To be printed on Trust headed notepaper (ideally without trust telephone number if Approved Contractor is handling the FREEPHONE calls). Text in square brackets needs to be edited.

[Date]

Dear Patient

Local Health Services Survey

We are inviting you to take part in a survey of patients who use the local health care services in your area. This is your chance to help shape and influence how health services are provided in the future.

What is the purpose of the survey?

Your views are very important in helping us to find out how well NHS services work and how they can be improved. This is part of our commitment, outlined in the NHS Plan, to design a health service around the patient.

Why have I been chosen?

Your name has been chosen at random, using a computer programme, from a list of all people registered with GP practices that are part of [Trust name] PCT. We are sending questionnaires to 1200 patients in your area.

Do I have to take part?

No. Taking part in the survey is **voluntary.** If you choose not to take part it will not affect the care you receive from the NHS in any way. If you do not want to take part in the survey, or to answer some of the questions, you do not have to give us a reason.

What would I have to do?

If you decide to take part, please complete the questionnaire and return it in the FREEPOST envelope. No stamp is needed. The questionnaire should take around 20 minutes to complete.

If you do not wish to take part, please could you return the blank questionnaire in the FREEPOST envelope. If we do not hear from you, we may send you a reminder.

Who is organising the survey?

This survey is being carried out by researchers from [NHS Trust name /name of survey company], the Healthcare Commission and the Co-ordination Centre for the Primary Care Trust Survey at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified. The Healthcare Commission will produce a public report on care at the trust, which will include the anonymous survey findings. This will be made available from the Commission’s website at [http://www.healthcarecommission.org.uk/nationalfindings/surveys/patientsurveys.cfm].

Will my taking part in this study be kept confidential?

Yes. You have been given a unique number so your name and address are not on the questionnaire, and your name and address will never be linked to your responses. Your responses will only be used to provide information about the quality of the services the trust provides and to help us to improve these services.

Your personal data are held in accordance with the Data Protection Act 1998 and the NHS Confidentiality Code of Practice. [[IF CONTRACTOR USED: [Your contact details have been passed to [survey contractor], only so that they can send you this questionnaire and process your response. [Survey contractor] will process your answers in confidence and keep them separate from your contact details.]]

The Co-ordination Centre for the Primary Care Trust Survey and the Healthcare Commission will produce anonymous statistics from the responses for each NHS Trust taking part in the survey. All name and address information relating to this survey will be destroyed within a maximum of three months of completion of the survey.

[NHS Trust name] has a leaflet for patients explaining how we use and handle your personal information, and what your rights are under the Data Protection Act 1998. If you would like further information or a copy of the leaflet, please write to us, or call [Freephone survey helpline].

Contact for further information

If you would like more information about the survey, or have questions on how to complete the questionnaire, you can call [our FREEPHONE help line /us] on [phone number] [at no cost to yourself] and we will do our best to help. The line is open between [opening time] and [closing time], [days].

Thank you

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar], [NHS Trust name]

Text in square brackets needs to be edited.

[Date]

[Name of Primary Care Trust]

We recently sent you a questionnaire about health care at [name of trust]. At the time of sending this note, we have not yet received your response.

Participation in the survey is voluntary, and if you choose not to take part it will not affect the care you receive from the NHS, and you do not need to give a reason. However, **your views are important to us** so we would like to hear from you. The return envelope you were sent with the questionnaire does not need a stamp.

If you have already returned your questionnaire – **thank you**, and please accept our apologies for troubling you.

If you have any queries about the survey, please call [us/our FREEPHONE] on [**Number**] between [times], [days e.g. Monday to Friday].

Chief Executive [or similar]

[NHS Trust Name]

To be printed on Trust headed notepaper (ideally without trust telephone number if Approved Contractor is handling the FREEPHONE calls). Text in square brackets needs to be edited.

[Date]

Dear Patient

Local Health Services Survey

Enclosed is a copy of a patient survey about your local health services. We originally sent the survey to you a few weeks ago. If you have already replied, please ignore this letter and accept our apologies.

What is the purpose of the survey?

Your views are very important in helping us to find out how well NHS services work and how they can be improved. This is part of our commitment, outlined in the NHS Plan, to design a health service around the patient.

Why have I been chosen?

Your name has been chosen at random, using a computer programme, from a list of all people registered with GP practices that are part of [Trust name] PCT. We are sending questionnaires to 1200 patients in your area.

Do I have to take part?

No. Taking part in the survey is **voluntary.** If you choose not to take part it will not affect the care you receive from the NHS in any way. If you do not want to take part in the survey, or to answer some of the questions, you do not have to give us a reason.

What would I have to do?

If you decide to take part, please complete the questionnaire and return it in the FREEPOST envelope. No stamp is needed. The questionnaire should take around 20 minutes to complete.

If you do not wish to take part, please could you return the blank questionnaire in the FREEPOST envelope. If we do not hear from you, we may send you a reminder.

Who is organising the survey?

This survey is being carried out by researchers from [NHS Trust name /name of survey company], the Healthcare Commission and the Co-ordination Centre for the Primary Care Trust Survey at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified. The Healthcare Commission will produce a public report on care at the trust, which will include the anonymous survey findings. This will be made available from the Commission’s website at [http://www.healthcarecommission.org.uk/nationalfindings/surveys/patientsurveys.cfm].

Will my taking part in this study be kept confidential?

Yes. You have been given a unique number so your name and address are not on the questionnaire, and your name and address will never be linked to your responses. Your responses will only be used to provide information about the quality of the services the trust provides and to help us to improve these services.

Your personal data are held in accordance with the Data Protection Act 1998 and the NHS Confidentiality Code of Practice. [[IF CONTRACTOR USED: [Your contact details have been passed to [survey contractor], only so that they can send you this questionnaire and process your response. [Survey contractor] will process your answers in confidence and keep them separate from your contact details.]]

The Co-ordination Centre for the Primary Care Trust Survey and the Healthcare Commission will produce anonymous statistics from the responses for each NHS Trust taking part in the survey. All name and address information relating to this survey will be destroyed within a maximum of three months of completion of the survey.

[NHS Trust name] has a leaflet for patients explaining how we use and handle your personal information, and what your rights are under the Data Protection Act 1998. If you would like further information or a copy of the leaflet, please write to us, or call [Freephone survey helpline].

Contact for further information

If you would like more information about the survey, or have questions on how to complete the questionnaire, you can call [our FREEPHONE help line /us] on [phone number] [at no cost to yourself] and we will do our best to help. The line is open between [opening time] and [closing time], [days].

Thank you

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar], [NHS Trust name]

GUIDANCE MANUAL FOR THE PRIMARY CARE TRUSTS SURVEY OF LOCAL HEALTH SERVICES 2008

THE CO-ORDINATION CENTRE FOR THE PRIMARY CARE TRUST SURVEY

picker INSTITUTE

making patients' views count

Last updated: 30th November 2007

Contacts

The Co-ordination Centre for the Primary Care Trust Survey[1]
Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

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Helen Sheldon

Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in this guidance manual, for example, by offering financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages. More guidance on how to reach ethnic minority groups can be found in Section 7. 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 Annual Health Check for that trust. If trusts want to make any adjustments to the method set out in this guidance, they will need to check with the Co-ordination Centre that the proposed alteration would not compromise comparability, and additional ethical approval is likely to be required also.

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] Previously the NHS Patient Survey Advice Centre

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1 Introduction: patient feedback and the NHS Plan

1.1 The Healthcare Commission

The national patient survey programme is owned by the Department of Health and has been operating since 2002. The Healthcare Commission administers the programme. The Healthcare Commission exists to inspect the quality and value for money of healthcare, to equip patients and the public with the best possible information about the provision of healthcare, and to promote improvements in healthcare. Patients' experiences of health services are at the heart of the Healthcare Commission's work: it is the aim of the Healthcare Commission 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, change over time, and variations between different patient groups. As well as supplying the Department of Health with data to assess performance against the targets on patient experience the survey programme provides an important source of data for screening self-assessment declarations in the annual health check, and data for the new national target on patient experience. Additionally, 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. Results can also be used by trusts in their self assessment declarations.

1.2 The Co-ordination Centre for patient surveys

The Co-ordination Centre for the Primary Care Trust Survey is based at the Picker Institute and works under contract to the Healthcare Commission to design, test, and co-ordinate the survey of Local Health Services.

1.3 Why we need patient feedback

Quality in health and medical care has two distinct dimensions. One has to do with the quality of care from the perspective of professional, technical standards; and the other dimension concerns the quality of care from the perspective of patients. Understanding the way patients experience the care they receive is essential to a complete assessment of the quality of healthcare, and this can only be obtained by asking the patients themselves.

It is important to adopt systematic, appropriate and effective ways to ask patients about their experiences, and use this information to shape and improve the way healthcare is delivered. This manual is designed to help staff in NHS primary care trusts to obtain patient feedback through patient surveys. It also provides guidance on how you may use the information you gather in quality improvement programmes and for monitoring performance. By following this guidance, you will also help to ensure that the survey results from your trust are comparable with other trusts, and with national benchmarks.

1.4 Patient feedback and the NHS 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 NHS 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 Healthcare Commission's programme of reviews and inspections.

1.5 The Annual Health Check

Information drawn from the core questions in the Local Health Services survey is one of the elements used by the Healthcare Commission to measure performance of trusts against the national core standards, and the patient experience element of the new national targets. These indicators will be used in the Annual Health Check of primary care trusts in England, due for publication in autumn 2008.

1.6 Measuring performance over time

In addition to the performance assessment, the Healthcare Commission will publish benchmarking data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data. Information collected nationally in a consistent way is also essential to support public and parliamentary accountability, through the monitoring of the Public Service Agreement targets. By asking each primary care trust to carry out the Local Health Services Survey in a consistent way, the Healthcare Commission is building up a detailed picture of patients' experiences in NHS primary care trusts. Also, by repeating the same surveys regularly, trusts will be able to monitor their own performance over time.

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

1.7 Basic requirements for NHS trust primary care 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 primary care 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 **30th November 2007** and tell them who is carrying out your survey (ie whether it will be carried out by an approved contractor or in-house) (e-mail: **primarycare@pickereurope.ac.uk**)
- The survey must be carried out using a postal questionnaire
- The sampling procedure set out in this guidance must be followed.
- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **10th January 2008**. A spreadsheet has been created for this purpose. For further details see Section 10 – Weekly monitoring
- The questionnaire must include the 56 core questions. See Section 12 - The core questions and question bank
- The standard covering letters and reminder letters (which can be found under the Primary Care section of the NHSSurveys website) must be used as outlined in Section 13 – Materials
- You should aim to obtain the highest response rate possible. For this survey, the target response rate is 60% (that is, you should get 720 returned questionnaires from the 1200 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 and publicising the survey
- Two reminders must be sent to non-responders, even if a 60% response rate is already achieved. These procedures are outlined in Section 14.6 – 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 15.3 – 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 15.4 – Submitting data to the Co-ordination Centre by **18th April 2008**
- Two paper copies each of the questionnaire you used and the covering letters for each mailing must be submitted to the Co-ordination Centre in the form outlined in Section 15.4 – Submitting data to the Co-ordination Centre by **25th April 2008**
- 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 July 2008** 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 3). Whichever route you take, you will need to address the guidance in sections 1 to 11 and 16 to 18 of this guide. Sections 13, 14 and 15 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 12 contains details of the questions in the core and bank questionnaires.

2 Setting up a project team

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

We suggest:

- **Establishing a workgroup.** Put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:
    - Board members
    - Doctors, nurses and other health care staff
    - Managers
    - Administrators
    - Patients and carers
    - Members of patient groups with a special interest in the trust
    - Caldicott Guardian
    - Staff or directors responsible for:
    - Clinical governance
    - Patient advice and liaison service (PALS)
    - Quality improvement
    - Strategic planning.

- **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 ask questions.

- **Not overlooking front-line staff.** These people have the most frequent direct contact with patients.

3 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 expertise 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 issues 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

3.1 Costs

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

Staff time

This is one of the largest expenditures, but it is sometimes overlooked. Be sure to include the cost of staff time, including salary and fringe benefits, and time spent away from other work. Please note that weekly submission will be required for each trust taking part in the Local Health Services Survey 2008, 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 1200 patients and the second and third mailings will be sent only to non-responders. (See Section 13 – 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 14.1 – 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 and staffing such a service needs to be included. (For details, see 14.2 – 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.

3.2 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.

3.3 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. A national survey of this kind requires continual staff involvement over a number of months. If you commission an approved contractor to carry out the survey, you should ensure that appropriate and realistic deadlines are set.

3.4 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 Healthcare Commission and Department of Health to contribute to performance assessment.

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 independent 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 30th November 2007.

4 Commissioning a survey from an approved contractor

The framework agreement set up by the Healthcare 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
- Weekly submissions of response rates and helpline calls
- Data entry, cleaning data and providing data to the Co-ordination Centre by the deadline
- Preparing standard reports for trusts.

Twelve organisations have been approved by the Healthcare 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.

4.1 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

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

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: David Henderson

Ipsos MORI
79-81 Borough Road
London
SE1 1FY

Tel: 0207 347 3178
Fax: 0207 347 3800
E-mail: david.henderson@ipsos-mori.com
Website: www.ipsos-mori.com

Marketing Sciences

Contact: Eileen Sutherland and Joy Owen

Marketing Sciences
8 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
103-135 Kings Road
Brentwood
Essex
CM14 4LX

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

CAPITA Health Service Partners (formally NHS Partners' Research and Information)

Contact: Cheryl Kershaw and Aimi Blueman

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

Tel: 01423 720212
Fax:
E-mail: Cheryl.kershaw@capita.co.uk; Aimi.blueman@captia.co.uk
Website: www.capitahsp.co.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, Tim Markham, Bridget Hopwood, Sheena MacCormick, Nick Richards, Nick Pothecary or Alison Wright

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
Derbyshire
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:	tgooderman@snapsurveys.com; rsutcliffe@snapsurveys.com; ewilliams@snapsurveys.com
Website:	www.snapsurveys.com

4.2 Contracts

Model honorary contracts have been provided by the Healthcare Commission to be used as templates for agreements between the trust and the approved contractor, in terms of the transfer of data. These can be found on the NHSSurveys website in both Word document and template formats. The four documents that are available are:

- A briefing note about the honorary contracts
- Guidance about the honorary contracts
- The model contract between the trust and the approved contractor, as organisations
- The honorary contract between the trust and individual staff members of approved contractors

These are designed as template contracts and trusts and approved contractors may agree on amendments to the wording and content when using them. We suggest that the contracts are used either as separate arrangements to the financial agreements made between trusts and approved contractors when commissioning a contractor, or combined with these to avoid 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.

5 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 principles[1]. It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors. Your trust's Caldicott guardian and legal advisors will be able to advise you on these matters.

New guidelines on the use and security of the data collected have been agreed by the Healthcare 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

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

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

5.1 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 commencing with fieldwork, 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 5.6). Templates for

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[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 begin fieldwork.

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 data protection are maintained.

Approved contractors

The framework agreement between the approved contractors and the Healthcare 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.

5.2 Patients' names and addresses

In order to comply with the Data Protection Act 1998 and common law duty of confidence, NHS trusts should not release the names, addresses or any other personal details of patients to anyone who is not employed by the trust, unless consent has been obtained from each patient. This includes releasing names and addresses for the purpose of mailing survey questionnaires to patients. The honorary contract (see Section 5.4) allows approved contractor staff to view this information without infringing the Data Protection Act 1998. Please note that under the new 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 (Community Health and Standards) Act 2003, the NHS confidentiality code of practice 2003[1] (which incorporates the Caldicott principles) and the Commission's own code of practice on confidential personal information[2].
- 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 a courier service approved by the Healthcare Commission: personal data should **not** be sent by recorded delivery. This procedure for sending data is in accordance with the Commission's policy for sharing RESTRICTED information as set out in its handbook for staff, "Handling information at the Healthcare Commission"[3].

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

[2] http://www.healthcarecommission.org.uk/_db/_documents/04012832.pdf

[3] http://www.healthcarecommission.org.uk/_db/_documents/04012828.pdf

- **Over the Internet**: An encrypted session based on the Transport Layer Security (TLS) or Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP) must be used. A key size of 256 bits or greater should be used. This is to ensure a high level of security, to protect against any accidental or intentional interception during the transfer of patients' details. Approved contractors should be able to provide guidance on the use of an encrypted session to Trusts.
- As the owners of the data, the method for transferring patient samples is ultimately the Trust's decision because the Trust remains legally responsible for the security and processing of the information it shares. The Healthcare Commission strongly recommends the two methods described above. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption is available from NHS Connecting for Health[1].

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

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 we 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].

5.3 Confidentiality and contractor responsibilities

Two common methods are practised by trusts, and advised by the Healthcare Commission, 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 14.

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 Healthcare Commission has developed a set of contracts for trusts and approved contractors carrying out the survey. The honorary contract makes named staff members of the approved contractor unpaid employees of the trust, allowing the trust to transfer patient data in a way that does not compromise patient confidentiality, and to avoid the need for each trust to develop its own arrangements. It is strongly recommended that these documents are reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required.

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[1] http://nww.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/

5.4 Model contract

A model contract has been drawn up by the Healthcare Commission. This is an agreement between the approved contractor and the trust contracting them. By signing it, the approved contractor is obliged to keep the information confidential at all times, and to comply with the Data Protection Act 1998. It provides the trust with some recourse if any breach of the Data Protection Act were to occur, as a result of the actions of the approved contractor. The model contract also ensures that approved contractor staff members sign and abide by the honorary contract. The honorary contract is set up between the trust and those members of the approved contractor staff who will have access to patients' information. The honorary contract describes how patients' personal data will be sent to the approved contractor, and how the data can be used. It also ensures that only those members of staff named in the contract will have access to the data.

The model and honorary contract in Word format is available under the Primary Care section of the website containing the survey guidance (www.NHSSurveys.org).

5.5 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 receiveing 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 sample reference 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.

5.6 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 be under the care of a particular team, 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 staff at the trust other than the Caldicott Guardian and survey leads recorded on the declaration of compliance (see Section 5.1)
2) Additional data analysts may be added later by a second submission of the declaration of compliance to the Co-ordination Centre (see Appendix 2). Additional data analysts cannot view the raw data until approval has been received from the Co-ordination Centre.
3) If data are to be presented to trust staff who have not signed the declaration using the declaration of compliance, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than 20 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):

	Q10. Have you seen a doctor from your GP practice/ health centre in the last 12 months?		
Ethnic category	**Yes**	**No**	**Total responses**
	%	**%**	**n**
White	81	19	261
Mixed	-	-	8
Asian	-	-	18
Black	79	21	52
Chinese or other	85	15	26

4) Do not present response information (including comments) in a form that allows an individual patient to be identified by the group receiving the information. For example, if you are presenting the results of a small number of patients, make sure that it will not be possible for the reader/audience to identify individual patients from their responses, 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 password protected). Access to the file should be given only to those individuals who have signed the declaration of compliance.

Approved contractor

1) Approved contractors must not provide raw data to the trust as a matter of course.
2) If the trust has a particular need for the raw data from the survey from the approved contractor, the contractor may provide an abridged version of this dataset to the trust upon request, providing that the steps below are undertaken first:
    a. The contractor must delete the variable pertaining to ethnicity
    b. The contractor must band year of birth into five age groups (16-35, 36-50, 51-65, 66-80, 80+). 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.

d. Verbatim comments that could lead to any staff identifying respondents must be removed, eg those mentioning patient, staff, or practice names[1].
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 sample reference 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 15. The response data will be anonymous when passed to the Co-ordination Centre and Healthcare Commission, and published and archived results will not identify patients.

If data are to be presented to trust staff, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than 20 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):

	Q10. Have you seen a doctor from your GP practice/ health centre in the last 12 months?		
Ethnic category	**Yes**	**No**	**Total responses**
	%	**%**	**n**
White	81	19	261
Mixed	-	-	8
Asian	-	-	18
Black	79	21	52
Chinese or other	85	15	26

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.

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 honorary contracts.

5.7 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.

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[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 Healthcare 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.

5.8 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of patients' names, and the questionnaires kept until 31st July 2008. 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.

6 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.

6.1 Ethical approval for the PCT survey

Multi-Centre Research Ethics Committee (MREC) approval has been obtained for the core questionnaire, the question bank, and the covering and reminder letters, all of which can be downloaded from the www.NHSSurveys.org 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. The MREC letter can be downloaded from the NHSSurveys website.

Further information on the ethical approval process can be found at National Research Ethics Service or by e-mailing queries@nationalres.org.uk.

6.2 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 Healthcare 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 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 Healthcare Commission takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.

The following table has been prepared by the Healthcare 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 Healthcare Commission for patient surveys. If you are required to seek approval from your research governance lead, you are advised to present this information to your Research and Development Manager in support of your request.

6.3 Responsibilities of NHS organisations who are carrying out research

Research Governance Framework	**Healthcare Commission sponsored patient surveys**
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	*The survey is carried out on the experiences of patients after they have received the care so this does not apply.*
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	*All Chief Executives are informed of the proposals of the survey. A similar letter has been sent to the Research and Development Managers of the trusts.*
Ensure patients or users and carers are provided with information on research that may affect their care.	*The survey does not affect the care of the patients. Anonymised results are used for the Annual Health Check and local quality improvement initiatives. Detailed guidance is issued to survey leads regarding the publicity of the results and its impact on patient care.*
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	*This requirement is not specific to this survey.*
Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	*The Healthcare Commission as sponsors of the study have sought ethics approval from MREC. There is a designated lead for each survey who is appointed by the Chief Executive.*
Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	*The Healthcare Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in Section 3.8 of the Research Governance Framework are followed thoroughly.*
Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	*Detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.*
Maintain the necessary links with clinical governance and/or best value processes.	*The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.*

Research Governance Framework	Healthcare 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]	*In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an honorary contract with the trust. These procedures are specifically detailed in the guidance notes.*
Put and keep in place systems to identify and learn from errors and failures.	*The Healthcare Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Healthcare Commission. The survey programme is constantly evaluated and reviewed in the light of these.*
Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	*This requirement is not specific to this survey.*
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	*The Healthcare 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 Healthcare Commission to co-ordinate the patient surveys.*
Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	*Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.*
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	*The results of the surveys are used for monitoring of core and developmental standards in the Annual Health Check.*

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[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).

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

There are a number of strategies you can adopt to facilitate the process of collecting resonses from non-English speakers within this survey:

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of who offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the patient and the interpreter (Note that trusts may already have arrangements with such a service). If you are a trust that intends to conduct the survey using an in-house team, and you do not have access to such a service, please contact the Co-ordination Centre for further advice
- A multi-language leaflet template is available on our site, and this can be included with your first and third mailings. Trusts and approved contractors can use this leaflet by inserting their appropriate helpline number. This gives directions in the 20 most common non-English languages spoken in England and also in EasyRead (routed to a separate number run by Mencap to help those with learning disabilities)
- Many households include at least one **competent English speaker** who can help the 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 for themselves.

8 Timetable

The time taken to complete the survey will depend on many factors. 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 timetable below.

Week	Task	See Section
1	**Inform Co-ordination Centre who is carrying out your survey by 30th November 2007 (in-house or using an approved contractor)**	3 & 4
1	**Decide on questions to be included in the survey (ie select from question bank or use the core questionnaire)**	12
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 honorary contract is signed**	5.2 &13.2
1	Print questionnaires and covering letters.	13
2	Set up FREEPOST address and helpline	14.1 & 14.2
2	Establish system for responding to telephone enquiries	14.2
2	Establish system for booking in questionnaires	14.2
2-4	**Request sample from your local NHAIS organsiation**	15.5
3-7	**Stick labels on pre-packed numbered questionnaires and reminders supplied by approved contractor (if NOT using honorary contract)**	14.4
6-7	**Check your own trust's records for any patient deaths**	15.4
7/8	Send out first questionnaires	14.4
7	Send first weekly response rate and helpline monitoring form to Co-ordination Centre (Thursday 10th January 2008)	10
7-21	Continue to respond to telephone enquiries	14.2
7-21	Log and process returned questionnaires	14.5
7-21	Enter data	15
9	**Check your own trust's records again for any patient deaths**	15.4
9-10	Send out first reminders to non-responders	14.6
10-11	Be prepared for a small peak in telephone calls as first reminders received	14.2
11	**Check your own trust's records for any patient deaths**	15.4
11-12	Send out second reminders to non-responders	14.6
20-21	Complete data entry	15
20-21	Check data for errors	15.3
21	Send data to Co-ordination Centre (by 18th April 2008 at the latest)	15 & 16

22	Send two copies of the questionnaire used, all covering letters and a copy of the checklist to the Co-ordination Centre (by 25th April 2008 at the latest)	10) & 11) 12)
22	Begin analysing trust's results and writing report	17
23+	**Disseminate results to staff, patients and the public**	18
	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 July 2008	5.8

9 The list of patients

NHS Connecting for Health has developed a computer programme that allows them to draw patient samples for each PCT. Your list of patients is a random sample drawn for all GP-registered patients aged 16 and over from your PCT on the database.

As in 2005, for the 2008 primary care trust survey, the list of patients who will take part in the survey will be supplied by the NHAIS Agency that hold the "home" (i.e., not "fringe") patient lists for the PCTs in their area[1].

9.1 What do PCTs need to do to obtain their sample of patients?

In order to obtain your patient sample, you will need to contact the NHAIS Agency that holds the data for the majority of your patients. The Co-ordination Centre will be sending you an email informing you of which organisation this is. You will need to ask the NHAIS Agency to perform the extract for your trust according to the guidance that has been issued to them.

You must not request your sample of patients before the 3rd December 2007.

9.2 What will the NHAIS organisation provide to the PCT?

The following items will be provided:

1. A comma-separated file comprising 'full' patient registration information
2. An anonymous file in comma-separated variable (CSV) format comprising only the patient details required by the Co-ordination Centre. The following fields are included:

Information included in the '*full*' comma-separated file

Each patient record (one record per patient) contains the following fields:

- Sample Reference Number (a unique reference number allocated to each patient selected: format "National PCT Code\NHAIS System cipher\4 digit sequence number"
- Patient Title
- First Forename
- Other Forenames
- Surname
- 5 address fields

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[1] The sample will only include patients held by an NHAIS organisation as a "home" primary care trust, not from other NHAIS organisations, who may hold part of your patient list as a "fringe" PCT.

- Postcode
- Patient’s age in years
- Patient’s sex
- National Practice code of this patient’s GP of Registration

Information included in the anonymous comma-separated file

The anonymous file contains the following fields for each patient record:

- Sample Reference Number
- Patient’s age in years
- Patient’s sex

9.3 What if my list contains fewer than 1200 patients?

It is possible that you will receive a list that is one or two patients short of the specified 1200 sample size. This is due to a slight time gap between when the full samples were originally drawn and when they became available to PCTs to request. It is possible that in this time, one or two patients on your sample died or changed registration and so their details would have been removed before you received the patient list. You do not need to worry about this. However, if you have fewer than 1185 patients in your list, you should check with your NHAIS organisation that the sample has been drawn correctly.

9.4 Deceased patients

The standard way of checking whether a patient has died is to send the list to the NHS strategic Tracing Service (NSTS). However, for these PCT surveys, that would not be a useful exercise, since the tracing service would use the same source for their information as Connecting for Health. The initial patient list will only include patients for whom Connecting for Health have not been informed of a death.

However, please be aware that this system is not foolproof and the record of a patient’s death may not yet have reached the NHAIS system. Also, a few patients may have died in the period between drawing the patient sample and the questionnaire being delivered. For this reason, we ask that you **check your trust records prior to mailing out the questionnaire for any record of a patient who has died since the sample was drawn**. You will also need to check your trusts records for any deaths again before the second and third mailings. You might at this stage want to send the list to NSTSIt is possible that some recently deceased patients might remain in your sample even after these steps are taken. You need to be prepared for this. Special sensitivity is required when dealing with telephone calls from bereaved relatives.

9.5 Organise the information into the sample file

You will need to keep the patient information in an electronic spreadsheet or database file, where you can record which questionnaires have been returned. At the end of the survey process, you will be asked to send an anonymised version of this information to the Co-ordination Centre.

First, you will need to add five new columns:

1. Day questionnaire received
2. Month questionnaire received
3. Year questionnaire received
4. 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.
5. The **Comments** column is useful for recording any additional information that may be provided when someone calls the FREEPHONE to inform you that the respondent has died or is no longer living at this address.

An example of the spreadsheet you should complete has been included below.

This file has three purposes:

1) It will be used to keep a record of which patients are yet to return questionnaires so that reminders can be sent to them.
2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from the 10th January 2008 until the closing date of the survey.
3) The anonymous data in this file (ie all the data **except** patient name and address information) will form part of the file that you will submit to the Co-ordination Centre when the survey is completed.

Table 1 – Sample Excel file of patient details

Sample reference number	**Title**	**Forename**	**Surname**	**Address1**		**Address5**	**Postcode**	*Age*	*Sex*	*Day of questionnaire being received*	*Month of questionnaire being received*	*Year of questionnaire being received*	*Outcome*	**Comments**
1AB\ABC\0001	Mrs	Alice	Abbot		--		AB1 1YZ	80	F	28	1	2008	3	Informed that patient had died
1AB\ABC\0002	Mr	Ivor	Ahmed		--		AB2 6XZ	39	M	22	1	2008	1	
					--									
1AB\ABC\1119	Ms	Ranbir	Singh		--		AB4 7MX	63	F	6	2	2008	2	Questionnaire returned undelivered by post office
1AB\ABC\1120	Ms	F	Young		--		AB9 5ZX	22	F					

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 with the sample information and sumitted to the Co-ordination Centre 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 is notified the patient will not be participating (patient deceased, moved address, too ill, or called to opt out).

Notes on Table 1

- **Sample Reference Number**: This number is unique for each patient. It can be seen in the example that numbers are in ascending order, starting at 1AB\ABC\0001 at the top of the list. The sampled attendences are numbered consecutlively, through to 1AB\ABC\1220 at the bottom of the list. This number will be included on the address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), 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.

- The **Sample Reference Number**, **Title**, **Forename**, **Surname**, **Address** fields and **Postcode** are used for printing out address labels. If you wish, you can use the "full" comma-searated file supplied by your NHAIS organisation and the mail merge feature in a word processing package for this purpose.

- **Age** is included so that the ages of those patients who send back questionnaires can be compared with the ages of non-responders. The patient list should only include patients aged between 16 and 120.

- **Sex** is coded as M=male and F=female. However, be aware that other systems may use different coding.

- **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 12/07/07.

- **Month 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, **not** a date format.

- **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.

- The **Outcome** field should be coded as follows:

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

- The **comments** column is useful for recording any additional information that may be provided when some calls the FREEPHONE. They may provide information that a patient has died or is no longer living at this address.

9.6 Using the patient sample file

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. Therefore, you should match up the anonymised patient information file with the data file once your survey is completed.

Alternatively, you should keep two copies of this file, one anonymised and the other with patient name and address details, but you will need to ensure that the “outcome” information, about whether patients have responded, or why they have not responded, is accurate and up-to-date in both files.

9.7 Sharing the patient sample file with an approved contractor

If you are working with an approved contractor and have an honorary contract, the full sample information **and** the name and address information should be sent to those contractor staff covered by the honorary contract. If you are working with an approved contractor, but **not** using an honorary contract to share patients’ name and address details, you should supply them with a version of the list shown in **Table 1 (Sample Excel file of patient details)**, with names and addresses removed. The contractor can use this list to record the outcome codes, and you should ensure that the contractor is kept up to date with any information that comes directly to the trust about patient deaths, etc.

9.8 Increasing sample size beyond minimum requirement

For this year's survey, your trust will not have the opportunity to increase the sample size above the 1,200 that will be provided to you. This is because the GP Patient Survey (GPPS), run by Ipsos MORI on behalf of the Department of Health, is due to be in field at the same time as the PCT survey and so the two sets of samples are being designed and drawn in a complimentary manner so that they do not overlap and so that nobody receives two questionnaires at around the same time. We have applied for ethical approval on the grounds that we will do everything we can to minimise the chances of people receiving both questionnaires.

Please do not increase your sample beyond the 1200 that will be provided to you.

10 Weekly monitoring

The Co-ordination Centre requires weekly submissions of outcome data and helpline calls for each trust taking part in the 2008 Local Health Services Survey. First submission of data must be made on Thursday 10th January 2008[1], 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 (primarycare@pickereurope.ac.uk) by the end of the workday every Thursday throughout the survey.

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. The co-ordination centres receives large numbers of monitoring files each week and it is essential that files are correctly named so that they can be automatically compiled.

For trusts carrying out the survey in-house:

When the data is submitted, the file name **must** be in the following format:
PCT08_<trust code>_<week of submission>.xls

e.g. PCT08_5LD_1.xls (first submission of monitoring data on 10th January)
PCT08_5A7_4.xls (fourth submission of monitoring data on 31st January)

For approved contractors:

When the data is submitted, the file name **must** be in the following format:
PCT08_<contractor code>_<week of submission>.xls

e.g. PCT08_CDP_1.xls (first submission of monitoring data on 10th January)
PCT08_CYH_4.xls (fourth submission of monitoring data on 31st January)

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

10.1 Response rate

The information submitted should contain the following data:

- The total number of patients in your sample i.e. the total number of all those included in the first mailing,
- The number of patients in each outcome field (see Section 9.4)

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[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 Healthcare Commission with regular updates on response rate at a national level.

10.2 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 rang the helpline to opt out of the survey (and did not require translation services), this call should just be recorded in the ‘overall total’ number of calls’ (ie first category).

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

This information allows the Co-ordination Centre to identify areas of concern to patients and to improve future surveys.

11 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 GP surgeries and communications with patients before or after their appointments, and in community newsletters. 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.

12 The core questions and question bank

Each trust must include in their survey at least the 56 core questions. There is a pre-designed core questionnaire on the www.NHSSurveys.org 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 primary care trust survey:

1) The **core primary care questionnaire**, which comprises 56 core questions.
2) The **enhanced questionnaire**, which includes the 56 core questions, with additional questions added from the bank of validated questions.

12.1 The core questionnaire

The core questionnaire consists of 56 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.

12.2 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[1] for the primary care trust survey and are available online, with the questions arranged in the appropriate sections.

You can add more questions by using the “Create your own survey” option on the website. The instructions on the website will guide you through the steps you need to take to create your own survey. On this web page, you will notice that some questions have tick boxes next to them, while other questions do not. Those questions that have tick boxes are the optional questions that can be selected or deselected from the question bank. The questions with no tick boxes (just bullet points) cannot be deselected because they are compulsory core questions, and they must be included in all NHS PCT surveys.

As you select questions from the question bank, they are placed in the appropriate section on the survey form, so that the questionnaire flows sensibly. For example, if you add further questions about *Seeing a doctor*, they will be put into the section under that heading. 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.

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[1] Also by the NHS Patient Survey Advice Centre prior to 2006.

13 Materials

13.1 Printing questionnaires

Questionnaire layout

The questionnaire is rigorously tested in the format of the core questionnaire. All questionnaires used by trusts should follow 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:

11. Did the doctor listen carefully to what you had to say?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

- Do not arrange the response options horizontally across the page, rearrange the question options, or change the order of the questions in the questionnaire.

You are strongly advised to use the version of the core questionnaire that is on the www.nhssurveys.org website and the compliation tool if you wish to add in extra questions from the question bank. It should not be necessary to type out the questionnaire from scratch and errors can be made if this happens.

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 1200, then you might want to print 1.7 x 1200, or approximately 2,040 copies.

13.2 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 around 2,000 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.

13.3 First mailing

You will need 1200 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).

13.4 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.

13.5 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).

14 Implementing the survey - practicalities

14.1 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.

14.2 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 sample reference 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 recent appointements or visits - which one should I refer to?

Patients should be advised to refer to their **most recent** visit.

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 up-to-date records, 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, and that the patient’s care will not be affected in any way if they do not respond. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of the patient’s responses. If the patient is willing to tell the staff member the identification number (sample reference 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 for each trust to the Co-ordination Centre. This is discussed in detail in Section 10.2.

14.3 Covering letters

The standard covering letter is available in Microsoft Word format on the primary care 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 Local Health Services 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.

14.4 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 sample reference 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 sample reference number.

Note on the sample reference number (SRN)

The sample reference 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 the 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 sample reference 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 – honorary contract

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

Approved contractors – no honorary contract

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

14.5 Booking in questionnaires

When questionnaires are received, match up the sample reference 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 July 2008, 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 reference 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.

14.6 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 is strongly recommended that you check your trust's records again before you send out reminders.

Approved contractors

When reminders are due to be sent out, approved contractors should send the pre-packed envelopes bearing the sample reference numbers of the non-responders. Again, the envelopes should be clearly marked with the sample reference number so that those carrying out the mailing can match these with their patient list and put on appropriate address labels.

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 sample reference 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 and you might also want to send your list to NSTS as an additional check.

15 Entering data

The data must be submitted to the Co-ordination Centre in the appropriate format by the deadline of 18th April 2008. If an approved contractor is used, they will be responsible for all of the data entry and checking, and when the survey is completed they should submit the data to the Co-ordination Centre in the correct format and supply the trust with an anonymised data set (see Section 5 on data protection issues).

15.1 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 primary care 2008 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 Q49 and Q50 that gives the instruction “Tick all that apply", each response option is treated as a separate question.

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[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

Q49. 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 ticked[1]

Q49 takes up seven columns in the data file, labelled as follows:

Column headings	**Q49_1**	**Q49_2**	**Q49_3**	**Q49_4**	**Q49_5**	**Q49_6**	**Q49_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.

15.2 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 56 compulsory core primary care trust 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 56 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 questionnaire. They also include the wordings of the 56 core

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[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 (.)

questions so that you can match them up. It is essential that you check carefully that the columns of data you select from any larger data set correspond to the 56 core survey questions.

15.3 Checking the data for errors

For the 2008 Local Health Services Survey, trusts and contractors are required to submit raw (‘uncleaned’) data to the Co-ordination Centre. For clarification, raw data is created by the following:

1) All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (e.g. where 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 Q49 and Q50, 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 Q53, 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 ‘2008’ 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.

15.4 Submitting data to the Co-ordination Centre

The data from the core questions of the 2008 Local Health Services 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 <NHStrustName>_PCT2008.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 Sample Reference 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 1200 patients in the original sample.

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

Field	Format	Data codes	Comments
Sample Reference Number	1AB\ABC\1111		The unique reference number allocated to each patient by the NHAIS organisation.
Age	NN or NNN		Format this simply as a number, not in date format.
Gender	M or F	M = Male F = Female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.)
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 January 2008, this column should read '15'.
Month of receiving questionnaire	N	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 January 2008, this column should read '1' (as January is the 1st month of the year).
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 survey (patient deceased, moved address, too ill, or called to	For example, if the questionnaire was received on 15th January 2008, this column should read '2008'.

---

[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
		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 56 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 is an example of the columns of data to be included in the file. Your file should have 1200 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 50% 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**						
Sample Reference Number	Age	Sex	Day of receiving questionnaire	Month of receiving questionnaire	Year of receiving questionnaire	Outcome	Q1	Q2	--	Q50_6	Q50_7	Q50_8	Q51
1AB\ABC\0001	80	F	21	1	2008	3							
1AB\ABC\0002	39	M	6	3	2008	1	1	1		1	1	0	8
1AB\ABC\0003	56	F	9	1	2008	6							
1AB\ABC\0004	24	F	10	1	2008	1	2			0	1	0	1
1AB\ABC\0005	72	F	21	1	2008	1	1	2		0	0	0	1
1AB\ABC\0006	18	M	30	1	2008	2							
1AB\ABC\1119	66	F	5	2	2008	6							
1AB\ABC\1120	52	F	1	3	2008	1	1			1	1	1	1

You should not send any of the patients’ written comments to the Co-ordination Centre.

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 15.5 - Checklist).

Delivery

Data may be sent on floppy disc or by e-mail. Hard copy documents should be posted to the address below:

Postal address:

Local Health Services Survey
Co-ordination Centre for Primary Care Trust Survey
Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

E-mail: primarycare@pickereurope.ac.uk

Deadline for submission

The data must be supplied by **18th April 2008**.

15.5 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below, and include this checklist when you submit 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 Healthcare Commission in your trust's performance assessment and your trust's scores will be set to a minimum value. We cannot accept re-submissions of data after the deadline.

A printable version of the checklist can be found on our website.

Check	Done?
1) Check that your **file name** follows the naming convention: <NHStrustName>_PCT2008.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 56 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) Check that all the data are in **numeric format** only (including dates)	
7) Check that you have completed the columns for the day, month and year you received the questionnaire back from patients	
8) 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	
9) Remove any **passwords**	
10) Include **two paper copies** of the questionnaire you used	
11) Include **two paper copies** of the covering letters you used for the first, the second and third mailing.	
12) Include **telephone and e-mail contact details of two people** who will be available to respond to any queries about the data	
13) Check that you have **not** included any columns of optional questions	
14) **Check again** that all data are correct, and that all values are in range!	

16 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.

16.1 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 56 core questions are automatically computed and displayed on the other sheets of the Excel workbook, which correspond to sections of the Local Health Services 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 (.).

16.2 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.

17 Reporting results

17.1 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 Healthcare Commission and NHSSurveys website to find out where your trust performs better or worse than other trusts.

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.

17.2 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.

18 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.

18.1 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

18.2 Dissemination of survey results

Engage key stakeholders

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 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

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 an 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

18.3 Identify key "change agents"

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

18.4 Develop an action plan

Having used your survey results to identify areas for improvement, we recommend you work with staff and patients 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.

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

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

19 Glossary

Ethics Committee

The purpose of Research Ethics Committees in reviewing a proposed study is to protect the dignity, rights, safety, and well-being of all actual or potential research participants. A favourable ethical opinion from the committee implies that the research does protect the participant's aforementioned rights.

Multi-Centre Research Ethics Committee (MREC)

A MREC can grant a favourable ethical opinion for studies carried out in multiple regions of England. The inpatient survey has applied and been given a favourable ethical opinion for the study to be carried out in all NHS hospital trusts in England.

Research Governance Framework

This outlines the principles of good research practice and is key to ensuring that health and social care research is conducted to high scientific and ethical standards.

Appendix 1: Declarations of data protection compliance

Declaration of compliance with the Data Protection Act 1998

DECLARATION

RELATING TO THE

[Name of survey eg 2008 Local Health Services Survey]

FOR TRUSTS USING IN-HOUSE SURVEY TEAMS

While carrying out the [**insert survey name**], 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 [**insert survey name**].

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 [**insert survey name here**].

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 [**insert survey name here**] 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 [**insert survey name here**].

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 [**insert survey name here**] 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 [**insert survey name here**].

Signature: ………………………………………….. Date: ………………………

Appendix 2: Declarations for additional data analysts

Declaration of compliance with the Data Protection Act 1998

DECLARATION
RELATING TO THE

[Name of survey eg 2008 Local Health Services 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 [**insert survey name**].

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 [**insert survey name here**].

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 [**insert survey name here**] and will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the [**insert survey name here**].

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 [**insert survey name here**] and will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the [**insert survey name here**].

Signature: ………………………………………….. Date: ………………………..

GUIDANCE ON DATA CLEANING FOR THE NHS NATIONAL SURVEY OF LOCAL HEALTH SERVICES 2008

THE CO-ORDINATION CENTRE FOR THE PRIMARY CARE TRUST SURVEY

picker INSTITUTE

making patients' views count

Last updated: 16th April 2008

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Updates

Before you use this document, check that you have the latest version, 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

Questions and comments

If you have any questions or concerns regarding this document, or if you have any specific queries regarding the submission of data, please contact the Co-ordination Centre:

By e-mail: primarycare@PickerEurope.ac.uk

By phone: 01865 208127

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1 Primary Care Trusts Survey 2008 – data cleaning

1.1 Introduction

Once fieldwork for the 2008 primary care trusts survey has been completed, participating trusts and contractors will be required to submit data to the Co-ordination Centre in a **raw ('uncleaned')** format. Following this, data for all trusts in the survey will be collated and the full dataset will be cleaned together to ensure that cleaning taking place on data pertaining to different trusts is comparable.

This document provides a description and specification of the processes that will be used by the Co-ordination Centre to clean and standardise data submitted by contractors and trusts as part of the 2008 survey of local health services. By following the guidance contained in this document, it should be possible to recreate this cleaning process.

If you have any comments or queries regarding this document please contact the Co-ordination Centre on **01865 208 127**, or e-mail us at **primarycare@pickereurope.ac.uk**.

1.2 The core and extended questionnaires

For the 2008 primary care trusts survey, all trusts have the option to use either the 56 item 'core' questionnaire or to use an extended questionnaire with further questions available from the 'question bank' for the survey. The Co-ordination Centre only requires data to be submitted for the 56 core items, and so all cleaning undertaken by ourselves will involve only these 56 core items. As such, this document looks only at the cleaning required for the core survey. Nonetheless, the rules and principles of data cleaning described here can be applied to data from an extended questionnaire.

1.3 Definitions

Definitions of terms commonly used in this document, as they apply to the 2008 primary care trusts survey are as follows:

Raw/uncleaned data: 'Raw' or 'uncleaned' data is data that has been entered verbatim from completed questionnaires without any editing taking place to remove contradictory or inappropriate responses; thus, all responses ticked on the questionnaire should be included in the data entry spreadsheet[1] (see Section 2: Submitting raw ('uncleaned') data, for detailed guidance on submitting raw data). The requirement for raw/uncleaned data does **not**, however, preclude the checking of data for errors resulting from problems with data entry or similar. Ensuring high data quality is paramount and errors resulting from data entry problems can and should be corrected by checking against the appropriate completed questionnaire.

---

[1] Except where: a) multiple responses have been ticked - set these to missing (The **exceptions** to this are for the 'tick all that apply' questions **Q49** and **Q50** where respondents may tick more than one response option) b) year of birth has been entered in incorrect format - if the patient's *intended* response is unambiguous from the questionnaire, then enter this.

Data cleaning: The Co-ordination Centre uses the term ‘data cleaning’ to refer to all editing processes undertaken upon survey data once the survey has been completed and the data has been entered and collated.

Routing questions: These are items on the questionnaire which instruct respondents to either continue on to the next question or to skip past irrelevant questions depending on their response to the routing question. For the 2008 local health services survey, the routing questions in the core questionnaire are **Q1, Q2, Q6, Q8, Q10, Q18, Q23, Q25, Q29, Q31, Q38, Q47** and **Q49**.

Filtered questions: Items on the questionnaire that are not intended to be answered by all respondents are referred to as ‘filtered’ questions. Whether individual respondents are expected to answer filtered questions depends on their responses to preceding routing questions. For the 2008 local health services survey, the filtered questions in the core questionnaire are **Q2—Q5[1], Q7—Q9[2], Q11—Q17, Q19—Q22, Q24, Q26—Q28, Q30—Q33[3], Q39, Q48, and Q50-Q51.**

Non-filtered questions: these are items in the questionnaire which are not subject to any routing/filtering and which should therefore be answered by all respondents. For the 2008 local health services survey, the non-filtered questions are **Q1, Q6, Q10, Q18, Q23, Q25, Q29, Q34—Q38, Q40—Q47, Q49, and Q52—Q56.**

Out-of-range data: This refers to instances where data within a variable has a value that is not permissible. For categorical data – as in the case of the majority of variables in this survey – this would mean a value not allowed in the data, for example, a value of ‘3’ being entered in a variable with only two response categories (1 or 2). For scalar data – eg year of birth – data is considered to be out-of-range if it specifies a value that is not possible (for instance, year of birth as 983 or 2983). Out-of-range responses entered into the dataset should not be automatically (eg, algorithmically) removed prior to submitting the data to the Co-ordination Centre (see Section 2: Submitting raw (‘uncleaned’) data).

Non-specific response: This is a loose term for response options that can be considered as not being applicable to the respondent in terms of directly answering the specific question to which they are linked. Most commonly, these are responses such as “don’t know/can’t remember”, which indicate a failure to recall the issue in question. Likewise, responses that indicate the question is not applicable to the respondent are considered ‘non-specific’ – for example, responses such as “I did not need to discuss anything” or “No treatment or action was needed”. A full listing of such responses for the 2008 local health services survey can be found in Appendix B: Non-specific responses.

---

[1] The range Q2-Q5 includes three separate sets of filtered questions; Q2-Q5, Q3-Q4 and Q4.

[2] The range Q6-Q9 includes two separate sets of filtered questions; Q6–Q9, and Q9.

[3] The range Q30-Q33 includes three separate sets of filtered questions; Q30–Q34, Q32-Q33 and Q33.

2 Submitting raw ('uncleaned') data

For the 2008 primary care trust survey, trusts and contractors are required to submit raw ('uncleaned') data to the Co-ordination Centre. For clarification, raw data is created as follows:

- **i)** 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)
- **ii)** Where a respondent has ticked more than one response category on a question, this should be set to 'missing' in the data. The **exceptions** to this are for the 'multiple response' questions, **Q49** and **Q50**, where respondents may tick more than one response option (ie. 'tick all that apply')
- **iii)** 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
- **iv)** 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 **Q53**, but written their *year* of birth in at the side of this, then the respondent's year of birth should be entered
- **v)** For the year of birth question, unrealistic responses should still be entered *except* following **iv)** above. For example, if a respondent enters '2008' 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
- **vi)** 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.

3 Editing/cleaning data after submission

3.1 Approach and rationale

The aim of the Co-ordination Centre in cleaning the data submitted to us is to ensure an optimal balance between data quality and completeness. Thus, we seek to remove responses that are known to be erroneous or inappropriate but do this in a relatively permissive way so as to enable as many responses as possible to contribute to the overall survey results.

3.2 Filters

Some of the questions included in the survey are only relevant to a subset of respondents, and in these cases filter instructions on the questionnaire are used to route respondents past questions that are not applicable to them. For example, people who tick "no" to **Q25** ("In the last 12 months, has anyone at your GP practice/ health centre referred you to a specialist (e.g. a hospital consultant)?") are instructed to skip all further questions on referrals (e.g. **Q26, Q27** and **Q28**).

It is necessary to clean the data to remove inappropriate responses where filter instructions have been incorrectly followed. In such cases, participants' responses to questions that were not relevant to them are deleted from the dataset. Responses are only deleted where respondents have answered 'filtered' questions despite ticking an earlier response on a routing question instructing them to skip these questions (eg a respondent ticking "No" to **Q25** but then answering the three questions about referrals as in the example above). Responses to 'filtered' questions are not removed where the response to the routing question is missing. For example, **Q11-Q17** are filtered by the response to **Q10** (e.g. if **Q10=2**), but if a respondent does not answer **Q10**, or if the **Q10** response is missing for any reason, then responses to **Q11-Q17** should not be removed.

Figure 1 (overleaf) shows a summary of all routing questions, and the filtered questions they relate to, that are included on the 2008 local health services survey. Please note that these instructions should be followed sequentially in order to be consistent with the procedures applied by the Co-ordination Centre.

Figure 1 - List of routing/filtering instructions

	ROUTING QUESTION		**RESPONSE VALUES**		**FILTERED QUESTIONS**
if	**Q1**	=	2	*then delete responses to:*	**Q2 – Q5**
if	**Q2**	=	1	*then delete responses to:*	**Q3 – Q4**
if	**Q2**	=	2, 5 OR 6	*then delete responses to:*	**Q3**
if	**Q6**	=	2	*then delete responses to:*	**Q7 – Q9**
if	**Q8**	=	2	*then delete responses to:*	**Q9**
if	**Q10**	=	2	*then delete responses to:*	**Q11 – Q17**
if	**Q18**	=	2 OR 3	*then delete responses to:*	**Q19 – Q22**
if	**Q23**	=	2	*then delete responses to:*	**Q24**
if	**Q25**	=	2	*then delete responses to:*	**Q26 – Q28**
if	**Q29**	=	2	*then delete responses to:*	**Q30 – Q33**
if	**Q31**	=	1	*then delete responses to:*	**Q32 – Q33**
if	**Q31**	=	2, 6 OR 7	*then delete responses to:*	**Q32**
if	**Q38**	=	1	*then delete responses to:*	**Q39**
if	**Q47**	=	5	*then delete responses to:*	**Q48**
if	**Q49_7**	=	1	*then delete responses to:*	**Q50_1, Q50_2, Q50_3, Q50_4, Q50_5, Q50_6, Q50_7, Q50_8, Q51**

Please note that these instructions should be followed sequentially in the order shown above.

A worked example of the cleaning process for removing unexpected responses to filtered questions is included in Appendix A: Example of cleaning.

3.3 Additional filter

In addition to the questions that having routing instructions given on the questionnaire, two further questions have also had the response options filtered. If a respondent says that they have not visited their GP practice/ health centre in the last 12 months (i.e. **Q6**=2) responses to **Q34** and **Q35** are deleted. If the respondent does not answer Q6 or if the the Q6 response is missing for any reason, then responses to **Q34** and **Q35** should not be removed.

Figure 2 – Additional filtering instruction

	ROUTING QUESTION		**RESPONSE VALUES**		**FILTERED QUESTIONS**
if	**Q6**	=	2	*then delete responses to:*	**Q34 – Q35**

3.4 Dealing with multiple response questions

For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For multiple response questions (**Q49** and **Q50)** that give the instruction "tick all that apply", each response option is treated as a separate question in the data entry spreadsheet.

Example

Q49. 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 ticked[1]

Q49 takes up seven columns in the data file, labelled as follows:

Column headings	**Q49_1**	**Q49_2**	**Q49_3**	**Q49_4**	**Q49_5**	**Q49_6**	**Q49_7**
Codings for this example	1	0	0	0	1	0	0

However, the last response options to Q49 and Q50 are exclusive options. If a respondent ticks option 7 to **Q49** (i.e. "I do not have a long-standing condition"), then options 1-6 should not have also been ticked; if any of these options have been ticked, they should be recoded from '1' to '0' when cleaning the data. The same applies for **Q50**; if response option 8 ("No difficulty with any of these") is ticked, options 1-7 should not have also been ticked. If they have been ticked, then they should be recoded from '1' to '0'

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[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 (.)

Example

Q49. 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

BEFORE CLEANING: Q49 is coded as follows:

Column headings	**Q49_1**	**Q49_2**	**Q49_3**	**Q49_4**	**Q49_5**	**Q49_6**	**Q49_7**
Codings for this example	1	0	0	0	1	0	1

AFTER CLEANING: Q49 is coded as follows:

Column headings	**Q49_1**	**Q49_2**	**Q49_3**	**Q49_4**	**Q49_5**	**Q49_6**	**Q49_7**
Codings for this example	0	0	0	0	0	0	1

When the data is cleaned, the responses to Q49_1 and Q49_5 are re-coded as ‘0’ because option 7 (i.e. “I do not have a long-standing condition”) has also been ticked.

3.5 Dealing with demographics

Basic demographic information, including age and sex of patients are included in the sample section of the data, but the ‘About You’ section at the end of the questionnaire also asks respondents to provide this information. In a minority of cases, the information provided from the sample frame and by the respondents does not correspond – for example, the sample may identify an individual as male only for them to report being female (eg **Q52=2**).

Because of this, and because questions about demographics tend to produce relatively high item non-response rates, it is not appropriate to rely on either source of data alone.

Where responses to demographic questions are present, it is assumed these are more likely to be accurate than sample frame information (since it is assumed that respondents are best placed to know their own sex or age)[1]. Where responses to demographic questions are missing, however, sample data are used in their place.

For demographic analysis on groups of cases, then, it is necessary to use some combination of the information supplied in the sample frame and by the respondents. To do this, we first copy all valid responses to survey demographic questions into a new variable. Where responses are missing we then copy in the relevant sample information (note that for a very small number of patients demographic information may be missing in both the sample and response sections; in such cases data must necessarily be left missing in the new variable).[2]

Certain demographic variables require special consideration during data cleaning:

Age (Q53)

A common error when completing year of birth questions on forms is for respondents to accidentally write in the current year – thus responses to Q53 of ‘2008’ will be set to missing during cleaning. Out-of-range responses will also be set to missing[3]. For the 2008 primary care trusts survey, out-of range responses are defined as **Q53≤1880 OR Q53≥2009**.

3.6 Usability and eligibility

Sometimes questionnaires are returned with only a very small number of questions completed. For the local health services survey 2008, questionnaires containing fewer than five responses are considered ‘unusable’ – we will delete all responses pertaining to such cases and outcome codes of 1 (‘returned useable questionnaire’) relating to these cases will be changed to 6 (‘questionnaire not returned’). Please note that the number of responses per questionnaire will be counted after all other cleaning, and that all responses remaining at this stage will be counted (including responses to the demographic questions and so on)[4]. This should only affect a very limited number of cases, and so should not have a significant impact on response rates.

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[1] Please note though that respondents will *not* be considered ineligible for the survey solely on the basis of their response to the year of birth question indicating that they are under the age of sixteen. This is because of the difficulty of inferring the source of errors when age from the sample information and year of birth from the response section are mismatched – in other words, because we cannot be *certain* whether this mismatch occurs due to an error in the sample file, an error in the patient’s completion of the questionnaire form, or an error in data entry *[see overleaf]*.

[2] Please note that whilst a combination of sample and response information is used for demographic analysis on groups of cases, **only the sample information is used to calculate response rates by demographic groups**. Unlike subgroup analysis of variables which is only carried out for respondents, response rates are calculated using all patients in the sample. Because response rates vary between groups with differing demographic variables, using response and sample data to calculate response rates would create a systematic source of bias in that we are only able to amend information for the *respondents*. Therefore, only the sample information should be used to calculate response rates by demographic groups.

[3] The majority of out-of range responses present in data relating to year of birth questions result from errors in data entry (for example, not keying one of the digits – so ‘1983’ may become 983, 183, 193, or 198). In such cases it is important that the responses be checked against the completed questionnaire forms, and data corrected if necessary, **prior** to submission of data to the Co-ordination Centre.

[4] Please note that the multiple choice questions, Q49 and Q50 are only counted once. So for example, even if Q49_1 and Q49_4 are ticked, this would count as only one response for the purpose of determining if a questionnaire is usable.

Outcome codes for respondents will also be changed if the respondents are believed to be under the age of sixteen and therefore ineligible for participation. Since the sample files for the survey have been drawn directly from the NHAIS system, this is unlikely to affect more than a handful of cases throughout the survey. Sample members will not, however, be removed from the sample if data on their age is missing from the sampling frame. If sample information on a respondent's age is missing, though, and their response to **Q53** indicates that they are under 16 (specifically, if **Q53 > 1992**) then the outcome code for that patient should be recoded from 1 ('returned completed questionnaire') to 5 ('ineligible for participation in the survey'). ***This should only be done where sample information is missing***. If sample information indicates a patient is aged 16 or over, but this is contradicted by the patient's response, then the patient's survey outcome should remain as 1. This is to avoid removing legitimate responses because of an overly conservative approach to assessing eligibility; in other words, where the patient's age is uncertain (because sample and response information contradict each other, and in different instances either of these may be accurate or inaccurate) the benefit of the doubt is given in any assessment of eligibility.

3.7 Missing responses

It is useful to be able to see the numbers of respondents who have missed each question for whatever reason. Responses are considered to be missing when a respondent is expected to answer a question but no response is present. For non-filtered questions, responses are expected from all respondents – thus any instance of missing data constitutes a missing response. For filtered questions, only respondents who have answered a previous routing question instructing them to go on to that filtered question or set of filtered questions are expected to give answers. Where respondents to the survey have missed a routing question, they are not expected to answer subsequent ‘filtered’ questions; thus only where respondents were explicitly instructed to answer filtered questions should such blank cells be coded as missing responses.

The Co-ordination Centre codes missing responses in the data with the value 999[1]. For results to be consistent with those produced by the Co-ordination Centre, missing responses should be presented but should not be included in the base number of respondents for percentages.

3.8 Non-specific responses

As well as excluding missing responses from results, the Co-ordination Centre also removes non-specific responses from base numbers for percentages. The rationale for this is to facilitate easy comparison between institutions by presenting only results from those patients who felt able to give an evaluative response to questions. For a full listing of ‘non-specific’ responses in the 2008 local health services survey, please see Appendix B: Non-specific responses.

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[1] This is an arbitrary value chosen because it is ‘out-of-range’ for all other questions on the survey.

4 Appendix A: Example of cleaning

4.1 Incorrectly followed routing

Figure 2: Example 'raw'/'uncleaned' data

Record Sample Reference Number	**Outcome** Outcome of sending questionnaire (N)	**Q1** Have you made an appointment with a doctor from your GP practice/ health centre in the last 12 months?	**Q2** The last time you saw a doctor from your GP practice/ health centre, how long did you wait for an appointment?	**Q3** What was the main reason you waited?	**Q4** How do you feel about the length of time you waited for an appointment with a doctor?	**Q5** If you want to make a doctor's appointment 3 or more working days in advance does your GP practice/ health centre allow you to do that?
A	6					
B	1	2	.	.	.	.
C	1	1	1	3	2	1
D	4					
E	1	2	2	.	.	.
F	6					
G	1	2	5	2	3	1
H	1	1	3	1	1	1

Figure 2 shows hypothetical raw/uncleaned data for eight sample members, five of whom have responded to the survey. It can be seen from this data that some of the respondents have followed filter instructions from routing questions incorrectly:

> Respondents 'E' and 'G' have reported that they haven't made a doctors appointment in the last 12 months (**Q1=2**), but have both responded to filtered questions ('E' has answered the first question after the filter (**Q2**) before skipping the remaining questions, whilst 'G' has answered **Q2**, **Q3**, **Q4** and **Q5**).

Following the cleaning instructions above will remove these inappropriate responses. Firstly, the filter instructions specify that:

if	**Q1**	=	2	*then delete responses to:*	**Q2 – Q5**

In accordance with this, all responses for **Q2**, **Q3**, **Q4** and **Q5** must be removed in cases where the respondent has ticked **Q1=2** ('waiting list or planned in advance'). Looking in column **Q1** we can see that three respondents, 'B', 'E' and 'G', have ticked **Q1=2**, so any responses they gave to questions two through to five should be removed. This will lead to one response being removed for patient 'E' (**Q2**) and four responses being removed for respondent 'G' (**Q2, Q3, Q4, and Q5**), who have for whatever reason followed the routing instructions incorrectly and continued to answer the section on making a doctors appointment.

Figure 3 (below) shows how the data would look following cleaning by the co-ordination centre to remove responses to filtered questions that should have been skipped – cells where responses have been removed are shaded.

Figure 3: Data from Figure 3 following cleaning

Record	**Outcome**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**
Sample Reference Number	Outcome of sending questionnaire (N)	Have you made an appointment with a doctor from your GP practice/ health centre in the last 12 months?	The last time you saw a doctor from your GP practice/ health centre, how long did you wait for an appointment?	What was the main reason you waited?	How do you feel about the length of time you waited for an appointment with a doctor?	If you want to make a doctor's appointment 3 or more working days in advance does your GP practice/ health centre allow you to do that?
A	6					
B	1	2	.	.	.	.
C	1	1	1	3	2	1
D	4					
E	1	2	.	.	.	.
F	6					
G	1	2	.	.	.	.
H	1	1	3	1	1	1

5 Appendix B: Non-specific responses

The following table lists all 'non-specific responses' included in the 2008 primary care trusts survey. Please note that this table also includes items from the question bank which are not included in the minimal 'core' questionnaire. Numbers in the final column indicate the response options that should be considered non-specific. Where the 'non-specific responses' column contains only a dash, the relevant question has no such response options.

CORE	BANK	Question	Non-specific responses
Q1	A1	Have you made an appointment with a doctor from your GP practice/ health centre in the last 12 months?	-
	A2	Was the last contact with a doctor from your GP practice about a medical problem for yourself or for a child in your care?	-
Q2	A3	The last time you saw a doctor from your GP practice/ health centre, how long did you wait for an appointment?	5, 6
Q3	A4	What was the main reason you waited?	-
Q4	A5	How do you feel about the length of time you waited for an appointment with a doctor?	-
Q5	A6	If you want to make a doctor's appointment 3 or more working days in advance does your GP practice/ health centre allow you to do that?	3
Q6	B1	Have you visited your GP practice/ health centre in the last 12 months?	-
Q7	B2	When you arrived, how would you rate the courtesy of the receptionist?	-
	B3	In the reception area, could other patients overhear what you talked about with the receptionist?	4
	B4	Were you offered the chance to speak to the receptionist in a private area?	-
Q8	B5	How long after your appointment time did you have to wait to be seen?	1, 6
Q9	B6	Did someone tell you how long you would have to wait?	4
Q10	C1	Have you seen a doctor from your GP practice/ health centre in the last 12 months?	-
Q11	C2	Did the doctor listen carefully to what you had to say?	-
Q12	C3	Were you given enough time to discuss your health or medical problem with the doctor?	4
Q13	C4	Were you involved as much as you wanted to be in decisions about your care and treatment?	-
Q14	C5	If you had questions to ask the doctor, did you get answers that you could understand?	4
Q15	C6	Did the doctor explain reasons for any treatment or action in a way that you could understand?	4, 5
Q16	C7	Did you have confidence and trust in the doctor?	-
	C8	Did the doctor know enough about your condition or treatment?	4
Q17	C9	Did the doctor treat you with respect and dignity?	-
	C10	Were you able to discuss any emotional issues that might be affecting your health (e.g. anxiety, depression)?	4
	C11	Were you able to discuss how your family and/or living situation might be affecting your health (e.g. housing problems, family responsibilities, work-related problems)?	4
Q18	D1	In the last 12 months, have you had any new medicine(s) (including tablets, suppositories, injections) prescribed to you by a doctor or nurse practitioner from your GP practice/ health centre?	3

CORE	BANK	Question	Non-specific responses
Q19	D2	Were you involved as much as you wanted to be in decisions about the best medicine for you?	-
Q20	D3	Were you given enough information about the purpose of the medicine?	4, 5
Q21	D4	Were you given enough information about any side-effects the medicine might have?	4, 5
Q22	D5	Were you given enough information about how to use the medicine (e.g. when to take it, how long you should take it for, whether it should be taken with food)?	4, 5
Q23	D6	Have you been taking any prescribed medicine(s) for 12 months or longer?	-
Q24	D7	In the last 12 months, have you seen anyone at your GP practice to check how you are getting on with this medicine (i.e. have your medicines been reviewed)?	3
	D8	In the last 12 months, have you asked a pharmacist for any advice on medicines?	-
	D9	Was the pharmacist's advice helpful?	4
	E1	In the last 12 months, have you had any tests (e.g. blood tests, swabs, smear tests) carried out by anyone from your health centre?	3
	E2	Was the purpose of the test(s) explained in a way you could understand?	4
	E3	Did someone tell you how you would get the results of your test(s)?	3
	E4	Did someone tell you when you should expect to get the results of your test(s)?	3
	E5	Did you get your test results on time?	3
	E6	Did someone explain the results of the tests in a way you could understand?	4, 5
Q25	F1	In the last 12 months, has anyone at your practice referred you to a specialist (e.g. a hospital consultant)?	-
Q26	F2	When you were referred to see a specialist, were you offered a choice of hospital for your first hospital appointment?	3
	F3	Did you GP tell you why you were not offered a choice about where you were referred to?	4
	F4	How many different choices were you offered? (Your choices may have included different hospitals or community based services, such as GPs with special interests or community clinics)	5
	F5	Overall, were you given enough information by your GP or another health care professional at your GP practice/ health centre to help you make your choice?	4
	F6	Who or what were your source or sources of information about the different places?	7
	F7	Were you given a choice about who you were referred to (i.e. which specialist)?	4
Q27	F8	When you first saw the person you were referred to, did he/she seem to have all the necessary information about you and your condition or treatment?	4, 5
Q28	F9	Did you receive copies of letters sent between the specialist and your GP?	4, 5
Q29	G1	Have you seen anyone else from a GP practice/ health centre other than a doctor in the last 12 months?	-
Q30	G2	The last time you saw someone other than a doctor from a GP practice/ health centre, who did you see?	-

CORE	BANK	Question	Non-specific responses
Q31	G3	The last time you saw this person, how long did you wait for an appointment?	6,7
Q32	G4	What was the main reason you waited?	-
Q33	G5	How do you feel about the length of time you waited for an appointment with this person?	-
	G6	Were you involved as much as you wanted to be in decisions about your care and treatment?	4
	G7	Did that person explain the reasons for any treatment or action in a way that you could understand?	4, 5
	G8	Did that person treat you with respect and dignity?	-
	G9	Did you have confidence and trust in that person?	-
	H1	In the past 12 months, have you tried ot contact your local health centre/ GP practice about a medical problem when the practice was closed, either on your own behalf or for someone else?	-
	H2	The last time you called the practice out of hours, did you get through to someone?	-
	H3	If a doctor or nurse came to visit you at home, how long did you wait from the time you finished the telephone call?	6
	H4	Overall, was the main reason you contacted the practice out of hours dealt with to your satisfaction?	-
	H5	Have you heard of NHS Direct (a 24 hour helpline staffed by nurses)?	3
	H6	In the last 12 months, have you contacted NHS Direct, either on your own behalf or on behalf of someone else?	-
	H7	Was your call to NHS Direct dealt with satisfactorily?	-
Q34	J1	Was the main reason you went to your GP practice/ health centre dealt with to your satisfaction?	-
Q35	J2	In your opinion, how clean is the GP practice/ health centre?	5
	J3	How easy do you find it to move around inside the practice/ health centre?	4
Q36	J4	Have you had a problem getting through to your GP practice/ health centre on the phone?	4
	J5	In the last 12 months, have you talked over the phone to a doctor from your GP practice/ health centre about a medical problem?	-
Q37	J6	In the last 12 months, have you ever been put off going to your GP practice/ health centre because the opening times are inconvenient for you?	-
	J7	If it were possible for your GP practice/ health centre to open at additional times, which of these times would you most like it to be open?	-
	J8	If your GP practice/ health centre were to be open either earlier in the morning or later in the evening, how many days a week would you want this to happen?	4
	J9	If your GP practice/ health centre were to be open extra hours but had to close for some of its normal hours to allow this, would this be acceptable to you?	-
	J10	Do you need help understanding English?	-
	J11	The last itme you saw someone from your local health centre/ GP practice, was there someone who could interpret for you?	-
Q38	K1	Do you visit a dentist regularly (that is at least once every 2 years)?	4
Q39	K2	Would you like to receive dental care as an NHS patient?	-
	K3	In the last 24 months, have you visited a dentist as an NHS patient?	3
	K4	Why did you go to a dentist?	-

CORE	BANK	Question	Non-specific responses
	K5	How long did it take to get an appointment?	-
	K6	Were you involved as much as you wanted to be in decisions about your dental care and treatment?	-
	K7	Did the dentist explain the reasons for any treatment or action in a way that you could understand?	4, 5
	K8	Did you have confidence and trust in the dentist?	-
	K9	Did dental staff do everything they could to help control any pain you experienced?	4, 5
	K10	Overall, was the main reason for this visit dealt with satisfactorily?	-
	K11	Have You tried to get out-of-hours dental treatment as an NHS patient during the past 12 months?	-
Q40	L1	In the last 12 months have you had your blood pressure taken by anyone from your GP practice/ health centre?	3
Q41	L2	In the last 12 months, have you been given advice from your GP practice/ health centre on your weight?	5
Q42	L3	In the last 12 months, have you been given advice or help from your GP practice/ health centre on eating a healthy diet?	4
Q43	L4	How regularly do you eat the recommended 5 portions of fruit or vegetables a day?	5
Q44	L5	In the last 12 months, have you been given advice or help from your GP practice/ health centre on getting enough exercise?	4
	L6	How many days a week on average, do you do at least 30 minutes of physical activity (e.g. brisk walking, cycling, sport, heavy housework/ gardening, or as part of a physically active job)?	5
	L7	Thinking about smoking, which of the following best applies to you?	-
Q45	L8	In the last 12 months, have you been given advice or help from your GP practice/health centre on giving up smoking?	1, 5
Q46	L9	In the last 12 months, have you been asked by someone at your GP practice/ health centre about how much alcohol you drink?	3
Q47	L10	In the last 12 months, have you been given advice or help from your GP practice/health centre on sensible alcohol intake?	4, 5
Q48	L11	How many units of alcohol do you normally drink in a week? (1 unit is roughly equivilant to one small glass of wine, half a pint of beer or one pub measure of spirits)	6
Q49_1	L12_1	I have a long-standing condition involving deafness or hearing impairment	-
Q49_2	L12_2	I have a long-standing condition involving blindness or are partially sighted	-
Q49_3	L12_3	I have a long-standing physical condition	-
Q49_4	L12_4	I have a long-standing condition involving a learning disability	-
Q49_5	L12_5	I have a long-standing mental health condition	-
Q49_6	L12_6	I have a long-standing condition involving an illness such as cancer, HIV, diabetes, CHD, or epilepsy	-
Q49_7	L12_7	I do not have a long-standing condition	-
Q50_1	L13_1	This condition causes me difficulty with everyday activities that people of my age can usually do	-
Q50_2	L13_2	This condition causes me difficulty at work, in education, or training	-
Q50_3	L13_3	This condition causes me difficulty with access to buildings, streets, or transport vehicles	-
Q50_4	L13_4	This condition causes me difficulty with reading or writing	-
Q50_5	L13_5	This condition causes me difficulty with people's attitudes to me because of my condition	-

CORE	BANK	Question	Non-specific responses
Q50_6	L13_6	This condition causes me difficulty with communicating, mixing with others, or socializing	-
Q50_7	L13_7	This condition causes me difficulty with other activities	-
Q50_8	L13_8	This condition does not cause me difficulty with any of these	-
Q51	L14	In the last 12 months, have you had enough support from local services or organisations to help you to manage your long-term health condition(s)? (Please think about all services and organisations, not just health services)	4,5
	L15	In the last 12 months, have you been offered a flu jab (influenza vaccination)?	4, 5
	L16	In the last 12 months, have you been given advice or help from your GP practice/ health centre on contraception/family planning?	4, 5
	L17	In the last 12 months, have you neen given advice or help from your GP practice/ health centre on safer sex?	4, 5
	M1	When did you last have an eye test?	3
	M2	Do you have any problems with your hearing which affect your everyday life?	-
	M3	Have you ever been provided with advice/assistance to enable you to cope with your hearing problem?	-
	M4	Do you have any difficulty carrying out your daily activities (dressing, washing, going to the toilet, moving about your home, cooking a meal etc)?	-
	M5	Have you been provided with advice to help you cope with carrying out your daily activities?	-
	N1	Would you know how to get involved in making decisions about the NHS in your area? (e.g. attending meetings, becoming a member of a local patients group)	-
	N2	Have you changed your GP (family doctor) within the last 12 months?	-
	N3	What was the reason for this change?	-
	N4	How easy was it to register with another GP (family doctor)?	-
	N5	Have you received a copy of Your Guide to Local Health Services? (This is a leaflet on local NHS services and how to access them).	3
	N6	Did you find the Guide to Local Health Services useful?	4
Q52	P1	Are you male or female?	-
Q53	P2	What was your year of birth?	-
Q54	P3	How old were you when you left full-time education?	-
Q55	P4	Overall, how would you rate your health during the past 4 weeks?	-
	P5	Are you the parent or guardian of anyone aged under 18 who lives with you?	-
	P6	Do you look after, or give special help to anyone who is sick, has a disability, or is an older person, other than in a professional capacity?	4
Q56	P7	To which of these ethnic groups would you say you belong? (Tick ONE only)	-

6 Submitting data

Data may be submitted to the Co-ordination Centre either by e-mail or by post (with the data on a CD or floppy disk). There is no requirement for the anonymised dataset to be password protected. Data should be submitted to the following address:

By e-mail: primarycare@PickerEurope.ac.uk

or

By post: Co-ordination Centre for the Primary Care Trust Survey
Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

Local Health Services Questionnaire

What is the survey about?

This survey is about your experience of the services provided by the NHS in your area. Your views are very important in helping us to find out how well the services work and how they can be improved.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/ her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. These instructions are always shown in blue text. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

Your participation in this survey is voluntary.

If you choose not to take part in this survey it will not affect the care you receive from the NHS in any way. If you do not wish to take part, or you do not want to answer some of the questions, you do not have to give us a reason.

Your answers will be treated in confidence.

A. MAKING AN APPOINTMENT

Please answer these questions thinking about any health care EITHER for yourself OR for a child in your care

1. Have you **made an appointment** with a doctor from your GP practice/ health centre in the last 12 months?

1 ☐ Yes ➔ **Go to 2**
2 ☐ No ➔ **Go to 6**

Thinking about your LAST appointment or home visit …

2. The **last** time you saw a doctor from your GP practice/ health centre, how long did you wait for an appointment?

1 ☐ I was seen without an appointment ➔ **Go to 5**
2 ☐ I was seen on the same working day ➔ **Go to 4**
3 ☐ I waited 1 or 2 working days ➔ **Go to 3**
4 ☐ I waited more than 2 working days ➔ **Go to 3**
5 ☐ It was a pre-planned appointment or visit ➔ **Go to 4**
6 ☐ Can't remember ➔ **Go to 4**

3. What was the main reason you waited? (**Tick ONE only**)

1 ☐ I wanted to see **my own choice** of doctor
2 ☐ I could not get an earlier appointment with **any** doctor at my GP practice/ health centre
3 ☐ It was **not convenient for me** to have an appointment at any earlier time
4 ☐ Another reason

4. How do you feel about the length of time you waited for an appointment with a doctor?

1 ☐ I was seen as soon as I thought was necessary
2 ☐ I should have been seen **a bit sooner**
3 ☐ I should have been seen **a lot sooner**

5. If you want to make a doctor's appointment **3 or more working days in advance** does your GP practice/ health centre allow you to do that?

1 ☐ Yes
2 ☐ No
3 ☐ Don't know/ Not sure

B. VISITING THE GP PRACTICE/ HEALTH CENTRE

6. Have you **visited** your GP practice/ health centre in the last 12 months?

1 ☐ Yes ➔ **Go to 7**
2 ☐ No ➔ **Go to 10**

Thinking about your LAST visit to the GP practice/ health centre…

7. When you arrived, how would you rate the courtesy of the receptionist?

1 ☐ Excellent
2 ☐ Very good
3 ☐ Good
4 ☐ Fair
5 ☐ Poor
6 ☐ Very poor

8. How long **after your appointment time** did you have to wait to be seen?

1 ☐ I did not have an appointment ➔ **Go to 9**
2 ☐ Seen on time or early ➔ **Go to 10**
3 ☐ Waited up to 15 minutes ➔ **Go to 9**
4 ☐ Waited 16-30 minutes ➔ **Go to 9**
5 ☐ Waited 31 minutes or longer ➔ **Go to 9**
6 ☐ Can't remember ➔ **Go to 9**

9. Did someone tell you how long you would have to wait?

1 ☐ Yes

2 ☐ No, but I would have liked to have been told

3 ☐ No, but I did not mind

4 ☐ Not sure/ Can't remember

C. SEEING A DOCTOR

10. Have you seen **a doctor** from your GP practice/ health centre in the last 12 months?

1 ☐ Yes ➔ **Go to 11**

2 ☐ No ➔ **Go to 18**

Thinking about the LAST TIME you saw a doctor from your GP practice/ health centre…

11. Did the doctor **listen carefully** to what you had to say?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

12. Were you given **enough time** to discuss your health or medical problem with the doctor?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ I did not need to discuss anything

13. Were you **involved** as much as you wanted to be in decisions about your care and treatment?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

14. If you had **questions** to ask the doctor, did you get answers that you could understand?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ I did not need to ask any questions

5 ☐ I did not have an opportunity to ask questions

15. Did the doctor explain the reasons for any treatment or action in a way that you could understand?

1 ☐ Yes, completely

2 ☐ Yes, to some extent

3 ☐ No

4 ☐ I did not need an explanation

5 ☐ No treatment or action was needed

16. Did you have **confidence and trust** in the doctor?

1 ☐ Yes, definitely

2 ☐ Yes, to some extent

3 ☐ No

17. Did the doctor treat you with **respect and dignity**?

1 ☐ Yes, all of the time

2 ☐ Yes, some of the time

3 ☐ No

D. MEDICINES (eg. tablets, ointment, oral contraceptives)

18. In the last 12 months, have you had any **new** medicine(s) (including tablets, suppositories, injections) prescribed for you by a doctor or nurse practitioner from your GP practice/ health centre?

1 ☐ Yes ➔ **Go to 19**

2 ☐ No ➔ **Go to 23**

3 ☐ Can't remember ➔ **Go to 23**

Thinking about the LAST time you had a new medicine prescribed for you by someone from your GP practice/ health centre…

19. Were you involved as much as you wanted to be in decisions about the best medicine for you?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No

20. Were you given enough information about the **purpose** of the medicine?

1 ☐ **Yes**, enough information
2 ☐ **Some**, but I would have liked more
3 ☐ I got **no information**, but I wanted some
4 ☐ I **did not want**/ **need** any information
5 ☐ Don't know/ Can't say

21. Were you given enough information about any **side-effects** the medicine might have?

1 ☐ **Yes**, enough information
2 ☐ **Some**, but I would have liked more
3 ☐ I got **no information**, but I wanted some
4 ☐ I **did not want**/ **need** any information
5 ☐ Don't know/ Can't say

22. Were you given enough information about **how to use** the medicine (e.g. when to take it, how long you should take it for, whether it should be taken with food)?

1 ☐ **Yes**, enough information
2 ☐ **Some**, but I would have liked more
3 ☐ I got **no information**, but I wanted some
4 ☐ I **did not want**/ **need** any information
5 ☐ Don't know/ Can't say

23. Have you been taking any prescribed medicine(s) for 12 months or longer?

1 ☐ Yes ➔ **Go to 24**
2 ☐ No ➔ **Go to 25**

24. In the last 12 months, have you seen anyone at your GP practice/ health centre to check how you are getting on with this medicine (i.e. have your medicines been reviewed)?

1 ☐ Yes
2 ☐ No
3 ☐ Don't know/ Not sure

E. REFERRALS

25. **In the last 12 months**, has anyone at your GP practice/ health centre referred you to a specialist (e.g. a hospital consultant)?

1 ☐ Yes ➔ **Go to 26**
2 ☐ No ➔ **Go to 29**

26. When you were referred to see a specialist, were you offered a choice of **hospital** for your first hospital appointment?

1 ☐ Yes
2 ☐ No
3 ☐ Don't know/ Can't remember

Thinking about the LAST specialist you were referred to…

27. When you first saw the person you were referred to, did he/ she seem to have all the necessary information about you and your condition or treatment?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I have not been yet
5 ☐ Don't know/ Can't remember

28. Did you receive **copies of letters** sent between the specialist and your GP?

1 ☐ Yes, as far as I know I received copies of **all** letters
2 ☐ I received copies of **some but not all** letters
3 ☐ No, I **did not receive copies** of any letters
4 ☐ I do not know if any letters were sent
5 ☐ I asked not to receive copies of letters

F. SEEING ANOTHER PROFESSIONAL FROM A GP PRACTICE/ HEALTH CENTRE

29. Have you seen anyone else from a GP practice/ health centre **other than a doctor** in the last 12 months?

1 ☐ Yes ➔ **Go to 30**
2 ☐ No ➔ **Go to 34**

30. The **last time** you saw someone other than a doctor from a GP practice/ health centre, who did you see? (**Tick ONE only**)

1 ☐ A practice nurse or nurse practitioner
2 ☐ A midwife
3 ☐ A district nurse
4 ☐ A health visitor
5 ☐ Someone else
6 ☐ I was not sure who I saw

31. The **last** time you saw this person, how long did you wait for an appointment?

1 ☐ I was seen without an appointment ➔ **Go to 34**
2 ☐ I was seen on the same working day ➔ **Go to 33**
3 ☐ I waited 1 working day ➔ **Go to 32**
4 ☐ I waited 2 working days ➔ **Go to 32**
5 ☐ I waited more than 2 working days ➔ **Go to 32**
6 ☐ It was a pre-planned appointment or visit ➔ **Go to 33**
7 ☐ Can't remember ➔ **Go to 33**

32. What was the main reason you waited? (**Tick ONE only**)

1 ☐ I wanted to see **my own choice** of professional
2 ☐ I could not get an earlier appointment with **any other professional** at my GP practice / health centre
3 ☐ It was **not convenient for me** to have an appointment at any earlier time
4 ☐ Another reason

33. How do you feel about the length of time you waited for an appointment with this person?

1 ☐ I was seen as soon as I thought was necessary
2 ☐ I should have been seen **a bit sooner**
3 ☐ I should have been seen **a lot sooner**

G. OVERALL ABOUT YOUR GP PRACTICE/ HEALTH CENTRE

34. Was the main reason you went to your GP practice/ health centre dealt with to your satisfaction?

1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No

35. In your opinion, how clean is the GP practice/ health centre?

1 ☐ Very clean
2 ☐ Fairly clean
3 ☐ Not very clean
4 ☐ Not at all clean
5 ☐ Can't say

36. Have you had a problem getting through to your GP practice/ health centre on the phone?

1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No
4 ☐ I have not tried to get through on the phone

37. In the last 12 months, have you ever been put off going to your GP practice/ health centre because the opening times are inconvenient for you?

1 ☐ Yes, often
2 ☐ Yes, sometimes
3 ☐ No

H. DENTAL CARE

38. Do you visit a dentist regularly (that is at least once every 2 years)?

1 ☐ Yes – as an NHS patient ➔ **Go to 40**
2 ☐ Yes – as a non-NHS patient ➔ **Go to 39**
3 ☐ No ➔ **Go to 39**
4 ☐ Don't know ➔ **Go to 39**

39. Would you **like to** receive dental care as an NHS patient?

1 ☐ Yes
2 ☐ No

J. HEALTH PROMOTION

40. In the last 12 months have you had your **blood pressure** taken by anyone from your GP practice/ health centre?

1 ☐ Yes
2 ☐ No
3 ☐ Not sure/ Can't remember

41. In the last 12 months, have you been given advice from your GP practice/ health centre on your **weight**?

1 ☐ Yes – I was told I should try to lose weight
2 ☐ Yes – I was told I should try to stay the same weight
3 ☐ Yes – I was told I should try to gain weight
4 ☐ No, but I would have liked some advice
5 ☐ No, but I did not want any advice

42. In the last 12 months, have you been given advice or help from your GP practice/ health centre on **eating a healthy diet**?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, but I would have liked help/ advice
4 ☐ No, but I did not want any help/ advice

43. How regularly do you eat the recommended 5 portions of fruit or vegetables a day?

1 ☐ Everyday
2 ☐ Most days but not everyday
3 ☐ 1-3 days per week
4 ☐ Less often than 1 day per week
5 ☐ Don't know/ Can't say

44. In the last 12 months, have you been given advice or help from your GP practice/ health centre on **getting enough exercise**?

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No, but I would have liked help/ advice
4 ☐ No, but I did not want any help/ advice

45. In the last 12 months, have you been given advice or help from your GP practice/ health centre on **giving up smoking**?

1 ☐ I have not smoked in the last 12 months
2 ☐ Yes, definitely
3 ☐ Yes, to some extent
4 ☐ No, but I would have liked help /advice
5 ☐ No, but I did not want any help/ advice

46. In the last 12 months, have you been asked by someone at your GP practice/ health centre about how much alcohol you drink?

1 ☐ Yes
2 ☐ No
3 ☐ Don't know/ Can't remember

47. In the last 12 months, have you been given advice or help from your GP practice/ health centre on **sensible alcohol intake**?

1 ☐ Yes, definitely ➔ **Go to 48**
2 ☐ Yes, to some extent ➔ **Go to 48**
3 ☐ No, but I would have liked help/advice ➔ **Go to 48**
4 ☐ No, but I did not want any help/advice ➔ **Go to 48**
5 ☐ I do not drink alcohol ➔ **Go to 49**

48. How many units of alcohol do you normally drink in a week? (1 unit is roughly equivalent to one small glass of wine, half a pint of beer or one pub measure of spirits)

1 ☐ I do not drink alcohol
2 ☐ Less than 14 units
3 ☐ Between 14-21 units
4 ☐ Between 22-29 units
5 ☐ More than 29 units
6 ☐ Don't know/ Can't say

49. Do you have any of the following long-standing conditions? (**Tick ALL that apply**)

1 ☐ Deafness or severe hearing impairment ➔ **Go to 50**
2 ☐ Blindness or partially sighted ➔ **Go to 50**
3 ☐ A long-standing physical condition ➔ **Go to 50**
4 ☐ A learning disability ➔ **Go to 50**
5 ☐ A mental health condition ➔ **Go to 50**
6 ☐ A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease or epilepsy ➔ **Go to 50**
7 ☐ No, I do not have a long-standing condition ➔ **Go to 52**

50. Does this condition(s) cause you difficulty with any of the following? **(Tick ALL that apply)**

1 ☐ Everyday activities that people your age can usually do
2 ☐ At work, in education, or training
3 ☐ Access to buildings, streets, or vehicles
4 ☐ Reading or writing
5 ☐ People's attitudes to you because of your condition
6 ☐ Communicating, mixing with others, or socialising
7 ☐ Any other activity
8 ☐ No difficulty with any of these

51. In the last 12 months, have you had enough support from local services or organisations to help you to manage your long-term health condition(s)? *(Please think about all services and organisations, not just health services)*

1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ No, but I have not needed such support
5 ☐ Don't know/ Can't say

K. ABOUT YOU

52. Are you male or female?

1 ☐ Male
2 ☐ Female

53. What was your **year** of birth?

(Please write in) e.g. | 1 | 9 | 3 | 4 |

54. How old were you when you left full-time education?

1 ☐ 16 years or less
2 ☐ 17 or 18 years
3 ☐ 19 years or over
4 ☐ Still in full-time education

55. Overall, how would you rate your health during the **past 4 weeks**?

1 ☐ Excellent
2 ☐ Very good
3 ☐ Good
4 ☐ Fair
5 ☐ Poor
6 ☐ Very poor

56. To which of these ethnic groups would you say you belong? **(Tick ONE only)**

a. WHITE

1 ☐ British

2 ☐ Irish

3 ☐ Any other White background **(Please write in box)**

☐

b. MIXED

4 ☐ White and Black Caribbean

5 ☐ White and Black African

6 ☐ White and Asian

7 ☐ Any other Mixed background **(Please write in box)**

☐

c. ASIAN OR ASIAN BRITISH

8 ☐ Indian

9 ☐ Pakistani

10 ☐ Bangladeshi

11 ☐ Any other Asian background **(Please write in box)**

☐

d. BLACK OR BLACK BRITISH

12 ☐ Caribbean

13 ☐ African

14 ☐ Any other Black background **(Please write in box)**

☐

e. CHINESE OR OTHER ETHNIC GROUP

15 ☐ Chinese

16 ☐ Any other ethnic group **(Please write in box)**

☐

OTHER COMMENTS

Is there anything particularly good about your local health care?

Is there anything that could be improved?

Any other comments?

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the FREEPOST envelope provided.

No stamp is needed