

GUIDANCE MANUAL FOR THE NHS OUTPATIENTS DEPARTMENT SURVEY 2009

THE CO-ORDINATION CENTRE FOR THE
ACUTE SURVEY PROGRAMME

Contacts

The Co-ordination Centre for the Acute Survey Programme
Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

Tel: 01865 208127
Fax: 01865 208101
E-mail: Outpatients.data@pickereurope.ac.uk
Website: www.nhssurveys.org

Key personnel

Sally Donovan (Manager)

Jason Boyd
Arwenna Davis
Elisabeth Garratt
Esther Howell
Julia Martin

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 within the national survey. 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 or materials set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability.

Updates

Before you start work on your survey, check that you have the latest version of this document, as there might be some small amendments from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will 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:

www.NHSSurveys.org

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1 Introduction: patient feedback and the NHS Plan

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 (CQC) is the new independent regulator of all health and adult social care in England and has administered the programme since April 1st 2009¹. The CQC inspects all health and adult social care services in England, whether they're provided by the NHS, local authorities, private companies or voluntary organisations. It also protects the interests of people detained under the Mental Health Act. Patients' experience of health services is at the heart of the Care Quality Commission's work: it is the aim of CQC and the Co-ordination Centre to see health services shaped by what matters most to patients and the public.

By ensuring that organisations carry out these surveys in a consistent and systematic way it is possible to build up a national picture of people's experience and, *with care*, to compare the performance of different organisations, monitor change over time, and identify variations between different patient groups. The surveys are expected to inform local improvement activity; they are seen as an important source of information for people to help them choose between providers and for informing commissioners of services. As well as supplying the Department of Health with data to assess performance against their national targets on patient experience, the survey programme provides an important source of data for the annual assessments. They have been previously used to form an 'experience of patients' indicator within the scored component of the Care Quality Commission's annual health check.

1.2 The Co-ordination Centre for patient surveys

The Co-ordination Centre for the Acute Survey Programme, of which the NHS Outpatients Department survey is part of, is based at the Picker Institute and works under contract to the Care Quality Commission to design, test, and co-ordinate the acute 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 guide staff in NHS hospital trusts through the standard methodology that is necessary for obtaining patient feedback through the national patient survey. It will help to ensure that the survey results from your trust are comparable with other trusts, and with national

¹ Before April 1st 2009, the national patient survey programme was carried out by the Healthcare Commission

benchmarks. This manual also provides suggestions for how you could use the information you gather in quality improvement programmes and for monitoring performance.

1.4 Patient feedback and the NHS Plan

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

The NHS Plan (2000) requires all NHS trusts to carry out local surveys asking patients their views on the services they have received. It is intended that measuring patients' experiences in a structured way will act as an incentive to make patient experience a real and central priority for the NHS. The national patient survey programme is an important mechanism for making the NHS more patient-focused and provides a quantifiable way of achieving this. Patient surveys can help deliver the NHS Plan commitments 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 Outpatients Department surveys will be used by the Care Quality Commission in its assessment of acute and specialist trusts in England, covering the period 2009/10. More information on how the data will be used will be provided by the Commission in due course.

1.6 Measuring performance over time

In addition to performance assessment, the Care Quality Commission will publish benchmarking data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data. Asking each hospital trust to carry out an Outpatients Department survey in a consistent way builds a detailed picture of patients' experiences in NHS hospital trusts. Information collected nationally in a consistent way is also essential to support public and parliamentary accountability. The Department of Health uses survey data to monitor improvements against the "self reported experience of patients/users" national indicator that makes up in measuring progress against the national target for the public service agreement (PSA)¹.

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 http://www.hm-treasury.gov.uk/media/3/A/pbr_csr07_psa19.pdf

1.7 Basic requirements for Outpatients Department 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. Those standards are set out in detail later in this document. In summary, they are as follows:

- You must contact the Co-ordination centre by **9th June 2009** and tell them who is carrying out your survey (ie whether it will be carried out by an approved contractor or in-house) by e-mail: **outpatients.data@pickereurope.ac.uk**
- The survey must be carried out using a postal questionnaire
- The samples of patients must consist of the most recent consecutive discharges up to the last day of either **March 2009** or **April 2009** or **May 2009** as outlined in *Section 10 – Compiling a list of patients*
- 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 patients*
- 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 **15th June and 10th July 2009** 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% (that is, you should get 500 returned questionnaires from the 850 mailed out). Three mailings will be necessary for most trusts 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. Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **2nd July 2009**. A spreadsheet has been created for this purpose. For further details see *Section 12 – Weekly monitoring*
- The questionnaire must include the 58 core questions. See *Section 14 - The core questions and question bank*
- The standard covering letters and reminder letters (which can be found under the outpatients section of the NHSSurveys website) must be used as outlined in *Section 15 – Materials*
- Two reminders must be sent to non-responders, even if a 60% response rate is already achieved. These procedures are outlined in *Section 16.6 – Sending out reminders*
- 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 17.3 – Checking for data errors*
- The data from the core questions, and the required information about the patient sample, must be submitted to the Co-ordination Centre in the form outlined in *Section 17.4 – Submitting data to the Co-ordination Centre* by **23rd October 2009**
- Two paper copies each of the questionnaire you used and the covering letters for each mailing must be submitted to the Co-ordination Centre by **23rd October 2009**
- 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 **31st January 2010** 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.

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 13 and 18 to 20 of this guide. Sections 15, 16 and 17 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. Section 14 contains details of the questions in the core and bank questionnaires. You can also use this guide to help you conduct the survey again locally after the national Outpatients Department survey 2009.

2 Setting up a project team

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

We suggest:

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

3 Important points to note

The **2009 core outpatients questionnaire** has been kept as similar as possible to the 2004 outpatients questionnaire to allow comparisons to be made between survey years. There are now **58** core questions, a net loss of 2 questions since the 2004 survey. When published, the development report will contain complete documentation about all changes made to the questionnaire and can be found on our website at www.NHSSurveys.org. The changes made to the core questionnaire are listed below:

Three new questions have been added to the core questionnaire:

- Q51. “Do you have any of the following long-standing conditions?”
- Q52. “Does this condition(s) cause you difficulty with any of the following?”
- Q53-Q57 Your own health state today

Five questions were removed from the core questionnaire:

- “Was it easy to get through the main entrance and move around in the Outpatients Department?”
- “How old were you when you left full-time education?”
- “Overall, how would you rate your health during the **past 4 weeks**?”
- “Do you have a long-standing physical or mental health problem or disability?”
- “Does this problem or disability affect your day-to-day activities?”

The 2009 **question bank** has been expanded and now includes 85 optional questions, a net gain of 44 questions.

New sample data requested: To allow more accurate interpretation of the data, we request that trusts submit two additional fields containing data on;

- main specialty code of the consultant with prime responsibility for the patient. This should be in the form NNN as outlined in the Updated National Specialty List which was implemented on 1 April 2004. See http://www.datadictionary.nhs.uk/web_site_content/supporting_information/main_specialty_and_treatment_function_codes.asp?shownav=1
- type of attendance (i.e. whether it was a first or follow-up appointment). This field has two codes; “1” for those attending their first appointment and “2” for those attending a subsequent appointment.

These fields should be left empty (a blank or full-stop) if this information is not available. Further information can be found in *Section 10.6 – Create the sample file*.

Weekly submissions: Weekly submissions of response rates (outcomes) and helpline monitoring information will be requested for each trust taking part in the Outpatients Department survey 2009 and we ask for the first submission on **2nd July 2009**. We will be using this data to generate weekly adjusted response rate data for the Care Quality Commission by trust name. This is discussed further in *Section 12*.

Isolating postal details from sample information: In the interests of data security, we suggest that the names, addresses and postcodes of each patient are removed from the rest of the sample information as soon as the sample is finalised. Prior to this, it is essential to provide each patient with a unique patient reference number (PRN) and to ensure this number is correctly applied to the two datasets. The “Outpatients2009_mailing data” file should be used to send out the questionnaires and reminders, and returning questionnaires should be logged in the “sample data” file. Before the reminders are mailed, the outcomes from the “sample data” file should be used to check hospital records for any deceased patients and to finalise the non-responders to be mailed to. Further information can be found in *Section 6.2 - Keeping patient mailing data and sample data separate* and *Section 10.9 – Separating mailing details from sample information*.

Approved contractors: The contact details of many approved contractors have been updated and can be found in *Section 5 - Commissioning a survey from an approved contractor*.

Data protection guidance: There has been some revision of the guidelines on data protection since the last Outpatients survey, specifically those relating to sending patient details to contractors. This should further clarify the security settings that are required, these are discussed in further detail in *Section 6.3 – Patients’ names and addresses*.

Page limit: A limit has been set on the maximum number of pages that can comprise the questionnaire booklet. This limit is set to 16 sides of A4 ie pages 1-16. Previous research carried out by the Picker Institute has shown that a patient questionnaire with more than 16 pages can result in a dramatic decrease in response rate.

Patient record number: The patient 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 patients’ names from their reporting of hospital 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 16.4 – Sending out questionnaires*.

Current inpatients: Trusts are instructed to exclude current inpatients from the sample when generated. This should be the only time current inpatients are excluded from the survey process. When checks for deceased patients are carried out immediately prior to each mailing, do not check for, or exclude, current inpatients at these times.

Ethnic category: Ethnic category as defined by the NHS Dictionary maintained by Connecting for Health should now be used instead of ethnic group. Ethnic category is a 17 item alphabetical code that will replace the 6 item code previously used in patient surveys. The code “Z” (“not stated”) should be used 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 patient had not been asked or the patient was not in a condition to be asked. 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*.

Demographics Batch Service (DBS): The NHS National Statistic Tracing Service has been replaced by the Demographics Batch Trace. The DBS traces records against the Spine Personal Demographics Service (PDS). Patient lists will need to be checked for deaths using this new service. The DBS uses a file transfer application to send and receive files and will not accept files sent by encrypted email or through the post on physical media. You will need to ensure you are familiar with the new method for submitting patient lists to be checked.

Embargo on results: Trust-level findings for the national Outpatients Department survey 2009 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.

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 submissions of response rates and helpline monitoring will be required for each trust taking part in the Outpatients Department survey 2009, 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 850 patients and the second and third mailings will be sent only to non-responders. (See *Section 15 – 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 *Section 16.1 – Setting up a FREEPOST address*).

Freephone service

This service gives patients 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 Section 16.2 – *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 questionnaires.

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 for the Care Quality Commission's annual assessment for 2009/10.

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 performance assessment 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, ie an in-house team or an approved contractor, you must inform the Co-ordination Centre by 9th June 2009.

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 re non-responses and reminders
- Support to ensure good response rates, eg FREEPHONE line
- Data entry, cleaning data and providing data to Co-ordination Centre by the deadline
- Preparing standard reports for trusts.

Twelve organisations have been approved by the Care Quality Commission to carry out surveys for the NHS patient survey programme. 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:

BMG Research

Contacts: Jenna Allen and Simon Maydew

BMG Research
Holt Court
Heneage Street West
Aston Science Park
Birmingham
B7 4AX

Tel: 0121 333 6006
Fax: 0121 333 6800
E-mail: jenna.allen@bmgresearch.co.uk
Simon.maydew@bmgresearch.co.uk
Website: www.bmgresearch.co.uk

CAPITA Health Service Partners

Contact: Cheryl Kershaw and Aimi Blueman

CAPITA Health Service Partners
30 Victoria Ave
Harrogate
North Yorkshire
HG1 5PR

Tel: 01423 720212
Fax: 01473 720222
E-mail: Cheryl.kershaw@capita.co.uk; Aimi.blueman@capita.co.uk
Website: www.capitahsp.co.uk

GFK NOP

Contact: Sarah McHugh, Joy Mhonda and Lisa Endersbee

GFK NOP
Ludgate House
245 Blackfriars Road
London
SE1 9UL

Tel: 0207 890 9000 (Switchboard)
Fax: 0207 890 9744
E-mail: sarah.mchugh@gfk.com, joy.mhonda@gfk.com, lisa.endersbee@gfk.com
Website: www.gfknop.co.uk

Ipsos MORI

Contact: Kate Duxbury

Ipsos MORI
79-81 Borough Road
London
SE1 1FY

Tel: 0207 347 3000
Fax: 0207 347 3800
E-mail: kate.duxbury@ipsos-mori.com
Website: www.ipsos-mori.com

Marketing Sciences

Contact: Eileen Sutherland and Joy Owen

Marketing Sciences
8 St Clement Street
Winchester
Hampshire
SO23 9DR

Tel (direct): Eileen: 01962 835414
Joy: 01962 835419
Fax: 01962 840486
E-mail: esutherland@marketing-sciences.com; jowen@marketing-sciences.com
Website: www.marketing-sciences.com

MSB Ltd

Contact: Don Porter

MSB Ltd
Winslow House
Ashurst Park
Church Lane
Sunninghill
Ascot
Berkshire
SL5 7ED

Tel: 01344 876 300
Fax: 01344 873 677
E-mail: Don@msbconsultancy.com
Website: www.msbconsultancy.com

The National Centre for Social Research

Contacts: Marian Bolden

National Centre for Social Research
Kings House
101-135 Kings Road
Brentwood
Essex
CM14 4LX

Tel: 01277 690101
Fax: 01277 226844
E-mail: M.Bolden@natcen.ac.uk
Website: www.natcen.ac.uk

Patient Dynamics

Contacts: Fiona Ware and Andrew Smith

PatientDynamics™
Riverside House
5 Nutfield Lane
High Wycombe
Buckinghamshire
HP11 2ND

Tel: 01494 536346
Fax: 01494 536146
E-mail: fiona.ware@patientdynamics.org.uk; andrew@patientdynamics.org.uk
Website: www.patientdynamics.org.uk

Patient Perspective

Contacts: Stephen Bruster, 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

Picker Institute Europe

Contacts: Dianna McDonald and Tim Markham

Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

Tel: 01865 208100
Fax: 01865 208101
E-mail: surveys@pickereurope.ac.uk
Website: www.pickereurope.org

Quality Health

Contacts: Dr Reg Race, Kerry Hibberd and Mandy Moore

Quality Health
Sutton Manor
Palterton Lane
Sutton Scarsdale
Chesterfield
S44 5UT

Tel: 01246 856263
Fax: 01246 855644
Email: reg.race@quality-health.co.uk; kerry.hibberd@quality-health.co.uk;
mandy.moore@quality-health.co.uk
Website: www.quality-health.co.uk

SNAP surveys

Contact: Tamara Gooderham, Emma Williams and Ralph Sutcliffe

SNAP Surveys
Mead Court
Cooper Road
Thornbury
Bristol
BS35 3UW

Tel: 01454 280860
Fax: 01454 281216
Email: tgooderham@snapsurveys.com; rsutcliffe@snapsurveys.com;
ewilliams@snapsurveys.com
Website: www.snapsurveys.com

5.2 Contracts with survey contractors

The Care Quality Commission has developed a document that we shall refer to as the 'service contract'. Further details are available in *Section 6 – Data protection and confidentiality*.

These can be found on the NHSSurveys website in both Word document and template formats. The two documents that are available are:

- A briefing note about the service contract
- The model service contract between the trust and the approved contractor, as organisations

The model 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. 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 (ie 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. You will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles¹. It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors (see *Section 5.2*). Your trust's Caldicott guardian and legal advisors should advise you on these matters.

Guidelines on the use and security of the data collected have been agreed by the Care Quality Commission and the co-ordination centres for the national NHS staff and patient survey programmes. These guidelines will help to ensure that data are handled in a manner most in keeping with the spirit of the Data Protection Act 1998 and the Market Research Society's *Guidelines for social research* (2005). They have implications for approved contractors and for NHS trusts conducting surveys in-house.

Their website below has further information:

<http://www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/PatientConfidentialityAndCaldicottGuardians/fs/en>

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

Further guidance can be found in the Market Research Society document at http://www.mrs.org.uk/standards/downloads/revise/legal/data_protection_social.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 (see Appendix 1), signed by the Caldicott Guardian and survey lead(s) for the trust, to the Co-ordination Centre. This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines (see *Section 6.8*). Templates for

¹ 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

You should take particular care to ensure that your use of patient data in carrying out the survey, complies with these 6 principles. In particular, you should be aware of the flows of patient data, and the issues which these present.

The Caldicott guidance and principles were incorporated into the NHS code of practice on confidentiality.

these declarations are available on the website containing the survey guidance (www.NHSSurveys.org). You must wait for confirmation of receipt from the Co-ordination 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.

6.2 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 patient responses cannot be matched to patients who made them. For this reason, we suggest that once the sample has been returned from the Demographic Batch Service (DBS) and the 850 patients are finalised, patient names, addresses and postcodes are removed from the sample file to an "Outpatients2009_mailing data" file. Before this is done, it is essential each patient is provided with a unique number (a patient reference number) and that this number is available and correctly matched on both the "Outpatients2009_mailing data" file and the sample information file.

6.3 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 16*.
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 a model service contract for trusts and approved contractors carrying out the survey to avoid the need for each trust to develop its own arrangements. It is strongly recommended the model service contract is reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required.

A model service contract and supporting guidance notes are available on our website (www.NHSSurveys.org).

6.4 Model service contract

A model service contract has been drafted by the Care Quality Commission (see section 5.2). 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 model contract 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 patients' information. The service contract describes how patients' personal data will be sent to the approved contractor, and how the data can be used.

The service contract is available under the outpatients section of the website containing the survey guidance (www.NHSSurveys.org).

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, and the NHS confidentiality code of practice 2003¹ (which incorporates the Caldicott principles).
- 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 service²: 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.

¹ http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=9722&Rendition=Web

² Contact the Care Quality Commission for more detail on approved couriers: patient.survey@cqc.org.uk

- 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 Health¹.

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)².

6.7 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. Patients' names and addresses will be seen by trust staff when generating the sample, while contractor staff will usually possess both patient details and patient responses. As long as the response data supplied to trusts do not include patient 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 patients' responses are anonymous.

¹ http://www.connectingforhealth.nhs.uk/igsecurity/gpg/gpg/NPFIT-FNT-TO-IG-GPG-0004.01%20GPG_%20%20NHS%20Cryptographic%20Algorithms.pdf – this document is only accessible from NHSnet.

² <http://www.winzip.com/>

6.8 Patient confidentiality

It is essential that any patient survey is conducted in such a way that patient confidentiality is respected and given a high priority. The covering letters that accompany the mailed questionnaires inform patients that their name and address will never be linked to their responses. Furthermore, patients' responses must not be presented to anyone in a way that allows individuals to be identified. For example, if a patient is known to have stayed on a particular ward, and his or her year of birth, sex and ethnic category are known from their survey responses, it might be possible to use this information to identify them. It would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

Trust level

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

	Q26. Were you given enough privacy when discussing your condition or treatment?			
Ethnic category	Yes, definitely	Yes, to some extent	No	Total responses
	%	%	%	n
White	71	10	19	261
Mixed	-	-	-	8
Asian	-	-	-	18
Black	69	13	18	52
Chinese or other	81	15	4	36

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

The electronic file containing the patients' names and addresses should be stored securely (ie encrypted) and destroyed when the last mailing process is complete.

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 two variables pertaining to ethnicity (eg both sample and response variables)

- b. The contractor must band year of birth into four age groups (16-35, 36-50, 51-65, 66+). This process should be repeated separately for both sample and response variables. The original year of birth variables (eg those specifying an exact year rather than age group) must then be deleted
- c. Additional information specific to a survey that can be used to identify individual patients must also be removed. For example, date of attendance must be removed.
- d. Verbatim comments that could lead to any staff identifying respondents must be removed, eg those mentioning patient, staff, ward, or unit names¹
- e. Receive confirmation from the trust that they have destroyed the names and addresses of the sampled patients, otherwise they will be able to identify individual patients 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 patients' 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 17. The response data will not contain names or addresses when passed to the Co-ordination Centre and Care Quality Commission, and published and archived results will not identify patients.

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

	Q26. Were you given enough privacy when discussing your condition or treatment?			
Ethnic category	Yes, definitely	Yes, to some extent	No	Total responses
	%	%	%	n
White	71	10	19	261
Mixed	-	-	-	8
Asian	-	-	-	18
Black	69	13	18	52
Chinese or other	81	15	4	36

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

¹ 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.

The electronic file containing the patients' names and addresses should be stored securely (ie password protected). Access to the file should be given only to those individuals who have signed the service contract.

6.9 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.

6.10 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of patients' names, and the questionnaires kept until **31st January 2010**. All mailing lists of patients' names and addresses should be stored on a separate computer to that containing survey data. Mailing lists of patients' names and addresses should be destroyed when the mailing process is complete.

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 Outpatients Department survey

Multi-Centre Research Ethics Committee (MREC) approval has been obtained for the NHS Outpatients Department survey and a substantial amendment submitted for changes regarding the core questionnaire, the question bank, and the covering and reminder letters, all of which can be downloaded from the NHSSurveys 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 MREC 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.

Trusts should notify the relevant R&D office that ethical approval has been obtained for the 2009 Outpatients Department survey. The MREC amendment letter can be downloaded from the NHSSurveys website.

Further information on the ethical approval process can be found at [National Research Ethics Service](http://www.nres.npsa.nhs.uk) (www.nres.npsa.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 Healthcare Commission (as predecessor 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 multi-centre 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 columns 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.	<i>The survey is carried out on the experiences of patients after they have received the care so this does not apply.</i>
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.	<i>All Chief Executives are informed of the proposals of the survey. Trusts should notify their Research and Development Managers of the survey.</i>
Ensure patients or users and carers are provided with information on research that may affect their care.	<i>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.</i>
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	<i>This requirement is not specific to this survey.</i>
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.	<i>The Care Quality Commission as sponsors of the study have sought ethics approval from MREC. There is a designated lead for each survey who is appointed by the Chief Executive.</i>
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.	<i>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.</i>
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.	<i>Detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.</i>
Maintain the necessary links with clinical governance and/or best value processes.	<i>The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.</i>

Research Governance Framework	Care Quality Commission sponsored patient surveys
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities. ¹	<i>In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an appropriate contract with the trust. These procedures are specifically detailed in the guidance notes.</i>
Put and keep in place systems to identify and learn from errors and failures.	<i>The Care Quality Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Care Quality Commission. The survey programme is constantly evaluated and reviewed in light of these.</i>
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.	<i>This requirement is not specific to this survey.</i>
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	<i>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.</i>
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.	<i>Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.</i>
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	<i>The results of the surveys are used for monitoring of trusts performance by the Care Quality Commission.</i>

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

8 Collecting data from non-English-speaking populations

The patients who respond to your survey should be representative of all of the patients who use the trust, so it is important that groups with limited understanding of English are not excluded. The core questionnaire and the question bank have been written in as **plain language** as possible to facilitate optimum understanding by all respondents. The questions have also been tested with patients from a range of ethnic categories.

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

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

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of which offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the patient and the interpreter (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 patient to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from non-English-speakers, although it is not ideal, as there is no control over the way in which a patient's family or friends translate questions or interpret their responses, and it does not allow the patient to answer the questions themselves.

9 Timetable

The survey fieldwork period for 2009 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 respond¹. Dissemination of the results to all staff, and to the local community and media, will take considerably longer. 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. If you are using an approved contractor for the survey, they will provide you with a timetable that might differ slightly to the suggested time periods below. As long as the specified three mailings take place and data is submitted to the Co-ordination Centre on or before 23rd October 2009, the timetable provided by the contractor should take precedence over the suggested intervals below.

Week	Task	See Section
1	Inform Co-ordination Centre who is carrying out your survey by 9th June 2009 (in-house or using an approved contractor)	4 & 5
1	Decide on questions to be included in the survey (ie select from question bank or use the core questionnaire)	14
1	Draw sample of patients to be included in the survey	10
1	Check sample for deceased patients using hospital records	10.3
1	Submit sample list to the Demographic Batch Service (DBS) to check for deceased patients	10.4
1 - 4	Submit anonymised sample to Co-ordination Centre before starting mailing process	11
1	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 & 15.2
1	Print questionnaires and covering letters.	15
2	Set up FREEPOST address and helpline	16.1 & 16.2
2	Establish system for responding to telephone enquiries	16.2
2	Establish system for booking in questionnaires	16.5
3	Send first weekly response rate and helpline monitoring form to Co-ordination Centre on 2 nd July 2009	12
3	Check your own trust's records again for any patient deaths	10.3
3-8	Stick labels on pre-packed numbered questionnaires and reminders supplied by approved contractor (if NOT using a service contract)	16.4
3-6	Send out first questionnaires	16.4
3-14	Continue to respond to telephone enquiries	16.2
3-14	Log and process returned questionnaires	16.5

¹ 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

3-14	Enter data	17
6-9	Check your own trust's records again for any patient deaths	10.3
6-9	Send out first reminders to non-responders	16.6
7-10	Be prepared for a small peak in telephone calls as first reminders received	16.2
9-12	Check your own trust's records for any patient deaths	10.3
9-12	Send out second reminders to non-responders	16.6
18	Complete data entry	17
18	Check data for errors	17.3
18	Send data to Co-ordination Centre (by 23 rd October 2009 at the latest)	17.4
19	Send two copies of the questionnaire used, all covering letters and a copy of the checklist to the Co-ordination Centre (by 23 rd October 2009 at the latest)	17.4
19	Begin analysing trust's results and writing report	18 & 19
20+	Disseminate results to staff, patients and the public	19 & 20
	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 31 st January 2010	6.10

10 Compiling a list of patients

This section explains how to draw a sample of patients. This task will need to be carried out by a member of staff at the NHS Trust. In hospital trusts, the sample will normally be drawn from the Patient Administration System (PAS). Prior to sending out questionnaires, the list will also have to be checked by the Demographics Batch Service¹ (DBS) to identify deceased patients.

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 patient list.

10.1 Compile a full list of patient attendances in one month

- 1) Select the month of Outpatients Department attendances that your survey will cover. This should be **either** March 2009 **or** April 2009 **or** May 2009².
- 2) Compile a list of all outpatient **attendances** at all outpatients departments **at all sites** in your trust during one month.
- 3) This is a list of attendances/visits, rather than a list of patients, so some patients will appear in the list more than once, but that does not matter at this stage.

The information you obtain about each patient will be used both for administering the survey and for sending to the Demographics Batch Service to check for deceased patients. It saves time and effort if all the information is gathered at the same time.

The list should **include**:

- **ALL** eligible adult patients (aged 16 and over), who have attended an Outpatients Department(s) within the trust for the chosen 'sampling month' (i.e. March or April or May 2009). Note, this should include patients attending any outpatient clinic within the Trust, wherever it is held. This would include any outpatient clinics run with the Emergency Department (A&E/Casualty), such as fracture clinics.

¹ The Demographics Batch Service (DBS) is the replacement service for the NHS Strategic Tracing Service (NSTS) batch trace.

² The choice of sample month differs from the last Outpatients survey so you will not be able to sample the same month as previous surveys, however trusts should select the month most reflective of their normal performance.

The list should **exclude**:

- **Deceased** patients
- Children or young persons aged **under 16 years** at time of their visit
- **Day case** or **day surgery** patients
- Attendances concerning **termination of pregnancy**
- Attendances by **private patients** (non-NHS)
- Any patients who are known to be **current inpatients**¹
- Attendances at **maternity** outpatients clinics (but do not exclude all gynaecology outpatients)
- Attendances at **Genito-Urinary Medicine (GUM)** or Sexually Transmitted Diseases (STD) clinics
- Attendances at **psychiatric** outpatients clinics
- Any appointments that the patient **did not attend**
- Patients **without a UK postal address** (but do not exclude if addresses are incomplete but useable, eg: no postcode).

Data fields to include in the list of attendances

You will need to keep the list in an electronic file in a programme such as Microsoft Excel or Access. The list should contain the following information:

- Patient Record Number
- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields
- Postcode
- Year of birth
- Gender
- Ethnic category
- Date of attendance at the Outpatients Department
- Main specialty code
- PCT of residence – should be coded using the **first three** characters of the PCT character codes (maintained by the Organisation Data Service)
- Attendance type – whether patient was attending first or subsequent appointment

¹ **Current inpatients:** Trusts are instructed to exclude current inpatients from the sample when generated. This should be the only time current inpatients are excluded from the survey process. When checks for deceased patients are carried out immediately prior to each mailing, do not check for, or exclude, current inpatients at these times. This improves the comparability of samples between trusts and thus reduces bias.

- Survey unit – e.g. hospital site **[optional]**
- Any other details required by the Demographics Batch Service (DBS). For batch tracing, DBS needs one of these trace datasets: NHS number plus **full** date of birth *or* surname, given name, gender and full date of birth.

10.2 Taking a sample of patients to send to the tracing service

It is likely that your full list will include thousands of attendances, but you will need to send questionnaires to only **850** patients.

Important note

You are aiming for **a response rate of at least 60%**, which means that you should have about 500 completed questionnaires if you send questionnaires to 850 patients. You will be able to maximise your response rate by following this guidance carefully, and you will need to send out two reminders. It is **not** acceptable to try to boost the number of responses you receive by including more patients when compiling the sample of 850 for the survey as this would bias the survey. The Co-ordination Centre will only be able to accept responses from the patients in your list of 850 that have been correctly sampled and mailed. (See section 10.12 for the accepted options for increasing your sample size)

The first step is to take a sample of patients to send to the Demographics Batch Service (DBS). It is likely that some of your patients will have died, so it is advisable to select an initial sample of at least 900 patients, which will later be reduced to 850. The procedure for doing this is as follows:

1. Put the list of **all** eligible attendances in your chosen month (i.e. March, April OR May 2009) into an electronic file in a programme that allows sorting by columns (for example, Microsoft Excel or Access).
2. Sort the list by patients' **year of birth** first, and then by **surname**, as shown in figure 1¹ (N.B. Ensure that you select all columns before sorting in Excel, otherwise the patient details will get mixed up). **Sorting should ensure that all attendances by the same patients come next to each other in the list and that patients are in order of oldest to youngest.**

¹ If you carry out two separate sorts opposed to one simultaneous sort (as depicted in figure 1), you will need to sort by surname first and then sort by year of birth in order for all attendances by the same patients to come next to each other *and* for patients to be in the order of oldest to youngest.



Figure 1 Example of a simultaneous sort in Excel by Year of Birth and then by Surname

3. Count the total number of attendances in the chosen month.
4. Calculate the sampling interval you will need to extract 900 patients from the total number of attendances, in order to select your pre-tracing sample of 900 patients. (See example below.)

Example

Number of Outpatients Department attendances at your trust in one month = 26,500

Sampling interval (i) = $26,500 \div 900 = 29.4$

5. Round **DOWN** your interval to the nearest whole number to give you a value which we will call i (in this example, i would be **29**.)
6. Create a new data column in your patient file (call this column '**interval**'). Fill this column with a repeating series of numbers, starting with 1 in the first row and then numbering each record consecutively through to **29**, then starting again at 1 through to 29, and so on until you get to the bottom of the list. (Remember to use your own value of i .)
7. Choose a random number, between 1 and the value of i (29). Let's assume the random number is **14** in this example.
8. The sample will be all those records with a value of **14** in the 'interval' column (remember to use your own random number). Delete all records with values that are **not equal** to **14**.

If you are using Excel, it might be easiest to sort the data by the new column 'interval' and then delete all the rows that **do not** have **14** in the interval column. (N.B. Ensure that you select all the columns before sorting in Excel, otherwise the patient details will get mixed up).

9. This will give you a list of patients consisting of every i^{th} record from the original list.¹ This should be **at least** 900 records. Save this sample into a new file (keeping the initial sample list in another file, in case you need to return to it later).

Note: You may have more than 900 records left after following this sampling procedure. This does not matter at this stage; please send all remaining records to DBS. After your file is returned from DBS, you will need to follow the instructions in section 10.5 to delete a **random selection** of records from the file to reduce it to 850 records.

10.3 Checks carried out by the trust

Once you have compiled your list of approximately 900 patients, you should carry out the following checks before you send the list to DBS to carry out a further check for deceased patients.

- **Duplications.** You should check your list to make sure patients' names do not appear more than once, and you should remove any duplicated names.²
- **Current inpatients.** Check that none of the patients are known to be current inpatients in your trust (or elsewhere, if possible)
- **Patient ages.** Check that all patients are aged 16 or over at the time of their attendance at the Outpatients Department
- **Postal addresses.** Exclude any 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 patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a patient if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias
- **Deceased patients.** Check hospital records do not have a record of a patient's death from a subsequent attendance or visit to hospital

¹ An advantage of using this sampling approach is that the age distributions of selected patients are representative of patients seen over the sampling period.

² This sampling procedure minimises the chances that patients will be duplicated in your final list. That is, in the above example, a patient could only be selected twice if they had 29 or more attendances to the Outpatients Department in 1 month. However, if your trust has particularly small numbers of attendances, you are more likely to have some duplicated patients.

Checks for deceased patients

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

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

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

You are also advised to check your hospital records for any further deaths prior to posting the second and third mailings, and to ensure that approved contractors are advised immediately if any patients in the sample die during the survey period.

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

Before sending out the questionnaires, the list of patients should be checked for any deaths by the Demographics Batch Service (DBS).

The DBS has replaced the NHS Strategic Tracing Service (NSTS) batch trace. 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).¹

Create a trace request file

Using your list of patients, you need to create a correctly-formatted batch trace request file to send to DBS. This file should be in the same format as that previously used by NSTS (this will include a header row, body and trailer row).

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

- NHS number and full date of birth (yyyymmdd) *OR*
- Surname, first name, gender and date of birth

Residential postcode is not essential but can be included but note that there must only be a single space in the middle of postcode. 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.

¹ 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

While the format of the request file is broadly consistent with that used by NSTS, the way in which the file is submitted to DBS differs. 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 if you do not know how to access and use the application. If your IT department cannot help, contact the DBS implementation team at: cfh.dbs-implementation@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.

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 www.cfh.nhs.uk/demographics/dbs.

Note

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

10.5 When the patient file is returned from DBS

The trace response file returned from DBS can be used to identify any patients that have died (indicated by a letter 'D') and therefore need to be deleted from the sample file. This will reduce the numbers in your sample list slightly.

You should not exclude patients just because it was not possible for DBS to match them on their records. If you did this, you would bias the sample.

If you have more than 850 patients remaining on your list

When your trace response file comes back from DBS, remove any patients from your sample list that have been identified as being deceased. Then if your list still has more than 850 patients you will need to delete a **random selection** of records from the file to reduce it to 850 records. To do this:

1. Calculate how many patients you need to remove by subtracting 850 from the number in your list. For example, if your list has 872 patients, you will need to remove 22 patients.
2. Calculate your sampling interval. In this example, it would be:

$$872/22 = 39.6$$

3. Note that an important difference between this random sampling and the previous procedure you used to select the original sample of 900 is that, at this stage, you are now selecting patients to exclude, rather than to include.
4. Now **ROUND UP** your sampling interval to the nearest whole number, to give you a value which we will call j. (In this example j would be 40.)
5. Create a new data column in your patient file (call this column 'interval'). Fill this column with a repeating series of numbers, starting with 1 in the first row and then numbering each record consecutively through to 40, then starting again at 1 through to 40, and so on until you get to the bottom of the list. (Remember to use your own value of j.)
6. Choose a random number, between 1 and the value of j (40). Let's assume the random number is 23 in this example.
7. The patients that will be excluded from the sample will be all those records with a value of 23 in the 'interval' column (remember to use your own random number).
8. Delete all records with values that are equal to 23. If you are using Excel, it might be easiest to sort the data by the new column 'interval' and then delete all the rows with 23 in the interval column. (N.B. Ensure that you select all the columns before sorting in Excel, otherwise the patient details will get mixed up).
9. This will give you a list of 850 patients.

Note: You may have slightly more than 850 records left after following the instructions above. If you have between 850 and 855 records, then please keep them all in the sample.

However, if you have more than 855 records remaining, please contact the Co-ordination Centre on **01865 208127** for advice on how to reduce your sample.

If you have fewer than 850 patients remaining on your list

If your patient list has fewer than 850 patients after deceased patients have been removed, you **MUST** contact the Co-ordination Centre on 01865 208127 or email outpatients.data@pickereurope.ac.uk.

10.6 Create the sample file

The list of 850 patients should be entered into the sample construction spreadsheet that can be downloaded from our site (www.nhssurveys.org/survey/397). The column headings match the validated spreadsheet produced by the Co-ordination Centre for final submission of data and so it will be advantageous for you to use this spreadsheet. Save this file as <NHStrustname>_Outpatients2009.

Table 1 – Sample construction spreadsheet of patient details

<i>Patient record number</i>	Title	Initials	Surname	Address1	Address5	Postcode	<i>Year of birth</i>	<i>Gender</i>	<i>Ethnic category</i>	<i>Day of attendance</i>	<i>Month of attendance</i>	<i>Year of attendance</i>	<i>Main specialty code</i>	<i>PCT of Residence</i>	<i>Attendance type</i>	<i>Day of questionnaire being received</i>	<i>Month of questionnaire being received</i>	<i>Year of questionnaire being received</i>	<i>Outcome</i>	Comments
1001	Mrs	AM	Abbot			AB1 1YZ	1934	2	A	5	3	2009	100	5LS	1				3	Informed that patient had died
1002	Mr	EC	Ahmed			AB2 6XZ	1970	1	J	20	3	2009	101	5LT	2	04	05	2008	1	
1849	Ms	K	Yoo			AB4 7MX	1950	2	R	17	3	2009	300	5LS	1					
1850	Ms	F	Young			AB9 5ZX	1946	2	A	14	3	2009	100	5GT	2	16	06	2008	1	

Important note about table 1

The headings of Table 1 are in three different colours:

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

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

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

The following information is compiled using hospital records:

- Patient Record Number¹
- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields
- 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.

- The **Year of Birth** should be included in the form of NNNN.
- **Gender** should be coded as 1 = male and 2 = female.
- **Ethnic Category**² coding has changed for the 2009 Outpatients Department survey. The ethnicity of a person is specified by that person, and should be coded using the 17 item alphabetical coding specified by NHS Connecting for Health³. The codes are as follows:

National Codes:

White

- A British
- B Irish
- C Any other White background

Mixed

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

Asian or Asian British

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

¹ This field will be a series of sequential numbers (for example, 1001 through to 1850). The patient record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or returned undelivered), you (or the Approved Survey Contractor) will be able to use these numbers to monitor which patients have returned their questionnaires and to identify any non-responders, who will need to be sent reminders.

² We realise that patient records might not always contain complete data on patients' 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.

³ These codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:
http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/enh/ethnic_category_code_de.asp?shownav=1

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 ¹

- **Day** of the month of attendance (1 or 2 digits; eg 7 or 26)*
- **Month** of attendance (1 or 2 digits; eg 03 or 4) *
- **Year** of attendance (4 digits; eg 2009) *
- **Main specialty code** is recorded in the form NNN as outlined in the Updated National Specialty List which was implemented on the 1 April 2004. See http://www.datadictionary.nhs.uk/web_site_content/pages/codes/main_specialty_and_treatment_function_codes.asp?shownav=1
- **PCT of Residence** should be coded using the **first three** characters of the PCT character codes (maintained by the Organisation Data Service²). They provide postcode files which link postcodes to the PCTs
- **Attendance type** should be coded as 1= first attendance, 2= follow-up attendance

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

- 1) **Patient record number.** This field will be a series of consecutive whole numbers (for example, 1001 through to 1850). This number is unique for each patient. It can be seen in the example that the numbers are in ascending order, starting at 1001 at the top of the list, through to 1850 at the bottom. The patient record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the approved contractor) will be able to use these numbers to monitor which patients have returned their questionnaires and to identify any non-responders, who will need to be sent reminders. If an approved contractor is used, you will need to agree with them on the range of serial numbers that will be used for your patients.
- 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 eg N or NN, **not** a date format eg 12/07/09.
- 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 patients opt out of the survey, etc.
1 = Returned useable questionnaire

¹ The code 'Z' should only be used if the patient was asked for their ethnic category but refused to provide it. If this code is missing for any other reason, ethnic category should be left blank in the sample information.

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

² See <http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods> for further details.

- 2 = Returned undelivered by the mail service or patient moved house
- 3 = Patient died
- 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire
- 5 = Patient was not eligible to fill in questionnaire
- 6 = questionnaire not returned (reason not known).

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.

10.7 Distribution of patient ages

You should check that patients of all ages are included in your sample, especially for those aged 16, 17 or 18 years or those over 75 years. We have found these age groups are the most likely to be excluded due to poor sampling.

Check that your sampled patients' ages cover the full range of expected ages. Ideally, you should do this by checking the distribution of ages on a histogram (See Figure 2). For most trusts the histogram should start out with few people at extreme old age before rising and flattening out for those aged around 60-80 years, before entering a slow decline to reflect as people get younger.

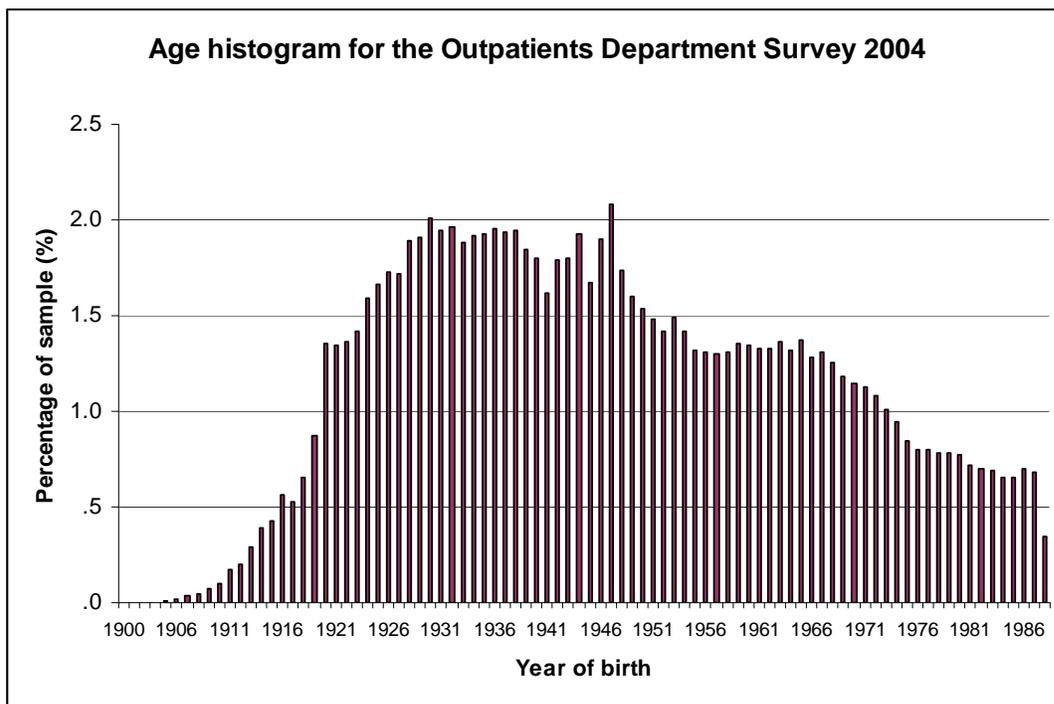


Figure 2 Example age histogram for Outpatients Department Survey

10.8 Distribution of patient gender

With the exception of hospitals specialising in one gender, your sample will probably have similar proportions of men and women. You should check each of these genders are included and that you can explain if the sample is skewed toward male or female patients.

10.9 Separating mailing details from sample information

At this point you should transfer the names, address and postcode for each patient in the sample to a new file. The patient reference number (PRN) for each patient should be copied to the new file, so that the two datasets are connected using the unique PRN. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as “Outpatients2009_mailing data”.

This file should be used for mailing purposes: it will be used to check for deceased service users prior to reminder mailings and will be cross-referenced with the sample file (<NHStrustname>_Outpatients2009) to identify service users who will need to be sent reminders.¹

As this “Outpatients2009_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 last mailing process is complete.

For patient confidentiality reasons, **it is essential that you do not keep patient name and address details in the same file as their survey response data.**

Table 2 – Example mailing file

<i>Patient record number</i>	Title	Initials	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
1001	Mrs	AM	Abbot		-				AB1 1YZ
1002	Mr	EC	Ahmed		--				AB2 6XZ
					--				
1849	Ms	K	Yoo		--				AB4 7MX
1850	Ms	F	Young		--				AB9 5ZX

¹ As shown in table 1(section 10.6), the ‘outcome’ field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which patients opt out etc...

10.10 Sharing the patient 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. names and addresses) both the sample file (“<NHStrustname>_Outpatients2009”) **and** the mailing file (“Outpatients2009_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 – Sample construction spreadsheet** but with the patient 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 patient deaths, etc.

10.11 Increasing sample size beyond minimum requirement

Your trust may wish to use the Outpatients Department survey as an opportunity to gather data in addition to that required by the Care Quality Commission. One way to do this is to increase the number of patients you sample, ensuring that you target sufficient numbers from each of the units you want to compare so that you can get enough responses to make comparisons. However, before you decide to do this, there are some important points to consider:

- The core sample for the 2009 Outpatients Department survey must be drawn as specified in this guide. It is 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
- Small, limited surveys are easier for in-house staff to handle than large surveys. You may wish to consider keeping the two things separate by doing the large patient survey on its own (either in-house or with an approved contractor) and then following it up with smaller, targeted in-house surveys.

To summarise

If you do choose to increase your sample size, it is essential that you ensure that the sample of patients you draw according to the requirements for the national survey can be easily distinguished from any additional patients you include in the sample.

You must **only** send the Co-ordination Centre data for the 850 patients sampled according to these guidelines.

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 file¹ **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 (sample construction spreadsheet) must be submitted, but name, address and postcode details must 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. Once the contractor has checked the sample they will 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. 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:

Date sample received	Date sample returned
15 th -22 nd June 2009	23 rd June 2009
23 rd -29 th June 2009	30 th June 2009
30 th -6 th July 2009	7 th July 2009
7 th -10 th July 2009	14 th July 2009

Samples should reach the Co-ordination Centre by the **10th July 2009 at the latest**. If they do 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 publication and assessments.

It is very important that the samples are mailed out as soon as possible after the sample has been approved by the Co-ordination Centre. Not only does this maximise the collection period for returning questionnaires, but it ensures that the checks made for deceased patients are as current as possible and therefore reduces the need for trusts to re-submit their sample to DBS.

¹ Created by removing the patients' names, addresses and postcodes.

12 Weekly monitoring

The Co-ordination Centre requires weekly submissions of outcome data and helpline calls for each trust taking part in the 2009 Outpatients Department survey. First submission of data must be made on Thursday 2nd July 2009¹, and every Thursday thereafter until the final date of submission. An Excel spreadsheet is available on 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 (outpatients.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:
OP09_<trust code>_<week of submission>.xls

e.g. OP09_RAC_1.xls (first submission of monitoring data on 2nd July 2009)
OP09_RY2_4.xls (fourth submission of monitoring data on 23rd July 2009)

For approved contractors:

When the data is submitted, the file name **must** be in the following format:
OP09_<contractor code>_<week of submission>.xls

e.g. OP09_ACP_1.xls (first submission of monitoring data on 2nd July 2009)
OP09_ACY_4.xls (fourth submission of monitoring data on 23rd July 2009)

The Co-ordination centre will notify each approved survey contractor of their unique 'contractor code' (which were first allocated for the maternity survey 2007).

12.1 Response rate

The information submitted should contain the following data:

- The total number of patients in your sample ie the total number of all those included in the first mailing,
- The number of patients in each outcome field (see *Section 10.6, 5*)

¹ This submission must be made regardless of whether mailing has commenced.

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.

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' (ie 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' (ie first category).

This information allows the Co-ordination Centre to identify areas of concern to patients 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:

- Patients can be expected to ask 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
- Heighten awareness of the survey and the importance the trust places on patient feedback through posters in the hospital. Also, it is sometimes a good idea to send a press release to the local media to gain publicity before the survey takes place
- Template staff briefings and information for use in press releases can be downloaded from the [NHSSurveys website](#).

14 The core questions and question bank

Each trust must include in their survey at least the 58 core questions. There is a pre-designed core questionnaire on the NHSurveys website, which includes only these questions. Trusts can also choose to use an “enhanced” questionnaire, where additional questions of local relevance may be added from a question bank of validated questions. The question bank will also be available online.

In summary, there are two options for carrying out the NHS Outpatients Department survey:

- 1) The **core outpatients questionnaire**, which comprises 58 core questions.
- 2) The **enhanced questionnaire**, which includes the 58 core questions, with additional questions added from the bank of validated questions.

14.1 The core questionnaire

The core questionnaire consists of 58 questions on 8 pages. These questions cover the issues that have been found to be most important to patients and **must** be included in your survey. The front page of the questionnaire explains the purpose of the survey and gives instructions on how to fill it in. In the pages that follow, the survey questions are divided into sections that broadly follow the patient's experience.

14.2 Using the question bank

The core questionnaire covers all the compulsory questions you need to ask to comply with the NHS national patient survey programme. However, you might want to ask more questions on some topics, and you can do this by adding from the question bank. All of the questions have been designed and tested by the Co-ordination Centre for the Acute Survey Programme and are available online, with the questions arranged in the appropriate sections.

For the question bank tool to work effectively, please use Microsoft Internet Explorer rather than other web browsers, such as Mozilla Firefox.

The core questions are clearly marked and must be included; additional questions can be selected for inclusion if your trust deems them to be particularly relevant at a local level. The question bank has been expanded since the survey was last run and so now includes many more additional questions to choose from. Please take care to maintain question order when adding from the question bank and check the question skips are appropriate for your new questionnaire. Data from these additional questions should not be submitted to the Co-ordination Centre at the end of the survey. Also take special care not to exceed 16 pages of questions as this may cause a decrease in response rate.

Please do not exceed 16 pages in your questionnaire. This could result in a significantly reduced response rate for your survey findings.

15 Materials

15.1 Printing questionnaires

Questionnaire layout

The questionnaire has been 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 in the core questionnaire, and then each of the response options presented on a separate line beneath the question, for example:

24. Did doctors and/or other staff talk in front of you as if you weren't there?

- Yes, definitely
- Yes, to some extent
- No

- 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.

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 8 sides of A4 paper.

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 patients 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 850, then you might want to print 1.7 x 850, or approximately 1,500 copies.

15.2 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. Therefore, depending on your response to the initial mailings, you will need approximately 1,200 to 1,600 sheets of trust headed notepaper. 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.

15.3 First mailing

You will need 850 of each of the following items:

- Printed questionnaires
- Large envelopes for mailing questionnaires to patient
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes
- FREEPOST envelopes for return of questionnaires
- Covering letters using the trust's letterhead
- Multi-language helpline sheet (recommended)¹.

15.4 Second mailing (first reminder)

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

- Reminder letters
- Envelopes
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes.

15.5 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 patient
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes
- FREEPOST envelopes for returning questionnaires
- Reminder letters
- Multi-language helpline sheet (if used in first mailing).

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

16 Implementing the survey - practicalities

16.1 Setting up a FREEPOST address

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

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

16.2 Setting up a FREEPHONE line

The covering letter to patients should include a telephone number for patients 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, many approved contractors offer this service.

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

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

I have had two or more outpatient appointments - which one should I refer to?

Patients should be advised to refer to their **most recent** outpatient appointment. Usually, this is the appointment covered by your sampling period but, for the few patients who have attended since you drew the sample; it is simpler to tell them to refer to their most recent visit. It will not make the results invalid if a few of the patients refer to a more recent episode than the others.

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

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

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

Relatives or carers may call to pass on this information. In some cases, they may offer to complete the questionnaire for the patient, but this is only advisable if there is a good chance that the responses are a true reflection of the patients' views.

The person to whom the questionnaire is addressed has died.

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

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

If a patient's spoken English is better than their written English, they may be willing to have someone, such as a family member, fill in a form on their behalf. It is also strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. A multi-language sheet 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

A few patients might call to say that they do not want to be involved in the survey, and fewer still may object to being sent the questionnaire in the first place. Staff should apologise to the patient and reiterate the statement in the covering letter - that taking part in the survey is voluntary, that the patient's care will not be affected in any way if they do not respond, and explain how their data is treated – thus far, as well as how it will be dealt with if they participate in the survey. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of the patient's responses. If the patient 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 patient. It is also advisable to ask the patient to ignore any future reminders that they might receive. These patients should be logged as outcome = four (opt out).

Making a record of the calls

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

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

16.3 Covering letters

The standard covering letter is available in Microsoft Word format on the outpatients 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 NHS Outpatients Department 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.

16.4 Sending out questionnaires

Mailing labels

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

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

Note on the patient record number (PRN)

The patient record number is a unique number allocated to all patients at the start of the survey that allows their responses to be kept separate from their name and address, but allows matching up of the response data with the sample data. It also allows 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 patients. The Royal National Institute of the Blind recommends the number be printed in size 14 font and located inside a box on the lower half of the front page of the questionnaire.

If patients 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 patient to the sample.

Questionnaire packs

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

- 1) A questionnaire **numbered with the patient record number**. The number must match the number on the address label, and the number on the list of patient details.
- 2) A covering letter.
- 3) 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. 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. The Royal Mail has recently published revised mailing prices; previous quotes for mailing may be out-of-date.

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 patient, 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 patient record numbers so that trust staff can match these with their patient list and put on appropriate patient address labels.

16.5 Booking in questionnaires

When questionnaires are received, match up the patient record numbers against the list of patients, so that you can record (in the *outcome* column) which patients 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 31st January 2010, 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 patient record numbers. Trusts should inform the contractor of any questionnaires that were returned to the trust undelivered, and of any patients who inform the trust that they do not wish to be included in the survey, or if any patient dies during the period of the survey. The contractor can then record these details in their own patient list, and ensure that reminders are not sent out to those patients.

16.6 Sending out reminders

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

Depending on the time that has elapsed since you first checked your patient list for deaths, it might be necessary to send your list back to the Demographic Batch 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 patient record numbers of the non-responders to the acute trust. Again, the envelopes should be clearly marked with the patient record number so that those carrying out the mailing can correctly label the address for each patient record number.

First reminders

The first reminder should be sent to patients who have not responded after **one to two weeks**. 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. We recommend approximately **ten** days between the mailing day of the first questionnaire and the mailing day of the first reminder.

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

The standard second reminder 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 deaths before sending out reminders.

17 Entering data

The data must be submitted to the Co-ordination Centre in the appropriate format by the deadline of **23rd October 2009**. 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 and abridged data set (see *Section 6* on data protection issues).

17.1 Entering and coding data from the core questionnaire

The data should be entered into the pre-designed Excel file, which can be found in the Outpatients Department 2009 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 patient's responses to the survey
- For each question, the small number next to the box ticked by the patient should be entered as the response
- If a response is missing for any reason, it should be left blank, or coded as a full stop (.)¹
- If two boxes are ticked (where only one should be ticked), 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 Q51 and Q52 that gives the instruction "Tick all that apply", each response option is treated as a separate question.

¹ 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

Q51. Do you have any of the following long-standing conditions? (Tick all that apply)

- 1 I have deafness or severe hearing impairment
- 2 I have blindness or are partially sighted
- 3 I have a long-standing physical condition
- 4 I have a learning disability
- 5 I have a mental health condition
- 6 I have a long-standing illness
- 7 I do not have a long-standing condition

Responses to each part of this question are coded: **1 if the box is ticked**
0 if the box is not ticked¹

Q51 takes up three columns in the data file, labelled as follows:

Column headings	Q51_1	Q51_2	Q51_3	Q51_4	Q51_5	Q51_6	Q51_7
Codings for this example	1	0	0	0	1	0	0

- 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.

17.2 Entering data from enhanced or customised questionnaires

If you are using an enhanced questionnaire, with questions added from the question bank, you will need to set up your own Excel file for entering all the data. Your data file will have columns corresponding to each of the questions in your questionnaire.

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

You will need to send the data from **only** the 58 compulsory core Outpatients Department survey questions to the Co-ordination Centre. To do this, you will need to transfer those columns of data that cover the responses to those 58 questions to the pre-designed Excel file available on the website. The columns of this standard Excel file are headed with the numbers corresponding to the question numbers in the core Outpatients questionnaire. They also include the wordings of the 58 core Outpatients Department questions so that you can match them up. It is essential that you

¹ **Please note:** if a respondent does not answer any part of a multiple response question, (ie does not tick any of the response options) then it should be left blank or coded as a full stop (.)

check carefully that the columns of data you select from any larger data set correspond to the 58 core Outpatients Department survey questions.

17.3 Checking the data for errors

For the 2009 Outpatients Department 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 (eg where patients answer questions that they have been directed to skip past, these responses should still be entered).
- 2) Where a respondent has ticked 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 Q51 and Q52, where respondents may tick 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 ticked a second response option, this second choice should be entered into the data.
- 4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a patient has written their date of birth in the boxes for Q50, 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 '2009' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.
- 6) Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the patient's intended response has not been captured. This includes 'out-of-range' responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Co-ordination Centre where they are found to have been entered inconsistently with the respondent's intended response.

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

17.4 Submitting data to the Co-ordination Centre

The data from the core questions of the 2009 Outpatients Department survey must be supplied to the Co-ordination Centre as one anonymised Excel file that includes information about the patient sample and responses. To comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre.

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 <NHTrustName>_Outpatient2009.xls
- Use one row of data for each patient in the sample
- Use one column of data for each item of patient information or response
- Patients who are missing their Patient Record Numbers should be added to the bottom of the list, and not matched to patients with similar demographics
- Missing data should be left blank or coded as a full stop (.).¹

Table 2 shows the information that must be provided for each of the 850 patients in the original sample.

Table 2 - Data fields to be included in file submitted to Co-ordination Centre

Field	Format	Data codes	Comments
Patient record number	N, NN, NNN or NNNN		The unique serial number allocated to each patient by the trust or approved contractor administering the survey.
Year of birth	NNNN		Format this simply as a number, not in date format.
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.)
Ethnic category	N	National Codes: White A British B Irish C Any other White background Mixed D White and Black Caribbean E White and Black African F White and Asian G Any other mixed background Asian or Asian British H Indian J Pakistani K Bangladeshi L Any other Asian background	Ethnic category should be included if the information is available.

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

Field	Format	Data codes	Comments
		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 attendance	N or NN		For example, if the patient attended on 15th April 2009, this column should read '15'.
Month of attendance	N or NN		For example, if the patient was admitted on 15th April 2009, this column should read '4'.
Year of attendance	NNNN		For example, if the patient attended on 15th April 2009, this column should read '2009'.
Main Specialty code	NNN	Use the codes as outlined in the Updated National Specialty List which was implemented on the 1st April 2004	Only supply the 'Main specialty' of the consultant with prime responsibility for the patient.
PCT of Residence	NNN	Use the character codes maintained by the Organisation Data Service	Only use the FIRST three characters of the PCT of residence code
Attendance type	N (1 or 2)	This shows if the patients' recent outpatient appointment was their first or subsequent appointment	If the patient was attending their first outpatient appointment, this should be coded '1'; if they were attending their 2 nd , 3 rd etc appointment this should be coded as '2'.
Day of receiving questionnaire	N or NN	This is the day you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 15th July 2009, this column should read '15'.
Month of receiving questionnaire	N or NN	This is the month you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 15th July 2009, this column should read '7'.
Year of receiving questionnaire	NNNN	This is the year you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the	For example, if the questionnaire was received on 15th July 2009, this column should read '2009'.

Field	Format	Data codes	Comments
		survey (patient deceased, moved address, too ill, or called to opt out)	
Outcome of sending questionnaire	N	1 = Returned useable questionnaire 2 = Returned undelivered by the mail service or patient moved house 3 = Patient died 4 = Patient reported too ill to complete questionnaire, opted out or returned blank questionnaire 5 = Patient was not eligible to fill in questionnaire 6 = questionnaire not returned (reason not known)	Remember to fill in all the blank cells with 6s when the survey is complete.
Responses to each of the 58 core questions	N or NN or NNNN		Each column must be clearly headed with the core questionnaire question number. Data should be coded using the numbers next to the response boxes on the printed surveys. There is no need to send the comments to the Co-ordination Centre.

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

Table 3 (below) is an example of the columns of data to be included in the file. Your file should have 850 rows (one for each patient 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 patient in the sample, but you will only have responses from about 60% of the patients (that is, those who have returned a completed questionnaire, and who will therefore have an outcome code "1").

Table 3 – Example of data file to be submitted to Co-ordination Centre

Patient Sample Information										Patient Response Information												
Patient record number	Year of birth	Gender	Ethnic category	Day of attendance	Month of attendance	Year of attendance	Main speciality code	PCT of Residence	Attendance type	Day of receiving questionnaire	Month of receiving questionnaire	Year of receiving questionnaire	Outcome	Q1	Q2	Q3		Q52_7	Q52_8		Q58	
1001	1934	2	A	04	03	2008	110	5LS					3									
1002	1970	1	C	16	03	2008	300	5LT	1	17	06	2009	1	3	1	2		0	1		8	
1003	1965	2	A	09	03	2008	300	5T4					6									
1004	1935	2	A	12	03	2008	130	5J3	1	03	07	2009	1	2	2			0	0		1	
1005	1929	2	C	23	03	2008	110	5PP	2	29	07	2009	1	1	5						1	
1006	1923	1	J	29	03	2008	100	5PP	1	12	08	2009	2									
1849	1950	2	R	02	03	2008	110	5LS					6									
1850	1946	2	A	19	03	2008	300	5GT	2	18	07	2009	1	6	1	4		1	0		1	

Additional information required

The following information should also be included when submitting the data file to the Co-ordination 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
- **Two blank paper copies** of the questionnaires, the covering letters and the reminder letters you used
- A completed copy of the **checklist** (See Section 17.5 - Checklist).

Delivery

Data may be sent on CD or by e-mail and should be password protected, with the password provided separately either by email or telephone (see *Section 6.6* of this document for details on the recommended encryption methods to use). Hard copy documents should be posted to the address below:

Postal address:

Outpatients Department Survey 2009
Co-ordination Centre for Acute Survey Programme
Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

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

Deadline for submission

The data must be supplied by **23rd October 2009**.

17.5 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below, and include this checklist when you submit the data and paper copies of the questionnaire and covering letters.

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 their general publication of the survey results and the use of the data in assessments. 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/Filestore/documents/Checklist_for_OP09_v1.doc.

Check	Done?
1) Check that your file name follows the naming convention: <NHStrustName>_Outpatients2009.xls)	
2) Check that you have saved the data sheet only as an Excel worksheet , rather than a workbook. (The frequency and percentage counts on the other pages of the workbook on the website are intended for your use only)	
3) Check that you have included data columns for all 58 core questions	
4) Check that you have not included any columns of optional questions	
5) Check that all data are correct , and that all values are in range	
6) Send data only for the 850 patients sampled from your trust in the chosen month	
7) Check that all the data are in numeric format only (including dates)	
8) Check that you have completed the columns for the day, month and year you received the questionnaire back from patients	
9) To comply with Data Protection regulations, any patient name and address details must be removed before the file is sent to the Co-ordination Centre	
10) Notify the Co-ordination Centre of the password separately from the data file, either by email or telephone	
11) Include two paper copies of the questionnaire you used	
12) Include two paper copies of the covering letters you used for the first, the second and third mailing.	
13) Include telephone and e-mail contact details of two people who will be available to respond to any queries about the data	
14) Check that you have not included any columns of optional questions	
15) Check again that all data are correct, and that all values are in range!	

18 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 frequency of responses to each question and some cross-tabulation of responses against demographic and other information.

18.1 Using the NHSSurveys website 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 58 core questions are automatically computed and displayed on the other sheets of the Excel workbook, which correspond to sections of the Outpatients Department core 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 (.).

18.2 Suggestions on data analysis

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

Use the data to help pinpoint problems

It is often tempting to focus on organisational strengths. This may be important for public relations and employee morale. However, if you emphasise only the positive, you may miss a critical opportunity to use the data to spur improvement.

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

"Drill down" into the data

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

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

Group similar questions together to provide summary analysis

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

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

Use statistical tests to make comparisons and subgroup analyses

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

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

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

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.

19 Reporting results

19.1 Prioritising your findings

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

Rank results by their magnitude

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

Compare your results against outside norms or benchmarks

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

Compare results within your organisation

Comparisons within organisations can facilitate networking among units or departments and the sharing of information about effective practices. Internal 'competitiveness' may also fuel improvement efforts.

Compare results over time

Investigating trends in survey results over time is another powerful analytical tool for prioritising areas for improvement. Analysis of trends allows you to focus on correcting aspects of performance that are slipping, although you should confirm any apparent changes between years are statistically significant.

Comparison with predefined goals

Another way to identify priorities is to set threshold or target goals prior to the survey. You would then focus on issues where performance does not meet these goals. This method is particularly effective when there is clear consensus on what those goals should be.

Correlation with overall measures

Correlating patient responses to specific questions with responses to the question about overall quality of care can help focus attention on issues that are important for patients.

Predictive value on overall measures (regression analysis)

Similar to correlation, regression analysis also gives a sense of the issues that most sharply affect patients' overall assessments of care. Regression analysis is superior to simple correlation, in that it can adjust for other things that have an impact on the overall measure, and it provides more precise estimates of how overall measures will change in response to improvement on individual items. Regression analysis is also more complex but in essence, it allows for a more level 'playing field'. There are limits to a univariate (crude) analysis and so regression analysis is an attractive option.

Ease of action

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

Areas of excellence

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

19.2 Writing the report

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

Tailor the document to the audience

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

Use graphics

- Data that are displayed visually can be easier to interpret.
- Display trends or comparisons in bar charts, pie charts, and line charts.
- Remember that colours don't photocopy or fax very well.

Keep the format succinct and consistent

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

Emphasise priorities clearly

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

20 Using results for quality improvement

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

20.1 Prepare in advance

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

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

20.2 Dissemination of survey results

Engage key stakeholders

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

- Staff throughout the trust as they will be responsible for tackling any problems identified by patients.
- Board members as they are involved in prioritising areas for improvement and shaping action plans. Their support is often crucial for the successful implementation of change.
- Patients have taken time to report their experiences so they it is important they are informed of the results via local meetings, newsletters and articles in the local press.
- Patient groups with special interest in the trust who may have a key role to play in initiating discussions with the board about priorities for improvement and be keen to monitor progress as it occurs.
- When reporting the results it is a good idea to also invite people to contribute their ideas on how services could be improved and to suggest ways in which they can become involved if they wish to.

Spread the Word

Disseminating survey results entails far more than producing and photocopying a report. Consider how to share the survey results in training sessions, staff and public meetings, employee newsletters, executive communications, process improvement teams, patient care conferences, and other communications channels. You may wish to consider the following:

- Determine whether information should be shared initially with only senior-level people, or whether (and when) it should be spread further afield

- Make presentations to your trust board and to as many groups of staff as possible, each tailored appropriately for the audience
- Organise a high profile event to publicise the results and invite staff and patients to contribute to improvement plans
- Encourage staff at all levels in the organisation to contribute their ideas for improving patients' experience
- Publish the survey results on your website, including any intranet site and give readers the opportunity to feed back their ideas
- Email staff to tell them about the survey results and the action plan
- Share information with other NHS organisations in your area and other partner organisations including local authorities
- Give the results to community organisations and ask them for their views and suggestions
- Publicise results via local press, radio and community newsletters
- Publish results in your trust newsletter along with details of improvement plans

Promote understanding

To assist others in understanding the results, we recommend the following:

- Present results in user-friendly formats. Remember not everyone will be an expert in reading graphs and deciphering data
- Communicate information in a visual way, perhaps in the form of posters which can be displayed around your organisation.
- Focus on key messages arising from the results and emphasise both the positive and negative themes
- Illustrate themes with relevant patient comments or other forms of patient feedback to put the results in context

20.3 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.

20.4 Prioritising areas for improvement

Compare with other trusts

Compare your trust's results with the benchmarks on the Care Quality Commission website to find out where your trust performs better or worse than other trusts.

Compare Departments within your trust

If your data allow it, further analysis of your results by sites or Departments will provide a more detailed breakdown of performance. You may be able to identify examples of good practice within your trust which can be applied to other areas requiring improvement.

Identify where patients report most room for improvement

Issues can be ranked according to the size of the problem. Look at questions where more patients indicate that their care was not perfect and could be improved. Select the questions where most problems are reported and focus on the issues that are a priority for your organisation.

Focus on areas where work is already underway and solutions can be easily identified

Focusing on issues that present solutions (e.g. improving information provided to patients about medications they are given when they leave hospital) and choosing topics currently being considered by existing groups in your Trust (e.g. the Clinical Governance Group) will help to gain the ownership and involvement of staff and patients and avoid duplication of effort.

Identify problems surrounding particular aspects of the patient experience

There may be particular aspects of care or elements of the patient experience where more problems are reported than others. For example:

- The length of wait to be seen
- Being given enough information about their condition or treatment
- Receiving information on tests
- The provision of information when leaving the department

20.5 Develop an action plan

Having used your survey results to identify areas for improvement, we recommend you work with staff and patients to prioritise and then identify the actions required. Decide on achievable timescales and on the individuals who will be responsible for taking this work forward. This will form the basis of an action plan which can be updated on a regular basis.

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

- Patient Advice and Liaison Service (PALS)
- Complaints
- Service Improvement/Modernisation Teams

Initially it is a good idea to focus on one or two key areas for improvement and not to attempt to tackle all of the issues at once. Publishing regular progress reports widely throughout your trust and the local area will help to enlist ongoing support. Repeat surveys can then be used to monitor any improvements.

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

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

Appendix 1: Declarations of data protection compliance

Declaration of compliance with the Data Protection Act 1998

**DECLARATION
RELATING TO THE
2009 Outpatients Department survey
FOR TRUSTS USING IN-HOUSE SURVEY TEAMS**

While carrying out the 2009 Outpatients Department survey, all trusts need to comply with:

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

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

For further information on the new guidelines, please see the "Data protection" section in the Guidance Manual for the 2009 Outpatients Department survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection" in the Guidance Manual for the 2009 Outpatients Department survey.

Signature: Date:

I, **[insert name of first survey lead]** the first Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2009 Outpatients Department survey and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2009 Outpatients Department survey.

Signature: Date:

I, **[insert name of second survey lead]** the second Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2009 Outpatients Department survey and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2009 Outpatients Department survey.

Signature: Date:

Appendix 2: Declarations for additional data analysts

Declaration of compliance with the Data Protection Act 1998

**DECLARATION
RELATING TO THE
2009 Outpatients Department survey
Additional data analysts**

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

For further information on the new guidelines, please see the "Data protection" section in the Guidance Manual for the 2009 Outpatients Department survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection" in the Guidance Manual for the 2009 Outpatients Department survey.

Signature: Date:

I, **[first additional data analyst]** the first additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2009 Outpatients Department survey and will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2009 Outpatients Department survey.

Signature: Date:

I, **[second additional data analyst]** the second additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2009 Outpatients Department survey and will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2009 Outpatients Department survey.

Signature: Date: