

# SAMPLING HANDBOOK FOR THE NHS COMMUNITY MENTAL HEALTH SERVICE USERS SURVEY 2014

THE CO-ORDINATION CENTRE FOR THE  
NHS PATIENT SURVEY PROGRAMME

## Contacts

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

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

## Key personnel

Chris Graham (Director)

Esther Ainley  
Hannah Atherton  
Kelsey Flott  
Caroline Killpack  
Jenny King  
Katherine Körner  
Nick Potheary  
Stephen Sizmur  
Mark Waters

## Adherence to the procedures outlined in this document

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

## Updates

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

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

---

## Contents

---

1	About this handbook.....	1
2	Compiling a list of service users .....	2
2.1	Who is being surveyed? .....	2
2.2	Compile a full list of current service users .....	2
2.3	Complete 'Section A' of the Chief Executive Declaration Form .....	5
2.4	Instructions for taking a sample of service users.....	5
2.5	Check the sample list .....	6
3	Submit the service user list to the Demographics Batch Service (DBS).....	8
3.1	Create a trace request file .....	8
3.2	Submitting the trace request file .....	8
3.3	The response file .....	9
3.4	When the service user file is returned from DBS.....	9
3.5	Complete 'Section B' of the Chief Executive Declaration Form .....	11
3.6	Create the sample file.....	11
3.7	Specific instructions for Mental Health Care Cluster.....	17
3.8	Separating mailing details from sample information .....	18
3.9	Sharing the service user sample file with an approved contractor.....	20
3.10	Making more use of the survey locally.....	21
4	Final sampling inspection by the Co-ordination Centre .....	23

---

# 1 About this handbook

This handbook is produced by the Co-ordination Centre for the Patient Survey Programme, on behalf of the Care Quality Commission.

This handbook is comprised of excerpts from the *Guidance Manual for the NHS Community Mental Health Service Users survey 2014* and is intended to assist in the sampling for the survey. This abridged handbook is aimed at those carrying out the sampling for, but not directly coordinating or managing, the mental health survey at each trust. Those who are co-ordinating the survey for the trust are strongly recommended to read the full guidance manual, with special attention to Section 3 entitled “What’s new for 2014?”

## Important

Please can you ensure that all sample lists are submitted to the Co-ordination Centre between **10th February** and **7th March 2014**. We recommend that sample lists are submitted as early as possible to allow for any queries which may arise.

An anonymised sample file should be submitted to the Co-ordination Centre prior to the first mailing. If you are using a contractor, your sample should be submitted to the contractor first and they will forward it to the Co-ordination Centre.

Please ensure that your sample list contains **no service user name or address information**. The sample list submitted to the Co-ordination Centre must be encrypted.

If you are an in-house trust, please send your patient list to [MentalHealth.data@pickereurope.ac.uk](mailto:MentalHealth.data@pickereurope.ac.uk)

If your Trust is using a contractor, please submit your sample list to your contractor who will then forward it to the Co-ordination Centre.

## 2 Compiling a list of service users

This section explains how to draw the sample of service users. This task will need to be carried out by a member of staff at the NHS Trust. Prior to sending out questionnaires, the list will also have to be checked by the Demographics Batch Service<sup>1</sup> (DBS) to identify deceased service users. Please follow the instructions below carefully and allocate sufficient work time to check the sample with DBS before the first mailing and within the trust prior to each mailing.

**N.B. It is essential that the person who draws the sample understands the importance of following these instructions carefully. Also, this 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.**

### 2.1 Who is being surveyed?

The sample for this survey is selected from all service users, aged 18 and over, seen by the NHS Trust - i.e., including those on the CPA and also those not on the CPA but receiving specialist care or treatment for a mental health condition. Details on the sampling period and who should be included and excluded are set out in *Section 2.2* below.

**Please note that your sample of service users should only be used for the purposes of distributing the MH14 survey and up to two reminder letters. This is because the precise use of the sample collated for the survey is described in the survey protocol that forms part of the ethical approval for the survey, and any additional use of the sample would therefore require a separate ethics application. For example, it would not be appropriate to send additional reminder letters to people in the sample, nor to contact them as a group either before or after the survey.**

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

- Compile a full list of all service users who were seen between **1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013**. Make sure that you take out any duplicated names.
- Include **all** teams within your trust providing specialist mental health services to service users eligible to receive this survey
- If your Trust does not already have all service users on one electronic list, you will need to **combine all the separate lists** so that you have one complete list and then select as outlined below. If some service users' details are not held electronically, it will be necessary to **type in their details**, so that all service users' details are held electronically.

---

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

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

Call the Co-ordination Centre on 01865 208127.

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

Call the Co-ordination Centre on 01865 208127

## Who to include:

Anyone (whether or not they were on the CPA) who used the Trust's community based treatment and care services **during the sample period of 1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013**, including the following:

- Outpatients services
- Day therapies services
- Adult services
- Services for older people
- Crisis teams
- Complex needs services
- Assertive outreach teams
- Early intervention and short-term intervention teams
- Recovery teams
- Home Treatment Teams
- Rehabilitation support teams
- Memory clinics
- Child and Adolescent Mental Health Services (CAMHS) service users who are **18 years of age or over** on the date the sample is drawn

Please note that service users who were seen during the sample period of 1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013 and meet these criteria should be included even if they have subsequently been discharged from these services.

## Who to leave out:

The following service users should be removed from the list:

- Anyone seen **only once ever** for an assessment (for example, those who were seen by a duty worker or a psychiatrist for a single assessment). Please note if the service user was seen once during the sampling period but also seen outside the sampling period, they **should be included** in the sample.
- Anyone seen for assessment only through a liaison service, even if they were seen more than once<sup>2</sup>
- Anyone primarily receiving drug & alcohol services
- Anyone primarily receiving Learning Disability services

<sup>2</sup> Some trusts operate liaison services for assessing the mental health needs of inpatients receiving care for physical health issues. As details of these services may vary from trust to trust, please contact the Co-ordination Centre if you are unsure whether some of your service users fall into this category.

- Anyone receiving specialist forensic services
- Anyone receiving psychological treatments from Improving Access to Psychological Therapies (IAPT) services
- Anyone primarily receiving Chronic Fatigue/ME services
- Anyone primarily receiving Psychosexual Medicine (sexual dysfunction) services
- Anyone receiving Gender Identity services
- Any service users who are **under 18 years of age** on the date the sample is drawn
- Any service users who are known to be **current inpatients** at the time of drawing the sample
- Service users who are known to have **died**
- Service users who **do not** have a **known UK address**<sup>3</sup>
- Service users who did not have contact with Mental Health Services **during the sample period of 1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013**
- Any **duplicated** names: Check that the same service user has not been included more than once
- Any **alias names** where the person's real name is already included in the list
- Any service user known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those service users from your sample list at this stage).

## Data fields to include in the list of attendances

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

You will need to keep the list in an electronic file in a programme such as Microsoft Excel or Access. The list should contain the following information (more detail can be found in *Section 3.6*):

- Service user Record Number
- Title (Mr, Mrs, Ms, etc.)
- First name
- Surname
- Address Fields
- Postcode
- Year of birth
- Gender
- Ethnic category
- Day of last contact<sup>4</sup>

<sup>3</sup> 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.

<sup>4</sup> This field indicates the last contact made overall and should include contact made after the end of the sampling period.

- Month of last contact
- Year of last contact
- CPA status<sup>5</sup>
- Mental Health Care Cluster (**Please note:** this must be drawn at the same time as the rest of the sample, but must not be submitted to your approved contractor or the Coordination Centre until further notice – see *Section 3.7 - Specific instructions for Mental Health Care Cluster* for more detail.)
- GP practice code

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

For survey results to be comparable across Trusts, the definitions used in the sampling process must be applied identically across Trusts. Therefore, once you have your **full list of all service users** who were seen between 1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013 and meet the specified eligibility criteria (i.e. the inclusion and exclusion criteria), please complete **section A** of the Chief Executive Declaration Form.

This form is in Appendix 6 of the full guidance and is also available to download from the NHS Surveys website at <http://www.nhssurveys.org/survey/1355>

## 2.4 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 2.2*) and completed section A of the Chief Executive Declaration Form (as described in *Section 2.3*)

Although the aim is to send questionnaires to 850 service users, you will 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 2.2* for details) and some may have died. We have estimated that around 50 users will need to be removed from the initial list, so you need to take a **simple random sample of 900** service users from your full list. This means that each eligible service user in the full list (the population) has an equal chance of being included in the sample. The procedure for doing this is as follows:

1. Put the list of service users into a Microsoft Excel file. The first row of this file should be headings (such as *name, year of birth*, etc). There should be one row for each service user below that.
2. Put the cursor in cell A1 and insert a blank column (Click Insert, then Columns). Give this column a heading: **Random**.
3. In cell A2, type =Rand()  
When you press Enter, a random number between 0 and 1 will be generated in that cell.
4. Copy the formula from Cell A2 to all the other cells in that column, so that each service user has a random number. To copy the formula, hover the cursor over the bottom right-hand corner of cell A2 so that the cursor becomes a black cross +, press and hold down the left mouse button and drag down column A.

---

<sup>5</sup> Please use current CPA status. For service users who have been discharged, please indicate CPA status at date of discharge, if known. Please do not exclude people with CPA status unknown.



5. You are now ready to sort the list of service users. Before you do this, it is essential that you **select all columns in your list, including the header row**. The simplest way of ensuring this is to click on the blank square above and to the left of Cell A1 or hold the Ctrl key and press 'A'. This selects all cells in the worksheet. If you do not select all cells in your list, you could mix up service users' details, or you could fail to sort some of the service users in the list.
6. Once you have highlighted all the cells, click Data, then Sort. At the bottom of the *Sort* dialogue box which appears on the screen, ensure that <My data has Header row> is selected. At the top of that dialogue box, use the drop-down box under "Sort by" to select **Random** and click **OK**.

The data will then be sorted by the random number. Do not worry that the random numbers change when you sort them and they do not look as if they are sorted in any order<sup>6</sup>. You can now select the top 900 service users in the file, that is, rows 1 to 901 as these will be a random selection of your service users. Note that to do this, you should **delete rows below 901** in your file. This will leave a file containing a header row plus 900 **rows of service user data**.

## 2.5 Check the sample list

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

- **Remove duplications.** Check your list to make sure service users' names do not appear more than once, and remove any duplicated names. Where possible, link any alias names so that only one name per service user appears in the list.
- **Postal addresses.** Check again that there are no addresses that are outside the UK.
- **Ages.** Check again that all service users are aged 18 and over.
- **Incomplete information on key name and address fields.** Check for any records with incomplete information on key fields (surname and address) and try to find more complete information. If key name and address fields cannot be verified, remove those individuals from the sample. In removing cases at this stage, please bear in mind that the more cases that are removed at this stage, the poorer the sample coverage and the greater the danger of bias. As a result, remove a service user only if there is insufficient name or address information for the questionnaire to have a reasonable chance of being delivered. **Do not exclude anyone simply because you do not have a postcode for them, or because you could not get a matched trace with DBS.**
- **Current inpatients.** Check again that none of the service users are known to be current inpatients in your Trust or elsewhere if possible.
- **Deceased service users.** Check that your Trust does not have a record of a service user's death.
- **Service user in sample period.** Check that all service users were seen in the sample period of **1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013**.
- **Distribution of service user ages.** Check that your sampled service users' ages cover the full range of expected ages (**aged 18 and over**). You can do this by plotting the service user ages on a histogram.
- Any service user known to have requested their details are not used for any purpose other than

---

<sup>6</sup> The random numbers change each time any cell in the worksheet is changed

their clinical care (if this is collected by your trust you should ensure that you remove those service users from your sample list at this stage).

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

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

The DBS has replaced the NHS Strategic Tracing Service (NSTS) batch trace. The DBS enables users to submit and receive a file containing relevant service user records electronically using dedicated client software. The service user records in the file are matched against the NHS Spine Personal Demographics Service (PDS).<sup>7</sup>

### 3.1 Create a trace request file

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

<http://www.connectingforhealth.nhs.uk/industry/docs/db5>

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

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

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

### 3.2 Submitting the trace request file

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

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

---

<sup>7</sup> The PDS is a national electronic database of NHS service user demographic details. The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

### 3.3 The response file

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

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

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

#### Note

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

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

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

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

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

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

You need to take a **simple random sample** of 850 service users from your DBS checked list. The procedure for doing this is as follows:

1. Put the list of service users into a Microsoft Excel file. The first row of this file should be headings (such as *name*, *year of birth*, etc). There should be one row for each service user below that.
2. Put the cursor in cell A1 and insert a blank column (Click Insert, then Columns). Give this column a heading: **Random**.
3. In cell A2, type =Rand()

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

4. Copy the formula from Cell A2 to all the other cells in that column, so that each service user has a random number. To copy the formula, hover the cursor over the bottom right-hand corner of cell A2 so that the cursor becomes a black cross +, press and hold down the left mouse button and drag down column A.
5. You are now ready to sort the list of service users. Before you do this, it is essential that you **select all columns in your list, including the header row**. The simplest way of ensuring this is to click on the blank square above and to the left of Cell A1 or hold the Ctrl key and press 'a'. This selects all cells in the worksheet. If you do not select all cells in your list, you could mix up service users' details, or you could fail to sort some of the service users in the list.
6. When all cells are highlighted, click Data, then Sort. At the bottom of the *Sort* dialogue box which appears on the screen, ensure that <My data has Header row> is selected. At the top of that dialogue box, use the drop-down box under "Sort by" to select **Random** and click **OK**.

The data will then be sorted by the random number. Do not worry that the random numbers change when you sort them and they do not look as if they are sorted in any order. You can now select the top 850 service users in the file, that is, rows 1 to 851 as these will be a random selection of your service users. Note that to do this, you should **delete rows below 851** in your file. This will leave a file containing a header row plus 850 rows of service user data.

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

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

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

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

### Important note

You are aiming for a response rate of at least 40%, which means that you should have at least 340 completed questionnaires. You will maximise your response rate by following this guidance carefully. It is **not** acceptable to try to boost the number of responses you receive by sending out questionnaires to a larger number of service users. The Co-ordination Centre will only be able to accept responses from the 850 correctly sampled service users in your list.

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

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

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

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

The Chief Executive is asked to:

- Confirm that the sampling has been undertaken according to the guidance for the survey;
- Verify that the sample includes service users aged 18 and over, seen by the NHS Trust in the three month sampling period 1<sup>st</sup> September 2013 and 30<sup>th</sup> November 2013 - ie, including those on the CPA and also those not on the CPA but receiving specialist care or treatment for a mental health condition

As mentioned in section 10.3, this form is in Appendix 6 of the full guidance and is also available to download from the NHS Surveys website.

Please return the completed form to the Co-ordination Centre when you submit your sample for checking<sup>8</sup>:

Mental Health 2014  
Patient Survey Co-ordination Centre  
Picker Institute Europe  
Buxton Court  
3 West Way  
Oxford OX2 0JB

### 3.6 Create the sample file

An example of the spreadsheet you should complete has been included below. This can be downloaded from our site and is entitled "*Sample construction spreadsheet*". The column headings will match to the validated spreadsheet produced by the Co-ordination Centre for final submission of data and so it will be advantageous for you to use this spreadsheet. Save this file as <NHStrustname>\_MH2014

This file has three purposes:

- 1) It will be used to keep a record of which service users have not returned questionnaires so that reminders can be sent to them.
- 2) It will be used to generate weekly response rates for your trust that must be forwarded to the Co-ordination Centre every Thursday from **6<sup>th</sup> March 2014** until the closing date of the survey.

---

<sup>8</sup> If you are using a survey contractor, then please send your form to the Co-ordination Centre at the same time as you submit your sample to your contractor for checking. Please note: the Co-ordination Centre can not check your sample until this form has been received.

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

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

<b>Service User Record Number</b>	<b>Title</b>	<b>Initials</b>	<b>Surname</b>	<b>Address1</b>	<b>Address5</b>	<b>Postcode</b>	<b>Year of Birth</b>	<b>Gender</b>	<b>Ethnic Category</b>	<b>Day of last contact</b>	<b>Month of last contact</b>	<b>Year of last contact</b>	<b>CPA Status</b>	<b>GP Practice Code</b>	<b>Day of questionnaire being received</b>	<b>Month of questionnaire being received</b>	<b>Year of questionnaire being received</b>	<b>Outcome</b>
MH14RNA0001	Mr s	A M	Abbott			AB11YZ	1971	2	A	2	09	2013	1	A81029				3
MH14RNA0002	Mr	E C	Ahmed			AB26XZ	1958	1	A	14	02	2014	3	B23567	22	3	2014	1
--																		
MH14RNA0849	Ms	K	Yoo			AB47MX	1987	2	M	21	10	2013	2	D39402				
MH14RNA0850	Ms	F	Young			AB95ZX	1946	2	Z	30	09	2013	1	E89032	6	4	2014	1

### Important note about table 1

The headings of Table 1 are in three different colours:

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

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

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

The following information is compiled using trust records:

- Title (Mr, Mrs, Ms, etc.)
- Initials (or First name)
- Surname



- Address Fields <sup>9</sup>
- Postcode

## Note

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

- The **Year of Birth** should be included in the form of NNNN.
- **Gender** should be coded as 1 = male and 2 = female.
- **Ethnic Category**<sup>10</sup> coding is the same as for last year's service user's survey. The ethnicity of a person is specified by that person, and should be coded using the 17 item alphabetical coding specified by NHS Connecting for Health<sup>11</sup>. The codes are as follow:

### National Codes:

#### White

- |   |                            |
|---|----------------------------|
| A | British                    |
| B | Irish                      |
| C | Any other White background |

#### Mixed

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

#### Asian or Asian British

- |   |                            |
|---|----------------------------|
| H | Indian                     |
| J | Pakistani                  |
| K | Bangladeshi                |
| L | Any other Asian background |

#### Black or Black British

- |   |           |
|---|-----------|
| M | Caribbean |
| N | African   |

<sup>9</sup> The address should be held as separate fields (e.g. street, area, town, and county), consistent with the address format required by the DBS.

<sup>10</sup> It is acknowledged that service user records might not always contain complete data on service users' ethnic category. However, this field should be included wherever possible. This data is required in order to evaluate non-response from different ethnic categories. This is in keeping with the aims of the Care Quality Commission and Department of Health to be more responsive to all ethnic groups and to ensure all groups are appropriately represented in their assessments.

<sup>11</sup> These codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:

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

P Any other Black background

**Other Ethnic Groups**

R Chinese

S Any other ethnic group

Z Not stated<sup>12</sup>

- **Trust Code.** This is an additional field to improve identification within the body of the data files. Appendix 5 lists all the codes valid for the survey. This code will remain constant throughout the file.
- **Unit or team** - Include this if you plan to compare units within your Trust. (This would not be submitted to the Co-ordination Centre)
- **Day of the month of last contact** (1 or 2 digits; e.g. 2 or 30) - Date fields must be supplied in separate columns. This field indicates the last contact made overall and should include contact made after the end of the sampling period.
- **Month of last contact** (1 or 2 digits; e.g. 9 or 10)
- **Year of last contact** (4 digits; e.g. 2013 or 2014)
- **CPA status** - should be coded 1 = service user is registered on 'new' CPA,  
2 = service user is NOT registered on new CPA  
3 = service user CPA status unknown

Trusts need to ensure that they include up to date CPA information for all service users as this information is used in the analysis of some questions. Ensuring this information is present will be part of the sample checking process undertaken by the Co-ordination Centre, as described in section 12. Please use current CPA status. For service users who have been discharged, please indicate CPA status at date of discharge, if known.

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

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

1) **Service user record number.** This number is unique for each service user. It should have the format MH14XXXNNNN, where XXX is the three letter trust/organisation code<sup>13</sup> and NNNN is the four digit unique number, ranging from 0001 to 0850.

In the example up, the numbers are in ascending order, starting at MH14RNA0001 at the top of the list, through to MH14RNA0850 at the bottom. The service user record number will be included on address labels and questionnaires. Later, when questionnaires are returned (whether completed or not), you (or the Approved Contractor) will use these numbers to monitor which service users have returned their questionnaires and to identify non-responders, who will need to be sent reminders. If an Approved Contractor is used, you need to agree with them the range of service

---

<sup>12</sup> The code "Z" should only be used if the service user was asked for their ethnic category but refused to provide it. If this code is missing for any other reason, ethnic category should be left blank in the sample information.

<sup>13</sup> See <http://www.connectingforhealth.nhs.uk/systemsandservices/data/ods/nhs-trusts>

user record numbers that will be used.

2) **Day of questionnaire being received.** This can only be completed if and when a questionnaire is received by the trust or approved contractor. It should be a one or two digit numerical response e.g. 1 or 15, **not** a date format e.g. 15/04/14.

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

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

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

1 = Returned useable questionnaire

2 = Returned undelivered by the mail service or service user moved house

3 = Service user died

4 = Service user reported too ill to complete questionnaire, opted out or returned blank questionnaire

5 = Service user was not eligible to fill in questionnaire

6 = Questionnaire not returned (reason not known).

The outcome column is left blank at first if the survey has not been returned (on table 1 you can see that Ms Yoo has not yet returned her questionnaire).

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

## 3.7 Specific instructions for Mental Health Care Cluster

### In brief

This year, we would like you to collect service users' mental health care clusters (also known as PbR currencies) when you draw your samples, but **this information is not to be submitted with the samples.**

If we later gain approval for you to share this data with us and your contractors, we will inform you through a separate e-bulletin. Until then, it must be stored within your trust.

### Background

The Care Quality Commission is currently seeking approval from the Health Research Authority Confidentiality Advisory Group under Section 251 of the NHS Act 2006 to include service users' care clusters in the data provided by trusts about their samples of service users.

Without this approval, care cluster data **must not** be included in the data provided to your contractors or the Coordination Centre.

However, you will need to collect this information when you draw your sample so that it can be submitted at a later date if approval is granted.

### Collecting Mental Health Care Cluster

Service users should have been assigned care clusters (also known as PbR currencies) using the current PbR (Payment by Results) guidance.<sup>14</sup> A service user's cluster may change following reassessment; please submit the most recent recorded care cluster. If a service user has been discharged from care, please submit the most recent care cluster before discharge.

In order to ensure a consistent methodology, this information must be drawn from your system at the same time as the sample itself is drawn.

Care clusters should be coded as follows:

0 Variance

1 Common mental health problems (low severity)

2 Common mental health problems

3 Non-psychotic (moderate severity)

4 Non-psychotic (severe)

5 Non-psychotic (very severe)

6 Non-psychotic disorders of overvalued ideas

7 Enduring non-psychotic disorders (high disability)

8 Non-psychotic chaotic and challenging disorders

10 First episode in psychosis

<sup>14</sup> <https://www.gov.uk/government/publications/mental-health-payment-by-results-arrangements-for-2013-14>

- 11 Ongoing recurrent psychosis (low symptoms)
- 12 Ongoing or recurrent psychosis (high disability)
- 13 Ongoing or recurrent psychosis (high symptom and disability)
- 14 Psychotic crisis
- 15 Severe psychotic depression
- 16 Dual diagnosis (substance abuse and mental illness)
- 17 Psychosis and affective disorder difficult to engage
  
- 18 Cognitive impairment (low need)
- 19 Cognitive impairment or dementia (moderate need)
- 20 Cognitive impairment or dementia (high need)
- 21 Cognitive impairment or dementia (high physical or engagement needs)
  
- 99 No cluster assigned

Before submitting your sample files to your approved contractor or the Coordination Centre, please ensure that you have removed the Mental Health Care Cluster variable. You should create a separate excel file which contains the Service User Record Number and the Mental Health Care Cluster only.

This can be done by copying and then pasting the Service User Record Number and the Mental Health Care Cluster into a separate spreadsheet. Please be very careful to do this accurately. You can then delete the Mental Health Care Cluster from your sample file. Please save this file using the name MH14\_CareCluster\_XXX, where XXX is your three character trust code (eg RW1).

The excel file containing the Service User Record Number and the Mental Health Care Cluster must be stored securely and in a separate location from the name and address file (see Section 6.5 of the full guidance for more details).

**It is very important that the Mental Health Care Cluster is not shared outside your trust unless you are notified by the Co-ordination Centre that this is can be done.**

### **Storing and submitting the data**

Please store this separately within your own system and **do not send** to your contractor or the Coordination Centre until further notice.

If approval is granted, we will require the cluster data to be sent in a separate excel spreadsheet containing Service User Record Number, Care Cluster Code and no other information -- in particular, it must not simply be appended to the existing sample data.

Please don't hesitate to contact the Coordination Centre at [mentalhealth.data@pickereurope.ac.uk](mailto:mentalhealth.data@pickereurope.ac.uk) if you have any queries.

## **3.8 Separating mailing details from sample information**

At this point you should transfer the names, address and postcode for each service user in the sample to a new file. The service user record number (SURN) for each service user should be copied to the new file, so that the two datasets are connected using the unique SURN. It is essential to ensure this number is correctly applied to the two datasets. Save this new file as "MH service users 2014\_mailing data".

This file should be used for mailing purposes: it will be used to check for deceased service users prior to reminder mailings and will be cross-referenced with the sample file (<NHStrustname>\_MH service users2014) to identify service users who will need to be sent reminders.<sup>15</sup>

As this “MH service users2014\_mailing data” file will only be used occasionally during the survey, we recommend you keep this file encrypted. The mailing data file should be destroyed when the survey is complete. This should be done by both the trust and the approved contractor, along with all other files created for the survey (aside from the survey response file).

For service user confidentiality reasons, **it is essential that you do not keep service user name and address details in the same file as their survey response data.**

---

<sup>15</sup> As shown in table 1 (*Section 3.6*), the ‘outcome’ field in the sample file is used to record which questionnaires are returned completed, or are returned undelivered, or which service users opt out etc...

Table 2 – Example mailing file

<i>Service user Record number</i>	Title	Initials	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
MH14RNA0001	Mrs	AM	Abbot	14 Station Road	London				AB1 1YZ
MH14RNA0002	Mr	EC	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
					--				
MH14RNA0849	Ms	K	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Camb	AB4 7MX
MH14RNA0850	Ms	F	Young	634 Tyne Road	Newcastle-Upon-Tyne	Tyne and Wear			AB9 5ZX

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

If you are working with an approved contractor and have a contract in place relating to the transfer of service user identifiable information (i.e. names and addresses) both the sample file (“<NHStrustname>\_MHservice users2014”) **and** the mailing file (“MHservice users2014\_mailing data”) file should be sent to the contractor staff in encrypted format (see *Section 6 - Encryption of personal data*).

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

### 3.10 Making more use of the survey locally

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

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

- The core sample for the 2014 Community Mental Health Service Users survey **must** be drawn as specified in this guide; any deviation from the guidance may make it impossible for the Care Quality Commission to use the data that you collect. It is therefore essential that **any additional sample drawn must be easily distinguished from the core sample, and that it is drawn in such a way as to not interfere with selection of the core sample.**
- Please note that the section 251 approval **pending** for the 2014 community mental health survey only covers the transfer of service users' information required for carrying out the Core survey. If you wish to collect any additional sample information you will need to seek advice from the Confidentiality Advisory Group as to whether further approval is needed. For further information please see: <http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/>
- If you are planning to undertake surveys more frequently than the national programme, then you should consider how any increased sample here will fit with the additional surveys you will be undertaking, and if you have a sufficient number of service users to sample. Guidance for carrying out local surveys is available on our website at: [www.nhssurveys.org/localsurveys](http://www.nhssurveys.org/localsurveys)

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

- Analyse or compare results for specific subgroups (for example, service users treated at different sites or service users of different ethnicities) in more detail than would be possible from a sample of 850 service users. By increasing the sample size you can ensure that you have a large enough sample of service users from each group<sup>16</sup>.
- Alternatively, if your trust regularly treats very large numbers of service users, you may wish to draw an extra sample of service users to survey additionally to those included in the main survey. For example, you could select service users seen at the trust in a different time period from those in the national survey and send them questionnaires either at the same time as or at some point after the national survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out a service user survey locally at the same time as the national survey you will need to ensure that you are **sampling two distinct and separate**

---

<sup>16</sup> See section 18 for more information on the reliability of data based on different numbers of respondents.



**groups of service users which do not overlap.** You must also ensure that the sample for the national survey is drawn as specified.

Guidance for carrying out a local survey of mental health inpatient services (carried out as part of the national patient survey programme in 2009) is available at <http://www.nhssurveys.org/localsurveys> so that organisations that wish to do so can begin to plan for future local surveys. To avoid duplication with the national 2014 Community Mental Health survey, the local Community Mental Health survey tool and materials have temporarily been removed from the website but will be made available towards the end of the fieldwork for the national survey.

### To summarise

If you do choose to increase your sample size, it is **essential** that you ensure that the sample of service users you draw according to the requirements for the national survey can be easily distinguished from any additional service users you include in the sample. Your approved survey contractor or the Co-ordination Centre will be able to advise you on this.

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

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

Trust data should still be checked for errors and received back from DBS before being forwarded to the Co-ordination Centre. An anonymised sample file<sup>17</sup> **must** be submitted to the Co-ordination Centre **prior** to the first mailing. This is to allow us to make final quality control checks. All columns *in red italics* in *Table 1 – Sample construction spreadsheet of service user details* must be submitted, but name, address and postcode details must be removed. **Trusts should encrypt their sample files before sending to the Co-ordination Centre for checking**<sup>18</sup>.

The Chief Executive Declaration form must also be sent to the Co-ordination Centre before your sample is **mailed out** (as described in *Section 3.5 - Complete 'Section B' of the Chief Executive Declaration Form*).

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

The Co-ordination Centre will be checking for extraordinary errors. These are more visible when viewing data from many trusts at one time. For this reason, samples will be checked as collated files. Emails discussing any sample anomalies will be returned to the trust or approved contractor which provided them within three working days of submission.<sup>19</sup>

Samples should be submitted **to the Co-ordination Centre** by the **7<sup>th</sup> March 2014**. If they are not, there is a risk your trust will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may then result in the data from the trust being excluded from the relevant Care Quality Commission assessments.

- **If you are conducting the survey through an approved contractor:** Please submit your sample to them; they will then submit it to us. The final deadline for the sample to be submitted to us is **7<sup>th</sup> March 2014**. If your contractor wishes to carry out additional checks before submitting the samples to us, **you may need to send your sample to them before this deadline**.

Trusts which have not submitted their sample for checking by the **14<sup>th</sup> March 2014** will be contacted by the Co-ordination Centre to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **21<sup>st</sup> March 2014**, then we are required to notify the Care Quality Commission of this and they will contact you to discuss any implications for inclusion in Care Quality Commission produced data.

Your first mailing should take place as soon as possible after your sample has been approved by the Co-ordination Centre but **must not be later than seven days** after this. A large time lag increases the likelihood of service users having died between the sample file being received back

---

<sup>17</sup> Created by removing the service users' names, addresses and postcodes.

<sup>18</sup> See *Section 6.6 – Encryption of personal data* for further information

<sup>19</sup> For example, if a sample is submitted on a Thursday, queries will be returned on or by the following Tuesday.

from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to your trust.

## Making the most of the fieldwork period

Because certain demographic groups (specifically younger service users and those from non-white ethnic categories) have been shown to take longer to respond to service user surveys, we strongly recommend that files are submitted within the three weeks specified for sample checking. The best way to ensure you can do this is to prepare before the start date of the survey (3<sup>rd</sup> March 2014). You can do this by:

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