

# THE DEVELOPMENT REPORT FOR THE 2011 INPATIENTS SURVEY

THE CO-ORDINATION CENTRE FOR THE  
NHS SURVEY PROGRAMME

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# 1 Introduction

This document details the development of the questionnaire used for the 2011 survey of adult inpatients in all NHS Acute trusts in England.

Both the core and bank questionnaire have undergone minor redevelopment for the 2011 survey. This report details the changes made from the 2010 versions.

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<sup>1</sup>.

## 1.1 Aims

The aims of the development work were to:

- update the core 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

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<sup>1</sup> Formerly the Healthcare Commission.

## 2 Amendments made to the questionnaires

### 2.1 Questions removed

Before cognitive testing was undertaken several decisions were already made by the Care Quality Commission (CQC) and the Department of Health (DH) regarding questions to be taken out of the questionnaire.

#### EQ-5D (Your own health state today)

This question was included in 2009 as a validated measure of health and well being. While it previously fed into Patient Reported Outcome Measures (PROMS), it is now felt that it is no longer necessary for this measure. Moreover, this question occupied half a page, and so it was decided before the start of cognitive testing that this question could be moved out of the core question, although retained in the question bank.

#### H1. Mobility

- 1  I have no problems in walking about
- 2  I have some problems in walking about
- 3  I am confined to bed

#### H2. Self-Care

- 1  I have no problems with self-care
- 2  I have some problems washing or dressing myself
- 3  I am unable to wash or dress myself

#### H3. Usual Activities (e.g. work, study, housework, family or leisure activities)

- 1  I have no problems with performing my usual activities
- 2  I have some problems with performing my usual activities
- 3  I am unable to perform my usual activities

#### H4. Pain / Discomfort

- 1  I have no pain or discomfort
- 2  I have moderate pain or discomfort
- 3  I have extreme pain or discomfort

## H5. Anxiety / Depression

- 1  I am not anxious or depressed
- 2  I am moderately anxious or depressed
- 3  I am extremely anxious or depressed

## Complaints

Prior to testing it was also decided by the CQC and DH that the question below on complaints should be removed from the core questionnaire, and relocated to the bank. Again, this served to free up space for new questions.

Did you want to complain about the care you received in hospital?

- 1  Yes **→ Go to Error! Reference source not found.**
- 2  No **→ Go to Error! Reference source not found.**

## 2.2 Questions added for testing

Following agreement with the patient survey programme leads at the CQC and the DH, the following changes were made to the 2011 inpatient questionnaire to be cognitively tested with recent inpatients.

## Consent

This question is taken from the question bank of the previous survey and is included following a request from the QRP team at CQC as there are relatively few evidence sources in this area. Policy leads at DH agreed that a question would be useful to add coverage of issues around informed consent.

Did you feel you could refuse any treatment that you did not agree with or did not want?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  No, but I wanted to follow the doctor's advice
- 5  I was not able to (e.g. because I was unconscious)

The testing of this question produced mixed results. In the first round all participants seemed to understand the question differently. Only one participant seemed to understand the question in the way that it was intended: asking if the patient was made to feel confident enough in the clinician/patient relationship to refuse treatment. She explained that she had wanted to refuse a certain type of painkiller because she was pregnant. Other participants, however, understood it in various ways. One participant ticked 'yes, completely' explaining that as an adult he felt that he always could refuse anything: he interpreted the question as trying to assess his own character. Another participant answered based on her medical knowledge, believing that the question was asking if she knew enough about medicine to have any input.

After discussion, the interviewing team felt that this question might only be understood correctly by those that had encountered this as an issue. An alternative approach was devised that used two questions:

Did you ever want to refuse any treatment whilst in hospital?

- 1  Yes
- 2  No
- 3  Don't Know

If you ever refused any treatment, did staff respect this?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I never refused any treatment

While this pair of items had the advantage of only asking those for whom consent had been an issue, they clearly address a slightly different question. They were tested alongside the current consent question for the remaining two rounds.

For the remaining rounds the original consent question tested poorly, with participants interpreting it in different ways. One participant answered based on how well informed they felt about their condition, another participant explained that she had ticked 'yes' because she knew she needed treatment to get better and a third stated that she was sure she could have refused treatment had she wanted to, but went on to tick 'no'. However, it is worth noting that three participants appeared to understand the question correctly in the last round. The alternative version seemed to be understood by all, although only one participant had wanted to refuse treatment and therefore she was the only one to give a specific response to the second question.

The Co-ordination Centre recommended that this question not be included in the Inpatient Core questionnaire for the 2011 survey, with the CQC agreeing. However, with the desire to include this issue in the survey still apparent it is hoped that the Co-ordination Centre will have the time to construct a more suitable question for the 2012 survey.

## Who filled in the Questionnaire?

This question was previously included in the Community Mental Health Questionnaire. One of the approved survey contractors, Picker Institute Europe, also suggested that the question be included as they felt that it would be interesting to see if proxy respondents are more critical than people filling in the questionnaire about themselves<sup>2</sup>.

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

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

The testing of this question in a cognitive interview is difficult as respondents have a researcher sitting with them. One participant asked the interviewee for support on this question but the remainder were able to keep in mind that they should answer as if they were alone.

This question was therefore recommended to the CQC and DH by the Co-ordination Centre for inclusion in the 2011 core questionnaire, who then chose to accept this recommendation.

## Religion

CQC have received numerous requests for this question to be included in order to enable the evaluation of the experiences of different equalities groups. The question itself is taken directly from the 2011 UK Census.

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<sup>2</sup> Older respondents to the survey are generally more positive in their responses, but this trend is reversed for the oldest age group. It is hypothesised that this reversal may be due to an increasing proportion of proxy responses pertaining to the oldest survey participants: adding this question on proxy response would allow an assessment of this.

What is your religion? (Tick ONE only)

- 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

One participant commented on the peculiarity that Christianity is given examples of denominations while the others are not. Conversely, another participant felt that they wanted to be able to tick their particular denomination but not the others. Overall however, the question tested well and was never misunderstood.

Therefore the Co-ordination Centre recommended that this question be part of the core questionnaire for the 2011 survey, a recommendation the CQC agreed with.

## Sexuality

CQC have received numerous requests for this question to be included in order to enable the evaluation of the experiences of different equalities groups. It is taken directly from the GPPS (General Practitioner Patient Service)

Which of the following best describes how you think of yourself? (Tick ONE only)

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

In the cognitive interviewing all participants understood this question and completed it correctly. Further, no participants seemed to show any great discomfort at answering. The Co-ordination Centre and the CQC agreed that this be included in the core questionnaire for the 2011 survey.

## Experience

This question is a variation of the overall experience question that appears in the GPPS. 'Experience' questions are favoured at the higher levels of the NHS, and there were clear problems with the previous overall question, such as the unbalanced nature of the scale. The Co-ordination Centre was therefore asked to test this question as an alternative overall indicator question.

Overall, how would you describe your experience of your hospital stay?

- 1  Very good
- 2  Fairly Good
- 3  Neither good nor poor
- 4  Fairly poor
- 5  Very poor

In the first round of testing all participants struggled with this question. One participant explained that she would find it difficult to say that she had had a good experience in hospital as being in hospital, regardless of the quality of the staff or facilities, is never where one would want to be. Other participants struggled to see it as an 'overall' question, with one interpreting the question as being specifically about the food and the facilities, rather than the care she received.

However, in the second and third rounds of questions the majority seemed to understand the question, believing that the question was inviting them to give an overall assessment of their care.

Although it seems this question tested slightly better than its predecessor, it was not felt that it was worth losing comparability with previous years for this minor improvement. Instead, the Co-ordination Centre and the CQC decided that the previous question be retained, and a new question to capture overall experience be developed for the 2012 survey.

### 2.3 Questions added during testing

In the process of conducting the cognitive interviews it is possible for interviewees to identify areas that the questionnaire is not covering. In such instances the interview team have a discussion about whether or not it would be useful to design a new question and then test it.

## Emotional Support

During the first round of testing it became clear from two separate interviews that participants felt there was no place in the questionnaire to record whether or not they received adequate emotional support during their time in hospital. This resonated with recent research from the King's Fund/King's College London that recommends the inclusion of more questions covering relational aspects of care such as emotional support in hospital.

The researchers at the Picker Institute Europe discussed these findings and decided that it would be worth testing the question below. For the remaining rounds the question below was added to the questionnaire and interviewers were instructed to probe participants on this question. This was done not just to test the validity of the question, but to ensure that it addressed different issues in the participant's mind to the previous question: "Did you find someone on the hospital staff to talk to about your worries and fears."

Do you feel you got enough emotional support from hospital staff during your stay?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No
- 4  I did not need any emotional support

In the second and third rounds of testing this question tested very well. All participants answered with ease, and when probed on what they took this question to mean in comparison with the previous 'worries and fears' question they answered that the item on 'worries and fears' was about questions you had regarding your medical condition and prognosis, whereas the new question was about whether or not staff tried to cheer you up when you were down or provided reassurance. For example, one participant, who had suffered an arm fracture, explained that when answering the 'worries and fears' question he was thinking about the answers the doctor gave him when he asked if he would be able to play badminton again soon, or if he would be able to sit his upcoming university exams. By contrast, he explained that when answering the 'emotional support' question he considered the way nurse tried to lift his mood. He talked about how much of a shock it could be to be on your way to lectures one minute, your day planned out, to being in hospital the next: consequently, the interviewee saw this emotional support as a vital aspect of his care.

Given the desire for the question shown in the first round of testing, its success in testing, and the wider demand for questions covering relational aspects of care, we recommend that this question should be included in the core questionnaire for the 2011 survey. The CQC accepted this recommendation and it was decided that the question be used in the 2011 survey core questionnaire.

## 3 Changes to guidance manual and survey protocol

The guidance manual is updated before every survey. It contains all the instructions needed to carry out the survey and what is required from each trust. Major 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 Inpatient Survey Guidance Manual.

**Survey fieldwork period:** The start date of the survey was scheduled for the **12<sup>th</sup> September 2011**. As in 2010, the allocated fieldwork period for the survey was 17 weeks. This means that the survey runs through the 2011 Christmas holidays and the date for final submission of data is the **13<sup>th</sup> January 2011**. We strongly encourage all trusts and survey contractors to make the most of the fieldwork period and to collect returned questionnaires for as long as possible before submitting data.

**New sample data requested:** To allow more accurate interpretation of the data, we request that trusts submit an additional two fields in their sampling spreadsheets for the 2011 survey. These will be the NHS site codes for the site hospital from which the patient was both admitted and discharged.

**Free text comments:** For the 2011 NHS Adult Inpatient survey there is a possibility that the DH and CQC may make central use of freetext comments. Therefore, this data may be required by the Co-ordination Centre at the end of the fieldwork period.

**Covering Letters:** The first mailing letter and second reminder letter have been rewritten for the 2011 survey. The previous version contained references to now dated policy documents, while there was a wider view that the information in the letter itself could be more concise, with a separate sheet of frequently asked questions for those respondents who may be interested. Also unique to the 2011 survey, is the option for trusts to include the name of the participant in the letter, rather than a generic greeting. It is hoped that these changes may go some way to addressing the steady decline in response rates experienced in recent years, not just in the national patient survey programme, but across the industry.