

**NHS trust-based patient  
surveys:  
acute hospital trusts  
Emergency Departments  
2004/05**

**Listening to your patients**

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

<http://www.NHSSurveys.org>

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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 unlikely event that there are major changes, we will e-mail all trust contacts directly to inform them of the change.

## **Outpatients Survey**

Acute NHS Trusts will also be required to carry out a survey of Outpatients Departments in 2004/05. A separate guidance manual, questionnaire and question bank for the Outpatients survey will be available from the NHS Surveys Advice Centre 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 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 Healthcare commission

The national patient survey programme is now being led by the Healthcare Commission. The Commission's aim is to improve the quality of patient care in the NHS. Patients' experience of health services is at the heart of the Healthcare Commission'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 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 the Healthcare Commission's programme of reviews and inspections.

### 1.4 Performance indicators

Information drawn from the core questions of the Emergency Survey will be used by the Healthcare Commission to create headline NHS Performance Indicators. These indicators will be used in Acute and Specialist Trust Performance Ratings, due for publication in the summer 2005. The results will also be used in the Healthcare Commission reviews of Emergency Departments in 2004/05.

In addition to the performance indicators, the Healthcare Commission will publish benchmarking data from the survey to allow trusts to make meaningful comparisons between themselves based on reliable data. Information collected nationally in a consistent way is also essential to support public and parliamentary accountability. By asking each acute trust to carry out surveys of both Outpatients and Emergency Department patients in a consistent way, the Healthcare Commission is building up a detailed picture of patients' experiences in acute NHS trusts. 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 Emergency Department surveys

For comparisons between and within trusts to be accurate, fair and effective, it is essential that the surveys be carried out using standard procedures in all 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 **30 July 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 survey's progress (e-mail: [acute.data@pickereurope.ac.uk](mailto:acute.data@pickereurope.ac.uk)).
- A postal questionnaire survey must be carried out, with **two reminders sent to non-responders**, even if the minimum 50% response rate is already achieved.
- A random sample of patients must be taken from all eligible patient attendances in one month. (The month should be June 2004, July 2004 or August 2004.)
- The sampling procedure set out in this guidance must be followed. To do this, you will need to work closely with the person in Patient Information who draws the sample, and check carefully that this guidance has been adhered to. See Section 9 - *Compiling a list of patients*.
- You should aim to obtain the highest response rate possible. For this survey, the target minimum is 50%, but many trusts will achieve higher response rates than that. Three mailings will be necessary to achieve this target.
- The questionnaire must include the 49 core questions. See Section 11 - *The Emergency Survey Core Questions and question bank*.
- The data must be checked carefully for errors before submitting it to the Advice Centre. See Section 14 - *Entering data*
- The data from the core questions, and the required information about the patient sample, must be submitted to the Survey Advice Centre in the form outlined in 14.5 - *Submitting data to the Patient Survey Advice Centre* by **5 November 2004**.
- Two paper copies each of the questionnaire you used, and the covering letters for **each mailing**, must be submitted to the Survey Advice Centre in the form outlined in 14.5 - *Submitting data to the Patient Survey Advice Centre* by **5 November 2004**.
- You must keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front and back pages) of all questionnaires returned to you until 30 April 2005 but please **do not** send these to the Advice Centre.
- You must keep a copy of the patient sample information (i.e. their names, addresses, year of birth ethnic group, gender, attendance dates) until 31<sup>st</sup> December 2004, in case your trust is included in the non-response follow-up survey to be carried out by researchers at BMRB.

## 1.6 How to use this guide

Trusts have the option of conducting the survey in house or using an approved contractor (see Section 4). Whichever route you take, you will need to address the guidance in Sections 1 to 11 and 15 to 16 of this guide. Sections 12 to 14 cover the practicalities of mailing out the survey, following-up responses and processing the data, and submitting it to the Advice Centre. These sections will be most relevant to approved contractors, or trusts undertaking the surveys themselves.

## 2 Setting up a project team

Whether you choose to do the survey in-house, or to use an Approved 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 underestimated. 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 12 – *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 13.1 - *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 13.2 - *Setting up a FREEPHONE line.*)

### **Data entry**

If the data are entered manually, you will need to allow enough staff time for this, and for checking the accuracy of the data file. Alternatively, a data processing or scanning company may be contracted to process the data. 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.

**N.B.** When you have decided who will carry out your survey, you must inform the Advice Centre by **30 July 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.

Thirteen organisations have been approved by the Healthcare Commission to carry out the local NHS Trust Emergency 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.

### 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: 0208 861 8703  
Fax: 0208 863 0957  
E-mail: [sam.mcguire@ipsos.com](mailto: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](mailto: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](mailto:info@mruk.co.uk); [london@mruk.co.uk](mailto:london@mruk.co.uk); [research@mruk.co.uk](mailto: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](mailto:esutherland@marketing-sciences.com)  
Website: [www.marketing-sciences.com/](http://www.marketing-sciences.com/)

## Market & Opinion Research International (MORI)

**Contacts:** Ben Cooke, Mark Gill

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

Tel: 0207 347 3000  
Fax: 0207 347 3800  
E-mail: ben.cooke@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

## NOP

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

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

Tel: 0207 890 9000 (Switchboard)  
Fax: 0207 890 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  
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1 Islington High Street  
London  
N1 9AH

Tel: 0207 675 1066

Fax: 0207 675 1908

E-mail: [rory.macneill@orc.co.uk](mailto:rory.macneill@orc.co.uk); [patientsurvey@orc.co.uk](mailto: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](mailto:andrew.smith@patientdynamics.org.uk)

### **Picker Institute Europe**

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

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Tel: 01865 208100

Fax: 01865 208101

E-mail: [surveys@pickereurope.ac.uk](mailto:surveys@pickereurope.ac.uk)

Website: [www.pickereurope.org](http://www.pickereurope.org)

## **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](mailto:QHConsult@aol.com)

Website: [www.quality-health.co.uk](http://www.quality-health.co.uk)

## **Taylor Nelson Sofres**

**Contact:** Susannah Quick

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

Tel: 0208 334 4200

Fax: 0208 334 4227

Email: [Susannah.quick@tns-global.com](mailto:Susannah.quick@tns-global.com)

Website: [www.tnsfres.com](http://www.tnsfres.com)

## 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 comply with the NHS Code of Practice on Confidentiality and the Caldicott Guidance (about which, more detail is given below).

As a part of this, you will need to take care that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors. Your trust's Caldicott Guardian and legal advisors will be able to advise you on matters of confidentiality and data protection.

The website below has further information:

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

### 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

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

Further information about the Data Protection Act can be found at:

<http://www.informationcommissioner.gov.uk>

## 5.2 Patients' names and addresses

In general, 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, unless appropriate security and contractual measures are in place. This includes releasing names and addresses for the purpose of mailing survey 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 13.
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.
  - The amount of patient information handed over to the contractor should be kept to the minimum necessary.
  - The patient information should be password-protected, and the password should only be known to the person in the trust who sends out the information and one or two people from the external contractor who receive the information.

## 5.3 Sample Honorary Contract

<b>[Name of NHS Trust]</b>	
<b>To: [Name of employee]</b>	<b>[Date]</b>
<ol style="list-style-type: none"><li>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.</li><li>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.</li><li>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.</li><li>4. The work will be carried out off-site at a location to be agreed with [name of external contractor].</li><li>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.</li><li>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 &amp; Safety at Work Acts 1974 (including Regulations and Codes of Practice issued thereunder).</li><li>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.</li><li>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.</li><li>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.</li><li>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.</li><li>11. Please sign and return this letter by way of confirmation of your agreement to the terms on which the appointment is made.</li><li>12. The offer and the acceptance of it should together constitute a contract between two parties.</li></ol>	
<b>FORM OF ACCEPTANCE</b>	
I hereby accept the terms and conditions set out above.	
Signed: .....	Date:.....
<b>[Name of employee]</b>	
Signed: ... (On behalf of the Trust)	Title: .....
<b>[NHS Trust]</b>	
Date:.....	

## 5.4 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 visited a particular department, 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.

## 5.5 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.

## 5.6 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 destroyed when the mailing process is complete, but **do not destroy it before 31st December 2004** as your trust might be included in the non-response follow-up survey to be carried out by BMRB.

## 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 survey

Multi-Centre Research Ethics Committee (MREC) approval has been obtained for the Core Questionnaire, the question bank, 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. You should inform the relevant Local Research Ethics Committees (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 the NHSSurveys website.

### 6.2 Ethical approval for adding your own questions

If you write your own questions, you will need to obtain ethical approval from the Local Research Ethics Committee (LREC) before you proceed. The LREC will want to see the letter from the MREC and any additional documents relating to the changes you intend to make. This process may take at least 2 months.

### 6.3 Further information on ethical approval

Further information on the ethical approval process can be found at [www.corec.org.uk/LRECContacts.htm](http://www.corec.org.uk/LRECContacts.htm) or by e-mailing [queries@corec.org.uk](mailto:queries@corec.org.uk).

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

The development of the survey, covering letters to patients, the questionnaire and the bank of questions 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.

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

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 Healthcare Commission. 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 the Healthcare Commission 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.

## 6.5 Responsibilities of organisations providing care

<b>Research Governance Framework</b>	<b>The Healthcare Commission patient surveys</b>
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	<i>The survey is carried out on the experiences of patients after they have received the care so this does not apply.</i>
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	<i>All Chief Executives are informed of the proposals of the survey. Similar letter has been sent to the R&amp;D Managers of the trusts.</i>
Ensure patients or users and carers are provided with information on research that may affect their care.	<i>The survey does not affect the care of the patients. Anonymised results are used for 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.</i>
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	<i>This requirement is not specific to this survey.</i>
Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	<i>The Healthcare Commission as sponsors of the study have sought ethics approval from MREC. There is a designated lead for each survey who is appointed by the Chief Executive.</i>
Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	<i>The Healthcare Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in section 3.8 of the Research Governance Framework are followed thoroughly.</i>

Research Governance Framework	The Healthcare Commission patient surveys
Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	<i>A detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.</i>
Maintain the necessary links with clinical governance and/or best value processes.	<i>The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.</i>
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities. <sup>1</sup>	<i>In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an honorary contract with the trust. These procedures are specifically detailed in the guidance notes.</i>
Put and keep in place systems to identify and learn from errors and failures.	<i>The Healthcare Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Healthcare Commission. The survey programme is constantly evaluated and reviewed in the light of these.</i>
Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	<i>This requirement is not specific to this survey.</i>
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	<i>The Healthcare Commission maintains a helpline facility, which can be used by patients or trusts to report any complaints. Similar arrangements are in place with the NHS Patient Survey Advice Centre who are commissioned by the Healthcare Commission to co-ordinate the patient surveys.</i>

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

<b>Research Governance Framework</b>	<b>The Healthcare Commission patient surveys</b>
Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	<i>Not applicable to the patient survey. Patient safety is not compromised, this being a postal survey.</i>
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	<i>The results of the surveys are used for performance monitoring and national star rating mechanisms</i>

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

The patients who respond to your survey should be representative of all of the patients who use the trust, so it is important that groups with limited understanding of English are not excluded. The Core Questionnaire and the question bank have been written in as **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 Healthcare Commission 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 the Healthcare Commission: [rekha.elaswarapu@Healthcarecommission.org.uk](mailto:rekha.elaswarapu@Healthcarecommission.org.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.language.co.uk>, e-mail [info@language.co.uk](mailto:info@language.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.

### Timetable

Week	Task	See Section
0	<b>Inform Survey Advice Centre about who is carrying out the survey (by 30 July 2004 at latest).</b>	3
1	<b>Draw sample of patients to be included in the survey</b>	9
1	<b>Submit sample list to NSTS to check for deceased patients</b>	9.5
1	<b>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</b>	5.2, 5.3 & 12.2
2	<b>Decide on questions to be included in the survey (i.e. select from question bank or use the Core Emergency Survey)</b>	11
2	Print questionnaires and covering letters.	12.1 & 12.2
2	Ensure you have enough envelopes, return envelopes and labels	12.3 to 12.6
2	Set up FREEPOST address and FREEPHONE line	13.1 & 13.2
2	Establish system for responding to telephone enquiries	13.2
3	Establish system for booking in questionnaires	13.5
3	Send out first questionnaires	13.4
3 - 8	<b>Stick labels on pre-packed numbered questionnaires supplied by approved contractor (if NOT using honorary contract)</b>	
3-12	Continue to respond to telephone enquiries	
3-12	Continue to book in returned questionnaires	
3-12	Enter data	14
4	<b>Check your trust's own records again for any patient deaths</b>	9.7
5-6	Send out first reminders to non-responders	0
5-6	Be prepared for a small peak in telephone calls as first reminders received	13.2
7	<b>Check your trust's own records again for any patient deaths</b>	9.7
8	Send out second reminders to non-responders	0
11	Complete data entry	
11	Check data for errors <b>*Very Important*</b>	14.4
12	Send data to Survey Advice Centre (by 5 November 2004 at latest)	14.5
12	Begin analysing trust's results and writing report	15 & 16

## 9 Compiling a list of patients

This section explains in detail how to draw the sample of patients. This task will need to be carried out by a 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 to do the task properly.**

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

### 9.1 Compile a full list of patient attendances in 1 month

- Select the month of Emergency Department attendances that your survey will cover. Depending on when you start, this should be **either** June 2004 **or** July 2004 **or** August 2004.
- Compile a full list of all patient **attendances** at all Emergency Departments (A&E /Casualty) **at all sites** in your trust during one month.
- This is a list of **attendances/visits**, rather than a list of patients, so some patients will appear in the list more than once, but that does not matter at this stage.

#### What to leave out

Attendances by the following patients should be removed from the list:

- Any attendances at **Minor Injuries Units**
- Any patients who were admitted to hospital via **Medical or Surgical Admissions Units** and therefore have not visited the Emergency Department
- Children **under 16** at the date of their arrival at the hospital
- Any patients who are known to be **current inpatients**
- Patients who are known to have **died**
- Patients who do not have a **known UK address**
- Planned attendances at **outpatient clinics which are run within the Emergency Department** (such as fracture clinics)

## 9.2 Data fields to include in the list of attendances

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

- Patient Record Number <sup>2</sup>
- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields <sup>3</sup>
- Postcode
- Year of birth
- Gender
- Ethnic category <sup>4</sup>
- Date of arrival at the Emergency Department
- Survey unit – e.g. hospital site <sup>5</sup> - **Optional**
- Any other details required by the NHS Strategic Tracing Service (NSTS). Wherever possible, this should include the NHS number. <sup>6</sup>

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<sup>2</sup> This field will be a series of sequential numbers (for example, 1001 through to 1850 but make sure it is a different number range than that used in your Outpatients Survey). The patient record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or returned undelivered), you (or the Approved Survey Contractor) will be able to use these numbers to monitor which patients have returned their questionnaires and to identify any non-responders, who will need to be sent reminders.

<sup>3</sup> 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.

<sup>4</sup> It is acknowledged that patient records might not always contain complete data on patients' ethnic category. However, this field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic categories. This is in keeping with the aims of the Health care commission and Department of Health to be more responsive to all ethnic groups and provide services that take account of their individual requirements.

<sup>5</sup> This is optional, but it might be useful information if you later want to compare hospital sites or units within the trust. However, you should discuss this fully with the approved survey contractor, who will advise on the minimum sample size required for such comparisons.

<sup>6</sup> 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 included in the list of service users (see Section 9.5 for more details on using the NSTS).

### 9.3 Taking a sample of patients to send to the tracing service

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

**Note:** You are aiming for a **response rate of at least 50%** (but many trusts will achieve a much higher response rate than that), which means that you should have about 450 completed questionnaires if you send questionnaires to 850 patients. You will be able to maximise your response rate by following this guidance carefully. 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 Survey Advice Centre will only be able to accept responses from the 850 patients in your list that have been correctly sampled.

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

1. Put the list of **all** eligible attendances in your chosen month (i.e. June, July OR August 2004) into an electronic file in a programme that allows sorting by columns (for example, Microsoft Excel or Access).
2. Sort the list by patients' **surnames**, and then by **year of birth** (N.B. Ensure that you select all columns before sorting in Excel, otherwise the patient details will get mixed up). Sorting should ensure that all attendances by the same patients come next to each other in the list.
3. Count the total number of attendances in the chosen month.
4. Calculate the sampling interval you will need to extract 900 patients from the total number of attendances, in order to select your pre-tracing sample of 900 patients. (See example below.)

#### **Example**

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

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

5. Round **down** your interval to the nearest whole number to give you a value which we will call  $i$  (in this example,  $i$  would be **29**.)

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

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

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

## 9.4 Check the sample list

Once you have compiled your list of 900 patients, it is important to carry out a few final checks before sending the data to the NSTS:

- **Duplications.** You should check your list to make sure patients' names do not appear more than once, and you should remove any duplicated names. <sup>7</sup>
- **Postal addresses.** Check again that there are no addresses that are outside the UK.
- **Patient ages.** Check again that all patients are aged 16 or over.
- **Incomplete information.** Check for any records with incomplete information on key fields (such as surname and address) and remove those patients. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a patient if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. The more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias.

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<sup>7</sup> This sampling procedure minimises the chances that patients will be duplicated in your final list. That is, in the above example, a patient could only be selected twice if they had 29 or more attendances to the Emergency Department in 1 month. However, if your trust has particularly small numbers of attendances, you are more likely to have some duplicated patients.

- **Current inpatients.** Check again that none of the patients are known to be current inpatients in your trust (or elsewhere, if known).
- **Deceased patients.** Check again 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.

## 9.5 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://www.nhsia.nhs.uk/nsts/>

The time required to carry out the checks depends partly on how compatible the list you submit to the NSTS is with their system requirement. 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.

## 9.6 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!**

## 9.7 When patient file is returned from the NSTS

### If you have more than 850 patients remaining in your list

When your patient list comes back from NSTS, if it is still greater than 850, you will need to delete a random selection of records to from the file to reduce it to 850 records. To do this:

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

$$872/22 = \underline{39.6}$$

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

## Too few patients in the list

If you have fewer than 850 patients in your list at this stage, please contact the Advice Centre.

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

## 9.8 Organise the patient information into the sample file

Once the file is returned from the NSTS, and you have reduced it to 850 patients, you need to keep the patient information in an electronic spreadsheet or database file, where you can record which questionnaires have been returned. At the end of the survey process, you will be asked to send an anonymised version of this information to the Patient Survey Advice Centre. You will also need to keep this file until 31<sup>st</sup> December 2004, in case your trust is included in the non-response follow up survey to be carried out by researchers at BMRB.

Firstly, you will need to add three new columns:

1. **Patient Record Number.** This field will be a series of consecutive numbers (for example, 1001 through to 1850 but make sure it is a different number range from that used in your Outpatients 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 *underlined red italics* will need to be included in the file sent to the Survey Advice Centre.

**Table 1 – Sample Excel file of patient details**

<i><u>Patient Record Number</u></i>	<b>Title</b>	<b>Initials</b>	<b>Surname</b>	<b>Address1</b>	<b>Postcode</b>	<i><u>Year of birth</u></i>	<i><u>Gender</u></i>	<i><u>Ethnic Category</u></i>	<i><u>Day of month of attendance</u></i>	<i><u>Month of attendance</u></i>	<i><u>Year of attendance</u></i>	<i><u>Outcome</u></i>	<b>Comments</b>
1001	Mrs	AM	Abbot			1925	2	1	1	7	2004	3	Informed Patient died
1002	Mr	EC	Ahmed			1937	1	3	2	7	2004	1	
1849	Miss	K	Yoo			1965	2	5	31	7	2004		
1850	Ms	F	Young			1941	2	1	31	7	2004	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 1001 at the top of the list, through to 1850 at the bottom. The patient record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the Approved 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.
- Make sure the number range you use for the **Patient Record Numbers** is different from that used for your Outpatients Survey.
- 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. Only patients aged over 16 should be included in the sample.

- **Gender** should be coded as 1 = male and 2 = female. However, be aware that other systems may use a different coding.
- **The Attendance Day, Month and Year** are recorded in separate columns and formatted as *general* or *numeric* (rather than as dates).
- **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 1<sup>st</sup> April 2001, but if your trust is using these categories, the data will need to be re-coded to these numeric codes.
- 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, so it can be seen that Miss Yoo has not yet returned her questionnaire; Mr Ahmed and Ms Young have returned theirs; and Mrs Abbott has died since the survey started.

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.\***

## 9.9 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.

## 9.10 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.

## 9.11 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 hospitals or units 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 ask doctors, nurses, patient liaison officers, or the Chief Executive's office about the survey, even when your covering letters give contact details for the survey 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 the hospital. Also, it is sometimes a good idea to send a press release to the local media to gain publicity before the survey takes place.
- Template staff briefings and information for use in press releases can be downloaded from the [NHSSurveys website](#).

# 11 The Emergency Survey Core Questions and question bank

Each trust must include in their survey at least the 49 Core Emergency Survey questions. There is a pre-designed Core Questionnaire on the NHSSurveys website, which includes only these questions. In addition, by using the "Create your own survey" option on the website, you can include supplementary questions from a bank of validated questions. These questions will be inserted into the appropriate places in the questionnaire, and the document will then be generated in .pdf format, ready for printing.

There is also a facility to design your own questions and response options on the website.

In summary, there are three options for carrying out the NHS Emergency department surveys:

1. The **Core Emergency Survey**, which comprises 49 core questions.
2. The **Enhanced Survey**, which includes all of the 49 Core Emergency Survey questions, with an additional bank of validated questions.
3. The **Customised Survey**, which is either the **Core** or **Enhanced** Survey with additional new questions designed by you.

If you design your own questions, it is essential that survey questions be **carefully designed and properly tested** before they are included in a questionnaire.

You should also be aware that, if you include new questions, you might need to obtain **ethical approval** before proceeding with sending out questionnaires, as any new questions will not have been pre-approved by ethics committees.

The surveys can be accessed from the NHSSurveys website.

## 11.1 The Core Emergency Survey

The Core Emergency Survey consists of 49 questions on 8 pages. These 49 questions cover the issues that have been found to be most important to patients and the questions that trusts said they found to be the most useful, and they must be included in your survey. 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 that broadly follow the patient's experience.

## 11.2 Using the question bank

The Core Emergency Survey covers all the compulsory questions you need to ask for the NHS national survey programme. However, you might want to ask more questions on some topics, and you can do this by using the "Create your own survey" option on the website. The instructions on the website will guide you through the steps you need to take to create your own survey.

You will notice that some questions have tick boxes next to them, while other questions do not. Those questions that have tick boxes are the optional questions, which can be selected or deselected from the question bank. The questions with no tick boxes (just bullet points) cannot be deselected because they are compulsory Core Emergency Survey questions, and they must be included in all NHS Trust Surveys.

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

## 11.3 The Customised Survey

From the NHSSurveys website, there is also an option to include additional questions that you design yourself.

It must be emphasised, however, that it is not advisable to design new survey questions unless you have considerable experience in doing so. The time, effort, costs and skills required to design survey questions are often under-estimated. For example, it is common for a single question to be re-worded ten or more times before it is considered acceptable. You would need to ensure that you have adequate time to carry out essential research with patients to check that questions are clear, appropriate and unambiguous. You may also need to seek approval from your Local Research Ethics Committee if you include new questions (See Section 6 - *Ethical issues, ethics committees & research governance* ).

## 12 Materials

### 12.1 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 Core Questionnaire, available in pdf format on the NHSSurveys website, is designed to fit on to 8 sides of A4 paper.

#### Number of questionnaires

When calculating the number of questionnaires to be printed, you will need to allow for sending out duplicate questionnaires 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  $850 \times 1.7$ , or approximately 1,500 copies.

### 12.2 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 1,500 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.

### 12.3 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

## 12.4 First mailing

You will need 850 of each of the following items:

- Printed questionnaires
- Large envelopes for mailing questionnaires to patient
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes
- FREEPOST envelopes for return of questionnaires
- Paper bearing the trust's letterhead for covering letters

## 12.5 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

## 12.6 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

## 13 Implementing the survey-practicalities

This section gives guidance on administering the NHS Trust Emergency Department Surveys using pre-designed surveys and pre-validated questions from the NHSSurveys website. The following topics are covered:

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

### 13.1 Setting up a FREEPOST address

A FREEPOST address allows patients to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the envelopes you send out with the questionnaires. Printed envelopes must comply with Royal Mail guidelines. Details of how to apply for a FREEPOST licence can be found at the Royal Mail website: <http://www.royalmail.com>. Alternatively, you can call your local Sales Centre on 0845 7950 950.

### 13.2 Setting up a FREEPHONE line

The covering letter to patients should include a telephone number for patients to call if they have any questions or complaints about the survey. You might want to set up a FREEPHONE line for this purpose. 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.

#### Common questions and comments

*I have had two or more hospital visits - which one should I refer to?*

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

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

Patients can be referred to the trust's PALS, the complaints manager or patient services manager.

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

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

*The person to whom the questionnaire is addressed has died.*

Even with the use of a deceased patients tracing service, it 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 would like to take part but English is not my first language.*

If a patient's spoken English is better than their written English, they may be willing to have someone 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 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 also 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.

### 13.3 Covering letters

The following covering letter has been given ethical approval for use in the NHS Trust Emergency Department Surveys. It should be printed on the trust's letterhead 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.

## Covering letter for first mailing

*To be printed on trust headed paper. Text in square brackets to be edited.*

Date

Dear patient

### **Emergency Department (A&E / Casualty) survey**

We are inviting you to take part in a survey of patients who have recently visited the Emergency Department (A&E/Casualty) at [Hospital A] [or Hospital B].

#### **What is the purpose of the survey?**

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

#### **Why have I been chosen?**

You are being invited to take part in this survey because you recently visited the Emergency Department. We are sending questionnaires to [850] randomly selected patients.

#### **Do I have to take part?**

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

#### **What would I have to do?**

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

If you do not wish to take part, please could you return the blank questionnaire in the FREEPOST envelope. If we do not hear from you in 2-3 weeks we may send you a reminder.

#### **Will my taking part in this study be kept confidential?**

Yes. You have been given a unique number so your name and address are not on the questionnaire. Information will not be passed on to doctors, nurses or other NHS health care staff in a way that allows you to be identified.

#### **Who is organising the survey?**

The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Healthcare Commission and the NHS Surveys Advice Centre at Picker Institute Europe. The results will be presented in a form that does not allow any individual's answers to be identified. The anonymous survey findings will be analysed by the Advice Centre and the Healthcare Commission and be available on their website at [<http://www.healthcarecommission.org.uk/NationalFindings/Surveys/fs/en>].

#### **Contact for further information**

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

**Thank you**

Yours faithfully

[Chief Executive name]

Chief Executive

[NHS Trust Name]

## 13.4 Sending out questionnaires

### Mailing labels

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

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

### Questionnaire packs

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

- 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
- A covering letter
- A large envelope, labelled with the FREEPOST address on it.

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.

## 13.5 Booking in questionnaires

When questionnaires are received, match up the Patient Record Numbers against the list of patients, so that you can record (in the *outcome* column) which patients have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until 30 April 2005, 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.

## 13.6 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 50%. In order to achieve this, you must send out two reminders to non-responders. **It is essential that you send out both reminders, even if you already have achieved the minimum 50% response rate.**

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

### 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. 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.

The following reminder slip has been given ethical approval for use in the NHS Trust Emergency Department Surveys. 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

*Text in square brackets needs to be edited.*

[Date]

**[Name of NHS Trust]**

Approximately three weeks ago we sent you a questionnaire about health care at [NHS Trust Name]. At the time of sending this note, we have not yet received your response.

Participation in the survey is voluntary, and if you choose not to take part it will not affect the care you receive from the NHS. 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 line /us] on [number] between [opening time] and [closing time], Monday to Friday.

## 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.

The following covering letter has been given ethical approval for use in the NHS Trust Emergency Department Surveys. A Word version is on the NHSSurveys website for you to download and add your own trust's details. It should be printed on the trust's letterhead paper. 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.

## Covering letter for second reminder

*To be printed on trust headed paper. Text in square brackets to be edited.*

Date

Dear patient

### **Emergency Department (A&E / Casualty) survey**

Enclosed is a copy of a patient survey about your visit to the Emergency Department (A&E/Casualty) of [Hospital A] or [Hospital B]. We originally sent the survey to you a few weeks ago. If you have already replied, please ignore this letter and accept our apologies.

#### **What is the purpose of the survey?**

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

#### **Why have I been chosen?**

You are being invited to take part in this survey because you recently visited the Emergency Department. We are sending questionnaires to [850] randomly selected patients.

#### **Do I have to take part?**

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

#### **What would I have to do?**

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

If you do not wish to take part, please could you return the blank questionnaire in the FREEPOST envelope.

#### **Will my taking part in this study be kept confidential?**

Yes. You have been given a unique number so your name and address are not on the questionnaire. Information will not be passed on to doctors, nurses or other NHS health care staff in a way that allows you to be identified.

#### **Who is organising the survey?**

The survey is being carried out by researchers from [NHS Trust name /name of survey company], the Healthcare Commission 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. The anonymous survey findings will be analysed by the Advice Centre and the Healthcare Commission and be available on their website at <http://www.healthcarecommission.org.uk/NationalFindings/Surveys/fs/en>.

#### **Contact for further information**

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

Thank you

Yours faithfully

[Chief Executive name]  
Chief Executive  
[NHS Trust Name]

## 14 Entering data

The data must be submitted to the Advice Centre in the appropriate format by the deadline on 5 November 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.

### 14.1 Entering and coding data from the Core Emergency Survey

The data should be entered into a pre-designed Excel file 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 (.).<sup>8</sup>
- 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.)

### 14.2 Entering data from Enhanced or Customised questionnaires

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

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<sup>8</sup> If you want to use this data input file on the website to display frequencies on the other pages of the workbook, you will need to fill in the blank cells with a full stop (.).

## 14.3 Adapting data file for sending data to the Advice Centre

You will need to send the data from the 49 compulsory Core Emergency Survey questions to the Advice Centre. To do this, you will need to transfer those columns of data that cover the responses to those 49 questions to the pre-designed Excel file available on the website. The columns of this standard Excel file are headed with the numbers corresponding to the question numbers in the Core Emergency Survey. They also include the wordings of the 49 Core Emergency Survey questions so that you can match them up. It is essential that you check carefully that the columns of data you select from your larger data set correspond to the 49 Core Emergency Survey questions.

## 14.4 Checking the data for errors

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. (You can do this by subtracting each cell in one data sheet in Excel from a comparison sheet. If there are no differences between the two sheets, each cell will be zero.)
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.

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

## 14.5 Submitting data to the Patient Survey Advice Centre

The data from the core questions of the Emergency Department Survey must be submitted to the NHS Patient Survey Advice Centre as one anonymised Excel file that includes information about the patient sample and responses.

### File format

- Microsoft Excel Worksheet (*not* Workbook). Any version of Excel is acceptable.
- File name should be in the form <NHSTrustName>\_Emergency2005.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 (.).<sup>9</sup>

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<sup>9</sup> Data may be missing for a number of reasons: the patient may have skipped a question or a set of questions by following instructions; a patient may have not answered for some other reason. However, all missing data should be left blank or coded as a full stop (.), regardless of the reason for the omission.

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

**Table 2 - Data fields to be included in file submitted to Advice Centre**

Field	Format	Data codes	Comments
Patient Record Number	NNNN		The unique serial number allocated to each patient by the trust or Approved Survey Contractor administering the survey
Year of birth	NNNN		
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.).
Ethnic category	N	1 = White 2 = Mixed 3 = Asian or Asian British 4 = Black or Black British 5 = Chinese 6 = Other ethnic category	Ethnic category should be included if the information is available
Day of attendance	N or NN	Format this field as a number, not a date	For example, if the patient attended the department on 16 <sup>th</sup> July 2004, this column should read 16.
Month of attendance	N	Format this field as a number, not a date	For example, if the patient attended the department on 16 <sup>th</sup> July 2004, this column should read 7.
Year of attendance	NNNN	Format this field as a number, not a date	For example, if the patient attended the department on 16 <sup>th</sup> July 2004, this column should read 2004.
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)	Outcome of sending questionnaire  Remember to fill in all the blank cells with 6s when the survey is complete.
Responses to each of the 49 Core questions	N or NN or NNNN		Each column must be clearly headed with the Core Questionnaire question number. Data should be coded using the numbers next to the response boxes on the printed surveys. There is no need to send the comments to the Advice Centre.

**N.B.** To comply with the Data Protection Act, name and address details must not be sent 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 50% of the patients (that is, those who have returned a completed questionnaire, and who will therefore have an outcome code "1").

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

<i>Patient Sample Information</i>							<i>Patient Response Information</i>								
<i>Patient Record Number</i>	<i>Year of birth</i>	<i>Gender</i>	<i>Ethnic Group</i>	<i>Day of month of attendance</i>	<i>Month of attendance</i>	<i>Year of attendance</i>	<i>Outcome</i>	<i>Q1</i>	<i>Q2</i>	<i>Q3</i>	<i>-</i>	<i>Q46</i>	<i>Q47</i>	<i>Q48</i>	<i>Q49</i>
1001	1934	2	1	1	7	2004	3								
1002	1970	1	3	2	7	2004	1	1	1	5		2	2		8
1003	1965	2	1	2	7	2004	6								
1004	1935	2	1	3	7	2004	1	2				3	2		1
1005	1929	2	1	3	7	2004	1	1	3	1		4	2		1
1006	1923	1	4	3	7	2004	2								
1849	1950	2	5	31	7	2004	6								
1850	1946	2	1	31	7	2004	1	1				3	1	2	1

## 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 may be sent on floppy disc or by e-mail:

Postal address:

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

e-mail: [acute.data@pickereurope.ac.uk](mailto:acute.data@pickereurope.ac.uk)

## Date

The data must be supplied by 5 November 2004.

## 14.6 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.

<b>Check</b>	<b>Done? Please initial</b>
1. Check that your <b>file name</b> follows the naming convention: <NHSTrustName>_Emergency2005.xls)	
2. Check that you have saved the data sheet only as an Excel <b>worksheet</b> , rather than a workbook. (The frequency and percentage counts on the other pages of the workbook on the website are intended for your use only.)	
3. Send data only for the <b>850 patients</b> sampled from your trust in the chosen month.	
4. Check that all <b>data are correct</b> , and that all values are in range.	
5. Check that you have included data columns for <b>all 49 core questions</b> .	
6. Check that you have <b>not</b> included any columns of optional questions.	
7. Check that all the data are in <b>numeric format</b> only.	
8. To comply with Data Protection regulations, any <b>patient name and address details</b> must be removed before the file is sent to the Survey Advice Centre.	
9. Remove any <b>passwords</b> .	
10. Include <b>two paper copies</b> of the questionnaire you used.	
11. Include <b>two paper copies</b> of the covering letters you used for the first mailing, the second mailing and the third mailing.	
12. Include <b>telephone and e-mail contact details of 2 people</b> who will be available to respond to any queries about the data.	
13. <b>Check again</b> that all data are correct, and that all values are in range!	
14. Remember to <b>keep a copy of the patient sample information until 31<sup>st</sup> December 2004</b> , in case your trust is included in the non-response follow-up survey to be carried out by researchers at BMRB.	

### 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 the Healthcare Commission in your trust's performance ratings, and those indicators will be set to a minimum. We cannot accept re-submissions of data after the deadline.

## 15 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.

### 15.1 Using the NHSSurveys website to look at results

Once you have entered the data from the core questions into the Excel file on the website, the counts and percentages of responses to each of the 49 core questions are automatically computed and displayed on other sheets of the Excel workbook, which correspond to sections of the Emergency Core Questionnaire. For each question, the numbers and percentages of respondents who gave each answer is shown. The number of missing responses will also be shown, as long as you have coded missing responses on the data sheet as a full stop (.).

### 15.2 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 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 scores, 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 score). 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.

## 16 Reporting results

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

#### Compare results within your organisation

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

#### 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.

#### Comparison 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

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

## 16.2 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.

## 17 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.

### 17.1 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.

### 17.2 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 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.

### 17.3 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.

### 17.4 Prioritising areas for improvement

#### Compare with other trusts

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

#### Compare departments within your trust

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

#### Identify where patients report most room for improvement

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

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

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

## Identify problems surrounding particular aspects of the patient experience

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

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

### 17.5 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.

### 17.6 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.

## 18 Appendix – Designing and testing new questions

This section gives guidance on designing your own questions and putting them into a survey. As noted in Section 11, the skill and effort required to design survey questions and put them together into a workable format is very often underestimated. For this reason, we **strongly recommend** that, unless you have considerable experience in questionnaire design, you should use only the standard pre-tested questions available on the NHSSurveys website.

However, we also recognise that there may be issues that are uniquely important for your trust that are not covered by the standard sets of questions. In such cases, it may be necessary to design your own questions.

### 18.1 Designing good questions

For a survey to produce accurate and useful results, the questions must be rooted in what patients say is important to them. Focus groups and patient complaint lines are a rich source of potential topics for survey questions. It is also important to pre-test questions with patients to get a sense of how relevant and understandable the questions are to them.

- **Topics should be specific enough to be relevant, but not so specific that the questions become tedious to answer**

The more specific the topic of a particular question, the easier it will be for those who use the data to act on the results. However, if questions cover processes in too much detail, respondents may lose interest before they complete the survey.

- **Avoid topics that are politically sensitive or might embarrass patients**

Sensitive topics can spur complaints about the survey and may lower response rates. These issues are better addressed in focus groups or face-to-face interviews.

- **Phrase questions in simple and straightforward language**

Long words, complex sentence structures and technical terms can confuse respondents and make interpretation of their responses very difficult.

- **Use single subject questions whenever possible**

Asking questions about two things at the same time ("double barrelled" questions) can lead to confusion and problems with interpretation. For example, a question that asked, "Did a nurse give you advice about caring for yourself at home or obtaining follow-up medical care?" would be difficult to answer. Respondents could be confused about how they should answer if their experiences of the advice given to them about those two issues differed. It would therefore be difficult to interpret responses to this question and it would not lend itself to an analysis that focused on either issue.

- **Avoid leading or biased questions**

Questions that focus too strongly on a positive or negative experience can lead a respondent towards a particular response. For example, a question such as, "Were you unhappy with the amount of time it took to get through the admission process?" might lead respondents toward negative responses, thereby overstating the problem.

- **Limit the number of "open-ended" questions**

Questions that call for a narrative response are often tempting, because they offer more detailed insights into respondents' experiences. However, such "open-ended" questions are difficult and expensive to input and analyse. They also add length to written surveys and can take respondents a long time to complete.

- **Consider the purpose of the question when selecting the wording and format**

Survey questions generally fall into two categories: those that ask patients to report about their experience and those that ask them to rate their experiences.

For example,

"Did \_\_ happen?" and "How much of \_\_ did you get?" are report questions.

"How would you rate \_\_?" and "Please rate \_\_ as poor, fair, good, very good, or excellent," are rating questions.

Rating questions are used to elicit opinions or summary judgments about care. Reporting questions are more factual assessments of specific processes of care and can be used more effectively to suggest a clear course of action.

## 18.2 Layout of the questionnaire

- **Survey questions should lead a patient through their experiences in as natural a way as possible**

Questions about similar issues should be grouped together. This allows for easier and more accurate recall. Also, where possible, it is preferable to put the questions in a sensible chronological order. For example, questions about admission should be put near the beginning of the questionnaire, while questions about discharge and follow-up should go towards the end.

- **Ensure that appropriate filters are included**

A filter is an introductory question, which asks the patient whether a topic area is relevant to them. For example, a section on pain and pain relief should begin with the filter "Were you ever in any pain?" Those who answer "no" to this question are guided to skip the pain section and go straight to the next section. However, complex filters can sometimes confuse respondents.

Table 4 is a comparison of three different types of question: rating questions, report questions and open-ended questions.

**Table 4 - Comparison of types of questions**

<b>Ratings</b>	<b>Reports</b>	<b>Open-ended</b>
<ul style="list-style-type: none"> <li>• Provide evaluations</li> <li>• Maximise variation by offering many response alternatives</li> <li>• May be influenced by feelings of gratitude</li> <li>• Evaluations tend to be positive</li> <li>• Good for summary measures (e.g., overall quality and overall satisfaction)</li> <li>• Dependent on expectations</li> </ul>	<ul style="list-style-type: none"> <li>• Find out about events; what happened</li> <li>• Objective, usually involve fewer response options than rating questions</li> <li>• Can be more specific than ratings</li> <li>• More actionable than ratings</li> <li>• Often easier to interpret than ratings</li> </ul>	<ul style="list-style-type: none"> <li>• Provide qualitative information</li> <li>• Unlimited topics</li> <li>• Good source for anecdotes</li> <li>• More difficult to analyse and summarise than closed questions</li> <li>• Useful source of quotations for reports</li> </ul>

## 18.3 Examples of survey questions

### Report question

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

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

### Rating question

**Q.** Overall, how would you rate the care you received?

- Poor
- Fair
- Good
- Very Good
- Excellent

### Open-ended question

What can we do to improve our services?

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## 18.4 Pre-testing survey questions

Before launching a full-scale survey with a new instrument or new questions, surveys should be discussed and tested with a smaller group of patients. All questions should be pre-tested in face-to-face *cognitive* interviews. The pre-test should be done with a small but *carefully chosen* sample of respondents — that is, a sample chosen to represent all types of patients who will be surveyed.

### Why bother with pre-testing?

Pre-testing is essential in order to:

- **Identify questions that are unclear, liable to misinterpretation, or difficult to answer**

All items in a survey must lend themselves to uniform interpretation if the information they generate is to be reliable and valid. Ambiguity is not acceptable. If respondents misunderstand or cannot answer questions, the data collection is fruitless. Pre-testing each question allows you to avoid wasting valuable resources collecting information that cannot be interpreted.

- **Discover parts of the questionnaire that place an unacceptable burden on the respondent**

By mixing types of questions (but not topics), you can avoid wearing respondents out. Asking too many questions about times and dates or other specific knowledge can cause a respondent to become frustrated and terminate an interview or toss aside a questionnaire before completing it.

- **Discover parts of the questionnaire that do not work, or that work with one population but not with another**

### Selecting patients for the pre-test

- The survey should be pre-tested among all types or subsets of respondents who will be included in the final survey.
- If the questionnaire is to be used in a population of varying age, ethnicity, income, and levels of literacy, for example, then the pre-test should be done with a similarly diverse group of respondents.
- The pre-test may include a small number of respondents. Diversity is more important than quantity in your pre-test.

## Suggestions for conducting a pre-test

- Conduct the pre-test in an environment that allows face-to-face, one-to-one contact with each respondent. Try to sit with respondents in a quiet place. Give them a paper-and-pencil version of the questionnaire you want to test and let them complete it on their own. Encourage them to ask questions about anything they do not understand. Take notes, and document the time it takes each person to complete the questionnaire. When they have completed the survey, ask specifically about the following:
- **Words.** Focus on meaning. Do they understand difficult words? Ask them to explain what they think some of the more difficult words mean.
- **Questions.** Focus on understanding. When they answered a question, what did they think it meant?
- **False positives.** Respondents may not say what they mean. (For example, they may say their admission was an emergency when in fact it was planned.) Probe for these classification misunderstandings - especially in questions that ask whether or not something happened.
- **False negatives.** Respondents may say something did not happen when in fact it did. Probe for events or conditions that may be misinterpreted. If a question asks about tests done in the hospital, for example, ask the patient what they thought "tests" meant.
- Try to make each respondent feel comfortable criticising the questions. For example:
  - *We know there are words and sentences and questions in here that aren't right, and other people have complained that some are hard to understand. Can you help us?*
  - *Were there any words or questions that were confusing, things that were hard to answer?*
  - *Did response scales put you off?*
  - *Were there questions that seemed irrelevant or silly or not important?*
  - *Were there important things we didn't ask about?*

One way to discover differences in meaning is to ask respondents to tell you, in their own words, what they think a question means. For example, consider the following question: "During your stay in hospital, did you have an operation or procedure?" You need to know if the respondent understands what "operation or procedure" means. Ask them to tell you what they think this question means.

- Pay close attention to body language and facial expressions, as well as to responses to direct questions. Some respondents may not feel comfortable answering questions about certain behaviours. If they feel uncomfortable answering a question, let them express their discomfort. Explain that you are not interested in their answer, but rather, in the source of their discomfort. Explain that you may eliminate questions if they are found to be inappropriate or poorly worded.