Board.

The Care Quality Commission 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:

- Please contact the Co-ordination Centre, by e-mail, no later than 5<sup>th</sup> April 2013 to tell us who is carrying out your survey (i.e. whether it will be carried out by an approved contractor or inhouse): maternity.data@pickereurope.ac.uk
- The survey must be carried out using the standard postal questionnaire.
- The sample of women must INCLUDE DETAILS as outlined in Section 10.6 *Create the sample file*
- If you are conducting the survey in-house then, before drawing the sample, you must submit a
  formal declaration to the Co-ordination Centre, as outlined in Section 6.1 Statements of
  compliance with data protection
- The samples must consist of all women who gave birth during February 2013 as outlined in Section 10 – Compiling a list of women [If your trust has fewer than 300 births in February, please contact the Co-ordination Centre for further advice on including women who had a baby in January 2013.]
- The sampling procedure set out in this guidance must be followed. To do this, you will need to work closely with the person who draws the sample, and check carefully that this guidance has been adhered to. For further details see Section 10 Compiling a list of women.
- Sample data must be submitted to the Co-ordination Centre for final checks before mailing as outlined in Section 11 - Final sampling inspection by the Co-ordination Centre. You should aim to submit these sample files to us between 8<sup>th</sup> April and 3<sup>rd</sup> May 2013 to allow sufficient fieldwork period to maximise your response rates.
- You should aim to obtain the highest response rate possible. For this survey, the target response rate is 60%. Three mailings will be necessary to achieve this target. However, trusts should facilitate higher response rates through maximising their collection period by commencing work as soon as possible and by publicising the survey to staff, patients and the community. See Section 13 *Publicising the survey*.
- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from 2<sup>nd</sup> May 2013 A spreadsheet has been created for this purpose. For further details see Section 12 Weekly monitoring.
- The standard covering letters and reminder letters (which can be found under the Maternity Survey section of the NHSSurveys website) must be used as outlined in Section 14 *Materials*
- Two reminders must be sent to non-responders, even if a 60% response rate is already achieved, as outlined in Section 15.7 Sending out reminders.
- Trusts will be asked to submit information on which women in their sample received their antenatal and postnatal care from their trust on **19**<sup>th</sup> **July** (see section 3.2 *Changes to the sampling and methodology*). Additional guidance on this process will be made available to trusts after the sample checking period.

- Two paper copies of the questionnaire and the covering letters used for each mailing should be submitted to the Co-ordination by 19<sup>th</sup> July 2013, as detailed in Section 3 – What's new for 2013
- The final data must be entered and coded as specified in Sections 16 Entering data and 16.2 Entering written comments ('free text') from patients and 16.1 Coding data before submitting it to the Co-ordination Centre
- The data must be checked carefully for errors before submitting it to the Co-ordination Centre. Specific advice on how to carry this out is included in Section 16.3 *Checking for data errors*.
- The data from the questions and the checklist must be submitted to the Co-ordination Centre in the form outlined in Section 16.4 – Submitting data to the Co-ordination Centre by 6<sup>th</sup> September 2013.
- The free text comments must also be submitted to the Co-ordination Centre. These should be included as part of the final data file. See Section 16.2 – Entering written comments ('free text') from patients.
- You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until 29<sup>th</sup> November 2013 but please do not send these to the Co-ordination Centre. These returned questionnaires may be needed to audit the data sent to the Co-ordination Centre.
- You must not delete the sample file from your records until 6<sup>th</sup> December 2013 in case there are any queries from the Co-ordination Centre.

#### 1.8 Why you need this guide

Trusts have the option of conducting the survey in house or using an approved contractor (see Section 4). Whichever route you take, you will need to address the guidance in sections 1 to 16 of this document. Sections 14, 15 and 16 cover the practicalities of mailing out the survey, following-up responses and processing data, and submitting it to the Co-ordination Centre. These sections will be most relevant to approved contractors, or trusts undertaking the surveys themselves.

## 2 Setting up a project team

Whether you choose to do the survey in-house, or to use an approved contractor, we recommend you set up a project team to assist you. The best way to ensure that your survey is a success is to work hard *in the beginning* to involve those people who have the most impact on patients' experiences and who will be responsible for responding to the results of the survey.

#### We suggest:

- **Establishing a workgroup.** Put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:
  - Board members
  - Doctors, midwives, nurses and other health care staff
  - Managers
  - Medical records personnel or Patient Administration System (PAS) staff
  - Patients and carers
  - Members of patient groups with a special interest in the trust
  - Caldicott Guardian
  - Staff or directors responsible for:
    - Midwifery
    - Clinical governance
    - Patient advice and liaison service (PALS)
    - Quality improvement
    - Strategic planning.
- Involving the person responsible for drawing the patient sample in planning meetings. It
  is essential that this person, and their line manager, understand the purpose of the survey and
  the importance of drawing the sample correctly.
- **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 who have the most frequent direct contact with patients.

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## 3 What's new for 2013?

#### 3.1 Changes to the questionnaire

The labour and birth section of the 2013 maternity questionnaire has been kept as similar as possible to the 2010 maternity questionnaire to allow comparisons to be made between survey years on those questions. There are 74 questions, a net loss of 3 questions since the 2010 core survey. Following focus group discussions with new mothers and consultation with stakeholders and NHS trusts, twenty three new questions exploring issues of continuity of care, communication, respecting decisions and choice have been added to the questionnaire (4 were taken from the 2010 question bank and 2 are demographic questions used in other national surveys):

- B4 Were you offered any of the following choices about where to have your baby?
- B10 During your antenatal check-ups, were you given enough time to ask questions or discuss your pregnancy?
- B11 During your antenatal checkups, did the midwives listen to you?
- C1 At the very start of your labour, did you feel that you were given appropriate advice and support when you contacted a midwife or the hospital?
- C3 During your pregnancy, what type of pain relief did you plan to use when giving birth?
- C4 Did the pain relief you used change from what you had originally planned?
- C5 Why did you not use the choice of pain relief that you had originally planned to?
- C11 If your partner or someone else close to you was involved in your care during your labour and birth, were they able to be involved as much as they wanted?
- C12 Did the staff treating and examining you introduce themselves?
- C14 If you raised a concern during labour and birth, did you feel it was taken seriously?
- C15 If you used the call button how long did it usually take before you got the help you needed?
- E4 Were your decisions about how you wanted to feed your baby respected by midwives?
- F4 Did you see the same midwife every time?
- F7 Did the midwife or midwives that you saw appear to be aware of the medical history of you and your baby?
- F8 Did you feel that the midwife or midwives that you saw always listened to you?
- F9 Did the midwife or midwives that you saw take your personal circumstances into account when giving you advice?
- F12 Did a midwife or health visitor ask you how you were feeling emotionally?

The following four questions were added to the survey from the 2010 maternity survey question bank; they had not been included in the 2010 'core' questionnaire:

- C18 Thinking about your care during labour and birth, were you treated with respect and dignity?
- D5 Thinking about your stay in hospital, how clean was the hospital room or ward you were in?
- D6 Thinking about your stay in hospital, how clean were the toilets and bathrooms you used?
- F10 Did you have confidence and trust in the midwives you saw after going home?

The following two demographic questions were added to the survey to be consistent with the questions included in other patient surveys:

- G6 What is your religion?
- G7 Which of the following best describes how you think of yourself?

A number of questions and/or response options have been amended and 24 questions have been removed from the questionnaire as they were no longer considered to be as relevant to women and/or will not provide useful data for quality improvement purposes.

A document describing all the changes to the questionnaire, and the reasons for such amendments, is available on the NHS Surveys website (http://www.nhssurveys.org/survey/1246)

Changes to instructions for completing the questionnaire: This year respondents will be asked to cross, rather than tick boxes (e.g.  $\boxtimes$  instead of  $\boxdot$ ) in the instructions for completing the questionnaire contained on the front page of the questionnaire

**Changes to required documentation:** This year the Co-ordination centre will require the data checklist and copies of the questionnaire, covering and reminder letters by the **19**<sup>th</sup> **July.** Please see Section 16.4 &16.5 for more information.

## 3.2 Changes to the sampling and methodology

**Unique record number**: The format of the patient record number has been revised for 2013. The number should be in the format MAT13XXXNNNN where XXX is your 3-digit trust code and NNNN is the 4 digit number relating to your sampled patients, e.g.

MAT13	ABC	0001
↑ Maternity survey 2013	↑ Trust Code for your Trust	↑ Unique patient ID

The record number is vital for the survey process in that it allows sample and response information to be matched in a manner that isolates the mothers' names from their reporting of their maternity experience. Information about the minimum font size and location, and what action to take if this number is removed from questionnaires, has been added to Section 15.5- Sending out questionnaires

**Sample size:** Please note the sample size will vary by trust as the sample should consist of all women who had a live birth during February 2013. If your trust has fewer than 300 eligible women who had a birth in February, then you will need to contact the Co-ordination Centre for advice on including women who gave birth in January 2013. For the 2013 maternity survey, the minimum sample size has increased from 250 to 300.

**Postcode sector**: We will require this additional piece of information in the sample file to make more use of the survey data. In 2010, the CQC published scored comparable data for 19 questions from the 77 questions in the survey, as those questions could be confidently attributed to the acute trust from which the sample of women was drawn. To make more use of the data received on antenatal and postnatal care in 2013, trusts will be asked to provide postcode sector in the sample files submitted to the co-ordination centre.

The information on postcode sector will be used at a later stage, alongside additional information on a trust's geographical boundary, to identify and check which women in the sample also received their antenatal and/or postnatal care from the trust at which they delivered. Trusts will not be required to carry out this identification process until the survey fieldwork has commenced (i.e. after the sample has been approved by the Co-ordination Centre and the mailings have started). This is to allow trusts more time to undertake this process. The Co-ordination Centre will supply trusts with a guidance document on how to identify those women in their sample that have also received their antenatal and postnatal care from the trust. Trusts will be asked to submit this information to the Co-ordination Centre on 19<sup>th</sup> July 2013 (This is the same deadline as when trusts should submit the paper copies of the questionnaire and covering letters used).

**General Medical Practice Code (GMPC):** We will require this piece of information to do additional analyses so it must be in both the sample and final data submissions.

Patients who have requested that their details are not used for secondary purposes such as research: If your trust has a mechanism in place to flag patients that do not wish their data to be used for secondary purposes, we advise that you refer to this when drawing your sample. Please see Section 6.2- Section 251 Approval for further detail.

**Free text comments:** For the 2013 maternity survey, respondents' written free text comments should also be submitted to the Co-ordination Centre in an anonymised format. This is discussed further in Section 16.2.

## 3.3 Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to women does not show any indication of the NHS Trust, in accordance with data protection regulations.

#### PO Box

For confidentiality reasons, there should be no indication on the outer envelopes that the documentation enclosed relates to healthcare in any way. Consequently in-house Trusts are advised to set up a PO Box so that mail which is undelivered can be returned (please see section 14.2 for further detail).

#### 3.4 Important information to remember

**Ethnic category**: Ethnic category will be requested in the standard 16 + 1 alphabetical format. However, during previous surveys there has been some confusion over what data should be coded

as "Z" ("not stated"). This code should be used **only** when a person had been asked for their ethnic category and had declined either because of refusal or genuine inability to choose. A blank or full-stop should still be used to indicate where ethnic category is "not known" i.e. where the woman had not been asked or she was not in a condition to be asked, e.g. unconscious. For most trusts, ethnic category will contain both "Z" codes **and** "blanks". Further information can be found in section 10.6 – *Create the sample file*.

**Embargo on results**: Trust-level findings for the 2013 national maternity survey should not be released outside of the trust until the national results are published by the Care Quality Commission. Please continue to use the results from your in-house survey teams or approved contractor to improve services, but wait until the survey results for all trusts are published by the Care Quality Commission before promoting your results in any way (either on your website, in press releases or any other external publicity) to the local community and media. You will receive, along with communications staff in your trust, advance notice of the publication date and will have time to prepare for your local announcements once the embargo is lifted.

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## 4 Deciding whether to use an approved contractor or carry out the survey in-house

Trusts may choose to carry out their surveys in-house, or to commission an approved contractor to carry out the work for them. We do not recommend you carry out large-scale surveys such as these in-house if you do not already have experience in carrying out surveys. Tracking large surveys with appropriate follow-up is an administratively complex task requiring dedicated resources for several months. Getting systematic feedback from patients requires money, resources and staff time. Considering the following questions can help you decide whether it makes sense for your trust to conduct the survey in-house or to commission an approved contractor:

- Costs
- Internal resources/Expertise
- Timing
- Quality and confidence in the findings

#### 4.1 Costs

The financial resources needed to carry out a survey in-house are often under-estimated. The following is a list of the main items of expenditure for a postal survey, including the two reminders that must be sent out for all NHS trust surveys.

#### Staff time

This is one of the largest expenditures, but it is sometimes overlooked. Be sure to include the cost of staff time, including salary and fringe benefits, and time spent away from other work. Please note that weekly submission of response rates and helpline monitoring information will be required for each trust taking part in the maternity survey, involving increased staff time for both trusts and contractors.

## Stationery and postage

You will need to cover the cost of stationery and postage for three mailings. The first mailing will go out to all eligible women who had a live birth in February (or January if required) and the second and third mailings will be sent only to non-responders. (See Section 14 –*Materials* for more details.) You will need to cover the cost of second class postage for three mailings, two of which will be greater than the standard letter rate, while the second mailing (first reminder slip) will be standard letter rate.

## Freepost licence

There is a charge for obtaining a freepost license which enables you to print a freepost address on return envelopes so that respondents can send back completed questionnaires at no cost to themselves. You will also be charged for each returned questionnaire. (For details, see 15.1 - Setting up a FREEPOST address).

#### PO Box

For confidentiality reasons, there should be no indication on the outer envelopes that the documentation enclosed relates to healthcare in any way. Consequently in-house Trusts are

advised to set up a PO Box so that mail which is undelivered can be returned to sender. There is a fee for setting up a PO Box. (For details, see 14.3– *Mail out envelopes*).

#### Freephone service

This service gives women who have received a questionnaire, or who have seen posters or presurvey publicity, easy access to advice and staff who can reassure them on any concerns they have about the survey. The cost of setting up such a service, and of staff time in responding needs to be included. (For details, see 15.3 - *Setting up a FREEPHONE line*).

#### Data entry

If the data are entered manually, you will need to allow enough staff time for this, and for checking the accuracy of the data file. Alternatively, a data processing or scanning company may be contracted to process the data for which there would be a charge. We recommend you allow enough time for agreeing the details of a contract with a company and discussing their specific requirements (such as the size of the response boxes). If you use in-house scanning equipment, allow time for setting it up to read the data correctly from guestionnaires.

#### Design and production of reports

This requires a considerable amount of skilled staff time.

#### 4.2 Internal resources

To carry out a survey effectively, the following areas of experience and skills are needed:

- Administration of postal surveys
- Communication with and co-ordination of multi-disciplinary teams
- Data entry, validation and cleaning
- Data analysis and interpretation, and familiarity with a statistical computing package
- Report writing.

#### 4.3 Timing

It is often possible to carry out small, localised surveys quickly in-house. However, even in the best of situations, other demands on staff can side-track them into other work. If you commission an approved contractor to carry out the survey, you should ensure that appropriate and realistic deadlines are set. The deadlines set by the Co-ordination Centre must be met in order for data to be submitted in time to the Care Quality Commission.

## 4.4 Quality and confidence in the findings

It is important to remember that the results of the survey will be used not only within the trust to identify areas for improvement but also by the Care Quality Commission and Department of Health to contribute to regulatory activities and possibly for other uses, such as the NHS Choices website. It is therefore essential that the data are as accurate and reliable as possible and that the information is gathered in the same way for all trusts. Using the expertise of an approved contractor may add credibility to the survey findings in the eyes of staff, patients and the general public.

When you have decided who will carry out your survey, i.e. an in-house team or an approved contractor, you must inform the Co-ordination Centre by 5<sup>th</sup> April 2013.

## 5 Commissioning a survey from an approved contractor

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

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

Three organisations have been approved by the Care Quality Commission to carry out surveys for the NHS patient survey programme and have been approved by the National Information Governance Board, under section 251 of the NHS Act 2006. Trusts may commission any one of these contractors without further tendering the survey work. Before committing to a contractor, you are advised to **check exactly what is covered** within the cost quoted.

Information about each of these organisations, including their prices, can be found on the NHSSurveys website.

#### 5.1 List of approved contractors

The following contractors have approved status for work on the national patient experience surveys programme:

#### **Patient Perspective**

Contacts: Stephen Bruster and Chris Henderson

Standingford House 26 Cave Street Oxford OX4 1BA

Tel: 01865 205100 Fax: 01865 205111

E-mail: stephen.bruster@patientperspective.org, chris.henderson@patientperspective.org

Website: www.PatientPerspective.org

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#### **Picker Institute Europe**

**Contacts**: Tim Markham and Yasmin Jennings

Buxton Court 3 West Way Oxford OX2 0JB

Tel: 01865 208100 Fax: 01865 208101

E-mail: surveys@pickereurope.ac.uk Website: www.pickereurope.org

#### **Quality Health**

Contacts: Dr Reg Race, Kerry Hibberd, Kimberley Smith and Mandy Moore

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

Tel: 01246 856263 Fax: 01246 855897

Email: reg.race@quality-health.co.uk; kerry.hibberd@quality-health.co.uk; kimberley.pollard@quality-health.co.uk; mandy.moore@quality-health.co.uk

Website: www.quality-health.co.uk

## 5.2 Contracts with survey contractors

The Care Quality Commission has produced a document that we shall refer to as the 'service contract', for NHS trusts to use as a template agreement when providing sampling details to their approved contractor. Further details are available in *Section 6– Data protection and confidentiality*. The CQC strongly recommend that the contract template is reviewed by your trust and legal advice is obtained to ensure each clause is relevant and accepted by the trust. Further details are available in *Section 6 – Data protection and confidentiality* 

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

- The groups, and numbers, of patients to be surveyed
- The survey methodology (i.e. postal questionnaire with two reminders to non-responders)
- Exactly what the survey provider and the trust are responsible for in carrying out the survey project (division of responsibilities)
- The main contact at the survey provider and the individual at the trust responsible for managing the project
- A timetable showing the dates when each task is to be carried out and by whom
- The version of the questionnaire to be used (core or enhanced)
- The outputs of the project. That is, types of and numbers of reports to be delivered and details of any presentations to be carried out by approved contractors
- The costs and a payment schedule.

## 6 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. If you have not already done so, please ensure that you add research to your Data Protection Act registration, as one of the purposes for processing personal data supplied by data subjects. You will also need to comply with the NHS Code of Practice on Confidentiality (2003)<sup>2</sup>, which incorporates the Caldicott principles (see textbox below). You should take particular care to ensure that your use of patient data in carrying out the survey complies with these 6 principles. In particular, you should be aware of the flows of patient data, and the issues which these present.

#### The Calidcott Principles

Each NHS trust has a Caldicott Guardian who is responsible for overseeing proper use of patient data. They have to ensure that any use of patient data conforms to the following principles:

**Principle 1**: Individuals, departments and organisations must justify the purpose(s) for which information is required

Principle 2: Don't use patient-identifiable information unless it is absolutely necessary

**Principle 3**: Use the minimum necessary patient-identifiable information

Principle 4: Access to patient-identifiable information should be on a strict need-to-know basis

Principle 5: Everyone should be aware of their responsibilities

Principle 6: Understand and comply with the law

It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors (see Section 5.2). Your trust's Caldicott Guardian and legal advisors should advise you on these matters.

The guidance presented in this document on the use and security of the data collected have been agreed by the Care Quality Commission and the Co-ordination Centre for the NHS Patient Survey Programme. These guidelines will help to ensure that data are handled in a manner most in keeping with the spirit of the Data Protection Act 1998 and the Market Research Society's *Guidelines for social research* (2005)<sup>3</sup>. They have implications for approved contractors and for NHS trusts conducting surveys in-house.

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

Further guidance can be found on the Market Research Society website: <a href="http://www.mrs.org.uk/standards/data\_protection/">http://www.mrs.org.uk/standards/data\_protection/</a>

http://www.dh.gov.uk/prod\_consum\_dh/groups/dh\_digitalassets/@dh/@en/documents/digitalasset/dh\_40692 54.pdf

<sup>&</sup>lt;sup>3</sup> http://the-sra.org.uk/wp-content/uploads/sra data protection.pdf

#### 6.1 Statements of compliance with data protection

#### In-house surveys

Each NHS trust has a Caldicott Guardian responsible for overseeing proper use of patient data. If you are conducting the survey in-house then, before mailing out the sample, you must submit a formal declaration, signed by the Caldicott Guardian and survey lead(s) for the trust, to the Coordination Centre (see NHSSurveys website). This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines (see Section 6.9). Templates for these declarations are available on the website containing the survey guidance (http://www.nhssurveys.org/surveys/488). You must wait for confirmation of receipt from the Coordination Centre before you mail out your sample.

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

#### Approved contractors

The framework agreement between the approved contractors and the Care Quality Commission contains clauses stating that the approved contractor will comply with the Data Protection Act so no declaration is required if a trust appoints a contractor from the approved list. The contractors' procedures and policies have also been reviewed as part of the recommendation for support under section 251 of the NHS Act 2006, granted by the National Information Governance Board (NIGB), and have each completed the relevant sections of the Information Governance Toolkit<sup>4</sup>.

#### 6.2 Section 251 Approval

Approval has been sought for the 2013 maternity survey under section 251 of the NHS Act 2006. The survey methodology was reviewed by the National Information Governance Board (NIGB) for approval. Their Ethics and Confidentiality committee (ECC) granted a recommendation of support (ECC 6-02 (FT16)/2012). However, this recommendation does not cover the transfer of patient identifiable information where a service user has indicated dissent - by this we mean instances where a woman has previously indicated that they do not want their information to be shared for purposes such as patient surveys.

Consequently, if any maternity service users have indicated that they do not want their records used for secondary purposes (e.g. they have asked to be excluded from all surveys or they do not want their address details shared for any reason other than clinical care), please ensure that these people are excluded from your mailing list before transferring the data to your survey contractor.

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 S 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

<sup>4</sup> https://www.igt.connectingforhealth.nhs.uk/

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

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

Keeping names and addresses separate from either sample information or respondent data is the best way to ensure that the survey responses cannot easily be matched to service users who made them. For this reason, we strongly recommend that once the sample has been returned from DBS and the list of women is finalised, service user names, addresses and full postcodes<sup>5</sup> are removed from the sample file to a "Maternity 2013\_mailing data" file. Before this is done, it is essential each woman is provided with a unique number (a unique reference number) and that this number is available and correctly matched on both the "Maternity 2013\_mailing data" file and the sample information file.

#### 6.4 Mailing questionnaires to patients

There are two common methods practised by trusts, and advised by the Care Quality Commission, when working with approved contractors:

- 1. The contractor delivers pre-packed serial-numbered envelopes containing questionnaires, covering letters and FREEPOST envelopes to the trust. The trust then attaches number-matched address labels to the envelopes and sends 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. This process is described in more detail in Section 15.
- 2. Alternatively, with the agreement of the trust's Caldicott Guardian, you may set up a written agreement between the trust and the external contractor. The Care Quality Commission has provided the template service contract for trusts and approved contractors carrying out the survey, to avoid the need for each trust to develop its own arrangements (see section 5.2) 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.

#### 6.5 Patients' names and addresses

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

Trusts/contractors must undertake to keep their products up to date to ensure that security is effective and must strictly observe the following guidance. The requirements that dictate the guidelines include the Data Protection Act 1998, the Health and Social Care Act (Community Health and Standards) Act 2003, the NHS confidentiality code of practice 2003<sup>6</sup> (which incorporates the Caldicott principles).

http://www.dh.gov.uk/prod\_consum\_dh/groups/dh\_digitalassets/@dh/@en/documents/digitalasset/dh\_40692 54.pdf

<sup>&</sup>lt;sup>5</sup> <u>Please note</u>: trusts will be required to include the woman's **postcode SECTOR** in a different field within their sample information file

- The Care Quality Commission strongly recommends that personal data such as names and addresses must be sent by trusts to contractors securely, either by post or over the Internet using an encrypted session.
- By post: Trusts should send the personal data to their contractor in the form of an encrypted data file. We strongly recommend that the 256-bit AES (Advanced Encryption Standard) encryption algorithm should be used for this purpose see below for further information on this. The password should be verbally given to a named individual at the contractor. Passwords should never be written on CD-ROMs or diskettes or otherwise included with encrypted material sent through the post. The encrypted database should be saved onto a CD-ROM or diskette, place it in a single sealed envelope or other container, annotated "Addressee only", and this should be sent to the contractor by Royal Mail Special Delivery or through an approved courier service<sup>7</sup>: personal data should not be sent by recorded delivery.
- Over the Internet: 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. Approved contractors should be able to provide guidance on the use of an encrypted session to Trusts.
- As the owners of the data, the method for transferring patient samples is ultimately the Trust's decision because the Trust remains legally responsible for the security and processing of the information it shares. The Care Quality Commission strongly recommends the two methods described above. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption is available from NHS Connecting for Health<sup>8</sup>.

Remember: if the data contains patient names and addresses, this can only be sent to the contractor by encrypted CD-ROM or diskette, or over the internet via a Care Quality Commission approved encrypted method.

## 6.6 Encryption of personal data

Any patient identifiable information sent between trusts and contractors should be in an encrypted format with password protection to help ensure good standards of information security. Many different encryption algorithms exist and not all of these are suitable, so both the Co-ordination Centre and the Care Quality Commission very strongly recommend the use of the **256-bit AES** (Advanced Encryption Standard) algorithm. There are several software tools that can be used to encrypt data in this way, the most commonly available of these being WinZip® (v9 and above)<sup>9</sup>.

## 6.7 Contractor responsibilities (service contract)

A service contract has been drafted by the Care Quality Commission. 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

<sup>&</sup>lt;sup>7</sup> Contact the Care Quality Commission for more detail on approved couriers: patient.survey@cqc.org.uk

<sup>8</sup> http://www.connectingforhealth.nhs.uk/systemsandservices/infogov/security

<sup>9</sup> http://www.winzip.com/

womens' information. The service contract describes how womens' 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 Word format is available under the Maternity survey section of the website (www.NHSSurveys.org).

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

#### 6.8 Patient anonymity

#### In-house surveys

It is important to ensure that any claims you make about patient anonymity are accurate; and you are obliged by law to honour any statements that you do make. In most cases where a survey is carried out in-house, it is not accurate to tell patients that their responses will be anonymous. The person who receives the completed questionnaires is usually able to match these responses to patient names and addresses.

#### Approved contractors

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.

## 6.9 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 recommendations are made:

#### Trust level

- 1) The raw data set should not be provided to any member of staff at the trust who do not need to view it, i.e. those who are not directly working on the project
- 2) Additional data analysts may be added later by a second submission of the declaration of compliance to the Co-ordination Centre (see NHSSurveys website for a copy of the declaration). Additional data analysts cannot view the raw data until approval has been received from the Co-ordination Centre.

3) If data are to be presented to other trust staff who have not signed the declaration using the declaration of compliance, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than 30 respondents should be suppressed (replaced by a dash). The data should be presented as in the following example. In this case, responses for the 'Mixed' and 'Asian' ethnic categories are suppressed (though the subgroup totals are shown):

	B5. Before your baby was born, did you plan to have a home birth?				
Ethnic category	c category Yes No Total res				
	%	%	n		
White	81	19	261		
Mixed	-	-	8		
Asian	-	-	18		
Black	79	21	52		
Chinese or other	85	15	36		

4) Do not present response information (including comments) in a form that allows an individual 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 individuals from their responses, and pay particular attention to the respondents' free text comments in this context.

The electronic file containing the patients' names and addresses should be stored securely (i.e. password protected). Access to the file should be given only to those individuals who have signed the declaration of compliance.

#### Approved contractor

- 1) Approved contractors must 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 must delete the variable pertaining to date of delivery
  - b. The contractor must delete the two variables pertaining to **ethnicity** (e.g. both sample variable and response variable G8)
  - c. The contractor must delete the responses to question **A1** on whether the woman gave birth to a single baby or more.
  - d. The contractor must delete the responses to questions **G2 and G3** on the woman's reproductive history
  - e. The contractor must delete the responses to question **G6 and G7** pertaining to the respondents' religion and sexual orientation
  - f. The contractor must **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 (e.g. those specifying an exact year rather than age group) must then be deleted

- g. Verbatim comments that could lead to any staff identifying respondents must be removed, e.g. those mentioning dates and patient and staff names<sup>10</sup>
- h. Receive confirmation from the trust that they have destroyed the names and addresses of the sampled women, otherwise they will be able to identify individual women by matching up the patient record number/serial numbers on the name and address list to those in the raw data file.

These steps MUST be followed before supplying raw data to trusts. This is to prevent the disclosure of a woman's identity by specific demographic factors. Different arrangements govern the supply of raw data to the co-ordination centres. The arrangements are described in full in Section 16. The response data will be anonymous when passed to the Care Quality Commission, and published and archived results will not identify patients.

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 sub-group totals are shown):

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

Furthermore, 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.

The electronic file containing the women's names and addresses should be stored securely (i.e. password protected). Access to the file should be given only to those individuals who have signed the service contracts.

## 6.10 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 transfer an unabridged version of the data set if there is a clear need to use the data from the previous year's surveys to allow year-on-year comparison.

<sup>&</sup>lt;sup>10</sup> Please be aware that there are exemptions allowing disclosure, such as the prevention of crime exemption which **might** allow disclosure of free text describing criminal matters actual or threatened. Neither the Care Quality Commission nor the Co-ordination centre can offer legal advice on these matters; the contractor or trust must seek its own independent legal advice before disclosing patients' comments to trusts.

## 6.11 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of women's names, and the questionnaires kept until <b>29</b> <sup>th</sup> <b>November 2013</b> . All mailing lists of women's names and addresses should be stored on a separate computer to that containing survey data. Mailing lists of women's names and addresses should be destroyed when the mailing process is complete. The final sample should be kept until <b>6</b> <sup>th</sup> <b>December 2013</b> when it can be deleted.			

## 7 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.

#### 7.1 Ethical approval for the maternity survey

Research Ethics Committee (REC) approval has been obtained for the maternity survey and a substantial amendment submitted for changes regarding the questionnaire, the covering and reminder letters, all of which can be downloaded from the NHS Surveys website. 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 2013 Maternity Survey. The REC letter can be downloaded from the NHS Surveys website.

Further information on the ethical approval process can be found at National Research Ethics Service (http://www.nres.nhs.uk) or by e-mailing queries@nres.npsa.nhs.uk

## 7.2 Research governance requirements

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

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

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

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

## 7.3 Responsibilities of NHS organisations who are carrying out research

Research Governance Framework	Care Quality Commission sponsored patient surveys
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	The survey is carried out on the experiences of patients after they have received the care so this does not apply.
Be aware 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. Similar letter has been sent to the Research and Development Managers of the trusts.
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 for the Annual Health Check and 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 survey does not affect the care of the patients. Anonymised results are used for the Care Quality Commission assessments, the Department of Health national monitoring of the relevant PSA target, and local quality improvement initiatives. Detailed guidance is issued to survey leads regarding the publicity of the results and its impact on patient care
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.

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<b>Research Governance Framework</b>	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. <sup>11</sup>	In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an 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

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<sup>&</sup>lt;sup>11</sup> When universities and hospitals employ staff on joint or dual contracts, they are expected to make joint arrangements for accountability and management. See *A Review of Appraisal, Disciplinary and Reporting Arrangements for Senior NHS and University Staff with Academic and Clinical Duties*, a report to the Secretary of State for Education and Skills, Professor Sir Brian Follett and Michael Paulson-Ellis, September 2001 (The Follett Report).

## 8 Collecting data from non-English-speaking populations

The women who respond to your survey should be representative of all of the women who use the trust, so it is important that groups with limited understanding of English are not excluded. The questionnaire has been written in as **plain language** as possible to facilitate optimum understanding by all respondents. The questions have been tested with women whose first language is not English.

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

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

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of who offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the patient and the interpreter. (Note that trusts may already have arrangements with such a service.) If you are a trust that intends to conduct the survey using an in-house team, and you do not have access to such a service, please contact the Co-ordination Centre for further advice
- A multi-language leaflet template is available on our site, and this can be included with your
  first and third mailings. Trusts and approved contractors can use this leaflet by inserting their
  appropriate helpline number. This gives directions in the 20 most common non-English
  languages spoken in England and also in EasyRead (routed to a separate number run by
  Mencap to help those with learning disabilities).
- Many households include at least one competent English speaker who can help the person
  to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from
  non-English-speakers, although it is not ideal, as there is no control over the way in which a
  patient's family or friends translate questions or interpret their responses, and it does not allow
  the woman to answer the questions directly.

## 9 Timetable

The time taken to complete the survey process will depend on many factors. The survey fieldwork period for the maternity survey is 18 weeks. We recommend making full use of this to maximise response from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond 12. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. within the recommended four week sample checking period) and mail out your questionnaire packs promptly once permission has been received. Dissemination of the results to all staff, and to the local community and media, can only start after the survey has been completed so this will take additional time to complete.

If you commission an approved contractor, much of the work will be done by them, but you will still have to be involved in some of the stages of the process, marked in **bold** in the table below.

Week	Task	See Section
0	Guidance and documents published	
2	Inform Co-ordination Centre who is carrying out your survey by 5 <sup>th</sup> April 2013 (name of approved contractor or in-house)	4
1-2	Draw sample of women to be included in the survey	10
1-2	Check sample for deceased women and infants using hospital records	10.2
2-3	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	10.3
2-3	Submit sample list to DBS to check for deceased women AND infants	10.4
3-6	Submit anonymised sample to Co-ordination Centre before starting mailing process	11 & 3.2
1-2	If using an approved contractor, supply them with trust headed paper and a signature of a senior executive and, if appropriate, ensure that the service contract is signed	5.2 &14.2
1-3	Print questionnaires and covering letters	14.1 & 15.4
2	Set up FREEPOST address and helpline	15.1 & 15.3
2	Ensure you have enough envelopes, return envelopes and labels	14.3
2	Establish system for responding to telephone enquiries	15.3
3	Establish system for booking in questionnaires	15.6

<sup>&</sup>lt;sup>12</sup> For details of this research carried out by the Picker Institute Europe see: http://www.nhssurveys.org/Filestore/documents/Extension\_of\_fieldwork\_for\_inpatient\_survey\_2007.pdf

4-7	Check your own trust's records again for any maternal or infant deaths	10.2
4-7	Stick labels on pre-packed numbered questionnaires and reminders supplied by approved contractor (if NOT using service contract)	4 &15.5
4-7	Send out first questionnaires	14.4
6	Send first weekly response rate and helpline monitoring form to Coordination Centre (2 <sup>nd</sup> May)	12
17	Send two copies of the questionnaire and covering letters to the Coordination Centre ( <b>19th July</b> )	16.4 & 16.5
17	Send data indicating whether women in your sample received their antenatal and postnatal care from the trust (19 <sup>th</sup> July) The Co-ordination centre will provide additional gudiance to help trusts carry out this process	To follow in separate guidance
4-23	Continue to respond to telephone enquiries	
4-23	Log and process returned questionnaires	15.6
4-23	Enter data	16
5-8	Check records for any deaths	10.2
5-8	Send out first reminders to non-responders	15.7
6-9	Be prepared for a small peak in telephone calls as first reminders received	
7-10	Check records again for any deaths	10.2
7-10	Send out second reminders to non-responders	15.7
23	Complete data entry	16
24	Check data for errors	16.3
24	Send final data to Co-ordination Centre and checklist (by <b>6</b> <sup>th</sup> <b>September</b> at the latest)	16.4
29	Send patients' written comments to the Co-ordination Centre in an anonymised format (by <b>7</b> <sup>th</sup> <b>October</b> at the latest)	16.2
24	Begin analysing trust's results and writing report	17 & 18
25	Disseminate results to staff	18 & 19
	You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until <b>29</b> <sup>th</sup> <b>November 2013</b>	6.11

## Key dates

Inform Co-ordination Centre who is carrying out survey	By 5 <sup>th</sup> April 2013
Submission of sample data prior to mailing	8 <sup>th</sup> April - 3 <sup>rd</sup> May 2013
Weekly monitoring starts	2 <sup>nd</sup> May 2013
Submission of data indicating which women received their antenatal and postnatal care from the trust	19 <sup>th</sup> July 2013
Submission of paper copies of the questionnaire and covering letters used	19 <sup>th</sup> July 2013
Submission of final data	6 <sup>th</sup> September 2013

Please remember to leave no more than 3 weeks between each mailing.

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## 10 Compiling a list of women

This section explains how to draw a sample of women. This task will need to be carried out by a member of staff at the NHS 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 the list will also have 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 before the first mailing and within the trust prior to each mailing.

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

#### 10.1 Compile a list of eligible women

Compile a list of all women who had a live birth consecutively between 1<sup>st</sup> February and 28<sup>th</sup> February 2013.

#### Note

If there are **fewer than 300 eligible women** who had a live birth in February, then please contact the Co-ordination Centre on 01865 208127 for advice on including women who gave birth in January 2013. Please note that the *minimum* sample size is 300

The information you obtain about each woman will be used both for administering the survey and for sending to the tracing service (DBS) to check for any deaths. It saves time and effort if all the information is gathered at the same time [See section 10.6 for a list of the data fields that you will need to include in your sample file for the survey].

The list should include:

- All women **aged 16 years or over** at the time of delivery, who have had a live birth within the trust, irrespective of which facility they use.<sup>13</sup> Women who gave birth at a separate maternity unit should still be included in the sample.
- 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 had previously had a baby
- 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.
- Include women even if their addresses are incomplete but still useable (e.g. no postcode).

<sup>&</sup>lt;sup>13</sup> Exclude any women whose baby was born in a unit managed by a Primary Care Trust if these cases are also included on your hospital databases.

#### **Exclusion criteria**

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

- women who are under age 16 at the time of delivery
- women who had any of the following ICD10 delivery outcomes or their equivalents<sup>14</sup>:
  - 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 infants have died since delivery<sup>15</sup>
- 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<sup>16</sup>
- where possible, women whose baby was taken into care (i.e. foster care, adopted) <sup>17</sup>
- women who gave birth in a private maternity unit or wing
- women who gave birth in a maternity unit managed by another provider
- women without a UK postal address (but do not exclude if addresses are incomplete e.g. no postcode)<sup>18</sup>
- 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).

<sup>&</sup>lt;sup>14</sup> If you do not use ICD10 codes in your systems, please use the appropriate equivalents to the codes listed above

<sup>&</sup>lt;sup>15</sup> 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.

<sup>&</sup>lt;sup>16</sup> 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.

<sup>&</sup>lt;sup>17</sup> 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.

<sup>&</sup>lt;sup>18</sup> Women whose address is in the British Islands (Isle of Man, the Channel Islands) are eligible for inclusion in the survey'

#### 10.2 Checks carried out by the trust

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

- **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 the tracing service (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
- again by the trust (for women or infants who may have died in hospital after submission of the sample to DBS).

You are also advised to repeat this check before the second and third mailings, and to 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. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias.
- **Duplications.** Check that the same 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 outs following publicity / contact with 16 and 17 year olds: Any women that were recorded by staff members to have decided to opt out of the survey after seeing the publicity

poster and/or the information sheet (i.e. given to women aged 16 and 17 years old by midwives).

#### 10.3 Validating 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.

#### 10.4 Submit the patient list to the Demographics Batch Service (DBS)

Before sending out the questionnaires, 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).<sup>19</sup>

### 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://www.connectingforhealth.nhs.uk/industry/docs/files/dbs/index.html

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 and date of birth and postcode (can be wildcarded eg 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 (ie 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.

<sup>&</sup>lt;sup>19</sup> 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.

#### Submitting the trace request file

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

If you have been set up to use DBS, then once you have created the request file, it should be placed in the client in-box. The DBS client will then send the file to the Spine and you will receive an email to say that file was received. The DBS processes the file overnight and it should be ready the following morning. You will be notified by email when the file has been processed. During periods of high demand for DBS service, it may take 48 hours for your file to be returned.

#### The response file

The 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, which is returned only when there is a single unique match. It is on this additional response that patients found to be deceased will be indicated.

Further information is available from:

http://www.connectingforhealth.nhs.uk/industry/docs/files/dbs/index.html

#### 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 patients may die in the period between running the check and the questionnaire being delivered. You may find that some recently deceased patients remain in your sample. You need to be prepared for this. Special sensitivity is required when dealing with telephone calls from bereaved relatives.

# 10.5 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 (maternity.data@pickereurope.ac.uk or 01865 208127).

#### 10.6 Create the sample file

An example of the spreadsheet you should complete has been included below. This is available to be downloaded from our site (www.NHSSurveys.org) and is entitled "Sample construction spreadsheet". The column headings will match to the validated spreadsheet for final submission of data produced by the Co-ordination Centre and so it will be advantageous for you to use this spreadsheet. Save this file as <NHStrustname>\_Maternity2013.

This file has three purposes:

- 1) It will be used to keep a record of which women have not returned questionnaires so that reminders can be sent to them.
- 2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from the **2<sup>nd</sup> May 2013** until the closing date of the survey.
- 3) The anonymous data in this file (i.e. all the data **except** women's name and address information) will form part of the file that you will submit to the Co-ordination Centre when the survey is completed.

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

Table 1 – Example: Sample construction spreadsheet

Record number	Trust code	Title	Initials	Surname	Address 1	Address 5	Full Postcode	Mother's Year of birth	Mother's Ethnic Group	f deliv	Month of delivery	Year of delivery	Actual Delivery Place	Place of birth: NHS Site code	Referring PCT code	GMPC	Postcode sector	Day of questionnaire being received	Month of questionnaire being received	Year of questionnaire being received	Outcome	Comments
MAT13RTE1001	RNH	Miss	AM	Abbot			AB1 1YZ	1969	Α	1	2	2013	2	RR115	5LS	A36548	AB1 1				3	Informed that woman's baby had died
MAT13RTE1002	RNH	Ms	EC	Ahmed			AB2 6XZ	1978	J	3	2	2013	0	RTE03	5LT	A36548	AB2 6	14	05	2013	1	
MAT13RTE1003	RNH		Р	Lane			AB3 8PL	1989	В	3	2	2013	2	RR115		A36548	AB3 8				4	
										:		:			:							
MAT13RTE1339	RNH	Mrs	К	Yoo			AB4 7MX	1982	R	27	2	2013	1		5LT	A36548	AB4 7					
MAT13RTE1340	RNH	Ms	F	Young			AB9 5ZX	1975	Α	28	2	2013	0	RTE03	5GT	A36548	AB9 5	19	06	2013	1	

# Important note about Table 1

The headings of Table 1 are in three different colours:

**Bold black** headings: these columns contain information on womens' names, addresses and comments that may allow them to be identified. This information should be deleted from all files sent to the Acute Co-ordination Centre

Red italic headings: these columns should be completed during the sampling phase and submitted to the Acute Co-ordination Centre prior to mailing for final inspection (see Section 0) and at the conclusion of the survey

Green italic headings: these columns should be completed when the woman responds to the survey, either by returning a completed questionnaire, or the trust is notified the woman will not be participating (deceased, moved address, too ill, or called to opt out).

The following information is compiled using hospital records:

- Trust code should be the three character code of your organisation (e.g. RNH), maintained by NHS Connecting for Health<sup>20</sup>
- Title (Ms. Mrs. Miss. etc)
- Initials (or First name)
- Surname
- Address Fields<sup>21</sup>
- Postcode

#### Note

The Patient Record Number, Title, Initials, Surname, Address fields and Postcode are used for printing out address labels. You (or your contractor) can use the mail merge function in a word processing package for this purpose. (See Section 15.5)

- The mother's **Year of Birth** should be included in the form of NNNN.
- The mother's Ethnic Group <sup>22</sup>should be coded using the 17 item alphabetical coding specified by NHS Connecting for Health<sup>23</sup>. The codes are as follow:

#### **National Codes:**

#### White

- Α British
- В Irish
- C Any other White background

#### Mixed

- White and Black Caribbean D
- Ε White and Black African
- F White and Asian
- G Any other mixed background

#### Asian or Asian British

- Indian
- J Pakistani
- K Bangladeshi
- Any other Asian background

#### **Black or Black British**

M Caribbean Ν

African

<sup>20</sup> A data file of NHS Organisation Codes can be downloaded from the Organisation Data Service on the Connecting for Health website (www.connectingforhealth.nhs.uk/systemsandservices/data/ods/data-files)

http://www.datadictionary.nhs.uk/data dictionary/attributes/e/enh/ethnic category code de.asp?shownav=1

<sup>&</sup>lt;sup>21</sup> The address should be held as separate fields (eg street, area, town, and county), consistent with the address format required by the DBS (formally NSTS).

<sup>&</sup>lt;sup>22</sup> It is acknowledged that hospital records might not always contain complete data on womens' 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 Care Quality Commission and Department of Health to be more responsive to all ethnic groups and to ensure all groups are appropriately represented in their assessments.

<sup>&</sup>lt;sup>23</sup> These codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:

P Any other Black background

#### Other Ethnic Groups

- R Chinese
- S Any other ethnic group
- Z Not stated
- 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. 2013)
- Actual delivery place: should be coded using the National Codes<sup>24</sup>:
  - 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 (maintained by NHS Connecting for Health)<sup>25</sup>. 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)
- Referring PCT should be coded using the first three characters of the PCT character codes of
  the PCT which will be billed for the care of that patient. For the most up-to-date list of PCT
  codes, please see the Connecting For Health data set, "Primary Care Trusts"
  http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods/datafiles
- **General Medical Practice Code (GMPC):** This is a new inclusion for the 2013 survey. Please record the six character organisation code of the GP practice at which the woman is registered. <a href="http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods/datafiles">http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods/datafiles</a>
- **Postcode sector:** Please record the mother's postcode '**sector**'. This is the first part of the 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

http://www.datadictionary.nhs.uk/data\_dictionary/attributes/a/acc/actual\_delivery\_place\_de.asp?shownav=1

<sup>&</sup>lt;sup>24</sup> The 'Actual place of delivery' codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:

<sup>&</sup>lt;sup>25</sup> A data file of NHS Trust Site Codes can be downloaded from the Organisation Data Service on the Connecting for Health website (http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods)

Additional information should also be entered on this spreadsheet. The details of this information are discussed below:

- 1) Record number (RN). This is a unique serial number which must be allocated to each woman by the trust (if the survey is being carried out in-house) or the contractor (if the survey is being carried out by an approved contractor). It should take the following format: MAT13XXXNNNN where XXX is your trust's 3 digit trust code and NNNN is the 4 digit number relating to your sampled women, e.g., 0001-0850. The PRN will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the approved contractor) will be able to use these numbers to monitor which women have returned their questionnaires and to identify any non-responders, who will need to be sent reminders. If an approved contractor is used, you will need to agree with them on the range of serial numbers that will be used for your women. Please note: this number should be available in, and correctly referenced for, every patient dataset for this survey (e.g. sample file, mailing file, final data).
- 2) Day of questionnaire being received. This can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be a one or two digit numerical response e.g. N or NN, not a date format e.g. 12/07/13.
- 3) **Month of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trusts or approved contractor. It should be a one or two digit numerical response, **not** a date format.
- 4) **Year of questionnaire being received**. This can only be completed if and when a questionnaire is received by the trusts or approved contractor. It should be a four digit numerical response, **not** a date format.
- 5) The **Outcome** field will be used 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
  - 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).

The outcome column is left blank at first if the survey has not been returned (on table 1 you can see that Ms Yoo has not yet returned her questionnaire).

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

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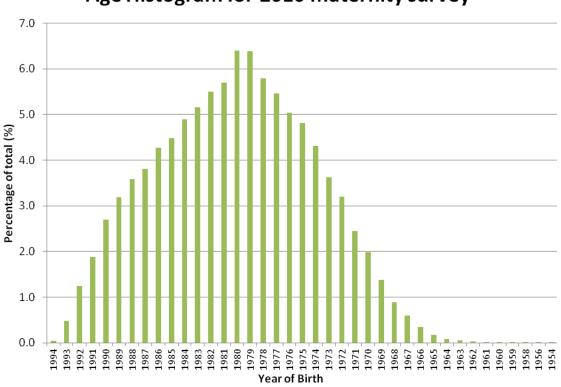
#### 10.7 Distribution of ages

You should check that women of all ages are included in your sample, especially for 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 2010 Maternity Survey

Age Histogram for 2010 maternity survey



### 10.8 Check for other sample errors

The most common sampling errors made in the 2010 survey resulted from trusts:

- Excluding women aged 16-17 years
- Excluding women who had a home birth
- Incorrect ethnicity coding
- Missing some sample information, such as year of birth data

Using the guidance correctly will prevent any errors and may reduce delays caused by missampling.

#### 10.9 Separating mailing details from sample information

At this point you should transfer the names, address and postcode for each woman in the sample to a new file. The record number for each woman should be copied to the new file, so that the two datasets are connected using the unique record number. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as "Maternity2013 mailing data".

This file should be used for mailing purposes: it will be used to check for deceased women & infants prior to reminder mailings and will be cross-referenced with the sample file (<NHStrustname>\_Maternity2013) to identify women who will need to be sent reminders.<sup>26</sup>

As this "Maternity2013\_mailing data" file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing data file should be destroyed when the survey is complete. This should be done by both the trust and the approved contractor, along with all other files created for the survey (aside from the survey response file).

#### Remember

For patient confidentiality reasons, it is essential that you do not keep patient name and full address details in the same file as their survey response data. (Please note: the postcode sector field should be kept in the sample file).

Table 2 - Example mailing file

Record number	Title	Initials	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
MAT13RTE1001	Mrs	AM	Cuthbert	14 Station Road	London				AB1 1YZ
MAT13RTE1002	Ms	EC	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
MAT13RTE1003									
	Miss	К	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4 7MX
MAT13RTE1339	Ms	F	Lane	634 Tyne Road	Moorfields	Tyne and Wear			AB9 5ZX

<sup>&</sup>lt;sup>26</sup> As shown in Table 1, the 'outcome' field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which women opt out etc...

#### 10.10 Sharing the sample file with an approved contractor

If you are working with an approved contractor and have a contract in place relating to the transfer of patient identifiable information (i.e. women's names and addresses) both the sample file ("<NHStrustname>\_Maternity2013") and the mailing file ("Maternity2013\_mailing data") file should be sent to the contractor staff in encrypted format (see Section 6.6 - Encryption of personal data).

If you are working with an approved contractor, but have chosen to mail out the questionnaires yourself, within the trust, you should supply them with just the sample file (this will resemble **Table 1 – Example: Sample construction spreadsheet** but with the women's names, addresses and postcodes removed). The contractor can use this list to record the outcome codes, but you should ensure that the contractor is kept up to date with any information that comes directly to the trust about maternal or infant deaths, etc.

# 10.11 Making more use of the survey locally

Up to this point, this section of the guidance has described in detail how sampling must be undertaken to provide the sample of women for the national survey. In addition to this minimum requirement, though, your trust may wish to use the NHS maternity survey as an opportunity to gather further data beyond that required by the Care Quality Commission. Increasing the sample size is a good way to do this.

Increasing the sample size for the survey may be helpful if, for example, you wish to:

- Analyse or compare results for specific subgroups (for example, women who gave birth at
  different maternity units or women of different ethnicities) in more detail than would be
  possible from this sample. By increasing the sample size you can ensure that you have a
  large enough sample of women from each group<sup>27</sup>
- Alternatively, if your trust manages a large number of deliveries, you may wish to draw an extra sample of women to survey additionally to those included in the main survey. For example, you could select women who gave birth in a different time period from those in the national survey and send them questionnaires either at the same time as or at some point after the national survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out an maternity survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of women which do not overlap. Guidance for carrying out a local survey, and all survey materials, will be made available at the end of May on our website at http://www.nhssurveys.org/localsurveys

If you are using an approved contractor for the survey then they will be able to advise you on the best way to increase your sample size to achieve your specific goals. If you are not using an approved contractor, then the Co-ordination Centre will be able to advise on any queries you might have via e-mail at advice@pickereurope.ac.uk or call 01865 208127. However, before you decide to do this, there are some important points to consider:

Please note that the section 251 approval sought for the 2013 Maternity survey only covers
the transfer of women's information required for carrying out the Core survey. If you wish to
collect any additional sample information you will need to seek advice from the Health
Research Authority Confidentiality Advisory Group (previously the National Information

<sup>&</sup>lt;sup>27</sup> See section 17 for more information on the reliability of data based on different numbers of respondents.

- Governance Board) as to whether further approval is needed. For further information please see: http://www.hra.nhs.uk/
- The core sample for the 2013 maternity survey must be drawn as specified in this guide; any deviation from the guidance may make it impossible for the Care Quality Commission to use the data that you collect. It is therefore essential that any additional sample drawn can be easily distinguished from the core sample, and that it is drawn in such a way as to not interfere with selection of the core sample.
- If you are planning to undertake surveys more frequently than the national programme, then you should consider how any increased sample here will fit with the additional surveys you will be undertaking. Guidance for carrying out local surveys is available on our website at: www.nhssurveys.org/localsurveys

#### To summarise

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

You must **only** send the Co-ordination Centre data for the women sampled according to these guidelines, and these women **must** be those who gave birth in February (and January in some cases). If you decide to carry out a maternity survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of women which do not overlap.

# 11 Final sampling inspection by the Co-ordination Centre

Trust data should still be checked for errors and received back from DBS before being forwarded to the Co-ordination Centre. An anonymised sample file<sup>28</sup> **must** be submitted to the Co-ordination Centre **prior** to the first mailing. This is to allow us to make final quality control checks. All columns *in red italics* in **Table 1 Example: Sample construction spreadsheet** must be submitted, but name, address and full postcode details must be removed. (The postcode sector should have been entered as an additional field in red italics, and the original full postcode entry, used for mailing, should be removed.)

If you are using an **approved contractor**, the sample should be checked as normal by the trust and by DBS before being submitted to the contractor. We strongly recommend the contractor carries out the same high standard of checks as in previous years, but will then submit the file to the Co-ordination Centre. The Co-ordination Centre will address any issues arising from these final checks to the approved contractor.

The Co-ordination Centre will be checking for extraordinary errors. These are more visible when viewing data from many trusts at one time. For this reason, samples will be checked as collated files. Emails discussing any sample anomalies will be returned to the trust or approved contractor which provided them on Tuesday of each week **at the very latest**. Initially, we will be working to the timetable included below but, if sufficient samples are submitted during a week, we hope to be able to respond to trusts and approved contractors earlier.

Please note: samples submitted on a Monday must be sent to the Co-ordination Centre by 11am for the samples to be returned to the trust or approved contractor the following day. Your first mailing should take place as soon as possible after your sample has been approved by the Co-ordination Centre but **must not be later than seven days** after this. A large time lag increases the likelihood of women (or their babies) having died between the sample file being received back from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to your trust.

# Making the most of the fieldwork period

Because certain demographic groups (specifically younger people and those from non-white ethnic categories) have been shown to take longer to respond to patient surveys, we strongly recommend that files are submitted within the four weeks specified for sample checking. The best way to ensure you can do this is to prepare before the start date of the sample checking period ( $8^{th}$  April  $-3^{rd}$  May). You can do this by:

- 1) Allocating sufficient time to the individual who will generate your sample to allow them to generate it, get it checked by midwifery staff, dispatch it to DBS, and to respond to queries or corrections specified by your contractor or the Co-ordination Centre
- 2) Discuss the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey
- 3) Ensure your trust is registered with DBS and that the person who submits your sample to them understands their requirements problems with data submitted to tracing services is one of the most significant obstacles in mailing out your survey in good time. Also, do not assume you are registered please check this ahead of time.
- 4) Printing of questionnaires and assembly of mailing packs can take place before the sample is signed off. Please ensure that the envelopes are left open though so that you can check the correct label is applied to the correct questionnaire. This means that you should decide on your questions as early as possible so arrange the times for any meetings that will discuss the questionnaires as early as possible.

<sup>&</sup>lt;sup>28</sup> Created by removing the womens' names, addresses and postcodes.

For the 2013 maternity survey, the specified sample submission dates are:

Date sample received	Date sample returned
8 <sup>th</sup> April - 15 <sup>th</sup> April 2013	16 <sup>th</sup> April 2013
16 <sup>th</sup> April - 22 <sup>nd</sup> April 2013	23 <sup>rd</sup> April 2013
23 <sup>rd</sup> April - 29 <sup>th</sup> April 2013	30 <sup>th</sup> April 2013
30 <sup>th</sup> April - 3 <sup>rd</sup> May 2013	7 <sup>th</sup> May 2013 <sup>29</sup>

Samples should be submitted to the Co-ordination Centre by the **3<sup>rd</sup> May 2013**. If they are not, there is a risk your trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may then result in the data from the trust being excluded from the relevant Care Quality Commission assessments.

Trusts which have not submitted their sample for checking by the 3<sup>rd</sup> May 2013 will be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the 10<sup>th</sup> May 2013, then we are required to notify the Care Quality Commission of this and they will contact you to discuss any implications for inclusion in Care Quality Commission produced data.

<sup>&</sup>lt;sup>29</sup> Please be aware that submitting a late sample may delay the mailing process

# 12 Weekly monitoring

The Co-ordination Centre requires weekly submissions of outcome data and helpline calls for each trust taking part in the 2013 Maternity survey. First submission of data must be made on Thursday  $2^{nd}$  May 2013<sup>30</sup>, and every Thursday thereafter until the final date of submission. An Excel spreadsheet is available on our website (www.nhssurveys.org) which must be used to return this information to the Co-ordination Centre. This information should be emailed to the Co-ordination Centre (maternity.data@pickereurope.ac.uk) by the end of the workday every Thursday throughout the survey.

#### Weekly submissions only apply to the core sample of patients

#### Important note

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

#### For trusts carrying out the survey in-house:

When the data is submitted, the file name **must** be in the following format: MAT13 <trust code> <week of submission>.xls

e.g. MAT13\_RAC\_1.xls (first submission of monitoring data on 2<sup>nd</sup> May)
MAT13\_RY2\_4.xls (fourth submission of monitoring data on 23<sup>rd</sup> May)

#### For approved contractors:

When the data is submitted, the file name **must** be in the following format: MAT13\_<contractor code>\_<week of submission>.xls

e.g. MAT13\_CDP\_1.xls (first submission of monitoring data on 2<sup>nd</sup> May)
MAT13\_CYH\_4.xls (fourth submission of monitoring data on 23<sup>rd</sup> May)

Each approved survey contractor should use their unique 'contractor code' (which were first allocated for the maternity survey 2007). If you do not know your contractor code, please contact the Co-ordination centre.

#### 12.1 Response rate

The information submitted should contain the following data:

- The total number of women in your sample, i.e. the total number of all those included in the first mailing
- The number of women in each outcome field (see Section 10.6, point 5)

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

<sup>&</sup>lt;sup>30</sup> This submission must be made regardless of whether mailing has commenced.

### 12.2 Helpline monitoring

The information you submit should contain the following data for each trust:

- The overall total number of calls received by the helpline for this survey. This total should also include the calls listed below:
- The total number of calls that led to completion of the questionnaire using the helpline (this should include completions via translation services)
- The total number of calls seeking assistance with language and translation (this should include completions via translation services)
- The total number of calls that led to completion of the questionnaire using translation services

#### **Examples**

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

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

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

This information allows the Co-ordination Centre to identify areas of concern to people who have received the questionnaire and to improve future surveys.

# 13 Publicising the survey

The following measures will help to increase response rates and reduce the number of questions and any complaints received about a survey:

#### 13.1 Pre-survey communication with staff

The best way to ensure your survey is a success is to work hard in the beginning to involve those people who have the most impact on women's maternity experiences and who will be responsible for responding to the results of the survey. We suggest you put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:

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

#### Keeping everyone informed

Notify as many staff members as possible about the survey, in case 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 in the first instance. 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)

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

# 13.2 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 recent mothers and the public through a number of ways, for example:

Send a press release to the local media to raise awareness of the survey and gain publicity
just before the survey takes place. Talk to your hospital's press office for more ways in
which you can gain publicity locally. Appendix 2 includes information which you can tailor
for publicising the survey externally.

# 14 Materials

#### 14.1 Printing questionnaires

#### Questionnaire layout

The questionnaire is rigorously tested in the format of the core questionnaire. All questionnaires used by trusts should emulate this format and should be comprised of the following:

- Two columns of questions on each page.
- Questions should be presented with a consecutive question number, followed by the exact question wording used and then each of the response options presented on a separate line beneath the question, for example:

A1.	Did you	give birth to	a single baby,	twins or mo	ore in your m	ost recent	t pregnancy?
-----	---------	---------------	----------------	-------------	---------------	------------	--------------

1	☐ A single baby
2	Twins
3	☐ Triplets, quads or more

- Please **do not** arrange the response options horizontally across the page, rearrange the question options, or change the order of the questions in the questionnaire.
- Please ensure that the final questionnaire is A4 size (or A3 paper folded to make an A4 booklet).
- We recommend you use a font size of no less than 11.

# Number of pages

It is practical to ensure that the number of pages in a questionnaire is a multiple of four so that sheets can be printed double-sided on A3 paper and folded to make an A4 booklet, stapled in the middle. If pages are stapled at the corner, there is a greater chance that some pages will become detached and get lost. The core questionnaire, available in PDF format on the NHSSurveys website, is designed to fit onto 12 sides of A4.

# Number of questionnaires

When calculating the number of questionnaires to be printed, you will need to allow for sending out duplicate questionnaires with second reminders. Printing costs can be unnecessarily high if a second print-run is required, so it is worth ensuring that the first print-run is sufficiently large to allow for contingencies. As a rule of thumb, multiply the number of women in the sample by 1.7 to obtain the total number of questionnaires required. So, if the number of first mailing questionnaires you intend to send out is 425, then you might want to print 1.7 x 425, or approximately 723 copies.

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

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

Furthermore, only the materials described below should be included in the mailings because of the immeasureable impact upon response rates to the survey.

#### 14.2 Trust headed paper

You will need headed paper from your trust for covering letters for the first and third mailing. A reminder letter is used for the second mailing. If an approved contractor is being used to carry out the survey work, it is preferable that the paper does not include a telephone number for the trust, as patients should call the contractor's FREEPHONE line, rather than the trust.

#### 14.3 Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to women does not show any indication of the NHS Trust, in line with data protection regulations. We would therefore recommend that the return address used on any mail out envelope(s) does not indicate Trust name or address. It is, however, important that we record questionnaires which are returned undelivered as this affects response rate. We would therefore advise that, where necessary (ie for Trusts conducting the survey in-house), a PO Box address is set up for envelopes which are returned undelivered.

Please note that the above does not apply to the address on the reply paid envelope (which can be a hospital address) as we assume that the patient is responsible for opening her own mail.

For further details on how to set up a PO Box please go to: http://www2.royalmail.com/delivery/inbound-mail/po-box

# 14.4 First mailing

You will need each of the following items for each woman in the sample:

- Printed questionnaires
- Large envelopes for mailing questionnaires to women
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for inhouse Trusts)
- FREEPOST envelopes for return of questionnaires
- Covering letters using the trust's letterhead
- Multi-language helpline sheet (recommended)<sup>31</sup>.

<sup>&</sup>lt;sup>31</sup> This document can be found on our website alongside the cover letters. The languages covered by this document are: Arabic, Bengali, Chinese (Cantonese), Farsi /Persian, Guajarati, Hindi, Kurdish, Chinese (Mandarin), Punjabi, Tamil, Thai, Turkish, Urdu, French, Italian, Polish, Portuguese, Russian, Somali, Spanish.

# 14.5 Second mailing (first reminder)

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

- Reminder letters
- Envelopes
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for inhouse Trusts)

# 14.6 Third mailing (second reminder)

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

- Printed questionnaires
- Large envelopes for mailing questionnaires to women
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes (PO Box address recommended for inhouse Trusts)
- FREEPOST envelopes for returning questionnaires
- Reminder letters
- Multi-language helpline sheet (if used in first mailing).

# 15 Implementing the survey - practicalities

#### 15.1 Setting up a FREEPOST address

A FREEPOST address allows people to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the envelopes you send out with the questionnaires. Printed envelopes must comply with Royal Mail guidelines. Details of how to apply for a FREEPOST licence can be found at the Royal Mail website: http://www.royalmail.com

Alternatively, you can call your local Sales Centre on 0845 7950 950.

#### 15.2 Setting up a PO Box

This is recommended for in-house Trusts to ensure that the mail out envelope(s) does not include any indication of the hospital address (please see Section 14.3 for further detail). Information on setting up a PO address can be found at:

http://www2.royalmail.com/delivery/inbound-mail/po-box

## 15.3 Setting up a FREEPHONE line

The covering letter to women should include a telephone number for them to call if they have any questions or complaints about the survey. All staff who are likely to take calls should be properly briefed about the details of the survey, and be aware of the questions or complaints they are likely to receive. If you run the survey in-house, you might want to set up a FREEPHONE line for this purpose. Alternatively, all approved contractors offer this service.

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

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

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

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

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

Relatives or carers may call to pass on this information. In some cases, they may offer to complete the questionnaire for the woman, but this is only advisable if there is a good chance that the responses are a true reflection of the women's views. It is also strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. A multi-language sheet template in the twenty most commonly spoken languages in England is available on our website, and trusts or contractors can make use of this by inserting the appropriate number for their helpline and/or translation service

#### The woman (or her baby) to whom the questionnaire is addressed has died

Even with the use of a deceased patients tracing service, and sample validation, it may not be possible to identify all deceased women or their babies, particularly those who have died most recently. It is very important that staff who take the calls are aware of this possibility and are prepared to respond sensitively to such calls. These women should be logged as outcome = three (i.e. woman or baby deceased).

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

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

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

As trusts have been asked to display posters in antenatal and postnatal care settings prior to the sampling period for the survey, some women may have already called the number provided to opt out of the survey. They should have called a trust number as an approved contractor would not yet have been employed.

If a questionnaire has been received, a few women might call to say that they do not want to be involved in the survey, and fewer still may object to being sent the questionnaire in the first place. Staff should apologise to the woman and reiterate the statement in the covering letter - that taking part in the survey is voluntary, and that their care will not be affected in any way if they do not respond. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of the woman's responses.

If the woman is willing to tell the staff member the identification number (patient record number) written on their survey, it might also be possible to prevent any further reminders being sent to that person, or they could be advised to return the questionnaire blank. It is also advisable to ask the woman to ignore any future reminders that they might receive. These women should be logged as outcome = four (opt out).

### Making a record of the calls

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

We are also asking for weekly submissions of helpline use for each trust to the Co-ordination Centre. This is discussed in detail in Section 12.2.

# 15.4 Covering letters

The standard covering letter is available in Microsoft Word format on the Maternity survey section of the NHSSurveys website for you to download and add your own trust's details. This letter has been given ethical approval for use in the 2013 Maternity Survey and changes are not permissible. It should be printed on the trust's letterhead paper. Two paper copies of the letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey. Please note, for the first mailing letter and second reminder mailing there is now the option to include patient name. We recommend this approach as there is evidence to show that this increases response

rate (we would recommend using patient title followed by surname). If patient name is used, please take great care that each letter is correctly matched to its corresponding questionnaire.

# 15.5 Sending out questionnaires

#### Mailing labels

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

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

#### Note on the record number

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

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

# Questionnaire packs

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

- 1) A questionnaire **numbered with the unique record number**. The number must match (or correspond to) the number on the address label and the number on the list of womens' details.
- 2) A covering letter.
- 3) The multi-language helpline sheet (recommended).
- 4) A large envelope, labelled with the FREEPOST address on it.
- 5) These items should be packed into an envelope that has a return address on the outside. (PO Box recommended for in-house Trusts). This should be the contact at the NHS trust, or the approved contractor.

# Postage

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

#### Approved contractors – mailing questionnaires

If an approved contractor is carrying out the work under a service contract, they will send out questionnaires directly to the women, and the return address label will be the approved contractor's address.

#### Approved contractors – trusts mailing questionnaires

If an approved contractor is carrying out most of the work but not operating under a service contract, they should send pre-packed questionnaires to the trust for mailing out. The envelopes should be clearly marked with the unique record numbers so that trust staff can match these with their sample list and put on appropriate address labels.

## 15.6 Booking in questionnaires

When questionnaires are received, match up the record numbers against the list of women, so that you can record (in the *outcome* column) which women have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until **29**<sup>th</sup> **November 2013**, but please **do not** send these to the Co-ordination Centre.

#### Approved contractors

If an approved contractor carries out the work, questionnaires will be returned directly to them, so they will be able to record these returns against the list of record numbers. Trusts should inform the contractor of any questionnaires that were returned to the trust undelivered, and of any women who inform the trust that they do not wish to be included in the survey, or if any woman (or baby) dies during the period of the survey. The contractor can then record these details in their own sample list, and ensure that reminders are not sent out to those women.

# 15.7 Sending out reminders

For results to be representative, it is essential to get a good response rate. To achieve this, you must send out two reminders to non-responders. Remember, it is essential that you send out both reminders, even if you already have achieved a 60% response rate.

Depending on the time that has elapsed since you first checked your sample list for deaths, it might be necessary to send your list back to the tracing service for a further check before you send out reminders.

# Approved contractors

If a trust is using an approved contractor but is carrying out the survey mailing in-house, the approved contractors should send the pre-packed envelopes bearing the record numbers of the non-responders to the trust. Again, the envelopes should be clearly marked with the record number so that those carrying out the mailing can match these with their sample list and put on appropriate address labels.

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#### First reminders

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

The standard first reminder is available in Microsoft Word format on the NHSSurveys website for you to download. It can be printed on A5. It has been given ethical approval so no changes are permitted. Two paper copies of the reminder letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

#### Second reminders

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

The envelopes should include the following:

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

The standard second reminder letter is available in Microsoft Word format on the NHSSurveys website for you to download and add your trust's details. It has been given ethical approval so no changes are permitted. Two paper copies of the second reminder letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

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

# 16 Entering data

The data must be submitted to the Acute Co-ordination Centre in the appropriate format by the deadline of 6<sup>th</sup> September 2013. If an approved contractor is used, they will be responsible for all of the data entry and checking, and when the survey is completed they should submit the data to the Co-ordination Centre in the correct format and supply the trust with an anonymised data set (see Section 6 on data protection issues).

#### 16.1 Entering and coding data from the questionnaire

The data should be entered into the pre-designed Excel file, which can be found in the Maternity 2013 survey section of the NHSSurveys website.

You will see that, at the bottom of the Excel screen, there are labelled tabs for each of the worksheets within the workbook. The first of these tabs is labelled "Data". Click on this tab to show the data entry window. Data should be entered using the following guidelines:

- Each row records one woman's responses to the survey.
- For each question, the small number next to the crossed box should be entered as the response. (However, there are some exceptions to this rule see last bullet point below).
- If a response is missing for any reason, it should be left blank, or coded as a full stop (.).<sup>32</sup>
- If two boxes are crossed (where only one should be crossed), the response should be left blank or coded as a full stop (.).
- For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For multiple response questions (B4, B8, C3, C5, C13, G4, G5) that give the instruction "Please cross all that apply", each response option is treated as a separate question.

<sup>&</sup>lt;sup>32</sup> If you want to use this data input file on the website to display frequencies on the other pages of the workbook, you will need to fill in the blank cells with a full stop (.).

Example					
B8. Which of the followin (Cross ALL that apply)	g health professionals did	you see	e for you	r <b>anten</b> a	ital check-ups?
₁ ✓ Midwife					
<sub>2</sub> GP (family doctor)					
₃ ✓ Hospital doctor (e.g.	a consultant				
<sub>4</sub> Other					
Responses to each part of thi	•			ssed crossed	l <sup>±</sup>
Question B12 takes up four c	olumns in the data file, lal	pelled as	follows	:	
Column head	ings B8 1	B8 2	B8 3	B8 4	

When saving this file to submit data to the Co-ordination Centre, please save only the first sheet as a worksheet, rather than saving the whole file as a workbook; the Co-ordination Centre does not need the additional formula pages.

0

0

### 16.2 Entering the patients' written comments

Codings for this example

The Care Quality Commission has asked the Co-ordination Centre to request all free text comments provided by respondents to the 2013 Maternity survey. Any analysis of these free text comments will be conducted in a way that would not allow individuals to be identified.

Please ensure that the comments have been **anonymised**, (i.e. by replacing any names of staff, and women with asterisks) before sending to the Co-ordination Centre. (If you have already used a different method for anonymising the comments, this is acceptable, but please provide details of the procedure you have used.)

Preferably, the anonymised women's written comments should be entered in the main data file alongside the responses to the 74 questions and submitted to the Co-ordination Centre on or before 6th September 2013.

Alternatively, if you are unable to submit the free text comments by this deadline, then you may submit them to the Co-ordination Centre anytime before the 7<sup>th</sup> October 2013. If you do submit the free text comments to the Co-ordination Centre after the main data submission on 6<sup>th</sup> September, then please ensure you include the same patient record number for that woman used in the final data set submitted by 6<sup>th</sup> September. Also include the respondents' year of birth, ethnic group and

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

outcome fields from the sample data. Include all women in the sample for each trust, not just those who made comments (some text boxes will therefore be blank). For example:

Patient Record Number	Year of Birth	Ethnic category	Outcome	Any other comments?
MAT13RTE1001	1986	Α	1	The care I received was of a very good standard
MAT13RTE1002	1978	Α	6	My Postnatal care fell short of my expectations
MAT13RTE1003	1990	G	1	
MAT13RTE1004	1979	Z	1	Finding a place to park was really difficult

# 16.3 Checking the data for errors

For the 2013 maternity survey, trusts and contractors are required to submit raw ('uncleaned') data to the Co-ordination Centre. For clarification, raw data is created by the following:

- 1) All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (e.g. where women answer questions that they have been directed to skip past, these responses should still be entered).
- 2) Where a respondent has crossed more than one response category on a question, this should be set to missing in the data. The **exception** to this is for the 'multiple response' questions (B4, B8, C3, C5, C13, G4, G5) where respondents may cross more than one response option.
- 3) Where a respondent has crossed out a response, this should not be entered in the data. Where a respondent has crossed out a response and instead crossed a second response option, this second choice should be entered into the data.
- 4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a woman has written their date of birth in the boxes for question G1, but written their year of birth in at the side of this, then the respondent's year of birth should be entered.
- 5) For the year of birth question, unrealistic responses should still be entered except following rule 4) above. For example, if a respondent enters '2013' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.
- 6) Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the patient's intended response has not been captured. This includes 'out-of-range' responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Co-ordination Centre where they are found to have been entered inconsistently with the respondent's intended response.

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

### 16.4 Submitting data to the Surveys Co-ordination Centre

The data from the 2013 maternity survey must be supplied to the Co-ordination Centre as one anonymised Excel file that includes information about the sample and responses. To comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre (with the exception of partial postcodes where entered for the identification of women receiving antenatal or postnatal care).

#### Required file format

Please submit the file to the following specifications:

- Use Microsoft Excel Worksheet (not Workbook). Any version of Excel is acceptable.
- The file name must be in the form <NHStrustName> Maternity2013.xls.
- Use one row of data for each woman in the sample.
- Use one column of data for each item of information or response.
- Respondents who are missing their unique 'Record Numbers' should be added to the bottom of the list, and not matched to women with similar demographics
- Missing data should be left blank or coded as a full stop (.).<sup>33</sup>

Table 3 shows the information that must be provided for each woman in the original sample.

Table 3 - Data fields to be included in file submitted to Co-ordination Centre

Field	Format	Data codes	Comments
Unique Record	N,		The unique serial number
number	NN, NNN		allocated to each woman by the
	or NNNN		trust or approved contractor
			administering the survey.
Trust code	NNN		This is the NHS organisation
			code (e.g. RNH) as maintained
			by NHS Connecting for Health
Mother's Year	NNNN		Format this simply as a number,
of birth			not in date format.
Mother's Ethnic	N	National Codes:	Ethnic category should be
Group			included if the information is
		White	available.
		A British	
		B Irish	
		C Any other White	
		background	
		Mixed	

<sup>&</sup>lt;sup>33</sup> Data may be missing for a number of reasons. The woman may have skipped a question or a set of questions by following instructions; a woman may have not answered for some other reason. However, all missing data should be left blank or coded as a full stop (.), regardless of the reason for the omission.

Field	Format	Data codes	Comments
		D White and Black Caribbean E White and Black African F White and Asian G Any other mixed background  Asian or Asian British H Indian J Pakistani K Bangladeshi L Any other Asian background  Black or Black British M Caribbean N African P Any other Black background  Other Ethnic Groups R Chinese S Any other ethnic group  Z Not stated	
Day of delivery  Month of	N or NN		For example, if the woman gave birth on February 15th 2013 this column should read 15.
delivery	IN OF ININ		For example, if the woman gave birth on February 15th 2013, this column should read 2.
Year of delivery	NNNN		For example, if the woman gave birth on February 15th 2013, this column should read 2013.
Actual delivery place	N	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/	This should be coded using the National Codes (These codes can be found in the NHS Data Dictionary provided by Connecting for Health <sup>34</sup> )

34

http://www.datadictionary.nhs.uk/data\_dictionary/attributes/a/acc/actual\_delivery\_place\_de.asp?shownav=1

Field	Format	Data codes	Comments
		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	
Place of birth: NHS Site Code	NNNN	Use the NHS Trust Site Codes maintained by Organisation Data Service (NHS Connecting for Health)	For example, RR115. 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)
Referring PCT code	NNN	Use the characters codes maintained by the Organisation Data Service (NHS Connecting for Health) to complete this field	Use the <b>first three</b> characters of the PCT which will be billed for the care of that patient.
GMPC	NNNNN	Use the character codes provided by Connecting for Health to complete this field	Use the six characters of the GMPC. To be included by all trusts.
Postcode sector	LLN N LLNL N, or LLNN N)	Include only the first digits, NOT the full postcode.	To be included if identifying women receiving antenatal or postnatal care from your trust. Leave blank otherwise.
Day of receiving questionnaire	N or NN	This is the day you received a returned questionnaire from a respondent, or are notified that the woman will not be participating in the survey (mother or baby deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 17th May 2013, this column should read 17.
Month of receiving questionnaire	N or NN	This is the month you received a returned questionnaire from a respondent, or are notified that the woman will not be participating in the survey (mother or baby deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 17th May 2013, this column should read 5.
Year of receiving questionnaire	NNNN	This is the year you received a returned questionnaire from a respondent, or are notified that the woman will not be participating in the survey (mother or baby deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 17th May 2013, this column should read 2013.

Field	Format	Data codes	Comments
Outcome of sending questionnaire	N	1 = Returned useable questionnaire 2 = Returned undelivered by the mail service or patient moved house 3 = Woman or baby died 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)	Remember to fill in all the blank cells with 6s when the survey is complete.
Responses to each of the survey questions	N or NN or NNNN		Each column must be clearly headed with the questionnaire question number. Data should be coded using the numbers next to the response boxes on the printed surveys.
Patients' free text comments: 'If there anything else you would like to tell us about your maternity care, please do so here'	Text		Verbatim comments that could lead to identification of respondents must be removed, e.g. those mentioning patient or staff names.

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

Table 4 is an example of the columns of data to be included in the file. Your file should have one row for each woman included in your sample. You will notice that there are several blank cells in the response section of the file. This is because the file includes a row for every woman in the sample, but you will only have responses from about 60% of the women (that is, those who have returned a completed questionnaire, and who will therefore have an outcome code "1").

Table 4 – Example of data file to be submitted to the Co-ordination Centre

	Sample Information												Response Information								
																					١
Record number	Mother's Year of birth	Mother's Ethnic Group	Day of delivery	Month of delivery	Year of delivery	Actual Delivery Place	Place of birth: Trust site code	Referring PCT code	GMPC	Postcode Sector	Day of receiving questionnaire	Month of receiving questionnaire	Year of receiving questionnaire	Outcome	A1	A2	A3	B1	B2		68
MAT13RTE1001	1969	Α	1	2	2013	2	RNH15	5LT	A36548	AB1 1	7	5	2013	3							
MAT13RTE1002	1976	С	2	2	2013	0	RNH03	5PP	A36548	AB2 6	13	6	2013	1	1	2	1	1	3		3
MAT13RTE1003	1972	Α	2	2	2013	2	RNH15	5PP	A36548	AB3 8	3	7	2013	6							
MAT13RTE1004	1967	Α	3	2	2013	0	RNH03	5UH	B12345	BB19 8	4	6	2013	1	2	1	2	1	4		1
MAT13RTE1005	1990	Α	3	2	2013	1	RNH15	5AP	F56789	BB2 9	31	5	2013	1	1	3	1	2	1		1
MAT13RTE1006	1981	D	4	2	2013	0	RNH03	5PP	J45678	AB18 6	12	5	2013	2							
								1													
MAT13RTE1444	1978	E	27	2	2013	2	RNH15	5LT	K45678	CC4 3	9	7	2013	6							
MAT13RTE1445	1984	Α	28	2	2013	1	RNH03	5PP	B12345	AB11 7	20	5	2013	1	1	1	2	1	2		1

# Additional information required

The following information should be included when submitting the final data file to the Coordination Centre:

- Contact details (telephone numbers and e-mail addresses) of at least two members of trust staff (usually the main and secondary contacts) who will be available to answer any queries about the data
- A completed copy of the checklist (See Section 16.5 Checklist).

Please note: a copy of the questionnaire and covering letters used in the survey should be sent to the Co-ordination Centre on  $19^{th}$  July.

# Delivery

Data may be sent on encrypted CD-ROMs or by e-mail (see section 6.6 of this document for details on the recommended encryption and delivery methods to use). Hard copy documents should be posted to the address below:

Maternity Survey 2013 Surveys Co-ordination Centre Picker Institute Europe Buxton Court 3 West Way Oxford OX2 0JB

E-mail: maternity.data@pickereurope.ac.uk

# Deadline for submission

The data must be supplied by 6th September 2013.

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#### 16.5 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below, and include this checklist when you submit your data. This checklist can be downloaded from the website (www.NHSSurveys.org).

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

If incorrect data are submitted, it is possible that the data will be considered unreliable and will not be used by the Care Quality Commission in your trust's performance assessment and your trust's scores will be set to a minimum value. We cannot accept re-submissions of data after the deadline.

A printable version of the checklist can be found on our website at: http://www.nhssurveys.org/survey/1245

	Check	Done?
1)	Check that your <b>file name</b> follows the naming convention:	
	<nhstrustname>_Maternity2013.xls)</nhstrustname>	
2)	Please send us your final data worksheet only. [We do not require the frequency	
	and percentage counts provided on the other worksheets of the data entry	
	workbook.]	
3)	Check that you have included data columns for all 74 questions	
4)	If you have increased your sample size beyond the minimum requirement, only	
	send data for the women who consecutively gave birth in your trust in February	
	2013 (or January and February 2013 if you had to sample back further)	
5)		
6)	Check that you have completed the columns for the day, month and year you	
	received the questionnaire back from women	
7)	Check that womens' written comments are in an <b>anonymised</b> format	
8)	To comply with Data Protection regulations, any woman's name and address	
	details must be removed before the file is sent to the Co-ordination Centre	
9)	Please zip, encrypt and password protect your data or password protect the	
	workbook before sending to the Co-ordination Centre (please contact the Co-	
	ordination Centre if you need any help doing this). Please notify the Co-ordination	
	Centre of the <b>password</b> separately from the data file	
10	Include telephone and e-mail contact details of two people who will be	
	available to respond to any queries about the data	

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# 17 Making sense of the data

The usefulness of your survey data will depend on how well you plan the survey process and on how effectively you analyse the data. Standard data analysis usually involves examination of the <a href="frequency">frequency</a><sup>35</sup> of responses to each question and some <a href="crosstabulation">crosstabulation</a> of responses against demographic and other information.

#### 17.1 Using the data entry spreadsheet to look at your results

Once you have entered the data from the core questions into the Excel file on the website (the Data Entry Spreadsheet), the counts and percentages of responses to each of the 74 core questions are automatically calculated and displayed on the other sheets of the Excel workbook. These correspond to sections of the maternity questionnaire (excluding the "Other Comments" section). For each question, the numbers and percentages of respondents who gave each answer is shown. The number of missing responses will also be shown, as long as you have coded missing responses on the data sheet as a full stop (.).

#### 17.2 Suggested approaches to data analysis

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

#### Use the data to help pinpoint problems

It is often tempting to focus on organisational strengths, as this is important for public relations and employee morale. However, if you emphasise only the positive, you may miss a critical opportunity to use the data for improvement. Identifying specific weaknesses provides constructive targets to work towards.

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

#### "Drill down" into the data

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

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

#### Group similar questions together to provide summary analysis

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

<sup>&</sup>lt;sup>35</sup> To review definitions of terms used in this guide, please use the glossary in the appendix. Terms included in the glossary are underlined and in blue font.

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

# Use statistical tests to make comparisons and subgroup analyses

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

#### Please note:

It is essential that any patient survey is conducted in such a way that patient confidentiality is respected and given a high priority. Womens' responses must not be presented to anyone in a way that allows individuals to be identified. It would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

- 1) The raw data set should not be provided to any member of staff at the trust who does not need to view it, i.e. those who are not directly working on the project
- 2) If data are to be presented to other trust staff, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than **30 respondents** should be suppressed (replaced by a dash).

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

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

#### Make use of the open-ended comments

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

Any information that could allow respondents to be identified, such as patient and staff names should be removed.

#### Use patient feedback data with other data

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

#### Perform analysis by sub-groups

You may want to compare the answer to a survey question between two different groups to see if the differences are significantly different (e.g. the answers for different aged women). However, comparing results *within* your trust considerably reduces the number of responses in each group.

This will impact upon the level of confidence you have in the results and, therefore, your ability to accurately detect differences between these groups.

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

Table 5: Confidence intervals\*

Number of respondents	Widest Confidence Interval (+/-) <sup>36</sup>
50	13.9%
100	9.8%
200	6.9%
300	5.7%
400	4.9%
500	4.4%
600	4.0%

<sup>\*</sup>at a 95% confidence level

If you are interested in looking at different sub-groups within your trust population (for example, women who gave birth at different maternity units in your trust), you will need to think about the number of respondents you need in each group, and how this will impact on the confidence you can have in the results. The Co-ordination Centre recommends a minimum of 100 respondents per group for comparison between sub-groups. Confidence intervals for analysis with groups of fewer than 100 respondents will be so large that there would be little certainty of detecting reliable statistical differences<sup>37</sup>

#### **Example**

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

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

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

<sup>&</sup>lt;sup>36</sup> This column (the widest confidence interval) shows the **maximum** margin of error for binomial estimates of proportions

<sup>&</sup>lt;sup>37</sup> A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the trust mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made.

# 18 Reporting results

#### NOTE:

Trust-level findings for the national maternity survey 2013 should not be released outside of the trust until the national results are published by the Care Quality Commission. Please continue to use the results from your in-house survey teams or approved contractor to improve services, but wait until the survey results for all trusts are published by the Care Quality Commission before promoting your results in any way (either on your website, in press releases or any other external publicity) to the local community and media. You will receive, along with communications staff in your trust, advance notice of the publication date and will have time to prepare for your local announcements once the embargo is lifted.

# 18.1 Prioritising your findings

Patient surveys can raise many important issues. To make sure that the data is used, the results must be presented clearly and logically. To help you with this task, you may like to consider the following suggestions:

# Rank results by their magnitude

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

## Compare your results against outside norms or benchmarks

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

#### Examine performance along themes or aspects of the maternity care pathway

If women report more problems with certain aspects of their maternity care pathway, it may be appropriate to pay extra attention to these areas (e.g. antenatal checkups). Dividing your results into themes for analysis (eg: information during pregnancy, support with feeding) can also help identify organisational strengths and weaknesses.

#### Compare results within your organisation

Comparisons within organisations can facilitate the sharing of information about effective practices among units. If survey results show that a number of units at your trust have problems in a certain area, they may be able to work together on improvement efforts. Initiatives are likely to be more effective when a number of staff are working on them, and internal 'competitiveness' may also encourage improvement efforts. If analysis by subgroup is carried out (e.g. comparing results between units), the results for any group consisting of fewer than **30 respondents** should not be shown.

#### Compare results over time

Investigating trends in survey results over time is a powerful analytical tool for prioritising areas for improvement. Analysis of trends allows you to focus on addressing aspects of performance that are deteriorating, and promoting those that are showing progress. You should confirm that any apparent changes between years are statistically significant. The nature of a trend in the data (does the trend go up, or down, or is there no trend) and the extent of any trends or changes (are

they steady, sharp rises or falls, or erratic) are good starting points for making comparisons over time. It should also be possible to measure the impact of any initiatives that have been introduced.

However, the composition of both the samples and the respondents can vary significantly between surveys, even if the sampling criteria remain unchanged. Certain groups of women respond more positively than others, such as multiparous women when compared with primiparous women; if your results improve significantly from one survey to the next but the proportion of multiparous women has increased, the improvement may be due to a change in those responding. One solution to this issue is to "standardise" your data, ie to control for these variations in population so that you can be more confident that any change reported is due to changes in service quality, not just those who are responding.

If comparing two or more sets of survey results, we suggest that you compare the key demographics of the respondents early in your analysis. If there are significant differences in the proportions of respondents by maternal age, ethnic group or parity, you may need to weight, or otherwise standardise, your data. Some analysis programmes can standardise your data for you but you may need to seek the assistance of a statistical expert before you attempt to control for variations in respondent demographics.

## **Comparison with predefined goals**

Setting threshold or target goals prior to the survey will help you focus on issues where performance does not meet them. This method is particularly effective when there is clear consensus on what those targets should be, for example on questions about choice of birth place and choice of pain relief. It can also be used to evaluate internal targets or elements of care that the trust is focusing on.

#### Ease of action

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

#### Areas of excellence

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

#### Summarise your data

Translating the large quantity of data you collect into accessible information is vital for imforming staff. Too much data will be overwhelming and make it difficult to identify key issues. Summarising your data will also help management make important decisions in response to the survey.

#### Don't overlook insignificant results

If there are areas that have shown little or no change from previous years, this suggests that additional work is needed for improvements to occur. This is often true of areas where making changes poses a significant challenge, and where attention to quality improvement is particularly important.

# 18.2 Writing the report

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

#### Tailor the document to the audience

- Use brief, succinct summaries for executive audiences.
- Include anonymised quotes from the women's freetext comments to illustrate data and figures
- Produce comprehensive summaries for those who will implement improvements. They will help achieve buy-in and generate action
- A separate resource booklet or data disks/CD-ROMs with full details may be important if staff or researchers have questions.
- Don't forget to acknowledge women and thank them for their participation in the survey

#### **Use graphics**

- Data that are displayed visually can be easier to interpret.
- Display trends or comparisons using graphics such as:
  - bar charts these are easy to read and can be used for effective comparison between questions and to show year on year changes
  - o **pie charts** these are useful for describing proportions that make up the whole, for example, the proportion of women who were and were not given a choice of pain relief
  - o line charts these are effective at showing trends over time

## Some tips for using graphics:

- Remember that colours don't photocopy or fax very well. For bar charts, try using different patterns instead
- Give each graph a clear title detailing which question(s) are being reported
- Make sure the categories or values of the variable are clearly identified
- Don't include too many graphics. Select those results that can be well illustrated using graphs or charts
- Using a consistent format throughout helps understanding
- Pie charts are more informative when there are a small number of categories

#### Keep the format succinct and consistent

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

#### **Emphasise priorities clearly**

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

# 19 Using results for quality improvement

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

# 19.1 Prepare in advance

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

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

# 19.2 Dissemination of survey results

#### **Engage key stakeholders**

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

- Staff throughout the trust (including volunteers) as they will be responsible for tackling any problems identified by women
- Local commissioners who purchase your services
- Board members as they are involved in prioritising areas for improvement and shaping action plans. Senior level support is often crucial for the successful implementation of change
- Recent mothers have taken time to report their experiences so it is important they are informed
  of the results via local meetings, newsletters and articles in the local press
- Patient groups with special interest in the trust who may have a key role to play in initiating
  discussions with the board about priorities for improvement and be keen to monitor progress as
  it occurs
- Other local healthcare organisations as they may be tackling similar issues
- Your communications department, as they can help publicise the survey and its findings
- When reporting the results invite people to contribute their ideas on how services could be improved and to suggest ways in which they can become involved.

#### **Spread the Word**

Disseminating survey results is more than just producing and photocopying a report. Consider how to share the survey results in a number of situations, for example:

- Training sessions you may wish to focus on a few specific topics to concentrate on
- Staff and public meetings this can inform patients and staff, and publicising findings commits the trust to improvement initiatives
- Employee newsletters this provides the opportunity for all staff to receive feedback
- Executive communications
- Process improvement teams

- Patient care conferences
- Information available on your website

When considering the best way to share your survey results, you should bear in mind the audience you are working with. You may wish to consider the following:

- Determine whether information should be shared initially with only senior-level staff, or if (and when) it should be spread further afield
- Make presentations to your trust board and to as many groups of staff as possible, each tailored appropriately for the audience
- Organise a high profile event to publicise the results and invite staff and patients to contribute to improvement plans
- Encourage staff at all levels in the organisation to contribute their ideas for improving women's maternity experiences
- Publish the survey results on your website, including any intranet site and give readers the opportunity to feed back their ideas
- Email staff to tell them about the survey results and the action plan
- Share information with other NHS organisations in your area and other partner organisations including local authorities
- Give the results to community organisations and ask them for their views and suggestions
- Publicise results via local press, radio and community newsletters
- Publish results in your trust newsletter along with details of improvement plans

# 19.3 Identify key "change agents"

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

# 18.4 Develop an action plan

Having used your survey results to identify areas for improvement, we recommend you work with staff and patients/women to prioritise the work needed, and then identify the actions required. Initially it is a good idea to focus on one or two key areas for improvement and not to attempt to tackle all of the issues at once. Set your goals and objectives and then divide tasks into manageable steps and achievable targets. Choose areas that show clear potential for improvement. If plans are too ambitous they may fail so it is important to be realistic and choose approaches that are likely to succeed. Small successes will help keep the momentum going and encourage continuous improvement. Focusing on issues that present solutions – for example, improving information provided to women about where they can give birth to their baby – and choosing topics currently being considered by existing groups in your trust will help to gain the ownership and involvement of staff and patients and avoid duplication of effort.

Work out realistic timescales for reaching your goals as well as details of how and when progress will be measured. Identify the individuals who will be responsible for taking this work forward. This will form the basis of an action plan which can be updated on a regular basis. An action plan template is included in the Picker Institute's guide to using patient feedback (see <a href="http://www.improvement.nhs.uk/documents/CR\_resources\_by\_type/patient\_experience/Pickerl\_UsingPatientFeedback">http://www.improvement.nhs.uk/documents/CR\_resources\_by\_type/patient\_experience/Pickerl\_UsingPatientFeedback</a> 2009.pdf).

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

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- Patient Advice and Liaison Service (PALS)
- Complaints
- Service Improvement/Modernisation teams
- Patient and Public Involvement (PPI) team
- Patient Panels

Publishing regular progress reports widely throughout your trust and the local area will help to enlist ongoing support. Repeat surveys can then be used to monitor improvements.

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

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

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

**Trust type: Acute and specialist** 

Survey: Women's experiences of maternity care

Example titles: What do women think about our maternity services?

**National maternity survey** 

Understanding women's experiences of maternity services

Women's views vital to drive service improvements in maternity care

[NHS Trust name / Hospital name] are carrying out a survey to find out what women think about their maternity care. Every NHS hospital trust in England that provides maternity care is carrying out this survey as part of the national patient survey programme led by the Care Quality Commission.

# Why are we doing another patient survey?

A maternity survey was carried out as part of the national patient survey programme in 2007 and in 2010. We are carrying out another survey, using a similar questionnaire and methodology, to [track any changes in women's experiences over time so we can continue to improve services / or to evaluate the success of quality improvement initiatives implemented since the last survey] Obtaining feedback from women and taking account of their views and priorities is vital for bringing about improvements in the quality of care.

#### When is the survey taking place?

Questionnaires will be posted to women between May and August. Up to two reminders will be sent to those who have not responded between these months.

Women are being asked about various aspects of their care, including antenatal check-ups during pregnancy, care during labour and birth, communication with health professionals, involvement, care in hospital after the birth, feeding the baby, and care at home after the birth.

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

The survey will be sent to [number] women, aged 16 years and over, who gave birth during {January and} February 2013. [If a survey contractor is being used: An external survey contractor, {name}, is administering the survey so that women's responses are anonymous] [If carrying out the survey in-house: Women's responses will be treated in confidence and their name and address will never be linked to their response.]

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

Results from the 2010 maternity survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here]

# When will the results of this survey be available?

The results of this survey will be used by the Care Quality Commission as part of their regulatory activities, and by the Department of Health. In addition to providing a national overview, the Care Quality Commission will publish data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data. The results will be published in the autumn on the Care Quality Commission's website: http://www.cqc.org.uk

## Where can I find out more?

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

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

Title: [NHS Trust name] seeks women's views or

Women's views vital to drive service improvements

Your chance to tell [NHS Trust name] about the quality of maternity care

[NHS Trust name] is carrying out a survey to find out what women think about the maternity care they have received. The trust plans to use this feedback to improve women's experiences of care. The results will be used to help [NHS Trust name] highlight areas where they perform well and to identify the areas where there is most room for improvement.

Women who had a baby at [Hospital/unit A and Hospital/unit B / and at home] during {January and} February may receive a questionnaire by post in May/August, asking about their experiences. They will be asked about various aspects of their care, including checkups during pregnancy, care during labour and birth, communication with health professionals, involvement, care in hospital after the birth, infant feeding, and care at home after the birth.

[NHS Trust name] believes that taking account of women's views and priorities is vital for bringing about improvements in the quality of care. Results from the survey will be used to [insert purpose of survey here, e.g. to track women's experiences of materity care since the last survey was undertaken in [2010] / or to measure the impact of changes made to improve maternity services based on feedback from the 2010 survey / or to find out if recent changes made to the service has led to an improvement in women's experiences]

Every NHS hospital trust in England that provides maternity services is carrying out this survey as part of a national programme led by the Care Quality Commission. This survey is part of the commitment, set out in the *NHS Plan*, to design a health service around the needs of patients.

Results from the previous 2010 maternity survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here]

To ensure confidentiality, the results of the survey will be presented in a form that does not allow any individual's answers to be identified. The results will be published in the autumn on the Care Quality Commission's website: http://www.cqc.org.uk

[A senior executive at the trust] says "We hope that women will take the time to help us with this survey. Their views are vital in helping us to find out how we are doing and how we can improve. This is an excellent way for women to help shape the services we provide in the future."

# **Appendix 3: Glossary**

#### Confidence interval

A confidence interval is an upper and lower limit within which you have a stated level of confidence that the true mean (average) lies somewhere in that range. These are commonly quoted as 95% confidence intervals, which are constructed so that you can be 95% certain that the true mean lies between these limits. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made.

#### Correlation

The extent to which two or more variables are related to one another. This is expressed as a 'correlation coefficient', which can range from 0 to 1, which indicates the strength and direction of a relationship between two variables. However, correlations do not necessarily indicate a causal relationship of two variables: we can know that they are related but one might not be causing the other.

#### Crosstabulation

Crosstabulations (also known as crosstabs) are used to present data about two variables in a table, which makes their relations more obvious. A crosstab table displays frequencies classified according to another variable (for example, overall ratings of antenatal care by age) which makes it easier to see the differences in ratings of data about antentatl care between different age groups.

#### Frequency

The number of times a particular response is given. For example, if 132 women who responded to your survey said that they had been given information about the NHS Choices webiste, and 24 respondents said that they were not given this information, the frequencies of these findings are 132 and 24, respectively. The data entry spreadsheet automatically displays the frequencies for each response option.

#### Missing responses

Information not available for a respondent – for example, when they fail to answer one of the survey questions that they should have answered. Data is not considered missing if the filter instructions on a questionnaire instruct the women not to answer certain questions.

#### **Population**

A group of people that you want to make generalizations about, e.g. all patients who have attended A&E, all women who have recently had a baby, all patients that have had an inpatient stay or outpatient appointment.

#### Regression analysis

A method of estimating the variability of a dependent variable by using information about one or more independent variables. Regression analysis aims to predict values of the dependent variable, given certain values of the independent variables. Because of its predictive power, regression analysis is more powerful than correlational analysis as we can assume a causal relationship between variables.

#### Sample

Because it is not practical to study an entire population (because the numbers would be too high), we select a group of people from the population – called a sample – that is expected to be representative of the population. The process of collecting information from a sample is referred to as sampling.

## Staged analysis

This involves analysing the data in progressive depth to identify both broad measures of overall performance and more detailed patterns in the findings.

# Statistical significance

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

# **Summary analysis**

Presenting the data from more than one question as one overall score to provide a total measure of an element of care. This involves calculating a mean response for the set of questions that you are interested in.

#### **Trend**

The movement in one direction of results to a particular question over a period of time. For example, if patients have reported progressibly higher levels of cleanliness over a number of survey years, we can say that there is a trend of improved ratings of cleanliness.