

2018 Community Mental Health Survey: Survey Development Report

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Updates

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This document is available from the Survey Coordination Centre website at:
www.nhssurveys.org/surveys/1138

Questions and comments

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1. Background

The Community Mental Health Survey has been conducted almost every year since 2004 as part of the NHS Patient Survey Programme (NPSP), coordinated by Picker on behalf of the Care Quality Commission (CQC). Its purpose is to understand, monitor and improve service users' experiences of NHS community mental health services. In 2017, over 12,000 participants from 56 NHS trusts and social enterprises told us about their experiences by taking part in the survey.

Data collected from the 2018 Community Mental Health Survey (CMH18) will be used by the CQC in its assessment of mental health trusts in England. The results are also used by NHS England and the Department of Health for performance assessment, improvement and regulatory purposes. These include the NHS Outcomes Framework (domain 4: Ensuring patients have a positive experience), the NHS England overall patient experience measure, the NHS Performance Framework, the cross-Whitehall Public Services Transparency Framework and NICE Quality Standards.

The survey methods used in this iteration are comparable to those of the 2017 survey. In preparation for the 2018 survey, some changes have been made to the design and content of the questionnaire and covering letters in response to a pilot study that was conducted alongside the 2017 survey as well as stakeholder feedback, policy, correlation analysis of the 2017 final data and cognitive testing. This report details these changes.

Cognitive testing

As is common practice in the NPSP, the revision and redevelopment of all questionnaires follows best practice. All question changes, regardless of how minor, are cognitively tested with recent service users. Cognitive testing (or interviewing) is a research method which tests new questions and questions used in previous years to check if they are interpreted and understood as intended by respondents. It also tests whether respondents are able to answer them appropriately with the response options provided.

The respondents were recruited via a number of means, such as local and national online and printed advertisements and on social media (Twitter, Facebook etc.). In total 21 respondents were recruited; 17 testing the CMH18 main stage survey and 4 testing a shorter version of the questionnaire for a pilot study to run alongside the CMH18 survey, representing service users from a wide demographic, geographic and service user experience profiles:

- Males: 5
- Females: 16
- Age range: 22 to 61 years of age
- Geographic locations: Oxfordshire, Worcestershire, Staffordshire and the Welsh borders
- Ethnic backgrounds: White British, White Irish, Lithuanian, Black African, Pakistani and Asian.

The questionnaire was tested during November 2017. Three waves of cognitive interviews were completed. After each wave findings were analysed and, where necessary, changes were made and tested in the subsequent wave of interviews.

Upon completion of cognitive testing, the questionnaire was submitted for a final round of stakeholder feedback, finalised and then submitted for ethical approval alongside the other service user-facing materials.

2. Changes to the questionnaire

Two formal advisory meetings were held as part of CMH18 development. The first advisory group meeting was held with a large group of stakeholders to identify any new potential topics of care for which questions could be added and to identify questions that are no longer necessary or useful. Drafts of the questionnaire were created following this meeting based on the discussions had as well as correlation analysis of the previous iterations' data and a policy review. The second advisory group meeting was held to review the questionnaire draft and to confirm which questions to remove.

In total, six new questions were added and six questions were removed. A further 10 questions were modified. The details of these changes are listed below.

Changes to the questionnaire title, section headings and instructions

During development of the 2018 questionnaire, the title of the questionnaire was changed from the "Service User Questionnaire" in the 2017 survey to the "NHS Community Mental Health Service User Questionnaire". The revised wording was initially taken from the 2017 pilot questionnaire and modified following the findings of cognitive testing. It was felt the revised title gave greater detail regarding the content and purpose of the questionnaire and would help to frame respondent's interpretations of questions around NHS-provided services.

It was also decided early in development to split the "Treatments" section of the 2017 questionnaire into two separate sections; "Medicines" and "Therapies". Doing so offers a more granular assessment of service user experiences of medicine and non-medicine based treatments to be undertaken.

Instructions which precede each section of the questionnaire help to frame respondent's interpretation of subsequent questions. During cognitive testing it was noticed a number of respondents were skipping these instructions, missing key information on how to correctly answer questions. It was therefore decided to change these instructions to bold text to help make this information more obvious to respondents. In addition, the instructions for the 'Support and Wellbeing' section of the 2017 were found to be long and convoluted, and subsequently revised to a much clearer, shorter alternative. Both of these alterations were found to be successful during the later rounds of cognitive testing.

Questions added to the questionnaire

The following questions are new and were thoroughly tested with service users during cognitive interviews:

Q23. Do you feel your medicines have helped your mental health?

- Yes, definitely
- Yes, to some extent
- No
- Not sure

Q29. Do you feel your NHS therapies have helped your mental health?

- Yes, definitely
- Yes, to some extent
- No
- Not sure

The above two questions were added in an attempt to measure how well medicine and non-medicine forms of treatment worked for service users. The wording for these questions changed during the course of cognitive testing. For round one, the wording for each question was as follows:

- Q23. Do you feel your medicines have improved your mental health needs?
- Q29. Do you feel these therapies have improved your mental health needs?

A number of service users found this wording problematic. For question 23, one service user stated they found the question 'patronizing' as they interpreted it to mean that a medicine-based intervention in isolation could result in a service user's full recovery. Across both questions, a number of other service users also found 'improved' to mean different things; either full recovery or progression toward full recovery. In addition, a number of service users found 'needs' to be confusing as they did not understand what 'needs' was referring to. For round 2, the word 'improved' was changed to 'helped' and 'needs' removed for each question to improve clarity and reduce confusion. These changes were well received by service users during the subsequent rounds of cognitive testing.

Though consideration to individual question wording is foremost based on service user interpretation and understanding, the similarity in wording between the medicine and non-medicine versions of the question does allow for potential comparison to understand which treatment service users feel are the most helpful at trusts.

Q30. How long were you on the waiting list before your NHS therapy began?

- Less than 1 month
- Between 1 and 2 months
- Between 2 and 6 months
- Between 6 months and 1 year
- More than 1 year

Don't know / can't remember

It is acknowledged that waiting times for mental health services are too long for many individuals¹. What we don't know is how this compares across trusts and if there are any differences in waiting times for different types of service users. This is especially important to measure as Government begins to implement waiting time standards across mental health services². Question 30 was therefore added to the 2018 questionnaire. During cognitive testing, the wording for this question did not change however service users did differ in terms of when they thought they were put on to the waiting list. Some referred to when they first approached their GP for assistance as when they were first put on the waiting list, whereas others referred to been put onto the waiting once they had been assessed by community mental health teams.

Q39. Do you have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more?

Include problems related to old age.

- Yes (routed to Q40)**
- No (routed to Q42)**

Q40. Do you have any of the following?

Select ALL conditions you have that have lasted or are expected to last for 12 months or more.

- Breathing problem, such as asthma**
- Blindness or partial sight**
- Cancer in the last 5 years**
- Dementia or Alzheimer's disease**
- Deafness or hearing loss**
- Diabetes**
- Heart problem, such as angina**
- Joint problem, such as arthritis**
- Kidney or liver disease**
- Learning disability**
- Mental health condition**
- Neurological condition**
- Another long-term condition**

Q41. Do any of these reduce your ability to carry out day-to-day activities?

- Yes, a lot**
- Yes, a little**
- No, not at all**

¹ <https://www.gov.uk/government/publications/mental-health-priorities-for-change>

² <https://www.gov.uk/government/publications/mental-health-services-achieving-better-access-by-2020>

The above three questions relate to understanding long-term conditions a service user may have and are included in other NHS Patient Survey Programme surveys. The aim of these questions is to give a better understanding as to who responds to the questionnaire and whether different people may have different experiences of care.

During cognitive testing, these questions tested well, with the vast majority of respondents able to answer the questions with ease. Of note is that a very small number of respondents who had a history of long-term mental health issues for a number of years referred only to their current period of poor mental health rather than taking their entire history of mental health into account when responding. Based on this interpretation, the respondent may not have had poor mental health for longer than 12 months or not expect their poor mental health to last longer than 12 months. The majority of service users however did refer to poor mental health over their life course when responding. In addition, the vast majority of service users ticked the response option “Mental health condition” when responding to question 40 with only one respondent unsure if this response option applied to them, given the questionnaire already addresses elements of their mental health.

Questions removed from the questionnaire

The following questions were removed for 2018. The item numbers shown are from the 2017 questionnaire.

Q4. Did the person or people you saw listen carefully to you?

- Yes, definitely**
- Yes, to some extent**
- No**
- Don't know / can't remember**

The above question was discussed in the first advisory group meeting where many stakeholders felt it unnecessary and possibly misleading. Correlation analysis found this question and question 5 to be highly correlated.

Q15. Were you involved as much as you wanted to be in discussing how your care is working?

- Yes, definitely**
- Yes, to some extent**
- No, but I wanted to be**
- No, but I did not want to be**
- Don't know / can't remember**

Similar questions to the above are asked regarding involvement in planning care, and deciding what medicines and therapies to receive. In addition, only service users who had a formal meeting in the previous 12 months to discuss how their care is working are routed to this question. Together, these issues indicate the question to be of limited value. It was

therefore agreed in the second advisory group meeting that the question could be removed to allow for more space for new questions.

Q20. Did you know who was in charge of organising your care while this change was taking place?

- Yes
- No
- Not sure

The section 'Changes in Who You See' apply to very few respondents and was felt one of the questions in this section could be removed to allow additional space for new questions.

Q22. In the last 12 months, have you tried to contract this person or team because your condition was getting worse?

- Yes (Go to 23)
- No (Go to 24)
- Can't remember (Go to 24)

The above question was used for routing respondents to the next relevant question however it was felt the question could be combined with the subsequent question in the 'Crisis Care' section to free space. See 'Q19' in the below section of 'Questions modified' for details of the newly combined question.

Q26. In the last 12 months, have you been prescribed any new medicines for your mental health needs?

- Yes (Go to 27)
- No (Go to 28)

This question was also used for routing respondents to the appropriate next question. We again felt this question could be combined with the subsequent question in this section, thus reducing complexity in the questionnaire.

Q39. Do the people you see through NHS mental health services help you with what is important to you?

- Yes, always
- Yes, sometimes
- No

Correlation analysis identified the above question to be highly correlated with questions 5, 6 and 12 which were all carried over to the 2018 questionnaire. Therefore, it was decided this question could be removed

Questions modified

The original questions from the 2017 questionnaire and the modified versions from the 2018 questionnaire are listed below. In this section, the original question as it was in the 2017 questionnaire is given followed by modified version for the 2018 survey, followed by an overview of the modification(s) made and the rationale behind them. Due to the modifications made to these questions, they are regarded as non-comparable to previous iterations.

The original question:

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

- A CPN (Community Psychiatric Nurse)**
- A psychotherapist / counsellor**
- A social worker**
- A psychiatrist**
- A mental health support worker**
- A GP**
- Another type of NHS health or social care worker**
- Don't know**

The modified version:

Q7. Is the main person in charge of organising your care and services...

- A GP**
- Another type of NHS health or social care worker (e.g. a community psychiatric nurse, psychotherapist, mental health support worker etc.)**
- Don't know / not sure**

This question has two main purposes; to identify the frequency of mental health care organised by primary care workers versus secondary care workers and to 'clean' the remaining questions in the 'Organising Your Care' section so that service users who ticked the 'A GP' response option do not provide data to the subsequent questions 8 and 9. The question was modified to allow space for appropriate formatting of the questionnaire to be maintained and to guide service users to think about the individual person who is most in charge of organising their care through having 'main' in bold text.

Following analysis of the CMH18 final data, it was found that a higher proportion of respondents gave the 'A GP' response compared to previous iterations. This subsequently resulted in more respondents being cleaned out of question 8 and 9 than was the case in previous years. It is believed that the increase in respondents giving the "A GP" response option was as a result of the changes made to question 7 rather than an actual increase the proportion of eligible service users for whom their GP as the main person in charge of their care. It was therefore decided to treat question 8 and 9 as non-comparable to previous iterations.

The original question:

Q23. When you tried to contact them, did you get the help you needed?

- Yes, definitely
- Yes, to some extent
- No
- I could not contact them

The modified question:

Q19. In the last 12 months, did you get the help you needed when you tried contacting this person or team?

- Yes, definitely
- Yes, to some extent
- No
- I could not contact them
- I have not tried contacting them in the last 12 months
- Can't remember

The revised question 19 combined question 22 and 23 from the 2017 survey, allowing space for additional questions. In combining the two questions, the wording “In the last 12 months...” was added in bold to ensure respondents continued to think about only the previous year in responding and for consistency with other such questions. In addition, two further non-specific responses options were added. In the vast majority of cognitive interviews, respondents found this question easy to answer.

The original question:

Q27. The last time you had a new medicine prescribed for your mental health needs, were you given information about it in a way that you were able to understand?

- Yes, definitely
- Yes, to some extent
- No
- I was not given any information

The modified question:

Q22. Were you given information about your medicines in a way that you were able to understand?

- Yes, definitely
- Yes, to some extent
- No
- I was not given any information
- I did not need any information

Due to the removal of the question prior to this one in the 2017 survey, it was decided this question did not need to solely address new medicines specifically so wording was changed

to allow service users on both new and existing medication to respond. We changed 'medicines' to bold text for consistency and added another non-specific response option for anyone who didn't need any information (e.g. those who have been on existing medication for a long time). When cognitively tested, respondents had no issue interacting with this question and were able to answer with ease.

The original question:

Q30. In the last 12 months, have you received any treatments or therapies for your mental health needs that do not involve medicine?

- Yes**
- No, but I would have liked this**
- No, but I did not mind**
- This was not appropriate for me**
- Don't know / can't remember**

The modified question:

Q26. In the last 12 months, have you received any NHS therapies for your mental health needs that do not involve medicine?

- Yes**
- No, but I would have liked this**
- No, but I did not mind**
- This was not appropriate for me**
- Don't know / can't remember**

The original question:

Q31. Were these treatments or therapies explained in a way you could understand?

- Yes, completely**
- Yes, to some extent**
- No**
- No explanation was needed**

The modified question:

Q27. Were these NHS therapies explained in a way you could understand?

- Yes, completely**
- Yes, to some extent**
- No**
- No explanation was needed**

The original question:

Q32. Were you involved as much as you wanted to be in deciding what treatments or therapies to use?

- Yes, definitely
- Yes, to some extent
- No, but I wanted to be
- No, but I did not want to be
- Don't know / can't remember

The modified question:

Q28. Were you involved as much as you wanted to be in deciding what NHS therapies to use?

- Yes, definitely
- Yes, to some extent
- No, but I wanted to be
- No, but I did not want to be
- Don't know / can't remember

Due to the splitting of the 'Treatments' section of the 2017 questionnaire into distinct 'Medicines' and 'NHS Therapies' sections for the 2018 survey, questions 26, 27 and 28 had the word 'treatments' removed and the word 'therapies' initially added to each question. During the early rounds of cognitive testing, it was found respondents struggled to differentiate between therapies provided by NHS mental health services and those provided by other organisations, such as those in the private sector. The word 'NHS' was therefore added to direct service users to only reference therapies provided by NHS mental health services. To further enforce this, the words 'NHS therapies' were put into bold text.

The original question:

Q36. Has someone from NHS mental health services supported you in taking part in an activity locally?

- Yes, definitely
- Yes, to some extent
- No, but I would have liked this
- I did not want this / I did not need this

The modified question:

Q34. In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?

- Yes, definitely

- Yes, to some extent
- No, but I would have liked this
- I did not want this / I did not need this

Upon review, it was felt question 36 in the 2017 survey was important as it allows us to understand the support trusts provide to service users, however we felt the existing wording was confusing. For the 2018 survey, the word “locally” was removed and wording around “joining a group” added.

During the round 1 of cognitive testing the wording of the question was as follows:

- Q34. Has someone from NHS mental health services supported you in joining a group or taking part in an activity?

It was commented by one respondent that although they responded positively, if the question had been asked in relation to the last 12 months alone, they would have responded negatively as she had not been given this support recently but had in the past. It was felt that the question should account for recent attempts by trusts to assist service users, as do the other questions which address trusts helping service users to find support from non-NHS organisations. The wording “In the last 12 months...” was therefore added as of round 2 of testing. Collectively, respondents found the question easy to answer and interpreted the question to cover support in joining/taking part in a wide range of groups and activities from gardening and weight loss groups, volunteering through to charity-run group therapy sessions.

Minor Changes

In addition to the modifications mentioned above, a number of minor changes from the 2017 survey were also made for the 2018 survey. These minor changes do not affect the comparability of the questions mentioned below.

- Questions 21 and 24 (Q25 and Q28 in the 2017 survey respectively) had the word “medicines” changed to bold text to be consistent with other questions in this section.
- Question 44 (same question number in the 2017 survey) had the pre-completed “19” from response box removed as it is possible respondents born in the year 2000 will be sampled for the Community Mental Health Survey for the first time.

3. Changes to the design of materials

A pilot study, run alongside the 2017 survey, concluded the success of introducing a redesigned questionnaire and covering letters. When combined, the redesigned questionnaire and covering letters generated a significant increase in response rate overall, amongst respondents aged 18-35s (a demographic group generally far less likely to respond) and people of a non-White background. Following the success of the 2017 pilot, the new questionnaire design and covering letters were rolled out for the CMH18.

Redesigned questionnaire

In comparison to the 2017 questionnaire, the amount of information on the front page has been reduced (as much of this is addressed in the covering letters), a more informal typeface adopted, a dark grey font used rather than black and colour and shading used to help highlight different parts of the questionnaire, all intended to make the questionnaire more appealing.

The questionnaire used for the 2018 Community Mental Health Survey is available here: www.nhssurveys.org/surveys/1139

Redesigned covering letter

In comparison to the covering letters used during the 2017 survey, the 2018 versions were completely reworked. The amount of information contained within them was reduced and repeated information was removed. Socio-normative messages (e.g. “thousands of other people have completed the survey”) were included, and potentially motivating and empowering messaging adopted. In addition, important information was highlighted in bold text that could otherwise be missed. Full colour and a more informal style of font were used throughout. Finally, the third covering letter (2nd reminder) was worded differently from the first; across the surveys in the NPSP these letters are near identical, however it follows that if the letter proves un-motivating in the first instance it is unlikely to change behaviours if sent out a second time.

The covering letters used for the 2018 Community Mental Health Survey are available here: www.nhssurveys.org/surveys/1140

4. Additional changes to the 2018 survey

A number of other changes from the 2017 survey were also adopted for the 2018 survey.

Submission of Care Cluster Codes

In previous survey years, service user's mental health care cluster code data was submitted directly to the Survey Coordination Centre following the approval of a trust's sample data. To reduce unnecessary processes and the risk of errors, we received information governance approval for care cluster code data to be submitted directly to trust's approved contractors in the same file as service user's other sample data. In-house trusts continue to submit this data directly to the Survey Coordination Centre, but included within the sample file.

Revised Sample Declaration Form

In line with changes adopted for the 2017 iteration of the Adult Inpatient Survey, the sample declaration form were altered to include free-text comment boxes. These boxes were included next to specific checks for trusts to provide an explanation for why a check may not be applicable ('N/A'). A larger free-text comment box is also provided for trusts to highlight any changes at their trust which may affect comparability of their 2018 data to previous years. For example, a trust may have merged with another, resulting in a very different sample profile for 2018. This in turn may mean year-on-year comparability of results may not be possible.

Collectively, these changes are designed to reduce queries regarding trust's sample data, in turn ensuring trusts can mail out in a timely fashion.

5. Pilot

We will be running a pilot study alongside the 2018 Community Mental Health Survey with the aim of the pilot to increase the overall response rates.

Four interventions will be tested:

- A. Shorter questionnaire:** The shorter questionnaire will contain questions that are also present in the questionnaire of the main survey, though about half the questions will be removed to reduce the number of pages from 8 to 4.
- B. Online survey package:** The 'online survey' will consist of an electronic version of intervention A - Shorter questionnaire. Service users receiving this intervention will not receive any paper materials; all contact will be via SMS text message. The first SMS contact will include introductory text with a link to the online survey which will also include an online version of the covering letter, the second SMS contact will include a reminder text with the link to the online survey and the third SMS contact will include a final reminder text with the link to the online survey. Due to the nature of this intervention, the CQC flyer and the multi-language sheet will not be included.
- C. SMS reminders:** This intervention consists of SMS based reminders being sent to service users that receive a paper questionnaire. Service users receiving this intervention will also be receiving the paper covering letter in the 1st and 3rd mailings but not the 2nd. In other words, the 1st paper reminder will be removed from this intervention and an SMS reminder sent instead. A second SMS reminder will be sent following the third mailing package, therefore service users will receive a total of two SMS reminders.
- D. No CQC flyer:** It is unclear whether the CQC flyers have an impact on response rate. To determine this, the absence of the flyer will be tested. Service users will therefore not receive the CQC flyer in the 1st and 3rd mailing packages, although they will still receive all other survey materials (questionnaire, covering letters, multi-language sheet)