



INSTRUCTION MANUAL FOR THE COMMUNITY MENTAL HEALTH SURVEY 2016

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 instruction 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 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 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 Introduction: The importance of patient feedback

1.1 The Care Quality Commission

The national patient survey programme was established by the Department of Health and has been operating since 2002. The Care Quality Commission (CQC) took over from its predecessor, the Healthcare Commission, in April 2009 and is responsible for administering the programme. The CQC is the independent regulator of health and social care in England and is responsible for administering the programme. It regulates care provided by the NHS, private companies and voluntary organisations. The CQC aims to ensure better care is provided for everyone – in hospitals, care homes and people's own homes.

As set out in Voices Into Action¹, the statement on involving people, the CQC is committed to involving people who use services in all its work, and ensuring that the providers of care services themselves involve people and respond to their views. The experiences of patients, people who use services, their carers and families are at the heart of the CQC's work: it is the aim of the CQC and the Co-ordination Centre to make sure better care is provided for everyone.

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

1.2 The Co-ordination Centre for patient surveys

The Co-ordination Centre for the NHS Patient Survey Programme, of which the Community Mental Health Survey 2016 is part, is based at Picker Institute Europe and works under contract to the Care Quality Commission to design, test, and co-ordinate the patient survey programme.

1.3 Why we need service user feedback

Quality in health and medical care has two distinct dimensions. One has to do with the quality of care from the perspective of professional, technical standards; and the other dimension concerns the quality of care from the perspective of people using services. Understanding the way people experience the care they receive is essential to a complete assessment of the quality of healthcare, and this can only be obtained by asking the service users themselves.

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

¹ http://www.cqc.org.uk/sites/default/files/documents/links1_guidance_local_groups.pdf

1.4 Patient feedback and the NHS Constitution

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

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

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

1.5 Care Quality Commission assessments

Information drawn from the questions in the survey will be used by the Care Quality Commission (CQC) in its assessment of mental health trusts in England. Questions from the survey will be used within CQC's intelligence model and within CQC's inspections of mental health services.

More information is available on the CQC website at: www.cqc.org.uk/content/mental-health

1.6 Measuring performance

In addition to the performance assessment, the Care Quality Commission will publish comparable data from the survey to allow trusts to make meaningful comparisons between themselves and national benchmarks based on reliable data. Asking each trust to carry out the Community Mental Health Survey 2016 in a consistent way builds a detailed picture of users' experiences in NHS Mental Health trusts.

Information collected nationally in a consistent way is also essential to support public and Parliamentary accountability. The results are also used by NHS England and the Department of Health (DH) for performance assessment, improvement and regulatory purposes. These include the NHS Outcomes Framework (domain 4: Ensuring patients have a positive experience), the DH overall patient experience measure, the NHS Performance Framework, the cross-Whitehall Public Services Transparency Framework and NICE Quality Standards.

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

1.7 Basic requirements for Community Mental Health Survey 2016

For comparisons between and within trusts to be accurate, fair and effective, it is essential that the surveys are carried out using a standard procedure in all NHS trusts. Furthermore, this is essential in order to comply with the procedures and standards covered by the Research Ethics Committee and Section 251 approvals. Those standards are set out in detail later in this document. In summary, they are as follows:

- Please let the Co-ordination Centre know the trust contacts who will be the key contacts throughout the survey process - their job titles, phone numbers and email addresses by **6th January 2016** - to allow us to communicate vital information about the Community Mental Health Survey 2016 (e-mail to: mh.cc@pickereurope.ac.uk);
- Confirm whether you will be conducting the survey in-house or by using one of the approved contractors by **6th January 2016**. If you are using an approved contractor, you will need to confirm with the Co-ordination Centre who this is by **19th January 2016** (e-mail to: mh.cc@pickereurope.ac.uk). If you are using a contractor, please refer to the manual for trusts using a contractor instead of this one;
- The survey must be carried out using a postal questionnaire;
- Please read the sections on drawing your sample, completing your **Sample Declaration** form and how to submit these to the Co-ordination Centre fully, as outlined in *Sections 8 – Compiling a list of service users & 9 – Submit the service user list to the Demographics Batch Service*;
- The samples must consist of all service users **aged 18 and over** who were seen between **1st September and 30th November 2015** as outlined in *Section 8*;
- The sampling procedure set out in this manual must be followed. To do this, you will need to work closely with the persons who draw and check the sample, and check carefully that the instructions have been adhered to. For further details see *Section 8*;
- **Your Caldicott Guardian must sign off the sample.** Please send the signed declaration form to the Co-ordination Centre **before** you submit your sample for checking;
- Sample data must be submitted to the Co-ordination Centre for final checks before mailing as outlined in *Section 10 – Final Sampling Inspection by the Co-ordination Centre*. Sample files must be submitted to the Co-ordination Centre between **18th January – 12th February 2016** to allow sufficient fieldwork period to maximise response rates. You should aim to obtain the highest response rate possible. Three mailings will be necessary to maximise response. Trusts should facilitate higher response rates through maximising their collection period by commencing work as soon as possible, and by publicising the survey to staff, service users and the community;
- Weekly submissions of details of response rates and helpline calls to the Co-ordination Centre will start from **3rd March 2016**. A spreadsheet has been created for this purpose. For further details see *Section 11 – Materials*.
- The standard covering letters and reminder letters (which can be found on the nhssurveys website <http://www.nhssurveys.org/surveys/888>) must be used as outlined in *Section 11 – Materials*;
- Two paper copies of the questionnaire and the covering letters for each mailing must be submitted to the Co-ordination Centre by **26th February 2016** in the form outlined in *Section 11.9 - Submitting hard copies of the questionnaire and cover letters*. You must **not** include any service user names or addresses on the letters you send to the Co-ordination Centre;

- Two reminders must be sent to non-responders. These procedures are outlined in *Section 14.7 – Sending out reminders*;
- The data must be checked carefully for errors before submitting to the Co-ordination Centre. Specific advice on how to carry this out is included in *Section 15.3 – Checking the for data errors*;
- The data from the survey, and the required information about the service user sample, must be submitted to the Co-ordination Centre in the form outlined in *Section 15.4 – Submitting data to the Co-ordination Centre* by **1st July 2016**;
- The free text comments must also be submitted to the Co-ordination Centre by **1st July 2016**. These should be included in full and as part of the main data file;
- You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until **16th December 2016** but please do not send these to the Co-ordination Centre. These returned questionnaires may be needed to audit the data sent to the Co-ordination Centre;
- Trusts are not permitted to publish their survey results prior to the official release of CQC national and trust level results as there might be differences which could cause confusion for people. However, trusts can start using their results internally to identify areas for quality improvement.

1.8 Why you need this guide

This guide is designed for trusts wishing to conduct the survey in house. You must be familiar with all aspects of this guide, but in particular, the sections on drawing the sample, data protection requirements the practicalities of mailing out the survey, and the processing and submission of data to the Co-ordination Centre.

2 Setting up a project team

We recommend you set up a project team to assist you in running the survey. The best way to ensure that your survey is a success is to work hard *in the beginning* to involve those people who have the most impact on service users' experiences and who will be responsible for responding to the results of the survey.

We suggest:

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

3 What's new for the 2016 survey?

Recording dissent: An essential requirement to meet the conditions of the 'Section 251 approval' for this survey is that any service user who has previously indicated dissent must be removed from the eligible survey population prior to sending the sample to an approved contractor. It is expected that trusts will have appropriate mechanisms in place for recording dissent. However, depending on the process that the trust has in place, this could potentially result in large numbers of service users being excluded from the survey population, which could in turn introduce bias to the sample. It is important that all consent requests are clearly worded and specific, to avoid any unnecessary removal of people from the samples (where they would otherwise have agreed to take part in the survey). Key contacts at trusts have already been contacted on 22nd October 2015 by the Co-ordination Centre on behalf of the Care Quality Commission by email to highlight the importance of this and to request details as to how this is collected. Please also refer to *Section 4.2 – Section 251 Approval*.

Sample Declaration Form: Some changes have been applied to the form: i) a new section has been added so we can accurately record the number of dissenters at the trust ii) the sample will need to be drawn and checked by different people within the trust – both will need to sign and date the declaration.

As was done previously, the form will also need to be signed by the Caldicott Guardian. The declaration form should be sent to the Co-ordination Centre and will need to be approved by them **before** you send your sample file.

CQC Intelligence Model:

A new indicator is being developed for Care Quality Commission's intelligence monitoring of trusts providing mental health services based on the community mental health survey. Trusts will be flagged as a risk if they either fail to submit a sample for the community mental health survey or if it becomes evident at a later date that an error has been made in drawing the sample that renders the data unusable. This will be included in the next version of the intelligent monitoring reports for trusts providing mental health services and will be based on the two most recent years of the community mental health survey. Further details will be included in the guidance that accompanies the reports. This indicator will be refreshed on an annual basis going forward.

Errors considered in the indicator may be 'minor' or 'major'. A minor error means that data is still able to be used despite the error. A 'major' error is so serious that data for a trust is unable to be used, and would be excluded from the CQC publication, and all other uses, such as in CQC's intelligence model, as well as by other organisations such as NHS England for use in their national statistics.

Making errors in drawing the sample, for example, neglecting to include a core group of eligible service users, effectively biases the sample, meaning an individual trust's results are not comparable to other trusts. If major errors are spotted during the sample checking phase, then the Co-ordination Centre will request that a fresh sample be drawn, however, errors are not always easy to spot in an anonymised file. If it only later becomes evident that a major error has been made and there is no time to submit a new sample for inclusion in the survey, the survey response data will be excluded from the CQC dataset, and the trust will be flagged as a risk in the CQC's intelligence model.

Ultimately, it is the trust's responsibility to ensure that the sample is drawn correctly. To help avoid making such errors, ensure that you follow the instructions very carefully when drawing your sample. You should also read the 'Sampling Errors Report' for the previous year's survey which highlights the errors that were made in compiling and submitting samples – it can be found here <http://www.nhssurveys.org/survey/1640>

Outcome code: A new code has been added to the 'Outcome' field to indicate service users who have been traced as being deceased after the sample file has been signed off by the persons who drew and checked the sample within your organisation and your Caldicott Guardian, and submitted to the Co-ordination Centre, but **before any mailings have been sent out. In these instances**, records are not to be removed from either the sample or mailing files. Instead, the new code of '7- *service user deceased prior to fieldwork*' should be used under the 'Outcome' field.

Note that in instances where the first mailing has been sent out and a service user is subsequently identified as having died, then the outcome code of '3 – *service user died*' should be used.

Questionnaire: There have been some proposed minor changes to the 2015 questionnaire, full details will be made available when ethical approval is granted. The questionnaire will be made available here: <http://www.nhssurveys.org/surveys/887>

The question changes take into account stakeholder requirements, with the question changes being tested among recent service users. A Survey Development Report will be made available in February 2016 and can be accessed here: <http://www.nhssurveys.org/surveys/885>.

Covering letters: These have been updated to make the tone more informal, though the content is very similar to last year.

3.1 Important information to remember

Service user record number: The format is an eleven character string of the form **MH16XXXNNNN**, where XXX is the three letter organisation/trust code (eg RW1) and NNNN is the unique identifying number assigned to individual service users.

The Service User Record Number must be assigned **by the trust** and **before** going through the DBS check, such that the unique identifier NNNN above will range from 0001 to 0900. This way we can be sure that the SURN in the sample file, the mailing file and the care cluster file all match. Of course, once the results of the DBS check have been returned, the Service User Record Numbers will not run consecutively due to some records being removed in order to reduce the sample size to the required 850 records.

CQC Flyer: Again this year, a CQC flyer will need to be included in mailings: for in-house trusts these will be sent to the nominated survey lead. The CQC flyer explains the role and purpose of CQC and how the survey data will be used by them. Please note that this flyer should only be used for the 850 sample. If you extend your sample size, the CQC flyer should not be included in the mailing packs for the additional sample.

Free text comments: As in last year's survey, **free text comments must be included in full** before submission to the Co-ordination Centre - see *point 5, Section 4.6 – Service User Confidentiality*;

Care Cluster data: Again, there is a requirement for Mental Health Care Cluster to be submitted directly to the Co-ordination Centre, detailed fully in *Section 9.7 – Specific instructions for mental health care cluster*.

Mental Health Care Cluster: Your trust's service users should have been assigned care clusters between 0-21 (also known as PbR currencies) using the current PbR (Payment by Results) guidance.¹ For more information, please see the NHS Data Dictionary: http://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/m/mental_health_care_cluster_de.asp?shownav=1.

This data must be **collected by the trust and submitted to the Co-ordination Centre**. Please be aware this will be collected during the sample checking period (it will be requested by the Co-ordination Centre once your sample has been approved). This is explained in *Section 9.7 – Specific instructions for mental health care cluster*.

Sampling months: The list of eligible service users must be compiled from those who have had contact with your organisation between **1st September** and **30th November 2015**. This is the same sampling period as last year's survey.

Weekly submissions: Weekly submissions of response rates (outcomes) and helpline monitoring information will again be requested for each trust taking part in the Community Mental Health Survey 2016 and we ask for the first submission on **3rd March 2016**. We will be using this data to generate weekly adjusted response rate data for the Care Quality Commission by trust name. This is discussed further in *Section 12 – Weekly monitoring*.

Hard copies of the questionnaire and covering letters: Two paper copies of the questionnaire and covering letters are to be submitted to the Co-ordination Centre by **26th February 2016**. You must ensure that the covering letters **do not include any service use name and address information**. See *Section 11.9 – Submitting hard copies of questionnaires and covering letters*.

Mail out envelopes: It is important that the envelope(s) which you use to mail out your survey materials to service users does not show any indication of the NHS Trust, in accordance with data protection regulations.

Service users who have requested that their details are not used for any other purpose than their clinical care, such as secondary purposes eg, research: If your trust has a mechanism in place to flag service users that do not wish their data to be used for secondary purposes, we advise that you refer to this when drawing your sample as these service users will need to be removed from your sample.

Ethnic category: Ethnic category will be requested in the standard 16 + 1 alphabetical format. However, in the past there was some confusion over what data should be coded as "Z" ("not stated"). This code should be used **only** when a person had been asked for their ethnic category and had declined either because of refusal or genuine inability to choose. A blank or full-stop should still be used to indicate where ethnic category is "not known" i.e. where the service user had not been asked or the service user was not in a condition to be asked, e.g. unconscious. For most trusts, ethnic category will contain both "Z" codes **and** "blanks". Further information can be found in *Section 9.6 – Create the sample file*.

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

Embargo on results: Trust-level findings for the national Community Mental Health Survey 2016 **must not** be released outside of the trust until the national results are published by the Care Quality Commission. Please continue to use the results from your in-house survey teams, but wait until the survey results for all trusts are published by the Care Quality Commission before promoting your results in any way (either on your website, in press releases or any other external publicity) to the local community and media. You will receive, along with communications staff in your trust, advance notice of the publication date and will have time to prepare for your local announcements once the embargo is lifted.

Letters: For the first mailing letter and second reminder mailing there is the option to include service user name. We recommend this approach as there is evidence to show that this increases response rate (we would recommend using service user title followed by surname). If service user name is used, please take great care that each letter is correctly matched to its corresponding questionnaire.

4 Data protection and confidentiality

When carrying out your survey, you will need to ensure that you comply with the Data Protection Act 1998, and ensure that all responses are kept confidential. **If you have not already done so, please ensure that you add research to your Data Protection Act registration, as one of the purposes for processing personal data supplied by data subjects.** You will also need to comply with the NHS Code of Practice on Confidentiality (2003), which incorporates the Caldicott principles¹.

It is your legal responsibility to ensure that you meet any guarantees of anonymity or confidentiality made in covering letters and on the questionnaire form. Your trust's Caldicott Guardian and legal advisors should advise you on these matters.

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

The website below has further information:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4069253

Information about the Data Protection Act 1998 can be found at the ICO – Information Commissioner's Office (<https://ico.org.uk/>)

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

4.1 Statements of compliance with data protection

Each NHS trust has a Caldicott Guardian responsible for overseeing proper use of service user data. Before mailing out the sample, you must submit a formal declaration (see *Appendix 3*), signed by the Caldicott Guardian and survey lead(s) for the trust, to the Co-ordination Centre. This declaration will certify that data shall only be displayed, reported, or disseminated in compliance with the new guidelines (see *Section 4.6*). Templates for these declarations are available on the NHS Surveys website <http://www.nhssurveys.org/surveys/889>.

¹ Each NHS trust has a Caldicott Guardian who is responsible for overseeing proper use of service user data. They have to ensure that any use of service user data conforms to the following principles:

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

You should take particular care to ensure that your use of service user data in carrying out the survey complies with these 6 principles. In particular, you should be aware of the flows of service user data, and the issues which these present. The Caldicott guidance and principles were incorporated into the NHS code of practice on confidentiality.

You must wait for confirmation of receipt from the Co-ordination Centre before you mail out your sample.

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

4.2 Section 251 Approval

Approval has been granted for the Community Mental Health Survey 2016 under section 251 of the NHS Act 2006 to provide a legal basis for trusts using a contractor to provide names and addresses to them. The survey methodology was reviewed by the Confidentiality Advisory Group at the Health Research Authority and submitted to the Secretary of State for Health for approval, which was granted on 16th December 2015. The letter will be available on the website here: <http://www.nhssurveys.org/surveys/899>. Although in-house trusts are not undertaking this, we expect them to follow all standard practices and procedures outlined in this manual in order to meet their responsibilities relating to data protection and information security.

The section 251 support does not cover the transfer of service user identifiable information where a service user has indicated dissent - by this we mean instances where a service user has explicitly indicated that they do not want their information to be shared for purposes such as service user surveys, or specifically stated that they do not want their details shared outside of the Trust.

Consequently, if anyone indicates that they do not want their records used for secondary purposes (e.g. they have asked to be excluded from all surveys or they do not want their address details shared for any reason other than their care), these people must be excluded from the mailing list. This should be done by trusts using their local records.

We expect trusts to process any opt outs from people using services/carers in the following way:

1. Any objection is to be recorded immediately and checks made to determine whether a mailing is underway. If a mailing is underway the caller will need to be advised that it might not be possible to prevent this mailing but assured that they will receive no future mailings;
2. People wishing to receive no further questionnaires can be identified with a flag/ code/ number on the mailing file;
3. When speaking to callers wishing to opt-out of future survey mailings, it is not appropriate to try and dissuade them from their intent. There is a risk that even well intentioned discussion around the benefits of the survey could be perceived as applying pressure to participate. The benefits of the survey should only be mentioned by call-takers in response to queries from callers. If someone feels strongly enough about the survey that they initiate contact to object, this needs to be respected and acted upon immediately to avoid upset and misunderstanding;
4. Callers are advised they are being removed from the mailing list for this survey only, and that if they wish to register their dissent against wider research participation at their trust, and this is not something that the person taking the call is able to help with, please ensure that you are able to direct the caller to PALS or the trust Information Governance Team as appropriate.

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

For more information on the fair processing of data, please see the Q&A on the NHS surveys website at:

http://www.nhssurveys.org/Filestore/documents/20120704_FAQs_on_fair_data_processing_draft4.pdf

It is very important that you follow the instructions set out in the survey instruction manual, as although the Section 251 approval does not cover in-house trusts as such, if CQC become aware of a breach of information security or patient confidentiality, the relevant CQC Inspector will be informed. All breaches will be considered by inspectors as a breach of regulation 20 (Records) and inspectors will make a decision as to whether enforcement activity is required.

4.3 Keeping service user mailing data and sample data separate

Keeping names and addresses separate from either sample information or respondent data is the best way to ensure that the service user responses cannot be matched to service users who made them. Keeping the two sets of information separate reduces the amount of information disclosed if either file were to be lost or shared with unauthorised individuals. It also means that only the necessary information is shared with those who need it – for example staff members who deal solely with the mailing need only the mailing file. **For this reason, we strongly recommend that once the sample has been returned from DBS and a final sample size of 850 has been drawn, service user names, addresses and postcodes should be removed from the sample file to a “MH16_mailingdata_XXX” file** (where XXX is the Trust code for your organisation).

Before this is done, it is essential each service user is provided with a unique number (a **Service User Reference Number**) and that this number is available and correctly matched on both the “MH16_mailingdata” file and the sample information file.

4.4 Mailing questionnaires to service users

An important issue regarding mailing questionnaires and data protection relates to the envelopes used to mail out questionnaires. Some people may not have told family or friends that they have used community mental health services and, under data protection regulations, it is important that this information remains confidential. Therefore it is important that the envelope(s) used to mail out your survey materials do not show any indication of the NHS Trust name. See *Section 11.5 – Mail Out Envelopes* for further details.

4.5 Service user anonymity

It is important to ensure that any claims you make about service user anonymity are accurate; and you are obliged by law to honour any statements that you do make. As you are carrying out the survey in house it is not accurate to tell service users that their responses will be anonymous. The person who receives the completed questionnaires is usually able to match these responses to service user names and addresses.

4.6 Service user confidentiality

It is essential that any service user survey is conducted in such a way that service user confidentiality is respected and given a high priority. The covering letters that accompany the mailed questionnaires inform service users that their name and address will never be linked to their responses. Furthermore, service users' responses must not be presented to anyone in a way that allows individuals to be identified. For example, if a service user's sex and ethnic category are known from their survey responses, it might be possible to use this information to identify them. It

would be unlawful to provide staff who may have had contact with respondents any information that would allow these respondents to be identified. The following recommendations are made:

Trust level

- 1) The raw data set **must not** be provided to any member of staff at the trust who does not need to view it, i.e. those who are not directly working on the project;
- 2) Additional data analysts may be added later by a second submission of the declaration of compliance to the Co-ordination Centre (see nhssurveys website for a copy of the declaration). Additional data analysts cannot view the raw data until approval has been received from the Co-ordination Centre;
- 3) If data are to be presented to other trust staff who have not signed the declaration using the declaration of compliance, only the aggregated totals for each question should be provided. If analysis by subgroup is carried out, the results for any group consisting of fewer than **30 respondents** should be suppressed (replaced by a dash). The data should be presented as in the following example. In this case, responses for the 'Mixed' and 'Asian' ethnic categories are suppressed (though the other subgroup totals are shown):

	Q24 In the last 12 months, have you been receiving any medicines for your mental health needs?		
Ethnic category	Yes	No	Total responses
	%	%	n
White	81	19	261
Mixed / multiple	-	-	8
Asian /Asian British	-	-	18
Black African / Caribbean / Black British	79	21	52
Other ethnic group	85	15	36

- 4) Do not present response information (including comments) in a form that allows an individual service user to be identified by the group receiving the information. For example, if you are presenting the results of a small number of service users, make sure that it will not be possible for the reader/audience to identify individual service users from their responses, and pay particular attention to the service users' free text comments in this context;
- 5) Free text comments **must be included in full** and not edited in any way, before submitting to the Co-ordination Centre, as a statement has been added to the questionnaire stating that any information provided in the free text box will be shared. **PLEASE NOTE:** This does not apply if you are publishing the comments, any comments that are published must have any identifiable information removed such as people's names or members of staff names, ethnicity, condition or health details.

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

4.7 Data encryption

As the owners of the data, the method for transferring sample and response data is ultimately your decision because the trust remains legally responsible for the security and processing of the information it shares. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption is available from NHS Connecting for Health see: <http://systems.hscic.gov.uk/infogov/security/infrasec/gpg/acs.pdf>

4.8 Storing completed questionnaires

Completed questionnaires must be stored in a separate location to lists of service users' names, and the questionnaires kept until **16th December 2016**. All mailing lists of service users' names and addresses should be stored on a separate computer to that containing survey data with access only to those who are covered by the statement of compliance with data protection. Mailing lists of service users' names and addresses should be destroyed when the mailing process is complete.

5 Ethical issues, ethics committees and research governance

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

5.1 Ethical approval for the Community Mental Health Survey 2016

Research Ethics Committee (REC) approval has been sought for the Community Mental Health Survey 2016 and a substantial amendment submitted for changes regarding the questionnaire and mailing letters, all of which will be published on the NHSSurveys website following ethical approval. **In order to comply with the ethical approval, the survey must be carried out according to the guidelines set out in this document.**

Trusts do not, therefore, need to seek individual ethical approval for this survey. If you wish, you can send your Local Research Ethics Committee(s) (LREC) a copy of the REC approval letter, but you are not required to do this and you do not need to wait for confirmation or approval from the LREC before starting your survey.

Your trust should notify the relevant Research & Development (R&D) office that ethical approval has been obtained for the Community Mental Health Survey 2016. The REC letter of approval can be found on our website at <http://www.nhssurveys.org/surveys/898>

Further information on the ethical approval process can be found at <http://www.nres.nhs.uk/> or by e-mailing nres.queries@nhs.net.

5.2 Research governance requirements

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

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

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

The following table has been prepared by the Care Quality Commission and is taken from Section 3.10 of the *Research Governance Framework for Health and Social Care (2005)*. The left-hand

column sets out the responsibilities of organisations providing care and the right-hand columns sets out the arrangements made by the Care Quality Commission for service user surveys. If you are required to seek approval from your research governance lead, you are advised to present this information to your Research and Development Manager in support of your request.

5.3 Responsibilities of NHS organisations who are carrying out research

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

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

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

6 Collecting data from non-English-speaking populations

The service users who respond to your survey should be representative of all of the service users who use the trust, so it is important that groups with limited understanding of English are not excluded. The questionnaire has been written in as **plain language** as possible to facilitate optimum understanding by all respondents.

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

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

- It is good practice to offer help or interpretation services to those who might require them. You can do this by subscribing to a specialist interpreting service, most of which offer telephone interpretation on a pay-as-you-go basis. This normally involves a three-way conversation between you (or your helpline operator), the service user and the interpreter. (Note that trusts may already have arrangements with such a service.) Please contact the Co-ordination Centre for further advice if you wish to do this;
- A multi-language leaflet template is available on the NHS surveys website <http://www.nhssurveys.org/surveys/888> and this can be included with your first and third mailings. Trusts can use this leaflet by inserting their appropriate helpline number. This gives directions in the 20 most common non-English languages spoken in England and also in EasyRead (routed to a separate number run by Mencap to help those with learning disabilities);
- Many households include at least one **competent English speaker** who can help the service user to fill in a questionnaire. In practice, this is often the most efficient way of gathering data from non-English-speakers, although it is not ideal, as there is no control over the way in which a service user's family or friends translate questions or interpret their responses, and it does not allow the service user to answer the questions themselves.

7 Timetable

The survey fieldwork period for 2016 is 18 weeks. We very strongly recommend making full use of this to maximise responses from younger and black and minority ethnic (BME) groups as previous research shows that these groups take longer to respond¹. If your service user population has high proportions of either group, it is especially vital you allow enough fieldwork time to capture responses from these people. The best way to optimise the length of available fieldwork is to ensure that you generate your sample promptly (i.e. within the recommended three week sample checking period) and mail out your questionnaire packs promptly once permission has been received. Dissemination of the results to all staff, and to the local community and media, can only start after the survey has been completed so this will take additional time.

Below is a timetable that may help you when planning the different stages of the survey - please note that you must send out the three specified mailings and submit survey data (including the free-text comments) to the Co-ordination Centre **by 1st July 2016**.

Week	Task	See Section
2	Inform the Co-ordination Centre of the names and contact details of two key contacts who will manage the survey on behalf of your trust – by 6th January 2016	1.7
-	Instruction manual to be published on NHS Surveys website (December 2015)	-
1-6	Draw sample of service users to be included in the survey	8
1-6	Check sample for deceased service users using trust records	8.5
3-6	Submit sample list to DBS to check for deceased service users	9
1-6	Print questionnaires and covering letters.	11, 14.4 & 14.5
1-6	Set up FREEPOST address and helpline	14.1 – 14.3
1-6	Establish system for responding to telephone enquiries	14.3
1-6	Establish system for booking in questionnaires	14.6
3-6	Have sample declaration form signed off and send to Co-ordination Centre, before submitting the sample file	8, 9 and 10
3-6	Submit anonymised sample to Co-ordination Centre before starting mailing process (18th January – 12th February 2016)	10
6	Send first weekly response rate and helpline monitoring form to Co-ordination Centre (3rd March 2016)	12

¹ For details of this research carried out by the Picker Institute Europe see http://www.nhssurveys.org/Filestore/documents/Extension_of_fieldwork_for_inpatient_survey_2007.pdf

5-7	Check your own trust's records again for any service user deaths	8.5
5-7	Stick labels on pre-packed numbered questionnaires	14.5
6-7	Send out first questionnaires	14.5
6-21	Continue to respond to telephone enquiries	14.3
8	Send hard copies of the questionnaire and cover letters to the Co-ordination Centre by 26th February 2016	11.9
6-21	Log and process returned questionnaires	14.6
6-21	Enter data	15
7-9	Check your own trust's records again for any service user deaths	8.5
7-9	Send out first reminders to non-responders	14.7
8-10	Be prepared for a small peak in telephone calls as first reminders received	14.3
10-12	Check your own trust's records for any service user deaths	8.5
10-12	Send out second reminders to non-responders	14.7
21	Complete data entry	15
21	Check data for errors	15.3
21	Send data including the free-text comments to Co-ordination Centre (by 1st July 2016 at the latest)	15.4
22+	Begin analysing trust's results and writing report, but do not release outside of the trust until published by CQC	
	Disseminate results to staff, service users, once published by CQC	
	You must keep hard paper copies (or scanned images of all of the pages of the questionnaires, including the front page) of all questionnaires returned to you until 16th December 2016	

Key dates

Inform Co-ordination Centre of key contacts	By 6 th Jan 2016
Submission of sample data to Co-ordination Centre	18 th Jan – 12 th Feb 2016
Approval of sample data by Co-ordination Centre	From 18 th Jan 2016
Weekly monitoring starts	3 rd March 2016
Start and close of fieldwork	22 nd Feb – 24 th June 2016
Send data to Co-ordination Centre	By 1 st July 2016

Mailing reminders

Please note that your second and final reminder must be mailed no later than Friday 27th May 2016

8 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.

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 below.

Please note that your sample of service users should only be used for the purposes of distributing the 2016 mental health 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.

8.1 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 Appendix 5 of this guidance and is also available to download from the NHS Surveys website at <http://www.nhssurveys.org/surveys/893>

8.2 Compile a full list of current service users

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

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

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 1st September and 30th 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 1st September and 30th 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 (1st September to 30th 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 1st September 2015;
 - All the service user's attendances were within the sampling period;
 - The service user's other attendance(s) fell after 30th November 2015.
- 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 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 not a current inpatient 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**²;
- Service users who did not have contact with Mental Health Services **during the sample period of 1st September and 30th November 2015**;
- Service users who have **only** been in contact via telephone or email, and have not been seen in person at all;
- Any **deduplicated** 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

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.

than their clinical care. These should have been removed prior to drawing up your list of eligible service users – please see Section 8.1 – ‘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 9.6 – 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 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 directly 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 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.

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.

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 mh.cc@pickereurope.ac.uk for advice.

8.3 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 1st September 2015 and 30th 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 Appendix 5 of this manual and is also available to download from the NHS Surveys website at <http://www.nhssurveys.org/surveys/893>

8.4 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 8.2*) and completed sections A and B of the Sample Declaration Form (as described in *Section 8.1 and 8.3*).

Although the aim is to send questionnaires to 850 service users, you will need to select more than 850 users initially. This is because your list of selected service users is likely to contain duplicate names or service users who are ineligible for the survey (see *Section 8.2* for details) and some may have died. We have estimated that around 50 users will need to be removed from the initial list, so you need to take a **simple random sample of 900** service users from your full list. This means that each eligible service user in the full list (the population) has an equal chance of being included in the sample. The procedure for doing this is as follows:

1. Put the list of service users into a Microsoft Excel file. The first row of this file should be headings (such as *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 is to click on the blank square above and to the left of Cell A1 or hold the Ctrl key and press 'A'. This selects all cells in the worksheet. If you do not select all cells in your list, you could mix up service users' details, or you could fail to sort some of the service users in the list;
6. Once you have highlighted all the cells, click Data, then Sort. At the bottom of the *Sort* dialogue box which appears on the screen, ensure that <My data has Header row> is selected. At the top of that dialogue box, use the drop-down box under "Sort by" to select **Random** and click **OK**.

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

8.5 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 8.2*). 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 **1st September 2015 and 30th 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**). You can do this by plotting the service user ages on a histogram;

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

- 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.**

9 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

9.1 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.

9.2 Submitting the trace request file

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

9.3 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://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.

9.4 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 is to click on the blank square above and to the left of Cell A1 or hold the Ctrl key and press 'a'. This selects all cells in the worksheet. If you do not select all cells in your list, you could mix up service users' details, or you could fail to sort some of the service users in the list;
6. When all cells are highlighted, click Data, then Sort. At the bottom of the *Sort* dialogue box which appears on the screen, ensure that <My data has Header row> is selected. At the top of that dialogue box, use the drop-down box under "Sort by" to select **Random** and click **OK**.

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

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 mh.cc@pickereurope.ac.uk with the password being supplied separately **by phone**. 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 mh.cc@pickereurope.ac.uk.

Important note

You are aiming for as high a response rate as possible. You will maximise your response rate by following this manual 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.

9.5 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 Sampling 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 1st September 2015 and 30th 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 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 mh.cc@PickerEurope.ac.uk. 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.

9.6 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 <http://www.nhssurveys.org/surveys/892> 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. Remember to remove the service user name and address information (the columns with the black header row), along with the care cluster codes (the column with the purple header row). Save this file as **<MH16_samplefile_XXX>** (where XXX is the Trust code 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 3rd March 2016 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, and the Care Cluster Code) will form part of the file that you will submit to the Co-ordination Centre when the survey is completed.

Table 1 – Sample construction spreadsheet of service user details

<i>Trust Code</i>	<i>Trust code</i>	<i>Service User Record Number</i>	<i>Title</i>	<i>First name</i>	<i>Surname</i>	<i>Address1</i>	<i>Address5</i>	<i>Postcode</i>	<i>Year of Birth</i>	<i>Gender</i>	<i>Ethnic Category</i>	<i>Day of last contact</i>	<i>Month of last contact</i>	<i>Year of last contact</i>	<i>CPA Status</i>	<i>CCG Code</i>	<i>Care Cluster Code</i>	<i>Day of questionnaire being received</i>	<i>Month of questionnaire being received</i>	<i>Year of questionnaire being received</i>	<i>Outcome</i>
RT V	RYG	MH16RN A0810	M r s		A b b o t			AB1 1YZ	1971	2	A	2	09	20 15	1	04 J	20				3
RT V	RYG	MH16RN A0898	M r		A h m e d			AB2 6XZ	1958	1	A	14	02	20 15	3	04 J	2	22	3	2016	1
	RYG	--																			
RT V	RYG	MH16RN A0745	M s		Y o o			AB4 7MX	1987	2	M	21	10	20 15	2	04 M	99				
RT V	RYG	MH16RN A0035	M s		Y o u n g			AB9 5ZX	1946	2	Z	30	09	20 15	1	04 J	5	6	4	2016	1

Important note about table 1

The headings of Table 1 are in 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

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

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).

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 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 Category**² 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

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.

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/end/ethnic_category_code_de.asp?shownav

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 ¹

- **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 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: <http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs>
- **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 Spreadsheet'. **Do not submit care cluster information as part of your mailing data or sample data file.** See Section 9.7 below for '*Specific instructions for mental health care cluster*' and Section 9.8

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.

'Separating mailing details from sample information').

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;

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. 15/04/16;

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 (identified after fieldwork has commenced)
- 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.

9.7 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: www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/m/mental_health_care_cluster_de.asp?shownav=1

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

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

- 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

Before submitting your sample file to the Co-ordination 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 Trust code, Service User Record Number and the Mental Health Care Cluster only. 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 Care Cluster Code 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 4.3 – Keeping service user mailing data and sample data separate*).

It is very important that the Mental Health Care Cluster is not shared 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 trust code, 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 mh.cc@pickereurope.ac.uk if you have any queries.

9.8 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 Trust code).

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.¹

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 mailings are 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

<i>Service user Record number</i>	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

9.9 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 2016 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 mh.cc@pickereurope.ac.uk or call 01865 208127. However, before you decide to do this, there are some important points to consider:

- The core sample for the Community Mental Health Survey 2016 **must** be drawn as specified in this guide; any deviation from the instruction manual 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 Co-ordination Centre, only the sample information required for the national survey. The Co-ordination 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: www.nhssurveys.org/localsurveys

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

- Analyse or compare results for specific subgroups (for example, service users treated at different sites or service users of different ethnicities) in more detail than would be possible from a sample of 850 service users. By increasing the sample size you can ensure that

you have a large enough sample of service users from each group;

- 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 2016, 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.

10 Final sampling inspection by the Co-ordination Centre

10.1 The sample declaration form

As per other surveys within the patient survey programme, one of the requirements for the 2016 Community Mental Health Survey is the completion of a Sample Declaration Form (see Appendix 5). This form is to be completed by the person drawing the sample, the person checking the sample and must be counter signed by the Caldicott Guardian: it is a checklist of different steps that must be actioned before the sample is ready for submission. The purpose of this is to try and prevent data breaches, and ensures that a number of data protection requirements are addressed.

You must submit your sample declaration form to the Co-ordination Centre directly before you submit your anonymised sample file. The Co-ordination Centre will confirm receipt and check that the form is fully completed and correct, before requesting that you send your sample file to them. Do not send your sample file until the Co-ordination Centre have confirmed they have approved the sample declaration form.

10.2 Sample checking by the Co-ordination Centre

Trust data should still be checked for errors and a DBS check completed 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, and the Care Cluster Code must be removed. **Trusts should encrypt their sample files before sending to the Co-ordination Centre for checking².**

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 **12th February 2016**. 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, and trusts will be penalised as set out in section three.

Trusts which have not submitted their sample for checking by the **19th February 2016** 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 **26th 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.

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.

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

Making the most of the fieldwork period

Because certain demographic groups (specifically younger service users and those from non-white ethnic categories) have been shown to take longer to respond to service user surveys, we strongly recommend that files are submitted at the start of the sample checking period. The best way to ensure you can do this is to prepare before the start date of the survey (**22nd February 2016**). You can do this by:

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

11 Materials

11.1 Questionnaires

Questionnaire layout

The questionnaire is rigorously tested in the format on the website at <http://www.nhssurveys.org/surveys/887>. All questionnaires used by trusts should emulate this format and should be comprised of the following:

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

Q5. Were you given **enough time** to discuss your needs and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

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

Please ensure that you do not add any logos to the questionnaire: only the CQC and NHS logo should appear on the questionnaire.

Number of pages

It is practical to ensure that the number of pages in a questionnaire is a multiple of four so that sheets can be printed double-sided on A3 paper and folded to make an A4 booklet, stapled in the middle. If pages are stapled at the corner, there is a greater chance that some pages will become detached and get lost. The questionnaire, available in PDF format on the nhssurveys website <http://www.nhssurveys.org/surveys/887>, is designed to fit onto 8 sides of A4 paper.

Number of questionnaires

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

Other mailings and inclusion of other information in the mailing packs

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

Only the materials described below should be included in the questionnaire packs because of the unmeasurable impact upon response rates to the survey. Additionally, the multi-region ethics board judged that inclusion of additional material that they had not viewed would invalidate the ethical approval they have given for the Community Mental Health Survey 2016 and the survey would therefore not be able to proceed.

11.2 Covering letters

These can be downloaded from our surveys website: <http://www.nhssurveys.org/surveys/888>.

Due to the ethical approval given, **no changes are permissible.**

Please note that you must send all 3 mailings (including the two reminder letters) even if a good response rate has already been achieved.

11.3 Trust headed paper

You will need headed paper from your trust for covering letters for the first and third mailing. A reminder letter is used for the second mailing. Therefore, depending on your response to the initial mailings, you will need approximately 1,200 to 1,600 sheets of trust headed notepaper.

11.4 CQC Flyer

For this survey, a survey flyer has been produced by the CQC. This flyer explains who the CQC are, the importance of gathering patient feedback and what will be done with the data collected. The flyer will be included in both the first and third mailings. It is hoped that it will highlight the importance and purpose of the survey to service users and provide evidence of how their feedback contributes to monitoring the performance of the NHS.

Please note that this flyer should only be used for the 850 sample. If you extend your sample size, the CQC flyer should not be included in the mailing packs for the additional sample.

These will be provided to you directly – please confirm a contact name and address for delivery.

11.5 Mail out envelopes

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

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

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

11.6 First mailing

You will need 850 of each of the following items:

- Printed questionnaires;
- Large envelopes for mailing questionnaires to service user; (these should be plain envelopes and have no identifiers on the outside – e.g. NHS logo, trust logo or trust name);
- Labels for addressing envelopes;
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house Trusts);
- FREEPOST envelopes for return of questionnaires;
- Covering letters using the trust's letterhead;
- Multi-language helpline sheet (recommended)¹;
- CQC flyer.

11.7 Second mailing (first reminder)

First reminders are sent to all service users who do not respond to the first mailing (except, of course, those who withdraw). The following items are needed:

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

The first reminder should be sent to service users who have not responded after **one to two weeks**. We recommend approximately **ten** days between the mailing day of the first questionnaire and the mailing day of the first reminder.

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

11.8 Third mailing (second reminder)

The second reminder should replicate the first mailing. The following items are needed:

- Printed questionnaires;
- Large envelopes for mailing questionnaires to service user; (these should be plain envelopes and have no identifiers on the outside – e.g. NHS logo, trust logo or trust name);
- Labels for addressing envelopes;
- Labels for sender address on reverse of envelopes (PO Box address recommended for in-house Trusts);
- FREEPOST envelopes for returning questionnaires;
- Reminder letters;
- Multi-language helpline sheet (if used in first mailing);
- CQC flyer.

Second reminders should be sent out approximately **two to three weeks** after the first reminder to service users who have not yet responded.

Please note: Trusts should send the full sample list to DBS in advance of the second and third mailings, for this survey. Any records that are returned as deceased should be removed from the mailing lists to ensure that a questionnaire is not sent to these people. Please ensure that you leave sufficient time to run deceased checks on the sample list, prior to any mailings being sent out. You will need to log these service users as 'Outcome 3 – service user died'.

11.9 Submitting hard copies of the questionnaire and cover letters

Hard copies of the questionnaire and cover letters must be submitted to the Co-ordination Centre **by 26th February 2016**. These must be the same as those sent out to your service users – with the trust letterhead, CEO's signature, etc.

Please submit:

- Two paper copies of the questionnaire;
- Two paper copies of the first mailing covering letter;
- Two paper copies of the first reminder letter;
- Two paper copies of the second reminder letter.

You **must ensure that you do not include any service users name and address** information on the copies of the covering letters and the reminder that you send to the Co-ordination Centre.

These must be sent to:

Community Mental Health Survey 2016
Patient Survey Co-ordination Centre
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0JB

12 Weekly Monitoring

The Co-ordination Centre requires weekly submissions of outcome data and helpline calls for each trust taking part in the Community Mental Health Survey 2016. First submission of data must be made on **Thursday 3rd March 2016**¹, and every Thursday thereafter until the final date of submission.

An Excel spreadsheet is available on our website <http://www.nhssurveys.org/surveys/901> which **must** be used to return this information to the Co-ordination Centre. This information should be emailed to the Co-ordination Centre (mh.cc@pickereurope.ac.uk) by the end of the workday every Thursday throughout the survey.

Weekly submissions only apply to the core sample of service users

Important note

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

When the data is submitted, the file name **must** be in the following format:

MH16_<trust code>_<week of submission>.xls

e.g. MH16_RRP_1.xls (first submission of monitoring data on 3rd March)

MH16_5JE_4.xls (fourth submission of monitoring data on 24th March)

12.1 Response rate

The information submitted should contain the following data:

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

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

12.2 Helpline monitoring

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

- The overall total number of calls received by the helpline for this survey. This total should also include the calls listed below:

¹ This submission must be made regardless of whether mailing has commenced.

- The total number of calls that led to completion of the questionnaire using the helpline (this should include completions via translation services);
- The total number of calls seeking assistance with language and translation (this should include completions via translation services);
- The total number of calls that led to completion of the questionnaire using translation services.

Examples

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

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

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

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

13 Publicising the survey

The following measures will help to increase response rates and reduce the number of questions or complaints that may be received about a survey, and some will help address the fair processing principle of the Data Protection Act:

13.1 Pre-survey communication with staff

The best way to ensure your survey is a success is to work hard in the beginning to involve those people who have the most impact on service users' experiences and who will be responsible for responding to the results of the survey. We suggest you put together a small team of people who are key stakeholders and involve them in decisions. Groups to consider include:

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

Keeping everyone informed

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

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

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

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

13.2 Publicising the survey externally

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

- Send a press release to the local media to raise awareness of the survey and gain publicity just before the survey takes place. Information to help you draft a press release is shown in *Appendix 2*. Talk to your trust's press office for more ways in which you can gain publicity locally;
- Put up posters which show the importance the trust places on gathering service user feedback. To be most effective at increasing your response rate, posters should be put up during the fieldwork period. A poster is available on the NHS surveys website at <http://www.nhssurveys.org/surveys/886>
- Consider using social media such as twitter or Facebook for example or other local social media to publicise the survey.

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

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

14 Implementing the survey – practicalities

14.1 Setting up a FREEPOST address

A FREEPOST address allows service users to return completed questionnaires at no cost to themselves. After you have paid for the licence, you will only pay for the responses you receive. The FREEPOST address can be printed on the envelopes you send out with the questionnaires. Printed envelopes must comply with Royal Mail guidelines. Details of how to apply for a FREEPOST licence can be found at the Royal Mail website: <http://www.royalmail.com>.

Alternatively, you can call your local Sales Centre on 0845 7950 950.

14.2 Setting up a PO Box

This is recommended to ensure that the mail out envelope(s) does not include any indication of the NHS trust address (please see *Section 11.5* for further detail). Information on setting up a PO address can be found at:

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

14.3 Setting up a FREEPHONE line

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

Where appropriate, ask the service users who call to tell you their service user record number, which should be on the address label of the envelope they received, and on the questionnaire itself. You can then use this number to identify people who do not want to receive any further reminders.

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

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

Service users can be referred to the trust's PALS or the complaints manager.

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

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

The person to whom the questionnaire is addressed has died.

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

to respond sensitively to such calls. These service users should be logged as outcome = 3 (service user deceased).

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

If a service user's spoken English is better than their written English, they may be willing to have someone, such as a family member, fill in a form on their behalf. It is also strongly recommended that you offer access to a telephone interpretation service, where the questionnaire can be filled in over the telephone. A multi-language sheet template in the twenty most commonly spoken languages in England is available on our website, and trusts can make use of this by inserting the appropriate number for their helpline and/or translation service.

I do not wish to participate in this survey

If you use posters to publicise your survey as recommended, some service users may call the number provided to opt out of the survey.

A few service users might call to say that they do not want to be involved in the survey, and fewer still may object to being sent the questionnaire in the first place. Staff should apologise to the service user and reiterate the statement in the covering letter - that taking part in the survey is voluntary, and that the service user's care will not be affected in any way if they do not respond.

A few additional points of guidance for people not wanting to participate in the survey.

1. Any objection is to be recorded immediately and checks made to determine whether a mailing is underway. If a mailing is underway the caller will need to be advised that it might not be possible to prevent this mailing but assured that they will receive no future mailings;
2. People wishing to receive no further questionnaires can be identified with a flag/ code/ number on the mailing file.

When speaking to callers wishing to opt-out of future survey mailings, it is not appropriate to try and dissuade them from their intent. There is a risk that even well intentioned discussion around the benefits of the survey could be perceived as applying pressure to participate. The benefits of the survey should only be mentioned by call-takers in response to queries from callers. If someone feels strongly enough about the survey that they initiate contact to object, callers are advised they are being removed from the mailing list for this survey only, and that if they wish to register their dissent against wider research participation at their trust, and this is not something that the person taking the call is able to help with, please ensure that you are able to direct the caller to PALS or the trust Information Governance Team as appropriate.

It is also advisable to ask the service user to ignore any future reminders that they might receive. These service users should be recorded as outcome = 4 (opt out) in the sample file.

Making a record of the calls

It is important to keep a record of the reasons service users called, as this can help to make improvements to future surveys and can provide useful additional information on service users' concerns. A standard form should be produced for completion by those taking the calls. The relevant details of each call can be recorded so that survey organisers can monitor any problems and remove service users who wish to be excluded from the mailing list.

We are also asking for weekly submissions of helpline use for each trust to the Co-ordination Centre. This is discussed in detail in *Section 12*.

14.4 Covering letters

The standard covering letter is available in Microsoft Word format on the Community Mental Health section of the NHSSurveys website for you to download and add your own trust's details <http://www.nhssurveys.org/surveys/888>. This letter has been given ethical approval for use in the Community Mental Health Survey 2016 and **changes are not permissible**. It should be printed on the trust's letterhead paper. Two paper copies of the letter you use must be sent to the Co-ordination Centre **by 26th February 2016. These must not contain any service user name and address information.**

Please note, for the first mailing letter and second reminder mailing there is the option to include service user name. We recommend this approach as there is evidence to show that this increases response rate (we would recommend using service user title followed by surname). If service user name is used, please take great care that each letter is correctly matched to its corresponding questionnaire.

14.5 Sending out questionnaires

Mailing labels

Three mailing labels are needed for each service user. One set of labels will be used for the first mailing, one for the first reminder and one for the second reminder.

We recommend using the mail merge feature in a word processing package to create the mailing labels from the database of service user names and addresses. **It is essential that the service user record number is on each address label**, as this has to be matched with the number on the front of the questionnaire. The label should not include any other information except the service users' name, address and postcode details, and the service user record number.

Note on the service user record number (SURN)

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

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

Questionnaire packs

The envelope sent to each service user at the first mailing should include the following:

- 1) A questionnaire **numbered with the service user record number**. The number must match the number on the address label, and the number on the list of service user details;
- 2) A covering letter;
- 3) The multi-language helpline sheet (recommended);
- 4) A large envelope, labelled with the FREEPOST address on it;
- 5) These items should be packed into an envelope that has a return address on the outside. (PO Box recommended.) This should be the contact at your trust;
- 6) CQC flyer.

Postage

The postage may exceed the standard letter rate. It is essential that the appropriate postage rate is paid.

14.6 Booking in questionnaires

When questionnaires are received, match up the service user record numbers against the list of service users, so that you can record (in the *outcome* column) which service users have returned questionnaires and will not therefore need to be sent reminders. You will need to keep paper copies (or scanned pictures of all of the pages of the questionnaires, including the front page) of any questionnaires that are returned to you until **16th December 2016**, but please **do not** send these to the Co-ordination Centre.

14.7 Sending out reminders

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

Depending on the time that has elapsed since you first checked your service user list for deaths, it might be necessary to send your list back to the tracing service (DBS) for a further check before you send out reminders.

First reminders

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

The standard first reminder is available in Microsoft Word format on the nhssurveys website for you to download <http://www.nhssurveys.org/surveys/888> It can be printed on A5 if desired. It has been given ethical approval so no changes are permitted. Two paper copies of the reminder letter you

use must be sent to the Co-ordination Centre **by 26th February 2016. This must not contain any service user name and address information.**

Second reminders

Second reminders should be sent out approximately **two to three weeks** after the first reminder to service users who have not yet responded.

The envelopes should include the following:

- 1) A questionnaire numbered with the service user record number. The number must match (or correspond to) the number on the address label and the number on the list of service user details;
- 2) A covering letter;
- 3) A multi-language helpline sheet (if used in first mailing);
- 4) A large envelope, labelled with the FREEPOST address on it;
- 5) These items should be packed into an envelope that has a return address on the outside. (PO Box recommended.) This should be the contact at your trust;
- 6) CQC flyer.

The standard second reminder letter is available in Microsoft Word format on the NHSSurveys website for you to download and add your trust's details <http://www.nhssurveys.org/surveys/888> It has been given ethical approval so no changes are permitted. Two paper copies of the second reminder letter you use must be sent to the Co-ordination Centre **by 26th February 2016. This must not contain any service user name and address information.**

Remember that you should check your trust's own records for deaths before sending out reminders. These should be logged as 'Outcome 3 – Service user died'.

15 Entering data

Final data must be submitted to the Co-ordination Centre in the appropriate format by the deadline of **1st July 2016**.

15.1 Entering and coding data from the questionnaire

The data should be entered into the pre-designed Excel file, which can be found in the Community Mental Health Survey section of the website www.nhssurveys.org.

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

- Each row records one service user's responses to the survey;
- For each question, the small number next to the box crossed by the service user should be entered as the response;
- If a response is missing for any reason, it should be left blank, or coded as a full stop (.)¹;
- If two boxes are crossed (where only one should be ticked), the response should be left blank or coded as a full stop (.), **except** for Q40 where the code of '98' should be used to indicate more than one number being circled or a non-integer has been selected;
- For most questions, each column corresponds to one survey question. However, there is one exception to this rule. For Q8 each response option is treated as a separate question. Please note that this question does not ask the respondent to choose all that apply. However, for the purpose of data submission this question should be treated as such.
- When saving this file to submit data to the Co-ordination Centre, please save only the first sheet as a worksheet, rather than saving the whole file as a workbook; the Co-ordination Centre does not need the additional formula pages.

Example

Q8. Is the person in charge of organising your care and services...

- 1 A CPN (Community Psychiatric Nurse)
- 2 A psychotherapist / counsellor
- 3 A social worker
- 4 A psychiatrist
- 5 A mental health support worker
- 6 A GP
- 7 Another type of NHS health or social care worker
- 8 Don't know

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

Responses to each part of this question are coded: **1 if the box is crossed**
0 if the box is not crossed¹

Q8 takes up eight columns in the data file, labelled as follows:

Column headings	Q8_1	Q8_2	Q8_3	Q8_4	Q8_5	Q8_6	Q8_7	Q8_8
Codings for this example	1	0	0	0	0	1	0	0

Coding Q40 'Overall' question

Please follow the rules detailed above for all questions with the exception of Q40. This is the 'Overall' question where instead of being asked to cross a box, people are asked to circle a number on an 11 point scale from 0-10. We recommend that this question is entered manually (rather than scanning it) and should only be entered where the response is unambiguous. If two boxes are circled or if people have provided an answer which is in any manner difficult to interpret e.g. they have drawn a mark between two of the numbers, please code this as '98'. If the question is left entirely blank, the response should be left blank or coded as a full stop (.).

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

You will need to send the data from **all** 47 Community Mental Health Survey 2016 questions to the Co-ordination Centre. To do this, you can use the pre-designed Excel file available on the website. The columns of this standard Excel file are headed with the numbers corresponding to the question numbers in the service user questionnaire. They also include the wordings of the 47 service user questions so that you can match them up. It is essential that you check carefully that the columns of data you select correspond to the 47 service user survey questions.

15.2 Entering the service users' written comments

The Care Quality Commission has asked the Co-ordination Centre to request all free text comments provided by respondents to the Community Mental Health Survey 2016. Any analysis of these free text comments will be conducted in a way that would not allow individuals to be identified.

For this year, the free text comments **must be included in full** so that they can be looked at in full by trusts, the CQC and researchers. The CQC felt that the uncensored comments would provide valuable feedback. Comments will, however, be anonymised prior to any publication of results.

There is a statement included in the questionnaire (under the free text comments box) that states: "Please note that the comments you provide in the box above will be looked at in full by the NHS Trust, Care Quality Commission and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback"

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

The written comments should be entered in the main data file alongside the responses to the questions and submitted to the Co-ordination Centre on or before **1st July 2016**.

15.3 Checking the data for errors

For the Community Mental Health Survey 2016, trusts are required to submit raw ('uncleaned') data to the Co-ordination Centre. For clarification, raw data is created by the following:

- 1) All responses should be entered into the dataset, regardless of whether or not the respondent was meant to respond to the question (e.g. where service users answer questions that they have been directed to skip past, these responses should still be entered);
- 2) Where a respondent has crossed more than one response category on a question, this should be set to missing in the data. The **exception** to this is Q8, where you should enter all the responses options selected (see *Section 15.1*) and Q40 where the code of '98' should be used;
- 3) Where a respondent has crossed out a response, this should not be entered in the data. Where a respondent has crossed out a response and instead chosen a second response option, this second choice should be entered into the data;
- 4) Where a respondent has given their response inconsistently with the formatting of the questionnaire but where their intended response is nonetheless unambiguous on inspection of the completed questionnaire, then the respondent's intended response should be entered. For example, where a service user has written their date of birth in the boxes for Q44, but written their year of birth in at the side of this, then the respondent's year of birth should be entered;
- 5) For the year of birth question, unrealistic responses should still be entered except following rule 4) above. For example, if a respondent enters '2016' in the year of birth box, this should still be entered unless the respondent has unambiguously indicated their actual year of birth to the side;
- 6) Once the data has been entered, no responses should be removed or changed in any way except where responses are known to have been entered incorrectly or where inspection of the questionnaire indicates that the service user's intended response has not been captured. This includes 'out-of-range' responses, which must not be automatically removed from the dataset. Responses in the dataset should only be changed before submission to the Co-ordination Centre where they are found to have been entered inconsistently with the respondent's intended response.

A data cleaning document will be provided during the fieldwork that will document all filtering and cleaning carried out on the collated dataset by the Co-ordination Centre so that you can duplicate this process after submitting the raw data to the Co-ordination Centre. This will be available on the NHS surveys website.

15.4 Submitting data to the Co-ordination Centre

The data from the questions for the Community Mental Health Survey 2016 must be supplied to the Co-ordination Centre as one anonymised Excel file that includes information about the service user sample and responses.

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

Required file format

Please submit the file to the following specifications:

- Use Microsoft Excel Worksheet (not Workbook). Any version of Excel is acceptable;
- The file name must be in the form **MH16_surveydata_XXX.xls** (where XXX is your Trust code);
- Use one row of data for each service user in the sample;
- Use one column of data for each item of service user information or response;
- Service users who are missing their Service User Record Numbers should be added to the bottom of the list, and not matched to service users with similar demographics;
- Missing data should be left blank or coded as a full stop (.).¹

Table 3 shows the information that must be provided for each of the 850 service users in the original sample.

Table 3 - Data fields to be included in file submitted to Co-ordination Centre

Field	Format	Codes & formats	Comments
Trust Code	NNN	Trust code	NHS Connecting for Health http://systems.hscic.gov.uk/data/ods/datadownloads/othernhs
Service User Record Number	MH16X XXNNN N		The unique serial number allocated to each service user by the Trust. This should include the survey code (MH16), followed by the trust code (e.g. RBQ), followed by a 4-digit number (0002, 0003, 0005, etc)
Year of Birth	NNNN		
Gender	N	1 = male 2 = female	If gender is not known or unspecified, this field should be left blank or coded as a full stop (.).

¹ Data may be missing for a number of reasons. The service user may have skipped a question or a set of questions by following instructions; a service user may have not answered for some other reason. However, all missing data should be left blank or coded as a full stop (.), regardless of the reason for the omission.

Ethnic Category	X	<p>White</p> <p>A British</p> <p>B Irish</p> <p>C Any other White background</p> <p>Mixed</p> <p>D White and Black Caribbean</p> <p>E White and Black African</p> <p>F White and Asian</p> <p>G Any other mixed background</p> <p>Asian or Asian British</p> <p>H Indian</p> <p>J Pakistani</p> <p>K Bangladeshi</p> <p>L Any other Asian background</p> <p>Black or Black British</p> <p>M Caribbean</p> <p>N African</p> <p>P Any other Black background</p> <p>Other Ethnic Groups</p> <p>R Chinese</p> <p>S Any other ethnic group</p> <p>Z Not stated</p>	<p>Ethnic category.</p> <p>The code “Z” (not stated) should be used when a person has been asked for their ethnic category and have refused or been unable to choose. A blank or full-stop should still be used where the service user’s ethnic category is unknown as they have not been asked or was not in a condition to be asked</p>
CPA Status	N	<p>1 = the service user is registered on ‘new’ CPA</p> <p>2 = the service user is not on new CPA</p> <p>3 = CPA status unknown</p>	
CCG Code	NNN	Use the character codes provided by HSCIC to complete this field	Use the three characters of the CCG.
Day of last contact or last review	N or NN	Format as a number , not a date	For example, if the service user last had contact on 20 th January 2016, this column should read 20.
Month of last contact or last review	N or NN	Format as a number , not a date	For example, if the service user last had contact on 20 th January 2016, this column should read 1.
Year of last contact or last review	NNNN	Format as a number , not a date	For example, if the service user last had contact on 20 th January 2016, this column should read 2016.
Day of receiving questionnaire	N or NN	This is the day you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 15 th March 2016, this column should read ‘15’.
Month of receiving questionnaire	N or NN	This is the month you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the	For example, if the questionnaire was received on 15 th March 2016, this column should read ‘3’ (as

		survey (patient deceased, moved address, too ill, or called to opt out)	March is the 3 rd month of the year).
Year of receiving questionnaire	NNNN	This is the year you received a returned questionnaire from a respondent, or are notified that the patient will not be participating in the survey (patient deceased, moved address, too ill, or called to opt out)	For example, if the questionnaire was received on 15 th March 2016, this column should read '2016'.
Outcome	N	<p>1 = Returned useable questionnaire 2 = Returned undelivered by the mail service or service user moved house 3 = Service user died* 4 = Service user too ill, opted out or returned blank questionnaire 5 = Service user not eligible 6 = Questionnaire not returned (reason not known) 7 = service user deceased prior to fieldwork</p> <p><i>*This would be once the first mailing had gone out</i></p>	<p>Outcome of sending questionnaire</p> <p>Remember to fill in all the blank cells with 6s when the survey is complete.</p>
Responses to each of the questions	N or string		Each column must be clearly headed with the question number. Take care with Q8, the multiple response question where there's one column for each response category. Data should be coded using the numbers next to the response boxes on the printed surveys.
Service users free text comments	Text		Please enter comments verbatim: the questionnaire includes a note to respondents to inform them that the comments will be used in full to ensure that full use can be made of the detailed feedback

NB: To comply with the Data Protection Act, name and address details must not be sent to the Co-ordination Centre. Please also make sure that if you are collecting any additional variables in your sample frame, other than those required by the national survey, you do not share these with the Co-ordination Centre.

Please remember that this file must not contain mental health care cluster code. As detailed in *Section 9.7*, this should have been removed and sent separately to the Co-ordination Centre.

Table 4 is an example of the columns of data to be included in the file. Your file should have 850 rows (one for each service user included in your sample). You will notice that there are several

blank cells in the response section of the file. This is because the file includes a row for every service user in the sample, but you will only have responses from about 30% of the service users (that is, those who have returned a completed questionnaire, and who will therefore have an outcome code “1”).

Table 4 – Example of data file to be submitted to Co-ordination Centre

Service user Sample Information										Service user Response							
Trust Code	Service User Record Number	Year of birth	Gender	Ethnic Category	Day of last contact	Month of last contact	Year of last contact	CPA Status	CCG Code	Day questionnaire received	Month questionnaire received	Year questionnaire received	Outcome	Q1	Q2	...	Q47
RT V	MH16 RTV0 002	197 1	2	A	2	09	2015	1	04J	4	4	2016	3				
RT V	MH16 RTV0 003	195 8	1	A	14	10	2015	1	04J	25	3	2016	1	3	1		1
RT V	MH16 RTV0 007	196 4	2	B	3	12	2015	3	04J				6				
RT V	MH16 RTV0 008	198 0	2	E	3	01	2015	2	04 M	3	3	2016	1	2	1		3
RT V	MH16 RTV0 009	195 1	2	A	3	02	2015	2	04J	17	3	2016	1	3	2		5
RT V	MH16 RTV0 010	197 9	1	G	14	09	2016	3	04 M				7				
RT V	MH16 RTV0 011	198 7	2	A	21	01	2015	1	04J				6				
RT V	MH16 RTV0 012	194 6	2	K	30	11	2015	2	04J	23	2	2016	1	3	1		1

Additional information required

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

- **Contact details** (telephone numbers and e-mail addresses) of at least two members of trust staff (usually the main and secondary contacts) who will be available to answer any queries about the data;
- A completed copy of the **checklist** (See *Section 15.5 - Checklist*).

Delivery

Data should be encrypted by e-mail to mh.cc@pickereurope.ac.uk, with the password provided separately by phone (see *Section 4* of this document for details on the recommended encryption and delivery methods to use).

As the owners of the data, the method for transferring sample and response data is ultimately your decision because the trust remains legally responsible for the security and processing of the information it shares. Trusts wishing to send information by encrypted email will need to seek their own specialist advice. Guidance on best practice in encryption and delivery methods to use is available from NHS Connecting for Health see:

<http://systems.hscic.gov.uk/infogov/security/infrasec/gpg/acs.pdf>

Deadline for submission

The data including the free-text comments must be supplied by **1st July 2016**.

15.5 Checklist

Before sending your data to the Co-ordination Centre, carry out the checks listed below, and include this checklist when you submit the final data-

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

If incorrect data are submitted, it is possible that the data will be considered unreliable, and will be flagged as a risk in CQC's intelligence model. We cannot accept re-submissions of data after the deadline, and likewise data is unlikely to then be included in the Care Quality Commission assessments.

The data should be entered into the pre-designed 'Data Entry Spreadsheet' which is located here <http://www.nhssurveys.org/surveys/880> along with the checklist below:

Checklist	Initials
1) Check that your file name follows the naming convention: <MH16_surveydata_XXX.xls> where XXX is your Trust or Contractor code)	
2) Check that you have saved the data sheet only as an Excel worksheet , rather than a workbook (the frequency and percentage counts on the other pages of the workbook on the website are intended for your use only)	
3) Check that you have included data columns for all 47 questions	
4) Check that all data are correct , and that all values are in range	
5) Check that you have included the free text comments as appropriate, and that they are included in full	
6) Send data only for the 850 randomly selected service users seen between 1 st September 2015 and 30 th November 2015	
7) Check that all the data are in numeric format only (including dates)	

8) Check that you have completed the columns for the day, month and year you received the questionnaire back from service users	
9) To comply with Data Protection regulations, any sample information relating to service user name and address details must be removed before the file is sent to the Co-ordination Centre	
10) Check that your data file does not include any data relating to care cluster	
11) Please zip, encrypt and password protect your data before sending to the Co-ordination Centre. Please remember to inform us of the password by phone	
12) Include telephone and e-mail contact details of two people who will be available to respond to any queries about the data – please enter details below	
13) Check again that all data are correct, and that all values are in range	
14) If you have collected any additional variables in your sample frame, other than those required by the national survey, and / or increased your sample size, check that these have been removed.	

First contact

Name:

Job title:

Phone number:

Email address:

Second contact

Name:

Job title:

Phone number:

Email address:

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

Example titles:

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

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

Understanding service users' experiences in [trust name]

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

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

Why are we doing another service user survey?

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

The results will help [NHS trust name] see where they perform well and to identify any areas where there is room for improvement.

The survey is part of a commitment to design a health service around the needs and priorities of patients and service users, and to take account of their feedback and views. It signals the value and importance of listening to the people who use services to drive improvement.

When is the survey taking place?

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

Service users are being asked about various aspects of their care, including [the quality of care and treatment, treatments, communication with health and social care workers, information, and support & wellbeing]

Who is the survey being sent to?

The survey will be sent to a sample of [number] service users, aged 18 years and over, who received community mental health services during [months].

How have the results from previous surveys been used?

Results from the 2015 community mental health user survey helped to identify areas where there was most room for improvement [a summary of the key findings from the previous survey and how the trust acted on the results can be inserted here]

When will the results of this survey be available?

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

Where can I find out more?

For more information about the survey, please contact [\[lead survey name and contact details\]](#)

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

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

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

People who have recently used services at [trust name] may receive a questionnaire in [month], asking about their experiences. They will be asked about various aspects of their care, including [the quality of care and treatment, treatments, communication with health and social care workers, information, and support & wellbeing]

Obtaining feedback from service users and taking account of their views and priorities is vital for bringing about improvements in the quality of care. The results will help [NHS trust name] see where they perform well and to identify any areas where there is room for improvement.

The survey is part of a commitment to design a health service around the needs and priorities of patients and service users, and to take account of their feedback and views. It signals the value and importance of listening to the people who use services to drive improvement.

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

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

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

Appendix 3: Declarations of data protection compliance

Declaration of compliance with the Data Protection Act 1998

**DECLARATION
RELATING TO THE
Community Mental Health Survey 2016
FOR TRUSTS USING IN-HOUSE SURVEY TEAMS**

While carrying out the Community Mental Health Survey 2016, all trusts need to comply with:

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

Due to the large amount of service user information requested by the Community Mental Health Survey 2016 programme, it has become necessary to regulate which individuals at a trust are able to view the raw data and some of the processed data. Only those trust staff who have completed this declaration will be authorised to view this restricted data. As the Caldicott Guardian is the designated person within the trust to supervise access to service user identifiable information, all declarations must be co-signed by the trust's Caldicott Guardian. If the trust's Caldicott Guardian does not authorise this, the trust must carry out the survey using an approved contractor.

For further information on the guidelines, please see the "Data protection and Confidentiality" section in the Instructions Manual for the Community Mental Health Survey.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the Community Mental Health Survey 2016 programme will conform to the guidelines set out under the section "Data protection and Confidentiality" in the Instructions Manual for the Community Mental Health Survey 2016.

Signature: Date:

I, **[insert name of first survey lead]** the first Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the Community Mental Health Survey 2016 and will ensure that data collected while carrying out the Community Mental Health Survey 2016 will conform to these requirements and the guidelines set out under the section "Data protection and Confidentiality" in the Instructions Manual for the Community Mental Health Survey 2016.

Signature: Date:

I, **[insert name of second survey lead]** the second Survey Lead for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the Community Mental Health Survey 2016 and will ensure that data collected while carrying out the Community Mental Health Survey 2016 will conform to these requirements and the guidelines set out under the section "Data protection and Confidentiality" in the Instruction Manual for the Community Mental Health Survey 2016.

Signature: Date:

Appendix 4: Declarations for additional data analysts

Declaration of compliance with the Data Protection Act 1998

**DECLARATION
RELATING TO THE
Community Mental Health Survey 2016
Additional data analysts**

If the trust requires additional data analysts to have access to the raw data set, this form must be completed and sent to the Co-ordination Centre, and a response received before access to the data set is granted. Only those trust staff who have completed this declaration will be authorised to view this restricted data. As the Caldicott Guardian is the designated person within the trust to supervise this access, all declarations must be co-signed by the Caldicott Guardian. If the Caldicott Guardian does not authorise this, the raw data set and responses from subgroups numbering fewer than 30 can only be viewed by the authorised survey leads.

For further information on the guidelines, please see the “Data protection and Confidentiality” section in the Instruction Manual for the Community Mental Health Survey 2016.

I, **[insert name of Caldicott Guardian]** the Caldicott Guardian for **[insert trust name]** declare the aforementioned trust to be compliant with the Data Protection Act 1998 and will ensure that data collected while carrying out the Community Mental Health Survey 2016 will conform to the guidelines set out under the section “Data protection and Confidentiality” in the Instruction Manual for the Community Mental Health Survey 2016.

Signature: Date:

I, **[first additional data analyst]** the first additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the Community Mental Health Survey 2016 and will conform to these requirements and the guidelines set out under the section “Data protection and Confidentiality” in the Instruction Manual for the Community Mental Health Survey 2016.

Signature: Date:

I, **[second additional data analyst]** the second additional data analyst for **[insert trust name]** declare I understand the requirements of the Data Protection Act 1998 as they relate to the Community Mental Health Survey 2016 and will conform to these requirements and the guidelines set out under the section “Data protection and Confidentiality” in the Instruction Manual for the Community Mental Health Survey 2016.

Signature: Date:

Appendix 5: Sample Declaration Form

Community Mental Health Survey 2016: Sample Declaration – In-house Trusts

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. 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 instruction manual <http://www.nhssurveys.org/surveys/891>

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 (mh.cc@pickereurope.ac.uk) **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 2016

Sample Declaration Form – In-House Trusts

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 1st September and 30th 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 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).

* 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 (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 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 1st September and 30th 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: