NHS trust-based patient surveys: acute and specialist hospital trusts

Young patients 2004

Listening to your patients

Last updated 20 February 2004

This document is available from the NHS Survey Advice Centre website at:

http://www.NHSSurveys.org

Contacts

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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 directly to inform them of the change.

Adult Survey

All acute and specialist NHS trusts in England will also be required to carry out a survey of patients aged 18 and over in 2003/04. A separate guidance manual and questionnaire for this survey is available from the NHSSurveys website.

Changes to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in the guidance manual. For example, offering financial inducements or lottery prizes to respondents. 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 this could affect the calculation of performance indicators. If trusts want to make any adjustments to the method set out in this guidance, they will need to seek local research ethics approval, and to check with the Advice Centre that the proposed alteration would not compromise comparability.

Please direct questions or comments about this guidance to:

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1 Introduction: patient feedback and the NHS Plan

1.1 The Commission for Health Improvement

The national patient survey programme is now being led by the Commission for Health Improvement (CHI). The Commission for Health Improvement's aim is to improve the quality of patient care in the NHS. Patients' experience of health services is at the heart of CHI's work.

1.2 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 health care, 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 health care is delivered. This manual is designed to help staff in acute and specialist NHS trusts to obtain patient feedback. It also provides guidance on how you may use the information in quality improvement programmes and for monitoring purposes. 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.

1.3 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 plan 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 Trust 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 CHI/CHAI's programme of reviews and inspections.

1.4 Performance indicators

Information drawn from the Young Patients surveys will be used by CHI/CHAI to create headline NHS Performance Indicators. These indicators will be used in Acute and Specialist Trust Performance Ratings, due for publication in summer 2004.

In addition to the performance indicators, CHI/CHAI 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. By asking each acute and specialist trust to carry out surveys of both Adult Inpatients and Children in a consistent way, CHI is building up a detailed picture of patients' experiences in acute NHS trusts across the country. Also, by repeating the same surveys on a bi-annual basis, trusts will be able to monitor their own performance over time.

1.5 Basic requirements for NHS trust Young Patient surveys

In order for comparisons between and within trusts to be accurate, fair and effective, it is essential that the surveys be carried out using a standard procedure in all NHS trusts. Those standards are set out in detail later in this document. In summary, they are as follows:

- You must contact the Survey Advice Centre by **16th January 2004** and tell them who is carrying out your survey (i.e. whether it will be carried out by an approved contractor or in-house), and who in your trust will be responsible for monitoring the survey's progress (e-mail: inpatient.data@pickereurope.ac.uk).
- A postal questionnaire survey must be carried out.
- The sampling procedure set out in this guidance must be followed.
- The questionnaire must be sent to 850 inpatients/day cases aged 0-17 discharged alive from the trust (excluding maternity and psychiatry patients).
- The sample of patients must consist of the most recent consecutive discharges up to the last date of **either** November 2003 **or** January 2004**.**
- The sampling procedure set out in this guidance must be followed.
- The response rate should be at least 60% and the sample size must be 850 patients. That is, you should get 500 returned questionnaires from the 850 mailed out. Three mailings will be necessary to achieve this target.
- The data file must be submitted to the Survey Advice Centre in the form outlined in 13.3 - *Submitting data to the Patient Survey Advice Centre* by **30th April 2004**.
- Two copies each of the questionnaire you used, and all of the covering letters for **each mailing** must be submitted to the Survey Advice Centre in the form outlined in 13.3 - *Submitting data to the Patient Survey Advice Centre* by **30th April 2004**.
- You must use the two standard 12-page Young Patients Questionnaires available on the NHSSurveys website. The parent or guardian version must be used for patients aged 0-11 and the version addressed directly to the patient must be sent to 12- to17-year-olds.
- The data must be checked carefully for errors before submitting it to the Advice Centre. See Section 13 - *Entering data*
- You must keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until 31st August 2004 but please **do not** send these to the Advice Centre.

1.6 How to use 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 9 and 14 to 16 of this guide. Sections 11, 12 and 13 cover the practicalities of mailing out the survey, following-up responses and processing the results. These sections will be most relevant to approved contractors, or trusts undertaking the surveys themselves.

2 Setting up a project team

Whether you choose to do the survey in-house, or to use an Approved Survey Contractor, you will need to set up a project team. Too often, key players and stakeholders are left out of planning and implementation phases of a patient survey and are forced to respond to results for which they feel no ownership. 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.

- **Establish a workgroup.** Put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:
    - Board members
    - Members of Patients' Forum (where established)
    - Doctors, nurses and other health care staff
    - Administrators
    - Medical records personnel or Patient Administration System staff
    - Patients and carers
    - Caldicott Guardian
    - Staff or directors responsible for:
        - Clinical governance
        - Patient advice and liaison service (PALS)
        - Quality improvement
        - Strategic planning
- **Involve the person responsible for drawing the patient sample** in planning meetings. It is essential that this person, and their line manager, understand the purpose of the survey and the importance of drawing the sample correctly.
- **Keep everyone informed.** Notify as many people as possible about ideas and activities. All departments in the trust that have contact with patients should be made aware when a survey is being conducted, in case patients ask questions.
- **Do not overlook front-line staff**, who have the most frequent direct contact with patients. Staff can become nervous and defensive if they are not formally told about a patient survey. These feelings can compromise the effectiveness of the survey and increase resistance to any negative feedback.

3 Approved Survey Contractor versus in-house surveys

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

- Costs
- Quality and confidence in the findings
- Timing
- Human resources

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 factor in the cost of staff time, including salary and fringe benefits, and time spent away from other work.

Materials

Stationery and postage

You will need to cover stationery and postage for three mailings. The first mailing will go out to 850 patients and second and third mailings will be sent only to non-responders. (See Section 11 – *Materials* for more details.) You will also 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

The FREEPOST address can be printed on return envelopes so that respondents can send back the survey at no cost to themselves. There is a charge for obtaining a FREEPOST licence. (For details, see 12.2 - *Setting up a FREEPOST address*.)

FREEPHONE service

This service gives patients easy access to advice and staff can reassure them on any concerns they have about the survey. The cost of setting up the service and of staff time in responding needs to be considered. (For details, see 12.3 - *Setting up a FREEPHONE line*.)

Data entry

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

Design and production of reports

This requires a considerable amount of skilled staff time.

3.2 Quality and confidence in the findings

Rigorous methodology is especially important if the data are to be used to compare experiences among groups of patients, to make precise estimates of problems or for Performance Indicators. A good survey provider will use methods that assure statistical validity and unbiased results.

Valid, credible comparisons can only be made using data that are collected with the same instrument, using similar methods. That is, by comparing like with like. All participating trusts should use the same sampling methods to ensure that you are comparing information about the same types of patients. Without such standardisation, comparative data will not be valid and reliable.

Since the results are to be used in a public forum, where their credibility might be questioned, it is advisable to hire an Approved Survey Contractor. Patients, too, might be sceptical about feedback that is collected by trusts themselves. Results that come from an independent source may be taken more seriously.

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. On the other hand, if you commission an Approved Contractor to carry out the survey, you should ensure that appropriate and realistic deadlines are set.

3.4 Human resources

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

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

When you have decided who will carry out your survey, you must inform the Advice Centre. The deadline for this is 16th January 2004.

4 Commissioning a survey from an Approved Contractor

The framework agreement set up by the Department of Health 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, e.g. FREEPHONE line
- Data entry, cleaning data and providing data to Survey Advice Centre by the deadline
- Preparing standard reports for trusts.

Fourteen organisations have been approved by the Department of Health to carry out the local NHS Trust Surveys. Trusts may commission one of these contractors without further tendering for the survey work. Before committing to a contractor, you are advised to **check exactly what is covered** within the cost quoted.

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

The standard documents submitted by Approved Contractors cover all surveys in the NHS survey programme, including Acute Trusts, Primary Care Trusts, Mental Health Trusts and Ambulance Trusts. Note that the Young Patients' Survey differs from the Adult Inpatient Survey in that there are only standard questionnaires, so contractors will not be able to insert extra questions from a question bank, or include any other extra questions. Therefore, it will not be appropriate for contractors to quote for the cost of adding extra questions.

4.1 List of approved contractors

Ipsos-RSL

Contact: Sam McGuire

Head of Social & Public Sector Research
Ipsos – RSL
Kings House
Kymberley Road
Harrow
HA1 1PT
Tel: 020 8861 8703
Fax: 020 8863 0957
E-mail: sam.mcguire@ipsos.com

Maritz

Contact: Gavin Sugden
Associate Director
Maritz Research
Seagate House
Globe Park
Marlow
SL7 1LW

Tel: 01628 895 508
Fax: 01628 478 869
E-mail: gsugden@maritz.co.uk

Market Research UK

Contact: Craig Taylor; Jo Cleaver; Rachel Cope

Market Research UK
King William House
13 Queen Square
Bristol
BS1 4NT

Tel : 0117 987 2844 (South/South West/Midlands);
0207 388 5228 (London/South East/ East);
0161 234 0130 (North)
Fax : 0117 987 3385; 0207 388 8644; 0161 234 0129
E-mail: info@mruk.co.uk; london@mruk.co.uk; research@mruk.co.uk

Marketing Sciences

Contact: Eileen Sutherland

Marketing Sciences
8 Clement Street
Winchester
Hants
SO23 9DR

Tel: 01962 842211
Fax: 01962 840486
E-mail: esutherland@marketing-sciences.com
Website: www.marketing-sciences.com/

Market & Opinion Research International (MORI)

Contacts: Tim Jennings, Mark Gill

MORI Health Research,
Market & Opinion Research International (MORI),
79-81 Borough Road
London
SE1 1FY

Tel: 020 7347 3000
Fax: 020 7347 3800
E-mail: tim.jennings@mori.com; mark.gill@mori.com
Website: www.mori.com

MSB Ltd

Contact: Stephen Harwood

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

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

NFO System Three

Contact: Carys Alty
Wembley Point
Harrow Road
Wembley
Middlesex
HA9 6DE

Tel: 020 8782 3000
Fax: 020 8900 1500
Email: carys.alty@nfoeurope.com
Website: www.nfoeurope.com

NOP

Contacts: Richard Glendinning, Tim Buchanan, Claire Ivins or Sarah McHugh

NOP Social and Political
Ludgate House
245 Blackfriars Road
London
SE1 9UL

Tel: 020 7890 9000 (Switchboard)
Fax: 020 7890 9744
E-mail: r.glendinning@nopworld.com; t.buchanan@nopworld.com; c.ivins@nopworld.com; s.mchugh@nopworld.com

Website: www.nop.co.uk

ORC International

Contact: Rory MacNeill

Account Manager
Public Sector Research
ORC International
Angel Corner House
1 Islington High Street
London
N1 9AH

Tel: 020 7675 1066
Fax: 020 7675 1908
E-mail: rory.macneill@orc.co.uk; patientsurvey@orc.co.uk

Patient Dynamics

Contact: Andrew Smith

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

Tel: 01494 536346
Fax: 01494 536146
E-mail: andrew.smith@patientdynamics.org.uk

Picker Institute Europe

Contacts: Stephen Bruster, Bridget Hopwood, Tim Markham or Nick Richards

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

PricewaterhouseCoopers

Contact: Dave Ingram, National Project Coordinator – Patient Surveys

PricewaterhouseCoopers
Erskine House
68-73 Queen Street
Edinburgh
EH2 4NH

Tel: 0131 260 4101
Fax: 0131 260 4008
E-mail: dave.ingram@uk.pwcglobal.com
Website: www.pwchealth.com/

Quality Health

Contact: Dr Reg Race

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

Tel: 01246 856263 or 851143
Fax: 01246 851143
Email: QHConsult@aol.com
Website: www.quality-health.co.uk

Taylor Nelson Sofres

Contact: Susannah Quick or Christine Jamieson

Taylor Nelson Sofres
Holbrooke House
34 – 38 Hill Rise
Richmond
Surrey
TW10 6UA

Tel: 020 8332 8551/8557
Fax: 020 8332 1090
Email: susannah.quick@tnsofres.com or Christine.jamieson@tnsofres.com
Website: www.tnsofres.com

4.2 Contracts

In addition to standard contractual terms and conditions, the contract should specify the following:

- The groups, and numbers, of patients to be surveyed
- The survey methodology (i.e. postal questionnaire with two reminders to non-responders)
- Exactly what the survey provider and the trust are responsible for in carrying out the survey project
- The main person at the survey provider and the person at the trust responsible for managing the project
- A timetable showing the dates on which each task is to be carried out and by whom
- Copies of the questionnaire(s) to be used
- 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 survey contractors
- The costs and a payment schedule.

5 Data protection and confidentiality

You will need to ensure that you comply with the Data Protection Act 1998, and that patient responses are kept confidential. You will also need to take care that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. Your trust's Caldicott Guardian will be able to advise you on matters of data protection.

5.1 Caldicott

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

Further information about the use of patient information and the Data Protection Act can be found at:

http://www.doh.gov.uk/dpa98/

5.2 Patients' names and addresses

To comply with the Data Protection Act, NHS trusts should not release the names, addresses and other personal details of patients to anyone who is not employed by the trust. This includes releasing names and addresses for the purpose of mailing questionnaires to patients.

If you commission an Approved Survey Contractor to carry out the survey, there are two common methods currently being practised by trusts working with 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 Sections 9 and 12.

2. Alternatively, with the agreement of the trust's Caldicott Guardian, you may set up an *honorary contract* between the trust and one or two people who are already employed by the external contractor. Those people then become unpaid employees of the trust (while continuing to be employees of the external contractor) during the period in which the survey is carried out. It is then permissible for the contracted employee to be given patient contact details for the purposes of sending out questionnaires and reminders to patients, and sticking address labels on to envelopes. The external contractor must be registered under the Data Protection Act and appropriate steps must be taken to protect patient confidentiality. A sample honorary contract is shown on the following page.

5.3 Points to remember

- The amount of patient information handed over to the contractor should be kept to a minimum.

- The patient information should be password-protected, and the password should only be known to one individual in the trust who sends out the information and one or two people from the external contractor who receive the information.

5.4 Sample Honorary Contract

[Name of NHS Trust]

To: [Name of employee] **[Date]**

1. We are pleased to offer you an honorary (unpaid) appointment with this Trust. The appointment is to enable you to carry out the necessary operations and procedures that will enable this Trust to participate in the NHS Patient Surveys.
2. The period of appointment covered will be from [1st date] to [2nd date]. However, your work during this period will be part-time and intermittent, and may well be complete before the end of the period.
3. Similarly the pattern of hours worked in any week will vary according to the requirements of the survey procedures. The number and distribution of hours will be a matter for mutual agreement between you and [name of external contractor]. You will of course be covered by the Working Time Regulations 1998 and will not be expected to follow other than standard procedures in respect of working time.
4. The work will be carried out off-site at a location to be agreed with [name of external contractor].
5. Since the appointment is unpaid, this contract carries no entitlement to paid holidays, bank holidays, sick pay etc. Your entitlements in these respects will be the responsibility of [name of external contractor] which is the organisation responsible for the overall design, conduct and reporting of the NHS Patient Survey.
6. It will be expected that you carry out your work in a manner which is safe and absent from risk to your own health and that of any other person who may be affected by your actions or omissions. It is also expected that you will co-operate with the Trust in complying with any relevant statutory regulation imposed by the Trust. Whilst on Trust premises you must comply with the requirements of the Health & Safety at Work Acts 1974 (including Regulations and Codes of Practice issued thereunder).
7. During the course of your work you may have access to information concerning the Trust’s staff, policies, finances or patients, which is strictly confidential. It is a condition of your appointment that in no circumstances will such information be passed on or discussed with any unauthorised person. A breach of confidentiality during this contract would result in its termination.
8. It follows from the above that any confidential information and data for which you are responsible should be kept under continuous review and stored in secure circumstances when it is off-site. The data will be disposed of in a safe manner, and any patient details will be destroyed before disposal.
9. If required to work on the Trust premises the Trust cannot accept responsibility for articles of personal property lost or damaged on their premises whether by burglary, fire, theft or otherwise. You are therefore advised to cover yourself in this respect against all risks.
10. Notwithstanding the above, for the purpose of employment insurance (and for no other purpose) you will be regarded as a Trust employee during the proper performance of your duties, provided that at all times you exercise all reasonable skills and judgement and always act in good faith.
11. Please sign and return this letter by way of confirmation of your agreement to the terms on which the appointment is made.
12. The offer and the acceptance of it should together constitute a contract between two parties.

FORM OF ACCEPTANCE

I hereby accept the terms and conditions set out above.

Signed: ……………………………………………………… Date:……………………………..

[Name of employee]

Signed: … …………………………………………… Title: ……………………………..
(On behalf of the Trust)

[NHS Trust]

Date:……………………..

5.5 Patient confidentiality

It is essential that any patient survey is conducted in such a way that respects patient confidentiality. That is, patients must be assured that doctors, nurses and other healthcare workers will not be able to identify individual patients' responses. Furthermore, their responses must not be presented to anyone in a way that allows individuals to be identified. For example, if a patient is known to have stayed on a particular ward, and his or her year of birth, sex and ethnic group are known from their survey responses, it might be possible to use this information to identify them. We would recommend that patient responses should be aggregated into groups of no less than 30 patients before data are presented to staff.

5.6 Patient anonymity

In-house surveys

It is important to ensure that any claims you make about patient anonymity are accurate. 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 sometimes 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 should be seen by trust staff only, while individual patients' responses should be seen by contractor staff only. As long as the response data supplied to trusts do not include Patient Record Numbers and are not provided to trusts in a way that allows individuals to be identified, it can reasonably be claimed that patients' responses are anonymous.

5.7 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of patients' names. Similarly, the electronic file containing the patients' names and addresses should be stored on a separate computer to that containing the survey data.

Any mailing lists of patients' names and addresses should be deleted or destroyed as soon as the mailing process is complete. However, when you destroy the name and address information, remember to keep the other information held in the same file (such as year of birth, sex and survey number) since this will be needed later.

6 Ethical issues, ethics committees & 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 Young Patient surveys

Multi-Centre Research Ethics Committee (MREC) approval has been obtained for the standard questionnaires, the covering letters and the reminder letters, all of which can be downloaded from the NHSSurveys website. In order to comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document.

You do not, therefore, need to seek ethical approval for this survey. However, you should inform the relevant LREC(s) and/or send them a copy of the MREC approval letter. You do not need to wait for confirmation or approval from the LREC before starting your survey. The MREC letters can be downloaded from the NHSSurveys website.

6.2 Further information on ethical approval

Further information on the ethical approval process can be found at www.corec.org.uk/LRECContacts.htm or by e-mailing queries@corec.org.uk.

6.3 Research governance requirements

The Research Governance Framework aims to ensure that health and social care research is conducted to high scientific and ethical standards. It spells out standards and 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 Commission for Health Improvement (CHI), as sponsor of this national survey, has taken steps to ensure that principles of research governance and ethics are followed thoroughly. A standard 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 development of the survey, covering letters to patients and the standard questionnaires have all been approved by a multi-centre ethics committee. The questionnaire and guidance notes on how to conduct the survey are produced by the NHS Patient Survey Advice Centre who are guided by peer reviewed research evidence in this area.

CHI has detailed arrangements in place for the management and monitoring of the surveys. Trusts and approved contractors are also required to set up a helpline for patients so that they can call with any questions.

The Department of Health has confirmed to CHI 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 to sponsor. As this national patient survey has multi-centre research ethics committee approval and CHI takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.

Trusts are invited to give permission for the surveys to go ahead after confirming they have the local research governance arrangements to support this type of study.

References

Research Governance Framework for Health and social care, Department of Health 2001

Research Governance Framework for Health and social care (Draft), Department of Health 2003

The following table has been prepared by the Commission for Health Improvement. It is taken from Section 3.10 of the *Research Governance Framework for health and social care.* The left-hand column sets out the responsibilities of organisations providing care and the right-hand columns sets out the arrangements made by CHI for this survey. If you are required to seek approval from your research governance lead, you are advised to present this information to your R&D Manager in support of your request.

Responsibilities of organisations providing care

Research Governance Framework	**CHI patient surveys**
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	*The survey is carried out on the experiences of patients after they have received the care so this does not apply.*
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	*All Chief Executives are informed of the proposals of the survey. Similar letter has been sent to the R&D 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 performance rating 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.	*CHI 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.	*CHI 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.	*A 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.*
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.	*CHI also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to CHI. 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.	*CHI maintains a helpline facility, which can be used by patients or trusts to report any complaints. Similar arrangements are in place with the NHS Patient Survey Advice Centre who are commissioned by CHI 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 performance monitoring and national star rating mechanisms*

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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 questionnaires have been written in as **simple language** as possible to facilitate optimum understanding by all respondents. The questions have also been tested with patients from a range of ethnic groups. For this survey, translated questionnaires are not being used. We do not recommend translation of questionnaires as the most effective way of obtaining feedback from minority language groups in postal surveys such as these. In considering this issue, it is worth noting the following points:

- It will be difficult or impossible 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.

- It might be appropriate to use **alternative data collection methods** to assess the experiences of non-English-speaking patients, or patients whose literacy levels are low. For example, it may be easier for some groups to report their experiences in focus groups or face-to-face interviews.

- The Commission for Health Improvement are carrying out further work to assess the options for seeking the views of ethnic minority groups. If you would like further information or would like to offer feedback on this topic, please contact Dr Rekha Elaswarapu at CHI: rekha.elaswarapu@chi.nhs.uk.

There are a number of strategies you can adopt to facilitate the process of collecting ethnic minority views within this survey:

- You could include a **multi-language leaflet** with the first mailing, offering help or translation services to those who might require it.

- You could offer patients whose spoken English is better than their written English the option of **completing the questionnaire over the telephone**, using a FREEPHONE line.

- Consider subscribing to a specialist interpreting service. Your trust may already be in touch with one in your area. Alternatively, you could use a national service, such as **Language Line.** (See http://www.languageline.co.uk, e-mail info@languageline.co.uk or call 020 7520 1430.) Telephone interpreting services in around 100 languages are offered on a pay-as-you-go basis. If required, a three-way conversation can be set up between you, the patient and the interpreter.

- 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 length of time taken to complete the survey process will depend on many factors. Assuming no delays, it is reasonable to allow about 12 weeks from start to finish. Dissemination of the results to all staff will take considerably longer. This timetable is based on the *minimum* expected duration of each stage. If you commission an Approved Contractor, most 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 Survey Advice Centre about who is carrying out the survey (by 16th January 2004 at the latest).**	3 & 4
1	**Draw sample of patients to be included in the survey**	9
1	**Submit sample list to Tracing Service to check for deceased patients**	9.4
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 5.4&11
1	Print questionnaires and covering letters. Ensure you have enough headed paper, envelopes, return envelopes and labels	11
2	Set up FREEPOST address and FREEPHONE line	12.2&12.3
2	Establish system for responding to telephone enquiries	12.3
3	Establish system for booking in questionnaires	12.6
3	**Check your own trust's records again for any patient deaths**	9.5
3 - 8	**Stick labels on pre-packed numbered questionnaires supplied by approved contractor (if not using honorary contract)**	12.5
3	Send out first questionnaires	12.5
3 - 12	Continue to respond to telephone enquiries	12.3
3 - 12	Continue to book in returned questionnaires	12.6
3 - 12	Enter data	13
5	Check your own trust's records for any patient deaths	9.5
5 - 6	Send out first reminders to non-responders	12.7
5 - 6	Be prepared for a small peak in telephone calls as first reminders received	12.3
8	Check your own trust's records for any patient deaths	9.5
8	Send out second reminders to non-responders	12.7
11	Complete data entry	13
11	Check data for errors ***Very Important***	13.2
12	Send data to Survey Advice Centre (by 30th April 2004 at the latest)	14&15
12	Begin analysing trust's results and writing report	15
13 -	Disseminate results to staff, patients and the public	15 & 16

9 Compiling a list of patients

This section explains how to draw the sample of patients. This task will need to be carried out by an identified member of staff at the NHS Trust.

N.B. It is essential that the person who draws the patient sample understands the importance of following these instructions carefully. Also, that person's line manager must give them the time and support they need do to the task properly.

We advise that you read all of this section before you start to compile your patient list.

In acute trusts, the sample will normally be drawn from the Patient Administration System (PAS). Prior to sending out questionnaires, the list will also have to be checked for deceased patients by the NHS Strategic Tracing Service (NSTS).

9.1 Compile a list of eligible patients

Eligible patients are all patients [2] aged 0-17 treated as inpatients or day cases in any part of your trust, including adult wards. Note that, for many trusts, the sampling period is likely to cover more than one month.

- **Find out how many patients are seen at your trust.** This will help you to decide on your sampling dates. To do this, you first need to find out how many eligible patients (day cases and inpatients discharged alive aged 0-17) you have in one month in your trust. If in any doubt about this, please call the Advice Centre on 01865 208127.
    - If you have **more than 850** eligible patients per month, your sample should include eligible patients dating back from the last day of either **January 2004** or **November 2003.**
    - If you have **300-850** eligible patients per month, your sample should include eligible patients dating back from the last day of **November 2003.** [3]
    - If you have **70-300** eligible patients per month, your sample should include eligible patients dating back from the last day of either **January 2004** or **December 2003** or **November 2003.**
    - If you have **fewer than 70** eligible patients per month, you should call the Advice Centre on 01865 208127.

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[2] See 9.2 for exceptions.

[3] If you started counting back from the end of January, you would have a fairly high proportion of patients in your sample who attended during the Christmas period, and this should be avoided as Christmas tends to be atypical.

- Once you have decided when your sampling period will end, compile a list of 900 eligible patients[4] consecutively discharged alive or attending as day cases from your trust leading up to the last day of the sampling month. That is, once you have decided on the last date you will include in the sample, you should count back through the list, including all eligible patients until you have 900 patients.

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

- The list should **not** include deceased patients, any patient aged 18 or over, maternity patients, newborn babies where the mother is the primary patient, psychiatry patients, children primarily treated by mental health services, patients admitted for termination of pregnancy, private patients, current inpatients, patients without a UK postal address or patients who were only admitted to a Neonatal Intensive Care Unit (NICU) or a SCBU (Special Care Baby Unit).

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[4] The final sample size must be no greater than 850, but this allows for some extra patients, once any deceased or ineligible patients have been taken out of the sample.

9.2 Checks on the patient list

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

- **Deceased patients.** Check that the patients were all discharged alive. Also check that the trust does not have a record of a patient's death from a subsequent admission or visit to hospital.
- **Current inpatients.** Check again that none of the patients are known to be current inpatients in your trust (or elsewhere, if known).
- **Newborn babies.** Exclude any babies where the mother is the primary patient.
- **Patient ages.** Check again that all patients are aged 0-17.
- **Postal addresses.** Exclude any addresses that are outside the UK.
- Check again that none of the patients were **only** in a Neonatal Intensive Care Unit (**NICU**) or a Special Care Baby Unit (**SCBU**).
- **Incomplete information.** Eliminate patient records with incomplete information on key fields (such as surname and address). However, do not exclude anyone simply because you do not have a postcode for them.
- **Duplications.** Check that the same patient has not been included more than once.
- **Maternity patients**. Check again that the list does not include maternity patients or babies from the delivery suite
- **Psychiatry patients**. Check again that the list does not include psychiatry patients or patients treated by Child and Adolescent Mental Health Services (CAMHS)
- **Private patients.** Remove any private patients from the sample.
- **Patients treated at private hospitals.** Remove any patients who were treated by the trust as NHS patients in private hospitals.
- Check that none of the patients were admitted for a **termination of pregnancy.**
- **Ward attenders.** Exclude any patients that just visited the ward (e.g. for a blood test) but were not admitted as a day case or did not have an overnight stay as an inpatient.

9.3 Data fields to include in the list of patients

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

- Initials (or First name)
- Surname
- Address Fields [5]
- Postcode
- Year of birth
- Gender
- Ethnic group [6]
- **Day** of the month of discharge or attendance (1 or 2 digits; e.g. 2 or 30)[7]
- **Month** of discharge or attendance (1 or 2 digits; e.g. 9 or 10)
- **Year** of discharge or attendance (4 digits; e.g. 2003)
- Whether the patient was an **inpatient** or **day case**
- Any other details required by the NHS Strategic Tracing Service (NSTS). [8] Wherever possible, this should include the NHS number.

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[5] The patient address should be held as separate fields (e.g. street, area, town, county, postcode). This should be consistent with the address format required by the NSTS.

[6] It is acknowledged that patient records might not always contain complete data on patients' ethnic group. However, this field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic groups. This is in keeping with the aims of CHI and Department of Health to be more responsive to all ethnic groups and provide services that take account of their individual requirements.

[7] This year, we are asking you to supply the date fields in separate columns. The purpose of this is to overcome the problems of trusts supplying dates in differing formats in Excel.

[8] The NHS number can give more accurate matching, especially if addresses are incomplete. It is advisable to liaise with the registered NSTS batch trace user (if this is not the same person who creates the sample list) to ensure that all the required fields are extracted when compiling the list of patients (see Section 9.4 for more details on using the NSTS).

9.4 Submit the sample list to the NHS Strategic Tracing Service (NSTS)

Before sending out the questionnaires, the list of patients will also have to be checked for any deceased patients by the NHS Strategic Tracing Service (NSTS).

The NSTS contact details are as follows:

Help desk telephone number:	0121 788 4001
Website:	http://nwww.nhsia.nhs.uk/nsts/

The time required to carry out the checks depends partly on the compatibility of the list you submit to the NSTS with their system requirements. To avoid any delay, check carefully that your list is in the correct format for NSTS.

The file returned from NSTS can be used to identify the records that need to be deleted from the sample file. This will reduce the numbers in the sample list slightly.

Note

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

9.5 Check the trust's records for patient deaths

One of the most reliable and up-to-date sources of information on patient deaths is your own trust's records. It is essential that you check that your trust has no record of a patient having died at your trust. Relatives are likely to be particularly offended if they receive a questionnaire or reminder from the trust where their relative died. Clearly, patients may also have died at home or while under the care of another trust, so you still need to check with the tracing service as well. You are also advised to repeat this check before the second and third mailings, and to ensure that approved contractors are advised of any patient death that occurs during the survey period.

Note from SchlumbergerSema (NSTS Partner)

Within your trust, there should be a "Caldicott Guardian delegated authority", who is the person authorised to send batch traces to the NSTS. You should ask this person to submit the batch trace request for the patient survey, as SchlumbergerSema will only accept submissions from this person.

The format of the patient survey files and accompanying paperwork must be identical to that submitted by trusts on a regular basis for NHS number tracing.

The full details are given in the new instruction manual:

SchlumbergerSema NHS Patient Survey File Creation Guide

This is available on the NHSSurveys website.

The basic requirements are:

- The file must contain all 27 fields listed in Appendix D of the NSTS manual, even if they contain no data.
- No column headings must be included.
- The file can be either in fixed length or Comma Separated Variable (CSV) format. CSV is more popular and easier to create.
- File must be able to be opened in Notepad or similar text editor.
- Excel spreadsheets are not permitted.
- It is advisable to send a spare tape or disk with your batch trace, so that the tracing service can record their results on that, rather than having to delete your original file to re-use your original disk or tape. This will speed up the process.
- When the file is returned from the NSTS, the deceased marker can be found in field 32, where there would be a 3 digit Q-Code or a D (deceased).

Remember to keep a copy of the file you send to NSTS!

9.6 Reduce the list to 850 patients

When your patient list comes back from NSTS, there should still be more than 850 patients in the list. You will therefore need to **remove the least recent** patients from your list so that only the 850 most recent patients remain in the list.

Important note

You are aiming for **a response rate of at least 60%**, which means that you should have about 500 completed questionnaires if you send questionnaires to 850 patients. You will be able to maximise your response rate by following this guidance carefully, and you will need to send out three reminders. It is **not** acceptable to try to boost the number of responses you receive by sending out questionnaires to a larger number of patients. The Advice Centre will only be able to accept responses from the 850 patients in your list that have been correctly sampled.

9.7 Organise the patient information into the sample file

Once the file is returned from the NSTS, you will need to keep the patient information in an electronic spreadsheet, 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 file in Microsoft Excel format to the Patient Survey Advice Centre.

Firstly, you will need to add three new columns:

1. **Patient Record Number.** This field will be a series of consecutive numbers (for example, 2001 through to 2850, but make sure it is a different number range from that used in your Adult Inpatient Survey).
2. 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.
3. 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.

Table 1 shows part of an example Excel file comprising patient details. Only the fields headed *in red italics* should be included in the file sent to the Patient Survey Advice Centre.

Table 1 – Sample Excel file of patient details

Patient Record Number	Forename	Surname	Address1		Address5	Postcode	Year of birth	Gender	Ethnic Group	Day of discharge or attendance	Month of discharge or attendance	Year of discharge or attendance	Inpatient or day case	Outcome	Comments
2001	Andrew	Abbot		--		AB1 1YZ	1987	1	1	30	11	2003	1	2	Questionnaire returned undelivered by post office
2002	Hassan	Ahmed		--		AB2 6XZ	2000	1	3	29	11	2003	2	1	
				--											
2849	Shinya	Ogura		--		AB4 7MX	1997	2	5	12	9	2003	2		
2850	Felicity	Young		--		AB9 5ZX	1999	2	1	12	9	2003	1	1	

Notes on Table 1

- **Patient Record Number.** This number is unique for each patient. It can be seen in the example that the numbers are in ascending order, starting at 2001 at the top of the list, through to 2850 at the bottom. The patient record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the Approved 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. If an approved contractor is used, you will need to agree with them on the range of serial numbers that will be used for your patients.

- The **Patient Record Number, Title**, **Initials**, **Surname**, **Address** fields and **Postcode** are used for printing out address labels. You can use mail merge in a word processing package for this purpose.

- The **Year of Birth** is included in the form NNNN.

- **Gender** should be coded as 1 = male and 2 = female. However, be aware that other systems may use a different coding.

- **Ethnic Group** should be coded using the broad categories 1 = White; 2 = Mixed; 3 = Asian or Asian British; 4 = Black or Black British; 5 = Chinese; 6 = any other ethnic Group. These are *based on* the standard categories introduced by the NHS Information Authority from 1st April 2001, but if your trust is using these categories, the data will need to be re-coded to these numeric codes.

- **The Day, Month and Year of discharge or attendance** are recorded in separate columns and formatted as *general* or *numeric* (rather than as dates).

- **Inpatient or day case** records what type of hospital admission the patient had. It is coded Inpatient=1 and Day Case=2.

- 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)

  Note that these codes have changed since the last survey.

  The outcome column is left blank at first if the survey has not been returned. It can be seen that Andrew Abbott's questionnaire was returned undelivered by the post office, Hassan Ahmed and Felicity Young have returned useable questionnaires, and Shinya Ogura has not yet returned her questionnaire.

  If the survey is being carried out in-house by the trust, you can use the file containing the patient name and address details to record the outcome information. If you are working with an Approved Survey Contractor, you should supply them with a list of record numbers (but patient names and addresses should be removed), against which they can record the outcome codes.

  Remember, you should only have 850 patients in the list at this stage.

9.8 Sharing the patient sample file with an approved contractor

If you are working with an Approved Survey 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 (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.

9.9 Using the patient sample file

This file has two purposes:

1. It will be used to keep a record of which patients have returned questionnaires so that reminders can be sent to them.

2. The anonymous data in this file (i.e. all the data **except** patient name and address information) will form part of the file that you will submit to the Advice Centre when the survey is completed.

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.

9.10 Comparing departments or hospitals within your trust

If you want to go beyond the minimum requirements, you could use the NHS Trust Survey programme as an opportunity to gather data about different units or hospitals within your trust. You could extend the number of patients you target, and ensure that you target sufficient numbers from each of the units you want to compare so that you can get enough responses to make comparisons. However, before deciding to do this, it is essential that you read the sampling guidance in this section, and that you do not mix up your standard survey sample with any additional patients.

Small limited surveys are easier for in-house administrative and volunteer staff to handle than are large surveys. You may wish to consider doing the large NHS Trust survey with an Approved Survey Contractor, and following it up with smaller, targeted in-house surveys.

Important note

If you choose to increase your sample size, it is essential that you ensure that the sample of patients you draw according to the requirements for the national survey can be easily distinguished from any additional patients you include in the sample. You need to send only the data from the 850 patients sampled according to these guidelines to the Advice Centre.

10 Publicising the survey

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

- Patients can be expected to call doctors, nurses, patient liaison officers, or the Chief Executive's office with questions about the survey, even when your covering letters give contact details for the survey managers 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 managers 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.

11 Materials

11.1 Printing questionnaires

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 questionnaires, which are available in pdf format on the NHSSurveys website, are designed to fit on to 12 sides of A4 paper.

Number of questionnaires

You will need to print two types of questionnaire: the Young Patient (Parents and Guardians) Questionnaire for patients aged 0-11 and the standard Young Patient Questionnaire for 12-17 year-olds. You need to ensure you have the right numbers of the Young Patient (Parents and Guardians) Questionnaire for patients aged 0-11 and the standard Young Patient Questionnaire for 12-17 year-olds, depending on the age mix of the patients treated at your trust.

When calculating the number of questionnaires to be printed, you will need to allow for sending out duplicate questionnaires as 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 number of questionnaires required. So, if the number of questionnaires you intend to send out is 850, then you might want to print 850 x 1.7, or approximately 1,500 copies in total.

Trust headed paper

You will need trust headed paper for covering letters for the first and third mailing. (A reminder slip is used for the second mailing.) Therefore, depending on your response to the initial mailings, you should need approximately 1,200 to 1,600 sheets of trust headed notepaper. If an approved contractor is being used to carry out the survey work, it is preferable that the paper does not include a telephone number for the trust, as patients should call the contractor's FREEPHONE line, rather than the trust.

11.2 Other items

You will also need:

- 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

11.3 First mailing

You will need 850 of each of the following items:

- Printed questionnaires (Make sure you have enough of each version, depending on your patients' age ranges.)
- 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
- Paper bearing the trust's letterhead for covering letters

11.4 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, around 55-75% of the original patient sample need to be sent first reminders. The following items are needed:

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

11.5 Third mailing (second reminder)

The second reminder should include the same items as the first mailing, and will need to be sent 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
- Paper bearing the trust's letterhead for covering letters

12 Implementing the survey

This section gives guidance on administering the NHS Trust Young Patient Surveys using pre-designed surveys. The following topics are covered:

- The Young Patient questionnaires
- Setting up a FREEPOST address
- Setting up a FREEPHONE line
- Covering letters
- Booking in questionnaires
- Sending out reminders

12.1 The Young Patient questionnaires

Each trust must use the standard 12-page Young Patient Questionnaires from the NHSSurveys wesbite. There are two pre-designed questionnaire on the NHSSurveys website (one for patients aged 0-11 and one for patients aged 12-17). These two questionnaires include the same questions, but they are phrased slightly differently, depending on whether an adult or the young patient themselves is most likely to be filling it in. Data from these two questionnaires can be put into the one file, since the questions and responses correspond exactly.

Each questionnaire consists of 89 questions, which cover the issues that have been found (through qualitative work with children and their parents and guardians) to be the most important to patients and their parents or guardians. The front page of the survey explains the purpose of the survey and gives instructions on how to fill it in. In the following pages, the survey questions are divided into sections in which questions relating to similar issues are grouped together.

12.2 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 at http://www.royalmail.com. Alternatively, you can call your local Sales Centre on 0845 7950 950.

12.3 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.

Common questions and comments

I/my child has had two or more hospital admissions - which one should we refer to?

Patients should be advised to refer to their **most recent** hospital inpatient admission. Usually, this is the admission covered by your sampling period but, for the few patients who have been re-admitted since you drew the sample, it is simpler to tell them to refer to their most recent stay. It will not make the results invalid if a few of the patients refer to a more recent episode than the others.

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

Patients or their guardians 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 has died.

Even with the use of a deceased patients tracing service, it will 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.

I/we would like to take part but English is not our first language.

If a patient's (or their guardian's) spoken English is better than their written English, they may be willing to have someone fill in a form on their behalf over the telephone. Alternatively, if your trust offers translation or interpreter services, participants could make use of these. For example, interpreters could read out the questions over the telephone in the patient's own language and record their answers on a questionnaire form.

I/we 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 the survey is voluntary, and that the patient’s care will not be affected in any way by their not responding. 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 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.

Making a record of the calls

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

It is useful 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 printed, so that the relevant details of each call can be recorded and survey organisers can monitor any problems and remove patients who wish to be excluded from the mailing list.

12.4 Covering letters

For the Young Patient survey, there are three versions of these covering letters, depending on the age of the patient.

Patients aged 0-11 should be sent a "Dear Parent/Guardian letter and the address on the envelope should be "The parent or guardian of….".

Patients aged 12-15 should be sent a "Dear Parent/Guardian letter and the address on the envelope should be "The parent or guardian of….".

Patients aged 16-17 should be sent a "Dear Patient" letter and the letters should be addressed directly to them.

The covering letters on the following pages have been given ethical approval for use in the NHS Trust Young Patient Surveys. They should be printed on the trust's letterhead paper. Word versions are on the NHSSurveys website for you to download and add your own trust's details. If you make alterations to these letters, you will need to seek the approval of your Local Research Ethics Committee (LREC), and to check with the Advice Centre that your changes are acceptable. Two paper copies of each of the letters you use must be sent to the Advice Centre when you submit your data at the end of the survey.

Covering letter for first mailing for the parents of patients aged 0-11

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 Parent/Guardian

Young patient survey

We are trying to find out what patients at [Hospital A] or [Hospital B] of the [NHS Trust name] think of the care they receive. This survey is part of our commitment, outlined in the NHS Plan, to design a health service around the patient. The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Commission for Health Improvement (CHI) and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified and the anonymous survey findings will be analysed by the Advice Centre and CHI.

We are asking you to give us your views by filling in the enclosed questionnaire. The questionnaire should only take about 20 minutes to complete. **The questions should be answered by a parent or guardian of the child named on the front of the envelope with the help of that child if possible.** Your views are very important in helping us to find out how good the hospitals are and how they can be improved. This is your chance to have a say in how services are provided in the future. A FREEPOST envelope is enclosed.

Your participation in the survey is entirely 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 wish to take part in the survey, or you do not want to answer some of the questions, you do not need to give us a reason. If you choose not to take part, please could you return the uncompleted questionnaire in the FREEPOST envelope provided and this will make sure you will not be contacted again. If we do not receive anything from you within three weeks, we may send you a reminder letter.

If you do decide to give us your views, you can rest assured that your answers will be kept confidential. No one outside the research team will be able to know which individual gave what answers. Information will not be passed on to doctors, nurses or other NHS health care staff in a form that allows you to be identified.

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

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar]

[NHS Trust name]

Covering letter for first mailing for the parents of patients aged 12-15

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 Parent/Guardian

Young patient survey

We are trying to find out what patients at [Hospital A] or [Hospital B] of the [NHS Trust name] think of the care they receive. This survey is part of our commitment, outlined in the NHS Plan, to design a health service around the patient. The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Commission for Health Improvement (CHI) and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified and the anonymous survey findings will be analysed by the Advice Centre and CHI.

We are asking **your child** to give us their views by filling in the enclosed questionnaire. The questions should be answered about **your child's** hospital experience from **their** point of view**.** Please complete the survey with your child if they need any assistance. Your child's views are very important in helping us to find out how good the hospitals are and how they can be improved. This is a chance to have a say in how services are provided in the future. The questionnaire should only take about 20 minutes to complete. A FREEPOST envelope is enclosed.

Participation in the survey is entirely voluntary. Choosing not to take part will not affect the care your child receives from the NHS in any way. If you do not wish to take part in the survey, or you do not want to answer some of the questions, you do not need to give us a reason. If you choose not to take part, please could you return the uncompleted questionnaire in the FREEPOST envelope provided and this will make sure you will not be contacted again. If we do not receive anything from you within three weeks, we may send you a reminder letter.

If your child decides to give us their views, you can rest assured that their answers will be kept confidential. No one outside the research team will know which individual gave what answers. Information will not be passed on to doctors, nurses or other NHS health care staff in a form that allows them to be identified.

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

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar]

[NHS Trust name]

Covering letter for first mailing for patients aged 16-17

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

Young Patient Survey

We are trying to find out what patients at [Hospital A] or [Hospital B] of the [NHS Trust name] think of the care they receive. This survey is part of our commitment, outlined in the NHS Plan, to design a health service around the patient. The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Commission for Health Improvement (CHI) and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified and the anonymous survey findings will be analysed by the Advice Centre and CHI.

We are asking you to give us your views by filling in the enclosed questionnaire. The questionnaire should only take about 20 minutes to complete. A FREEPOST envelope is enclosed. Your views are very important in helping us to find out how good the hospitals are and how they can be improved. This is your chance to have a say in how services are provided in the future.

Your participation in the survey is entirely 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 wish to take part in the survey, or you do not want to answer some of the questions, you do not need to give us a reason. If you choose not to take part, please could you return the uncompleted questionnaire in the FREEPOST envelope provided and this will make sure you will not be contacted again. If we do not receive anything from you within three weeks, we may send you a reminder letter.

If you do decide to give us your views, you can rest assured that your answers will be kept confidential. No one outside the research team will be able to know which individual gave what answers. Information will not be passed on to doctors, nurses or other NHS health care staff in a form that allows you to be identified.

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

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar]

[NHS Trust name]

12.5 Sending out questionnaires

Mailing labels

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

We recommend using the mail merge feature in a word processing package to create the mailing labels from the database of patient names and addresses. **It is essential that the Patient Record Number is on each address label,** as this has to be matched with the number on the front of the questionnaire.

Questionnaire packs

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

1. A questionnaire numbered with the Patient Record Number. The number must match (or correspond to) the number on the address label and the number on the list of patient details.
2. A covering letter.
3. A large envelope, labelled with the FREEPOST address on it.
4. 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

Note

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

Approved contractors – no honorary contract

If an approved contractor is carrying out most of the work, they should send pre-packed questionnaires to the trust for mailing out. The envelopes should be clearly marked with the Patient Record Numbers so that trust staff can match these with their patient list and put on appropriate patient address labels.

Approved contractors – honorary contract

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

12.6 Booking in questionnaires

When questionnaires are received, match up the Patient Record Numbers against the list of patients, so that you can record (in the *outcome* column) which patients have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until 31st August 2004, but please **do not** send these to the Advice Centre.

Approved contractors

If an approved contractor carries out the work, questionnaires will be returned directly to them, so they will be able to record these returns against the list of Patient Record Numbers. Trusts should inform the contractor of any questionnaires that were returned 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.

12.7 Sending out reminders

For results to be representative, it is essential to get a good response rate. The minimum response rate for this survey is 60%. In order to achieve this, you will need to send out two reminders to non-responders.

After the first mailing, you can expect 30-45% of patients to have returned completed questionnaires within 2-3 weeks. First reminders should be sent out after 2-3 weeks and you can expect the percentage of returned questionnaires to rise by about 20%. The second reminder sent out after a further 2-3 weeks should bring the final proportion of returned questionnaires to 60-75%.

Depending on the time that has elapsed since you first checked your patient list for deaths, it might be necessary to send your list to the tracing service for a further check before you send out reminders. In any case, before sending out reminders you should check your own trust's records to check that there is no record of the patient's death in your own trust.

Working with approved contractors

When reminders are due to be sent out, survey contractors should send the pre-packed envelopes bearing the Patient Record Numbers of the non-responders to the trust. Again, the envelopes should be clearly marked with the Patient Record Number so that trust staff 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 two to three weeks. This should be a short note. There is only one version of this note, which can be used for all patients aged 0-17.

Ethical approval has been obtained for the reminder letter printed below. It can be printed on an A5 or sheet of paper. A Word version is on the NHSSurveys website for you to download and add your own trust's details. If you make alterations to it, you will need to seek the approval of your local research ethics committee (LREC), and to check with the Advice Centre that your changes are acceptable. Two paper copies of the letter you use must be sent to the Advice Centre when you submit your data at the end of the survey.

First reminder letter for all age groups

Text in square brackets needs to be edited

[Date]

[Name of NHS Trust]

Approximately two weeks ago we sent you a questionnaire about the care at [NHS Trust Name]. At the time of sending this note, we do not seem to have received a response from you.

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 [our FREEPHONE help line /us] on [**number**] between [opening time] and [closing time], [days], and we will do our best to answer any questions you might have.

Second reminders

Second reminders should be sent out after a further two to three weeks to patients who have not yet responded. The envelopes should include the following:

1. A questionnaire numbered with the Patient Record Number. The number on the address label must match the number on the list of patient details.

2. A covering letter.

3. A large envelope, labelled with the FREEPOST address on it.

As with the covering letters for the first mailing, there are three versions of these second reminder covering letters, depending on the age of the patient.

Patients aged 0-11 should be sent a "Dear Parent/Guardian letter and the address on the envelope should be "The parent or guardian of….".

Patients aged 12-15 should be sent a "Dear Parent/Guardian letter and the address on the envelope should be "The parent or guardian of….".

Patients aged 16-17 should be sent a "Dear Patient" letter and the letters should be addressed directly to them.

The following covering letters have been given ethical approval for use in the NHS Trust survey programme. Word versions of these letters are on the NHSSurveys website for you to download and add your own trust's details. They should be printed on the trust's letterhead paper. If you make alterations to them, you will need to seek the approval of your local research ethics committee (LREC), and to check with the Advice Centre that your changes are acceptable. Two paper copies of the letters you use must be sent to the Advice Centre when you submit your data at the end of the survey.

Covering letter for second reminder for parents of patients aged 0-11

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]

Young patient survey

Dear Parent/Guardian

Enclosed is a copy of a questionnaire about the care your child received at [Hospital A] or [Hospital B] of the [NHS Trust name]. We originally sent the questionnaire to you a few weeks ago. **Your views are very important in helping us to find out how good the hospitals are and how they can be improved**, **so we would like to hear from you.** If you have already replied, please ignore this letter and accept our apologies.

We are asking you to give us your views by filling in the enclosed short questionnaire. The questionnaire should only take about 20 minutes to complete. **The questions should be answered by a parent or guardian of the child named on the front of the envelope with the help of that child if possible.** A FREEPOST envelope is enclosed.

This survey is part of our commitment, outlined in the NHS Plan, to design a health service around the patient. The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Commission for Health Improvement (CHI) and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified and the anonymous survey findings will be analysed by the Advice Centre and CHI. This is your chance to have a say in how hospital services are provided in the future.

Your participation in the survey is entirely 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 wish to take part in the survey, or you do not want to answer some of the questions, you do not need to give us a reason. If you do not return the questionnaire, you need do nothing more, and you will receive no further reminders.

If you do decide to give us your views, you can rest assured that your answers will be kept confidential. Information will not be passed on to doctors, nurses or other NHS health care staff in a form that allows you to be identified.

If you have any questions or need help with filling out the questionnaire, you can call [our FREEPHONE help line/ us] on [**phone number**] [at no cost to yourself]. The line is open between [opening time] and [closing time], [days] and we will try our best to answer any questions you may have.

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar]

[NHS Trust name]

Covering letter for second reminder for parents of patients aged 12-15

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]

Young patient survey

Dear Parent/Guardian

Enclosed is a copy of a questionnaire about the care your child received at [Hospital A] or [Hospital B] of the [NHS Trust name]. We originally sent the questionnaire to you a few weeks ago. **Your child's views are very important in helping us to find out how good the hospitals are and how they can be improved**, **so we would like to hear from you.** If you have already replied, please ignore this letter and accept our apologies.

We are asking **your child** to give us their views by filling in the enclosed short questionnaire. The questions should be answered about **your child's** hospital experience from **their** point of view. Please complete the survey with your child if they need any assistance. The questionnaire should only take about 20 minutes to complete. A FREEPOST envelope is enclosed.

This survey is part of our commitment, outlined in the NHS Plan, to design a health service around the patient. The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Commission for Health Improvement (CHI) and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified and the anonymous survey findings will be analysed by the Advice Centre and CHI. This is a chance to have a say in how hospital services are provided in the future.

Participation in the survey is entirely voluntary. Choosing not to take part will not affect the care your child receives from the NHS in any way. If you do not wish to take part in the survey, or you do not want to answer some of the questions, you do not need to give us a reason. If you do not return the questionnaire, you need do nothing more, and you will receive no further reminders.

If your child decides to give us their views, you can rest assured that your answers will be kept confidential. Information will not be passed on to doctors, nurses or other NHS health care staff in a form that allows you to be identified.

If you have any questions or need help with filling out the questionnaire, you can call [our FREEPHONE help line/ us] on [**phone number**] [at no cost to yourself]. The line is open between [opening time] and [closing time], [days] and we will try our best to answer any questions you may have.

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar]

[NHS Trust name]

Covering letter for second reminder to patients aged 16-17

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]

Young patient survey

Dear Patient,

Enclosed is a copy of a questionnaire about the care you received at [Hospital A] or [Hospital B] of the [NHS Trust name]. We originally sent the questionnaire to you a few weeks ago. **Your views are very important in helping us to find out how good the hospitals are and how they can be improved, so we would like to hear from you.** If you have already replied, please ignore this letter and accept our apologies.

We are asking you to give us your views by filling in the enclosed short questionnaire. The questionnaire should only take about 15 to 20 minutes to complete. A FREEPOST envelope is enclosed.

This survey is part of our commitment, outlined in the NHS Plan, to design a health service around the patient. The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Commission for Health Improvement (CHI) and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form which does not allow any individual's answers to be identified and the anonymous survey findings will be analysed by the Advice Centre and CHI. This is your chance to have a say in how hospital services are provided in the future.

Your participation in the survey is entirely 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 wish to take part in the survey, or you do not want to answer some of the questions, you do not need to give us a reason. If you do not return the questionnaire, you need do nothing more, and you will receive no further reminders.

If you do decide to give us your views, you can rest assured that your answers will be kept confidential. Information will not be passed on to doctors, nurses or other NHS health care staff in a form that allows you to be identified.

If you have any questions or need help with filling out the questionnaire, you can call [our FREEPHONE help line/ us] on **[phone number]** [at no cost to yourself]. The line is open between [opening time] and [closing time], [days] and we will try our best to answer any questions you may have.

Yours faithfully

[signature]

[print name of signatory]

Chief Executive [or similar]

[NHS Trust name]

13 Entering data

The data must be submitted to the Advice Centre in the appropriate format by the deadline on 30th April 2004. If an Approved Survey 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 Advice Centre in the correct format and supply the trust with an anonymised data set.

13.1 Entering and coding data from the questionnaires

The data from both questionnaires should all be entered into one file – the pre-designed Excel spreadsheet, which can be found in the Young Patient section on 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 (.). [9]
- If two boxes are ticked (where only one should be ticked), the response should be left blank or coded as a full stop (.).
- When saving this file to submit data to the Advice Centre, please save only the first sheet as a **worksheet**, rather than saving the whole file as a workbook. (This saves disk space.)

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[9] 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 (.).

13.2 Checking the data for errors

When the data have been entered, they need to be checked carefully for errors. That is:

1. Have the data been entered accurately? You can check this by double-entering the survey responses, and comparing the lines of data for any discrepancies. (For example, you can do this by subtracting each cell in one data sheet in Excel from a comparison sheet in the same workbook and comparing the results. If there are no differences between the two sheets, each cell will be zero, showing that the two sheets match.)

2. Are all the data entries valid responses for that question? For example, if a question allows three response options: "1", "2" or "3", check that your data do not include any other numbers. If out-of-range numbers are found, go back to the original questionnaire and check those responses.

3. Scanned data are also likely to contain errors and must be checked.

13.3 Submitting data to the Patient Survey Advice Centre

The data must be supplied to the NHS Patient Survey Advice Centre for the calculation of performance indicators. You are asked to submit one anonymised Excel file that includes information about the patient sample and responses.

File format

- Microsoft Excel Worksheet (not Workbook). Any version of the software is acceptable.
- File name must be in the format <NHSTrustName>_YoungPatient2004.xls.
- One row of data for each patient in the sample.
- One column of data for each item of patient information or response.
- Missing data should be left blank or coded as a full stop (.). [10]

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

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[10] Data may be missing because the patient skipped a question or set of questions by following instructions. Alternatively, 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.

Table 2 - Data Fields

Field	Format	Data codes	Comments
Patient Record Number	N, NN, NNN or NNNN		The unique serial number allocated to each patient by the trust or Approved Survey Contractor administering the survey.
Year of birth	NNNN		Format this simply as a number, not in date format.
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.).
Ethnic Group	N	1 = White 2 = Mixed 3 = Asian or Asian British 4 = Black or Black British 5 = Chinese 6 = Other ethnic group	Ethnic Group should be included if the information is available.
Day of discharge	N or NN		For example, if the patient was discharged on Sept 16th 2003, this column should read 16.
Month of discharge	N or NN		For example, if the patient was discharged on Sept 16th 2003, this column should read 9.
Year of discharge	NNNN		For example, if the patient was discharged on Sept 16th 2003, this column should read 2003.
Inpatient or day case	N	1 = inpatient 2 = day case	
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 89 questions	N or NN or NNNN		Each column must be clearly headed with the 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 Advice Centre.

Table 3 is an example of the columns of data to be included in the file. Your file should have 850 rows (one for each patient included in your sample). You will notice that there are several blank cells in the response section of the file. This is because the file includes a row for every patient in the sample, but you will only have responses from about 60% of the patients (that is, those who have returned a completed questionnaire, and who therefore have an outcome code "1").

Table 3 – Example of data file to be submitted to Advice Centre

Patient Sample Information ***Patient Response Information***

Patient Record Number	*Year of birth*	*Gender*	*Ethnic Group*	*Day of discharge or attendance*	*Month of discharge or attendance*	*Year of discharge or attendance*	*Inpatient or day case*	*Outcome*	*Q1*	*Q2*	*Q3*	--	*Q85*	*Q86*	*Q87*	*Q88*	*Q89*
2001	1987	1	1	30	11	2003	1	2									
2002	2000	1	3	29	11	2003	2	1	1	2	2		1	2	3	1	2
2003	1990	2	1	29	11	2003	1	6									
2004	1989	2	1	29	11	2003	1	2					2	4	1	2	2
2005	2002	2	1	28	11	2003	1	1	2				2	3	2	2	1
2006	2000	1	4	28	11	2003	2	6									
2849	1997	2	5	12	11	2003	2	6									
2850	1999	2	1	12	11	2003	1	1	1	2	7		2	5	1	2	1

You do not need to send any of the patients' written comments to the Advice Centre.

Additional information

The following information should also be included when submitting the data file:

- **Contact details** (telephone numbers and e-mail addresses) of at least two personnel who will be available to answer any queries about the data.
- Two blank **paper copies** of the questionnaires you used, the covering letters and the reminder letters.
- A completed copy of the **checklist** on the following page.

Delivery

Trust survey data (on floppy disc) and additional information should be sent by post to the following address:

Young Patient Survey
Advice Centre for NHS Patient Survey Programme
Picker Institute Europe
King's Mead House
Oxpens Road
Oxford
OX1 1RX

Data files may also be e-mailed to: inpatient.data@pickereurope.ac.uk

Date

The data must be supplied by **30th April 2004**.

13.4 Checklist

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

Check	Done?
1. Check that your **file name** follows the naming convention: <NHSTrustName>_YoungPatient2004.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 are intended for your use only.)	
3. Check that all **data are correct**, and that all values are in range.	
4. Send data only for the **850 patients** consecutively discharged from your trust in the chosen month.	
4. To comply with Data Protection regulations, any **patient name and address details** must be removed before the file is sent to the Survey Advice Centre.	
5. Remove any **passwords**.	
6. Include **two paper copies** of the questionnaire you used.	
7. Include **two paper copies** of the covering letters you used for the first mailing, the second mailing and the third mailing.	
8. Include **contact details of 2 people** who will be available to respond to any queries about the data.	
9. Check that you have included data columns for **all 89 questions.**	
10. Check that all the data are in **numeric format** only.	
11. **Check again** that all data are correct, and that all values are in range! ***See note below***.	

Very important

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

If incorrect data are submitted, it is likely that the data will be considered unreliable and will not be used by CHI in your trust's performance ratings. We cannot accept re-submissions of data after the deadline.

14 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 an analysis of the frequency of responses to each question and some cross-tabulation of responses against demographic and other information.

14.1 Using the NHSSurveys website to look at results

Once you have entered the data from the questionnaires into the Excel file on the website, the counts and percentages of responses to each of the questions are automatically computed and displayed on the other sheets of the Excel workbook, which correspond to the sections of the questionnaire. 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 (.).

14.2 Suggestions on data analysis

The following suggestions should help 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 where improvements are needed is to analyse responses in terms of "problem scores" - that is, 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, too, as 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 a staged 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 and presenting an analysis of many questions in a way that is comprehensive, logical and not overwhelming is a significant challenge. To make the data more compelling, and to speed up the analysis:

- Link questions that cover similar topics or processes
- Combine several questions into a single composite measure (by averaging problem rates, 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 groups). These tests take into account the number of responses, the variation in responses, and values of the items you are comparing (such as average problem rate). 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 provide 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.

15 Reporting results

15.1 Prioritising your report

Patient surveys can raise many compelling and important issues. How do you decide what issues to focus on first? The following suggestions can help with these decisions.

Rank problems 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. For example, if 40% of the patients in a survey report a problem with privacy when discussing their condition or treatment, and if this problem rate is the largest, then quality improvement efforts might focus first on this issue.

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 CHI 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 a powerful analytical tool for prioritising. Analysis of trends allows you to focus on correcting aspects of performance that are slipping. For informative analysis of trends, however, sample sizes for each survey period must be large enough to achieve stable estimates of performance.

Compare with predefined goals

One way to rationalise 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

In some organisations, it is clear which overall or summary measures are most important. For example, a single overall rating on the quality of care may be of particular interest. Correlating patient responses to specific questions with this single most important indicator can help focus attention in a way that improves the overall measure. (It is important to remember that the distribution of survey responses is unlikely to be *normal* in the statistical sense, and so rank-based correlation methods are more appropriate e.g. Spearman's rank correlation coefficient.)

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 is only so far you can take a univariate (crude) analysis and so regression analysis is an attractive option.

Ease of action

Many organisations focus initially on the issues that most easily present solutions. 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.

15.2 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.

Gear the format 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 resource booklet or data diskettes with full details may be important when problems arise, or if researchers have questions.

Use graphics

- Data that are displayed visually are 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 graphic elements 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.
- Highlight the most important items - for example, use bold type.

16 Using results for quality improvement

Applying the lessons and implementing change is the most useful aspect of the survey process. It is essential that this 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.

16.1 Prepare carefully

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

- The multi-disciplinary steering group should be responsible for developing a dissemination strategy to engage all of the relevant stakeholders and the co-ordination of improvement work.
- Publicise the survey before it happens. Engaging staff from the start will help to ensure their support with improvement initiatives. Involving the local media and informing the public will encourage a good response rate from patients.

16.2 Dissemination of survey results

Engage key stakeholders

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

- Staff throughout the trust should be engaged in the dissemination process as they will be responsible for tackling any problems identified by patients.
- It is vital that board members are informed about the outcomes of the survey and that they are involved in prioritising areas for improvement and shaping action plans. Their support is crucial for the successful implementation of change.
- Patients have taken time to report their experiences so they have a right to be informed of the results via local meetings, newsletters and articles in the local press.
- Survey results should also be made available to members of Patients' Forums. They have a key role to play in initiating discussions with the board about priorities for improvement and they will be keen to monitor progress as it occurs.

- Key findings should also be reported in Your Guide to Local Health Services (Patient's Prospectus). When reporting these results it is a good idea to invite people to contribute their ideas on how services could be improved and to suggest ways in which they can become involved if they wish to.

Spread the Word

Disseminating survey results entails far more than producing and photocopying a report. Consider how to share results in training sessions, meetings, employee newsletters, executive communications, process improvement teams, patient care conferences, and other communications channels.

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

Promote understanding

- Make sure the results are presented in user-friendly formats. Remember not everyone will be an expert in reading graphs and deciphering data
- Pictures speak louder than words. 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.

16.3 Identify key "change agents"

- The people who can motivate others to change and who hold the keys to improvement in the organisation are not necessarily the most senior people.

- Identify those who hold the keys in your organisation, and involve these "change agents" early in the survey process.

16.4 Prioritising areas for improvement

Compare with other trusts

Compare your trust's results with the benchmarks on the CHI and NHSSurveys website to find out where your trust performs better or worse than other trusts.

Compare departments within your trust

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

Identify where patients report most room for improvement

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

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

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

Identify problems surrounding particular aspects of the patient experience

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

- The admission process
- Being seen and treated by one type of health professional
- Receiving information on medicines
- Discharge arrangements.

16.5 Develop an action plan

After using your survey results to identify areas for improvement, work with staff and patients to prioritise these 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. 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.

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

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