

The development report for the 2011 Community Mental Health Service Users survey

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1. Introduction

This document details the development of the questionnaire used for the 2011 Community Mental Health survey of Service Users in all NHS Mental Health trusts in England.

There has been a change in the organisation co-ordinating the survey this year. This will be done by the Patient Survey Co-ordination Centre, based at the Picker Institute Europe. The development work was carried out by the Picker Institute Europe as part of the national patient survey programme overseen by the Care Quality Commission.

Since the 2010 survey, the questionnaire has been developed so that it continues to provide the most useful and relevant feedback possible, both in terms of issues that are most important to service users and in terms of policy evaluation. The questionnaire has undergone some changes and this document seeks to outline these.

1.1 Aims

The aims of the development work were to:

- update the questionnaire with questions relevant to new or amended policy
- make minor amendments to questions to improve their validity
- design questions in collaboration with stakeholders and project sponsors that could be used for service improvement or measurement
- remove questions that were not useful for quality improvement purposes or not in line with current policy

Evidence used for this work

To assess which amendments to make to the questionnaire, the following steps were carried out:

- Analysis of the 2010 survey data to examine item non response rates and floor /ceiling effects.
- Consultation with stakeholders at the Department of Health and Care Quality Commission regarding the scope of the survey and to take account of policy priorities. External stakeholders were also consulted.
- Carrying out cognitive interviews with service users to test the revised questionnaire.

2. Changes made to the questionnaire

In order to make the survey as useful as possible for trusts, the questionnaire has been revised and expanded for this survey. This section summarises the changes that have been made to the 2010 Community Mental Health Service Users survey in preparation for the 2011 survey.

The overall content of the questionnaire and topic areas remain the same as the previous survey, the questionnaire comprises 55 questions over 8 pages, which remains unchanged.

Minor amendments have been made to several questions both to improve comprehension and for consistency across surveys. These amendments are detailed below. Changes are shown with deletions struck-through and insertions underlined

Front page

Following the 2010 survey, it was felt that further clarification was needed about who is eligible for the survey and how service users have been selected to undertake it. It emerged that some respondents had thought they were not eligible to take part in the survey, either because of their condition, or because they were no longer in contact with Mental Health Services even though they had been seen in the sampling period. The following text has been added:

What is the survey about?

This survey is about the health and social care you receive through NHS mental health services. This might include contact with psychiatrists or psychiatric nurses, social workers, mental health support workers, occupational therapists, psychologists, psychotherapists or other mental health or social care workers, including those helping people with dementia, depression or other types of mental health problem.

The information will be used to help improve NHS mental health services.

Who should complete the questionnaire?

This questionnaire is being sent to a random sample of people who have had contact with the NHS mental health service during the period July-September 2010. We're interested in your views of that experience, even if your contact has only been limited or has now finished.

2.1 New items added to the questionnaire

Talking therapies section

Since the 2010 national survey, a total of 2 questions were added to the Community Mental Health Service Users survey. Following consultation with stakeholders, it was felt the 'Talking Therapies' Section needed a further question to help evaluate access to these services and the following amendments have been made as a result of testing.

Q17. In the last 12 months, has an NHS mental health or social care worker discussed any of these sorts of talking therapy for you? (Please do not include discussions with your GP)

Yes

No

Some of the interviewees at cognitive testing had accessed talking therapies (outside of a NHS mental health trust) through their GP, so ticked 'Yes' for this question. Subsequent questions focus on NHS mental health workers and services. Clarification that discussions with GPs are excluded was therefore added.

Q19. In the last 12 months, did you ask an NHS mental health or social care worker to arrange any of these sorts of talking therapy for you? (Please do not include discussions with your GP)

Yes →Go to 21

No →Go to 21

2.2 Changes made to existing questions

Your Care and Treatment

This question order has changed. Originally, this was the second question (2010 survey) but it was decided it was a more appropriate and less confusing introduction to the survey than Q1 (see below). Because of this order change, answer options were also added. A list of the most common type of mental health or social care workers has been included in the question text, to clarify for respondents exactly what is meant by 'someone' from NHS mental health services. The 7th response option has been added, with routing instructions, to exclude anyone who should not have received the survey.

Q1. When was the **last time** you saw someone from the NHS mental health services?

This may have been a psychiatrist, psychiatric nurse, social worker, mental health support worker, occupational therapist, psychologist, psychotherapist or other mental health or social care worker. (Please do not include your GP.)

- 1 In the last month
- 2 1-3 months ago
- 3 4-6 months ago
- 4 7-12 months ago
- 5 More than 12 months ago
- 6 Don't know/can't remember
- 7 I have never seen anyone from NHS mental health services

A number of issues were raised such as how to interpret 'how long', especially if there had been several episodes of contact rather than continuous contact: the wording has been amended slightly, so that it is clearer that timing should begin from the first point of contact. Response option 5 has been altered because of the question location change and also for respondents who feel their treatment is now over, to tick the appropriate box.

Q2. Overall, How long have you been in contact with NHS mental health services?

- 1 Less than 1 year
- 2 1 to 5 years
- 3 6 to 10 years
- 4 More than 10 years
- 5 I ~~have never been~~ am no longer in contact with NHS mental health services
- 6 Don't know/ Can't remember

Health and Social Care Workers

The words 'health and social care workers' have been replaced with 'NHS healthcare workers or social care workers' in Question 3 and the introductory text to Questions 4 and 6, to be consistent with the rest of the questionnaire.

In addition, Q3 had further amendments made to the question text to explicitly exclude GPs. This follows recommendations during testing to eliminate confusion over who was seen, as the questionnaire covers secondary mental health only. Further response options and amendments to guidance in the introductory text have been made for clarity as detailed below.

Q3. Which of the following ~~health~~ **NHS healthcare workers** or social care workers have you seen **most recently for your mental health condition?** (Please do not include your GP)

If your most recent contact involved more than one health or social care worker, please tick the person you have seen most regularly

~~TICK ONE BOX ONLY. (IF YOU HAVE SEEN MORE THAN ONE PERSON, PLEASE TICK THE MAIN PERSON.)~~

- 1 CPN – Community Psychiatric Nurse
- 2 Social Worker
- 3 Psychiatrist
- 4 Mental Health Support Worker
- 5 Occupational Therapist
- 6 Psychologist
- 7 Psychotherapist
- 8 Other NHS healthcare worker or social care worker
- 9 Don't know/can't remember

Medications

The words medications and medicines have been replaced with 'medication' in Questions 9 to 16 for consistency. During testing, it also emerged that further clarification of the term 'mental health worker' was needed and therefore examples have been added and GPs specifically excluded, (see Questions 11 and 16 below):

Q9. In the last 12 months, have you taken any prescribed medication for your mental health condition?

- 1 Yes → Go to 10
2 No → Go to 17

Q10. Do you think your views were taken into account in deciding which medication to take?

- 1 Yes, definitely
2 Yes, to some extent
3 No

Q11. In the last 12 months, ~~have~~ has any ~~new medications~~ medication (e.g. tablets, injections, liquid medicines, etc.) been prescribed for you by ~~a~~ an NHS mental health worker such as a psychiatrist or a community psychiatric nurse? (Please do not include prescriptions from your GP.)

- 1 Yes
2 No
3 Can't remember

The LAST time you had a new medication prescribed for you...

Q12. Were the **purposes** of the medication explained to you?

- 1 Yes, definitely
2 Yes, to some extent
3 No

Q13. Were you told about possible **side effects** of the medication?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Q14. The last time you had a new medication prescribed for your mental health condition, were you given information about it in a way that was **easy to understand**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Q15. Have you been on any prescribed medication for 12 months or longer for your mental health condition?

- 1 Yes **→ Go to 16**
- 2 No **→ Go to 17**

Q16. In the last 12 months, has a an NHS mental health worker or social care worker checked with you about **how you are getting on with your medicines medication** - i.e. have your medicines been reviewed? (Please do not include reviews by your GP)

- 1 Yes
- 2 No

Talking Therapies

The following questions have been amended to better address the issue of access to these services. The amendments are intended to break the process down into a discussion of the therapies, receipt of at least one of the therapy types, requests for therapy (which have not yet led to receipt), and helpfulness of therapy received. Appropriate routing has also been added and the explanation before question 17 has been revised as follows:

“The next ~~three~~ four questions are about **talking therapies**. By talking therapies we mean ~~psychological~~ psychological therapies such as counselling, cognitive behavioural therapy (CBT~~faith and spirituality based counselling, art, music or drama therapy~~) and anxiety management.”

In addition to the new Question 17, the following minor amendments have been made to the wording of question 18 , to ensure consistency with the rest of the questionnaire:

Q18. In the last 12 months have you ~~had~~ received any of these sorts of talking therapies from NHS mental health services?

- 1 Yes →Go to 20
- 2 No →Go to 19

Q20. Did ~~If you had any find the NHS~~ talking therapy from NHS Mental Health Services you received in the last 12 months, ~~did you find it helpful?~~

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 ~~I did not have any talking therapy~~ Can't say at present

Your Care Co-ordinator

An explanation of a 'Care Co-ordinator' has been added for clarity above question 21.

"A Care Co-ordinator (or lead professional) is someone from NHS Mental Health Services who keeps in regular contact with you. This person could be a Community Psychiatric Nurse (CPN), a Psychiatrist or a Social Worker, ~~and may be known as a 'lead professional'."~~

At Q21 'Don't know' has been removed from the third option to avoid confusion between the interpretation of 'No' and 'Don't know', which was found to occur in the 2010 survey.

Q21. Do you know who your Care Co-ordinator (or lead professional) is?

- 1 Yes
- 2 No
- 3 ~~Not sure/ Don't know~~

At Q23 the response option 'not applicable' has been removed because its purpose was unclear.

Q23. How well does your Care Co-ordinator (or lead professional) organise the care and services you need?

- 1 Very well
- 2 Quite well
- 3 Not very well
- 4 Not at all well
- 5 ~~Not applicable~~

Your Care Plan

The introductory text in the Care Plan section above question 24 has been amended as follows:

“A care plan shows(or recovery plan) is a document or letter, drawn up by NHS mental health services, that sets out your mental health needs and how these will be met. It might be a document given to you by someone in NHS Mental Health Services, or it might be a letter, explaining explains how your care has been planned.”

The text has been simplified to avoid repetition and to reflect the use of the term ‘recovery plan’ by some trusts. ‘Care plan’ has been amended to ‘NHS Care plan’ in all questions, because there was some confusion among respondents in the 2010 survey who had both NHS care plans and care plans from other non NHS organisations such as MIND.

Q24. Do you **understand** what is in your NHS care plan?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I don't understand it
- 4 Not sure I don't know/can't remember what is in my care plan
- 5 I do not have a care plan

At Q26 additional wording has been added to help explain the term ‘goals’ in this context.

Q26. Does your NHS care plan set out your **goals**? This might include the changes you want to make to your life as your care progresses or the things you want to achieve.

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

At Q27 the wording has been amended to reflect the fact that for some service users, it will be too early for them to have achieved any goals. It will also still be relevant for those who have finished treatment

Q27. Have NHS mental health services ~~you receive~~ helped you ~~to achieve~~ start achieving these goals?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Q28 has been expanded to give a further explanation for the word 'crisis'.

Q28. Does your NHS care plan cover what you should do if you have a crisis (e.g. if you are not coping or if you may need to be admitted to a mental health ward)?

- Yes, definitely
- Yes, to some extent
- No

Q29 "Have you been given (or offered) a written or printed copy of your NHS care plan?" was at the start of the 'Your Care Plan' section in the 2010 survey (Q23) and has now been relocated to the end of this section. This was to avoid any confusion about whether respondents who didn't have a written copy of their care plan should be answering questions about its content and design.

Your Care Review

The introductory text in the 'Care Review section' above question 30 has been amended for simplification. The words 'care plan' have also been replaced by 'care' in this and subsequent questions (and introductory text before Question 33), so that these are open to those respondents who do not believe they have a care plan:

"A care review is a meeting ~~with~~between you and ~~the people or person involved in your care in which you~~staff from NHS mental health services to discuss how your care plan ishas been working."

At Q30 The word 'plan' has been deleted

Q30. **In the last 12 months** have you had a care review meeting to discuss your care ~~plan~~?

- 1 Yes, I have had more than one
- 2 Yes, I have had one
- 3 No, I have not had a care review in the last 12 months
- 4 Don't know / Can't remember

At Q31 the question is about whether the service user was told they could bring a friend, relative or advocate, and not about whether they wanted to. Therefore this response option has been removed.

Q31. Were you **told** that you could bring a friend, relative or advocate to your care review meetings?

- 1 Yes
- 2 No
- 3 Don't know / Can't remember
- 4 ~~I did not want to invite a friend, relative or advocate~~

At Q35 the word 'NHS' has been added in for clarification and consistency with the rest of the questionnaire.

Q35. Did you discuss whether you needed to continue using NHS mental health services?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

Crisis Care

The order of the 'Crisis Care' and 'Day to Day Living' sections has been swapped since the previous survey because cognitive testing showed this led to a more natural progression through the questionnaire.

Regarding Q38, this question has been amended and simplified from the previous year's question which read, "The last time you called the number, how long did it take you to get through to someone?", with response options ranging from 'immediately' to 'a day or more'. This question caused confusion when, for example, a respondent had called twice, not getting through on the first occasion but getting through immediately on the second attempt (which may have been a few days later). It seemed likely that different respondents would interpret the question in different manners. The wording was amended to make clear that the question related to difficulties in getting through on the last occasion the respondent called.

Q38. ~~The last time you called the number, how long did it take you to get through to someone~~ did you have any problems getting through to someone?

- 1 Yes
2 No

Day to day living

The following question has been split into two individual questions, to make it easier to answer and in order to deal with these as separate issues:

2010

Q37. In the last 12 months, did anyone in mental health services ask you about your alcohol intake or use of non-prescription drugs?

2011

Q40. ~~In the last 12 months, did~~ Has anyone in NHS mental health services ~~ask~~ ever asked you about your alcohol intake ~~or use of non-prescription drugs?~~

- 1 Yes,
2 No
3 Don't know/ Can't remember

Q41. Has anyone in NHS mental health services ever asked you about your use of non-prescription drugs?

- 1 Yes
2 No
3 Don't know/ Can't remember

Questions 40 and 41 have also been moved to the start of the day to day living section because the timeframe has now been removed to help with analysis.

In the 2010 survey, this section had different response options to the questions, some asking about 'help', others asking about 'support', therefore the responses have been amended for consistency, to make it easier for respondents:

At Q42 amendments have been made to the wording and response options to make this question more consistent with the rest of the survey and other questions in this section.

Q42. In the last 12 months, ~~did anyone~~ have you received support from anyone in NHS mental health services ask you about any in getting help with your **physical health needs** you might have?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 ~~Don't know/ Can't remember~~ I do not have any physical health needs

At Q43 this question has been simplified and amended so that it is in line with the other questions. A response option has also been added to cater for those respondents who did not need or want help.

Q43. In the last 12 months, ~~did~~ have you received support from anyone in NHS mental health services give you enough support with in getting help with your **care responsibilities** (including looking after children)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 I ~~can't remember~~ did not need any support
- 5 I do not have any caring responsibilities

Q44-Q46 have been amended to be consistent with other questions in the survey:

Q44. In the last 12 months, have you received ~~help~~ support from anyone in NHS mental health services in getting help with **finding or keeping work** (e.g. being referred to an employment scheme)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked ~~help~~ support
- 4 I did not need any ~~help~~ support
- 5 I am unable to work because of my mental health problems

Q45. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with **finding and/or keeping your accommodation**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked ~~help~~ support
- 4 I did not need any ~~help~~ support

Q46. In the last 12 months, have you received ~~help~~ support from anyone in NHS mental health services in getting help with **financial advice or benefits** (e.g. Housing Benefit, Income Support, Disability Living Allowance)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked ~~help~~ support
- 4 I did not need any ~~help~~ support

Overall

At Q47 the word 'NHS' has been inserted for consistency:

Q47. Overall, how would you rate the care you have received from NHS mental health services in the last 12 months?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

At Q48 the fourth response option was removed because it does not directly answer the question.

Q48. Have NHS mental health services involved a member of your family or someone else close to you, as much as you would like?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 ~~No family or friends were involved~~
- 5 My family or friends did not want or need to be involved
- 6 I did not want my family or friends to be involved

About YOU

The following changes were made to the About You' section, with the original text considered rather complex and lengthy.

~~Q49 person named on the front of the envelope that the questionnaire was sent in. If you are helping someone to fill in the questionnaire, the answers given should still be from the point of view of the person named on the envelope. This includes the following background questions on gender and date of birth.~~

Who was the main person or people that filled in this questionnaire?

- 1 The **service user/client** (named on the front of the envelope)
- 2 A **friend or relative** of the service user/client
- 3 **Both** service user/client and friend/relative together
- 4 The service user/client with the help of a health professional

Reminder. All the questions should be answered from the point of view of the person named on the envelope. This includes the following background questions on gender and date of birth.

Q54. The original question was not effective for people who were self employed or those whose work hours varied from week to week because of the effect of their health or for other reasons. Furthermore, the response option 'no' was rather ambiguous and overlapped with other options that also include 'no' (no, I am retired etc). Both of the above made respondent answers difficult to interpret. The question was therefore changed to better include self employed people and people who were in paid but flexible work in terms of hours. The 'no' option was also removed.

54. Are you currently in paid work?

TICK ALL THAT APPLY

- 1 Yes, I am working between 1-15 hours a week
- 2 Yes, I am working 16 or more hours a week
- 4 ~~No~~
- 3 Yes, but my working hours vary
- 5 No, I am retired
- 6 No, I work on a casual basis
- 7 No, I am a full-time student
- 8 No, I do voluntary work

3. Changes to guidance manual and survey protocol

The guidance manual has been updated in preparation for the 2011 survey. It contains all the instructions needed to carry out the survey and what is required from each trust. The key changes to the survey methodology are discussed below but a full list of all changes can be found in chapter 3 (“what’s new for 2011”) of the 2011 Community Mental Health Service Users survey guidance manual.

Survey Co-ordination: This year, the Community Mental Health Service User survey will be co-ordinated by the Patient Survey Co-ordination Centre based at Picker Institute Europe

Survey fieldwork period: Weekly monitoring will start on the **13th January 2011** and the fieldwork period for the survey will be 16 weeks.

Approved contractors: The contact details of the approved contractors have been updated for 2011 and can be found in the guidance manual.