NHS trust-based surveys:
Mental Health Service Users 2004/05

Listening to your service users

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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.

The non-response study

A non-response study is being commissioned by the Healthcare Commission for which ethical approval is being sought currently. A few trusts will be randomly selected to take part in the study to be conducted by researchers from BMRB – a social research organisation. If your trust is selected for inclusion in this study, you will be contacted by BMRB in January and you might be asked to follow slightly different guidance on sending out reminders for a small subset of your patients.

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: service user 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 care in the NHS. Service users' experience of health services is at the heart of the Healthcare Commission's work.

1.2 Why we need service user 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 service users. Understanding the way service users 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 service users themselves.

It is important to adopt systematic, appropriate and effective ways to ask service users 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 Mental Health Trusts, combined Mental Health and Social Care Trusts, and PCTs responsible for providing secondary mental health services to obtain service user 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 Service user feedback and the NHS Plan

Improving the experience of each individual service user is at the centre of the NHS Plan reforms. Obtaining feedback from service users 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 service users their views on the services they have received. It is intended that measuring service users' experiences in a structured way will act as an incentive to make service user experience a real and central priority for the NHS. The NHS Trust Survey programme is an important mechanism for making the NHS more user-focused and provides a quantifiable way of achieving this. Surveys of service users can help deliver the NHS Plan commitments by:

- Providing information to support local quality improvement initiatives
- Tracking changes in service user 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 Service User Survey will be used by the Healthcare Commission to create headline NHS Performance Indicators. These indicators will be used in Mental Health Trust Performance Ratings, due for publication in summer 2005.

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 mental health trust to carry out surveys of service users in a consistent way, the Healthcare Commission is building up a detailed picture of service users' experiences in Mental Health NHS Trusts across the country. Also, by repeating the same surveys on an annual basis, trusts will be able to monitor their own performance over time.

1.5 Basic requirements for the Mental Health 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 **30th November 2004** and tell them who is carrying out your survey (i.e. whether it will be carried out by an approved contractor or in-house), and who in your trust will be responsible for monitoring the survey's progress (e-mail: mentalhealth.data@pickereurope.ac.uk).
- You should aim to obtain the highest possible response rate. For this survey, the target minimum is 40%, but many trusts will achieve higher response rates. **Two reminders must be sent to non-responders**, even if a 40% response rate is already achieved.
- A postal questionnaire survey must be carried out.
- The sampling procedure set out in this guidance must be followed. To do this, you will need to work closely with the person in the information department who draws the sample, and check carefully that this guidance has been adhered to. See Section 10 - *Compiling a sample of service users for the survey*.
- Your Chief Executive must sign off the sample before you send out questionnaires, and you must send a signed declaration that the sample has been signed off by **14th January 2005**.
- The questionnaire must be sent to a random sample of 850 adults aged 16-64 who are on the trust's Care Programme Approach (CPA) register on the date specified.
- The questionnaire must be the standard 8-page Mental Health Questionnaire 2005 available on the NHSSurveys website.
- The covering letters must be the standard ones printed in this document and available in word format on the NHSsurveys website.
- The data from the Mental Health Questionnaire, and information about the service user sample, must be submitted to the Survey Advice Centre in the form outlined in Section 14.3 - *Submitting data to the Patient Survey Advice Centre* by **7th April 2005**.
- Two 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 14.3 - *Submitting data to the Patient Survey Advice Centre* by **7th April 2005**.
- The data must be checked carefully for errors before submitting it to the Advice Centre. See Section 14 -*Entering data*.

- If your trust is selected for the non-response follow-up survey to be carried out by researchers at BMRB, you will be contacted and you will need to follow alternative guidance on the number of reminders you send to a few of the patients.
- 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 31st August 2005 but please **do not** send these to the Advice Centre.

1.6 How to use this guide

Trusts have the option of conducting the survey in house or using an approved contractor (see Section 3). Whichever route you take, you will need to address the guidance in Sections 1 to 11 and 15 to 17 of this guide. Sections 12, to 14 cover the practicalities of mailing out the survey, following-up responses and processing the data and submitting them 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 service user 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 service users' 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, social workers and other health care staff
    - Administrators
    - Medical records personnel or Patient Administration System staff
    - Service users 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 service user 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 service users should be made aware when a survey is being conducted, in case service users ask questions.
- **Do not overlook front-line staff**, who have the most frequent direct contact with service users. Staff can become nervous and defensive if they are not formally told about a service user survey. These feelings can compromise the effectiveness of the survey and increase resistance to any negative feedback.
- Use local service user networks and organisations to publicise the survey.

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 service users requires money, resources and staff time. Considering the following questions can help you decide whether it makes sense for your trust to conduct the survey in-house or to commission an Approved Survey Contractor:

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

3.1 Costs

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

Staff time

This is one of the largest expenditures, but it is sometimes overlooked. Be sure to factor in the cost of staff time, including salary and fringe benefits, and time spent away from other work.

Materials

Stationery and postage

You will need to cover stationery and postage for three mailings. The first mailing will go out to 850 service users 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 13.2 - *Setting up a FREEPOST address*.)

FREEPHONE service

This service gives service users 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 13.4 - *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 service users, 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 service users. 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. Service users, too, might be sceptical about feedback that is collected by trusts themselves. Results that come from an independent source may be taken more seriously.

3.3 Timing

It is often possible to carry out small, localised surveys quickly in-house. However, even in the best of situations, other demands on staff can side-track them into other work. On the other hand, if you commission an Approved Contractor to carry out the survey, you should ensure that appropriate and realistic deadlines are set.

3.4 Human resources

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

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

When you have decided who will carry out your survey, you must inform the Survey Advice Centre by 30th November 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

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

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

The standard documents submitted by Approved Contractors cover surveys in all types of NHS trusts, including Acute Trusts, and Primary Care Trusts. Note that the Mental Health Surveys differ from some of the other trust-based surveys in that there is only one standard questionnaire, so contractors will not be able to insert extra questions from a question bank, or include any other extra questions. Therefore, it will not be appropriate for contractors to quote for the cost of adding extra questions.

4.1 List of approved contractors

Ipsos-RSL

Contact: Sam McGuire

Head of Social & Public Sector Research
Ipsos – RSL
Kings House
Kymberley Road
Harrow
HA1 1PT
Tel: 0208 861 8703
Fax: 0208 863 0957
E-mail: sam.mcguire@ipsos.com

Maritz

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

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

Market Research UK

Contact: Craig Taylor; Jo Cleaver; Rachel Cope

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

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

Marketing Sciences

Contact: Eileen Sutherland

Marketing Sciences
8 Clement Street
Winchester
Hants
SO23 9DR

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

Market & Opinion Research International (MORI)

Contacts: Michele Corrado, 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:	Michele.corrado@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
Angel Corner House
1 Islington High Street
London
N1 9AH

Tel: 0207 675 1066
Fax: 0207 675 1908
E-mail: rory.macneill@orc.co.uk; patientsurvey@orc.co.uk

Patient Dynamics

Contact: Andrew Smith

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

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

Picker Institute Europe

Contacts: Karen Bullen, Tim Markham or Nick Richards

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

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

Quality Health

Contact: Dr Reg Race

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

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

Taylor Nelson Sofres

Contact: Susannah Quick

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
Website: www.tnsofres.com

4.2 Contracts

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

- The groups, and numbers, of service users 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 service users' 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 service user data. They have to ensure that any use of service user 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 service user-identifiable information unless it is absolutely necessary
- **Principle 3** – Use the minimum necessary service user-identifiable information
- **Principle 4** - Access to service user-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 Service users' 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 service users. Completed questionnaires can then be returned to the contractor and, by checking the Record Numbers on returned questionnaires, they can inform the trust which service users need to be sent reminders. This process is described in more detail in Sections 10 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 service user contact details for the purposes of sending out questionnaires and reminders to service users, 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 service user confidentiality. A sample honorary contract is shown on the following page.

5.3 Points to remember

- The amount of service user 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.

5.4 Sample Honorary Contract

[Name of NHS Trust]

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

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

FORM OF ACCEPTANCE

I hereby accept the terms and conditions set out above.

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

[Name of employee]

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

[NHS Trust]

13. Date:……………………..

5.5 Confidentiality

It is essential that any service user survey is conducted in such a way that respects confidentiality. That is, service users must be assured that doctors, nurses, social workers and other trust staff will not be able to identify individual's responses. Furthermore, their responses must not be presented to anyone in a way that allows individuals to be identified. For example, if a service user is known to be under the care of a particular team, 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 responses should be aggregated into groups of no less than 30 service users before data are presented to staff.

5.6 Service user anonymity

In-house surveys

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

Approved Contractors

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. Service users' names and addresses should be seen by trust staff only, while individual responses should be seen by contractor staff only. As long as the response data supplied to trusts do not include Service User Record Numbers and are not provided to trusts in a way that allows individuals to be identified, it can reasonably be claimed that responses are anonymous.

5.7 Storing completed questionnaires

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

Any mailing lists of patients' names and addresses should be destroyed when the mailing process is complete, but **do not destroy it before 31st August 2005** 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 service user anonymity, and they will want to check that proposed research projects will not cause physical or mental harm to service users.

6.1 Ethical approval for the mental health survey

The NHS Surveys Advice Centre has obtained Multi-Centre Research Ethics Committee (MREC) approval for the standard Mental Health Questionnaire, the covering letters and reminder letters, all of which can be downloaded from the NHSSurveys website. In order to comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document and those documents must be used.

You do not, therefore, need to seek ethical approval for this survey. If you wish, you can send your Local Research Ethics Committees (LREC(s)) a copy of the MREC approval letter, but you are not required to do this and you do not need to wait for confirmation or approval from the LREC before starting your survey. The MREC letters can be downloaded the NHSSurveys website under the Mental Health section.

6.2 Further information on ethical approval

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

6.3 Research governance requirements

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

The 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 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 methods, the questionnaire and covering letters to patients, 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.

Responsibilities of organisations providing care

Research Governance Framework	**Healthcare Commission patient and service user surveys**
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	*The survey is carried out on the experiences of service users after they have received the care so this does not apply.*
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	*All Chief Executives are informed of the proposals of the survey.*
Ensure patients or users and carers are provided with information on research that may affect their care.	*The survey does not affect the care of the service users. 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 care.*
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	*This requirement is not specific to this survey.*
Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	*The Healthcare Commission as sponsors of the study have sought ethics approval from MREC.* *There is a designated lead for each survey who is appointed by the Chief Executive.*
Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	*The Healthcare Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in section 3.8 of the Research Governance Framework are followed thoroughly.*
Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	*A detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.*

Maintain the necessary links with clinical governance and/or best value processes.	*The guidance notes very strongly recommend the trusts to maintain these links and follow best practice evidence.*
Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities.[1]	*In situations where trusts opt to use the services of an external contractor to draw the sample for the survey, the contractor is required to enter into an honorary contract with the trust. These procedures are specifically detailed in the guidance notes.*
Put and keep in place systems to identify and learn from errors and failures.	*The Healthcare Commission also undertakes consultations with the trusts in order to ensure that the errors and failures are reported back to the Healthcare Commission. The survey programme is constantly evaluated and reviewed in the light of these.*
Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	*This requirement is not specific to this survey.*
Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	*The Healthcare Commission maintains a helpline facility, which can be used by service users 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 and service user surveys.*
Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	*Not applicable to the service user survey. Patient safety is not compromised, this being a postal survey.*
Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	*The results of the surveys are used for performance monitoring and national star rating mechanisms*

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

7 Collecting data from non-English-speaking populations

The service users who respond to your survey should be representative of all of the service users who use the trust, so it is important that groups with limited understanding of English are not excluded. The Service User questionnaire has been written in as **simple language** as possible to facilitate optimum understanding by all respondents. The questions have also been tested with service users 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 service users or their specific language from their records before questionnaires are sent out because language spoken is not usually included on 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 service users, or service users 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 Sarah Scobie at the Healthcare Commission: sarah.scobie@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 service users whose spoken English is better than their written English the option of **completing the questionnaire over the telephone**, using a FREEPHONE line.

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

- Many households include at least **one competent English speaker** who can help the service user 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 service user's family or friends translate questions or interpret their responses, and it does not allow the service user 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 8-11 weeks from start to finish. Dissemination of the results to all staff will take considerably longer. This timetable is based on the *minimum* expected duration of each stage. If you commission an Approved Contractor, most of the work will be done by them, but you will still have to be involved in some of the stages of the process, marked in **bold** in the timetable below.

Week	Task	See Section
0	**Inform Survey Advice Centre about who is carrying out the survey (by 30th November 2004 at the latest).**	3 & 4
1	**Draw sample of service users to be included in the survey**	9
1	**Ask Chief Executive to sign off sample and submit declaration to Advice Centre (by 14th January 2005 at the latest)**	10.5
1	**Submit sample list to NSTS to check for deceased service users**	10.6
1	**If using an approved contractor, supply them with trust headed paper and a signature of a senior executive and, if appropriate, ensure that the honorary contract is signed**	5.4 & 12.2
1	**Set up P.O. Box** (if carrying out survey in-house)	13.3
1	Print questionnaires and covering letters. Ensure you have enough headed paper, envelopes, return envelopes and labels	12 & 13.5
2	Set up FREEPOST address and FREEPHONE line	13.2&13.4
2	Establish system for responding to telephone enquiries	13.4
3	Establish system for booking in questionnaires	13.7
3	Check your own trust's records again for any service user deaths	10.7
3	Send out first questionnaires	13.6
4	Send out first reminders to non-responders	13.8
3 - 6	**Stick labels on pre-packed numbered questionnaires supplied by approved contractor (if NOT using honorary contract)**	13.6
3 - 9	Continue to respond to telephone enquiries	13.4
3 - 9	Continue to book in returned questionnaires	
3 - 10	Enter data	14
4 - 5	Be prepared for peak in phone calls as first reminders received	13.4
6	Send out second reminders to non-responders	13.8
8-11	Complete data entry	14
8-11	Check data for errors ***Very Important***	14.2
8-11	Send data to Survey Advice Centre (by 7th April 2005 at the latest)	14.3
10-12	Begin analysing trust's results and writing report	15&16
12 -	Disseminate results to staff, service users and the public	16&17

9 A reliable CPA list

For reliable comparisons to be made between trusts, it is essential that the definitions of Enhanced and Standard CPA are applied consistently. Before undertaking the survey, all trusts should ensure that their CPA lists conform to the following guidance taken from the CPA handbook (page 6), published by CPA association in February 2001. A complete copy of this guide can be obtained from the Care Programme Approach Association (CPAA). (See www.cpaa.co.uk).

Care Programme Approach Association (CPAA) Guidance on CPA levels

Levels of need

In order to target resources effectively, and promote a consistent national approach, services are required to deliver the Care Programme Approach according to two levels of need:

- Standard; and
- Enhanced.

The characteristics of people on Standard CPA will include some of the following:

- they require the support or intervention of one agency or discipline or they require only low key support from more than one agency or discipline;
- they are more able to self-manage their mental health problems;
- they have an active informal support network;
- they pose little danger to themselves or others;
- they are more likely to maintain appropriate contact with services.

People on enhanced CPA are likely to have some of the following characteristics:

- they have multiple care needs, including housing, employment etc, requiring inter-agency co-ordination;
- they are only willing to co-operate with one professional or agency but they have multiple care needs;
- they may be in contact with a number of agencies (including the Criminal Justice System),

Account may also need to be taken of the definition of the levels given on page 53 of the National Service Framework for Mental Health (NSF).

10 Compiling a sample of service users for the survey

This section explains how to draw the sample of service users. 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 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 service user list.

10.1 Compile a full list of current service users

- If you are in any doubt about these sampling instructions, please call the Surveys Advice Centre on 01865 208127.

- Compile a full list of all service users on *either* standard or enhanced CPA who are seen between **1st September 2004 and 30th November 2004**. Make sure you take out any duplicated names.

    - Include **all** teams covered by your trust.

    - If your trust does not already have all service users on one electronic list, you will need to **combine all the separate lists** so that you have one complete list.

    - If some service users' details are not held electronically, it will be necessary to **type in their details**, so that all service users' details are held electronically.

    - Remember to include service users on both **standard** and **enhanced** CPA.

If you do not have an adequate CPA list:

- Call the Surveys Advice Centre on 01865 208127.

If you do not have adequate information on date of last contact:

- Include all service users who have had a care review in the last 12 months – including on-going care in psychiatric outpatients, with a clinical psychologist, social worker or with another mental health professional.

Who to leave out

The following service users should be removed from the list:

- Anyone seen **only once** for an assessment (For example, those who were seen by a psychiatrist for a single assessment)
- Any children who are **under 16** on the date the sample was drawn
- Anyone aged **65 or older**
- Any service users who are known to be **current inpatients**
- Service users who are known to have **died**
- Service users who do not have a **known UK address**
- Service users who have not had contact with Mental Health Services in **the last 3 months**
- Any **duplicated** names
- Any **alias names** where the person's real name is already included in the list.

10.2 Data fields to include in the list of service users

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:

- Service User Record Number[2]
- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields [3]
- Postcode
- **Year** of birth
- Gender
- Ethnic group [4]
- **Day** of the month of last contact (1 or 2 digits; e.g. 2 or 30)[5]
- **Month** of last contact (1 or 2 digits; e.g. 9 or 10)
- **Year** of last contact (4 digits; e.g. 2004)
- Whether the service user is on Enhanced or Standard CPA
- Any other details required by the NHS Strategic Tracing Service (NSTS). Wherever possible, this should include the NHS number. [6]

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[2] This will be a series of sequential numbers (for example, 1001 through to 1850), which 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 service users have returned their questionnaires and to identify the non-responders, who will need to be sent reminders.

[3] The 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.

[4] This field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic groups. This is in keeping with the aims of the Healthcare Commission and Department of Health to be more responsive to all ethnic groups and provide services that take account of their individual requirements.

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

[6] 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 10.5 for more details on using the NSTS).

10.3 Taking a sample

It is likely that your full list will include thousands of service users, but you will need to send questionnaires to only **850** service users. Taking a sample can only take place once you have compiled the full list of eligible service users as described in Section 10.2.

Note: You are aiming for **a response rate of at least 40%**, which means that you should have about 340 completed questionnaires if you send questionnaires to 850 service users. 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 service users. The Survey Advice Centre will only be able to accept responses from the 850 service users in your list that have been correctly sampled.

In order to select the 850 service users to be included in your sample, you need to take a **simple random sample** of 850 service users from your full list. This means that each eligible service user in the full list (the population) has an equal chance of being included in the sample. The procedure for doing this is as follows:

1. Put the list of service users into a Microsoft Excel file. The first row of this file should be headings (Such as name, Year of birth, CPA level, etc). There should be one row for each service user below that.

2. Put the cursor in cell A1 and insert a blank column (Click Insert, then Columns). Give this column a heading: **Random**.

3. In cell A2, type `=Rand()`

   When you press Enter, a random number between 0 and 1 will be generated in that cell.

4. Copy the formula from Cell A2 to all the other cells in that column, so that each service user has a random number.

5. You are now ready to sort the list of service users. Before you do this, it is essential that you **select all columns in your list, including the header row**. The simplest way of ensuring this it to click on the blank square above and to the left of Cell A1. This selects all cells in the worksheet. If you do not select all cells in your list, you could mix up service users' details, or you could fail to sort some of the service users in the list.

6. Once all cells are highlighted, click Data, then Sort. At the bottom of the *Sort* dialogue box that comes up on the screen, ensure that <My data has Header row> is selected. At the top of that dialogue box, use the drop-down box under "Sort by" to select **Random** and click **OK**.

7. The data will then be sorted by the random number. Do not worry that the random numbers change when you sort them and they do not look as if they are sorted in any order.[7] You can now select the top 850 service users in the file, as these will be a random selection of your service users. Note that to do this, you should **delete rows below 851** in your file as the first row contains the header information.

10.4 Check the sample list

Once you have compiled your list of 850 service users, it is important to carry out a few final checks before sending the list to the NSTS:

- **Duplications.** You should check your list to make sure service users' names do not appear more than once, and you should remove any duplicated names. Where possible, link any alias names so that only one name per service user appears in the list.

- **Postal addresses.** Check again that there are no addresses that are outside the UK.

- **Ages.** Check again that all service users are aged between 16 and 64.

- **Incomplete information on key name and address fields.** Check for any records with incomplete information on key fields (surname and address) and try to find more complete information. If key name and address fields cannot be verified, remove those individuals from the sample. However, do not exclude anyone simply because you do not have a postcode for them. Only remove a service user 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.

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

- **Deceased service users.** Check that the service users are alive. (See next section for further details.) Also check that your trust does not have a record of a service user's death.

- **Service user in last 3 months.** Check that all service users have been seen in the last 3 months.

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[7] The random numbers change each time any cell in the worksheet is changed.

10.5 Ask your Chief Executive to sign off the sample

For survey results to be comparable results across trusts, the definitions used in the sampling process must be applied identically in trusts. Therefore, for the 2005 survey, we are requesting Chief Executives to sign off the sample before questionnaires are sent out. The purpose of this is to ensure that the sample has been drawn according to the guidelines set out in this document and that the definitions of standard CPA and enhanced CPA have been applied appropriately. A letter was sent to Chief Executives on 8th November 2004, informing them that they would be asked to sign off the sample before the survey is carried out. A copy of the letter and the sign-off declaration form can be found on the NHSsurveys website. The Chief Executive is asked to:

- Verify that the CPA status of sample members is complete and correct
- Confirm that the sampling has been undertaken according to the guidance for the survey
- Supply the trust's implemented definition of enhanced CPA.

A paper copy of the signed declaration should be sent to the Advice Centre at the following address by **14th January 2005**.

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

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

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

The NSTS contact details are as follows:

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

The time required to carry out the checks depends partly on 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 service user list has been checked for deaths, some service users may die in the period between running the check and the questionnaire being delivered. You may find that some recently deceased service users remain in your sample. You need to be prepared for this. Special sensitivity is required when dealing with telephone calls from bereaved relatives.

10.7 Check the trust's records for service user deaths

Other valuable sources of information on service user deaths are your own trust's records and the records of acute trusts in your area. It is essential that you check that your trust has no record of a service user having died at your trust. If you are able to check with your local acute trusts, you should also do this. Relatives are likely to be particularly offended if they receive a questionnaire or reminder from the trust where their relative died.

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 service user survey, as SchlumbergerSema will only accept submissions from this person.

The format of the service user 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!

10.8 Organise the service user information into the sample file

Once the file is returned from the NSTS, you will need to keep the service user 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. (See Section 14.3 for details of how to do this.)

Firstly, you will need to add three new columns:

1. **Service User Record Number.** This field will be a series of consecutive numbers (for example, 1001 through to 1850).
2. The **Outcome** field will be used to record which questionnaires are returned to the freepost address, or are returned undelivered, or which service users 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 service user details. Only the fields headed in red italics should be included in the file sent to the Patient Survey Advice Centre.

Table 1 – Sample Excel file of service user details

Service User Record Number	Title	Initials	Surname	Address1		Address5	Postcode	*Year of Birth*	*Gender*	*Ethnic Group*	*Day of last contact*	*Month of last contact*	*Year of of last contact*	*Level of CPA*	*Outcome*	Comments
1001	Mrs	AM	Abbott		--		AB1 1YZ	1971	2	1	2	10	2004	1	3	Informed service user died
1002	Mr	EC	Ahmed		--		AB2 6XZ	1958	1	3	14	11	2004	2	1	
					--											
1849	Miss	K	Yoo		--		AB4 7MX	1987	2	5	21	10	2004	1		
1850	Ms	F	Young		--		AB9 5ZX	1946	2	1	30	12	2004	1	1	

Notes on Table 1

- **Service User Record Number.** This number is unique for each service user. 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 service user record number will be included on address labels and on questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the Approved Contractor) will be able to use these numbers to monitor which service users 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 service users.

- The **Service User 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.

- **Year of birth** is included in the form NNNN. The service user list should only include service users aged between 16 and 65.

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

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

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

- **Level of CPA** records whether the service user is on Standard or Enhanced CPA. It is coded 1 = Standard and 2 = Enhanced.

- The **Comments** column is useful for recording any additional information that may be provided if anyone informs you that the service user has died or is no longer living at this address.

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

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

The outcome column is left blank at first if the survey has not been returned, so it

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.

10.9 Sharing the service user sample file with an approved contractor

If you are working with an Approved Survey Contractor, but **not** using an honorary contract to share service users' 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 service user deaths, or requests to be excluded from the survey sample, etc.

10.10 Using the sample file

This file has two purposes:

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

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

For confidentiality reasons, **it is essential that you do not keep service user name and address details in the same file as their survey response data**. Therefore, you should match up the anonymised service user 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 service user name and address details, but you will need to ensure that the "outcome" information, about whether service users have responded, or why they have not responded, is accurate and up-to-date in both files.

10.11 Comparing departments or teams 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 teams within your trust. You could extend the number of service users 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 service users.

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 Tust 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 service users you draw according to the requirements for the national survey can be easily distinguished from any additional service users you include in the sample. You need to send the data to the Advice Centre from only the 850 service users sampled according to these guidelines.

11 Maximising service users' receptiveness to the survey

11.1 Publicising the survey

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

- Heighten awareness of the survey and the importance the Trust places on service user feedback through posters in outpatients departments and communications with service users before admission or at discharge, and in community newsletters. Also, it is sometimes a good idea to send a press release to the local media to gain publicity before the survey takes place.

- Service users can be expected to call doctors, nurses, patient liaison officers, Outpatients Departments, or the Chief Executive's office with questions about the survey, even when your covering letters give contact details for the survey managers and the dedicated helpline. Notify front line staff and executive offices that a survey is being conducted, and give them the name and number of a contact person. Survey managers should be prepared to respond to these calls quickly.

- Template staff briefings and information for use in press releases can be downloaded from the NHSSurveys website.

11.2 Improving response rates

In autumn 2003, the Patient Survey Advice Centre carried out further pilot testing of three approaches to enhancing response rates to the mental health survey:

- Sending an advance letter, informing service users that they would be receiving a questionnaire
- Sending a third reminder to non-responders
- Including a £2 gift voucher with the first questionnaire.

The following is a summary of the findings.

Advance letter

Service users were sent an advance letter 1 or 2 weeks before they received the first questionnaire. The letter explained that they should expect to receive a questionnaire in the next week or so, gave some information about the survey process and included a telephone number to call if they had any questions. This intervention achieved an increase in response rate of between 1.7% and 2.9% (depending on whether the results were taken before or after a third reminder was sent).

Third Reminder

Service users who had not returned their questionnaires after the standard three mailings (first questionnaire, first reminder, second reminder) were sent a further third reminder slip. This intervention achieved an overall increase in response rate of 0.8 to 2.5%.

Gift voucher

A £2 Co-op gift voucher was included in the first questionnaire as an advance "thank you" for completing the questionnaire.

The response rate for the group of service users that received the voucher was between 4.4% and 6% higher than that of those who received no voucher (depending on whether the results were taken before or after a third reminder was sent).

If you choose to use this method, you might also want to consider using other types of voucher, such as *High Street Vouchers*, which include a small donation to charity. (See www.vouchers4charity.co.uk)

Further details of these response rate tests can be found in the report detailing the development of the survey under Mental Health surveys on the NHSSurveys website.

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 Mental Health Questionnaire, available in pdf format on the NHSSurveys website, is designed to fit on to eight 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 service users in the sample by 1.7 to obtain the number of questionnaires required. So, if the number of questionnaires you intend to send out is 850, then you might want to print 850 x 1.7 or approximately 1,500 copies.

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 service users 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 service user
- 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 service user
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes. (This should be a P.O. Box if the survey is being carried out in-house. See Section 13.3 for further details.)
- 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 service users who do not respond to the first mailing (except, of course, those who withdraw). Usually, around 55-80% of the original service user 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 45-75% 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 service user
- 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 Mental Health Surveys using the pre-designed questionnaire from the NHSSurveys website. The following topics are covered:

- The Mental Health Questionnaire
- Setting up a FREEPOST address
- IMPORTANT: Setting up a PO Box for mail returned undelivered
- Setting up a FREEPHONE line
- Sending out questionnaires
- Covering letters
- Booking in questionnaires
- Sending out reminders

13.1 The Mental Health Questionnaire

Each trust must use the standard 8-page Mental Health Questionnaire. There is the pre-designed questionnaire on the NHSSurveys website. The Mental Health Questionnaire consists of 57 questions, which cover the issues that have been found (through qualitative work with service users) to be the most important to service users. The front page of the survey explains the purpose of the survey and gives instructions on how to fill it in. In the following pages, the survey questions are divided into sections in which questions relating to similar issues are grouped together.

13.2 Setting up a FREEPOST address

A FREEPOST address allows service users 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.

13.3 IMPORTANT: Setting up a PO Box for mail returned undelivered

When you send out questionnaires, you will need to put a return address on the envelope so that undelivered mail can be returned without the need to open the envelope. If an approved contractor is used, their return address should be put on the envelope. If you are carrying out the survey in-house, you should set up a PO Box, so that the return address does not give an indication that the addressee has been in contact with mental health services. At time of going to press, the cost of running a PO Box is £42 for six months, or £84 to redirect post from a PO Box to another address. You can find out more about these services by contacting Royal Mail on
Tel: 08457 740 740.

13.4 Setting up a FREEPHONE line

The covering letter to service users should include a telephone number for service users 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. If you run the survey in-house, you might want to set up a FREEPHONE line for this purpose. Alternatively, many Approved Contractors offer this service.

Common questions and comments

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

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

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

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

The person to whom the questionnaire is addressed has died.

Even with the use of a deceased persons tracing service, it will not be possible to identify all deceased service users, 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 service user'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 service user's own language and record their answers on a questionnaire form.

I do not wish to participate in this survey.

A few service users 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 service user and reiterate the statement in the covering letter - that the survey is voluntary, and that their care will not be affected in any way by their not participating. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of their responses. If the service user 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 person. It is also advisable to ask the service user to ignore any future reminders that they might receive.

Making a record of the calls

Where appropriate, ask the service users who call to tell you their Service User 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 service users called, as this can help to make improvements to future surveys and can provide useful additional information on service users' 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 service users who wish to be excluded from the mailing list.

13.5 Covering letters

The following covering letter has been given ethical approval for use in the NHS Trust Mental Health 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 notepaper (ideally without trust telephone number if Approved Contractor is handling the FREEPHONE calls). Text in square brackets needs to be edited.

[Date]

Dear service user

Service User Survey

We are inviting you to take part in a survey of service users who have recently been in contact with mental health services from the National Health Service.

What is the purpose of the survey?

Your views are very important in helping us to find out how well the services work and how they can be improved. This is your chance to have a say in how mental health services are provided in the future.

Why have I been chosen?

You are being invited to take part in this survey because you have recently been in contact with mental health services. We are sending questionnaires to 850 randomly selected service users in your area.

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 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. Your responses will not be passed to psychiatrists or other mental health care staff in a form 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 will 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]

13.6 Sending out questionnaires

Mailing labels

Three mailing labels are needed for each service user. 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 service user names and addresses. **It is essential that the Service User 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 service user at the first mailing should include the following:

1. A questionnaire numbered with the Service User Record Number. The number must match (or correspond to) the number on the address label and the number on the list of service user details.

2. A covering letter.

3. 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 Approved Contractor's address (if one is used), or an address that does not identify mental health services as the sender. (See Section 13.3 - *IMPORTANT: Setting up a PO Box for mail returned undelivered*) for further details.)

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 the work without an honorary contract, they should send pre-packed questionnaires to the trust for mailing out. The envelopes should be clearly marked with the Service User Record Numbers so that trust staff can match these with their service user list and put on appropriate service user 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 service users, and the return address label will be the approved contractor's address.

13.7 Booking in questionnaires

When questionnaires are received, match up the Record Numbers against the list of service users, so that you can record (in the *outcome* column) which service users have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until 31st August 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 Service User Record Numbers. Trusts should inform the contractor of any questionnaires that were returned undelivered, and of any service users who inform the trust that they do not wish to be included in the survey, or if any service user dies during the period of the survey. The contractor can then record these details in their own service user list and ensure that reminders are not sent out to those service users.

13.8 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 40%, but it is expected that many trusts will achieve a higher response rate. **It is essential that you send out both reminders, even if you already have achieved the minimum response rate.**

First reminders should be sent out about 1 week after the first mailing. The second reminder sent out after a further 2-3 weeks after that.

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

Approved contractors

When reminders are due to be sent out, survey contractors should send the pre-packed envelopes bearing the Service User Record Numbers of the non-responders. Again, the envelopes should be clearly marked with the Service User Record Number so that trust staff can match these with their service user list and put on appropriate address labels.

First reminders

The first reminder should be sent to service users who have not responded after one week. This should be a short note.

The following reminder slip has been given ethical approval for use in the NHS Trust Mental Health Surveys. It can be printed on A5 paper. A Word version is on the NHSSurveys website for you to download and add your own trust's details. If you make alterations to it, you will need to seek the approval of your Local Research Ethics Committee (LREC), and to check with the Advice Centre that your changes are acceptable. Two paper copies of the letter you use must be sent to the Advice Centre when you submit your data at the end of the survey.

First reminder letter

Text in square brackets needs to be edited.

[Date]

Service User Survey

A questionnaire about health care at [Name of NHS Trust] was recently posted to you.

At the time of sending this note, we have not yet received your response. If you have already returned your questionnaire – Thank you, and please accept our apologies for troubling you.

Participation in the survey is voluntary. 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 do not wish to take part, you do not need to give a reason and the care you receive from the NHS will not be affected. In case you did not receive the questionnaire, if we do not hear from you in the next couple of weeks, another copy of the questionnaire will automatically be sent to you.

If you have any questions or comments about the survey, or need help with filling out the questionnaire, please do not hesitate to contact [us/our FREEPHONE help line] on [**number**]. The line is open between [opening time] and [closing time], [days], and we will do our best to answer any questions you might have.

Thank you for your time.

Second reminders

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

1. A questionnaire numbered with the Service User Record Number. The number on the address label must match the number on the list of service user details.

2. A covering letter.

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

The following covering letter has been given ethical approval for use in the NHS Trust Mental Health 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

Service User Survey

Enclosed is a copy of the questionnaire that was posted to you a few weeks ago about your care from [NHS Trust name]. 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 services work and how they can be improved. This is your chance to have your say in how mental health services should be provided in the future.

Why have I been chosen?

We are inviting you to take part in this survey because you have recently been in contact with [NHS Trust name]. We have sent similar questionnaires to 850 other service users in your area, who have also been chosen at random.

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. You can rest assured that your answers will be kept confidential. Your responses will not be passed to psychiatrists or other mental health care staff in a form 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 will 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 of 7th April 2005. 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 Mental Health Questionnaire

The data should be entered into the pre-designed Excel file, which can be found in the Mental Health Trust section of the NHSSurveys website.

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

- Each row records one service user's responses to the survey
- For each question, the small number next to the box ticked by the service user should be entered as the response.
- If a response is missing in a returned useable questionnaire, it should be left blank, or coded as a full stop (.). [8]
- If two boxes are ticked (where only one should be ticked), the response should be left blank or coded as a full stop (.).
- When saving this file to submit data to the Advice Centre, please save only the first sheet as a **worksheet**, rather than saving the whole file as a workbook. (This saves disk space.)

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[8] 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 (on rows where service users have returned questionnaires) with a full stop (.).

14.2 Checking the data for errors

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

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

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

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

14.3 Submitting data to the Patient Survey Advice Centre

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

File format

- Microsoft Excel Worksheet (not Workbook). Any version of the software is acceptable.
- File name must be in the format <NHSTrustName>_MentalHealth2005.xls
- One row of data for each service user in the sample
- One column of data for each item of service user information or response.
- Missing data should be left blank or coded as a full stop (.). [9]

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

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[9] Data may be missing because the service user skipped a question or set of questions by following instructions. Alternatively, a service user may have not answered for some other reason. However, all missing data should be left blank or coded as a full stop (.), regardless of the reason for the omission.

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

Field	Format	Data codes	Comments
Service User Record Number	NNNN		The unique serial number allocated to each service user 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 Group	N	1 = White 2 = Mixed 3 = Asian or Asian British 4 = Black or Black British 5 = Chinese 6 = Other ethnic group	Ethnic group should be included if the information is available. Do NOT automatically code unknown ethnic groups as 6 – this group is only for those patients who are known not to belong to any of the other 5 named groups.
Day of last contact or last review	N or NN	Format this field as a number, not a date	For example, if the service user last had contact on Nov 16th 2004, this column should read 16.
Month of last contact or last review	N or NN	Format this field as a number, not a date	For example, if the service user last had contact on Nov 16th 2004, this column should read 9.
Year of last contact or last review	NNNN	Format this field as a number, not a date	For example, if the service user last had contact on Nov 16th 2004, this column should read 2004.
Level of CPA	N	1 = Standard 2 = Enhanced	
Outcome	N	1 = Returned useable questionnaire 2 = Returned undelivered by the mail service or service user moved house 3 = Service user died 4 = Service user reported too ill to complete questionnaire, opted out or returned blank questionnaire 5 = Service user 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 57 questions			Each column must be clearly headed with the question number. Data should be coded using the numbers next to the response boxes on the printed surveys. There is no need to send the comments to the Advice Centre.

N.B. To comply with the Data Protection Act, details that allow individuals to be identified must not be sent to the Survey 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 service user 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 service user in the sample, but you will only have responses from about 40-50% of the service users (that is, those who have returned a completed questionnaire, and who therefore have an outcome code "1").

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

Service User sample information									***Service user response information***						
Service User Record Number	*Year of birth*	*Gender*	*Ethnic Group*	*Day of last contact*	*Month of last contact*	*Year of of last contact*	*Level of CPA*	*Outcome*	*Q1*	*Q2*	*Q3*	--	*Q55*	*Q56*	*Q57*
1001	1971	2	1	2	10	2004	1	3							
1002	1958	1	3	14	11	2004	2	1	3	1	2		2	3	11
1003	1964	2	1	3	10	2004	1	6							
1004	1980	2	1	3	11	2004	1	1	2	1	3		4	4	
1005	1951	2	1	3	12	2004	1	1	3	2			3	4	
1006	1979	1	4	14	11	2004	2	6							
1849	1987	2	5	21	10	2004	1	6							
1850	1946	2	1	30	12	2004	1	1	3	1	1		3	4	1

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

Additional information

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

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

Delivery

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

Postal address:

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

e-mail:mentalhealth.data@pickereurope.ac.uk

Date

The data must be submitted by **7th April 2005**.

14.4 Checklist

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

Check	**Done? Please *initial***
1. Check that your **file name** follows the naming convention: <NHSTrustName>_MentalHealth2005.xls)	
2. Check that you have saved the data sheet only as an Excel **worksheet**, rather than a workbook. (The frequency and percentage counts on the other pages of the workbook on the NHSSurveys website are intended for your use only.)	
3. Check that all **data are correct**, and that all values are in range.	
4. Send data only for the **850 service users** sampled according to the sampling procedures defined in Section 10.	
5. Check that you have included data columns for **all 57 questions.**	
6. Check that all the data are in **numeric format** only.	
7. To comply with Data Protection regulations, any **service user name and address details must be removed** before the file is sent to the Survey Advice Centre.	
8. Remove any **passwords**.	
9. Include **two paper copies** of the questionnaire you used.	
10. Include **two paper copies** of the covering letters you used for the first mailing, the second mailing and the third mailing.	
11. Include **telephone and e-mail contact details of 2 people** who will be available to respond to any queries about the data.	
12. **Check again** that all data are correct, and that all values are in range! ***See note below***.	

Very important

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

If incorrect data are submitted, it is likely that the data will be considered unreliable and will not be used by 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 Mental Health Questionnaire into the Excel file on the website, the numbers and percentages of responses to each of the 57 Mental Health Survey questions are automatically computed and displayed on the other sheets of that Excel workbook, which correspond to the sections of the Mental Health 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 service user survey raises. One reasonable way to control the number of analytical questions is to conduct a staged analysis.

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

Use statistical tests to make comparisons and subgroup analyses

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

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

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

Use service user feedback data with other data

Service user feedback data provide one valuable source of information about how service users 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

Service user 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 service users in a survey report not being told about the side effects of their medications , and if this problem rate is the largest, then quality improvement efforts might focus first on this issue.

Compare your results against outside norms or benchmarks

A common method of prioritising is to select issues that compare unfavourably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Compare your trust's results with the benchmarks on the 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.

Compare with predefined goals

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

Correlation with overall measures

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

Predictive value on overall measures (regression analysis)

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

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 service user 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 service users.
- 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.
- Service users 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, service user 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 service users to contribute to improvement plans.
- Encourage staff at all levels in the organisation to contribute their ideas for improving service users' 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 service user comments or other forms of service user 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, wards or departments will provide a more detailed breakdown of performance. You may be able to identify examples of good practice within your trust which can be applied to other areas requiring improvement.

Identify where service users report most room for improvement

Issues can be ranked according to the size of the problem. Look at questions where more service users 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 service users 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 service users and avoid duplication of effort.

Identify problems surrounding particular aspects of the service user experience

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

- Being seen and treated by one type of health professional
- Receiving information on medications
- Crisis care

17.5 Develop an action plan

After using your survey results to identify areas for improvement, work with staff and service users 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 service user survey results with other activities in the trust. Use other sources of user 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 service users can provide valuable information and faster feedback.