

The development report for the 2012 Community Mental Health Service Users survey

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1 Introduction

This document details changes to the questionnaire used for the 2012 Community Mental Health survey of Service Users in all NHS Mental Health trusts in England.

There have been minimal changes to the questionnaire this year.

The aims of this development report are to:

- detail changes to the questionnaire
- detail changes to the survey methodology
- summarise findings from cognitive interviews conducted with service users

2 Changes made to the questionnaire

The questionnaire was revised fairly extensively in 2011 to improve some of the questions and response options. Minimal changes have been made to the questionnaire in 2012; these include a number of simplifications to certain sections of the questionnaire, the re-inclusion of a question last used in the 2010 Community Mental Health Survey and also the insertion of questions on religion and sexual orientation, which are now mandatory to the national survey programme.

Changes to the questionnaire are detailed below with deletions struck-through and insertions underlined.

2.1 New items added to the questionnaire

Three new questions have been added. These are as follows:

Q39 was last included in the 2010 Community Mental Health survey and re-instated in 2012. This was reinstated as physical health is one of the key principles on the mental health strategy *No Health Without Mental Health*¹. Please note that 'NHS' has been added to the question text (ie 'NHS mental health services' in 2012 as compared to 'mental health services' in 2010). This is to ensure consistency with other questions in 2012 survey.

Q39 In the last 12 months, did anyone in NHS mental health services ask you about any physical health needs you might have?

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

Q53 and Q54 have been inserted as these are now mandatory questions for all national surveys.

Q53 What is your religion?

- 1 No religion
- 2 Buddhist
- 3 Christian (including Church of England, Catholic, Protestant, and other Christian denominations)
- 4 Hindu
- 5 Jewish
- 6 Muslim
- 7 Sikh
- 8 Other
- 9 I would prefer not to say

¹ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766

Q54 Which of the following best describes how you think of yourself?

- 1 Heterosexual/straight
- 2 Gay/Lesbian
- 3 Bisexual
- 4 Other
- 5 I would prefer not to say

2.2 Items removed from the core questionnaire

Three questions have been removed from the questionnaire. These are as follows:

Q17 and Q19 have been removed from the 'Talking Therapies' section of the questionnaire. This was in order to simplify this section and to allow space for the new questions detailed in the previous section. These were removed as it is difficult to score trusts fairly on questions regarding access to talking therapies, as for example, another type of therapy may have been more appropriate.

Please note that the following introductory text was included prior to Q17, '*The next two questions are about **talking therapies**. By talking therapies we mean therapies such as counselling, cognitive behavioural therapy (CBT) and anxiety management.*'

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

1 Yes

2 No

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.)

1 Yes

2 No

Q38 was removed as it did not yield particularly actionable information for trusts as the reasons for not getting through were not known. It was also considered that this information could be equally well captured by the addition of a category to Q36 (Q39 in the 2011 questionnaire). Please see Section 2.3 for further detail.

Q38 The last time you called the number, did you have any problems getting through to someone?

1 Yes

2 No

2.3 Changes made to existing questions

Only two questions have been amended. Q36 has had an additional category added to capture people unable to get through on the telephone.

Q36 The last time you called the number, did you get the help you wanted?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I could not get through to anyone

Q55 asks respondents to provide their ethnic background (please see overleaf). This has been amended in order to be in line with the census question of this type. This question is now being used in all national surveys.

Q55 What is your ethnic group? (Tick ONE only)

a. WHITE

1 ~~British~~ English/Welsh/Scottish/Northern Irish/British

2 Irish

3 Gypsy or Irish Traveller

4 Any other white background, write in
(Please write in box)

b. MIXED/MULTIPLE ETHNIC GROUPS

5 White and Black Caribbean

6 White and Black African

7 White and Asian

8 Any other Mixed/ multiple ethnic background, write in
(Please write in box)

c. ASIAN/ OR ASIAN BRITISH

9 Indian

10 Pakistani

11 Bangladeshi

12 Chinese

13 Any other Asian background, write in
(Please write in box)

d. BLACK/AFRICAN/CARIBBEAN/ BLACK BRITISH

14 ~~Caribbean~~ African

15 ~~African~~ Caribbean

16 Any other Black/ African/ Caribbean background, write in
(Please write in box)

e. CHINESE OR OTHER ETHNIC GROUP

17 Chinese Arab

18 Any other ethnic group, write in
(Please write in box)

3 Changes to guidance manual and survey protocol

The guidance manual has been updated in preparation for the 2012 survey. It contains all the instructions needed to carry out the survey and what is required from each trust. Full details about survey methodology can be found in the 2012 Community Mental Health Service Users survey guidance manual, available on the NHS surveys website at: <http://www.nhssurveys.org/surveys/612>

Amendments to survey are as follows:

This was the first year that Section 251 approval was sought for the survey, which was granted on the basis that the age of service users included in the survey was changed from 16 years and over to 18 years and over. Section 251 approval also required that Trusts ensured that any service users who had indicated that they did not want their details used for secondary purposes, such as research, were excluded from the survey.

The covering letters were heavily revised to bring them in line with letters for other surveys in the national patient programme. Trusts conducting the survey in-house were requested to set up a PO Box for confidentiality reasons. This was to ensure that there was no indication on mail out envelopes that the survey enclosed related to healthcare in any way, allowing undelivered envelopes to be returned to sender.

With regard to sampling, the survey was granted approval to collect GP code in the sample frame. This is collected in preparation for the emergence of CCG's (Clinical Commissioning Groups). The classification of CPA status was amended slightly to enable a distinction between service users not registered on new CPA and service users whose CPA status was unknown.

4 Summary of cognitive testing

4.1 Introduction

From October to December 2011, the Picker Institute carried out research to test for an appropriate overarching question to be included in all national surveys². As the mental health questionnaire made up part of the study, it was decided that cognitive testing of the mental health questionnaire would be done at the same time. This explains a higher number of interviews than would normally be done for the small number of changes made to the questionnaire between 2011/12.

Interviews were carried out between 18th October and 6th December 2011. Participants were recruited first by a recruitment agency and then through an advert in a local paper. The age and sex of the respondents were as follows:

- 9 women (aged 27-65)
- 9 men (aged 21-65)

The ethnic background of the respondents was:

- 16 white
- 1 Asian
- 1 Black Caribbean

Interviews were carried out predominantly with service users with depression.

² The report for this project may be found on the NHS surveys website at: www.nhssurveys.org/survey/1186

4.2 New and amended questions

New Questions

The questions added to the survey consisted of questions relating to sexual orientation and religion in the demographic section, which are now mandatory in all national surveys. Both questions were easily understood and were not perceived as unnecessarily intrusive.

A question included in the 2010 survey was reinstated, “Q39 In the last 12 months, did anyone in NHS mental health services ask you about any physical health needs you might have?” This question was generally interpreted as whether or not the participant had a physical disability/medical condition, although it was also understood as relating to keeping fit and help with physical activities.

[The respondent] understood [the question] as whether there was anything physically wrong with her.

“General day-to-day, washing, dressing, moving around, going out, everything that you take for granted, washing, keeping clean, anything that comes under that, everything you do, not just getting from A to B.”

The participant understood this to mean his physical condition, which he said was generally very good, but that when he is depressed he can't be bothered to exercise.

Three struggled to understand the meaning of the question.

“I can't really see how this would fit into mental health. This is a bit of a funny question.”

The participant hesitated here, looked confused, and then asked what we meant by ‘physical health needs’. Asked what he would answer if he was at home alone he said that he would not answer the question and instead put a question mark next to the question.

For Q39 she was confused as to what this meant, “Is that things like cardio? What do they mean by physical health? I'm not sure what they mean but I wasn't asked so I'll tick ‘no’”. She answered Q40 by saying that she does not have any physical health needs.

Amended Questions

Two questions were amended. The first with regard to an out of hours helpline, “Q36 The last time you called the number, did you get the help you wanted?” had an additional option added “I could not get through to anyone”.

This was a double routed question, so actually was applicable to only one participant. This respondent answered ‘Yes, to some extent’ because their mental health care worker did not

always answer the phone. It should be noted that he answered about his situation in general rather than “the last time” the number was called. It is not, however, anticipated that this amendment will cause any major issues for respondents.

The ethnic group question was also amended to bring it into line with the census and other national surveys. This did not cause any issues for respondents.

4.3 Issues with existing questions

The testing highlighted some issues with the interpretation of a number of the existing questions which are outlined below.

The “Health and Social Care Workers” section was rather problematic for a number of respondents.

Q3 Which of the following 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 frequently.

The above was difficult for some to answer as they did not know the job title of the person(s) they had seen. Also, a number of people mentioned that they had seen a ‘counsellor’, which is not included on the list.

“People are referred to as a counsellor; you don’t always know what their correct title is.”

The participant spent some time here looking at the various options. He said that these weren’t names that meant too much to him as he knew the people he had dealt with more by name. He hesitated on ‘occupational therapist’, before deciding that he was pretty sure his counsellor was a psychotherapist.

A number of participants also multi coded the question, with one respondent ticking 7 of the 9 possible options.

With regard to Q4-Q8, these questions refer to the member of staff specified at Q3. If only one member of staff is selected at Q3, and this is the main person dealing with the service user, participants tended not to experience any difficulty answering the subsequent questions. It was apparent, however, that many had seen multiple members of staff and their answers to Q4-Q8 became somewhat muddled. For some it was more appropriate to refer to the person who had the biggest influence on their care rather than the last person they had seen.

Although the participant had no problem understanding the question [Q3], she did state that she did not really want to answer in these terms. She had seen her mental health worker that morning, but this wasn’t the most important person to her care, and she would rather answer in reference to her psychologist. She ended up answering many of the following questions as a mixture of the staff she had seen.

...she answered [Q4] thinking about the 2 people she saw most frequently (she ticked the most negative response for both people). By [Q5] she was only thinking about the person she had the most contact with which was her social worker.

In three cases, participants included contact with their GP when answering (despite instructions in the questionnaire not to), either because they had not noticed the instruction or because they ignored it.

Although the participant had seen a counsellor recently he answered most questions in relation to his GP, saying that it was through him that he managed his condition (depression).

[re Q1]...Further, the note stating to exclude the GP was not seen.... The participant explained that in answering this question she was thinking about her social worker, her GP, a psychologist and a mental health support worker.

The participant stated straight away that he felt he should be able to answer in terms of his GP....explaining that people, particularly in mental health services, did not distinguish between mental health services and other NHS services, and that they were all one family and he saw them as one service.

At Q5 respondents were asked whether they considered that their views were taken into account. At least two participants who were receiving talking therapy found this question difficult to answer.

The participant answered 'yes, to some extent'. He explained that counselling was a little odd, and that you couldn't really answer this question easily about it. He said in counselling he was made to give his views on things, but that the purpose really was to get him in the correct state of mind.

The participant hesitated on this question. She didn't know what kind of 'views' we were referring to. She said that part of therapy was to challenge your views, thinking about her general world view. She ended up simply putting a question mark on this question.

A number of respondents struggled with questions in the 'Day to Day Living' section. In addition to the comments regarding Q39 detailed in the previous section, in two cases at Q40 'In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your physical health needs?' the respondent selected the third option, 'No, but I would have liked support' but then scored out 'but I would have liked support'. In both cases, the respondent had a physical condition but did not consider this related to their mental health care.

A further question asked about care responsibilities eg for children (Q41 'In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your care responsibilities (including looking after children)?')

Three respondents understood the question in terms of their own personal care.

The participant answered 'I did not need any support for this', although she did say that she understood this to include care for herself. She said that there had been times when she was not able to look after herself and help in this respect would have been welcomed.

The respondent was a bit confused by what the question meant although the text in brackets helped. She decided that it meant care for her in trying to get out to do things that would make her feel better. At first she ticked she didn't have any care responsibilities and then changed this to 'no, but I would have liked support'.

The participant has care responsibilities (several family members with disabilities, for whom she is a part-time carer and major source of financial and administrative support) but understood this question to refer to her own care needs resulting from her physical disabilities. In other contexts she talked about what the interviewer understands to be her care responsibilities (things she does for her family that are necessitated by their disabilities), but she did not mention these at all when discussing this question.

It is therefore recommended that particular attention is given to the 'Health and Social Care Workers' and 'Day to Day' sections of the questionnaire when the survey next undergoes major revision. These sections, although not problematic for all concerned, proved rather confusing and difficult to answer for a significant minority.