

# SAMPLING HANDBOOK FOR THE COMMUNITY MENTAL HEALTH SURVEY 2016

FOR TRUSTS USING AN APPROVED CONTRACTOR

THE CO-ORDINATION CENTRE FOR THE NHS PATIENT SURVEY PROGRAMME



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#### Adherence to the procedures outlined in this document

It is not permissible to deviate from the agreed protocol as set out in the instruction manual <u>http://www.nhssurveys.org/surveys/891</u>. Section 251 approval has been granted for this project to provide a legal basis for trusts using a contractor to provide names and addresses to them. Any breach of the conditions of the support will be reported to the CQC and the Confidentiality Advisory Group at the Health Research Authority.

It is also not permissible to offer financial inducements or lottery prizes to respondents. Similarly, we do not recommend translation of questionnaires into other languages within the national survey. 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 the instruction manual, 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 on the Co-ordination Centre website www.nhssurveys.org

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# 1 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.

Please note: It is essential that the persons who draw and check the sample understand the importance of following these instructions carefully. Also, these persons line managers 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, both of which can have serious implications.

If an error in a sample is discovered at the close of fieldwork, data for the trust may not be suitable for inclusion in the survey publication, and, as discussed in section three in this manual, may incur penalties in the CQC's intelligence model.

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

# 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 1.2* below.

Please note that your sample of service users should only be used for the purposes of distributing the Mental Health Survey 2016 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.

# 1.1 Complete 'Section A' of the Sample Declaration form

Before you begin drawing your list of eligible service users, please complete Section A of your sample declaration form giving details of the service user population aged 18+ at your trust prior to removing any who have indicated dissent (at box 'A' of the form) and then the number of people who have indicated dissent (at 'B' on the form).

This form is in the Appendix of this handbook and is also available to download from the NHS Surveys website at <a href="http://www.nhsurveys.org/surveys/893">http://www.nhsurveys.org/surveys/893</a>

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

# 1.2 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 and 30<sup>th</sup>
   November 2015. 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;

#### If you do not have an adequate list of service users...

OR

#### ... 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 and 30**<sup>th</sup> **November 2015**, 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;
- Service users with dementia;
- 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 and 30<sup>th</sup> November 2015 and meet these criteria **must** 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 (1<sup>st</sup> September to 30<sup>th</sup> November 2015) but also seen outside the sampling period, they should be included in the sample. It is possible that:
  - The service user's other attendance(s) fell prior to 1<sup>st</sup> September 2015;
  - All the service user's attendances were within the sampling period;
  - The service user's other attendance(s) fell after 30<sup>th</sup> November 2015.
- Anyone seen for assessment only through a liaison service, even if they were seen more than once<sup>1</sup>;
- Anyone primarily receiving drug & alcohol services;
- Anyone primarily receiving Learning Disability services;
- Anyone primarily receiving specialist forensic services;
- Anyone primarily 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 primarily 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;
  - Note: any service user who is <u>not a current inpatient</u> but has previously been an inpatient at the trust should be included
- Service users who are known to have **died**;
- Service users who do not have a known UK address<sup>2</sup>;
- Service users who did not have contact with Mental Health Services during the sample period of 1<sup>st</sup> September and 30<sup>th</sup> November 2015;
- Service users who have <u>only</u> been in contact via telephone or email, and have not been seen in person at all;
- 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

<sup>&</sup>lt;sup>1</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.

<sup>&</sup>lt;sup>2</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.

than their clinical care. These should have been removed prior to drawing up your list of eligible service users – please see Section 1.1 – *Complete Section A of your Sample Declaration form*?

### 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 2.6 – Create the sample file*):

- 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>1</sup>;
- Month of last contact;
- Year of last contact;
- CPA status<sup>2</sup>;
- CCG Code;
- 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- see Section 2.7 Specific instructions for Mental Health Care Cluster for more detail.)

<sup>&</sup>lt;sup>1</sup> This field indicates the last contact made overall and should include contact made after the end of the sampling period up until the date the sample was drawn (and not extending beyond this date). Date of last contact should include actual attendances only; scheduled appointments that were not attended should not be included.

<sup>&</sup>lt;sup>2</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.

Please note: the sample must be drawn in accordance with the procedures outlined in this instruction manual, and all inclusion and exclusion criteria followed correctly. Do not include or exclude any service users based on any other criteria, for example, manually removing service users from your sample who you feel should not complete the survey.

If you have any queries, please phone the Co-ordination Centre on: 01865 208 127 or email <u>mh.cc@pickereurope.ac.uk</u> for advice.

# 1.3 Complete 'Section B' of the Sample 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 and 30<sup>th</sup> November 2015 and meet the specified eligibility criteria (i.e. the inclusion and exclusion criteria), please complete **Section B** of the Sample Declaration form. Please note, at box 'C' of Section B, the figure you enter here should be your number of eligible service users after you have removed those who have indicated dissent.

This form is in the Appendix of this manual and is also available to download from the NHS Surveys website at <a href="http://www.nhssurveys.org/surveys/893">http://www.nhssurveys.org/surveys/893</a>

# 1.4 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 1.2*) and completed **Sections A and B** of the **Sample Declaration** Form (as described in *Sections 1.1 and 1.3*).

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 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 *Service User Record Number, 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 <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;

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

# 1.5 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 (see 'Who to leave out' at Section 1.2). 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 on the date the sample is drawn.
- 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 and 30<sup>th</sup> November 2015.
- **Distribution of service user ages.** Check that your sampled service users' ages cover the full range of expected ages (aged 18 and over).
- Any service user known to have requested their details are not used for any purpose other than their clinical care.
- Before submitting your sample files to DBS for checking, ensure that you have removed the information relating to Mental Health Care Cluster.

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

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

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

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

# 2.1 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://systems.hscic.gov.uk/demographics

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.

# 2.2 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: <u>demographics@nhs.net</u> 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>&</sup>lt;sup>1</sup> The PDS is a national electronic database of NHS service user demographic details. The PDS does not hold any clinical or sensitive data such as ethnicity or religion.

# 2.3 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 see: http://systems.hscic.gov.uk/demographics

#### 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.

# 2.4 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 *Service User Record Number, 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 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 Patient Survey Co-ordination Centre. The Patient Survey Co-ordination Centre will address any issues arising from these final checks to the Approved Contractor.

Your approved contractor will submit your sample file to the Co-ordination Centre.

#### 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 <u>mh.cc@pickereurope.ac.uk</u>.

#### Important note

You are aiming for as high a response rate as possible. 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.

# 2.5 Complete 'Sections C & D' of the Sampling Declaration Form

Once you have finalised your sample of 850 service users, please complete 'Sections C and D' of the Sample Declaration Form to show the numbers by CPA status and your definitions of CPA at Section C. At Section D, please be aware that new to the survey this year, we require the sample to be drawn and checked by different people within the trust – both will need to sign the declaration form. Please then ask your Caldicott Guardian to sign off the sample.

Caldicott Guardians are requested to sign off the sample before questionnaires are sent out to ensure that the sample has been drawn correctly and to confirm that they are assured that no service user identifiable data is being sent outside of the trust.

The Caldicott Guardian 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 2015 and 30<sup>th</sup> November 2015 - ie, including those on the CPA and also those not on the CPA but receiving specialist care or treatment for a mental health condition;
- Confirm that deceased checks have been run on the sample file, and that they are content with the level of checks undertaken (Please note that as custodians of the data, if insufficient checks are taken to remove deceased service users from the sample frame, this is a risk that the trust takes);
- Confirm that you have separated the sample file from the mailing file (see Section 2.8);
- Confirm that you have removed mental health care cluster data from the sample file and will send this separately to the Co-ordination Centre (see *Section 2.7*).

You must email your sample declaration form to your approved contractor for approval **before** you submit your separate anonymised sample file and mailing file to them. Your approved contractor will need to confirm that they have checked your sampling declaration form and are ready to receive your files, before you send them on.

# 2.6 Create the sample file

An example of the spreadsheet you should complete has been included below. This can be downloaded from the NHS Surveys website and is entitled '*Sample construction spreadsheet*' <u>http://www.nhssurveys.org/surveys/892.</u>

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

Trust Code	Trust code	Service User Record Number	Title	First name	Surname	Address1	Address5	Postcode	Year of Birth	Gender	Ethnic Category	Day of last contact	Month of last contact	Year of last contact	CPA Status	CCG Code	Care Cluster	Day of questionnaire being received	Month of questionnaire being received	Year of questionnaire being received	Outcome
RT V	RYG	MH16RN A0001	M r s	AM	A bb ott			AB1 1YZ	1971	2	A	2	09	20 15	1	04 J	20				3
RT V	RYG	MH16RN A0002	M r	EC	A h m ed			AB2 6XZ	1958	1	A	14	02	20 15	3	04 J	2	22	3	2015	1
	RYG																				
RT V	RYG	MH16RN A0849	M s	K	Y 00			AB4 7MX	1987	2	М	21	10	20 15	2	04 M	99				
RT V	RYG	MH16RN A0898	M s	F	Y ou ng			AB9 5ZX	1946	2	Z	30	09	20 15	1	04 J	5	6	4	2015	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 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 your approved contractor for inspection, before they then forward this to the Co-ordination Centre for approval

*Purple italic* heading: this is the data relating to service users' care cluster codes. It should only be present in your own Sample Construction Spreadsheet, and the Care Cluster file. **Do not copy across to your mailing data file or your sample file.** 

*Green italic* headings: these columns will be completed by your approved contractor during fieldwork

Follow the additional instructions in the Sample Construction Spreadsheet.

The following information is compiled using trust records:

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

- Address Fields<sup>1</sup>;
- Postcode;
- 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>2</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>3</sup>. The codes are as follow:

#### National Codes:

#### White

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

#### Mixed

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

#### Asian or Asian British

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

#### Black or Black British

- M Caribbean
- N African
- P Any other Black background

#### Other Ethnic Groups

- R Chinese
- S Any other ethnic group
- Z Not stated<sup>1</sup>

http://www.datadictionary.nhs.uk/data\_dictionary/attributes/e/end/ethnic\_category\_code\_de.asp?shownav

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

<sup>&</sup>lt;sup>2</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>&</sup>lt;sup>3</sup> These codes can be found in the NHS Data Dictionary provided by Connecting for Health on the following website:

- **Trust Code** this is an additional field to improve identification within the body of the data files. 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. 2015 or 2016);
- 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.

- CCG code please provide the 3 character CCG code. This should be the CCG which will be billed for the care of the person using service. Please see: <u>http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs</u>
- Care Cluster Code You will see there is a column for the service user's Care Cluster code. The care cluster information will be gathered when you draw the sample, but only so you can align the Trust Code and Service User record Numbers with the care cluster codes. The Care Cluster Code will need to be removed and submitted in a separate 'Care Cluster file'. Do not submit care cluster information as part of your mailing data or sample data files. See Section 2.7 – Specific instructions for mental health care cluster and Section 2.8 – Separating mailing details from sample information below for more detail.

Additional information should also be entered on this 'Sample Construction 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 **MH16XXXNNNN**, where XXX is the three letter trust/organisation code and NNNN is the four digit unique number.

In the example above, the numbers are in ascending order, starting at MH16RNA0002 at the top of the list, through to MH16RNA0898 at the bottom – note that the unique four digit identifier will be any number from 0001 to 0900 as assigned pre-DBS checks. The service user record number will be included on address labels and questionnaires. Later, when questionnaires are returned (whether completed or not), you 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;

<sup>&</sup>lt;sup>1</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.

2) **Day of questionnaire being received**. This can only be completed if and when a questionnaire is received by your approved contractor. They will use a one or two digit numerical response e.g. 1 or 15, **not** a date format e.g. 15/04/16;

3) **Month of questionnaire being received**. This can only be completed if and when a questionnaire is received by your approved contractor. They will use 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 your approved contractor. They will use a four digit numerical response, **not** a date format;

- 5) The **Outcome** field will be used by your contractor 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 (after fieldwork had started)

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)
- 7 = Service user deceased prior to fieldwork

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.

# 2.7 Specific instructions for Mental Health Care Cluster

#### In brief

As per last 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 within the sample file.** 

We have obtained approval for you to submit this information to the Co-ordination Centre but it must be sent in a separate file to your sample information. You **must not send this information to your approved contractor**, as we do not have section 251 approval for this.

#### Background

The Care Quality Commission has sought 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.

You will need to collect this information when you draw your sample so that it can be submitted to the Co-ordination Centre once your sample has been approved.

#### **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>1</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, which is as specified in the NHS Data Dictionary: <a href="http://www.datadictionary.nhs.uk/data\_dictionary/nhs\_business\_definitions/m/mental\_health\_care\_cluster\_de.asp?shownav=1">http://www.datadictionary.nhs.uk/data\_dictionary/nhs\_business\_definitions/m/mental\_health\_care\_cluster\_de.asp?shownav=1</a>

Please submit codes in the below format (for example, use '1' not '01'). Please ensure that the data you submit is as complete as possible and that you follow up any records that are missing this code. Any trusts with large amounts of missing data will be contacted by the Co-ordination Centre to confirm this is correct and clarify the reasons. If no cluster is assigned please code this as 99.

Contact the Co-ordination Centre if you have any queries: mh.cc@pickereurope.ac.uk:

#### 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
- 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

<sup>&</sup>lt;sup>1</sup> <u>https://www.gov.uk/government/publications/mental-health-payment-by-results-arrangements-for-2013-14</u>

Before submitting your sample files to your approved contractor please ensure that you have removed the Mental Health Care Cluster variable. You should use the template provided on the NHS Surveys website that contains the Trust Code, Service User Record Number and the Mental Health Care Cluster <u>only</u>. This Care Cluster spreadsheet can be found here: http://www.nhssurveys.org/surveys/879

This can be done by copying and then pasting the Trust Code, Service User Record Number and the Mental Health Care Cluster into the template file. Please be very careful to do this accurately. Please then delete the Care Cluster Code from your Sample Construction Spreadsheet. Please save this file using the name **MH16\_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 2.8 – Separating mailing details from sample information).

It is very important that the Mental Health Care Cluster is <u>not shared</u> outside your trust until the Co-ordination Centre has notified you that they are ready to receive the care cluster data file. The Co-ordination Centre will contact you directly about providing them with the care cluster information: you will also be given specific instructions on how to do this.

#### Storing and submitting the data

Please store this separately within your own system and **do not send to your approved contractor**. You will need to send the care cluster data to the Co-ordination Centre in a separate file containing only the Service User Record Number (the unique identifier given to each service user) and the care cluster they are assigned to.

To do this, the main IT contact at your trust will be contacted by a member of the Co-ordination Centre with personalised logon details for the FTP secure server. This information will be needed for them to deposit the data for a member of the Co-ordination Centre to pick up.

This information will be provided once your sample has been approved so please ensure that you've told the Co-ordination Centre who this IT contact will be and provide contact details for the links to be set up. The Co-ordination Centre will contact your trust directly to receive the data: you must not provide this information to your contractor.

Please don't hesitate to contact the Co-ordination Centre at <u>mh.cc@pickereurope.ac.uk</u> if you have any queries.

# 2.8 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 "**MH16\_mailingdata\_XXX**" (where XXX is your NHS Trust code, eg: R1F).

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 **(MH16\_samplefile\_XXX)** to identify service users who will need to be sent reminders.<sup>1</sup>

As this "**MH16\_mailingdata\_XXX**" 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 mailing 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).

Please note: there should be three separate files- anonymised sample file, the mailing file containing mailing information (name and address details), and the care cluster file containing Trust Code, Service User Record Number and the Care Cluster data.

Service user Record number	Title	Name	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
MH16RNA0002	Mrs	Anna	Abbot	14 Station Road	London				AB1 1YZ
MH16RNA0003	Mr	Eric	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
MH16RNA0849	Ms	Kate	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4 7MX
MH16RNA0898	Ms	Fiona	Young	634 Tyne Road	Newcastle-Upon- Tyne	Tyne and Wear			AB9 5ZX

 Table 2 – Example mailing file

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

If you have a contract in place relating to the transfer of service user identifiable information (i.e. names and addresses) both the sample file ("**MH16\_samplefile\_XXX**") **and** the mailing file ("**MH16\_mailingdata\_XXX**") should be sent to the contractor staff in encrypted format (see *Section 4.4 – Services users' names and addresses* in the main instruction manual for details <u>http://www.nhssurveys.org/surveys/891</u>).

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 4.4 – Services users' names and addresses* in the main instruction manual).The contractor can use this list to record the outcome codes, but you should ensure that the contractor

<sup>&</sup>lt;sup>1</sup> As shown in table 1 (*Section 2.6*), 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...

is kept up to date with any information that comes directly to the trust about service user deaths, etc.

# 2.10 Sample checking

Once you have submitted your sample declaration form to your contractor, and they are happy to receive your separate sample and mailing files, the contractor will undertake their own internal checks on the data. You may well get some queries from your contractor so please respond to these quickly as they cannot submit the sample file to us in the Co-ordination Centre until they have resolved those queries with you.

The Co-ordination Centre will then check the sample file, sent to us by your contractor, and we will respond to them with any queries. They may come back to you for clarification, and please respond quickly to those queries so the sample can be approved and mailing can begin.

Contractors will set deadlines for when they will need your sample file by, however, the Coordination Centre will be checking these files between 18<sup>th</sup> January and 12<sup>th</sup> February 2016 so we must have received your file from your contractor within this time frame.

Trusts which have not submitted their sample for checking by the **19<sup>th</sup> February 2016** will be contacted by the Co-ordination Centre directly to discuss any problems you are having and how we can help with the process. However, if samples are not received by the **26<sup>th</sup> February 2016** 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.

# Appendix: Sample Declaration Form

### **Community Mental Health Survey 2016: Sample Declaration**

This declaration is to be signed by your trust's Caldicott Guardian, and the members of staff responsible for drawing and checking the sample of service users as set out in the instruction manual for the survey.

# This checklist will be used for audit purposes to ensure that the sample conforms to the instruction manual and if all steps are completed, will greatly help avoid any breaches of confidentiality occurring.

The national survey has received 'Section 251 approval' from the Health Research Authority to enable data to be transferred to survey contractors for the purposes of this survey only. In order to be operating under that approval, you must follow the steps outlined below, otherwise the 'approval' will not apply. For more information on the approval requirements and confidentiality, please refer to the survey instruction manual <u>http://www.nhssurveys.org/surveys/891</u>

#### For staff drawing the sample:

Please complete this form once you have drawn your sample. You must send this checklist to your approved contractor **before** you send your sample file. Your contractor will confirm that you are able to send your sample file to them once they have checked this form. **PLEASE NOTE: the sample file will not be opened unless this form is submitted fully complete.** 

#### Additional variables and additional records:

Additional sample variables, and / or additional sample records, other than those required for the national survey, are not covered by the section 251 approval.

If you have decided to share additional sample variables or additional sample records with your approved contractor, you must liaise with your Caldicott Guardian before you provide this information. For more information please see section 4.3 of the survey instruction manual.

If you do share this information with your approved contractor, your contractor will remove this information from the anonymised sample file before submitting it to the Co-ordination Centre.

#### **Approved contractors:**

Please note that there is a box for you to initial confirming that you have removed additional sample variables and / or additional records from the anonymised sample file before submission to the Co-ordination Centre.

# **Community Mental Health Survey 2016**

# Sample Declaration Form – Trusts using an approved contractor

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

#### SECTION A: Service users at this Trust who have indicated dissent

- (A) Total service user population before dissenters removed
- (B) Total number of service users removed due to dissent

#### **SECTION B:** Service users at this Trust who meet the eligibility criteria

- (C) Total number of eligible service users at the Trust who used services between 1<sup>st</sup> September and 30<sup>th</sup> November 2015, and meet all other eligibility criteria\*
- (D) Number of service users on new CPA
- (E) Number of service users not on new CPA
- (F) Number of service users where CPA status not known

#### **SECTION C**: sample of service users included in 2016 survey

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

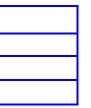
#### **CPA** definitions

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

(K)	On new CPA:	
(J)	Not on new CPA:	

#### **SECTION D:** Submission of sample to your contractor

Please complete this form once you have drawn your sample but **before** you have submitted your sample to your approved contractor. Please send this form to them, they will then check and approve your form before you are able to send your anonymised sample file.



<sup>\*</sup> Note that (C) should be equal to the sum of (D), (E) and (F)

<sup>\*</sup> For almost all Trusts, this figure will be 850 and (G) should be equal to the sum of (H), (I) and (J)

Please confirm that the following tasks have been completed on behalf of your NHS trust by initialling the boxes and signing the declaration:

The sample has been checked by the Demographic Batch Service (DBS)	
A random sample of 850 service users has been drawn exactly in line with the step by step process in the instruction manual, and all exclusion and inclusion criteria applied correctly	
The sample has been drawn and then checked by a different member of staff at the Trust.	
The sample and mailing files have been separated, with no identifiable information (name and address) in the sample file (also referred to as the anonymised file).	
Mental Health Care Cluster data has been removed from the main sample data and will be submitted to the Co-ordination Centre separately.	
The anonymised sample file contains the following variables ONLY: NHS Trust code Service User Record Number ( <b>THIS IS NOT THE NHS NUMBER – the SURN for the survey</b> ) Year of birth Gender Ethnic category Day, month and year of last contact CPA status	
CCG code The sample file has been prepared and is ready to send to the contractor <b>once confirmation</b>	
has been given by them	
APPROVED CONTRACTORS: Additional sample variables and / or additional records have been removed from the sample file prior to sending the anonymised sample file to the Co-ordination Centre	

**Please note** you will be required to amend or update the sample and mailing files if any errors or deviations are identified during the sample check conducted by your contractor (or, subsequent to this, by the Co-ordination Centre).

You will also be sending a separate mailing file to your contractor- that file will contain the names and addresses. If you have not separated the sample file and the mailing file before sending to the approved contractor, or your sample file contains any other directly identifiable data, your contractor is obliged to report this to the Care Quality Commission. Your trust will have to consider logging the incident as a serious incident on the Information Governance Toolkit - see the 'Guidance for Reporting, Managing and Investigation Information Governance Serious Incidents Requiring Investigation'. The Confidentiality Advisory Group at the Heath Research Authority will also be notified by CQC. If sample files are sent to the Survey Co-ordination Centre mistakenly containing names and addresses, or any other directly identifiable data, the Co-ordination Centre are obliged to report this to the Care Quality Commission, who in turn must report it to the Confidentiality Advisory Group at the Heath Research Authority.

#### Declaration

The above information is accurate. I confirm that the sample has been drawn in accordance with the instruction manual. I confirm that the sample has been drawn from all databases of service users held by this Trust. I confirm that the sample reflects the proportion of service users who were on CPA and those not on CPA between 1<sup>st</sup> September and 30<sup>th</sup> November 2015.

Signed:		Date:						
Name of person drawing sample:		Trust name:						
Email address:		Telephone:						
Signed:		Date:						
Name of person checking sample:		Trust name:						
Email address:		Telephone:						
Signed:		Date:						
Caldicott Guardian:		Email address:						
Section E for approved contractors:								

Please write in how many service users in the sample were replaced:

Please note the reason(s) for these replacements: