National patient survey programme

NHS Community Mental Health Service Users Survey

Guidance Manual 2010

Updated 7th December 2009

This document and other documents referenced within are available from NHS Community Mental Health Service Users Survey link at:

nhspatientsurveys.org.uk

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Updates

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

Changes to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in the guidance manual. The terms of the ethical approval do not permit these types of alteration. Furthermore, such alterations might mean that the comparability of the survey would be compromised, and this could affect the calculation of performance indicators. If Trusts want to make any minor changes to the methods set out in this guidance, they must first check with the Coordination Centre that the proposed changes would not compromise comparability.

Please direct questions or comments about this guidance to:

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Introduction

The Care Quality Commission and the NHS national patient survey programme

The national patient survey programme was established by the Department of Health and has been operating since 2002. The Care Quality Commission (CQC) took over from its predecessor, the Healthcare Commission, in April 2009 and is responsible for administering the programme. The CQC is the independent regulator of all health and adult social care in England. It inspects all health and adult social care services in England to make sure that essential common standards of quality are met everywhere care is provided, from hospitals to private care homes. As set out in the Commission's statement on involving people, "Voices Into Action"[1], the Commission is committed to involving people who use services in everything it does and ensuring that services themselves involve users and respond to their views. The experiences of patients and service users are at the heart of the Care Quality Commission's work: it is the aim of the Care Quality Commission and the Coordination Centre to make sure better care is provided for everyone.

The surveys are expected to inform local improvement activity; they are seen as an important source of information for people and for informing commissioners of services. The information from the survey will provide performance indicators for CQC's Periodic Review for 2009/10. In addition, the survey results are used as a data source by the Department of Health and are made available to the public via the Commission's website.

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[1] http://www.cqc.org.uk/publications.cfm?fde_id=12419

How to use this guide

This guide outlines the requirements and procedures for carrying out the NHS Community Mental Health Service Users survey. By ensuring that organisations carry out these surveys in a consistent and systematic way it is possible to build up a national picture of peoples' experiences and, with care, to compare the performance of different organisations, changes over time, and variations between different groups of patients.

As detailed in Section 1, Trusts have the option of conducting the survey in-house or by using an Approved Contractor. Whichever you choose, you will need to address the guidance in Sections 1 to 5 of this guide. Sections 6, 7 and 8 cover the practicalities of mailing out the survey, following-up responses and processing the data and submitting them to the Coordination Centre. These sections will be most relevant to Approved Contractors, or Trusts undertaking the surveys themselves.

Basic requirements for national NHS Community Mental Health Survey 2010

For comparisons between and within Trusts to be accurate and fair, the surveys must be carried out using standard procedures in all Trusts. Those standards are set out in detail later in this document. In summary, they are as follows:

Tell the Coordination Centre who is carrying out your survey (i.e. whether it will be carried out by an Approved Contractor or in-house) by **4th December 2009**.

Give the Coordination Centre contact details of two people in your Trust who will be responsible for the survey's progress by **4th December 2009**.
Email: CommunityUsersSurvey@natcen.ac.uk

Follow the sampling procedure set out in this guidance. Work closely with the person in the information department who draws the sample, and check carefully that this guidance is followed exactly. This process can be started as of **27th November 2009** and the sample should be available to your Chief Executive for signing off by **14th December 2009** at the latest. See Section 5 - *Compiling a sample of service users for the survey*.

Your Chief Executive must sign off the sample before it is submitted to the Co-ordination centre for checking, and you must send a signed declaration that the sample has been signed off. The signed declaration must reach the Co-ordination

Centre by **21ˢᵗ December 2009**.

Send the DBS checked sample to the Coordination Centre by **18ᵗʰ December 2009**.

Send questionnaires to **a random sample of 850 service users aged 16 and over (please note there is no upper age limit).** See section *5 – compiling a sample of service users for the survey*.

Use only the **standard 8-page Mental Health Questionnaire 2010** downloaded from the NHS Community Mental Health Service Users Survey link at: www.nhspatientsurveys.org.uk.

Use only the **standard covering letters** downloaded from the NHS Community Mental Health Service Users Survey link at: www.nhspatientsurveys.org.uk.

Send two reminders to non-responders, even if a 40% response rate is already achieved

A raw dataset must be submitted to the Coordination Centre in the form outlined in Section 8.2 *Submitting data to the Coordination Centre* - by **5pm on 19ᵗʰ April 2010**. This deadline is determined by the requirement for data from the survey for the CQC's Periodic Review for 2009/2010.

Two copies of each of the paper documents you used, (questionnaire and covering letters for **each mailing)** must be submitted to the Coordination Centre in the form outlined in 8.2- *Submitting data to the Coordination Centre* - by **5pm on 19ᵗʰ April 2010**.

Keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front and back pages) of all returned questionnaires until **31ˢᵗ August 2010** but **do not** send these to the Coordination Centre.

Timetable

The timetable below sets out important dates for the 2010 survey. If you commission an Approved Contractor, most of the work will be done by them, but all Trusts have to be involved in some of the stages of the process.

Latest date to complete	Task	See Section
27/11/2009	Guidance and all documents available for download from the Coordination Centre website	
04/12/2009	Inform Coordination Centre who is carrying out the survey (in-house or Approved Contractor) and send contact details of two Trust personnel	
11/12/2009	Draw sample of service users (sampling period July,Aug,Sept)	5
14/12/2009	Ask Chief Executive to sign off sample, submit declaration to Coordination Centre (to be received by **21/12/2009**)	5.6
14/12/2009	Submit checked service user sample list to DBS to check for deceased service users	5.8
14/12/2009	Set up P.O. Box (if carrying out survey in-house)	7.3
14/12/2009	Set up FREEPOST address and FREEPHONE line (in-house model)	7.2 & 7.4
16/12/2009	Print questionnaires & covering letters. Ensure you have enough headed paper, envelopes, return envelopes and labels (in-house model)	7.1 & 7.5
16/12/2009	If using an Approved Contractor, supply them with Trust headed paper, signature of senior executive and (if appropriate) signed contract	7.5
04/01/2010	Reduce sample size to 850 (if required)	5.9
04/01/2010	Supply Approved Contractor with sample	5.12
07/01/2010	Supply anonymised sample to Coordination Centre	5.9
11/01/2010	Coordination Centre return checked sample to Trusts	5.9
12/01/2010	Establish system for responding to telephone enquiries	7.4
12/01/2010	Establish system for booking in questionnaires (in-house model)	7.8
12/01/2010	Check your own Trust's records again for service user deaths and notify Approved Contractor	5.10
14/01/2010	Stick labels on pre-packed numbered questionnaires supplied by Approved Contractor	7.7
15/01/2010	Send out first questionnaires	7.7

15/01/2010	Send first weekly progress and helpline monitoring sheet to the Coordination Centre	6
Jan-Mar 2010	Book in returned questionnaires	7.8
Jan-Mar 2010	Enter questionnaire data	8
Jan-Mar 2010	Respond to telephone enquiries	7.4
28/01/2010	Check your own Trust's records again for service user deaths and notify Approved Contractor	7.9
29/01/2010	Send out first reminders to non-responders	7.9
11/02/2010	Check your own Trust's records again for service user deaths and notify Approved Contractor	7.9
12/02/2010	Send out second reminders to non-responders	7.9
15/04/2010	Complete data entry	
21/04/2010	**Very Important:** check data for errors	8.1
26/04/2010	Send raw data, paper documents and checklist to Coordination Centre	8.2

What's New for the 2010 Survey

Following a review of the CPA by the Department of Health ('Refocusing the Care Programme Approach: Policy and Practice Guidance'), and a series of stakeholder workshops, the Care Quality Commission has reviewed the questionnaire and sampling methodology used in the survey and agreed certain modifications for the 2010 survey.

Sampling Methodology.

Since the last community survey, there have been changes to the Care Programme Approach in that typically only service users previously under the Enhanced CPA are expected to be on the 'new' CPA. However, the 2010 survey will cover a sample drawn from **all service users** aged 16 and over who have been in contact with mental health services in the three month period 1st July 2009 to 30th September 2009 (please note, there is no upper age limit). The key difference is that service users not registered on CPA will be included for the first time.

Questionnaire.

The questionnaire has also been revised to reflect changes to the way services are provided and there are a number of new questions and several questions from past surveys have been removed or revised. These changes follow consultation with service users and providers. The new questionnaire has also been cognitively tested with mental health service users, and all new questions have been shown to be relevant and comprehensible. Information on the development and testing of the questionnaire will be made available on the website: www.nhspatientsurveys.org.uk

The questionnaire now comprises 55 questions over 8 pages. The previously approved questionnaire comprised 58 questions over 8 pages.

Multiple Response Question

There is one multiple-response question (tick all that apply) – Q53, where rules for data-entry are different from the other questions that are single response (tick one box only) questions.

NSTS / DBS

The Demographic Batch Service (DBS) has replaced the NHS Strategic Tracing Service (NSTS) batch trace. The DBS enables users to submit and receive a file containing relevant patient records electronically using dedicated client software. The patient records in the file are matched against the NHS Spine Personal Demographics Service.

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1.   Commissioning an Approved Contractor

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

- Provide support to Trusts on sampling

- Print questionnaires, covering letters and reminders and provide consumables

- Ensure the correct postage is paid for each mailout.

- Handle returned questionnaires, liaise with Trusts on reminders

- Offer support to ensure good response rates. e.g. offer FREEPHONE line

- Complete data entry and submit data to the Coordination Centre by the deadline

- Prepare reports for Trusts

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

Further information about each of these organisations, can be found on the NHS Community Mental Health Service Users Survey link at www.nhspatientsurveys.org.uk.

List of Approved Contractors

The following contractors have approved status for work on the national patient experience surveys programme:

BMG Research
Contacts: Jenna Allen and Simon Maydew

Holt Court,
Heneage Street,
West Aston Science Park,
BIRMINGHAM,
B7 4AX

Tel: 0121 333 6006 Fax: 0121 333 6800
E-mail: jenna.allen@bmgresearch.co.uk   Simon.maydew@bmgresearch.co.uk
Website: www.bmgresearch.co.uk

CAPITA Health Service Partners
(Formerly NHS Partners' Research and Information)
Contacts: Cheryl Kershaw and Aimi Blueman

Capita Health Service Partners,
30 Victoria Avenue,
Harrogate,
North Yorkshire,
HG1 5PR

Tel: 01423 720212
E-mail: cheryl.kershaw@capita.co.uk   aimi.blueman@capita.co.uk
Website: www.capitahsp.co.uk

GFK NOP
Contact: Sarah McHugh, Joy Mhonda and Lisa Endersbee

GFK NOP,
Ludgate House,
245 Blackfriars Road,
London,
SE1 9UL

Tel: 0207 890 9000 (Switchboard) Fax: 0207 890 9744
E-mail: sarah.mchugh@gfk.com   joy.mhonda@gfk.com   lisa.endersbee@gfk.com
Website: www.gfknop.co.uk

Ipsos MORI
Contact: Kate Duxbury

Ipsos MORI,
79-81 Borough Road,
London,
SE1 1FY

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

Marketing Sciences
Contacts: Eileen Sutherland and Joy Owen

Marketing Sciences,
8 Clement Street,
Winchester,
Hampshire,
SO23 9DR

Tel (direct): Eileen: 01962 835414 Joy: 01962 835419 Fax: 01962 840486
E-mail: esutherland@marketing-sciences.com   jowen@marketing-sciences.com
Website: www.marketing-sciences.com

MSB Ltd
Contact: Don Porter

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

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

The National Centre for Social Research
Contact: Marian Bolden

National Centre for Social Research,
Kings House,
103-135 Kings Road,
Brentwood,
Essex,
CM14 4LX

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

Patient Dynamics
Contacts: Fiona Ware and Andrew Smith

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

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

Picker Institute Europe
Contacts: Dianna McDonald and Angus Maxwell

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

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

Quality Health
Contacts: Dr Reg Race, Kerry Hibberd and Mandy Moore

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

Tel: 01246 856263 Fax: 01246 855644
Email: reg.race@quality-health.co.uk   kerry.hibberd@quality-health.co.uk
mandy.moore@quality-health.co.uk
Website: www.quality-health.co.uk

SNAP surveys
Contacts: Tamara Gooderham, Emma Williams and Ralph Sutcliffe

SNAP Surveys,
Mead Court,
Cooper Road,
Thornbury,
Bristol,
BS35 3UW

Tel: 01454 280860 Fax: 01454 281216
Email: tgooderham@snapsurveys.com   .rsutcliffe@snapsurveys.com
ewilliams@snapsurveys.com
Website: www.snapsurveys.com

1.1 Contracts with survey contractors

The Care Quality Commission has recently revised the contracts that have previously been made available for use with the national patient surveys, to reflect recent shifts in the approach taken to such matters. The model honorary contracts have been replaced by a document that we shall refer to as the 'service contract'. Further details are available in Section 1.2 – Data protection and confidentiality, and Section 2.4 – Service Contract.

These can be found at www.nhspatientsurveys.org.uk 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 model service contract between the trust and the approved contractor, as organisations

The model 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.

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 patients to be surveyed
- The survey methodology (i.e. postal questionnaire with two reminders to non-responders)
- Exactly what the survey provider and the trust are responsible for in carrying out the survey project (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.

1.2 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. You will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles (see section 2.1). It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. It will also be necessary to establish appropriate contractual arrangements with any contractors. Your Trust's Caldicott Guardian and legal advisors will be able to advise you on these matters.

The Care Quality Commission and the survey Coordination Centres have agreed new guidelines on the use and security of the data collected from 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.

This website below has further information:

http://www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentialityandcaldicottguardians

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

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

2.1 Statements of compliance with data protection

In-house surveys

Each NHS Trust has a Caldicott Guardian responsible for overseeing proper use of patient data. If you are conducting the survey in-house, before drawing the sample, you must submit a formal declaration (see Appendix 1), signed by the Caldicott Guardian and survey lead(s) for the Trust, to the NHS Community Mental Health Users Survey Coordination Centre. This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines. Templates for these declarations are available on the website containing the survey guidance (www.nhspatientsurveys.org.uk). You must wait for confirmation of receipt from the Coordination Centre before you draw your sample.

Caldicott Principles

Each NHS Trust has a Caldicott Guardian who is responsible for overseeing proper use of patient data. They have to ensure that any use of patient data conforms to the following principles:

> **Principle 1** - Individuals, departments and organisations must justify the purpose(s) for which information is required
>
> **Principle 2** - Don't use patient-identifiable information unless it is absolutely necessary
>
> **Principle 3** – Use the minimum necessary patient-identifiable information
>
> **Principle 4** - Access to patient-identifiable information should be on a strict need-to-know basis
>
> **Principle 5** – Everyone should be aware of their responsibilities
>
> **Principle 6** - Understand and comply with the law

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

The Caldicott guidance and principles were incorporated into the NHS code of practice on confidentiality. If the Caldicott Guardian is unable to make such a declaration, then the Trust must use an Approved Contractor to ensure that appropriate standards of confidentiality data protection are maintained.

Approved Contractors

The framework agreement between the Approved Contractors and the 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.

2.2   Service users' names and addresses

Trusts and their 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[2] (which incorporates the Caldicott principles).

The Care Quality Commission strongly recommends that 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.

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 whenever possible. A key size of at least 128 bits must be used. This is to ensure a high level of security, to protect against any accidental or intentional interception during the transfer of patients' details.

Approved contractors should be able to provide guidance on the use of an encrypted session to Trusts.

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

As the owners of the data, the method for transferring patient samples is ultimately the Trust's decision because the Trust remains legally responsible for the security and processing of the information it shares. The 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[3].

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

Mailing processes and sharing sample information with an approved contractor

If you commission an Approved Contractor to carry out the survey, there are two common methods currently being practised by Trusts and contractors, as advised by the Care Quality Commission:

Method 1

1. The Trust allocates serial numbers to their list of sampled service users.

2. The contractor delivers pre-packed serial-numbered questionnaire packs to the Trust.

3. The Trust attaches number-matched address labels to the envelopes and posts them out.

4. Completed questionnaires are returned directly to the contractor and the contractor checks off the Serial Numbers on returned questionnaires.

5. When the reminders are ready to be sent out, the contractor sends pre-packed serial-numbered questionnaire packs to the Trust for those service users who have not yet returned questionnaires or opted out.

This process is described in more detail in Sections 5 and 7

Method 2

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[3] http://nww.connectingforhealth.nhs.uk/igsecurity/gpg/gpg/NPFIT-FNT-TO-IG-GPG-0004.01%20GPG_%20%20NHS%20Cryptographic%20Algorithms.pdf – this document is only accessible from NHSnet.

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 will provide a set of contracts for trusts and approved contractors carrying out the survey to avoid the need for each trust to develop its own arrangements. It is strongly recommended that these documents are reviewed by each trust and approved contractor to ensure they are satisfied with them, and to amend where required.

A model service contract and supporting guidance notes are available on our website at:

www.nhspatientsurveys.org.uk

2.3   Encryption of personal data

Any patient identifiable information sent between trusts and contractors should be in an encrypted format with password protection to help ensure good standards of information security. Many different encryption algorithms exist and not all of these are suitable, so 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 SR1 and above).

2.4   Service Contract

A model 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 service contract also ensures that approved contractor staff members sign and abide by the service contract. The service contract is set up between the trust and the approved contractor who will have access to patients' information. The service contract describes how patients' personal data will be sent to the approved contractor, and how the data can be used.

The model service contract in Word format is available on the NHS Community Mental Health Service Users Survey link at:

www.nhspatientsurveys.org.uk

2.5   Confidentiality

Any service user survey must respect confidentiality and this confidentiality must be given high priority. That is, service users must be given reliable assurances that doctors, nurses, social workers and other Trust staff will not be able to identify any individual's responses.

At Trust Level

If data are to be presented to trust staff who have not signed the declarations of compliance with the Data Protection Act, 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 shown in the example in Figure 1. In this case responses for the 'Mixed' and 'Asian' ethnic groups are suppressed because there are fewer than 20 service users in each of these sub-groups (though sub-group totals are shown).

Figure 1 – Example of presentation of aggregated data

Ethnic group	Yes %	No %	Total responses n
White	81	19	261
Mixed	-	-	8
Asian	-	-	18
Black	79	21	52
Other Group	85	15	36

Furthermore, do not present response information (including verbatim comments) in a form that allows individuals to be identified by the group receiving the information. If you are presenting the results of a small number of service users, make sure that it will not be possible for staff to identify individual patients from their responses, and pay particular attention to the patients' free text comments in this context. For example, if a service user is known to be under the care of a particular team and his or her year of birth, sex and ethnic group are known from their survey responses, it might be possible to use this information to identify them.

Approved Contractors

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 (16-35, 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 the age group) must then be deleted.

c. Day, month, and year of last contact must be removed. As it could be used to identify individual patients must also be removed.

d. Verbatim comments that could lead to any staff identifying respondents must be removed, e.g. those mentioning service user, staff, and ward or unit names[4]

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 patient 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 user's identity by specific demographic factors. Different arrangements govern the supply of raw data to the Coordination Centres. The response data will be anonymous when passed to the Mental Health Survey Coordination Centre and Care Quality Commission.

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.

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.

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[4] 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 Coordination Centre can offer legal advice on these matters; the contractor or trust must seek its own independent legal advice before disclosing patients' comments.

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

<u>Sharing of survey data between contractors</u>

If a Trust is 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.

2.6   Service user anonymity

In-house surveys

It is important to ensure that any claims you make about anonymity are accurate. The raw data set should not be provided to any staff at the Trust other than the Caldicott Guardian and survey leads recorded on the declaration of compliance with the Data Protection Act 1998 for Trusts using in-house survey teams (Appendix 1). 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.

If additional data analysts or staff join the in-house survey team, the declaration of compliance with the Data Protection Act (additional data analysts) must be submitted to the Coordination Centre (Appendix 2). An additional data analyst cannot view the raw data until approval has been received from the Coordination Centre.

Approved Contractors

Anonymity can sometimes be achieved if there is a clear separation between the information seen by an Approved Contractor and the information held by the Trust. Service users' names and addresses should be seen by Trust staff only, while individual responses should be seen by contractor staff only. As long as the response data supplied to Trusts do not include Service User Serial Numbers and are not provided to Trusts in a way that allows individuals to be identified, it can reasonably be claimed that responses are anonymous.

2.7   Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of service

users' names. Similarly, the electronic file containing the service users' names and addresses should be stored separately to that containing the survey data. Any lists of service users' names and addresses should be destroyed when the mailing process is complete.

3.   Ethical issues, ethics committees & research governance

3.1   Ethical approval for the mental health survey

The Coordination Centre has obtained Multi-Centre Research Ethics Committee (MREC) approval for the standard Mental Health Questionnaire, the covering letters and reminder letters. You do not, therefore, need to seek ethical approval for this survey. Further information on the ethical approval process can be found on the National Research Ethic Service (NRES) website, www.nres.npsa.nhs.uk.

The MREC letters can be downloaded from the NHS Community Mental Health Service Users Survey link at: www.nhspatientsurveys.org.uk

To comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document.

3.2   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. The development of the survey methods, the questionnaire and covering letters to service users, have all been approved by an MREC. The questionnaire and guidance notes on how to conduct the survey are produced by the Mental Health Surveys Coordination Centre and approved by the Care Quality Commission.

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 sponsored by the Trust. As this national service user survey has MREC approval and the Care Quality Commission takes responsibility for it as sponsor, this would duplicate work and delay implementation unnecessarily.

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

The following table has been prepared by the Care Quality Commission. It is based on Section 3.10 of the Research Governance Framework for Health and social care (2nd Edition, 2005, amended April 2006), available at http://www.dh.gov.uk/assetRoot/04/12/24/27/04122427.pdf). 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 this survey. If you are required to seek approval from your research governance lead, you are advised to present this information to your R&D Manager in support of your request.

Responsibilities of organisations providing care

Research Governance Framework	Care Quality Commission patient and service user surveys
• Retain responsibility for the quality of all aspects of participants' care whether or not some aspects of care are part of a research study.	*The survey is carried out on the experiences of service users after they have received the care so this does not apply.*
• Be aware and maintain a record of all research undertaken through or within the organisation, including research undertaken by students as part of their training.	*All Chief Executives are informed of the proposals of the survey. Trusts should notify their Research and Development Managers of the survey.*
• Ensure patients or users and carers are provided with information on research that may affect their care.	*The survey does not affect the care of the service users. Anonymised results are used for performance rating and local quality improvement initiatives. Detailed guidance is issued to survey leads regarding the publicity of the results and its impact on care.*
• Be aware of current legislation relating to research and ensure that it is implemented effectively within the organisation.	*This requirement is not specific to this survey.*

• Ensure that all research involving participants for whom they are responsible has ethical approval and that someone with the authority to do so has given written permission on behalf of the care organisation before each study begins.	*The Care Quality Commission as sponsors of the study have sought ethics approval from MREC.* *There is a designated lead for each survey who is appointed by the Chief Executive.*
• Ensure that no research with human participants, their organs, tissue or data, begins until an identified sponsor, who understands and accepts the duties set out in this framework, has confirmed it accepts responsibility for that research.	*The 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.*
• Ensure that written agreements are in place regarding responsibilities for all research involving an external partner, funder and/or sponsor, including agreement with the University or other employer in relation to student supervision.	*A detailed guidance is issued to all the Trusts, which spells out the responsibilities of all parties involved in the survey.*
• Maintain the necessary links with clinical governance and/or best value processes.	*The guidance notes very strongly recommend the Trusts to maintain these links and follow best practice evidence.*
• Ensure that, whenever they are to interact with individuals in a way, which has a direct bearing on the quality of their care, non-NHS employed researchers hold honorary NHS contracts and there is clear accountability and understanding of responsibilities.[5]	*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.*

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[5] 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).

• Put and keep in place systems to identify and learn from errors and failures.	*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 the light of these.*
• Put and keep in place systems to process, address and learn lessons from complaints arising from any research work being undertaken through or within the organisation.	*This requirement is not specific to this survey.*
• Ensure that significant lessons learnt from complaints and from internal enquiries are communicated to funders, sponsors and other partners.	*The 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 NHS Patient Survey Coordination Centre who are commissioned by the Care Quality Commission to Coordinate the patient and service user surveys.*
• Ensure that any research-related adverse events are included in reports to the National Patient Safety Agency in line with the standard procedures of the organisation; or to the systems for adverse events reporting in social care.	*Not applicable to the service user survey. Patient safety is not compromised, this being a postal survey.*
• Permit and assist with any monitoring, auditing or inspection required by relevant authorities.	*The results of the surveys are used for monitoring of trusts performance by the Care Quality Commisssion*

4.   Publicising the Survey

You can heighten awareness of the survey and show the importance your Trust places on service user feedback through the following channels:

- posters in outpatients departments

- direct communications with service users before admission or at discharge

- community newsletters

- a press release in the local media

Service users might ask clinical staff, patient liaison officers, or the Chief Executive's office about the survey, even though your covering letters give contact details for the survey managers and the dedicated helpline. Notify front line staff and executive offices that a survey is being conducted, and give them the name and number of a contact person. Survey managers should be prepared to respond to these calls quickly.

Template staff briefings and information for use in press releases can be downloaded from the NHS Community Mental Health Service Users Survey link at www.nhspatientsurveys.org.uk

5. Compiling a sample of service users for the survey

This section explains how to draw the sample of service users. This task will need to be carried out by a member of staff at the NHS Trust.

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

5.1   Making sure your list of service users is reliable

The sample for this survey is selected from **all service users,** aged 16 and over, seen by the NHS Trust - ie, including those on the CPA and also those not on the CPA but still receiving specialist care or treatment for a mental health condition.

5.2   Compile a full list of current service users

- If you are in any doubt about these sampling instructions, please call the Coordination Centre on 01277 690218.

- Compile a full list of all service users who were seen between **1ˢᵗ July 2009 and 30ᵗʰ September 2009**. Make sure that you take out any duplicated names.

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

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

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

Call the Coordination Centre on 01277 690218.

If your trust has recently merged with another trust and you are unable to amalgamate your databases:

Call the Coordination Centre on 01277 690218 for further sampling advice

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

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

Who to leave out

The following service users should be removed from the list:

- Anyone seen **only once** for an assessment (For example, those who were seen by a psychiatrist for a single assessment.)

- Anyone primarily receiving drug & alcohol services

- Anyone primarily receiving Learning Disability services.

- Anyone attending specialist forensic services

- Any children who are **under 16** on the date the sample is drawn

- Any service users who are known to be **current inpatients**

- Service users who are known to have **died**

- Service users who **do not** have a **known UK address**

- Service users who did not have contact with Mental Health Services **during the sample period of 1st July 2009 and 30th September 2009**.

- Any **duplicated** names

- Any **alias names** where the person's real name is already included in the list.

5.3 Data fields to include in the list of service users

The following information should be kept in a file in Microsoft Excel or Access:

- **Service User Serial Number** - This is a series of sequential numbers (for example, 1001 through to 1850). They will be included on address labels and on questionnaires

- **Title** (Mr, Mrs, Ms, etc.)

- **Initials** (or First name)

- **Surname**

- **Address Fields** - The address should be held as separate fields (e.g. street, area, town, and county). This should be consistent with the address format required by the DBS.

- **Postcode**

- **Year** of birth

- **Gender** 1=male, 2=female

- **Ethnic category.**   Coded using the 17 item alphabetical coding specified by NHS Connecting for Health (e.g. A through to Z)

- **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. 2009)

- Any other details required by the Demographic Batch Service (DBS). Wherever possible, this should include the NHS number. The NHS number can give more accurate matching, especially if addresses are incomplete. It is advisable to liaise with the registered DBS batch trace user (if this is not the same person who creates the sample list) to ensure that all the required fields are included in the list of service users (see Section 5.8 for more details on using the DBS).

- Unit or team - Include this if you plan to compare units within your Trust.

5.4 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 5.2.

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 5.5 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*, y*ear 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 it 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**.

7. The data will then be sorted by the random number. Do not worry that the random numbers change when you sort them and they do not look as if they are sorted in any order[6]. 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.

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 Coordination Centre will only be able to accept responses from the 850 correctly sampled service users in your list.

5.5 Check the sample list

If the list comprises fewer than 900 services 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) and the Coordination Centre:

- **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 16 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

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

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 the service users are alive. (See section 5.7 for further details.) Also 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 **1st July 2009 and 30th September 2009**.

- **Distribution of service user ages.** Check that your sampled service users' ages cover the full range of expected ages (aged 16 and over). You can do this by plotting the service user ages on a histogram.

5.6   Ask your Chief Executive to sign off the sample

For survey results to be comparable across Trusts, the definitions used in the sampling process must be applied identically across Trusts. Therefore, Chief Executives are requested to sign off the sample before questionnaires are sent out. The purpose of this is 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 16 and over) who are registered on the CPA, **and those who are not registered**, who have been in contact with mental health services in the three month period 1st July 2009 to 30th September 2009.

A paper copy of the signed declaration should be sent to the Co-ordination Centre at the following address by 21st December 2009.

Mental Health Surveys Co-ordination Centre
National Centre for Social Research
Kings House
101-135 Kings Road
Brentwood

CM14 4LX

5.7   Additional checks on the sample

The list of service users has to undergo the following external checks after it has been signed off by your Chief Executive:

- Checks for any deceased service users by the DBS.
- Checks by the Coordination Centre.

Questionnaires cannot be sent out until both checks have been completed.

5.8   Submit the list to the Demographic Batch Service (DBS)

Before sending out the questionnaires, the list of service users will also have to be checked for any deceased service users by the 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 patient records electronically using dedicated client software. The patient records in the file are matched against the NHS Spine Personal Demographics Service.

Create a trace request file
Using your list of patients, you need to create a correctly-formatted batch trace request file to send to DBS. This file should be in the same format as that previously used by NSTS (this will include a header row, body and trailer row).

For each patient you will need to include as a minimum:
- NHS number and full date of birth (yyyymmdd) OR
- Surname, first name, gender and date of birth

Residential postcode is not essential but can be included but note that there must only be a single space in the middle of postcode. 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.

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 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 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 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.

The response file
The DBS will return a header row, response body and trailer row. The response 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, which is returned only when there is a single unique match. It is on this additional response that patients found to be deceased will be indicated.

Further information is available from www.cfh.nhs.uk/demographics/dbs.

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

When the patient file is returned from DBS
The trace response file returned from DBS can be used to identify any patients 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 patients just because it was not possible for DBS to match them on their records. If you did this, you would bias the sample.

5.9   Submit the file to the Coordination Centre for checking

It has been agreed that once the checked sample has been returned from DBS it

should be submitted to the Coordination Centre for final checking. First reduce the file to 850 service users by repeating the steps carried out before (section 5.4) 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*, y*ear 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 <u>I</u>nsert, then <u>C</u>olumns). 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 it 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 <u>D</u>ata, then <u>S</u>ort. At the bottom of the *Sort* dialogue box which appears on the screen, ensure that <My data has Header <u>r</u>ow> 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 Community Mental Health Survey Coordination Centre. The Mental Health Survey Coordination 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 Coordination Centre should be **without** service user names and addresses and should be submitted as a password protected file to CommunityUsersSurvey@natcen.ac.uk with the password being supplied separately either by email or telephone. **This should be by 7ᵗʰ January 2010**

The Coordination Centre will return the checked sample file to the Trust/Approved Contractor by 11ᵗʰ January 2010.

5.10 Check the Trust's records for service user deaths

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

Making the most of the fieldwork period

Because certain demographic groups (specifically younger people and those from non-white ethnic groups) have been shown to take longer to respond to surveys, we strongly recommend that files are submitted for sample checking by the date specified (18th December 2009). The best way to ensure you can do this is to prepare before the start date of the survey.

You can do this by:

1) Allocate 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) Discuss the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey

3) Ensure 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. This means that you should decide on your questions as early as possible so arrange the times for any meetings that will discuss the questionnaires as early as possible.

We strongly recommend that your first mailing takes place as soon as possible in the new year. This will maximise the possible fieldwork time and your trusts response rate. A large time lag increases the likelihood of patients 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.

5.11 Organise the service user information into the sample file

Once the file is returned from the Coordination Centre, you will need to keep the service user information in an electronic spreadsheet or database file, where you can record which questionnaires have been returned. At the end of the survey, you will send an anonymised version of this information to the Coordination Centre. (See Section 8.2 for details of how to do this.)

Firstly, you will need to add four new columns:

1. **Trust Code.** This field is to improve identification once the data files are returned to the Coordination Centre. See Appendix 3 Trust Names and Codes.

2. **Service User Serial Number.** This field will be a series of consecutive numbers (for example, 1001 through to 1850).

3. 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.

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

Table 1 shows part of an example Excel file comprising service user details. Only the fields headed *in red italics* should be included in the file sent to the Coordination Centre.

Table 1 – Sample Excel file of service user details

Trust Code	Service User Serial Number	Title	Initials	Surname	Address1	Address5	Postcode	Year of Birth	Gender	Ethnic Category	Day of last contact	Month of last contact	Year of last contact	Registered on CPA	Outcome	Comments
RTV	1001	Mrs	AM	Abbott		--	AB1 1YZ	1971	2	A	2	08	2009	1	3	Informed that service user died
RTV	1002	Mr	EC	Ahmed		--	AB2 6XZ	1958	1	A	14	09	2009	2	1	
	--					--										
RTV	1849	Ms	K	Yoo		--	AB4 7MX	1987	2	M	21	09	2009	2		
RTV	1850	Ms	F	Young		--	AB9 5ZX	1946	2	Z	30	07	2009	1	1	

Notes on Table 1

- **Trust Code.** This is an additional field to improve identification within the body of the data files. Appendix 3 lists all the codes valid for the survey. This code will remain constant throughout the file.

- **Service User Serial Number.** This number is unique for each service user. In the example, the numbers are in ascending order, starting at 1001 at the top of the list, through to 1850 at the bottom. The service user serial 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 serial numbers that will be used.

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

- **Year of birth** is included in the form NNNN. The service user list should only

include service users aged 16 and over.

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

- **Ethnic Category** coding has changed for the NHS Community Mental Health Service Users 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. 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

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, e.g. unconscious.

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

- **Registered on CPA** field should be coded 1 if the service user is registered on 'new' CPA, and 2 for all other service users.

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

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

  The outcome column is left blank at first if the survey has not been returned so, for example in Table 1, it can be seen that Ms Yoo has not yet returned her questionnaire.

  If the survey is being carried out in-house by the Trust, you can use the file containing the service user name and address details to record the outcome information – but you should not enter responses into this file.

5.12 Sharing the service user sample file with an Approved Contractor

If you are working with an Approved Survey Contractor, but have chosen to mail out the questionnaires yourself, within the trust, you should supply them with a version of the list shown in Table 1 (with names and addresses removed). If a contract is in place regarding transfer of patient-identifiable information, the Approved Contractor will require the full sample list by 4th January 2010. The contractor can use this list to record the outcome codes, and you should ensure that the contractor is kept up to date with any information that comes directly to the Trust about, for example, service user deaths, or requests to be excluded from the survey sample.

5.13 Using the sample file

This file has two purposes:

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

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

For confidentiality reasons, **do not keep name and address details in the same file as survey response data**. You will need to match up the *anonymised* service user information file with the data file once your survey is completed.

5.14 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 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. 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 units 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

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.

Please remember that the core sample for the 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 can 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.

Should you need advice on how to do this, please contact the Coordination Centre.

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6.   Weekly Progress

The Coordination 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 information must be made on 15th January 2010 even though you may not have started mailing, and every Friday thereafter until the final date of submission. An Excel spreadsheet is available on www.nhspatientsurveys.org.uk and this should be used to return this information to the Coordination Centre. This information should be emailed to CommunityUsersSurvey@natcen.ac.uk by 3.00 pm every Friday throughout the survey.

Weekly submissions only apply to the core sample of patients.

6.1 Response rate
The information submitted should contain the following :
- The total number of patients in your sample i.e. the total number of all those included in the first mailing,
- The number of patients in each outcome field (see Section 8.2)

This will allow the Coordination Centre to monitor progress at a Trust level and to identify Trusts that may need assistance.

6.2 Helpline monitoring
The information you submit should contain the following data for each Trust:

- The total number of calls received by the helpline for this survey
  The total number of calls that led to completion of the questionnaire using the helpline
- The total number of calls seeking assistance with language and translation
- The total number of calls that led to completion of the questionnaire using translation services

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

7. Implementing the survey - practicalities

7.1 Materials

Questionnaires

Each Trust must use the standard 8-page Mental Health Questionnaire. This is available on the new NHS Community Mental Health Service Users Survey link at:

www.nhspatientsurveys.org.uk

It is designed to fit onto eight sides of A4 paper and consists of questions which cover the issues which have been found (through qualitative work with service users) to be the most important to service users.

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, pages are likely to become detached and get lost.

Number of questionnaires

You 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. Depending on the response rate to the first mailing, you should need **approximately 1,500 copies**.

Trust headed paper

You need Trust headed paper for covering letters for the first and third mailing. (A reminder slip is used for the second mailing.) You need the same number of sheets of headed paper as questionnaires: i.e. approximately **1,500 sheets**.

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 switchboard.

Other items

You also need:

- Large **envelopes** for mailing questionnaires to service users (mailings 1 and 3)

- **Labels** for addressing envelopes

- **Labels for sender address** on reverse of envelopes

- **C5 FREEPOST envelopes** for return of questionnaires

- **DL envelopes** for mailing reminder slips to service users (mailing 2)

- **Multi-language sheets** to be included in all three mailings (see section 7.6).

7.2   Setting up a FREEPOST address

A FREEPOST address allows service users to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the C5 return 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: www.royalmail.com. Alternatively, you can call your local Sales Centre on 0845 7950 950.

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

When sending out questionnaires, you need to put a return address on the envelope so that undelivered mail can be returned without the need to open the envelope. If an Approved Contractor, their return address should be put on the envelope. If you are carrying out the survey in-house or using an Approved Contractor but are carrying out the mailings in-house, you should set up a PO Box, so that the return address does not give an indication that the addressee has been in contact with mental health services. At time of going to press, the cost of running a PO Box is £51 for six months, and a further £51 to redirect post from a PO Box to another address. You can find out more about these services by contacting Royal Mail on

Tel: 08457 740740.

7.4   Setting up a FREEPHONE line

The covering letter to service users should include a telephone number for service users to call if they have any questions or complaints about the survey.   All staff who are likely to take calls should be properly briefed about the details of the survey, and be aware of the questions or complaints they are likely to receive. If you run the survey in-house, you might want to set up a FREEPHONE line for this purpose. Alternatively, many Approved Contractors offer this service.

Common questions and comments

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

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

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

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

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

Even with the use of a deceased persons tracing service, it will not be possible to identify all deceased service users, particularly those who have died most recently. It is very important that staff who take the calls are aware of this possibility and are prepared to respond sensitively to such calls.

- *I would like to take part but English is not my first language.*

It is strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. Most approved survey contractors will offer this. A multi-language sheet template in the twenty most commonly spoken languages in England is available on the website, and Trusts or contractors can make use of this by inserting the appropriate number for their helpline and/or translation service.

Alternatively, if a service user's spoken English is better than their written English, they may be willing to have someone fill in a form on their behalf over the telephone.

- *I do not wish to participate in this survey.*

A few service users might call to say that they do not want to be involved in the survey, and fewer still may object to being sent the questionnaire in the first place. Staff should apologise to the service user and reiterate the statement in the covering letter - that the survey is voluntary, and that their care will not be affected in any way by their not participating. It might be helpful to point out the purpose of the survey, and to emphasise the potential value of their responses. It is also advisable to ask the service user to ignore any future reminders that they might receive, however every effort should be made to prevent the service user from receiving further mailings. The staff member should attempt to ascertain as much information about the service user as possible (name, address, Service User Serial number) so that the refusal can be logged to prevent further mailings. The Service User Serial number should be on the address label of the envelope received by the service user, and on the questionnaire itself.

7.5   Covering letters

The standard covering letter for the first mailing can be downloaded from the NHS Community Mental Health Service Users Survey link at:

www.nhspatientsurveys.org.uk

You can add your own Trust's details and print it on the Trust's letterhead paper. 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 switchboard. The text of the standard covering letter has been given ethical approval and alterations are not permitted. Please send two paper copies of the letter you use to the Coordination Centre when you submit your data. If using an Approved Contractor, supply them with Trust headed paper, signature of senior executive and (if appropriate) signed contract by 16th December 2009.

7.6   Multi-language sheet

It is good practice to offer access to a telephone interpretation service, where the service users who do not speak English can complete questionnaire over the telephone, ask questions about the survey and exclude themselves from the survey. This normally involves a three-way conversation between you (or your helpline operator), the service user and the interpreter. Most approved survey contractors will offer this service and some Trusts may already have arrangements with such a service.

A multi-language leaflet template is available for downloading on the web site, and this can be included with all mailings. Please note that this has been revised since the last survey. 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).

Trusts carrying out the survey in-house should make their own arrangements for gaining access to a telephone interpretation service. The Coordination Centre will provide no such service this year.

7.7   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. **The Service User Serial Numbers should be printed on the address labels,** as they have to be matched with the numbers on the front of the questionnaires. The label should not include any other information except the patients' name, address and postcode details, and the patient Serial number.

Note on the Service User Serial number (SUSN)

The patient serial number is a unique number allocated to all patients at the start of the survey that allows their responses to be kept separate from their names and address, but allows matching up of the response data with the sample data. It also allows respondents to identify themselves without the need to provide name or address information if they contact the Trust or contractor. The SURN should be placed centrally and large enough to be visible to all patients. The Royal National Institute of the Blind recommends the number be printed in size 14 font and located inside a box on the lower half of the front page of the questionnaire.

If patients remove this number from the cover page and then return the questionnaire, please add their response information in an additional row to the bottom of the data file before submitting it to the Coordination Centre. Do not attempt to match this data to a non-responder of similar demographics, but instead inform the Coordination centre about this respondent and they will be treated as an additional patient to the sample.

Questionnaire packs

The first mailing should be sent by 15th January 2010. The envelope sent to each service user at the first mailing should include the following:

1. A questionnaire marked with the Service User Serial Number. This must also match (or correspond to) the number on the address label and the number on your electronic list of service user details.

2. The standard covering letter.

3. A C5 return envelope, labelled with the FREEPOST address on it.

4. A multi-language sheet

These items should be packed into an envelope which has a return address on the outside. This should be the Approved Contractor's address or, otherwise, an address that does not identify Mental Health Services as the sender. (See Section 7.3 - *IMPORTANT: Setting up a PO Box for mail returned undelivered* for further details.)

Postage

The postage will be at **large letter rate.** It is essential that the appropriate postage rate is paid.

Approved Contractors – mailing carried out within the Trust

In this case, the Approved Contractor sends pre-packed questionnaires to the Trust for mailing out. The envelopes should be clearly marked with the Service User Serial Numbers so that Trust staff can match these with their service user list and put on appropriate service user address labels. The return address on the outside of the envelope for undelivered mail is the PO Box which the Trust has set up.

Approved Contractors – mailing carried out by approved contractor

In this case, the Approved Contractor sends out questionnaires directly to service users, and the return address on the outside of the envelope for undelivered mail is the Approved Contractor's address.

7.8   Booking in questionnaires

When questionnaires are received, match up the Serial 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 need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until 31st August 2010, but please **do not** send these to the Coordination 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 Serial Numbers. Trusts should forward to the contractor any questionnaires which are returned to them, whether or not they have been completed. The contractor should also be informed of any service user who dies or withdraws from the survey for any reason. The contractor will then record these details to ensure that reminders are not sent out to those service users.

7.9   Sending out reminders

It is essential to get a good response rate. The minimum response rate for this survey is 40%, but it is expected that many Trusts will achieve a higher response rate. **It is essential that you send out both reminders, even if you have already achieved the**

minimum response rate.

First reminders should be sent out by 29th January 2010 (two weeks after the first mailing). Second reminders should be sent out by 12th February 2010, after a further two weeks.

Before sending out reminders you should check your Trust's records to check that there is no record of the service user's death in your own Trust.

Approved Contractors

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

First reminders

The standard first reminder slip, which can be downloaded from the NHS Community Mental Health Service Users Survey link, should be sent to service users who have not responded after **two weeks**. Service users should also be sent a multi-language sheet.

You can add your own Trust's details. The standard reminder slip has been given ethical approval and alterations are not permitted. Please send two paper copies of the reminder slip you use to the Coordination Centre when you submit your data.

Second reminders

The standard covering letter for the second reminder can be downloaded from the NHS Community Mental Health Service Users Survey link. It should be sent to service users who have not responded after **a further two weeks**.

You can add your Trust's details and print it on Trust headed paper. Remember, if you are using an Approved Contractor, in order to minimise calls to the Trust it is not advisable to use Trust headed paper which includes a Trust telephone number. The text of the reminder covering letter has been given ethical approval and alterations are not permitted. Please send two paper copies of the letter you use to the Coordination Centre when you submit your data.

The second reminder envelopes should include the following:

1. A questionnaire marked with the Service User Serial Number. This must also match (or correspond to) the number on the address label and the number on your electronic list of service user details.

2. A covering letter.

3. A C5 return envelope, labelled with the FREEPOST address on it.

4. A multi-language sheet.

This should be mailed using the large letter rate.

8. Entering and coding questionnaire data

The data should be entered into the pre-designed Excel file, which can be found on the NHS Community Mental Health Service Users Survey link.

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 worksheet. Data should be entered thus:

- Each row records one service user's responses to the survey

- For each question, the small number next to the box ticked by the service user should be entered as the response.

- If a response is missing in a returned useable questionnaire, it should be left blank, or coded as a full stop (.).[7]If two boxes are ticked (where only one should be ticked), the response should be left blank or coded as a full stop (.).

- When saving this file to submit data to the Coordination Centre, please save only the first sheet as a **worksheet**, rather than saving the whole file as a workbook. (This saves disk space.)

Multiple-response question (Q53)

For most questions, each column corresponds to one survey question. However, there is one exception to this rule. For multiple response question Q53 that gives the instruction "Tick all that apply", each response option is treated as a separate question.

For each response option for Q53, please enter a 1 if that option has been ticked and a 0 if it has not been ticked. However, please leave all of the response options blank if none have been ticked.

8.1 Checking for errors

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[7] If you want to use this data input file on the website to display frequencies on the other pages of the workbook, you will need to fill in the blank cells (on rows where service users have returned questionnaires) with a full stop (.).

For the NHS Community Mental Health Service Users Service Users survey, trusts and contractors are required to submit raw ('uncleaned') data to the Coordination 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 (eg where patients answer questions that they have been directed to skip past, these responses should still be entered).
2. Where a respondent has ticked more than one response category on a question, this should be set to missing in the data.
3. Where a respondent has crossed out a response, this should not be entered in the data. Where a respondent has crossed out a response and instead ticked a second response option, this second choice should be entered into the data
4. Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a patient has written their date of birth in the boxes for Q50, 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 '2009' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side.
6. Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the patient's intended response has not been captured. This includes 'out-of-range' responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Coordination 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 Coordination Centre so that trusts and approved contractors can duplicate this process after submitting the raw data to the Coordination Centre.

8.2 Submitting data to the Coordination Centre

The data must be submitted to the Coordination Centre in the appropriate format by the deadline of **26th April 2010**. If an Approved Survey Contractor is used, they will be responsible for all of the data entry and checking and, when the survey is completed, they should submit the data to the Coordination Centre in the correct format and supply the Trust with an anonymised data set. Where an Approved Contractor is working on behalf of more than one Trust, the **data for all Trusts** should be submitted in **one file** with each row of data being clearly flagged with a Trust identifier.

File format

- Microsoft Excel Worksheet (not Workbook). Any version of Excel is acceptable.

- File name must be in the format <NHSTrustName>_MentalHealth2010.xls

- One row of data for each service user in the sample

- One column of data for each item of service user information or response.

- Missing data should be left blank or coded as a full stop (.). [8]

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

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

Table 2 - Data fields to include in file submitted to Coordination Centre

Field	Format	Codes & formats	Comments
Trust Code	NNN	See Appendix 3 Trust Names and Codes	NACS administrative code for trust
Service User Serial Number	NNNN		The unique serial number allocated to each service user by the Trust or Approved Survey Contractor
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	**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	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, e.g. unconscious

Registered on CPA	N	1= the service user is registered on 'new' CPA 2 = for all other service users.	
Day of last contact or last review	N or NN	Format as a **number**, not a date	For example, if the service user last had contact on 20th September 2009, this column should read 20.
Month of last contact or last review	N or NN	Format as a **number**, not a date	For example, if the service user last had contact on 20th September 2009, this column should read 9.
Year of last contact or last review	NNNN	Format as a **number**, not a date	For example, if the service user last had contact on 20th September 2009, this column should read 2009.
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 Q53, the multiple response question where this 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.

N.B. To comply with the Data Protection Act, details that allow individuals to be identified must **not** be sent to the Coordination Centre.

Table 3 shows the data that should be included in the file you submit. It should have 850 rows (one for each service user included in your sample). There will be several blank cells in the response section of the file because the file includes a row for every service user in the sample, but you will not have responses from all of them.

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

Service user sample information   Service user response information

Trust Code	Service User Serial Number	Year of birth	Gender	Ethnic Category	Day of last contact	Month of last contact	Year of last contact	Registered on CPA	Outcome	Q1	Q2	..	Q53_7	Q54	Q55
RTV	1001	1971	2	A	2	08	2009	1	3						
RTV	1002	1958	1	A	14	09	2009	1	1	3	1		1	3	11
RTV	1003	1964	2	B	3	07	2009	2	6						
RTV	1004	1980	2	E	3	09	2009	2	1	2	1		0	4	1
RTV	1005	1951	2	A	3	09	2009	2	1	3	2		0	4	1
RTV	1006	1979	1	G	14	07	2009	2	6						
RTV	1849	1987	2	A	21	07	2009	1	6						
RTV	1850	1946	2	K	30	08	2009	2	1	3	1		1	4	1

You are not required to send the service users' written comments to the Coordination Centre, but these should be supplied to Trusts by Approved Contractors. Please note that the guidelines on data protection set out in Section 2 should be followed.

Additional information

The following information should also be submitted at the same time as the data file:

- **Contact details** (telephone numbers and e-mail addresses) of at least two personnel who will be available to answer any queries about the data.

- Two blank **paper copies** each of the questionnaires you used, the covering letters and the reminder letters.

- A completed copy of the **checklist** on the following page.

Delivery

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

Postal address:

Mental Health Surveys Coordination Centre
National Centre for Social Research
Kings House
101-135 Kings Road
Brentwood
CM14 4LX
E-mail: CommunityUsersSurvey@natcen.ac.uk

Date

The data must be submitted by **5 pm on 26th April 2010**.

8.3   Checklist

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

Check	Please initial
1. Your **file name** should follow the naming convention: **<NHSTrustName>_MentalHealth2010.xls>**	
2. Save the data sheet only as an Excel **worksheet** (rather than a workbook).	
3. All **data are correct**.	
4. All **values are in range**.	
5. Send data **only for the 850 service users** sampled according to the sampling procedures defined in Section 8.	
6. Check that you have included data for **all questions**.	
7. Check that all the data are in **numeric format only except Trust Code and Ethnic Category**.	
8. To comply with Data Protection regulations, any service user name and address details must be removed before the file is sent to the Coordination Centre.	
9. **Remove any passwords** from the data file	
10. Include **two paper copies of the questionnaire** you used.	
11. Include **two paper copies of all 3 letters** you used for the first mailing, the second mailing and the third mailing.	
12. **Check again** that all data are correct, and that all values are in range! **SEE NOTE BELOW.**	

| 13. Include **the names of two staff members** who can answer questions about the data (at least one must be a member of Trust staff who was involved in the sampling). The other may be another member of staff from the Trust, or from the Approved Contractor.

Name 1:_____ Tel:_____

Name 2:_____ Tel:_____ | |

Note

It is **essential** that these checks are carried out thoroughly. The Coordination Centre is not obliged to make corrections to data supplied by Trusts or Approved Contractors. If incorrect data are submitted, it is likely that the data will be considered unreliable and will not be used by the Care Quality Commission in your Trust's performance ratings and those indicators will be set to a minimum. We cannot accept re-submissions of data after the deadline.

9.   Additional information

9.1 Involvement of non-English speaking populations

The patients who respond to your survey should be representative of all registered service users, so it is important that groups with limited understanding of English are not excluded. The NHS Mental Health Service Users Questionnaire has been written in as simple language as possible to facilitate optimum understanding by all respondents. The questions have also been tested with service users from a range of ethnic groups.

Multi-language FREEPHONE service

It is strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. Most approved survey contractors will offer this. A multi-language sheet template in the twenty most commonly spoken languages in England is available on the website, and Trusts or contractors can make use of this by inserting the appropriate number for their helpline and/or translation service. Non-English-speaking patients can call these numbers to ask questions about the survey or fill in the questionnaire over the phone with an interpreter.

Translation of questionnaires

For this survey, translated questionnaires are not being used. We do not recommend translation of questionnaires as an effective way of obtaining feedback from minority language groups in postal surveys such as these. Translation is not recommended for a number of reasons. For example:

- Grammatical differences and semantic variation can alter the meaning of the text. Although there are recommended models of good practice for translation, these do not extend to self-completion questionnaires. To make robust comparisons we would need to ensure that the idioms, etc. are understood – i.e. through rigorous cognitive testing of different groups. The costs of doing this would be considerable.

- The Care Quality Commission's experience, and that of others working in patient survey research, is that the uptake of translated questionnaires is very low (typically less than 1%).

- There is no evidence that translating questionnaires significantly increases response rates from ethnic minority groups.

Other ways of increasing responses from non-English speaking groups

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

- Many households include at least one competent English speaker, who can help the patient to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from non-English-speakers, although it is not ideal, as there is no control over the way in which a patient's family or friends translate questions or interpret their responses.

- It is often helpful to liaise with the local ethnic community organisations. These organisations may be able to help the respondents if the respondents are members of that group.

- Publicising the survey through BME communities may helps to raise the profile of the survey and encourage participation.

9.2   Copyright 2010 NHS Mental Health Service Users Survey questionnaire

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Applications for reproduction of the questionnaire should be made in writing to:
The Surveys Team, Care Quality Commission
Finsbury Tower, 103-105 Bunhill Row London EC1Y 8TG
e-mail: patient.survey@carequalitycommission.org.uk

9.3   Data archive
The Care Quality Commission intends to archive the anonymised survey data with the Essex Data Archive after the analysis is completed.

9.4   Embargo on results
Trust-level findings for the national survey of community mental health service users 2010 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.

Appendix 1: Declarations of data protection compliance

Declaration of compliance with the Data Protection Act 1998

DECLARATION RELATING TO THE

**[Name of survey e.g. NHS Community Mental Health Service Users Survey 2010]
FOR TRUSTS USING IN-HOUSE SURVEY TEAMS**

While carrying out the **[insert survey name]**, all Trusts need to comply with:

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

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

For further information on the new guidelines, please see the "Data protection" section in the Guidance Manual for the **[insert survey name]**.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert Trust name]** declare the aforementioned Trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection" in the Guidance Manual for the **[insert survey name here]**.

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

I, **[insert name of first survey lead]** the first Survey Lead for **[insert Trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the **[insert survey name here]** and will ensure that data collected while carrying

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

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

I, [insert name of second survey lead] the second Survey Lead for [insert Trust name] declare I understand the requirements of the Data Protection Act 1998 as they relate to the [insert survey name here] and will ensure that data collected while carrying out the NHS patient survey programme will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the [insert survey name here].

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

Appendix 2: Declarations for additional data analysts
Declaration of compliance with the Data Protection Act 1998

DECLARATION
RELATING TO THE
[Name of survey e.g. NHS Community Mental Health Service Users Survey 2010]

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

For further information on the new guidelines, please see the "Data protection" section in the Guidance Manual for the [insert survey name].

I, [insert name of Caldicott Guardian] the Caldicott Guardian for [insert Trust name] declare the aforementioned Trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the NHS patient survey programme will conform to the guidelines set out under the section "Data protection" in the Guidance Manual for the [insert survey name here].

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

I, [first additional data analyst] the first additional data analyst for [insert Trust name] declare I understand the requirements of the Data Protection Act 1998 as they relate to the [insert survey name here] and will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the [insert survey name here].

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

I, [**second additional data analyst**] the second additional data analyst for [**insert Trust name**] declare I understand the requirements of the Data Protection Act 1998 as they relate to the [**insert survey name here**] and will conform to these requirements and the guidelines set out under the section "Data protection" in the Guidance Manual for the [**insert survey name here**].

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

Appendix 3: Trust Names and Codes.

Trust Name	Trust Code
2gether NHS Foundation Trust	RTQ
5 Boroughs Partnership NHS Trust	RTV
Avon and Wiltshire Mental Health Partnership NHS Trust	RVN
Barnet, Enfield and Haringey Mental Health NHS Trust	RRP
Barnsley PCT	5JE
Bedfordshire and Luton Mental Health and Social Care NHS Trust	RV7
Berkshire Healthcare NHS Foundation Trust	RWX
Birmingham and Solihull Mental Health NHS Trust	RXT
Bradford District Care Trust	TAD
Cambridgeshire and Peterborough Mental Health Partnership NHS Trust	RT1
Camden and Islington Mental Health and Social Care Trust	TAF
Central and North West London NHS Foundation Trust	RV3
Cheshire and Wirral Partnership NHS Foundation Trust	RXA
Cornwall Partnership NHS Trust	RJ8
Coventry and Warwickshire Partnership NHS Trust	RYG
Cumbria Partnership NHS Trust	RNN
Derbyshire Mental Health Services NHS Trust	RXM
Devon Partnership NHS Trust	RWV
Dorset Healthcare NHS Foundation Trust	RDY
Dorset PCT	5QM
Dudley and Walsall Mental Health Partnership NHS Trust	RYK
East London NHS Foundation Trust	RWK
Greater Manchester NHS Foundation Trust	RXV
Hampshire Partnership NHS Trust	RW1
Herefordshire PCT	5CN
Hertfordshire Partnership NHS Foundation Trust	RWR
Humber Mental Health Teaching NHS Trust	RV9
Isle Of Wight NHS PCT	5QT
Kent and Medway NHS and Social Care Partnership Trust	RXY
Lancashire Care NHS Trust	RW5
Leeds Partnership NHS Foundation Trust	RGD
Leicestershire Partnership NHS Trust	RT5
Lincolnshire Partnership NHS Trust	RP7
Manchester Mental Health and Social Care Trust	TAE
Mersey Care NHS Trust	RW4
Milton Keynes PCT	5CQ

Norfolk and Waveney Mental Health Partnership NHS Trust	RMY
North East Lincolnshire Care Trust Plus	TAN
North East London Mental Health NHS Trust	RAT
North Essex Partnership NHS Foundation Trust	RRD
North Staffordshire Combined Healthcare NHS Trust	RLY
North Yorkshire and York PCT	5NV
Northamptonshire Healthcare NHS Trust	RP1
Northumberland, Tyne and Wear NHS Trust	RX4
Nottinghamshire Healthcare NHS Trust	RHA
Oxfordshire and Buckinghamshire Mental Health Partnership NHS Trust	RNU
Oxleas NHS Foundation Trust	RPG
Pennine Care NHS Trust	RT2
Plymouth Teaching PCT	5F1
Portsmouth City Teaching PCT	5FE
Rotherham Doncaster and South Humber Mental Health NHS Foundation Trust	RXE
Sandwell Mental Health NHS and Social Care Trust	TAJ
Sheffield Care Trust	TAH
Somerset Partnership NHS and Social Care Trust	RH5
South Essex Partnership University NHS Foundation Trust	RWN
South London and Maudsley NHS Foundation Trust	RV5
South Staffordshire and Shropshire Healthcare NHS Foundation Trust	RRE
South West London and St George's Mental Health NHS Trust	RQY
South West Yorkshire Mental Health NHS Trust	RXG
Suffolk Mental Health Partnership NHS Trust	RT6
Surrey and Borders Partnership NHS Trust	RXX
Sussex Partnership NHS Foundation Trust	RX2
Tavistock and Portman NHS Foundation Trust	RNK
Tees, Esk and Wear Valleys NHS Trust	RX3
West London Mental Health NHS Trust	RKL
Wolverhampton City PCT	5MV
Worcestershire Mental Health Partnership NHS Trust	RWQ