

# GUIDANCE MANUAL FOR THE NHS COMMUNITY MENTAL HEALTH SERVICE USERS SURVEY 2012

THE CO-ORDINATION CENTRE FOR THE  
NHS PATIENT SURVEY PROGRAMME



Making patients' views count

Last updated: 22<sup>nd</sup> May 2012

## Contacts

The Co-ordination Centre for the NHS Patient Survey Programme  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford  
OX2 0JB

Tel: 01865 208127  
Fax: 01865 208101  
E-mail: [Mentalhealth.data@pickereurope.ac.uk](mailto:Mentalhealth.data@pickereurope.ac.uk)  
Website: [www.nhssurveys.org](http://www.nhssurveys.org)

## Key personnel

Grace Baker  
Chris Graham  
Esther Howell  
Caroline Killpack  
Jenny King  
Katherine Körner  
Sheena MacCormick  
Stephen Sizmur  
Catherine Turney  
Mark Waters

## Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in this guidance manual, for example, by offering financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages within the national survey. More guidance on how to reach ethnic minority groups can be found in Section 8. The terms of the ethical approval do not permit these types of alteration. Furthermore, such alterations might mean that the comparability of the survey would be compromised, and such results may not be acceptable for computation of the relevant measures within the Care Quality Commission assessments for that trust. If trusts want to make any adjustments to the method or materials set out in this guidance, they will need to seek local research ethics approval, and check with the Co-ordination Centre that the proposed alteration would not compromise comparability.

## Updates

Before you start work on your survey, check that you have the latest version of this document, as there might be some small amendments from time to time (the date of the last update is on the front page). In the very unlikely event that there are any major changes, we will e-mail all trust contacts and contractors directly to inform them of the change.

This document is available from the Co-ordination Centre website at:  
**[www.NHSSurveys.org](http://www.NHSSurveys.org)**

---

## Contents

---

1	Introduction: patient feedback and the NHS Plan.....	1
2	Setting up a project team.....	5
3	What's new for the 2012 survey? .....	6
4	Deciding whether to use an approved contractor or carry out the survey in-house .....	8
5	Commissioning a survey from an approved contractor .....	11
6	Data protection and confidentiality .....	13
7	Ethical issues, ethics committees and research governance .....	21
8	Collecting data from non-English-speaking populations.....	24
9	Timetable.....	25
10	Compiling a list of service users .....	28
11	Submit the service user list to the Demographics Batch Service (DBS) ..	33
12	Final sampling inspection by the Co-ordination Centre .....	44
13	Weekly Monitoring.....	46
14	Publicising the survey.....	48
15	Materials.....	50
16	Implementing the survey - practicalities.....	53
17	Entering data .....	58
18	Making sense of the data .....	68
19	Reporting results .....	71
20	Using results for quality improvement.....	74
	Appendix 1: Suggested text for pre-survey communication with staff .....	78
	Appendix 2: Suggested template text for pre-survey article for external media	79
	Appendix 3: Declarations of data protection compliance .....	80
	Appendix 4: Declarations for additional data analysts .....	81
	Appendix 5: Trust Names and Codes.....	82
	Appendix 6: Chief Executive Declaration Form .....	84

---

# 1 Introduction: The importance of patient feedback

## 1.1 The Care Quality Commission

The national patient survey programme was established by the Department of Health and has been operating since 2002. The Care Quality Commission (CQC) is the independent regulator of health and social care in England and is responsible for administering the programme. It regulates care provided by the NHS, private companies and voluntary organisations. The CQC aims to ensure better care is provided for everyone – in hospitals, care homes and people's own homes

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

## 1.2 The Co-ordination Centre for patient surveys

The Co-ordination Centre for the Patient Survey Programme, of which the NHS Community Mental Health Service Users survey is part, is based at Picker Institute Europe and works under contract to the Care Quality Commission to design, test, and co-ordinate the patient survey programme.

## 1.3 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 patients. Understanding the way patients experience the care they receive is essential to a complete assessment of the quality of healthcare, and this can only be obtained by asking the patients themselves.

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

## 1.4 Patient feedback and the NHS Constitution

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

The NHS Constitution requires that NHS services reflect the needs and preferences of patients, their families and their carers. It is therefore important that all NHS trusts to carry out surveys asking patients their views on the services they have received. It is intended that measuring patients' experiences in a structured way will act as an incentive to make patient experience a real and central priority for the NHS. The national patient survey programme is an important mechanism for making the NHS more patient-focused and provides a quantifiable way of achieving this by:

- providing information to support local quality improvement initiatives
- tracking changes in patient experience locally over time
- providing information for active performance management
- providing information to support public and parliamentary accountability
- providing information for the Care Quality Commission's programme of reviews and inspections.

## 1.5 Care Quality Commission assessments

Information drawn from the survey will be used by the Care Quality Commission in its assessment of trusts in England. The survey results will be used when producing the CQC quality and risk profiles (QRP) for NHS trusts. The QRP is a tool that gathers all relevant information about a trust in one place. It enables the CQC to assess where risks lie and prompt front line regulatory activity, such as inspection. The profiles support teams to make robust judgements about the quality of services and will be used in conjunction with CQC's guidance about compliance documents. Information from the survey will be mapped to relevant essential standards as described in the compliance documents. The QRPs will be shared with NHS trusts and lead Commissioners. More information is available at: <http://www.cqc.org.uk/organisations-we-regulate/registered-services/guidance-about-compliance>

## 1.6 Measuring performance over time

In addition to the performance assessment, the Care Quality Commission will publish benchmarking data from the survey to allow trusts to make meaningful comparisons between themselves and national benchmarks based on reliable data. Asking each trust or PCT to carry out the Community Mental Health Service Users survey in a consistent way builds a detailed picture of service users' experiences in NHS Mental Health trusts. Information collected nationally in a consistent way is also essential to support public and parliamentary accountability. The results are used by the Department of Health for performance assessment, improvement and regulatory purposes. They feed into a published series of National Statistics reported as an Overall Patient Experience Measure, and are used in the NHS Performance Framework and NICE Quality Standards. In 2011, the Department used a number of the survey questions to develop a community mental health indicator, as part of the NHS Outcomes Framework indicators under 'Domain 4: Ensuring patients have a positive experience'. The indicator will be used for performance assessment and improvement in services for patients receiving care in the community

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

## 1.7 Basic requirements for NHS Community Mental Health Survey 2012

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

- Please let the Co-ordination Centre know your two trust contacts, their job titles, phone numbers and email addresses by **20<sup>th</sup> January 2012** to allow us to communicate vital information about the 2012 NHS Community Mental Health Service User survey to you. (e-mail: **Mentalhealth.data@pickereurope.ac.uk**)
- You must contact the Co-ordination Centre, by e-mail, no later than **20<sup>th</sup> January 2012** to tell us who is carrying out your survey (i.e. whether it will be carried out by an approved contractor or in-house): **Mentalhealth.data@pickereurope.ac.uk**
- The survey must be carried out using a postal questionnaire
- The samples must consist of all service users who were seen between **1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011** as outlined in *Section 10 – Compiling a list of service users*
- The sampling procedure set out in this guidance must be followed. To do this, you will need to work closely with the person who draws the sample, and check carefully that this guidance has been adhered to. For further details see *Section 10 – Compiling a list of service users*
- **Your Chief Executive must sign off the sample.** Please send the signed declaration form to the Co-ordination Centre when you submit your sample for checking (If you are using a survey contractor, then please send the form to the Co-ordination Centre at the same time as you submit your sample to your contractor)
- Sample data must be submitted to the Co-ordination centre for final checks before mailing as outlined in *Section 12 – Final sampling inspection by the Co-ordination Centre*. You should submit your sample file to us between **6<sup>th</sup> February and 24<sup>th</sup> February 2012** to allow sufficient fieldwork period to maximise your response rates
- You should aim to obtain the highest response rate possible. For this survey, the target response rate is 40% (that is, you should get 340 returned questionnaires from the 850 mailed out). Three mailings will be necessary for most trusts to achieve this target. However, trusts should facilitate higher response rates through maximising their collection period by commencing work as soon as possible, and by publicising the survey to staff, service users and the community.
- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **16<sup>th</sup> February 2012**. A spreadsheet has been created for this purpose. For further details see *Section 13 – Weekly monitoring*
- The standard covering letters and reminder letters (which can be found under the Community Mental Health section of the NHSSurveys website) must be used as outlined in *Section 15 – Materials*
- Two reminders must be sent to non-responders, even if a 40% response rate is already achieved. These procedures are outlined in *Section 16.7 – Sending out reminders*
- The data must be checked carefully for errors before submitting it to the Co-ordination Centre. Specific advice on how to carry this out is included in *Section 17.2 – Checking for data errors*

- The data from the survey, and the required information about the service user sample, must be submitted to the Co-ordination Centre in the form outlined in *Section 17.3 – Submitting data to the Co-ordination Centre* by **15<sup>th</sup> June 2012** (was 1<sup>st</sup> June 2012)
- Two paper copies of the questionnaire and the covering letters for each mailing must be submitted to the Co-ordination Centre on **15<sup>th</sup> June 2012** (was 1<sup>st</sup> June 2012) in the form outlined in *Section 17.3 – Submitting data to the Co-ordination Centre*
- You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until **15<sup>th</sup> September 2012** (was 1<sup>st</sup> September 2012) but please do not send these to the Co-ordination Centre. These returned questionnaires may be needed to audit the data sent to the Co-ordination Centre.

## 1.8 Why you need this guide

Trusts have the option of conducting the survey in house or using an approved contractor (see Section 4). Whichever route you take, you will need to address the guidance in sections 1 to 14 and 18 to 20 of this guide. Sections 15, 16 and 17 cover the practicalities of mailing out the survey, following-up responses and processing data, and submitting it to the Co-ordination Centre. These sections will be most relevant to approved contractors, or trusts undertaking the surveys themselves.

## 2 Setting up a project team

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

We suggest:

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



## 3 What's new for the 2012 survey?

**Questionnaire:** There have been **some minor changes** made to the 2012 Community Mental Health Service User questionnaire. Some questions have been revised. These changes will be outlined in the survey development report, which will be available on the website in due course.

**Age:** The survey has been granted section 251 approval from the National Information Governance Board (NIGB) under section 251 of the NHS Act 2006 on the basis that 16 and 17 year olds are excluded from the 2012 survey(Ref number: ECC 8-05(a)/2011).

**Weekly submissions:** Weekly submissions of response rates (outcomes) and helpline monitoring information will again be requested for each trust taking part in the Service User Survey 2012 and we ask for the first submission on **16<sup>th</sup> February 2012**. We will be using this data to generate weekly adjusted response rate data for the Care Quality Commission by trust name. This is discussed further in *Section 13 – Weekly Monitoring*.

**Letters:** The first letter and second reminder letter have been heavily revised for the 2012 survey to be consistent with changes made to the letters for other surveys in the programme.

**Approved contractors:** The contact details of the approved contractors have been updated for 2012 and can be found in *Section 5 - Commissioning a survey from an approved contractor*. If you are using a contractor, you must use one of the approved contractors listed in this Guidance document.

**PO Box:** For confidentiality reasons, there should be no indication on the outer envelopes that the documentation enclosed relates to healthcare in any way. Consequently Trusts conducting the survey in-house are advised to set up a PO Box so that mail which is undelivered can be returned (please see *Section 15 - Materials* for further detail).

**Service users who have requested that their details are not used for secondary purposes:** If your Trust has a mechanism in place to flag service users that do not wish their data to be used for secondary purposes such as research, we advise that you remove these service users when drawing your sample. For further detail please see *Section 6.2 - Section 251 Approval*.

**Service user record number:** to ensure that each respondent has a unique number in the collated datafile, we now require the SURN to be recorded in the following format: MH12#####\*\* (where MH12 is the survey code, ##### is a 5 digit number sequence and \*\* is the trust code. Further information can be found in section *11.5 – Create the sample file*

**GP code:** The survey has been granted approval to include GP codes for 2012. This information should now be provided in the sample checking and data entry spreadsheets. Further information can be found in section *11.5 – Create the sample file*.

**CPA status:** To maintain consistency with the CEO declaration forms, it has been decided that if a 'service user is NOT registered on new CPA' and 'service user CPA status unknown' this will now be separated and coded '2' and '3' respectively. For further details please see *Section 11 - Submit the service user list to the Demographics Batch Service (DBS)*

## 3.1 Important information to remember

**Service user record number:** The service user record number is vital for the survey process in that it allows sample and response information to be matched in a manner that isolates the service users' names from their reporting of their experience. Information about the minimum font size and location, and what action to take if this number is removed from questionnaires, has been added to *Section 16.5 – Sending out questionnaires*.

**Ethnic category:** Ethnic category will be requested in the standard 16 + 1 alphabetical format. However, in the past there was some confusion over what data should be coded as “Z” (“not stated”). This code should be used **only** when a person had been asked for their ethnic category and had declined either because of refusal or genuine inability to choose. A blank or full-stop should still be used to indicate where ethnic category is “not known” i.e. where the service user had not been asked or the service user was not in a condition to be asked, e.g. unconscious. For most trusts, ethnic category will contain both “Z” codes **and** “blanks”. Further information can be found in section *11.5 – Create the sample file*.

**Embargo on results:** Trust-level findings for the national Community Mental Health Service Users survey 2012 should not be released outside of the trust until the national results are published by the Care Quality Commission. Please continue to use the results from your in-house survey teams or approved contractor to improve services, but wait until the survey results for all trusts are published by the Care Quality Commission before promoting your results in any way (either on your website, in press releases or any other external publicity) to the local community and media. You will receive, along with communications staff in your trust, advance notice of the publication date and will have time to prepare for your local announcements once the embargo is lifted.

## 4 Deciding whether to use an approved contractor or carry out the survey in-house

Trusts may choose to carry out their surveys in-house, or to commission an approved contractor to carry out the work for them. We do not recommend you carry out large-scale surveys such as these in-house if you do not already have experience in carrying out surveys. Tracking large surveys with appropriate follow-up is an administratively complex task requiring dedicated resources for several months. Getting systematic feedback from 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 contractor:

- Costs
- Internal resources/Expertise
- Timing
- Quality and confidence in the findings

### 4.1 Costs

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

#### Staff time

This is one of the largest expenditures, but it is sometimes overlooked. Be sure to include the cost of staff time, including salary and fringe benefits, and time spent away from other work. Please note that weekly submission will be required for each trust taking part in the Mental Health Service User survey 2012, involving increased staff time for both trusts and contractors.

#### Stationery and postage

You will need to cover the cost of stationery and postage for three mailings. The first mailing will go out to 850 service users and the second and third mailings will be sent only to non-responders. (See *Section 15 – Materials* for more details.) You will need to cover the cost of second class postage for three mailings, two of which will include the questionnaire.

#### Freepost licence

There is a charge for obtaining a freepost license which enables you to print a freepost address on return envelopes so that respondents can send back completed questionnaires at no cost to themselves. You will also be charged for each returned questionnaire. (For details, see *16.1 – Setting up a FREEPOST address*).

## PO Box

For confidentiality reasons, there should be no indication on the outer envelopes that the documentation enclosed relates to healthcare in any way. Consequently in-house Trusts are advised to set up a PO Box so that mail which is undelivered can be returned to sender. There is a fee for setting up a PO Box. (For details, see **Error! Reference source not found.**– *Mail out envelopes*).

## Freephone service

This service gives service users easy access to advice and staff who can reassure them on any concerns they have about the survey. The cost of setting up such a service, and of staff time in responding, needs to be included. (For details, see 16.3 – *Setting up a FREEPHONE line*).

## Data entry

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

## Design and production of reports

This requires a considerable amount of skilled staff time.

## 4.2 Internal resources

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

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

## 4.3 Timing

It is often possible to carry out small, localised surveys quickly in-house. However, even in the best of situations, other demands on staff can side-track them into other work. If you commission an approved contractor to carry out the survey, you should ensure that appropriate and realistic deadlines are set. The deadlines set by the Coordination Centre must be met in order for data to be submitted in time to the Care Quality Commission.

## 4.4 Quality and confidence in the findings

It is important to remember that the results of the survey will be used not only within the trust to identify areas for improvement but also by the Care Quality Commission and Department of Health

to contribute to performance assessment and possibly for other uses, such as the NHS Choices website.

It is therefore essential that the data are as accurate and reliable as possible and that the information is gathered in the same way for all trusts. Using the expertise of an approved contractor may add credibility to the survey findings in the eyes of staff, service users and the general public.

**When you have decided who will carry out your survey, i.e. an in-house team or an approved contractor, you must inform the Co-ordination Centre by 20th January 2012.**

## 5 Commissioning a survey from an approved contractor

The framework agreement set up by the Care Quality Commission covers the core survey process. Approved contractors are expected to provide the following services:

- Advising on sampling, providing support to trusts for sampling
- Printing questionnaires, covering letters, reminders and providing consumables
- Handling receipt of questionnaires, liaising with trusts re non-responses and reminders
- Support to ensure good response rates, e.g. FREEPHONE line
- Data entry, cleaning data and providing data to Co-ordination Centre by the deadline
- Preparing standard reports for trusts.

Two organisations have been approved by the Care Quality Commission to carry out surveys for the NHS service user survey programme. Trusts may commission any one of these contractors without further tendering the survey work. Before committing to a contractor, you are advised to **check exactly what is covered** within the cost quoted.

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

### 5.1 List of approved contractors

The following contractors have approved status for work on the Community Mental Health Service User survey programme. If a Trust chooses to use a contractor, it is a requirement of the survey that one of the following approved contractors is used:

#### Picker Institute Europe

**Contacts:** Matt Cadby and Stephen Bough

Buxton Court  
3 West Way  
Oxford  
OX2 0JB

Tel: 01865 208100  
Fax: 01865 208101  
E-mail: [Matt.cadby@pickereurope.ac.uk](mailto:Matt.cadby@pickereurope.ac.uk); [Stephen.Bough@pickereurope.ac.uk](mailto:Stephen.Bough@pickereurope.ac.uk)  
Website: [www.pickereurope.org](http://www.pickereurope.org)

## Quality Health

**Contacts:** Dr Reg Race, Kerry Hibberd and Kimberley Pollard

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

Tel: 01246 856263

Fax: 01246 855644

Email: [reg.race@quality-health.co.uk](mailto:reg.race@quality-health.co.uk); [kerry.hibberd@quality-health.co.uk](mailto:kerry.hibberd@quality-health.co.uk);  
[kimberley.pollard@quality-health.co.uk](mailto:kimberley.pollard@quality-health.co.uk)

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

## 5.2 Contracts with survey contractors

The Care Quality Commission has produced a document that we shall refer to as the 'service contract', for NHS trusts to use as a template agreement when providing sampling details to their approved contractor. Further details are available in *Section 6 – Data protection and confidentiality*.

We suggest that the service contract is used as either an arrangement separate to the financial agreement made between a trust and an approved contractor when commissioning that contractor, or combined with the financial agreement to minimise the administrative burden. In either case, trusts should specify the following when confirming the requirements of the contractor:

- The groups, and numbers, of 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 (division of responsibilities)
- The main contact at the survey provider and the individual at the trust responsible for managing the project
- A timetable showing the dates when each task is to be carried out and by whom
- The outputs of the project. That is, types of and numbers of reports to be delivered and details of any presentations to be carried out by approved contractors
- The costs and a payment schedule.

## 6 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. **If you have not already done so, please ensure that you add research to your Data Protection Act registration, as one of the purposes for processing personal data supplied by data subjects.** You will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles<sup>1</sup>.

It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors (see section 5.2). Your trust's Caldicott guardian and legal advisors should advise you on these matters.

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

The website below has further information:

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

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

Further guidance can be found in the Market Research Society document at [http://www.mrs.org.uk/standards/downloads/revised/legal/data\\_protection\\_social.pdf](http://www.mrs.org.uk/standards/downloads/revised/legal/data_protection_social.pdf)

---

<sup>1</sup> 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 service user data in carrying out the survey, complies with these 6 principles. In particular, you should be aware of the flows of service user data, and the issues which these present. The Caldicott guidance and principles were incorporated into the NHS code of practice on confidentiality.



## 6.1 Statements of compliance with data protection

### In-house surveys

Each NHS trust has a Caldicott Guardian responsible for overseeing proper use of service user data. If you are conducting the survey in-house then, before mailing out the sample, you must submit a formal declaration (see Appendix 3), signed by the Caldicott Guardian and survey lead(s) for the trust, to the Co-ordination Centre. This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines (see Section 6.9). Templates for these declarations are available on the website containing the survey guidance ([www.NHSSurveys.org](http://www.NHSSurveys.org)). You must wait for confirmation of receipt from the Co-ordination Centre before you mail out your sample.

If the Caldicott Guardian is unable to make such a declaration, then the trust must use an approved contractor to ensure that appropriate standards of confidentiality and data protection are maintained.

### Approved contractors

The framework agreement between the approved contractors and the Care Quality Commission contains clauses stating that the approved contractor will comply with the Data Protection Act so no declaration is required if a trust appoints a contractor from the approved list.

## 6.2 Section 251 Approval

This year it was decided that approval should be sought for the National Community Mental Health Survey 2012 under section 251 of the NHS Act 2006. The survey methodology was reviewed by the National Information Governance Board (NIGB) for approval. Their Ethics and Confidentiality committee (ECC) granted a recommendation of support on 13<sup>th</sup> January 2012. However, this recommendation does not cover the transfer of service user identifiable information where a service user has indicated dissent - by this we mean instances where a service user has explicitly indicated that they do not want their information to be shared for purposes such as service user surveys, or specifically stated that they do not want their details shared outside of the Trust.

Consequently, if any service users have indicated that they do not want their records used for secondary purposes (e.g. they have asked to be excluded from all surveys or they do not want their address details shared for any reason other than clinical care), please ensure that these service users are excluded from your mailing list. This should be done using your local records.

**Please discuss this issue with your Caldicott Guardian to ensure that any service users who have indicated that they do not wish to have their details shared for purposes such as this survey, yet may have sufficient address details visible in PAS, are not included in the sample that is submitted to contractors.**

## 6.3 Keeping service user mailing data and sample data separate

Keeping names and addresses separate from either sample information or respondent data is the best way to ensure that the service user responses cannot be matched to service users who made them. **For this reason, once the sample has been returned from DBS and the 850 service users are finalised, service user names, addresses and postcodes should be removed from the sample file to a “Mental Health 2012\_mailing data” file.** Before this is done, it is essential each service user is provided with a unique number (a service user reference number) and that this number is available and correctly matched on both the “Mental Health 2012\_mailing data” file and the sample information file.

## 6.4 Mailing questionnaires to service users

There are two common methods practised by trusts, and advised by the Care Quality Commission, when working with approved contractors:

1. The contractor delivers pre-packed serial-numbered envelopes containing questionnaires, covering letters and FREEPOST envelopes to the trust. The trust then attaches number-matched address labels to the envelopes and sends them out to 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 Section 16.
2. Alternatively, with the agreement of the trust's Caldicott Guardian, you may set up a written agreement between the trust and the external contractor. The Care Quality Commission has provided the template service contract for trusts and approved contractors carrying out the survey, to avoid the need for each trust to develop its own arrangements (see section 5.2). It is strongly recommended that these documents are reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required.

## 6.5 Service users' names and addresses

Please note that under the data protection guidelines for service user surveys, the following principles **must** be followed:

- Trusts/contractors must undertake to keep their products up to date to ensure that security is effective and must strictly observe the following guidance. The requirements that dictate the guidelines include the Data Protection Act 1998, the Health and Social Care Act (Community Health and Standards) Act 2003, the NHS confidentiality code of practice 2003<sup>1</sup> (which incorporates the Caldicott principles).
- The Care Quality Commission strongly recommends that personal data such as names and addresses must be sent by trusts to contractors securely, either by post or over the Internet using an encrypted session.
- **By post:** Trusts should send the personal data to their contractor in the form of an encrypted data file. We strongly recommend that the **256-bit AES** (Advanced Encryption Standard) encryption algorithm should be used for this purpose – see below for further information on this. The password should be verbally given to a named individual at the contractor. **Passwords should never be written on CD-ROMs or diskettes or otherwise included with encrypted material sent through the post.** The encrypted database should be saved onto a CD-ROM or diskette, place it in a single sealed envelope or other container, annotated “Addressee only”, and this should be sent to the contractor by Royal Mail Special Delivery or through an approved courier service<sup>2</sup>: personal data should **not** be sent by recorded delivery.
- **Over the Internet:** An encrypted session based on the Transport Layer Security (TLS) or Secure Sockets Layer (SSL) protocol (for example as with HTTPS or SFTP) must be used. A key size of 256 bits or greater should be used. This is to ensure a high level of security, to protect against any accidental or intentional interception during the transfer of service users' details. Approved contractors should be able to provide guidance on the use of an encrypted session to Trusts.
- As the owners of the data, the method for transferring service user samples is ultimately the Trust's decision because the Trust remains legally responsible for the security and processing of the information it shares. The Care Quality Commission strongly recommends the two methods described above. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption is available from NHS Connecting for Health<sup>3</sup>.

**Remember: if the data contains service user names and addresses, this can only be sent to the contractor by encrypted CD-ROM or diskette, or over the internet via a Care Quality Commission approved encrypted method.**

---

<sup>1</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/idcplg?IdcService=GET\\_FILE&dID=9722&Rendition=Web](http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=9722&Rendition=Web)

<sup>2</sup> Contact the Care Quality Commission for more detail on approved couriers: [patient.survey@cqc.org.uk](mailto:patient.survey@cqc.org.uk)

<sup>3</sup> [http://www.connectingforhealth.nhs.uk/igsecurity/gpg/gpg/NPFIT-FNT-TO-IG-GPG-0004.01%20GPG\\_%20%20NHS%20Cryptographic%20Algorithms.pdf](http://www.connectingforhealth.nhs.uk/igsecurity/gpg/gpg/NPFIT-FNT-TO-IG-GPG-0004.01%20GPG_%20%20NHS%20Cryptographic%20Algorithms.pdf) – this document is only accessible from NHSnet.

## 6.6 Encryption of personal data

Any service user identifiable information sent between trusts and contractors should be in an encrypted format with password protection to help ensure good standards of information security. Anonymised sample files sent between trusts/contractors and the Co-ordination Centre (i.e. for sample checking and final data submission) should also be encrypted with password protection. Many different encryption algorithms exist and not all of these are suitable, so both the Coordination Centre and the Care Quality Commission very strongly recommend the use of the **256-bit AES** (Advanced Encryption Standard) algorithm. There are several software tools that can be used to encrypt data in this way, the most commonly available of these being WinZip® (v9 and above)<sup>1</sup>.

## 6.7 Contractor responsibilities (service contract)

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

The service contract in Word format is available under the Community Mental Health section of the website containing the survey guidance ([www.NHSSurveys.org](http://www.NHSSurveys.org)).

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

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

The service contract is designed to be used as a template contract; trusts and approved contractors may agree on amendments to the wording and content when using them.

## 6.8 Service user anonymity

### In-house surveys

It is important to ensure that any claims you make about service user anonymity are accurate; and you are obliged by law to honour any statements that you do make. In most cases where a survey is carried out in-house, it is not accurate to tell 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.

---

<sup>1</sup> <http://www.winzip.com/>

## Approved contractors

Service user anonymity can be achieved if there is a clear separation between the information seen by an approved contractor and the information held by the trust. Service users' names and addresses will be seen by trust staff when generating the sample, while contractor staff will usually possess both service user details and service user responses. As long as the response data supplied to trusts do not include service user record numbers or any other detail that allows individuals to be identified or linked, it can reasonably be claimed, with regard to the trust and trust staff, that service users' responses are anonymous.

## 6.9 Service user confidentiality

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

### Trust level

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

<b>Q17. In the last 12 months have you received any of these sorts of talking therapies from NHS mental health services?</b>			
<b>Ethnic category</b>	<b>Yes</b>	<b>No</b>	<b>Total responses</b>
	<b>%</b>	<b>%</b>	<b>n</b>
White	81	19	261
Mixed / multiple	-	-	8
Asian / African / Carribean	-	-	18
Black	79	21	52
Other	85	15	36

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

The electronic file containing the service users' names and addresses should be stored securely (i.e. password protected).

## Approved contractor

- 1) Approved contractors must not provide raw data to the trust as a matter of course.
- 2) If the trust has a particular need for the raw data from the survey from the approved contractor, the contractor may provide an abridged version of this dataset to the trust upon request, providing that the steps below are undertaken first:
  - a. The contractor must delete the two variables pertaining to ethnicity (e.g. both sample and response variables)
  - b. The contractor must band year of birth into five age groups (18-35, 36-50, 51-65, 66+). This process should be repeated separately for both sample and response variables. The original year of birth variables (e.g. those specifying an exact year rather than age group) must then be deleted
  - c. Additional information specific to a survey that can be used to identify individual service users must also be removed.
  - d. Verbatim comments that could lead to any staff identifying respondents must be removed, e.g. those mentioning service user or staff names.,<sup>1</sup>
  - e. Receive confirmation from the trust that they have destroyed the names and addresses of the sampled service users, otherwise they will be able to identify individual service users by matching up the service user record number/serial numbers on the name and address list to those in the raw data file.

These steps **MUST** be followed before supplying raw data to trusts. This is to prevent the disclosure of a service users identity by specific demographic factors. Different arrangements govern the supply of raw data to the co-ordination centres. The response data will be anonymous when passed to the Co-ordination Centre and Care Quality Commission, and published and archived results will not identify service users.

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

<b>Q17. In the last 12 months have you received any of these sorts of talking therapies from NHS mental health services?</b>			
<b>Ethnic category</b>	<b>Yes</b>	<b>No</b>	<b>Total responses</b>
	<b>%</b>	<b>%</b>	<b>n</b>
White	81	19	261
Mixed / Multiple	-	-	8
Asian / African / Carribbean	-	-	18
Black	79		52
Chinese or other	85	15	36

<sup>1</sup> Please be aware that there are exemptions allowing disclosure, such as the prevention of crime exemption which **might** allow disclosure of free text describing criminal matters actual or threatened. Neither the Care Quality Commission nor the Co-ordination Centre can offer legal advice on these matters; the contractor or trust must seek its own independent legal advice before disclosing service users' comments to trusts.

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

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

## 6.10 Sharing of survey data between contractors

If a trust will be using a different approved contractor than in the last survey year, contractors are permitted to transfer an unabridged version of the data set if there is a clear need to use the data from the previous year's surveys to allow year-on-year comparison.

## 6.11 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of service users' names, and the questionnaires kept until **15<sup>th</sup> September 2012** (was 1<sup>st</sup> September 2012). All mailing lists of service users' names and addresses should be stored on a separate computer to that containing survey data. Mailing lists of service users' names and addresses should be destroyed when the survey is complete.



## 7 Ethical issues, ethics committees and research governance

Research Ethics Committees provide independent advice to participants, researchers, care organisations and professionals on the extent to which proposals for research studies comply with recognised ethical standards. The purpose of Research Ethics Committees in reviewing a proposed study is to protect the dignity, rights, safety and well-being of all actual or potential research participants. They will also seek reassurances regarding issues such as data protection, confidentiality and service user anonymity, and they will want to check that proposed research projects will not cause physical or mental harm to service users.

### 7.1 Ethical approval for the Community Mental Health Service Users survey

Research Ethics Committee (REC) approval has been obtained for the Community Mental Health Service user Survey and a substantial amendment submitted for changes regarding the questionnaire and mailing letters, all of which can be downloaded from the NHSSurveys website. In order to comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document.

Trusts do not, therefore, need to seek individual ethical approval for this survey. If you wish, you can send your Local Research Ethics Committee(s) (LREC) a copy of the REC 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.

Your trust should notify the relevant R&D office that ethical approval has been obtained for the 2012 Community Mental Health Service User survey. The REC letter of approval can be found on our website.

Further information on the ethical approval process can be found at [National Research Ethics Service](#) or by e-mailing [queries@nationalres.org.uk](mailto:queries@nationalres.org.uk).

### 7.2 Research governance requirements

The *Research Governance Framework* (2002, 2003, 2005) aims to ensure that health and social care research is conducted to high scientific and ethical standards. It spells out standards and the responsibilities of various parties involved in the research. One of the main purposes of the framework is to reduce unacceptable variations in research practice.

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

The Department of Health has confirmed to the Care Quality Commission that it would be inappropriate for individual trusts to follow the same local research governance processes as they would if the survey were a study the trust is sponsoring. As this national service user survey has research ethics committee approval and the Care Quality Commission takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.



The following table has been prepared by the Care Quality Commission and is taken from Section 3.10 of the *Research Governance Framework for health and social care (2005)*. The left-hand column sets out the responsibilities of organisations providing care and the right-hand columns sets out the arrangements made by the Care Quality Commission for service user surveys. If you are required to seek approval from your research governance lead, you are advised to present this information to your Research and Development Manager in support of your request.

### 7.3 Responsibilities of NHS organisations who are carrying out research

<b>Research Governance Framework</b>	<b>Care Quality Commission sponsored service user surveys</b>
Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	<i>The survey is carried out on the experiences of service users after they have received the care so this does not apply.</i>
Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	<i>All Chief Executives are informed of the proposals of the survey. Trusts should notify their Research and Development Managers of the survey.</i>
Ensure service users or users and carers are provided with information on research that may affect their care.	<i>The survey does not affect the care of the service users. Anonymised results are used for the Care Quality Commission assessments, the Department of Health national monitoring of the relevant PSA target, and local quality improvement initiatives. Detailed guidance is issued to survey leads regarding the publicity of the results and its impact on service user care.</i>
Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	<i>This requirement is not specific to this survey.</i>
Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	<i>The Care Quality Commission as sponsors of the study have sought ethics approval from a REC. There is a designated lead for each survey who is appointed by the Chief Executive.</i>
Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	<i>The Care Quality Commission as sponsors have undertaken steps to ensure that all the duties of the sponsors listed in Section 3.8 of the Research Governance Framework are followed thoroughly.</i>
Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	<i>Detailed guidance is issued to all the trusts, which spells out the responsibilities of all parties involved in the survey.</i>

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

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

## 8 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 questionnaire has been written in as **plain language** as possible to facilitate optimum understanding by all respondents.

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

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

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

## 9 Timetable

The survey fieldwork period for 2012 is 16 weeks. We recommend making full use of this to maximise response from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond<sup>1</sup>. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. within the recommended three week sample checking period) and mail out your questionnaire packs promptly once permission has been received. Dissemination of the results to all staff, and to the local community and media, can only start after the survey has been completed so this will take additional time to complete.

If you commission an approved contractor, much of the work will be done by them, but you will still have to be involved in some of the stages of the process, marked in **bold** in the table below. If you are using an approved contractor for the survey, they will provide you with a timetable that might differ slightly to the suggested time periods below. As long as the specified three mailings take place and data is submitted to the Co-ordination Centre no later than the **1<sup>st</sup> June 2012**, the timetable provided by the contractor should take precedence over the suggested intervals below.

Week	Task	See Section
0	<b>Guidance to be published on website (16<sup>th</sup> January 2012)</b>	-
1	<b>Inform Co-ordination Centre who is carrying out your survey by 20<sup>th</sup> January 2012 (in-house or using an approved contractor)</b>	4
1-6	<b>Draw sample of service users to be included in the survey</b>	10
1-6	<b>Check sample for deceased service users using trust records</b>	10.5
3-6	<b>Submit sample list to DBS to check for deceased service users</b>	11
1-6	<b>If using an approved contractor, supply them with trust headed paper and a signature of a senior executive and, if appropriate, ensure that the service contract is signed</b>	15.2
1-6	Print questionnaires and covering letters.	15.1& 16.4
1-6	Set up FREEPOST address and helpline	16.1& 16.3
1-6	Establish system for responding to telephone enquiries	16.3
1-6	Establish system for booking in questionnaires	16.6
4-6	<b>Have sample signed off by Chief Executive and send declaration form to the Co-ordination Centre</b>	10.3 and 11.5

<sup>1</sup> For details of this research carried out by the Picker Institute Europe see [http://www.nhssurveys.org/Filestore/documents/Extension\\_of\\_fieldwork\\_for\\_inpatient\\_survey\\_2007.pdf](http://www.nhssurveys.org/Filestore/documents/Extension_of_fieldwork_for_inpatient_survey_2007.pdf)

4-6	Submit anonymised sample to Co-ordination Centre before starting mailing process <b>(6<sup>th</sup> February- 24<sup>th</sup> February 2012)</b>	12
5	Send first weekly response rate and helpline monitoring form to Co-ordination Centre <b>(16<sup>th</sup> February 2012)</b>	13
5-7	<b>Check your own trust's records again for any service user deaths</b>	10.5
5-7	<b>Stick labels on pre-packed numbered questionnaires (if NOT using a service contract)</b>	16.5
5-7	Send out first questionnaires	16.5
5-20	Continue to respond to telephone enquiries	16.3
5-20	Log and process returned questionnaires	16.6
5-20	Enter data	17
7-9	<b>Check your own trust's records again for any service user deaths</b>	10.5
7-9	Send out first reminders to non-responders	16.7
8-10	Be prepared for a small peak in telephone calls as first reminders received	16.3
10-12	<b>Check your own trust's records for any service user deaths</b>	10.5
10-12	Send out second reminders to non-responders	16.7
22 (was 20)	Complete data entry	17
22 (was 20)	Check data for errors	17.2
22 (was 20)	Send data to Co-ordination Centre (by <b>15<sup>th</sup> June 2012</b> [was 1 <sup>st</sup> June 2012] at the latest)	17.3
22 (was 20)	Send two copies of the questionnaire used, all covering letters and a copy of the checklist to the Co-ordination Centre (by <b>15<sup>th</sup> June 2012</b> [was 1 <sup>st</sup> June 2012] at the latest)	17.3
23+ (was 21+)	Begin analysing trust's results and writing report	18
	<b>Disseminate results to staff, service users</b>	20

	<p>You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until <b>15<sup>th</sup> September 2012</b> (was 1<sup>st</sup> September 2012)</p>	
--	--	--

## 10 Compiling a list of service users

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. Prior to sending out questionnaires, the list will also have to be checked by the Demographics Batch Service<sup>1</sup> (DBS) to identify deceased service users. Please follow the instructions below carefully and allocate sufficient work time to check the sample with DBS before the first mailing and within the trust prior to each mailing.

**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. An incorrectly drawn sample can delay the start of the survey or can result in the questionnaires being sent to the wrong service users.**

**Please read all of this section before you start to compile your service user list.**

### 10.1 Who is being surveyed?

The sample for this survey is selected from all service users, aged 18 and over, seen by the NHS Trust - ie, including those on the CPA and also those not on the CPA but receiving specialist care or treatment for a mental health condition. Details on the sampling period and who should be included and excluded are set out in section 10.2 below.

**Please note that your sample of service users should only be used for the purposes of distributing the MH12 survey and up to two reminder letters. This is because the precise use of the sample collated for the survey is described in the survey protocol that forms part of the ethical approval for the survey, and any additional use of the sample would therefore require a separate ethics application. For example, it would not be appropriate to send additional reminder letters to people in the sample, nor to contact them as a group either before or after the survey.**

### 10.2 Compile a full list of current service users

- Compile a full list of all service users who were seen between **1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011**. Make sure that you take out any duplicated names.
- Include **all** teams within your trust providing specialist mental health services to service users eligible to receive this survey
- 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 and then select as outlined below. 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.

---

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

**If you do not have an adequate list of service users:**

Call the Coordination Centre on 01865 208127.

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

Call the Coordination Centre on 01865 208127

## Who to include:

Anyone (whether or not they were on the CPA) who used the Trust's community based treatment and care services **during the sample period of 1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011**, including the following:

- Outpatients services
- Day therapies services
- Adult services
- Services for older people
- Crisis teams
- Complex needs services
- Assertive outreach teams
- Early intervention and short-term intervention teams
- Recovery teams
- Home Treatment Teams
- Rehabilitation support teams
- Memory clinics

## 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 duty worker or a psychiatrist for a single assessment.)
- Anyone primarily receiving drug & alcohol services
- Anyone primarily receiving Learning Disability services
- Anyone receiving specialist forensic services
- Anyone receiving psychological treatments from IAPT services
- Anyone primarily receiving Chronic Fatigue/ME services
- Anyone primarily receiving Psychosexual Medicine (sexual dysfunction) services
- Anyone receiving Gender Identity services
- Any service users who are **under 18 years of age** on the date the sample is drawn
- Any service users who are known to be **current inpatients** at the time of drawing the sample
- Service users who are known to have **died**



- Service users who **do not** have a **known UK address**
- Service users who did not have contact with Mental Health Services **during the sample period of 1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011**
- Any **duplicated** names: Check that the same service user has not been included more than once
- Any **alias names** where the person's real name is already included in the list.
- Any service user known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those service users from your sample list at this stage).

## Data fields to include in the list of attendances

**Please note: not all these fields are required by DBS but it will save time and effort if all the information is gathered at the same time.**

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 (more detail can be found in section 11.6):

- Service user Record Number
- Title (Mr, Mrs, Ms, etc.)
- First name
- Surname
- Address Fields
- Postcode
- Year of birth
- Gender
- Ethnic category
- Day of last contact
- Month of last contact
- Year of last contact
- CPA status
- GP code

### 10.3 Complete 'Section A' of the Chief Executive Declaration Form

For survey results to be comparable across Trusts, the definitions used in the sampling process must be applied identically across Trusts. Therefore, once you have your **full list of all service users** who were seen between 1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011 and meet the specified eligibility criteria (i.e. the inclusion and exclusion criteria), please complete **section A** of the Chief Executive Declaration Form.

This form is in Appendix 6 of this guidance and is also available to download from the NHS Surveys website at: <http://www.nhssurveys.org/survey/612>

## 10.4 Instructions for taking a sample of service users

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) and completed section A of the Chief Executive Declaration Form (as described in Section 10.3)

Although the aim is to send questionnaires to 850 service users, you need to select more than 850 users initially. This is because your list of selected service users is likely to contain duplicate names or service users who are ineligible for the survey (see Section 10.2 for details) and some may have died. We have estimated that around 50 users will need to be removed from the initial list, so you need to take a **simple random sample of 900** 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*, 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. To copy the formula, hover the cursor over the bottom right-hand corner of cell A2 so that the cursor becomes a black cross +, press and hold down the left mouse button and drag down column A.
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 is to click on the blank square above and to the left of Cell A1 or hold the Ctrl key and press 'A'. 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 you have highlighted all the cells, click Data, then Sort. At the bottom of the *Sort* dialogue box which appears 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**.

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<sup>1</sup>. You can now select the top 900 service users in the file, that is, rows 1 to 901 as these will be a random selection of your service users. Note that to do this, you should **delete rows below 901** in your file. This will leave a file containing a header row plus 900 **rows of service user data**.

---

<sup>1</sup> The random numbers change each time any cell in the worksheet is changed

## 10.5 Check the sample list

If the list comprises fewer than 900 service users please contact the Coordination Centre. When you have compiled your list of 900 service users, it is important to carry out a few final checks before sending the list for checking by the Demographic Batch Service (DBS):

- **Remove duplications.** Check your list to make sure service users' names do not appear more than once, and 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 18 and over.
- **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. In removing cases at this stage, please bear in mind that the more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias. As a result, remove a service user only if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. Do not exclude anyone simply because you do not have a postcode for them, or because you could not get a matched trace with DBS.
- **Current inpatients.** Check again that none of the service users are known to be current inpatients in your Trust or elsewhere if possible.
- **Deceased service users.** Check that your Trust does not have a record of a service user's death.
- **Service user in sample period.** Check that all service users were seen in the sample period of **1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011.**
- **Distribution of service user ages.** Check that your sampled service users' ages cover the full range of expected ages (aged 18 and over). You can do this by plotting the service user ages on a histogram.
- Any service user known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those service users from your sample list at this stage).

# 11 Submit the service user list to the Demographics Batch Service (DBS)

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

The DBS has replaced the NHS Strategic Tracing Service (NSTS) batch trace. The DBS enables users to submit and receive a file containing relevant service user records electronically using dedicated client software. The service user records in the file are matched against the NHS Spine Personal Demographics Service (PDS).<sup>1</sup>

## 11.1 Create a trace request file

Using your list of service users, you need to create a correctly-formatted batch trace request file to send to DBS. You should take advice from your local Trust PAS team on the correct format to submit files. Technical details on the file format are available from:

<http://www.connectingforhealth.nhs.uk/industry/docs/dbs>

For each service user you will need to include as a minimum:

- NHS number and full date of birth (yyyymmdd) – this is the recommended approach *OR*
- Surname, first name, gender, date of birth and postcode (can be wildcarded eg LS1\*)

Although residential postcode can be omitted it is recommended to avoid incorrect matches. Due to the way addresses are recorded throughout the NHS, it is very difficult to get an exact match on address lines. For this reason, **do not** include address lines in the trace request file.

## 11.2 Submitting the trace request file

While the format of the request file is broadly consistent with that used by NSTS, the way in which the file is submitted to DBS differs. The DBS does **not** accept the transfer of files by encrypted emails or on physical media. Instead, **request and response files must be transferred electronically using the dedicated DBS client software**. The DBS client software should have already been installed on a server within your trust. Please speak to a member of your IT department or PAS team if you do not know how to access and use the application. If your IT department cannot help, contact the DBS implementation team at: [cfh.dbs-implementation@nhs.net](mailto:cfh.dbs-implementation@nhs.net) and they should be able to advise you.

If you have been set up to use DBS, then once you have created the request file, it should be placed in the client in-box. The DBS client will then send the file to the Spine and, if you are registered, you will receive an email to say that file was received. The DBS processes the file overnight and it should be ready the following morning. You will be notified by email when the file has been processed. During periods of high demand for DBS service, it may take 48 hours for your file to be returned.

---

<sup>1</sup> The PDS is a national electronic database of NHS service user demographic details. The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

## 11.3 The response file

The DBS will return a header row, response body and trailer row. The response row will be in two parts:

- The response containing all the data supplied in the request record, together with a trace outcome indicator. The main record is returned in all cases.
- An additional response column, which is returned only when there is a single unique match. It is on this additional response column that service users found to be deceased will be indicated.

Further information is available from [www.cfh.nhs.uk/demographics/dbs](http://www.cfh.nhs.uk/demographics/dbs)

### Note

Please be aware that tracing services are not foolproof 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.

## 11.4 When the service user file is returned from DBS

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

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

### If you have more than 850 service users remaining on your list

When your service user list is returned by DBS, and you have removed all deceased service users, there should still be more than 850 service users in the list. You will need to reduce the file to 850 service users by repeating the steps carried out before which are repeated here for your convenience. **Do not exclude service users just because DBS could not find a match.**

You need to take a **simple random sample** of 850 service users from your DBS checked list. 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*, 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. To copy the formula, hover the cursor over the bottom right-hand corner

of cell A2 so that the cursor becomes a black cross +, press and hold down the left mouse button and drag down column A.

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 is to click on the blank square above and to the left of Cell A1 or hold the Ctrl key and press 'a'. 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. When all cells are highlighted, click Data, then Sort. At the bottom of the *Sort* dialogue box which appears 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**.

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. You can now select the top 850 service users in the file, that is, rows 1 to 851 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. This will leave a file containing a header row plus 850 rows of service user data.

If you are using an Approved Contractor, the sample should be checked as normal by the Trust and by DBS before being submitted to the contractor. We strongly recommend the contractor carries out the same high standard of checks as in previous years, but will then submit the file to the Patient Survey Co-ordination Centre. The Patient Survey Co-ordination Centre will address any issues arising from these final checks to the Approved Contractor.

To safeguard the confidentiality of service users' records, the sample file submitted to the Co-ordination Centre should be **without** service user names and addresses and should be submitted as a password protected file to [MentalHealth.Data@pickereurope.ac.uk](mailto:MentalHealth.Data@pickereurope.ac.uk) with the password being supplied separately either by email or telephone

### If you have fewer than 850 service users remaining on your list

If your service user list has fewer than 850 service users after deceased service users have been removed, you **MUST** contact the Co-ordination Centre on 01865 208127 or email [MentalHealth.data@pickereurope.ac.uk](mailto:MentalHealth.data@pickereurope.ac.uk).

#### Important note

You are aiming for a response rate of at least 40%, which means that you should have at least 340 completed questionnaires. You will 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 Co-ordination Centre will only be able to accept responses from the 850 correctly sampled service users in your list.

**Remember, you should only have 850 service users in the list at this stage.**

## 11.5 Complete 'Section B' of the Chief Executive Declaration Form

Once you have finalised your sample of 850 service users, please complete 'section B' of the Chief Executive Declaration Form and then ask your Chief Executive to sign off the sample.

Chief Executives are requested to sign off the sample before questionnaires are sent out to ensure that the sample has been drawn correctly.

The Chief Executive is asked to:

- Confirm that the sampling has been undertaken according to the guidance for the survey;
- Verify that the sample includes service users aged 18 and over, seen by the NHS Trust in the three month sampling period 1<sup>st</sup> July 2011 to 30<sup>th</sup> September 2011 - ie, including those on the CPA and also those not on the CPA but receiving specialist care or treatment for a mental health condition

As mentioned in section 10.3, this form is in Appendix 6 of this guidance and is also available to download from the NHS Surveys website at: <http://www.nhssurveys.org/survey/612>

Please return the completed form to the Co-ordination Centre when you submit your sample for checking<sup>1</sup>:

Patient Survey Co-ordination Centre  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford. OX2 0JB

## 11.6 Create the sample file

An example of the spreadsheet you should complete has been included below. This can be downloaded from our site (<http://www.nhssurveys.org/survey/615>) and is entitled "*Sample construction spreadsheet*". The column headings will match to the validated spreadsheet produced by the Co-ordination Centre for final submission of data and so it will be advantageous for you to use this spreadsheet. Save this file as <NHStrustname>\_MH2012.

This file has three purposes:

- 1) It will be used to keep a record of which service users have not returned questionnaires so that reminders can be sent to them.
- 2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from **16<sup>th</sup> February 2012** until the closing date of the survey.
- 3) 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 Co-ordination Centre when the survey is completed.

---

<sup>1</sup> If you are using a survey contractor, then please send your form to the Co-ordination Centre at the same time as you submit your sample to your contractor for checking. Please note: the Co-ordination Centre can not check your sample until this form has been received.



**Table 1 – Sample construction spreadsheet of service user details**

<b>Service user Record Number</b>	<b>Title</b>	<b>Initials</b>	<b>Surname</b>	<b>Address1</b>	<b>Address5</b>	<b>Postcode</b>	<b>Year of Birth</b>	<b>Gender</b>	<b>Ethnic Category</b>	<b>Day of last contact</b>	<b>Month of last contact</b>	<b>Year of last contact</b>	<b>CPA Status</b>	<b>GP Code</b>	<b>Day of questionnaire being received</b>	<b>Month of questionnaire being received</b>	<b>Year of questionnaire being received</b>	<b>Outcome</b>
MH12-10001-RNA	Mrs	A M	Abbott			AB1 1YZ	1971	2	A	2	08	2011	1	A81 029				3
MH12-10002-RNA	Mr	E C	Ahmed			AB2 6XZ	1958	1	A	14	09	2011	3	B23 567	22	3	2012	1
--																		
MH12-18049-RNA	Ms	K	Yoo			AB4 7MX	1987	2	M	21	09	2011	2	D39 402				
MH12 18050-RNA	Ms	F	Young			AB9 5ZX	1946	2	Z	30	07	2011	1	E89 032	6	4	2012	1

### Important note about table 1

The headings of Table 1 are in three different colours:

**Bold black** headings: these columns contain information on service users' names, addresses and comments that may allow them to be identified. This information should be deleted from all files sent to the Co-ordination Centre. This data, along with a copy of the Service user Record Number should be removed from the sample file after when the 850-service user sample is finalised to create the "mailing data" file

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

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

The following information is compiled using trust records:

- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname
- Address Fields <sup>1</sup>
- Postcode

<sup>1</sup> The address should be held as separate fields (e.g. street, area, town, and county), consistent with the address format required by the DBS.



## Note

The **Service user Record Number, Title, Initials, Surname, Address** fields and **Postcode** are used for printing out address labels. You (or your contractor) can use the mail merge function in a word processing package for this purpose.

- The **Year of Birth** should be included in the form of NNNN.
- **Gender** should be coded as 1 = male and 2 = female.
- **Ethnic Category**<sup>1</sup> coding is the same as for last year's service user's survey. The ethnicity of a person is specified by that person, and should be coded using the 17 item alphabetical coding specified by NHS Connecting for Health<sup>2</sup>. The codes are as follow:

### National Codes:

#### White

A	British
B	Irish
C	Any other White background

#### Mixed

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

#### Asian or Asian British

H	Indian
J	Pakistani
K	Bangladeshi
L	Any other Asian background

#### Black or Black British

M	Caribbean
N	African
P	Any other Black background

#### Other Ethnic Groups

R	Chinese
S	Any other ethnic group
Z	Not stated <sup>3</sup>

<sup>1</sup> It is acknowledged that service user records might not always contain complete data on service users' ethnic category. However, this field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic categories. This is in keeping with the aims of the Care Quality Commission and Department of Health to be more responsive to all ethnic groups and to ensure all groups are appropriately represented in their assessments.

<sup>2</sup> These codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:

[http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/e/enh/ethnic\\_category\\_code\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/e/enh/ethnic_category_code_de.asp?shownav=1)

<sup>3</sup> The code "Z" should only be used if the service user was asked for their ethnic category but refused to provide it. If this code is missing for any other reason, ethnic category should be left blank in the sample information.

- **Trust Code.** This is an additional field to improve identification within the body of the data files. Appendix 5 lists all the codes valid for the survey. This code will remain constant throughout the file.
- **Unit or team** - Include this if you plan to compare units within your Trust. (This would not be submitted to the coordination centre)
- **Day of the month of last contact** (1 or 2 digits; e.g. 2 or 30) - Date fields must be supplied in separate columns.
- **Month of last contact** (1 or 2 digits; e.g. 9 or 10)
- **Year of last contact** (4 digits; e.g. 2012)
- **CPA status** - should be coded 1 = service user is registered on 'new' CPA,  
2 = service user is NOT registered on new CPA  
3 = service user CPA status unknown

Trusts need to ensure that they include up to date CPA information for all service users as this information is used in the analysis of some questions. Ensuring this information is present will be part of the sample checking process undertaken by the coordination centre, as described in section 12.

- **GP code** – (A letter, followed by 5 digits i.e. A81001)

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

1) **Service user record number.** This number is unique for each service user. In the example, the numbers are in ascending order, starting at MH12-10001-RNA at the top of the list, through to MH12-18050- RNA at the bottom. The service user record number will be included on address labels and questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the Approved Contractor) will use these numbers to monitor which service users have returned their questionnaires and to identify non-responders, who will need to be sent reminders. If an Approved Contractor is used, you need to agree with them the range of service user record numbers that will be used.

2) **Day of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be a one or two digit numerical response e.g. N or NN, **not** a date format e.g. 12/09/11.

3) **Month of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trusts or approved contractor. It should be a one or two digit numerical response, **not** a date format.

4) **Year of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trusts or approved contractor. It should be a four digit numerical response, **not** a date format.

5) The **Outcome** field will be used to record which questionnaires are returned to the freepost address, or are returned undelivered, or which service users opt out of the survey, etc.

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 (on table 1 you can see that Ms Yoo has not yet returned her questionnaire).

- 6) The **Comments** column is useful for recording any additional information that may be provided when someone calls the helpline – for example, to inform you that the respondent has died or is no longer living at this address.

## 11.7 Separating mailing details from sample information

At this point you should transfer the names, address and postcode for each service user in the sample to a new file. The service user record number (SURN) for each service user should be copied to the new file, so that the two datasets are connected using the unique SURN. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as “MH service users 2012\_mailing data”.

This file should be used for mailing purposes: it will be used to check for deceased service users prior to reminder mailings and will be cross-referenced with the sample file (<NHStrustname>\_MH service users2012) to identify service users who will need to be sent reminders.<sup>1</sup>

As this “MH service users2012\_mailing data” file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing data file should be destroyed when the survey is complete.

For service user 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.**

---

<sup>1</sup> As shown in table 1(section 11.5), the ‘outcome’ field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which service users opt out etc...

Table 2 – Example mailing file

<i>Service user Record number</i>	Title	Initials	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
MH12-10001-RNA	Mrs	AM	Abbot	14 Station Road	London				AB1 1YZ
MH12-10002-RNA	Mr	EC	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
					--				
MH12-18049-RNA	Ms	K	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4 7MX
MH12-18050-RNA	Ms	F	Young	634 Tyne Road	Newcastle-Upon-Tyne	Tyne and Wear			AB9 5ZX

## 11.8 Sharing the service user sample file with an approved contractor

If you are working with an approved contractor and have a contract in place relating to the transfer of service user identifiable information (i.e. names and addresses) both the sample file (“<NHStrustname>\_MHservice users2012”) **and** the mailing file (“MHservice users2012\_mailing data”) file should be sent to the contractor staff in encrypted format (see *Section 6 - Encryption of personal data*).

If you are working with an approved contractor, but have chosen to mail out the questionnaires yourself, within the trust, you should supply them with just the sample file (this will resemble **Table 1 – Sample construction spreadsheet of service user details** but with the service user names, addresses and postcodes removed). This file should be sent to the contractor in encrypted format (see *Section 6.6 – Encryption of personal data*) The contractor can use this list to record the outcome codes, but you should ensure that the contractor is kept up to date with any information that comes directly to the trust about service user deaths, etc.

## 11.9 Making more use of the survey locally

Up to this point, this section of the guidance has described in detail how sampling must be undertaken to provide the basic required sample of 850 service users for the national survey. In addition to this minimum requirement, though, your trust may wish to use the NHS Community Mental Health Service User survey as an opportunity to gather further data beyond that required by the Care Quality Commission. Increasing the sample size is a good way to do this.

If you are using an approved contractor for the survey then they will be able to advise you on the best way to increase your sample size to achieve your specific goals. If you are not using an approved contractor, then the coordination centre will be able to advise on any queries you might have via e-mail at [mentalhealth.data@pickereurope.ac.uk](mailto:mentalhealth.data@pickereurope.ac.uk) or call 01865 208127. However, before you decide to do this, there are some important points to consider:

- The core sample for the 2012 Community Mental Health Service Users survey **must** be drawn as specified in this guide; any deviation from the guidance may make it impossible for the Care Quality Commission to use the data that you collect. It is therefore essential that **any additional sample drawn must be easily distinguished from the core sample, and that it is drawn in such a way as to not interfere with selection of the core sample.**
- If you are planning to undertake surveys more frequently than the national programme, then you should consider how any increased sample here will fit with the additional surveys you will be undertaking.

Increasing the sample size for the survey may be helpful if, for example, you wish to:

- Analyse or compare results for specific subgroups (for example, service users treated at different sites or service users of different ethnicities) in more detail than would be possible from a sample of 850 service users. By increasing the sample size you can ensure that you have a large enough sample of service users from each group<sup>1</sup>.
- Alternatively, if your trust regularly treats very large numbers of service users, you may wish to draw an extra sample of service users to survey additionally to those included in the main survey. For example, you could select service users seen at the trust in a different time period from those in the national survey and send them questionnaires either at the same time as or at some point after the national survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out a service user survey locally at the same time as the national survey you will need to ensure that you are **sampling two distinct and separate groups of service users which do not overlap**. You must also ensure that the sample for the national survey is drawn as specified.

Guidance for carrying out a local survey of mental health inpatient services (carried out as part of the national patient survey programme in 2009) is available at <http://www.nhssurveys.org/localsurveys> so that organisations that wish to do so can begin to plan for future local surveys. To avoid duplication with the national 2012 community health survey, the local community health survey tool and materials have temporarily been removed from the website but will be made available towards the end of the fieldwork for the national survey.

---

<sup>1</sup> See section 18 for more information on the reliability of data based on different numbers of respondents.

## To summarise

If you do 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. Your approved survey contractor or the coordination centre will be able to advise you on this.

You must **only** send the Co-ordination Centre data for the 850 service users sampled according to these guidelines. If you decide to carry out a Mental Health service user survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of service users which do not overlap and that any additional sample is drawn in such a way as to not interfere with selection of the core sample.

## 12 Final sampling inspection by the Co-ordination Centre

Trust data should be checked for errors and received back from DBS before being forwarded to the Co-ordination Centre. An anonymised sample file<sup>1</sup> **must** be submitted to the Co-ordination Centre **prior** to the first mailing. This is to allow us to make final quality control checks. All columns *in red italics* in **Table 1 – Sample construction spreadsheet of service user details** must be submitted, but name, address and postcode details must be removed. **Trusts should encrypt their sample files before sending to the co-ordination centre for checking<sup>2</sup>.**

The Chief Executive Declaration form must also be sent to the Co-ordination Centre before your sample is **mailed out** (as described in section 11.5).

If you are using an **approved contractor**, the sample should be checked as normal by the trust and by DBS before being submitted to the contractor. We strongly recommend the contractor carries out the same high standard of checks as in previous years, but will then submit the file to the Co-ordination Centre. The Co-ordination Centre will address any issues arising from these final checks to the approved contractor.

The Co-ordination Centre will be checking for extraordinary errors. These are more visible when viewing data from many trusts at one time. For this reason, samples will be checked as collated files. Emails discussing any sample anomalies will be returned to the trust or approved contractor which provided them on Friday of each week **at the very latest<sup>3</sup>**. Initially, we will be working to the timetable included below but, if sufficient samples are submitted during a week, we hope to be able to respond to trusts and approved contractors earlier.

For the 2012 Mental Health Service User survey, the specified sample submission dates are:

Date sample received	Date sample returned
6 <sup>th</sup> -10 <sup>th</sup> February 2012	13 <sup>th</sup> February 2012
13 <sup>th</sup> - 17 <sup>th</sup> February 2012	20 <sup>th</sup> February 2012
20 <sup>th</sup> – 24 <sup>th</sup> February 2012	27 <sup>th</sup> February 2012

Samples should be submitted to the Co-ordination Centre by the **24<sup>th</sup> February 2012**. If they are not, there is a risk your trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may then result in the data from the trust being excluded from the relevant Care Quality Commission assessments.

Trusts which have not submitted their sample for checking by the **24<sup>th</sup> February 2012** will be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **2<sup>nd</sup> March 2012**, then we are required to notify the Care Quality Commission of this and they will contact you to discuss any implications for inclusion in Care Quality Commission produced data.

<sup>1</sup> Created by removing the service users' names, addresses and postcodes.

<sup>2</sup> See *Section 6.6 – Encryption of personal data* for further information

<sup>3</sup> Please note: any samples submitted on a Friday (i.e. 10<sup>th</sup>, 17<sup>th</sup> or 24<sup>th</sup>), must reach the Co-ordination Centre by **11am** if the sample is to be checked by the following Monday.

Your first mailing should take place as soon as possible after your sample has been approved by the Co-ordination Centre but **must not be later than seven days** after this. A large time lag increases the likelihood of service users having died between the sample file being received back from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to your trust.

### Making the most of the fieldwork period

Because certain demographic groups (specifically younger service users and those from non-white ethnic categories) have been shown to take longer to respond to service user surveys, we strongly recommend that files are submitted within the three weeks specified for sample checking. The best way to ensure you can do this is to prepare before the start date of the survey (13<sup>th</sup> February 2012). You can do this by:

- 1) Allocating sufficient time to the individual who will generate your sample to allow them to generate it, dispatch it to DBS, and to respond to queries or corrections specified by your contractor or the Co-ordination Centre
- 2) Discussing the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey
- 3) Ensuring your trust is registered with DBS and that the person who submits your sample to them understands their requirements – problems with data submitted to tracing services is one of the most significant obstacles in mailing out your survey in good time. Also, do not assume you are registered – please check this ahead of time.
- 4) Printing of questionnaires and assembly of mailing packs can take place before the sample is signed off. Please ensure that the envelopes are left open though so that you can check the correct label is applied to the correct questionnaire.



## 13 Weekly Monitoring

The Co-ordination Centre requires weekly submissions of outcome data and helpline calls for each trust taking part in the NHS Community Mental Health Service Users survey. First submission of data must be made on Thursday **16th February 2012**<sup>1</sup>, and every Thursday thereafter until the final date of submission. An Excel spreadsheet is available on our website ([www.nhssurveys.org](http://www.nhssurveys.org)) which **must** be used to return this information to the Co-ordination Centre. This information should be emailed to the Co-ordination Centre ([Mentalhealth.data@pickereurope.ac.uk](mailto:Mentalhealth.data@pickereurope.ac.uk)) by the end of the workday every Thursday throughout the survey.

### **Weekly submissions only apply to the core sample of service users**

#### Important note

It is important that the structure of the Excel weekly monitoring spreadsheet is not altered and that the correct file name is used when submitting the data.

#### **For trusts carrying out the survey in-house:**

When the data is submitted, the file name **must** be in the following format:  
MH12\_<trust code>\_<week of submission>.xls

e.g. MH12\_RRP\_1.xls (first submission of monitoring data on 16th February 2012)  
MH12\_5JE\_4.xls (fourth submission of monitoring data on 8th March 2012)

#### **For approved contractors:**

When the data is submitted, the file name **must** be in the following format:  
MH12\_<contractor code>\_<week of submission>.xls

e.g. MH12\_ACP\_1.xls (first submission of monitoring data on 16th February 2012)  
MH12\_ACY\_4.xls (fourth submission of monitoring data on 8th March 2012)

***Each approved survey contractor should use their unique 'contractor code'. If you do not know your contractor code, please contact the Co-ordination centre.***

<sup>1</sup> This submission must be made regardless of whether mailing has commenced.

## 13.1 Response rate

The information submitted should contain the following data:

- The total number of service users in your sample i.e. the total number of all those included in the first mailing,
- The number of service users in each outcome field

This will allow the Co-ordination Centre to monitor progress at a trust level and to identify trusts that may need assistance. It will also allow us to provide the Care Quality Commission with regular updates on response rate at a trust level.

## 13.2 Helpline monitoring

The information you submit should contain the following data for each trust:

- The overall total number of calls received by the helpline for this survey. This total should also include the calls listed below:
- The total number of calls that led to completion of the questionnaire using the helpline (this should include completions via translation services)
- The total number of calls seeking assistance with language and translation (this should include completions via translation services)
- The total number of calls that led to completion of the questionnaire using translation services

### Examples

If a caller rang the helpline and completed the questionnaire over the phone using translation services, then this call should be recorded in all four 'categories'.

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

If a caller rang the helpline to opt out of the survey or to ask a question (and did not require translation services), this call should just be recorded in the 'overall total' number of calls' (ie first category).

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

# 14 Publicising the survey

## 14.1 Pre-survey communication with staff

The best way to ensure 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. We suggest you put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:

- Caldicott Guardian
- Board members
- Doctors, nurses and other health care staff
- Members of service user groups with a special interest in the trust
- Service users and carers
- Medical records personnel or Patient Administration System (PAS) staff
- Managers
- Staff or directors responsible for:
  - Clinical governance
  - Patient advice and liaison service (PALS)
  - Quality improvement
  - Strategic planning

### **Keeping everyone informed**

Notify as many staff members as possible about the survey, in case service users contact the trust asking questions about the questionnaire they have received. Service users can be expected to ask receptionists, doctors, nurses, patient liaison officers, or the Chief Executive's office about the survey, even when your covering letters give contact details for the survey manager(s) and the dedicated helpline. Notify front line staff and executive offices that a survey is being conducted, and give them the name and number of a contact person. Survey manager(s) should be prepared to respond to these calls quickly.

Staff could be notified of the survey through a variety of methods:

- Electronic (e.g. e-bulletins, website, intranet)
- Paper-based (e.g. staff briefings, newsletters, flyers, posters)
- Face-to-face (e.g. meetings, presentations and events)

*Appendix 1* includes information which you can tailor for publicising the survey to staff.

## 14.2 Publicising the survey externally

To help promote involvement and maximise response rates, the survey can be publicised to service users and the public through a number of ways, for example:

- Send a press release to the local media to raise awareness of the survey and gain publicity just before the survey takes place. Information to help you draft a press release is shown in *Appendix 2*. Talk to your trusts press office for more ways in which you can gain publicity locally.
- Put up posters which show the importance the trust places on gathering service user feedback. To be most effective at increasing your response rate, posters should be put up during the fieldwork period.

We also recommend that posters publicising the survey should allow service users to **opt out** if they do not wish to take part by providing a survey helpline phone number they can call. You can then remove any service users who wish to opt out of the survey.

To encourage service users to respond, we recommend you illustrate how the trust has acted on the results of the previous Community Mental Health Service User surveys carried out by the trust. Service users are likely to be more motivated to take part in the survey if they can see tangible outcomes from a previous survey.

# 15 Materials

## 15.1 Printing questionnaires

### Questionnaire layout

The questionnaire is rigorously tested in the format on the website at <http://www.nhssurveys.org/>. All questionnaires used by trusts should emulate this format and should be comprised of the following:

- Two columns of questions on each page
- Questions should be presented with a consecutive question number, followed by the exact question wording used in the questionnaire, and then each of the response options presented on a separate line beneath the question, for example:

Q8. Were you given **enough time** to discuss your condition and treatment?

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

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

### Number of pages

It is practical to ensure that the number of pages in a questionnaire is a multiple of four so that sheets can be printed double-sided on A3 paper and folded to make an A4 booklet, stapled in the middle. If pages are stapled at the corner, there is a greater chance that some pages will become detached and get lost. The questionnaire, available in PDF format on the NHSSurveys website, is designed to fit onto 8 sides of A4 paper.

### Number of questionnaires

When calculating the number of questionnaires to be printed, you will need to allow for sending out duplicate questionnaires with second reminders. Printing costs can be unnecessarily high if a second print-run is required, so it is worth ensuring that the first print-run is sufficiently large to allow for contingencies. As a rule of thumb, multiply the number of service users in the sample by 1.7 to obtain the total number of questionnaires required. So, if the number of first mailing questionnaires you intend to send out is 850, then you might want to print 1.7 x 850, or approximately 1,500 copies.

### Including other information in the mailing packs

Trusts should only use their sample information to mail out the three official survey mailings. The sample list should not be used for any other type of mailing ie Trusts should not mail their own letter to the sample list prior to the first mailing being despatched.

Furthermore, no other material should be included in the questionnaire packs because of the unmeasurable impact upon response rates to the survey. Additionally, the Multi-region ethics board judged that inclusion of additional material that they had not viewed would invalidate the ethical approval they have given for the Community Mental Health Service Users survey and the survey would therefore not be able to proceed.

## 15.2 Trust headed paper

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

## 15.3 Mail out envelopes

It is important that the envelope(s) which you use to mail out your survey materials to service users does not show any indication of the NHS Trust. Some service users may not have told family or friends that they are receiving mental health services and, under data protection regulations, it is important that this information remains confidential to the service user. We would therefore recommend that the return address used on any mail out envelope(s) does not indicate Trust name or address. It is, however, important that we record questionnaires which are returned undelivered as this affects response rate. We would therefore advise that, where necessary (ie for Trusts conducting the survey in-house), a PO Box address is set up for envelopes which are returned undelivered.

Please note that the above does not apply to the address on the reply paid envelope (which can be a hospital address) as we assume that the service user is responsible for opening his or her own mail.

For further details on how to set up a PO Box please go to:  
<http://www2.royalmail.com/delivery/inbound-mail/po-box>

## 15.4 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 (PO Box address recommended for in-house Trusts)
- FREEPOST envelopes for return of questionnaires
- Covering letters using the trust's letterhead

- Multi-language helpline sheet (recommended)<sup>1</sup>.

## 15.5 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). The following items are needed:

- Reminder letters
- Envelopes
- Labels for addressing envelopes
- Labels for sender address on reverse of envelopes. (PO Box address recommended for in-house Trusts)

## 15.6 Third mailing (second reminder)

The second reminder should replicate the first mailing. 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 (PO Box address recommended for in-house Trusts)
- FREEPOST envelopes for returning questionnaires
- Reminder letters
- Multi-language helpline sheet (if used in first mailing).

---

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

## 16 Implementing the survey - practicalities

### 16.1 Setting up a FREEPOST address

A FREEPOST address allows 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.

### 16.2 Setting up a PO Box

This is recommended for in-house Trusts to ensure that the mail out envelope(s) does not include any indication of the NHS trust address (please see Section **Error! Reference source not found.** for further detail). Information on setting up a PO address can be found at:

<http://www2.royalmail.com/delivery/inbound-mail/po-box>

### 16.3 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. All staff who are likely to take calls should be properly briefed about the details of the survey, and be aware of the questions or complaints they are likely to receive. If you run the survey in-house, you might want to set up a FREEPHONE line for this purpose. Alternatively, many approved contractors offer this service.

Where appropriate, ask the 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.

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

#### **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 or the complaints manager. Approved contractors should be given the contact details of the PALS office or an appropriate member of trust staff so that they can refer callers to that person.

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

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



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

Even with the use of a deceased service users tracing service, it may 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. These service users should be logged as outcome = three (service user deceased).

### **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, such as a family member, fill in a form on their behalf. It is also strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. A multi-language sheet template in the twenty most commonly spoken languages in England is available on our website, and trusts or contractors can make use of this by inserting the appropriate number for their helpline and/or translation service.

### **I do not wish to participate in this survey**

A few 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 taking part in the survey is voluntary, and that the service user's care will not be affected in any way if they do not respond. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of the service user's responses. If the service user is willing to tell the staff member the identification number (service user record number) written on their survey, it might also be possible to prevent any further reminders being sent to that service user. It is also advisable to ask the service user to ignore any future reminders that they might receive. These service users should be logged as outcome = four (opt out).

## **Making a record of the calls**

It is important 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 produced for completion by those taking the calls. The relevant details of each call can be recorded so that survey organisers can monitor any problems and remove service users who wish to be excluded from the mailing list.

We are also asking for weekly submissions of helpline use for each trust to the Co-ordination Centre. This is discussed in detail in Section 13.2.

## **16.4 Covering letters**

The standard covering letter is available in Microsoft Word format on the Community Mental Health section of the NHSSurveys website for you to download and add your own trust's details. This letter has been given ethical approval for use in the Community Mental Health Service User survey and changes are not permissible. It should be printed on the trust's letterhead paper. Two paper copies of the letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

## 16.5 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. The label should not include any other information except the service users' name, address and postcode details, and the service user record number.

#### Note on the service user record number (SURN)

The service user record number is a unique number allocated to all service users at the start of the survey that allows their responses to be kept separate from their name and address, but allows matching up of the response data with the sample data. It also allows them to identify themselves if they contact the trust or contactor without needing to provide name and address information. This should be centrally placed and large enough to be visible to all service users. The Royal National Institute of the Blind recommends the number be printed in size 14 font and located inside the box on the lower half of the front page of the questionnaire.

If service users delete this number from the cover page and then returned the questionnaire, please add their response information in an additional row to the bottom of the data file before submitting it to the Co-ordination Centre. Please do not attempt to match this data to a non-responder of similar demographics, but instead inform the co-ordination centre about this respondent and they will be treated as an additional service user to the sample.

### 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 the number on the address label, and the number on the list of service user details.
- 2) A covering letter.
- 3) The multi-language helpline sheet (recommended)
- 4) A large envelope, labelled with the FREEPOST address on it.
- 5) These items should be packed into an envelope that has a return address on the outside. This should be the contact at the NHS trust, or the approved contractor.

### Postage

The postage may exceed the standard letter rate. It is essential that the appropriate postage rate is paid. The Royal Mail has recently published revised mailing prices; previous quotes for mailing may be out-of-date.

## Approved contractors – mailing questionnaires

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

## Approved contractors – trusts mailing questionnaires

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

## 16.6 Booking in questionnaires

When questionnaires are received, match up the service user 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 **15<sup>th</sup> September 2012** (was 1<sup>st</sup> September 2012), but please **do not** send these to the Co-ordination Centre.

## Approved contractors

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

## 16.7 Sending out reminders

For results to be representative, it is essential to get a good response rate. To achieve this, you must send out two reminders to non-responders. **Remember, it is essential that you send out both reminders, even if you already have achieved a 40% response rate.**

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 back to the tracing service (DBS) for a further check before you send out reminders.

## Approved contractors

If a trust is using an approved contractor but is carrying out the survey mailing in-house, the approved contractors should send the pre-packed envelopes bearing the service user record numbers of the non-responders to the Mental health trust. Again, the envelopes should be clearly marked with the service user record number so that those carrying out the mailing can correctly label the address for each service user record number.

## First reminders

The first reminder should be sent to service users who have not responded after **one to two weeks**. The first reminder should reach the participant while they are still in possession of the first questionnaire, and the optimal time for this will vary between trusts. We recommend approximately **ten** days between the mailing day of the first questionnaire and the mailing day of the first reminder.

The standard first reminder is available in Microsoft Word format on the NHSSurveys website for you to download. It can be printed on A5. It has been given ethical approval so no changes are permitted. Two paper copies of the reminder letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

## Second reminders

Second reminders should be sent out approximately **two to three weeks** after the first reminder to 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 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 multi-language helpline sheet (if used in first mailing)
- 4) A large envelope, labelled with the FREEPOST address on it.

The standard second reminder letter is available in Microsoft Word format on the NHSSurveys website for you to download and add your trust's details. It has been given ethical approval so no changes are permitted. Two paper copies of the second reminder letter you use must be sent to the Co-ordination Centre when you submit your data at the end of the survey.

**Remember that you should check your trust's own records for deaths before sending out reminders.**

## 17 Entering data

Final data must be submitted to the Co-ordination Centre in the appropriate format by the deadline of **15<sup>th</sup> June 2012** (was 1<sup>st</sup> June 2012).

If an approved contractor is used, they will be responsible for all of the data entry and checking, and will submit all data to the Co-ordination Centre in the correct format and supply the trust with an anonymised data set (see Section 6 on data protection issues).

### 17.1 Entering and coding data from the questionnaire

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

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

- Each row records one 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 for any reason, it should be left blank, or coded as a full stop (.)<sup>1</sup>
- If two boxes are ticked (where only one should be ticked), the response should be left blank or coded as a full stop (.)
- For most questions, each column corresponds to one survey question. However, there are some exceptions to this rule. For multiple response questions such as Q52 and Q53 that gives the instruction "Tick all that apply", each response option is treated as a separate question.
- When saving this file to submit data to the Co-ordination Centre, please save only the first sheet as a worksheet, rather than saving the whole file as a workbook; the Co-ordination Centre does not need the additional formula pages.

---

<sup>1</sup> If you want to use this data input file on the website to display frequencies on the other pages of the workbook, you will need to fill in the blank cells with a full stop (.)

## Example

### Q52. Are you currently in paid work? (Tick all that apply)

- 1  Yes, I am working between 1-15 hours a week
- 2  Yes, I am working 16 or more hours a week
- 3  No, I am retired
- 4  No, I do voluntary work
- 5  No, but I am a full time student
- 6  No, other reason

Responses to each part of this question are coded: **1 if the box is ticked**  
**0 if the box is not ticked**<sup>1</sup>

Q52 takes up six columns in the data file, labelled as follows:

Column headings	Q52_1	Q52_2	Q52_3	Q52_4	Q52_5	Q52_6
Codings for this example	1	0	0	0	1	0

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

You will need to send the data from **all** 55 Community Mental Health Service User survey questions to the Co-ordination Centre. To do this, you can use the pre-designed Excel file available on the website. The columns of this standard Excel file are headed with the numbers corresponding to the question numbers in the service user questionnaire. They also include the wordings of the 55 service user questions so that you can match them up. It is essential that you check carefully that the columns of data you select correspond to the 55 service user survey questions.

---

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

## 17.2 Checking the data for errors

For the 2012 Community Mental Health Service Users survey, trusts and contractors are required to submit raw ('uncleaned') data to the Co-ordination Centre. For clarification, raw data is created by the following:

- 1) All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (e.g. where service users answer questions that they have been directed to skip past, these responses should still be entered).
- 2) Where a respondent has ticked more than one response category on a question, this should be set to missing in the data. The **exception** to this is for the 'multiple response' question Q52, where respondents may tick more than one response option.
- 3) Where a respondent has crossed out a response, this should not be entered in the data. Where a respondent has crossed out a response and instead ticked a second response option, this second choice should be entered into the data.
- 4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a service user has written their date of birth in the boxes for Q49, but written their year of birth in at the side of this, then the respondent's year of birth should be entered.
- 5) For the year of birth question, unrealistic responses should still be entered except following rule 4) above. For example, if a respondent enters '2012' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.
- 6) Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the service user's intended response has not been captured. This includes 'out-of-range' responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Co-ordination Centre where they are found to have been entered inconsistently with the respondent's intended response.

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

## 17.3 Submitting data to the Co-ordination Centre

The data from the questions for the 2012 Community Mental Health Service User survey must be supplied to the Co-ordination Centre as one anonymised Excel file that includes information about the service user sample and responses.

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

## Required file format

Please submit the file to the following specifications:

- Use Microsoft Excel Worksheet (not Workbook). Any version of Excel is acceptable
- The file name must be in the form <NHTrustName>\_MHservice user2012.xls
- Use one row of data for each service user in the sample
- Use one column of data for each item of service user information or response
- Service users who are missing their Service user Record Numbers should be added to the bottom of the list, and not matched to service users with similar demographics
- Missing data should be left blank or coded as a full stop (.).<sup>1</sup>

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

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

Field	Format	Codes & formats	Comments
Trust Code	NNN	See Appendix 5 Trust Names and Codes	NACS administrative code for trust
Service User Record Number	MH12-NNNNN-XXX		The unique serial number allocated to each service user by the Trust or Approved Survey Contractor. This should include the survey code (MH12) followed by a 5-digit number in sequence (10000,10001, 10002 etc), followed by the trust code (i.e. RBQ)
Year of Birth	NNNN		
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.).
Ethnic Category	A	<b>White</b> <b>A</b> British <b>B</b> Irish <b>C</b> Any other White background <b>Mixed</b> <b>D</b> White and Black Caribbean <b>E</b> White and Black African <b>F</b> White and Asian <b>G</b> Any other mixed	Ethnic category.  The code "Z" (not stated) should be used when a person has been asked for their ethnic category and have refused or been unable to choose. A blank or full-stop should still be used where the patient's ethnic category is unknown as they have not been asked or was not in a condition to be asked

<sup>1</sup> Data may be missing for a number of reasons. The service user may have skipped a question or a set of questions by following instructions; 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.



		background <b>Asian or Asian British</b> <b>H</b> Indian <b>J</b> Pakistani <b>K</b> Bangladeshi <b>L</b> Any other Asian background <b>Black or Black British</b> <b>M</b> Caribbean <b>N</b> African <b>P</b> Any other Black background <b>Other Ethnic Groups</b> <b>R</b> Chinese <b>S</b> Any other ethnic group <b>Z</b> Not stated	
CPA Status	N	1= the service user is registered on 'new' CPA 2 = the service user is not on new CPA 3=CPA status unknown	
GP code	NNNNNN		GP codes should be coded using the 6-digit GP codes that can be found on the Connecting for Health website: <a href="http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods/genmedprac/datafiles/epracur.zip">http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods/genmedprac/datafiles/epracur.zip</a> The file lists the GP practice code (col. A) and practice name (col. B) of all practices in England
Day of last contact or last review	N or NN	Format as a <b>number</b> , not a date	For example, if the service user last had contact on 20 <sup>th</sup> September 2011, this column should read 20.
Month of last contact or last review	N or NN	Format as a <b>number</b> , not a date	For example, if the service user last had contact on 20 <sup>th</sup> September 2011, this column should read 9.
Year of last contact or last review	NNNN	Format as a <b>number</b> , not a date	For example, if the service user last had contact on 20 <sup>th</sup> September 2011, this column should read 2011.
Day of receiving questionnaire	N or NN	This is the day you received a returned questionnaire from a	For example, if the questionnaire was received on 15th March 2012, this column should read '15'.

		respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	
Month of receiving questionnaire	N or NN	This is the month you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 15th March 2012, this column should read '3' (as March is the 3 <sup>rd</sup> month of the year).
Year of receiving questionnaire	NNNN	This is the year you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 15th March 2012, this column should read '2012'.

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 too ill, opted out or returned blank questionnaire 5 = Service user not eligible 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 questions			Each column must be clearly headed with the question number. Take care with Q52, the multiple response question where there's one column for each response category. 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 Coordination Centre.

**NB:** To comply with the Data Protection Act, name and address details must not be sent to the Coordination 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% of the service users (that is, those who have returned a completed questionnaire, and who will therefore have an outcome code "1").

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

Service user Sample Information										Service user Response								
Trust Code	Service User Record Number	Year of birth	Gender	Ethnic Category	Day of last contact	Month of last contact	Year of last contact	CPA Status	GP code	Day questionnaire	Month questionnaire	Year questionnaire received	Outcome	Q1	Q2	Q3	Q4	Q5
RTV	MH12-10001-RTV	1971	2	A	2	08	2011	1	P92001	4	4	2011	3					
RTV	MH12-10002-RTV	1958	1	A	14	09	2011	1	P92006	25	3	2011	1	3	1	1	1	1
RTV	MH12-10003-RTV	1964	2	B	3	07	2011	3	P92001				6					
RTV	MH12-10004-RTV	1980	2	E	3	09	2011	2	P92001	3	3	2011	1	2	1	3	1	4
RTV	MH12-10005-RTV	1951	2	A	3	09	2011	2	P92003	17	3	2011	1	3	2	5	2	13
RTV	MH12-10006-RTV	1979	1	G	14	07	2011	3	P92003				6					
RTV	MH12-10007-RTV	1987	2	A	21	07	2011	1	P92001				6					
RTV	MH12-10007-RTV	1946	2	K	30	08	2011	2	P92006	23	2	2011	1	3	1	1	5	17

### Additional information required

The following information should also be included when submitting the data file to the Co-ordination Centre:

- **Contact details** (telephone numbers and e-mail addresses) of at least two members of trust staff (usually the main and secondary contacts) who will be available to answer any queries about the data
- **Two blank paper copies** of the questionnaires, the covering letters and the reminder letters you used
- A completed copy of the **checklist** (See Section 17.4 - Checklist).

## Delivery

Data should be encrypted and sent on CD-ROMs or by e-mail, with the password provided separately either by email or telephone (see section 6 of this document for details on the recommended encryption and delivery methods to use). Hard copy documents should be posted to the address below:

Postal address:

Community Mental Health Service User Survey 2012  
Patient Survey Co-ordination Centre  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford  
OX2 0JB

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

## Deadline for submission

The data must be supplied by **15<sup>th</sup> June 2012** (was 1<sup>st</sup> June 2012).

## 17.4 Checklist

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

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

**If incorrect data are submitted, it is possible that the data will be considered unreliable and will not be used by the Care Quality Commission in your trust's performance assessment and your trust's scores will be set to a minimum value. We cannot accept re-submissions of data after the deadline, and likewise data is unlikely to then be included in the Care Quality Commission assessments.**

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

<http://www.nhssurveys.org/survey/1157>

Check	Done?
1) Check that your <b>file name</b> follows the naming convention: <NHStrustName>_MHservice user2012.xls)	
2) Check that you have saved the data sheet only as an Excel <b>worksheet</b> , rather than a workbook. (The frequency and percentage counts on the other pages of the workbook on the website are intended for your use only)	
3) Check that you have included data columns for <b>all 55 questions</b>	
4) Check that all <b>data are correct</b> , and that all values are in range	
5) Send data only for the <b>850 randomly selected service users</b> seen between 1st July 2011 and 30th September 2011	
6) Check that all the data are in <b>numeric format</b> only (including dates)	
7) Check that you have completed the columns for the day, month and year you received the questionnaire back from service users	
8) To comply with Data Protection regulations, any <b>service user name and address details</b> must be removed before the file is sent to the Co-ordination Centre	
9) If you password protect your file, please notify the Co-ordination Centre of the <b>password</b> separately from the data file.	
10) Include <b>two paper copies</b> of the questionnaire you used	
11) Include <b>two paper copies</b> of the covering letters you used for the first, the second and third mailing.	
12) Include <b>telephone and e-mail contact details of two people</b> who will be available to respond to any queries about the data	
13) <b>Check again</b> that all data are correct, and that all values are in range!	

## 18 Making sense of the data

The usefulness of your survey data will depend on how well you plan the survey process and on how effectively you analyse the data. Standard data analysis usually involves examination of the frequency of responses to each question and some cross-tabulation of responses against demographic and other information.

### 18.1 Using the NHSSurveys website to look at your results

Once you have entered the data from the questions into the Excel file on the website (the Data Entry Spreadsheet), the counts and percentages of responses to each of the 55 questions are automatically computed and displayed on the other sheets of the Excel workbook, which correspond to sections of the Community Mental Health Service user questionnaire (excluding the "Other Comments" section). For each question, the numbers and percentages of respondents who gave each answer is shown. The number of missing responses will also be shown, as long as you have coded missing responses on the data sheet as a full stop (.).

### 18.2 Suggestions on data analysis

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

#### Use the data to help pinpoint problems

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

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

#### "Drill down" into the data

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

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

## Group similar questions together to provide summary analysis

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

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

## Use statistical tests to make comparisons and subgroup analyses

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

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

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

## Use service user feedback data with other data

Service user feedback data provides 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.

## Perform analysis by sub-groups

You may want to compare the answer to a survey question between two different groups to see if the differences are significantly different (e.g. the answers for men versus women, or between service users treated under different specialties). However, comparing results *within* your trust considerably reduces the number of responses in each group. This will impact upon the level of confidence you have in the results and, therefore, your ability to accurately detect differences between these groups.

Table 5 (below) shows the level of confidence you would achieve for various numbers of respondents.



**Table 4: Confidence intervals\***

Number of respondents	Widest Confidence Interval (+/-) <sup>1</sup>
50	13.9%
100	9.8%
200	6.9%
300	5.7%
400	4.9%
500	4.4%
600	4.0%

\*at a 95% confidence level

If you are interested in looking at different sub-groups within your trust population (for example, service users treated at different sites in your trust), you will need to think about the number of respondents you need in each group, and how this will impact on the confidence you can have in the results. The Co-ordination Centre recommends a minimum of 100 respondents per group for comparison between sub-groups. Confidence intervals for analysis with groups of fewer than 100 respondents will be so large that there would be little certainty of detecting reliable statistical differences<sup>2</sup>

#### **Example**

For a trust, 400 service users responded in total. Taking a particular question, of which 50% of respondents answered 'Yes', from the table we can see that the widest confidence interval for 400 respondents would be +/- 4.9%. We would therefore be 95% confident that the true results would be between 45.1% and 54.9% - that is, if you had surveyed the entire population of inservice users at a trust.

However, if we are looking at the results for this particular question *by eight different groups of service users* (assuming an equal number of respondents in each region), there would only be 50 respondents in each group. If there are 50 respondents and 50% answered 'Yes', the confidence interval would be +/- 13.9%, so the true results could be between 36.1% and 63.9%.

If you are using a survey contractor to help you carry out your survey, they should be able to advise you on the minimum sample size for comparisons by particular sub-groups

<sup>1</sup> This column (the widest confidence interval) shows the **maximum** margin of error for binomial estimates of proportions

<sup>2</sup> A **confidence interval** is an upper and lower limit within which you have a stated level of confidence that the trust mean (average) lies somewhere in that range. The width of the confidence interval gives some indication of how cautious we should be; a very wide interval may indicate that more data should be collected before any conclusions are made.

# 19 Reporting results

## 19.1 Prioritising your findings

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

### Rank results by their magnitude

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

### Compare your results against outside norms or benchmarks

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

### Compare results within your organisation

Comparisons within organisations can facilitate networking among units or departments and the sharing of information about effective practices. Internal 'competitiveness' may also fuel improvement efforts. You will need to ensure that you have collected this information in your sample frame.

### Compare results over time

Investigating trends in survey results over time is another powerful analytical tool for prioritising areas for improvement. Analysis of trends allows you to focus on correcting aspects of performance that are slipping, although you should confirm any apparent changes between years are statistically significant. Results from the 2012 survey will only be comparable with those from the 2010 and 2011 surveys. This is because changes were made to the sampling methodology and the questionnaire in 2010 following changes made to the Care Programme Approach by the Department of Health as set out in 'Refocusing the Care Programme Approach: Policy and Practice Guidance'.

### Comparison with predefined goals

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

### Correlation with overall measures

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

## Predictive value on overall measures (regression analysis)

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

## Ease of action

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

## Areas of excellence

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

## 19.2 Writing the report

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

### Tailor the document to the audience

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

### Use graphics

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

### Keep the format succinct and consistent

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

## Emphasise priorities clearly

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

## 20 Using results for quality improvement

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

### 20.1 Prepare in advance

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

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

### 20.2 Dissemination of survey results

#### Engage key stakeholders

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

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

#### Spread the Word

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

- Determine whether information should be shared initially with only senior-level people, or whether (and when) it should be spread further afield
- Make presentations to your trust board and to as many groups of staff as possible, each tailored appropriately for the audience
- Organise a high profile event to publicise the results and invite staff and 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
- Publish results in your trust newsletter along with details of improvement plans

## Promote understanding

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

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

## 20.3 Identify key "change agents"

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

## 20.4 Prioritising areas for improvement

### Compare with other trusts

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

### Compare Departments within your trust

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

## Identify where 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 the proportion of service users who said that the purposes of any new medication were explained to them) 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:

- Access to crisis care
- Being given enough information about their medication
- Receiving talking therapies
- Being listened to and treated with respect and dignity

## 20.5 Develop an action plan

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

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

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

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

## 20.7 Use already existing resources

The Department of Health has published the guide 'Understanding what matters: A guide to using patient feedback to transform care', which can be found on their website at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099780](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780). This guide may help you get the most from your survey results



## Appendix 1: Suggested text for pre-survey communication with staff

### Example titles:

What do our service users think about the [trust name]?

Getting service users' views on the quality of care in [trust name]

Understanding service users' experiences in [trust name]

Service user views vital to drive service improvements in [trust name]

We [or NHS Trust name] are carrying out a survey to find out what service users think about the community mental health care they receive.

### Why are we doing another service user survey?

A survey of community mental health service users was carried out as part of the national patient survey programme in 2010. We are carrying out another survey, using a similar questionnaire and methodology, to [track any changes in service users' experiences over time so we can continue to improve services / or to evaluate the success of quality improvement initiatives implemented since the last survey]

Obtaining feedback from service users and taking account of their views and priorities is vital for bringing about improvements in the quality of care.

### When is the survey taking place?

Questionnaires will be posted to a sample of service users during [month]. Reminders will be sent to those who have not responded during [month(s)].

Service users are being asked about various aspects of their care, including [the quality of care and treatment, medication management, communication with health and social care workers, information, and day to day living]

### Who is the survey being sent to?

The survey will be sent to a sample of [number] service users, aged 18 years and over, who received community mental health services during [months]. [An external survey contractor, {name}, is administering the survey so that service users' responses are anonymous]

### How have the results from previous surveys been used?

Results from the 2011 community mental health user survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here]

### When will the results of this survey be available?

The results of this survey will be available in [month/date] in [location of where results will be published or shared with staff]. The survey findings will be reported in [format, e.g. a summary report, at a meeting etc...]. By working with both staff and service users we will use the feedback from this survey to further help improve service user's experiences at the trust.

### Where can I find out more?

For more information about the survey, please contact [lead survey name and contact details]

## Appendix 2: Suggested template text for pre-survey article for external media

**Title:**            [\[NHS Trust name\] seeks service user views or Service user views vital to drive service improvements in \[NHS Trust name\]](#)  
[Your chance to tell \[NHS Trust name\] about quality of care](#)

[NHS Trust name] is carrying out a survey to find out what community mental health service users think about the care they receive. The trust plans to use this feedback to improve service users' experiences. The results will be used to help [NHS Trust name] highlight areas where they perform well and to identify the areas where there is most room for improvement.

Service users who have recently been a community mental health service user at [trust name] may receive a questionnaire in [month], asking about their experiences. They will be asked about various aspects of their care, including [the quality of care and treatment, medication management, communication with health and social care workers, information, and day to day living]

Obtaining feedback from service users and taking account of their views and priorities is vital for bringing about improvements in the quality of care. Results from the survey will be used to [insert purpose of survey here, e.g. to track service users' experiences of care received at the trust since the last survey was undertaken in [2011] / or to measure the impact of changes made at the trust based on feedback from the 2011 survey / or to find out if recent changes made to the service has led to an improvement in service users' experiences]

Results from the 2011 Community Mental Health Service user survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here]

The results of the survey will be presented in a form that does not allow any individual's answers to be identified. The results will be published by [NHS Trust name] in [month and year].

[A senior executive at the trust] says "We hope that our service users will take the time to help us with this survey. Their views are vital in helping us to find out how we are doing and how we can improve. This is an excellent way for service users to help shape the services we provide in the future."

Please contact [NHS trust staff name/us] on [freephone} telephone number] or email [email address] if you have any queries or concerns about the survey.

## Appendix 3: Declarations of data protection compliance

### Declaration of compliance with the Data Protection Act 1998

---

#### DECLARATION RELATING TO THE

#### 2012 NHS Community Mental Health Service User survey FOR TRUSTS USING IN-HOUSE SURVEY TEAMS

---

While carrying out the 2012 NHS Community Mental Health Service User survey, all trusts need to comply with:

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

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

For further information on the guidelines, please see the "Data protection" section in the Guidance Manual for the 2012 Community Mental Health Service User survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS Community Mental Health Service User survey programme will conform to the guidelines set out under the section "Data protection" in the Guidance Manual for the 2012 mental health service user survey.

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

I, **[insert name of first survey lead]** the first Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2012 Community Mental Health Service user survey and will ensure that data collected while carrying out the NHS Community Mental Health Service User survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2012 Community Mental Health Service User survey.

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

I, **[insert name of second survey lead]** the second Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2012 Mental health service user survey and will ensure that data collected while carrying out the NHS service user survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the 2012 Community Mental Health Service User survey.

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

## Appendix 4: Declarations for additional data analysts

### Declaration of compliance with the Data Protection Act 1998

---

**DECLARATION  
RELATING TO THE  
2012 Community Mental Health Service User survey  
Additional data analysts**

---

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

For further information on the guidelines, please see the “Data protection” section in the Guidance Manual for the 2012 Community Mental Health Service User survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS Community Mental Health Service User survey programme will conform to the guidelines set out under the section “Data protection” in the Guidance Manual for the 2012 NHS Community Mental Health Service User survey.

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

I, **[first additional data analyst]** the first additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2012 Mental health service user survey and will conform to these requirements and the guidelines set out under the section “Data protection” in the Guidance Manual for the 2012 Community Mental Health Service User survey.

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

I, **[second additional data analyst]** the second additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the 2012 Community Mental Health Service user survey and will conform to these requirements and the guidelines set out under the section “Data protection” in the Guidance Manual for the 2012 Community Mental Health Service User survey.

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

## Appendix 5: Trust Names and Codes.

TAD	Bradford District Care Trust
TAE	Manchester Mental Health and Social Care Trust
TAF	Camden and Islington NHS Foundation Trust
TAH	Sheffield Health and Social Care NHS Foundation Trust
TAJ	Black Country Partnership NHS Foundation Trust
R1A	Worcestershire Health and Care NHS Trust
RHA	Nottinghamshire Healthcare NHS Trust
RKL	West London Mental Health NHS Trust
RLY	North Staffordshire Combined Healthcare NHS Trust
RQY	South West London and St George's Mental Health NHS Trust
RRP	Barnet, Enfield and Haringey Mental Health NHS Trust
RT5	Leicestershire Partnership NHS Trust
RT6	Suffolk Mental Health Partnership NHS Trust
RVN	Avon and Wiltshire Mental Health Partnership NHS Trust
RW4	Mersey Care NHS Trust
RWV	Devon Partnership NHS Trust
RXY	Kent and Medway NHS and Social Care Partnership Trust
RYG	Coventry and Warwickshire Partnership NHS Trust
RYK	Dudley and Walsall Mental Health Partnership NHS Trust
RAT	North East London NHS Foundation Trust
RDY	Dorset Healthcare University NHS Foundation Trust
RGD	Leeds Partnerships NHS Foundation Trust
RH5	Somerset Partnership NHS Foundation Trust
RJ8	Cornwall Partnership NHS Foundation Trust
RMY	Norfolk and Waveney Mental Health NHS Foundation Trust
RNN	Cumbria Partnership NHS Foundation Trust
RNU	Oxford Health NHS Foundation Trust
RP1	Northamptonshire Healthcare NHS Foundation Trust
RP7	Lincolnshire Partnership NHS Foundation Trust
RPG	Oxleas NHS Foundation Trust
RRD	North Essex Partnership NHS Foundation Trust
RRE	South Staffordshire and Shropshire Healthcare NHS Foundation Trust
RT1	Cambridgeshire and Peterborough NHS Foundation Trust
RT2	Pennine Care NHS Foundation Trust
RTQ	2gether NHS Foundation Trust
RTV	5 Boroughs Partnership NHS Foundation Trust
RV3	Central and North West London NHS Foundation Trust
RV5	South London and Maudsley NHS Foundation Trust
RV9	Humber NHS Foundation Trust
RW1	Southern Health NHS Foundation Trust
RW5	Lancashire Care NHS Foundation Trust
RWK	East London NHS Foundation Trust

RWN	South Essex Partnership University NHS Foundation Trust
RWR	Hertfordshire Partnership NHS Foundation Trust
RWX	Berkshire Healthcare NHS Foundation Trust
RX2	Sussex Partnership NHS Foundation Trust
RX3	Tees, Esk and Wear Valleys NHS Foundation Trust
RX4	Northumberland, Tyne and Wear NHS Foundation Trust
RXA	Cheshire and Wirral Partnership NHS Foundation Trust
RXE	Rotherham, Doncaster and South Humber NHS Foundation Trust
RXG	South West Yorkshire Partnership NHS Foundation Trust
RXM	Derbyshire Healthcare NHS Foundation Trust
RXT	Birmingham and Solihull Mental Health NHS Foundation Trust
RXV	Greater Manchester West Mental Health NHS Foundation Trust
RXX	Surrey and Borders Partnership NHS Foundation Trust
5CQ	Milton Keynes PCT
5F1	Plymouth Teaching PCT
5MV	Wolverhampton City PCT
5NV	North Yorkshire and York PCT
5QT	Isle of Wight NHS PCT
R1C	Solent NHS Trust
TAN	North East Lincolnshire Care Trust Plus

## Appendix 6: Chief Executive Declaration Form

### Community Mental Health Service User Survey Declaration by the Chief Executive

Please provide the information requested in each of the boxes on this form. This will be used for audit purposes to ensure that the sample conforms to the guidance.

#### SECTION A: Service users at this Trust who meet the eligibility criteria (see next page)

- (A) Total number of eligible service users at the Trust who used services between 1<sup>st</sup> July and 30<sup>th</sup> September 2011\*
- (B) Number of service users on new CPA
- (C) Number of service users not on new CPA
- (D) Number of service users where CPA status not known


#### SECTION B: sample of service users included in 2012 survey

- (E) Number of service users in the sample\*
- (F) Number of service users in this sample on new CPA
- (G) Number of service users in this sample not on new CPA
- (H) Number of service users in this sample where CPA status not known


#### CPA definitions

This Trust's implementation definitions of CPA are as follows:

(I) On new CPA:

(J) Not on new CPA:


#### Declaration

The above information is accurate. I confirm that the sample has been drawn in accordance with the guidance. I confirm that the sample has been drawn from all databases of service users held by this Trust and not part thereof. I confirm that the sample reflects the proportion of service users who were on CPA and those not on CPA between 1st July 2011 and 30th September 2011.

Signed:

Date:

Chief Executive name:

Trust name:



#### Please return this form to:

Community Mental Health Survey 2012  
The Patient Survey Co-ordination Centre  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford OX2 0JB

\* Note that (A) should be equal to the sum of (B), (C) and (D)

\* For almost all Trusts, this figure will be 850 and (E) should be equal to the sum of (F), (G) and (H)

## Eligibility criteria

### Who to include:

Anyone (whether or not they were on the CPA) who used the Trust's community based treatment and care services **during the sample period of 1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011**, including the following:

- Outpatients services
- Day therapies services
- Adult services
- Services for older people
- Crisis teams
- Complex needs services
- Assertive outreach teams
- Early intervention and short-term intervention teams
- Recovery teams
- Home Treatment Teams
- Rehabilitation support teams
- Memory clinics

### 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 duty worker or a psychiatrist for a single assessment.)
- Anyone primarily receiving drug & alcohol services
- Anyone primarily receiving Learning Disability services
- Anyone receiving specialist forensic services
- Anyone receiving psychological treatments from IAPT services
- Anyone primarily receiving Chronic Fatigue/ME services
- Anyone primarily receiving Psychosexual Medicine (sexual dysfunction) services
- Anyone receiving Gender Identity services
- Any service users who are **under 18 years of age** on the date the sample is drawn
- Any service users who are known to be **current inpatients** at the time of drawing the sample
- Service users who are known to have **died**
- Service users who **do not** have a **known UK address**
- Service users who did not have contact with Mental Health Services **during the sample period of 1<sup>st</sup> July 2011 and 30<sup>th</sup> September 2011**.
- Any **duplicated** names: Check that the same service user has not been included more than once
- Any **alias names** where the person's real name is already included in the list.



- Any service user known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those service users from your sample list at this stage).