

SAMPLING INSTRUCTION MANUAL FOR THE COMMUNITY MENTAL HEALTH SURVEY 2015

FOR TRUSTS CONDUCTING THE SURVEY IN-HOUSE

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 this guidance manual. Please note that 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. Although in-house trusts are not undertaking this, we expect them to follow the standard practices and procedures outlined here, in the interest of protecting people's confidentiality, maintaining high standards, and adhering to the Data Protection Act. For example, trusts must not send patient identifiable data such as patient names and/or addresses to the Co-ordination Centre.

It is also not permitted to offer 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 6. 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 directly to inform them of the change.

This document is available from the Co-ordination Centre website at: **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 Service¹ (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 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, both of which can have serious implications.

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 below.

Please note that your sample of service users should only be used for the purposes of distributing the MH15 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.

1.1 Compile a full list of current service users

- Compile a full list of all service users who were seen between 1st September 2014 and 30th November 2014. 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.

¹ 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**st **September 2014 and 30**th **November 2014**, 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 1st September 2014 and 30th November 2014 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 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 once¹;

- Anyone primarily receiving drug & alcohol services;
- Anyone primarily receiving Learning Disability services;
- 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 address²;
- Service users who did not have contact with Mental Health Services during the sample period of 1st September 2014 and 30th November 2014;
- 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 9.6*):

- Service user Record Number;
- Title (Mr, Mrs, Ms, etc.);
- First name;
- Surname;
- Address Fields;
- Postcode;

¹ 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.

² 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.

- Year of birth;
- Gender;
- Ethnic category;
- Day of last contact¹;
- Month of last contact;
- Year of last contact;
- CPA status²;
- CCG code;
- Mental Health Care Cluster (Please note: this must be drawn at the same time as the rest of the sample, and submitted to the Co-ordination Centre in a separate file to the anonymised sample details – see Section 9.7 – Specific instructions for mental health care cluster for more detail.)

1.2 Complete 'Section A' 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 1st September 2014 and 30th November 2014 and meet the specified eligibility criteria (i.e. the inclusion and exclusion criteria), please complete **section A** of the Sample Declaration form.

This form is in Appendix 1 of this guidance and is also available to download from the NHS Surveys website at http://www.nhsurveys.org/survey/1507

1.3 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 8.1*) and completed section A of the Sample Declaration Form (as described in *Section 8.2*).

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 8.1* 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 *Service User Record Number, name*, year of birth, etc). There should be one row for each service user below that;

¹ This field indicates the last contact made overall and should include contact made after the end of the sampling period.

² 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.

- 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;
- 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 order¹. 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**.

1.4 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;

¹ The random numbers change each time any cell in the worksheet is changed

- **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 1st September 2014 and 30th November 2014;
- **Distribution of service user ages.** Check that your sampled service users' ages cover the full range of expected ages (**aged 18 and over**). You can do this by plotting the service user ages on a histogram;
- Any service user known to have requested their details are not used for any purpose other than their clinical care (if this is collected by your trust you should ensure that you remove those service users from your sample list at this stage);
- Before submitting your sample files to DBS for checking, ensure that you have removed the information relating to Mental Health Care Cluster.

2 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 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).¹

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://www.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.

¹ 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 is available from http://nww.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;
- 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.

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 <u>mh.cc@pickereurope.ac.uk</u> with the password being supplied separately either by email or telephone. The Patient Survey Co-ordination Centre will check your sample file and contact you with any arising issues to discuss with you.

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 'Section C' of the Sampling Declaration Form

Once you have finalised your sample of 850 service users, please complete 'Section B' of the Sampling Declaration Form and 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 1st September 2014 and 30th November 2014 - 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 9.8);
- 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 9.7*).

Please ensure the form is completed and signed by the Caldicott Guardian, prior to emailing the scanned form to <u>mh.cc@PickerEurope.ac.uk</u>. Electronic signatures are permitted within the forms if this is a useful addition.

Please note that you must submit this form and wait for the Co-ordination Centre to confirm that they are happy to receive your sample file. Do not send your anonymised sample file until you have received this confirmation.

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". 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 **<MH15_samplefile_XXX** (where XXX is the Trustcode for your organisation).

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 until the closing date of the survey;

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

Trust Code	Trustcode	Service User Record Number	Title	Firstname	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	MH15RN A0810	M r s		A bb ott			AB1 1YZ	1971	2	A	2	09	20 14	1	04 J	20				3
RT V	RYG	MH15RN A0898	M r		A h m ed			AB2 6XZ	1958	1	A	14	02	20 14	3	04 J	2	22	3	2015	1
	RYG																				
RT V	RYG	MH15RN A0745	M s		Y 00			AB4 7MX	1987	2	М	21	10	20 14	2	04 M	99				
RT V	RYG	MH15RN A0035	M s		Y ou ng			AB9 5ZX	1946	2	Z	30	09	20 15	1	04 J	5	6	4	2015	1

Table 1 – Sample construction spreadsheet of service user details

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 10*) 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.);
- First name;
- Surname;
- Address Fields ¹;
- Postcode;

Note

The Service User Record Number, Title, Firstname, Surname, Address fields and Postcode are used for printing out address labels. You 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 Category² 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 Health³. 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

³ 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

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

² 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.

- 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 stated¹
- **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. 2014 or 2015);
- **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 10. 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>
- Mental Health Care Cluster (see Section 9.7 below for specific instructions)

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

¹ 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.

1) **Service user record number.** This number is unique for each service user. It should have the format **MH15XXXNNNN**, where XXX is the three letter trust/organisation code and NNNN is the four digit unique number.

In the example up, the numbers are in ascending order, starting at MH15RNA0002 at the top of the list, through to MH15RNA0898 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;

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

3) **Month of questionnaire being received**. This can only be completed if and when a questionnaire is received by you. 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 you. 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.

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.

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.¹ 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: <u>www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/m/mental_health_care_cluste</u> <u>r_de.asp?shownav=1</u>

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

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

¹ https://www.gov.uk/government/publications/mental-health-payment-by-results-arrangements-for-2013-14

- 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 file to the Coordination Centre, 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 Service User Record Number and the Mental Health Care Cluster <u>only</u>.

This can be done by copying and then pasting the 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 Mental Health Care Cluster from your sample file. Please save this file using the name **MH15_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 4.4 – Keeping service user mailing data and sample data separate).

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 as part of your sample file** to the Co-ordination Centre. 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.

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 "MH15_mailingdata_XXX" (where XXX is your Trustcode).

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 (**MH15_samplefile_XXX**) to identify service users who will need to be sent reminders.¹

As this "**MH15_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 survey is complete. This should be done 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.

¹ As shown in table 1 (*Section 9.6*), 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

Service user Record number	Title	Name	Surname	Address1	Address2	Address3	Address4	Address5	Postcode
MH15RNA0002	Mrs	Anna	Abbot	14 Station Road	London				AB1 1YZ
MH15RNA0003	Mr	Eric	Ahmed	Flat 7	Short Street	Oxford			AB2 6XZ
MH15RNA0849	Ms	Kate	Yoo	The Maltings	Birch Road	Little Abington	Cambridge	Cambs	AB4 7MX
MH15RNA0898	Ms	Fiona	Young	634 Tyne Road	Newcastle-Upon- Tyne	Tyne and Wear			AB9 5ZX

2.9 Making more use of the survey locally

Up to this point, this section of the guidance has described in detail how sampling must be undertaken to provide the basic required sample of 850 service users for the national survey. In addition to this minimum requirement, though, your trust may wish to use the NHS Community Mental Health Survey 2015 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.

The Co-ordination Centre will be able to advise on any queries you might have via e-mail at <u>mh.cc@pickereurope.ac.uk</u> or call 01865 208127. However, before you decide to do this, there are some important points to consider:

- The core sample for the Community Mental Health Survey 2015 **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 you **must not** send the additional sample file information to the Coordination Centre, only the sample information required for the national survey. The Coordination Centre have no need for such information, and if any sensitive or identifiable data is sent to them in error, appropriate action must be taken by the trust and it may affect your IG toolkit score;
- 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: <u>www.nhssurveys.org/localsurveys</u>

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;

• Alternatively, if your trust regularly treats very large numbers of service users, you may wish to draw an extra sample of service users to survey additionally to those included in the main survey. For example, you could select service users seen at the trust in a different time period from those in the national survey and send them questionnaires either at the same time as or at some point after the national survey. By running the survey locally in addition to the national survey, you can establish a more frequent pattern of reporting enabling you to track experience over time, or test the impact of recent quality improvement initiatives. If you decide to carry out a service user survey locally at the same time as the national survey you will need to ensure that you are sampling two distinct and separate groups of service users which do not overlap. You must also ensure that the sample for the national survey is drawn as specified.

Guidance for carrying out a local survey of mental health inpatient services (carried out as part of the national patient survey programme in 2009) is available at http://www.nhssurveys.org/localsurveys so that organisations that wish to do so can begin to plan for future local surveys. To avoid duplication with the Community Mental Health Survey 2015, 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: 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 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.

Please make sure that you do not send the co-ordination centre any additional sample or sample variables.

3 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 file¹ **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 checking²**.

The Sample Declaration form must be sent to the Co-ordination Centre before you send your sample to the Co-ordination Centre. The Co-ordination Centre will confirm they are happy to receive your sample file once they have received your sample declaration form. **Do not send your sample file until the Co-ordination Centre have confirmed they have sample declaration form.**

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 you within three working days of submission.³

Samples should be submitted **to the Co-ordination Centre** by the **27**th **February 2015**. If they are not, there is a risk you will not have enough time to correct any problems in the sample and complete the survey with an acceptable response rate. Major errors may then result in the data from the trust being excluded from the relevant Care Quality Commission assessments.

Trusts which have not submitted their sample for checking by the 5th March 2015 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 12th March 2015, 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 from DBS and the questionnaire being received, increasing the risk of distress to family members and complaints to your trust.

¹ Created by removing the service users' names, addresses and postcodes.

² See Section 4 – Data protection and confidentiality for further information

³ For example, if a sample is submitted on a Thursday, queries will be returned on or by the following Tuesday.

Making the most of the fieldwork period

Because certain demographic groups (specifically younger service users and those from nonwhite ethnic categories) have been shown to take longer to respond to service user surveys, we strongly recommend that files are submitted at the start of 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 (16th February 2015). You can do this by:

- 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 the Co-ordination Centre;
- Discussing the work with your Caldicott Guardian to ensure they are available to sign off any necessary documents for the survey;
- 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.

Appendix 1: Sampling Declaration Form

Community Mental Health Survey 2015: Sampling Declaration

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

This checklist will be used for audit purposes to ensure that the sample conforms to the guidance 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. Although in-house trusts are not undertaking this, we expect them to follow the standard practices and procedures outlined here, in the interest of protecting patient confidentiality and maintaining high standards. For example, trusts must not send service user identifiable data such as names and/or addresses to the Co-ordination Centre. 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 guidance manual [link]

For staff drawing the sample:

Please complete this form once you have drawn your sample. You must send this checklist to the Co-ordination Centre (<u>mh.cc@pickereurope.ac.uk</u>) **before** you send your sample file. The Co-ordination Centre 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.**

If you have decided to use additional sample variables for analysis or include more than 850 records in your sample, these must not be included in the anonymised sample file that you provide to the Co-ordination Centre. Additional sample variables, and / or additional sample records, other than those required for the national survey, are not covered by the section 251 approval.

Community Mental Health Survey 2015

Sample Declaration Form

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

SECTION A: Service users at this Trust who meet the eligibility criteria

- (A) Total number of eligible service users at the Trust who used services between 1st September and 30th November 2014^{*}
- (B) Number of service users on new CPA
- (C) Number of service users not on new CPA
- (D) Number of service users where CPA status not known

SECTION B: sample of service users included in 2015 survey

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

CPA definitions

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

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

SECTION C: Submission of sample to Co-ordination Centre

Please complete this form once you have drawn your sample but **before** you have submitted your sample to the Co-ordination Centre. Please send this form to the Co-ordination Centre who will confirm receipt before you are able to send your anonymised sample file (mh.cc@PickerEurope.ac.uk).

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

People who indicated dissent have been removed from the sample.

PLEASE WRITE IN HOW MANY WERE REMOVED:

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

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

The sample has been checked by the Demographic Batch Service (DBS)	
The sample has been checked by Trust staff as outlined in the guidance manual.	
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 (THIS IS NOT THE NHS NUMBER – the SURN for the survey) Year of birth Gender Ethnic category Day, month and year of last contact CPA status CCG code	
The anonymised sample file does not contain any additional service user records over the basic sample size of 850 records OR any additional sample variables	
The sample file has been prepared and is ready to send to the Co-ordination Centre once confirmation has been given by them	

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 the Survey Co-ordination Centre.

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. 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'.

Declaration

The above information is accurate. I confirm that the sample has been drawn in accordance with the guidance. I confirm that the sample has been drawn from all databases of service users held by this Trust. I confirm that the sample reflects the proportion of service users who were on CPA and those not on CPA between 1st September 2014 and 30th November 2014.

Signed:	Date:	
Name of person drawing sample:	Trust name:	

Email address:		
Signed:	Date:	
Caldicott Guardian:	Email address:	