



National Cancer Patient Experience Survey Programme

Cognitive Testing Report 2010

The National Cancer Patient Experience Survey Programme
is run by Quality Health on behalf of the Department of Health

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1. Introduction

- 1.1. Cancer patient experience surveys were conducted in 2000 and 2004 in a limited number of NHS Trusts. The 2010 survey was planned to cover all NHS Trusts across England and to provide some longitudinal comparisons with the previous surveys.
- 1.2. The 2004 questionnaire was revised by Rachel Reeves for the Department of Health to bring it up to date with current cancer care. Her document 'Changes to Cancer Questionnaire 2010' can be found in Appendix A to this report. This documents the revisions that were made to the 2004 questionnaire and which produced version 1.1 of the 2010 questionnaire.
- 1.3. During the period in which the questionnaire was developed, it went through a large number of revisions, some of which included very minor changes. This report details the cognitive testing process undertaken and maps the changes made between the versions of the questionnaire used for testing.
- 1.4. The full versions of the questionnaire used for testing are available in a separate appendix to this report.
- 1.5. During the development period discussions also took place about the universe of patients to be surveyed. This included discussions about the inclusion of day case patients and the types of cancer that were to be included. Documents from the 2000 and 2004 surveys were consulted as well as HES data to arrive at the final sampling framework. These discussions also lead to revisions of the questionnaire.

2. Executive Summary

2.1. Methodology

- a. The cognitive testing of the questionnaire was conducted with volunteers provided by Macmillan. All volunteers had agreed to participate in the process and were called prior to being interviewed to agree the times of interviews with them, to explain who would be undertaking the interview and to explain the process to them.
- b. The questionnaire went through four rounds of cognitive testing during which 25 patients who had different types of cancer participated in detailed interviews about the questionnaire and the covering letter. As well as the cognitive testing interviews, ongoing discussions were held with members of the Cancer Advisory Group and other people with cancer to ascertain their views.
- c. The most recent version of the questionnaire was mailed out to interviewees before each round of the testing so that it could be completed prior to the interview. This simulated the postal methodology that was to be used for the live survey.

2.2. Changes to the Questionnaire Resulting from the Testing

- a. The main conclusion that can be derived from the cognitive testing is that the questionnaire as given to interviewees was generally found to be easy to understand, with acceptable routing and largely clear meanings of concepts, timescales, and specialist terms. The issues to be addressed were relatively minor in the context of the length of the questionnaire.
- b. The key changes that were made to the questionnaire during this process were:
 - i. Restructuring to more closely follow the patient pathway to ensure that patients understood at what point in their care the questions were referring to.
 - ii. Refinements to questions to remove ambiguity and to ensure clarity for patients, and to ensure that the data collected was providing the information that was being sought.
 - iii. Removal of some questions which were found not to be providing useful information, and the addition of new questions where it was felt there were gaps in the questionnaire or omissions.
 - iv. Changes to section headings, prompts and routing to more clearly define for patients what particular aspect or point in their care they should be focusing their response on and to ensure that only those patients who should answer particular sections did answer them. This included using the term 'cancer care' or similar in many places to ensure that patients did not answer in respect of another episode of treatment for another condition.

- c. Very little comment was made about the covering letter or language leaflet and no changes were required to these documents. Where comments were made these were positive about the clarity or helpfulness of the letter. Interviewees also found the explanation in the letter as to which hospitals the questionnaire referred to easy to understand.

2.3. General Points about the Questionnaire

- a. Not one interviewee found the use of the word 'cancer' in the questionnaire problematic, in fact, most felt it was right and proper to have clarity.
- b. Interviewees were asked if any important issues had been omitted; although some comments were made about sections that could be expanded these mainly reflected the interviewee's personal experience (usually not positive) but were not related to actual gaps or omissions in the questionnaire.
- c. Interviewees were also asked if there were any questions they found offensive or upsetting. The only question which did elicit some negative response on this issue was the question about sexual orientation which a small number of interviewees were not happy with and either refused to answer or answered reluctantly.

- 2.4. Whilst making revisions to the questionnaire, the need to retain questions for longitudinal comparisons with the 2000 and 2004 surveys was recognised and a separate report was produced to show which questions were comparable with the previous surveys.

3. Changes to the Questionnaire Before Cognitive Testing

- 3.1. Before cognitive testing of the questionnaire began, a number of changes were made arising from discussions with members of the Cancer Advisory Group and Quality Health. A number of the revisions made were to bring further clarity to the questionnaire or to use the same wording in questions as those asked in the national patient survey.
- 3.2. Prompt text before questions and some questions themselves was reworded throughout the questionnaire to add 'about cancer' or 'for your cancer'. This was done to clarify for patients' which episode of care was being referred to and to ensure that, as far as was possible, patients did not answer in relation to episodes of care which were not for cancer treatment.
- 3.3. Prompt text was also added at the start of the 'About You' section to inform people who might be helping a patient to complete the questionnaire that the personal information requested in the questionnaire should be that of the patient and not the person helping.
- 3.4. The following questions in version 1.1 of the questionnaire were revised before cognitive testing began:

<p>1. How many times did you see your GP (family doctor) about this problem before you were told you would need to go to a hospital?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p>	<p>Question changed to: 'Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?'</p>
<p>2. After your GP first told you that you would need to see a hospital doctor, how long did you have to wait before your first appointment with a hospital doctor?</p> <p>1 <input type="checkbox"/> I was seen the same day or next day</p> <p>2 <input type="checkbox"/> I was seen after 2-7 days</p> <p>3 <input type="checkbox"/> I was seen in 1 to 2 weeks</p> <p>4 <input type="checkbox"/> I was seen in 2 to 4 weeks</p> <p>5 <input type="checkbox"/> Waited 1 to 4 months</p> <p>6 <input type="checkbox"/> Waited more than 4 months</p> <p>7 <input type="checkbox"/> Don't know/Can't remember</p>	<p>Response options 2 and 3 combined to read: 'I was seen after 2-14 days'. Option 4 changed to '3 to 4 weeks'. Two new response options added: 'I did not see my GP before going into hospital' and 'I chose to have a later appointment than the one I was offered'.</p>

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<p>4. How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?</p> <p>1 <input type="checkbox"/> Less than 3 months</p> <p>2 <input type="checkbox"/> 3-6 months</p> <p>3 <input type="checkbox"/> 6-12 months</p> <p>4 <input type="checkbox"/> More than 12 months</p>	<p>An additional response option added: 'don't know / can't remember'.</p>
<p>5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?</p> <p>1 <input type="checkbox"/> I got worse</p> <p>2 <input type="checkbox"/> I got better</p> <p>3 <input type="checkbox"/> I stayed about the same</p>	<p>Response options amended to replace 'I' with 'my health'.</p>
<p>10. Did you understand the explanation of what was wrong with you?</p> <p>1 <input type="checkbox"/> Yes I completely understood what was said</p> <p>2 <input type="checkbox"/> Yes, I understood some of what was said</p> <p>3 <input type="checkbox"/> No, I did not understand what was said</p> <p>4 <input type="checkbox"/> Can't remember</p>	<p>All response options amended to replace 'what was said' with 'it'.</p>
<p>11. When you were told you had cancer, were you also given this information in writing?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given anything in writing</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>This question was removed.</p>
<p>25. The last time you saw your Clinical Nurse Specialist, did she/he spend enough time with you?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>Question amended to replace: 'did she/he spend enough time with you?' with 'do you feel that the time you spent with them was too long, too short or about right?'</p> <p>Response options also changed to: 'Too short, About right, Too long'.</p>
<p>39. While you were in hospital, were you given enough support to cope with anxiety or depression?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked more support</p> <p>4 <input type="checkbox"/> I did not have anxiety or depression</p>	<p>Question changed to read: 'While you were in hospital, were you given enough emotional support?'</p> <p>Response option 4: 'have anxiety or depression' replaced with 'need emotional support'.</p>

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<p>47. Beforehand, were you given clear written information about your test?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, I was not given written information about the test</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Response options 1 and 2 changed to read: 'Yes, and it was easy to understand' 'Yes, but it was difficult to understand'</p>
<p>48. During the procedure do you think the hospital staff did everything they could to make you comfortable?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p>	<p>This question was removed.</p>
<p>49. Afterwards, did a member of staff explain the results of the test in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>A new 5th response option was added: 'I was told I would get the results at a later date'</p>
<p>52. Beforehand, were you given clear written information about your operation?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, I was not given written information about the operation</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Response options 1 and 2 changed to read: 'Yes, and it was easy to understand' 'Yes, but it was difficult to understand'</p> <p>Response option 3: 'the operation' replaced with 'my operation'.</p>
<p>54. Before you left hospital, were you given clear written information about your medicines?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Response options 1 to 3 were changed to: 'Yes, and it was easy to understand' 'Yes, but it was difficult to understand' 'No, I was not given written information about my medicines'</p>
<p>55. Were you given clear written information about the possible side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, I was not given written information about side effects</p> <p>4 <input type="checkbox"/> I did not need this information</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Response options 1 to 3 were changed to: 'Yes, and it was easy to understand' 'Yes, but it was difficult to understand' 'No, I was not given written information about side effects of treatment'</p> <p>Response option 4 was removed.</p>

<p>63. Did hospital staff organise help with coping at home or housework from social services or other organisations?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, but I would have liked help</p> <p>3 <input type="checkbox"/> It was not necessary</p> <p>4 <input type="checkbox"/> Don't know/ Can't remember</p>	<p>Question replaced with: After leaving hospital, were you given enough care and help from health or social services?</p> <p>Response options changed to: 'Yes, definitely' 'Yes, to some extent ' 'No' 'I did not need help from health or social services' 'Don't know/ Can't remember'</p>
<p>68. Did you have confidence and trust in the main person you saw at your last outpatients appointment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>This question was removed.</p>
<p>72. As far as you know, was your GP given enough information about your condition and the treatment given by the hospital?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Question amended to replace: 'given by the hospital?' with 'you had at the hospital?'</p>
<p>80. To which of these ethnic groups would you say you belong?</p> <p>1 <input type="checkbox"/> White</p> <p>2 <input type="checkbox"/> Black - Caribbean</p> <p>3 <input type="checkbox"/> Black - African</p> <p>4 <input type="checkbox"/> Black – Other Black Groups</p> <p>5 <input type="checkbox"/> Indian</p> <p>6 <input type="checkbox"/> Pakistani</p> <p>7 <input type="checkbox"/> Bangladeshi</p> <p>8 <input type="checkbox"/> Chinese</p> <p>9 <input type="checkbox"/> Other (please write in box below)</p>	<p>Response options were changed to those used in the national patient surveys as follows:</p> <p>a. WHITE British Irish Any other White background (Please write in box)</p> <p>b. MIXED White and Black Caribbean White and Black African White and Asian Any other Mixed background (Please write in box)</p> <p>c. ASIAN OR ASIAN BRITISH Indian Pakistani Bangladeshi Any other Asian background (Please write in box)</p> <p>d. BLACK OR BLACK BRITISH Caribbean African Any other Black background (Please write in box)</p> <p>e. CHINESE OR OTHER ETHNIC GROUP Chinese Any other ethnic group (Please write in box)</p>

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<p>82. Which of the following best describes your sexual orientation? (Tick one box only)</p> <p>1 <input type="checkbox"/> Heterosexual (opposite sex) 2 <input type="checkbox"/> Bisexual (both sexes) 3 <input type="checkbox"/> Gay or Lesbian (same sex) 4 <input type="checkbox"/> Other 5 <input type="checkbox"/> Prefer not to answer</p>	<p>This question was moved to follow question 78. which asks about the patient's gender.</p>
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- 3.5. All the above changes to version 1.1 of the questionnaire led to version 2.3 which was used for the first round of cognitive testing.

4. Background to the Cognitive Testing

- 4.1. Many of the questions in 2010 are the same as questions in the 2000 and 2004 questionnaires, or in the National In Patients Survey. All these questions had already been subject to the process of cognitive testing. It was decided therefore, that although all questions in 2010 would be tested, greater emphasis would be placed on the new questions, their place in the survey as a whole, instructions for routing, and those questions with more complex terminology or timescale assessments involved. It is known from evidence from the patient help lines run by Quality Health for the NPS system and for PROMs that the issues of timescale assessment and the meaning of NHS terminology and words which are unusual for the reader are ones which prove difficult to understand for some patients.
- 4.2. The cognitive testing was done in a number of phases. For each phase of the testing we simulated the postal methodology which is used for most national patients' surveys and is to be used in the live phase for the cancer survey. Questionnaires were therefore sent to participants who were asked to complete the questionnaire before the interview. This style of testing was used to help determine the participant's ability to complete the questionnaire on their own, and to follow routing instructions.
- 4.3. Interviewees were talked through the questionnaire with the interviewer asking what answer was given to each question, recording the answers on screen, and then asking a number of scripted questions. If required, spontaneous follow up questions were allowed to probe further into the interviewee's reasons for giving the answer they did and their understanding of the question. Templates of each version of the questionnaire tested were drawn up which included potential issues and follow up questions by question. The templates allowed interviewers to type in responses in real time and to record question answers given by the interviewees.
- 4.4. In phase 1, 10 people were selected from a list of volunteers provided by Macmillan. The patients were selected to cover as many different cancer types as possible, to include men and women, and to include any individuals from ethnic minority or non British backgrounds or cultures who might be identifiable as potentially being from these backgrounds.
- 4.5. In each phase of testing, the selected individuals were telephoned to tell them:
 - a. Who Quality Health were, who the individual interviewer would be, and that we were testing the questionnaire for the Department of Health's Cancer Survey Programme.
 - b. That we would like to send them a questionnaire in the post which we would like them to complete.
 - c. That we would like to arrange a time when it would be convenient to phone them to talk through their answers to the questionnaire, with an estimated time for completion of the interview (one hour).
 - d. We told them that the purpose of the interview would be to find out if there was anything they did not understand or found difficult to answer, or if they thought anything important was missing from the questionnaire.

- 4.6. As soon as each person had agreed, a questionnaire was posted out to them with a covering letter explaining the process and the appointment for the call was logged.
- 4.7. Whilst undertaking the cognitive testing, the content of the questionnaire was still under review and a number of changes were made during each phase of the testing as well as after each phase. Some of these amendments were minor changes or corrections to text or numbering, others were more fundamental. The consequence was that phases of testing overlapped slightly with revised versions of the questionnaire being used during the same phase.
- 4.8. Phase 2 of the testing followed the same methodology as phase 1. Another group of 10 volunteers from the Macmillan list were interviewed. This phase of the testing also included the covering letter and the language leaflet which were to go out with the questionnaire. Both the covering letter and language leaflet were the same as, or similar to, materials used with other surveys, and had therefore undergone some testing prior to use with this survey.
- 4.9. In phase 3 it was hoped to identify people who have lower reading ages and who may be from social classes C2, D and E, of which there are significant numbers in the area where Quality Health is located, and who are underrepresented in the Macmillan volunteer group. It was also hoped to interview more people from non English backgrounds where these were available.
- 4.10. Contact was made with a Trust local to Quality Health who agreed to distribute 40 questionnaire packs to patients. The packs included a letter asking for their help and requesting that they call Quality Health if they would agree to participate. Unfortunately this elicited no response. Contact however was made independently with a small number of local people who had cancer and who agreed to participate in the testing.
- 4.11. Overall 25 people participated in the cognitive testing:
 - a. 16 participants were women and 9 were men.
 - b. 24 described themselves as white British, one as Indian.
 - c. Ages ranged from 38 to 78 with 9 being in the 55 to 64 age group.
 - d. Participants came from many parts of the country: Dorset, Hampshire, Gloucestershire, Surrey, West Sussex, Oxfordshire, Essex, Suffolk, Norfolk, Derbyshire, Nottinghamshire, S Yorkshire and N Yorkshire.
 - e. Participants had the following types of cancer: Gastrointestinal Stromal Tumour, Breast Cancer, Bowel/Rectum, Thyroid, Colon, Vulva, Ovarian, Cancer of the tongue, Prostate, Oesophageal, Inflammatory Breast Cancer, Soft Tissue Sarcoma.

5. First round of Cognitive Testing – Questionnaire version 2.3

- 5.1. 9 interviews took place using version 2.3 of the questionnaire.
- 5.2. In the main, all interviewees found the questionnaire easy to answer and many questions were answered quickly with little or no need for further discussion. None of the interviewees had difficulty distinguishing between types of nurse, the meaning of “Clinical Nurse Specialist”, or understanding the medical terminology in the questionnaire.
- 5.3. Remembering when events occurred was also not a problem. Comments such as “something you never forget”, “traumatic experience not forgotten”, and “can’t imagine anyone not remembering” were used in relation to questions about referral to hospital and how long they waited for appointments etc. All patients used prominent ‘date markers’ in their mind associating the diagnosis or treatment of their cancer with other events in their lives, or the event was so etched on their memories that they could not forget the general time frame.
- 5.4. Those areas where issues did arise are set out below, with any agreed revisions to the questionnaire arising from them.

a. Referral

Question 1. asks how many times the patient saw their GP before going to hospital.

It was clear that not all patients were referred to hospital by their GP. This was particularly true for women with breast cancer who may have been referred via the breast screening service and have had little or no contact with their GP at this stage.

It was agreed to insert a routing guide into question 1 to take account of this.

b. Finding out what was wrong

Questions 6 to 8. ask about who told the patient they had cancer and if they had someone with them.

Some patients reported more than one person being present when they were told that they had cancer e.g. a doctor and a nurse.

It is clear that in most cases it is purely fortuitous that the patient has someone with them when they are told they have cancer. Only 1 patient said “the hospital made sure I had a family member with me”, others said it was “by accident”. One patient was told “over the phone”. All but one interviewee said they would want someone with them when they were told.

Question 9. asks how the patient felt about the way they were told they had cancer.

One interviewee suggested that this question should ask “how well it was done” rather than was it done sensitively. Other interviewees said this was an excellent question or that sensitivity was the main issue.

It was agreed not to change these questions but to continue testing them.

c. Deciding on treatment

Question 13. asks about explanations of side-effects.

Some interviewees reported no explanations of side effects and therefore found question 13 difficult to answer as they did not feel any of the options applied to them.

It was agreed to remove the word “properly” from response option 3 to take account of this.

d. Most recent hospital admission

Prompt text to this section refers to ‘the last time you went into hospital for a one-day treatment or to stay overnight’.

Some interviewees were confused by this section and decided “it was about a stay in hospital” or answered “about surgery, not the odd treatments for chemo”. Interviewees did not interpret ‘admission’ as relating to a ‘one day treatment’ but rather as an inpatient episode.

It was agreed to remove ‘one day treatment or’ so that the section only referred to overnight stays.

e. Hospital doctors

Questions 17 to 21. ask about doctors communication, knowledge and attitude.

One interviewee said they did not see a doctor the last time they went to hospital.

It was agreed not to change these questions but to continue testing them.

f. Hospital care and treatment

Question 40. asks about control of side-effects.

One interviewee was not sure if this included all treatment including outpatient treatment.

It was agreed not to change this question but to continue testing it.

g. Test Procedures

Question 42. asks if patients have had a test procedure.

Some interviewees did not understand that question 42 referred to tests which related to their cancer and answered for other conditions.

It was agreed that the words “for your cancer” should be inserted after “test procedure” in the question to clarify this, and to remove ‘x-ray’ from the list of examples.

Question 43. asks what test procedure the patient had.

Some patients said they had had more than one test on the day in question: “had a scan and endoscopy”, “had scan and x-ray” and “had two different tests”.

It was agreed that the question should not be multi-choice but that the answer options needed revising to remove ‘x-ray’ and replace this with ‘mammogram’, and to add ‘CT’ to the examples of types of scan.

h. Information

Question 52. asks about written information about medicines.

It is clear that many interviewees answering this question think that it refers to the leaflets inside medicine packets rather than special information given to them by the hospital: “only what was in the box”, “with prescription”, “do you mean the leaflet inside the boxes?”.

It was agreed not to change this question at this point in time but to continue testing it.

Question 53. asks about written information about side-effects.

It was noticed that the question asks about side-effects of ‘treatment’ but response option 3 talks about ‘my medicines’.

It was agreed to change ‘medicines’ in response option 3 to ‘treatment’.

i. Outpatient appointments

Question 63. asks what the main reason was for the appointment.

Two interviewees would have liked to have ticked more than one answer option on this question.

Given that the question does use the word “main”, it was agreed not to change this question but to continue testing it.

Question 67. asks about continuity of care from doctors.

It was agreed to remove this question and replace it with a question about doctors having patients documentation which was felt to be a more relevant issue.

j. Care from GPs and Practice Nurses

Question 68. asks if patients received copies of letters to GPs.

One interviewee would have liked another response option: “some, not all”.

It was agreed not to change this question given that there was a ‘not sure’ option and this would diminish its comparability with the data from the national patients survey which may be useful.

Questions 70 to 72. ask about information given to GPs, and control of pain and side-effects.

Many interviewees said their GP was not involved in their care in relation to these questions: “tricky to answer, GP not really involved”, “not relevant, because it was dealt with by a specialist nurse at hospital”, “did not answer these as managed by hospital”. One interviewee who said their GP had not been involved in their care in relation to pain control or control of side effects of treatment had in fact (in respect of question 71) ticked response option 3 – “No, they could have done more” – which indicated a concern that the GP et al should have been more involved.

It was agreed to add a further response option to these questions: ‘My GP and practice nurses were not involved’.

k. Longstanding conditions

Question 77. asks if patients have any long-standing conditions.

Some interviewees found it hard to decide if the condition they had fitted into this question: “does high blood pressure count”, “unsure where to put ulcerative colitis”. In essence respondents were unsure whether to use the catch all line “a long standing physical condition”.

It was agreed not to change this question but to continue testing it.

l. How long since first treatment

Question 78. asks patients how long it is since they were first treated for cancer.

All interviewees found this easy to answer: “like a birthday, you always remember”, “significant episode so very clear in mind”, “easy, it was daughter’s wedding”. Our concern about patients’ ability to remember timeframes in this context seems unfounded.

5.5. Other changes to the questionnaire

- a. A number of general changes were made to the questionnaire arising from testing or the ongoing discussions taking place with the DH. These were:
 - i. To revise the prompt text to sections and questions throughout the questionnaire to replace all instances where patients are asked to think about the last time they went into hospital with a more specific direction to think about 'the hospital named in the covering letter'. This was to clarify for patients the episode of care that the questionnaire was referring to.
 - ii. To remove 'at any hospital' and replace this with 'at the hospital named in the covering letter' in the section about outpatient appointments which was again to help clarify for patients which episode the questionnaire was referring to.

5.6. General points that arose during testing

- a. During these interviews three women, two with breast cancer and one with ovarian cancer, commented that they had gone to their GP before they were diagnosed, and when they first had symptoms of their cancer, and were sent away without referral. Two were told by their GP that they were experiencing symptoms of the menopause. In one of these cases no further action was taken by the GP, in the other the GP did also refer the patient for tests. Another woman with a lump in her breast was just told not to worry.
- b. One Asian patient felt she was not told properly, if at all, about side effects of treatment and found out at a later stage that there were specific side-effects relating to non-white patients which were never mentioned to her.

5.7. The table below shows the questions that were revised or changed following the testing of version 2.3 of the questionnaire.

<p>1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p> <p>6 <input type="checkbox"/> Don't know/Can't remember</p>	<p>1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital → Go to Q4</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p> <p>6 <input type="checkbox"/> Don't know/Can't remember</p>
<p>13. Were the possible side effects of different treatments explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, side effects were not properly explained</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Not sure / Can't remember</p>	<p>13. Were the possible side effects of different treatments explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, side effects were not explained</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Not sure / Can't remember</p>
<p>42. During the last 12 months, have you had a test procedure (such as a biopsy, endoscopy, x-ray or scan) at this hospital?</p> <p>1 <input type="checkbox"/> Yes → Go to Q43</p> <p>2 <input type="checkbox"/> No → Go to Q48</p>	<p>42. During the last 12 months, have you had a test procedure for your cancer (such as a biopsy, endoscopy or scan) at the hospital named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q43</p> <p>2 <input type="checkbox"/> No → Go to Q48</p>
<p>43. The last time you had a test procedure, what was it?</p> <p>1 <input type="checkbox"/> Biopsy</p> <p>2 <input type="checkbox"/> Endoscopy</p> <p>3 <input type="checkbox"/> Scan (e.g. MRI) or ultrasound</p> <p>4 <input type="checkbox"/> X-ray</p> <p>5 <input type="checkbox"/> Something else</p>	<p>43. The last time you had a test procedure, what was it?</p> <p>1 <input type="checkbox"/> Biopsy</p> <p>2 <input type="checkbox"/> Endoscopy</p> <p>3 <input type="checkbox"/> Scan (e.g. MRI or CT) or ultrasound</p> <p>4 <input type="checkbox"/> Mammogram</p> <p>5 <input type="checkbox"/> Something else</p>
<p>53. Were you given clear written information about the possible side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about side effects of medicines</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>53. Were you given clear written information about the possible side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about side effects of treatment</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>

<p>67. The last 2 times you had an outpatients appointment with a hospital doctor, was it...?</p> <p>1 <input type="checkbox"/> With the same doctor both times</p> <p>2 <input type="checkbox"/> With two different doctors</p> <p>3 <input type="checkbox"/> I have only had one appointment with a doctor</p>	<p>67. The last time you had an appointment with a doctor at the hospital named in the covering letter, did they have the right documents, such as medical notes, x-rays and test results?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> Don't know / Can't remember</p>
<p>70. Do you think your GP and practice nurses did everything they could to help control your pain?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any pain</p>	<p>70. Do you think your GP and practice nurses did everything they could to help control your pain?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any pain</p> <p>5 <input type="checkbox"/> My GP and practice nurses were not involved</p>
<p>71. Do you think your GP and practice nurses did everything they could to help control the side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any side effects</p>	<p>71. Do you think your GP and practice nurses did everything they could to help control the side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any side effects</p> <p>5 <input type="checkbox"/> My GP and practice nurses were not involved</p>
<p>72. Do you think your GP and practice nurses did everything they could to help you cope with anxiety or depression?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have anxiety or depression</p>	<p>72. Do you think your GP and practice nurses did everything they could to help you cope with anxiety or depression?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have anxiety or depression</p> <p>5 <input type="checkbox"/> My GP and practice nurses were not involved</p>

6. Second round of Cognitive Testing – Questionnaire versions 3.2 and 3.4

- 6.1. A number of versions of the questionnaire were produced following the testing of version 2.3. The changes that were made after testing version 2.3 are documented above and this resulted in the second round of testing using versions 3.2 and then 3.4 of the questionnaire.
- 6.2. 3 participants were interviewed using version 3.2 of the questionnaire; a further 4 were interviewed using version 3.4.
- 6.3. For this phase of the testing, interviewees were also sent the draft covering letter and the language leaflet as well as the revised questionnaires.
- 6.4. None of the interviewees had any problems understanding the covering letter or the language leaflet or had any comments to make about these documents. All interviewees understood that the covering letter was referring them to the hospital named in the letter as the place they should be answering the questionnaire about although it had not been possible to put this information in the covering letter sent as it was not known from the information we had about the interviewees.
- 6.5. As with the first phase, interviewees found the questionnaire easy to answer and many questions were answered quickly with little or no need for further discussion. None of the interviewees had difficulty distinguishing between types of nurse, the meaning of “Clinical Nurse Specialist”, or understanding the medical terminology in the questionnaire.
- 6.6. Remembering when events occurred was also not a problem and no-one found the use of the word cancer in the questionnaire problematic.
- 6.7. One respondent asked why there was no question about occupational grouping – a good point we think.
- 6.8. The areas where issues arose during this phase of testing are set out below, with any agreed revisions to the questionnaire arising from them.

a. Referral

Question 1. asks how many times the patient saw their GP before going to hospital.

We were asked to probe how patients answered if they had had multiple visits to their GP, possibly about other issues than their cancer. One respondent in this group was clear that he had visited his GP about 5 times, some for related issues before cancer was diagnosed; he did not have difficulty remembering the sequence of events. One respondent who had been picked up on breast screening and didn't go to her GP was confused as to how to answer questions 2 and 3 in her circumstances. A further respondent said her condition “was picked up by the dermatologist” and she did not see her GP; this person though the routing was appropriate in her circumstances.

It was felt that there would be a range of scenarios given the diverse group of patients being surveyed and that the question did cover all eventualities and so no changes were made at this point. It was however agreed to change the routing instruction on this question to take the respondent to question 6 rather than question 4 as it was felt that questions 4 and 5 were not applicable to patients who had not seen their GP.

Question 2. asks how many times the patient saw their GP before going to hospital.

One respondent was confused about whether we were measuring the gap between GP and consultant clinic; or whether we were measuring the gap between GP and “the scan”. A second respondent (a teacher) thought that some people would have difficulty with the length of this sentence i.e. the question length; however, he had no difficulty understanding what was being asked.

It was agreed to put ‘first appointment with a hospital doctor’ in bold in both questions 2 and 3 to direct patients to respond in relation to seeing doctors rather than just going for tests.

Question 4. asks how long it was from the time the patient first thought something was wrong to them first seeing a hospital doctor.

Patients were clear about the general time that they thought something was wrong, if they were aware of being unwell at all (and some were not aware). No one suggested that a third party prompted them. One person said she would have liked a shorter time than 3 months in answer option 1.

No changes were considered necessary to this question.

Question 5. asks if the patient’s health got worse whilst waiting.

A breast cancer patient who had been picked up through a routine mammogram made the point that as the process was so fast to diagnosis that there was no time for it to get worse.

No changes were considered necessary to this question; those patients having very fast treatment can still answer and the new routing to question 1 would mean patients not seeing their GP would be routed round this question.

b. Finding out what was wrong

Questions 6. asks about who told the patient they had cancer.

As previously, some patients reported more than one person being present when they were told that they had cancer. There was further evidence of demand for a ‘more than one of the above’ option. One interviewee said “I know other cancer patients who had been told by more than one professional”.

*It was still felt that most respondents would be able to answer in relation to the **first and main** person who told them so no changes were made to this question.*

Questions 7 and 8. ask if the patient had someone with them or if they would like someone with them when they were told they had cancer.

One respondent thought there should be a “can’t remember” option for question 7. He also made the point that in his experience Doctors found it harder to discuss bad news when there was more than one person in the room. Also further evidence from other respondents that there was no indication that bad news would be given before the appointment took place; and (extensively) that they were not told they could bring someone. Another respondent was told by the Consultant and then taken into a further room by the Macmillan nurse and the Consultant then offered to tell his wife who was waiting outside.

*It was agreed to replace questions 7 and 8 with a new question asking if they **had been told they could bring someone with them.***

Questions 10. asks about understanding of explanations of what was wrong.

Further evidence emerged from respondents that their understanding of the information given was that they had cancer and the detail did not sink in until later in terms of prognosis etc. However, two respondents claimed to understand a set of wider issues, e.g. the kind of cancer, some elements of future treatment and prognosis etc.

It was not felt that any changes were required to this question.

Question 11. asks if the patient was given written information about the type of cancer they had.

One respondent said that she didn’t get leaflets because she wasn’t on a specialist cancer ward. Another respondent said that written information was important, but that he received none, and would have liked something to take home and digest. Another said that the volume of information given was massive and by implication off-putting. Another said that the information given was not easily understandable nor was it difficult – a lot of information given in writing. Another respondent said that giving written info was the underpinning of information giving as it gave a fallback position that patients could refer to if they did not take all the information in when given it.

It was not felt that any changes were required to this question.

c. Deciding on treatment

Question 12. asks if treatment risks and benefits were explained.

3 respondents said they were not told of alternative treatments. Another respondent had a rare cancer and there was little information about it, so naturally he received little. Another respondent said they took someone with them and they took notes on points of detail to assist subsequent recall. Another respondent said that although there were different types of treatment offered as part of a unified package, he did not get the impression of there being genuine alternatives of competing merit on offer. The strong impression that we have received is that most respondents are being told that there is “a treatment” and only one treatment.

It was not felt that any changes were required to this question.

Questions 13 and 14. ask about explanations and written information about side-effects.

There was further evidence of confusion over these questions; one respondent said that side effects could be caused by both chemotherapy and surgery and he wasn't sure what the questions related to. Several respondents were confused by these questions, following the point re Q12 (i.e. no real alternatives given to the treatment offered).

It was agreed to clarify these questions by removing the word 'different' so that the questions were just about explanations and written information of side effects and not also about different treatments.

Question 15. asks about involvement in decisions on care and treatment.

One respondent wasn't clear whether she was talking about involvement at the time of diagnosis and treatment decision, or in respect of the whole patient experience. A second respondent said she was referring to all treatment and not just to the diagnosis / discussion phase, as did three other respondents who were answering in respect of the whole patient experience. Only one respondent said they were replying in respect of the diagnosis / discussion phase.

It was agreed to replace this question with one asking about involvement in decisions about which treatment patients would have.

d. Hospital doctors

Question 19. asks if doctors knew enough about the patient's condition.

One respondent interpreted the question as dealing with the type of cancer he had rather than his individual case. Another said that she was referring to her specific position as an individual when answering the question. Another respondent confirmed he was replying in respect of his personal position combined with the known treatment for his cancer.

*It was agreed to change this question to ask if patients thought the doctors knew enough **about how to treat their cancer** to overcome the confusion in patients' minds between 'doctors having specialist knowledge' and 'knowing enough about the individual patient'.*

e. Clinical Nurse Specialist

Question 22. asks if patients were given the name of the CNS or key worker.

'Key worker' was interpreted as a Macmillan Nurse by one respondent. Another respondent thought a key worker was "one down from a CNS". One respondent said these terms were all familiar and there was no problem of understanding therefore. Another respondent said he was not at all aware of the term CNS. One respondent said he thought option 3 should have a routing arrow attached to it.

It was agreed to remove the words 'or key worker' from this question and to insert a routing arrow after option 3.

Question 23. asks how easy it was to contact the CNS.

We tested to see if patients interpreted this as being about the mechanics of getting through on the phone, or how comfortable they felt doing it. Two respondents said they had never considered the issue of being 'comfortable' in contacting the CNS; they interpreted this as a communication question.

Some patients felt that it was not an either or situation and the ease of contact varied.

It was agreed to add another response option; 'sometimes easy, sometimes difficult' to this question to address this issue.

Question 26. asks about asking the CNS important questions.

There was further evidence that patients would like the question drafted in the present tense. No patient disagreed in this cohort.

It was agreed to amend this question to put it into the present tense.

Question 27. asks if the CNS knew enough about the patient's condition.

The same issues apply as to Q19. Any changes made to Q19 should also be applied to Q27.

After discussion it was felt that this question was not really relevant to CNSs and it was therefore agreed that it should be removed.

f. Other hospital nurses

Question 28. asks about asking hospital nurses important questions.

One respondent had difficulty in distinguishing between the performance and attitude of one set of nurses in one hospital and another set of nurses in another hospital. This point is however dealt with in the prompt text before the question. Other respondents had no difficulty in distinguishing between types of nurses.

It was agreed to change the heading of this section to 'Ward Nurses' and the text of each question (28-31) from 'hospital' to 'ward' nurses to increase patient understanding of which type of nurse was being asked about given the different contexts in which patients would come across nurses.

g. Hospital care and treatment

Question 38. asks about emotional support.

It was agreed to amend this question to make it clear that it referred to emotional support from hospital staff rather than friends or family.

Question 40. asks about control of side-effects.

One respondent interpreted this as referring to the side effects of any surgery or drugs; another referred to advice given on avoiding perfume, soap, deodorants etc. Patients regarded this question as covering a wide range of potential issues with very broad coverage.

It was agreed to move this question into the section about outpatient care and to reword it to reference side effects of radiotherapy, chemotherapy and cancer drug treatment and to move it into the new 'Hospital care as an outpatient' section.

h. Test Procedures

Question 43. asks what test procedure the patient had.

Because the word "Last" was in bold 2 interviewees said it was clear which box to tick. However 3 interviewees said they would have liked to tick more than one box as they had more than one test on the same day. This issue also emerged in phase 1. The only possible change that could be made would be to change the question to a multiple choice one, as logically some of these test options COULD be experienced together in one day.

*It was agreed to remove this question and to revise the previous question (42) which asks whether patients had tests during the last 12 months to ask if patients had tests **before being diagnosed with cancer** and to change the heading of the section to 'Diagnostic Tests'.*

It was also agreed to replace the word 'test' in questions 44 to 46 with 'test(s)' to cover those patients who had more than one test on the same day.

Question 47. asks about explanations of test results.

It was felt that the word 'afterwards' in this question was redundant and that the response option saying that the patient 'would get the results at a later date' should be removed as many patients may get the results sometime later. The revised question could then be answered by patients whether they got the results immediately or at some later point.

i. Operations

Question 49. asks about explanations of what would be done.

It was agreed to reword this question to make it clearer about the timeframe being asked about by replacing 'beforehand' with 'before you had your operation'.

j. **Information before leaving hospital**

Question 52. asks about written information about medicines.

One respondent said that it was easy to distinguish between new and old cancer medicines as he was talked through the instructions on the box each time a new medicine was prescribed.

One respondent said that they had had previous operations / treatment and that therefore there was no need for them to receive further written information about their medicines. Another respondent said they only received the information inserts in the medication boxes.

If question 52 is intended to capture information **being given by hospitals about medication** other than the generic box leaflets, this question is not capturing this information.

*It was agreed to change this question to make it clear that it is about information **from hospital staff**. It was also agreed to add a new response option: 'I did not have any new medicines'.*

Question 53. asks about written information about side effects of treatment.

It was agreed to remove this question as there was already a question about written information on side effects earlier in the questionnaire and it was therefore confusing for patients to ask a similar question again.

Question 55. asks if information was given to the patient's family.

One respondent said that the information should be given to her and not to a family member. She had answered NO i.e. option 3.

It was agreed to include a new response option in this question to cover this point: 'I did not want my family or friends to be given information'.

Question 56. asks if patients were told who to contact if they were worried.

One respondent was specifically against a "not necessary" option; his reasoning was that it was important to get responses to this question as this was a key issue and he didn't want the data diluted.

Question 57. asks if patients were told about support groups.

We tested whether patients included national helplines in their understanding of this question. Further evidence was given of 3 respondents who did include national helplines in their response. One however said they did not.

It was agreed that no changes were necessary to these questions.

Question 59. asks if patients were told about free prescriptions.

It was agreed to clarify this question by replacing 'were you told' with 'did hospital staff tell you'.

k. Arranging home support

Question 60. asks if hospital staff helped organise home support.

We tested if the examples given in the question were adequate. 4 respondents commented that the examples given in the question were comprehensive enough. One respondent thought that including the example of Macmillan Nurses might help.

Question 61. asks if patients were given enough help.

One respondent did not know what was meant by health and social services. One respondent said he was well informed about who ran what.

After discussion it was agreed to replace 'health visitor' with 'home help' in the examples of home support given in question 60 and to add the examples to question 61.

l. Outpatient appointments

Question 62. asks if patients have had outpatient appointments.

It was agreed to clarify this question by rewording it and focusing on appointments with 'a cancer doctor'.

Question 63. asks what the main reason was for the appointment.

No respondents had problems with the terminology in the question, however there was further evidence of patients wanting to tick more than one box, as they attended for at least two purposes at the last OPD appointment.

It was agreed to remove this question and replace it with two separate questions about radiotherapy and chemotherapy in a new section: 'Hospital care as an outpatient'.

Question 64. asks about waiting after appointment times.

There was further evidence that patients were NOT including "early time" in the total waiting time. No one said they included it. One respondent said that there was a case for asking about whether they were told why a wait occurred (as in the OPD survey).

It was agreed to reword the question to focus the question on appointments with doctors. It was also agreed not to add any further questions here as this would lengthen the questionnaire.

Question 65. asks how long patients spent with the person they saw.

There was further evidence of patients thinking that this was a useful question to have in the survey (5 respondents).

It was agreed to reword this question to focus it on outpatients appointments with a cancer doctor.

Question 66. asks about privacy at appointments.

It was agreed to remove this question as it was felt that it was hard to maintain privacy on these occasions and the question did not focus on a particular aspect of privacy so little would be learned from it.

Question 67. asks about doctors having patient's information.

One respondent said she was thinking specifically of notes and other documents relevant to her case. This was what she thought would be "right" i.e. the defining word in the question. Another respondent said that notes were not always there but when answering the question she was thinking of the organisational issues that led to the notes etc. not being present. Another "got the impression of organisation" in the examples quoted in the question.

It was agreed to reword this question to focus it on appointments with a cancer doctor.

m. Care from GPs and Practice Nurses

Question 69. asks if GPs were given enough information.

2 respondents said they could not make judgements about whether their GP was given enough information, as it was intrinsically difficult to know. One respondent said however that they were in a position to know whether their GP was given enough info – but this was someone involved with national organisations in cancer and very atypical. However, most patients used the 'don't know' option so they were able to answer the question.

No changes were required to this question.

Questions 70 to 72. ask about information given to GPs, and control of pain and side-effects.

Strong evidence (from almost all respondents) of patients feeling that it is the GP's responsibility to provide front-line support to cancer patients and it is therefore appropriate to ask about the role of the GP.

No changes were required to this question.

n. About the patient

Question 76. asks patients to describe their sexual orientation.

5 respondents said it was odd (one said bizarre) to be asked about sexual orientation; one of this group said there was too much being made of these issues and its very divisive. 3 said they understood why some people would mind. One said they didn't mind. In conjunction with the comments in the first round, it demonstrates strong evidence that this question is disliked.

After discussion it was agreed to keep this question and carry on testing it.

Question 77. asks if patients have any long-standing conditions.

Some evidence that the words “other than cancer” would help clarify the question – two respondents confirmed that this would assist completion. More than one patient did not know how to classify conditions they had and whether they should be regarded as long term conditions.

It was agreed not to change this question but to continue testing it.

o. How long since first treatment

Question 78. asks patients how long it is since they were first treated for cancer.

All interviewees found this easy to answer: “like a birthday, you always remember”, “significant episode so very clear in mind”, “easy, it was daughter’s wedding”. Our concern about patients’ ability to remember timeframes in this context seems unfounded.

6.9. Other changes to the questionnaire

- a. A number of general changes were made to the questionnaire arising from testing or the ongoing discussions taking place with the DH. These were:
 - i. To re-order the questionnaire to make it fit more closely to the patient pathway as some patients had felt that the order of the questions made answering some of them confusing. This re-ordering also included changing some headings e.g. ‘Test Procedures’ to ‘Diagnostic Tests’. Question 16 about admission date changes was also moved to the Operations section of the questionnaire and reworded.
 - ii. To replace ‘at the hospital named in the covering letter’ wherever it appeared in the questionnaire to ‘at one of the hospitals named in the covering letter’. After discussion it was felt that patients would have different parts of their treatment in different hospitals within the same Trust and it was important to capture these different aspects of care. The front cover of the questionnaire and the covering letter was also amended to reflect this point.
 - iii. A new section was added to the questionnaire: ‘Support for people with cancer’ to follow the section on ‘Clinical Nurse Specialists’ and three questions were moved into this section from the ‘Information before leaving hospital’ section. These were questions 57 to 59 which ask about information on self-help groups, financial help and free prescriptions (which was slightly revised). It was felt that people were likely to be given this information closer to the time that they were diagnosed, but if they did get it later they would still be able to answer the questions.
 - iv. Prompts under the headings ‘Operations’, ‘Hospital doctors’, ‘Ward nurses’, ‘Hospital care and treatment’, ‘Information given to you before you left hospital’ and ‘Arranging home support’ were all changed to add ‘for an operation’ before ‘for your cancer’.
 - v. A new question was added asking if patients felt they were treated as a person rather than ‘as a number’ as this is an issue often raised by patients.
 - vi. The text on the comments page was revised to replace ‘NHS healthcare’ with ‘NHS cancer care’.

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6.10. The table below shows the questions that were revised or changed following the testing of versions 3.2 and 3.4 of the questionnaire on the left, with the revised questions as they appear in version 4.2 of the questionnaire on the right.

<p>1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital → Go to Q4</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p> <p>6 <input type="checkbox"/> Don't know/Can't remember</p>	<p>1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital → Go to Q6</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p> <p>6 <input type="checkbox"/> Don't know/Can't remember</p>
<p>7. When you were first told that you had cancer, did you have a family member or friend with you?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>	<p>12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?</p> <p>1 <input type="checkbox"/> Yes, and I brought someone with me</p> <p>2 <input type="checkbox"/> Yes, but I did not bring someone with me</p> <p>3 <input type="checkbox"/> No, I had not been told I could bring someone with me</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>
<p>8. When you were first told that you had cancer, did you want a family member or friend to be with you?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> I did not mind</p>	<p>Removed with 7 and replaced by 12 above.</p>
<p>13. Were the possible side effects of different treatments explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, side effects were not explained</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Not sure / Can't remember</p>	<p>13. Were the possible side effects of treatment(s) explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, side effects were not explained</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Not sure / Can't remember</p>

<p>14. Before you started your treatment, were you given clear written information about the side effects of different treatments?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand 2 <input type="checkbox"/> Yes, but it was difficult to understand 3 <input type="checkbox"/> No, I was not given written information about side effects 4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>18. Before you started your treatment, were you given clear written information about the side effects of treatment(s)?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand 2 <input type="checkbox"/> Yes, but it was difficult to understand 3 <input type="checkbox"/> No, I was not given written information about side effects 4 <input type="checkbox"/> Don't know / Can't remember</p>
<p>15. Were you involved as much as you wanted to be in decisions about your care and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p>	<p>19. Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p>
<p>16. The last time you went into hospital, was your admission date changed by the hospital?</p> <p>1 <input type="checkbox"/> No 2 <input type="checkbox"/> Yes, it was changed once 3 <input type="checkbox"/> Yes, it was changed 2 or 3 times 4 <input type="checkbox"/> Yes, it was changed 4 times or more</p>	<p>29. The last time you went into hospital for an operation, was your admission date changed to a later date by the hospital?</p> <p>1 <input type="checkbox"/> No 2 <input type="checkbox"/> Yes, it was changed once 3 <input type="checkbox"/> Yes, it was changed 2 or 3 times 4 <input type="checkbox"/> Yes, it was changed 4 times or more</p>
<p>19. Do you think the doctors treating you knew enough about your condition and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know/ Not sure</p>	<p>35. Do you think the doctors treating you knew enough about how to treat your cancer?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know / Not sure</p>
<p>22. Were you given the name of a Clinical Nurse Specialist or Key Worker who would be in charge of your care?</p> <p>1 <input type="checkbox"/> Yes → Go to Q23 2 <input type="checkbox"/> No → Go to Q28 3 <input type="checkbox"/> Don't know / Not sure</p>	<p>20. Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?</p> <p>1 <input type="checkbox"/> Yes → Go to Q21 2 <input type="checkbox"/> No → Go to Q25 3 <input type="checkbox"/> Don't know / Not sure → Go to Q25</p>
<p>23. How easy is it for you to contact your Clinical Nurse Specialist?</p> <p>1 <input type="checkbox"/> Easy 2 <input type="checkbox"/> Difficult 3 <input type="checkbox"/> I have not tried to contact her/him</p>	<p>21. How easy is it for you to contact your Clinical Nurse Specialist?</p> <p>1 <input type="checkbox"/> Easy 2 <input type="checkbox"/> Sometimes easy, sometimes difficult 3 <input type="checkbox"/> Difficult 4 <input type="checkbox"/> I have not tried to contact her/him</p>

<p>26. When you had important questions to ask your Clinical Nurse Specialist, how often did you get answers you could understand?</p> <p>1 <input type="checkbox"/> All or most of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Rarely or never 4 <input type="checkbox"/> I did not ask any questions</p>	<p>23. When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?</p> <p>1 <input type="checkbox"/> All or most of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Rarely or never 4 <input type="checkbox"/> I did not ask any questions</p>
<p>27. Do you think your Clinical Nurse Specialist knew enough about your cancer and its treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know/ Not sure</p>	<p>Removed</p>
<p>28. When you had important questions to ask a hospital nurse, how often did you get answers you could understand?</p> <p>1 <input type="checkbox"/> All or most of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Rarely or never 4 <input type="checkbox"/> I did not ask any questions</p>	<p>38. When you had important questions to ask a ward nurse, how often did you get answers you could understand?</p> <p>1 <input type="checkbox"/> All or most of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Rarely or never 4 <input type="checkbox"/> I did not ask any questions</p>
<p>29. Did you have confidence and trust in the hospital nurses treating you?</p> <p>1 <input type="checkbox"/> In all of them 2 <input type="checkbox"/> In some of them 3 <input type="checkbox"/> In none of them</p>	<p>39. Did you have confidence and trust in the ward nurses treating you?</p> <p>1 <input type="checkbox"/> In all of them 2 <input type="checkbox"/> In some of them 3 <input type="checkbox"/> In none of them</p>
<p>30. Do you think the hospital nurses knew enough about your condition and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know/ Not sure</p>	<p>40. Do you think the ward nurses knew enough about how to treat your cancer?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know / Not sure</p>
<p>31. Did nurses talk in front of you as if you weren't there?</p> <p>1 <input type="checkbox"/> Yes, often 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No</p>	<p>41. Did ward nurses talk in front of you as if you weren't there?</p> <p>1 <input type="checkbox"/> Yes, often 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No</p>

<p>38. While you were in hospital, were you given enough emotional support?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked more support</p> <p>4 <input type="checkbox"/> I did not need emotional support</p>	<p>48. Were you given enough emotional support from hospital staff?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, I would have liked more support</p> <p>4 <input type="checkbox"/> I did not need emotional support</p>
<p>40. Do you think the hospital staff did everything they could to help control the side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any side effects</p>	<p>59. Did hospital staff do everything possible to control the side effects of your chemotherapy, radiotherapy or cancer drug treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I have not had radiotherapy chemotherapy or cancer drug treatment</p> <p>5 <input type="checkbox"/> I have not had any side effects</p>
<p>42. During the last 12 months, have you had a test procedure for your cancer (such as a biopsy, endoscopy or scan) at the hospital named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q43</p> <p>2 <input type="checkbox"/> No → Go to Q48</p>	<p>6. Before you found out you had cancer did you have diagnostic test(s) such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q7</p> <p>2 <input type="checkbox"/> No → Go to Q11</p>
<p>43. The last time you had a test procedure, what was it?</p> <p>1 <input type="checkbox"/> Biopsy</p> <p>2 <input type="checkbox"/> Endoscopy</p> <p>3 <input type="checkbox"/> Scan (e.g. MRI or CT) or ultrasound</p> <p>4 <input type="checkbox"/> Mammogram</p> <p>5 <input type="checkbox"/> Something else</p>	<p>Removed</p>
<p>47. Afterwards, did a member of staff explain the results of the test in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> I was told I would get the results at a later date</p> <p>6 <input type="checkbox"/> Don't know / Can't remember</p>	<p>10. Did a member of staff explain the results of the test(s) in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>

<p>49. Beforehand, did a member of staff explain what would be done during the operation?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>30. Before you had your operation, did a member of staff explain what would be done during the operation?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>52. Before you left hospital, were you given clear written information about your medicines?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about my medicines</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>51. Before you left hospital, did hospital staff give you clear written information about any new medicines you were given?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about my medicines</p> <p>4 <input type="checkbox"/> I did not have any new medicines</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>53. Were you given clear written information about the possible side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about side effects of treatment</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Removed</p>
<p>55. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> No family or friends were involved</p> <p>5 <input type="checkbox"/> My family or friends did not want or need information</p>	<p>54. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> No family or friends were involved</p> <p>5 <input type="checkbox"/> My family or friends did not want or need information</p> <p>6 <input type="checkbox"/> I did not want my family or friends to be given information</p>

<p>59. Were you told that you could get free prescriptions?</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know/ Can't remember</p>	<p>27. Did hospital staff tell you that you could get free prescriptions?</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>
<p>60. Did hospital staff help to organise nursing or other health services you would need at home? (For example, a district nurse, health visitor or physiotherapist).</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked help 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know/ Can't remember</p>	<p>55. Did hospital staff help to organise nursing or other health services you would need at home? (For example, a district nurse, home help or physiotherapist).</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked help 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>
<p>61. After leaving hospital, were you given enough care and help from health or social services?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> I did not need help from health or social services 5 <input type="checkbox"/> Don't know/ Can't remember</p>	<p>56. After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> I did not need help from health or social services 5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>62. During the last 12 months, have you had an outpatients appointment at the hospital named in the covering letter to get treatment for your cancer or to see a specialist?</p> <p>1 <input type="checkbox"/> Yes → Go to Q63 2 <input type="checkbox"/> No → Go to Q68</p>	<p>61. In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q62 2 <input type="checkbox"/> No → Go to Q65</p>

<p>63. What was the main reason for your most recent outpatients appointment?</p> <p>1 <input type="checkbox"/> To have radiotherapy</p> <p>2 <input type="checkbox"/> To have chemotherapy</p> <p>3 <input type="checkbox"/> To see a doctor</p> <p>4 <input type="checkbox"/> To see a nurse</p> <p>5 <input type="checkbox"/> Something else</p>	<p>57. During the last 12 months, have you had radiotherapy at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>5 <input type="checkbox"/> Don't know / Not sure</p> <p>58. During the last 12 months, have you had chemotherapy at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>5 <input type="checkbox"/> Don't know / Not sure</p>
<p>64. How long after the stated appointment time did the appointment start?</p> <p>1 <input type="checkbox"/> Seen on time, or early</p> <p>2 <input type="checkbox"/> Waited up to 5 minutes</p> <p>3 <input type="checkbox"/> Waited 6 - 15 minutes</p> <p>4 <input type="checkbox"/> Waited 16 - 30 minutes</p> <p>5 <input type="checkbox"/> Waited 31 - 60 minutes</p> <p>6 <input type="checkbox"/> Waited 1 to 2 hours</p> <p>7 <input type="checkbox"/> Waited more than 2 hours</p> <p>8 <input type="checkbox"/> Don't know/Can't remember</p>	<p>62. The last time you had an outpatients appointment with a doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?</p> <p>1 <input type="checkbox"/> Seen on time, or early</p> <p>2 <input type="checkbox"/> Waited up to 5 minutes</p> <p>3 <input type="checkbox"/> Waited 6 - 15 minutes</p> <p>4 <input type="checkbox"/> Waited 16 - 30 minutes</p> <p>5 <input type="checkbox"/> Waited 31 - 60 minutes</p> <p>6 <input type="checkbox"/> Waited 1 to 2 hours</p> <p>7 <input type="checkbox"/> Waited more than 2 hours</p> <p>8 <input type="checkbox"/> Don't know / Can't remember</p>
<p>65. Do you feel that the time you spent with the main person you saw was too long, too short or about right?</p> <p>1 <input type="checkbox"/> Too short</p> <p>2 <input type="checkbox"/> About right</p> <p>3 <input type="checkbox"/> Too long</p>	<p>63. The last time you had an outpatients appointment with a cancer doctor, was the time you spent with them too long, too short or about right?</p> <p>1 <input type="checkbox"/> Too short</p> <p>2 <input type="checkbox"/> About right</p> <p>3 <input type="checkbox"/> Too long</p>
<p>66. Were you given enough privacy during your most recent outpatients appointment?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> It was not necessary</p>	<p>Removed</p>

67. The last time you had an appointment with a doctor at the hospital named in the covering letter, did they have the right documents, such as medical notes, x-rays and test results?

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

64. The **last** time you had an appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?

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

7. Third round of Cognitive Testing – Questionnaire version 4.2

- 7.1. The changes that were made after testing versions 3.2 and 3.4 are documented above and this resulted in the third round of testing using version 4.2 of the questionnaire.
- 7.2. 4 participants were interviewed using version 4.2 of the questionnaire. Interviewees were also sent the draft covering letter and the language leaflet as well as the revised questionnaire as was done in the previous round of testing.
- 7.3. Far fewer issues arose in this phase of testing. Most of the questions had already been extensively tested and the revised ordering of the sections of the questionnaire improved patients' understanding of the questionnaire.
- 7.4. The areas where issues did arise during this phase of testing are set out below, with any agreed revisions to the questionnaire arising from them.

a. Diagnostic Tests

Question 6. asks if patients had diagnostic tests before finding out that they had cancer.

One patient said that they had been diagnosed by their GP before having tests.

It was agreed to revise the question to remove 'Before you found out you had cancer' and replace this with 'Did you have diagnostic tests for cancer' to address this point.

Question 9. asks if patients were given clear written information about tests.

It was agreed to remove the word 'clear' from this question and all other similar questions (15, 18, and 31) as it was redundant given that the response options then say 'easy to understand' and 'difficult to understand'.

Question 10. asks if staff explained results of tests.

It was agreed to remove the reference to staff explaining results as it may be that results are explained by GPs.

b. Finding out what was wrong

Question 12. asks if patients were told they could bring someone when told they had cancer.

Some interviewees found this question difficult as they were not aware of what they were going to be told when going to hospital and therefore only had someone with them by chance. This was also the case in earlier phases of testing.

It was agreed to change the response options to this question to remove reference to patients taking someone with them to reflect this.

Question 15. asks if patients were given written information about the type of cancer.

One patient said they were given written information at a later stage; another said they did not need information.

It was agreed to add a new response option: 'I did not need written information'. The word 'clear' was also removed from the question as in 9 above.

c. Deciding the best treatment

Question 16. asks if patients were told about risks and benefits.

Two patients said that they had not been told about any different treatments so did not know how to answer this question.

It was agreed to revise this question just to ask if patients had been offered a choice of treatments.

d. Clinical Nurse Specialist

Questions 22 and 24. ask about CNSs listening carefully and spending enough time with patients.

One patient said they did not see the CNS but spoke to them on the phone.

It was agreed to reword these questions to use both 'saw' and 'spoke to' to cover both meetings and telephone calls.

e. Operations

Question 29. asks about changes to admission dates.

It was agreed to clarify this question by adding 'cancer' before 'operation' to focus patients on this specific type of operation rather than one for another condition.

Question 32. Asks about explanations about how operations have gone.

It was agreed to remove the 'don't know / can't remember' response option as it was felt that this was not necessary.

f. Ward nurses

Question 40. asks if ward nurses knew enough about treating cancer.

It was agreed to remove this question as it was felt that it was not appropriate to ward nurses.

g. Hospital care and treatment

Question 48. asks about emotional support.

It was agreed to add the words 'from staff' to the last response option to clarify this response.

h. Information before leaving hospital

Question 51. asks about information on new medicines.

One interviewee found this hard to answer as they were given new medicines in hospital but not to take home; another said they had written information but when questioned said it was the leaflet in the medicine packet.

It was agreed to remove this question as it was clear that interviewees were answering about written information in medicine packets and not from the hospital and it would therefore not given any useful results.

i. Home support

Question 55. asks about staff organising home support.

It was agreed to remove this question as there was too much overlap with the following question.

j. Outpatient care

Question 59. asks about side effects of treatment.

One patient had not yet had any treatment and did not therefore know how to answer this and subsequent questions.

It was agreed to remove this question and add in two new questions about side effects which related to radiotherapy and chemotherapy separately. It was also agreed to put routing into questions 57 and 58 (which ask if patients have had radiotherapy and chemotherapy respectively) for patients who have not had any treatment.

k. Outpatient appointments

Question 62. asks about waiting times.

It was agreed to insert the word 'cancer' before 'doctor' in this question to clarify in patients minds which outpatient episode is referred to.

l. Care from GPs

Question 65. asks about patients having copies of letters sent to GPs.

One interviewee said she received letters but only because she asked for them.

It was agreed to remove this question as it was felt that it would not provide any useful information.

Questions 67 to 69. ask about aspects of care from GPs.

It was agreed to remove these questions to ask a more generic question about support for patients from general practices.

m. Overall care

Question 71. asks patients if they felt they were treated as a whole person.

It was agreed to replace 'as a number' in this question with 'as a set of cancer symptoms'.

7.5. A number of general changes were made to the questionnaire following testing and discussions:

- a. Prompt text at the beginning of sections about doctors, ward nurses, hospital care, information before leaving, and home support was revised to include both patients having operations and those staying overnight for their cancer. Consequently routing was also changed on question 28 which asks if patients had an operation, to skip those who did not have an operation to the next section about doctors rather than skipping all hospital sections.
- b. Question 45. about information on condition and treatment was moved to the 'overall care' section at the end of the questionnaire as it was felt that this was a more appropriate place for it as patients could reflect on their whole experience at this point.
- c. The section heading 'care from your GP and practice nurses' was changed to 'care from your general practice' to include all GPs in a practice.
- d. Question 74. about sexual orientation was moved to become the penultimate question as it was felt that this was a more appropriate place for it.

7.6. The table below shows the questions that were revised or changed following the testing of version 4.2 of the questionnaire on the left, with the revised questions as they appear in version 5.2 of the questionnaire on the right.

<p>6. Before you found out you had cancer did you have diagnostic test(s) such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q7 Error! Reference source not found.</p> <p>2 <input type="checkbox"/> No → Go to Q11</p>	<p>6. Did you have diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q7</p> <p>2 <input type="checkbox"/> No → Go to Q11</p>
<p>9. Beforehand, were you given clear written information about your test(s)?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about the test</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>9. Beforehand, were you given written information about your test(s)?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about the test(s)</p> <p>4 <input type="checkbox"/> I did not need written information</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>10. Did a member of staff explain the results of the test(s) in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>10. Were the results of the test(s) explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, but I would have liked an explanation</p> <p>4 <input type="checkbox"/> I did not need an explanation</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?</p> <p>1 <input type="checkbox"/> Yes, and I brought someone with me</p> <p>2 <input type="checkbox"/> Yes, but I did not bring someone with me</p> <p>3 <input type="checkbox"/> No, I had not been told I could bring someone with me</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> It was not necessary</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>

<p>15. When you were told you had cancer, were you given clear written information about the type of cancer you had?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about the type of cancer I had</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>15. When you were told you had cancer, were you given written information about the type of cancer you had?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about the type of cancer I had</p> <p>4 <input type="checkbox"/> I did not need written information</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>16. Before your cancer treatment started, were the risks and benefits of different types of treatment explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, different treatments were not properly explained</p> <p>4 <input type="checkbox"/> I was told there was only one type of treatment for my cancer</p> <p>5 <input type="checkbox"/> Not sure/ Can't remember</p>	<p>16. Before your cancer treatment started, were you given a choice of different types of treatment?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, but I would have liked a choice</p> <p>3 <input type="checkbox"/> I was not given a choice because only one type of treatment was suitable for me</p> <p>4 <input type="checkbox"/> Not sure/ Can't remember</p>
<p>22. The last time you saw your Clinical Nurse Specialist, did she/he listen carefully to you?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>22. The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>
<p>24. The last time you saw your Clinical Nurse Specialist, do you feel that the time you spent with them was too long, too short or about right?</p> <p>1 <input type="checkbox"/> Too short</p> <p>2 <input type="checkbox"/> About right about right</p> <p>3 <input type="checkbox"/> Too long</p>	<p>24. The last time you saw or spoke to your Clinical Nurse Specialist, do you feel that the time you spent with them was too long, too short or about right?</p> <p>1 <input type="checkbox"/> Too short</p> <p>2 <input type="checkbox"/> About right about right</p> <p>3 <input type="checkbox"/> Too long</p>
<p>29. The last time you went into hospital for an operation, was your admission date changed to a later date by the hospital?</p> <p>1 <input type="checkbox"/> No</p> <p>2 <input type="checkbox"/> Yes, it was changed once</p> <p>3 <input type="checkbox"/> Yes, it was changed 2 or 3 times</p> <p>4 <input type="checkbox"/> Yes, it was changed 4 times or more</p>	<p>29. The last time you went into hospital for a cancer operation, was your admission date changed to a later date by the hospital?</p> <p>1 <input type="checkbox"/> No</p> <p>2 <input type="checkbox"/> Yes, it was changed once</p> <p>3 <input type="checkbox"/> Yes, it was changed 2 or 3 times</p> <p>4 <input type="checkbox"/> Yes, it was changed 4 times or more</p>

<p>32. After the operation, did a member of staff explain how it had gone in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>32. After the operation, did a member of staff explain how it had gone in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation</p>
<p>40. Do you think the ward nurses knew enough about how to treat your cancer?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know / Not sure</p>	<p>Removed</p>
<p>48. Were you given enough emotional support from hospital staff?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, I would have liked more support 4 <input type="checkbox"/> I did not need emotional support</p>	<p>46. Were you given enough emotional support from hospital staff?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, I would have liked more support 4 <input type="checkbox"/> I did not need emotional support from staff</p>
<p>51. Before you left hospital, did hospital staff give you clear written information about any new medicines you were given?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand 2 <input type="checkbox"/> Yes, but it was difficult to understand 3 <input type="checkbox"/> No, I was not given written information about my medicines 4 <input type="checkbox"/> I did not have any new medicines 5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Removed</p>
<p>55. Did hospital staff help to organise nursing or other health services you would need at home? (For example, a district nurse, home help or physiotherapist).</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked help 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Removed</p>

<p>59. Did hospital staff do everything possible to control the side effects of your chemotherapy, radiotherapy or cancer drug treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I have not had radiotherapy chemotherapy or cancer drug treatment</p> <p>5 <input type="checkbox"/> I have not had any side effects</p>	<p>54. Did hospital staff do everything possible to control the side effects of radiotherapy?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I have not had any side effects from radiotherapy</p> <p>56. Did hospital staff do everything possible to control the side effects of chemotherapy?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I have not had any side effects from chemotherapy</p>
<p>62. The last time you had an outpatients appointment with a doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?</p> <p>1 <input type="checkbox"/> Seen on time, or early</p> <p>2 <input type="checkbox"/> Waited up to 5 minutes</p> <p>3 <input type="checkbox"/> Waited 6 - 15 minutes</p> <p>4 <input type="checkbox"/> Waited 16 - 30 minutes</p> <p>5 <input type="checkbox"/> Waited 31 - 60 minutes</p> <p>6 <input type="checkbox"/> Waited 1 to 2 hours</p> <p>7 <input type="checkbox"/> Waited more than 2 hours</p> <p>8 <input type="checkbox"/> Don't know / Can't remember</p>	<p>59. The last time you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter, how long after the stated appointment time did the appointment start?</p> <p>1 <input type="checkbox"/> Seen on time, or early</p> <p>2 <input type="checkbox"/> Waited up to 5 minutes</p> <p>3 <input type="checkbox"/> Waited 6 - 15 minutes</p> <p>4 <input type="checkbox"/> Waited 16 - 30 minutes</p> <p>5 <input type="checkbox"/> Waited 31 - 60 minutes</p> <p>6 <input type="checkbox"/> Waited 1 to 2 hours</p> <p>7 <input type="checkbox"/> Waited more than 2 hours</p> <p>8 <input type="checkbox"/> Don't know / Can't remember</p>
<p>65. Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?</p> <p>1 <input type="checkbox"/> Yes, I received copies</p> <p>2 <input type="checkbox"/> No, I did not receive copies</p> <p>3 <input type="checkbox"/> Not sure / Don't know</p>	<p>Removed</p>
<p>67. Do you think your GP and practice nurses did everything they could to help control your pain?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any pain</p>	<p>63. Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> My general practice was not involved</p>

<p>68. Do you think your GP and practice nurses did everything they could to help control the side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any side effects</p> <p>5 <input type="checkbox"/> My GP and practice nurses were not involved</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Removed</p>
<p>69. Do you think your GP and practice nurses did everything they could to help you cope with anxiety or depression?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have anxiety or depression</p> <p>5 <input type="checkbox"/> My GP and practice nurses were not involved</p>	<p>Removed</p>
<p>71. Sometimes people with cancer feel they are treated “as a number”, rather than a whole person. In your NHS care over the last year, did you feel like that?</p> <p>1 <input type="checkbox"/> Yes, often</p> <p>2 <input type="checkbox"/> Yes, sometimes</p> <p>3 <input type="checkbox"/> No</p>	<p>66. Sometimes people with cancer feel they are treated “as a set of symptoms”, rather than a whole person. In your NHS care over the last year, did you feel like that?</p> <p>1 <input type="checkbox"/> Yes, often</p> <p>2 <input type="checkbox"/> Yes, sometimes</p> <p>3 <input type="checkbox"/> No</p>

8. Fourth round of Cognitive Testing – Questionnaire version 5.2

- 8.1. The changes that were made after testing version 4.2 are documented above and this resulted in the fourth round of testing using version 5.2 of the questionnaire.
- 8.2. A further 4 patients were interviewed in this phase of the testing. As previously, all were sent the covering letter, language leaflet and questionnaire and asked to complete the questionnaire before the interview took place.
- 8.3. Most questions were found very easy to answer by interviewees and reworded questions worked much better. Prompts were found easy to follow and on most questions interviewees simply amplified their answers rather than showing any lack of understanding of questions.
- 8.4. The issues that were raised in this round of testing and any subsequent changes are set out below.

a. Seeing GPs

Question 1. asks how many times patients saw their GP before diagnosis.

1 patient had difficulty with this because they went to their GP with unrelated health problems and cancer was found as a result of the tests that were undertaken. Another patient found it problematic as it was not clear at the time that they went to their GP that their health problems were related to cancer. A similar issue was raised by another patient in a previous round of testing.

It was agreed to amend response option 6 to replace 'can't remember' with can't say' to address this issue.

Questions 2 - 4. ask about waits to see a hospital doctor.

One patient has a rare type of cancer and saw hospital doctors other than cancer doctors before her final diagnosis. She queried whether these questions were meant to be specifically about cancer doctors? She was confused by this.

After discussion it was agreed that the prompt at the beginning of this section should help patients to answer these questions correctly so no changes would be made.

b. Diagnostic tests

Question 6. asks if patients had diagnostic tests.

It was agreed to add 'In the last 12 months' at the beginning of this question to clarify the timeframe for patients.

Question 9. asks if patients were given written information about tests.

It was agreed to change response option 3 from 'No, I was not given written information' to 'No, but I would have liked written information'.

c. Finding out what was wrong

Question 11. asks who told the patient they had cancer.

One patient wanted to tick more than one response option on this question because a doctor and a nurse had been present when they were told.

It was agreed that making this multi-choice would make analysis more difficult and as decided previously, it was felt that patients should be able to choose who actually told them even if two people had been present.

Question 12. asks if patients were told they could bring a family member.

The new response options tested much better on this question. However, one patient was told they had cancer over the phone and this had arisen in previous phases of testing.

It was agreed to add a new response option: 'told by phone or letter' to address this issue.

d. Deciding the best treatment

Question 16. asks if patients were given a choice of treatment.

This question is testing much better with all patients being able to answer it easily.

Question 19. asks if patients were involved in decisions.

One patient could not answer because only one treatment was suitable for them given the type of cancer that they had.

It was agreed to add a new response option: 'only one type of treatment was suitable' to address this, and to revise option 3 to add after no: 'but I would like to have been more involved'.

e. Support for people with cancer

Questions 25 and 26. ask if patients were told about support groups or how to get financial help.

3 patients said they were given leaflets about support groups and / or financial help so strictly were not **told** by staff.

It was agreed to revise these questions to ask if patients had been 'given information' to address this.

f. Hospital care and treatment

Question 48. asks if patients were treated with respect and dignity.

It was agreed to specifically mention 'doctors, nurses and other hospital staff' in the context of this question and to change the response options from always, sometimes, no, to always, most of the time, some of the time, never.

g. Care as an outpatient

Question 57. asks if staff did everything for patients pain.

It was agreed to add 'or day case' to this question as currently it only mentions outpatients.

h. Care from GPs

Question 63. asks about support from GPs and nurses.

The new formulation for this question tested well.

i. About you

Question 70. Asks how long patients have been treated for.

It was agreed to revise the response options on this question to make the last option more than 5 years rather than more than 10 years.

- 8.5. A number of general changes were made to the questionnaire arising out of the testing and discussions about the layout and cohorts of patients answering particular groups of questions. These changes were:
- a. Routing was required for day case patients who had not had an operation or stayed overnight so should not be answering questions 33 to 52. A new question was inserted at the beginning of the hospital doctors section to address this issue.
 - b. Many patients are having radiotherapy and chemotherapy as day patients but questions 53 – 57 which ask about this treatment are headed 'care as an outpatient'. One patient was very confused by this. This section heading was changed to 'care as a day patient / outpatient' to answer this point.
 - c. Prompt text was changed throughout the questionnaire to replace 'for your cancer' with 'for cancer care', and new prompts were added where sections went onto new pages.
 - d. A prompt was added at the beginning of the 'support for people with cancer' section to get patients to think about these questions in the context of when their treatment first started.
 - e. Some text was put into bold to emphasise certain words or phrases to help to reinforce with patients what issues are being asked about.
 - f. Question 46 about emotional support was reworded and moved to the section about care as a day or outpatient as it was felt that support was more likely to be required at this point in a patient's treatment.

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- g. A new question was added at the end of the questionnaire to ask patients if they could be contacted again in future about their health and healthcare. This was done to provide a cohort of patients that could be followed up either for longitudinal research or with other types of questionnaire.

8.6. The table below shows the questions that were revised or changed following the testing of version 5.2 of the questionnaire on the left, with the revised questions as they appear in the final version (5.6) of the questionnaire on the right.

<p>1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital → Go to Q6</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p> <p>6 <input type="checkbox"/> Don't know / Can't remember</p>	<p>1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?</p> <p>1 <input type="checkbox"/> None - I did not see my GP before going to hospital → Go to Q6</p> <p>2 <input type="checkbox"/> I saw my GP once</p> <p>3 <input type="checkbox"/> I saw my GP twice</p> <p>4 <input type="checkbox"/> I saw my GP 3 or 4 times</p> <p>5 <input type="checkbox"/> I saw my GP 5 or more times</p> <p>6 <input type="checkbox"/> Don't know / Can't say</p>
<p>6. Did you have diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q7</p> <p>2 <input type="checkbox"/> No → Go to Q11</p>	<p>6. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?</p> <p>1 <input type="checkbox"/> Yes → Go to Q7</p> <p>2 <input type="checkbox"/> No → Go to Q11</p>
<p>9. Beforehand, were you given written information about your test(s)?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, I was not given written information about the test(s)</p> <p>4 <input type="checkbox"/> I did not need written information</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>9. Beforehand, were you given written information about your test(s)?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand</p> <p>2 <input type="checkbox"/> Yes, but it was difficult to understand</p> <p>3 <input type="checkbox"/> No, but I would have liked written information about the test(s)</p> <p>4 <input type="checkbox"/> I did not need written information</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>
<p>12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> It was not necessary</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>12. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> It was not necessary</p> <p>4 <input type="checkbox"/> I was told by phone or letter</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>

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<p>19. Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p>	<p>19. Were you involved as much as you wanted to be in decisions about which treatment(s) you would have?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would like to have been more involved 4 <input type="checkbox"/> Only one type of treatment was suitable for me</p>
<p>25. Did hospital staff tell you about support or self-help groups for people with cancer?</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>25. Did hospital staff give you information about support or self-help groups for people with cancer?</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>
<p>26. Did hospital staff tell you how to get financial help or benefits?</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>26. Did hospital staff give you information about how to get financial help or benefits?</p> <p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know / Can't remember</p>
<p>46. Were you given enough emotional support from hospital staff?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, I would have liked more support 4 <input type="checkbox"/> I did not need emotional support from staff</p>	<p>58. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, I would have liked more support 4 <input type="checkbox"/> I did not need emotional support from staff</p>
<p>48. Overall, do you feel you were treated with respect and dignity while you were in hospital?</p> <p>1 <input type="checkbox"/> Yes, always 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No</p>	<p>48. Were you treated with respect and dignity by the doctors and nurses and other hospital staff?</p> <p>1 <input type="checkbox"/> Always 2 <input type="checkbox"/> Most of the time 3 <input type="checkbox"/> Some of the time 4 <input type="checkbox"/> Never</p>

<p>57. While you were being treated as an outpatient, did hospital staff do everything they could to help control your pain?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any pain</p>	<p>57. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any pain</p>
<p>70. How long is it since you were first treated for this cancer?</p> <p>1 <input type="checkbox"/> Less than 1 year</p> <p>2 <input type="checkbox"/> 1 to 5 years</p> <p>3 <input type="checkbox"/> 5 to 10 years</p> <p>4 <input type="checkbox"/> More than 10 years</p> <p>5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>71. How long is it since you were first treated for this cancer?</p> <p>1 <input type="checkbox"/> Less than 1 year</p> <p>2 <input type="checkbox"/> 1 to 5 years</p> <p>3 <input type="checkbox"/> More than 5 years</p> <p>4 <input type="checkbox"/> Don't know / Can't remember</p>

Changes to cancer questionnaire 2010

Rachel Reeves, NHS Contracting, Department of Health

18th Feb 2010

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1 General notes

1.1 Questionnaire length

The questionnaire has been reduced from 16 pages to 12. This will help to maximise response rates, readability and acceptability to people with lower reading abilities - an equality issue. The questionnaire should be a multiple of 4 pages so that it can be printed on A3 paper and folded into an A4 booklet. There is space for a few more questions in the 12-page version.

1.2 Multiple response questions

All "Tick all that apply" questions have been removed (except the disability question at the end) because experience shows they don't work well, especially when almost all of the other questions ask people to "Tick one box only" so it confuses them. Responders and they are more likely to tick the boxes that come higher up the list, so results are skewed by the order in which items are listed.

1.3 Focus on most recent events

There are now several prompts throughout the questionnaire to remind people to focus on their most recent experiences: this is important so that staff see the results as being contemporary. For example:

Thinking about the LAST time you went into hospital for a one-day treatment or to stay overnight...

A Clinical Nurse Specialist is a specialist cancer nurse who makes sure you get the right care and gives you help and advice on coping with cancer.

Still thinking about the LAST time you went into hospital

Thinking about the LAST time you had a test procedure....

The phrase "During this visit" has been removed from questions because it wasn't improving clarity and it is likely to imply an outpatient visit, rather than an inpatient or day case "admission", which is what it is supposed to refer to.

1.4 Consistency with 2004 questionnaire

Where questions are very similar to those used in the current inpatient survey, they have been kept as close as possible to the original question, even when, in some cases, the wording could be improved.

1.5 Reorganisation of sections

The order of the questions has been changed so that it follows a likely chronological order for most patients from GP referral, diagnosis, deciding on the best treatment inpatient admission, hospital doctors, clinical specialist nurses, hospital nurses, test procedures, operation procedures, information before going home, GP care and outpatient care. Within that chronological order, new section headings have been added.

1.6 Self-contained questions

Where possible, questions have been re-worded to make them more self-contained. That is, they should not rely on the reader remembering the topic covered in the previous question. Many of the 2004 questions did not meet that criterion.

2 Actions on questions in 2004 questionnaire

Table 1 itemises each of the 2004 questions, indicating whether it has been revised, removed or retained.

Table 1: Questions retained, removed or revised from 2004 cancer questionnaire

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A1	Thinking about the first hospital visit involving treatment for that condition, how many nights were you in hospital during that visit?	Removed			Not needed because length of stay will be included in the sample information supplied by the trust.
A2	Was the date of this first hospital visit ever cancelled or postponed by the hospital? (Yes, the appointment was cancelled or postponed once/ Yes, the appointment was cancelled or postponed more than once/ No, the appointment was not cancelled or postponed by the hospital/ Can't remember)	Revised	17	The last time you went into hospital, was your admission date changed by the hospital? 1 <input type="checkbox"/> No 2 <input type="checkbox"/> Yes, it was changed once 3 <input type="checkbox"/> Yes, it was changed 2 or 3 times 4 <input type="checkbox"/> Yes, it was changed 4 times or more	Simpler wording. Better to focus on most recent admission. Used recent inpatient survey question.
A3	Before or during this visit, were you given the name of a particular hospital doctor or surgeon who would be in overall charge of your care?	Removed			Purpose of question not clear. No evidence that patients often have a problem with this.

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A4	Before or during this visit, were you given the name of a particular hospital nurse who would be in overall charge of your care?	Revised	23	Were you given the name of a Clinical Nurse Specialist or Key Worker who would be in charge of your care? 1 <input type="checkbox"/> Yes → Go to Q 2 <input type="checkbox"/> No → Go to Q 3 <input type="checkbox"/> Don't know / Not sure	This question is a hangover from "Named Nurse" policy, which applied to all inpatients a few years ago but is now obsolete. However, there is now a policy for cancer patients to have a named specialist nurse so the new section on <i>Clinical Nurse Specialist</i> reflects that.
A5	During this visit, in your opinion, were there enough doctors on duty to care for you in hospital?	Removed			Question makes little sense when applied to doctors- it was probably included as a mirror to the "were there enough nurses" question
A6	During this visit, in your opinion, were there enough nurses on duty to care for you in hospital? (There were always or nearly always enough on duty/ There were sometimes enough on duty/ There were rarely or never enough on duty)	Slightly revised	33	In your opinion, were there enough nurses on duty to care for you in hospital? 1 <input type="checkbox"/> There were always or nearly always enough on duty 2 <input type="checkbox"/> There were sometimes enough on duty 3 <input type="checkbox"/> There were rarely or never enough on duty	
A7	During this visit, did you have confidence and trust in the hospital doctors who treated you?(In all of them/ In some of them/ In none of them)	Kept same	19		

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A8	During this visit, did you have confidence and trust in the hospital nurses who treated you?(In all of them/ In some of them/ In none of them)	Slightly revised	30	Did you have confidence and trust in the hospital nurses treating you? 1 <input type="checkbox"/> In all of them 2 <input type="checkbox"/> In some of them 3 <input type="checkbox"/> In none of them	
A9	If you did not have confidence in all the hospital doctors and nurses, why did you not have confidence in them? (PLEASE WRITE IN THE BOX BELOW)	Removed			Not practical to analyse open responses in large-scale survey. End of questionnaire gives opportunity for such comments.
A10	During this visit, were you treated with respect and dignity by the doctors and nurses and other hospital staff? (Always/ Most of the time/ Some of the time/ Never)	Revised	42	Overall, did you feel you were treated with respect and dignity while you were in the hospital? 1 <input type="checkbox"/> Yes, always 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No	Changed to match current inpatient questionnaire.
A11	During this visit, did the hospital doctors explain your condition, treatment or tests in a way that you found easy or difficult to understand?	Removed			Now covered by a number of other questions under specific sections: diagnosis, test procedures and operations.
A12	During this visit, when you had questions to ask the hospital doctors, how often did you get answers you could understand?(All or most of the time/Some of the time/ Rarely or never/I did not ask any questions)	Slightly revised	18	When you had important questions to ask a doctor, how often did you get answers that you could understand? 1 <input type="checkbox"/> All or most of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Rarely or never 4 <input type="checkbox"/> I did not ask any questions	

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A13	During this visit, when you had questions to ask the hospital nurses, how often did you get answers you could understand?(All or most of the time/Some of the time/ Rarely or never/I did not ask any questions)	Slightly revised	29	When you had important questions to ask a hospital nurse, how often did you get answers you could understand? 1 <input type="checkbox"/> All or most of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Rarely or never 4 <input type="checkbox"/> I did not ask any questions	
A14	During this visit, did you ever think that the hospital doctors or nurses were deliberately not telling you certain things that you wanted to know?(Often/ Sometimes/ Only once/ Never)	Slightly revised	34	While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know? 1 <input type="checkbox"/> Often 2 <input type="checkbox"/> Sometimes 3 <input type="checkbox"/> Only once 4 <input type="checkbox"/> Never	
A15	During this visit, did the doctors or nurses or other hospital staff ever talk about your case in front of you as if you were not there?	Revised	21, 32	Did [doctors/hospital nurses] talk in front of you as if you weren't there? 1 <input type="checkbox"/> Yes, often 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No	Two separate questions about nurses and doctors - more useful for directing quality improvements. Rest of question updated to current inpatient questionnaire. The words "your case" removed because they might suggest the patient is synonymous with their illness.
A16	During this visit, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different? (Often/ Sometimes/ Only once/ Never)	Slightly revised	35	While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different? 1 <input type="checkbox"/> Often 2 <input type="checkbox"/> Sometimes 3 <input type="checkbox"/> Only once 4 <input type="checkbox"/> Never	

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A17	During this visit, were you involved in the decisions about your treatment and care as much as you wanted, or would you have liked to be more involved? (Involved as much as I wanted/ Involved but would have liked to have been more involved/ Not involved at all/ Can't remember)	Revised	16	Were you involved as much as you wanted to be in decisions about your care and treatment? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	Moved to section headed "Deciding on the best treatment for you" and revised to match current inpatient questionnaire. Only 3 response options is simpler.
A18	During this visit, if you were involved in decisions about your treatment and care do you feel that your views were taken into account by the staff treating you?	Removed			Already covered by A17
A19	During this visit, did doctors or nurses involve your family or friends in decisions about your treatment? (Yes, they were involved but given too little information/ Yes, they were involved and given the right amount of information/ Yes, they were involved, but were given too much information/ No, they were not involved, though I would have liked them to be/ No, I did not want my family or friends to be involved/ I had no family or friends available to be involved)	Revised	22	If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> No family or friends were involved 5 <input type="checkbox"/> My family did not want or need information 6 <input type="checkbox"/> I did not want my family or friends to talk to a doctor	Changed to match current inpatient questionnaire. Original question too complicated - response options cover information and involvement.

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A20	During this visit, when discussing your condition or treatment with doctors or nurses did you have enough privacy during your discussions? (Every time/ Some of the time / Never / I did not have any discussions)	Revised	37	Were you given enough privacy when discussing your condition or treatment? 1 <input type="checkbox"/> Yes, always 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No	Used current inpatient survey version - simpler with 3 response options and covers other staff, not just doctors and nurses.
A21	During this visit, did you have enough privacy while the doctors were examining you?(Every time / Some of the time / Never / I was not examined)	Revised	38	Were you given enough privacy when being examined or treated? 1 <input type="checkbox"/> Yes, always 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No	Used current inpatient survey version - simpler with 3 response options and covers other staff as well as doctors
A22	During this visit, which of these tests or treatments did you have?	Removed			Purpose of question not clear. Not practical to analyse open responses in large-scale survey. End of questionnaire gives opportunity for such comments.
A23	During this visit, did the hospital doctors or nurses discuss the purpose of your operation or other treatment with you? (Yes, and I completely understood what was said/ Yes, and I understood some of what was said/ Yes, but I did not understand what was said/ No, the purpose was not discussed at all/ I did not want to discuss it/ I did not have an operation or treatment/ Can't remember)	Revised	45	Thinking about the LAST time you had a test procedure.... Beforehand, did a member of staff explain the purpose of the test? 1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember	One question in Tests/procedures section. Also question13 in "Deciding on the best treatment for you" 51 in "Operations" cover information on operations and treatments.

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A24	During this visit, did the hospital doctors or nurses tell you about possible side effects of your operation or other treatment? (Yes, and I completely understood what was said/ Yes, and I understood some of what was said/ Yes, but I did not understand what was said/ No, side effects were not discussed at all/ I did not need an explanation/ Can't remember)	Revised	55	Were you given clear written information about the possible side effects of your treatment? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, I was not given written information about side effects 4 <input type="checkbox"/> I did not need this information 5 <input type="checkbox"/> Don't know / Can't remember	Simpler response options, in line with other similar questions about information. Also, questions 14 and 15 in "Deciding on the best treatment for you" cover pre-treatment information on side effects.
A25	After your operation or other treatment, did the hospital doctors or nurses discuss with you how well it had gone? (Yes, and I completely understood what was said/ Yes, and I understood some of what was said/ Yes, but I did not understand what was said/ No, it was not discussed at all/ I did not want to discuss it/ Can't remember)	Revised	53	After the operation, did a member of staff explain how it had gone in a way you could understand? 1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember	Used current inpatient survey version - simpler with 4 shorter response options.
A26	At that time, did you want to be given more information or less information about the outcome of your treatment, or was the amount of information about right? (I would have preferred more information/ I would have preferred less information/ The amount of information was about right/ Can't remember)	Revised	36	How much information were you given about your condition or treatment? 1 <input type="checkbox"/> Not enough 2 <input type="checkbox"/> The right amount 3 <input type="checkbox"/> Too much	Used question similar to current inpatient survey version – simpler. .

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A27	During this visit, were you ever in any pain or discomfort?	Removed			This was a filter question (to guide those who did not have pain away from pain questions) but it's not needed any more.
A28	Were hospital staff aware that you were in pain or discomfort?	Removed			Not useful question for quality improvement.
A29	When you had this pain or discomfort, was it usually severe, moderate or mild?	Removed			Not useful question for quality improvement.
A30	During this visit, do you think that the hospital staff did everything they could to help with this pain or discomfort? (All of the time/ Some of the time/Not at all)	Slightly revised	40	Do you think the hospital staff did everything they could to help control your pain? 1 <input type="checkbox"/> All of the time 2 <input type="checkbox"/> Some of the time 3 <input type="checkbox"/> Not at all 4 <input type="checkbox"/> I did not have any pain	Used similar to current inpatient survey version with "did not have pain" option, rather than previous filter question.
A31, A32	During this visit, did you ever feel so anxious or depressed that you felt that you needed help to cope? Were hospital staff aware that you were experiencing this anxiety or depression?	Removed			Not necessary and not useful for quality improvement. Covered by above question about support with anxiety and depression.
A33	During this visit, do you think that the hospital staff did everything they could to help with this anxiety or depression?	Revised	39	While you were in hospital, were you given enough support to cope with anxiety or depression? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked more support 4 <input type="checkbox"/> I did not have anxiety or depression	

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
A34	During this visit, did all staff involved in your treatment and care provide you with adequate emotional support?	Removed			Difficult to answer because staff are likely to have differed. Covered by above question about support with anxiety and depression.
A35	During this visit, did you feel that your religious beliefs were adequately taken into consideration by the hospital staff treating you?	Removed			Respect for religious beliefs rated very low importance by patients.
A36	During this visit, did you have access to a hospital chaplain or other religious counsellor if you needed one?	Removed			Respect for religious beliefs rated very low importance by patients.
A37, A38, A39	During this visit, were you told what to do if you wanted to complain about the care you received? If you complained, was your complaint satisfactorily addressed? If you complained, what did you complain about? (PLEASE WRITE IN THE BOX BELOW)	Removed			Small minority of patients want to complain or do complain. This information is better gathered through complaints.
B1	Before you left hospital on that occasion, did the hospital doctors or nurses spend enough time telling you what would happen after you left hospital?	Removed			Length of time spent not the most important factor and not useful for quality improvements

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
B2	Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital? (No/Yes/Can't remember)	Slightly revised	56	Were you given clear written information about what you should or should not do after leaving hospital? 1 <input type="checkbox"/> No 2 <input type="checkbox"/> Yes 3 <input type="checkbox"/> Can't remember	Response options not in line with similar questions but kept same as 2004.
B3, B4	Were you able to fully understand the written or printed information? Did the written or printed information adequately cover all the issues you needed it to cover?	Removed			Covered by revised question about written information.
B5	If it did not adequately cover all the areas you needed, what information was missing or could have been covered better? (PLEASE WRITE IN BOX BELOW)	Removed			Impractical to analyse open responses in large-scale survey. End of questionnaire gives opportunity for such comments
B6	Did the hospital staff take your family or home situation into account before planning to send you home from hospital?	Removed			Too vague to be useful for quality improvement
B7	Before you left hospital, did a member of hospital staff discuss with you what additional help from the NHS or elsewhere you might need in order for you to be able to resume your usual activities e.g. household chores or returning to work?	Revised	63	Did hospital staff organise help with coping at home or housework from social services or other organisations? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked help 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know/ Can't remember	Not sure what the original question meant. It's wordy and seems to be covering a wide range of issues. The important issue is not whether a discussion took place but whether help was arranged

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
B8	Before you left hospital, were you offered any information about any financial or other benefits, from the NHS or elsewhere, to which you might be entitled? (Yes/ No/ Can't remember)	Revised	60	Did hospital staff tell you how to get financial help or benefits? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know/ Can't remember	Revised question simpler and includes "not necessary" option.
B9	Would you have liked to have been offered such information?	Removed			Already covered by revised question
B10	Before you left hospital, were you told about a support or self-help group for people with your condition?	Revised	59	Did hospital staff tell you about support or self-help groups for people with cancer? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked information 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know/ Can't remember	
B11	Did the hospital staff discuss whether you would need any nursing or other health services after you left hospital? (For example, a district or community nurse, health visitor, physiotherapist, and so on).	Revised	62	Did hospital staff help to organise nursing or other health services you would need at home? (For example, a district nurse, health visitor or physiotherapist). 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No, but I would have liked help 3 <input type="checkbox"/> It was not necessary 4 <input type="checkbox"/> Don't know/ Can't remember	The important issue is not whether a discussion took place but whether help was arranged
B12	Did the hospital staff tell you whom to contact if you were worried about your condition or treatment after you left hospital?(Tick ALL that apply: GP/ Community Nurse/district nurse/specialist nurse/ A private nurse/ None/ Other (PLEASE WRITE IN BOX BELOW))	Revised	58	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 3 <input type="checkbox"/> Don't know / Can't remember	Not useful to know who they were told to contact. "Tick all that apply" poor style.

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
B13	After you left hospital, which of the following people were involved in looking after you?(TICK ALL THAT APPLY.....)	Removed			Not useful to know who was involved unless we ask specific questions about each person. "Tick all that apply" poor style.
B14	As far as you know, was your GP given enough information about your treatment or condition by the hospital? (Yes/ No/ Don't know)	Slightly revised	72	As far as you know, was your GP given enough information about your condition and the treatment given by the hospital? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 3 <input type="checkbox"/> Don't know / Can't remember	Previous wording was ambiguous
B15	After you left hospital, how well did the care provided by the NHS meet your needs?	Removed			Too vague to be useful for quality improvement
B16	After you left hospital, was medical advice, support and treatment available 24 hours a day if you needed it?	Replaced	24	How easy is it for you to contact your Clinical Nurse Specialist? 1 <input type="checkbox"/> Easy 2 <input type="checkbox"/> Difficult 3 <input type="checkbox"/> I have not tried to contact her/him	
B17, B18	After you left hospital, were you ever in any pain or discomfort as a result of your condition? After you left hospital, when you had this pain or discomfort, was it usually severe, moderate or mild?	Removed			See A27-A30 above
B19	After you left hospital, did you feel that you were given enough medication or other help with this pain or discomfort by the medical staff looking after you?	Revised	73	Do you think your GP and practice nurses did everything they could to help control your pain? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, they could have done more 4 <input type="checkbox"/> I did not have any pain	

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
B20	After you left hospital, did you ever experience overwhelming tiredness as a result of your condition?	Removed			Not sure it's a useful question for quality improvement
B21	Did you feel that the GP or nurse looking after you gave you enough help with this overwhelming tiredness?	Removed			Not sure it's a useful question for quality improvement
B22, B23	After you left hospital, did you ever feel so anxious or depressed as a result of your condition that you felt that you needed help to cope? Did you feel that the GP or nurse looking after you gave you enough help with this anxiety or depression?	Revised	75	Do you think your GP and practice nurses did everything they could to help you cope with anxiety or depression? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, they could have done more 4 <input type="checkbox"/> I did not have anxiety or depression	Incorporates 2 questions.
B24	After leaving hospital, did you receive adequate treatment for any other symptoms of your condition not already covered in this section?	Removed			Too vague to be useful for quality improvement
B25	What symptoms did you not receive adequate treatment for? (PLEASE WRITE IN THE BOX BELOW)	Removed			Impractical to analyse open responses in large-scale survey.
B26	After leaving hospital, were you involved in any decisions about your continuing care as much as you wanted, or would you have liked to be more involved?	Removed			?Not sure it's a useful question for quality improvement. Seems to cover a very wide range of issues

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C1	Had you visited a General Practitioner (GP) about this condition at any point before you attended hospital? (Yes/ No)	Revised	1	How many times did you see your GP (family doctor) about this problem before you were told you would need to go to a hospital? 1 <input type="checkbox"/> None - I did not see my GP before going to hospital 2 <input type="checkbox"/> I saw my GP once 3 <input type="checkbox"/> I saw my GP twice 4 <input type="checkbox"/> I saw my GP 3 or 4 times 5 <input type="checkbox"/> I saw my GP 5 or more times	New question covers number of GP visits prior to referral
C2	After your GP FIRST referred you to see a hospital doctor about your condition, how long did you have to wait before you had your first appointment with a hospital doctor? (Was seen by hospital doctor/consultant the same day or next day/ More than 2 days, but within 1 week/ More than 1 week, but within 2 weeks/ More than 2 weeks, but within 1 month/ More than 1 month, but within 3 months/ More than 3 months, but within 6 months/ More than 6 months, but within 1 year/ More than 1 year/ Can't remember)	Revised	2	After your GP first told you that you would need to see a hospital doctor, how long did you have to wait before your first appointment with a hospital doctor? 1 <input type="checkbox"/> I was seen the same day or next day 2 <input type="checkbox"/> I was seen after 2-7 days 3 <input type="checkbox"/> I was seen in 1 to 2 weeks 4 <input type="checkbox"/> I was seen in 2 to 4 weeks 5 <input type="checkbox"/> Waited 1 to 4 months 6 <input type="checkbox"/> Waited more than 4 months 7 <input type="checkbox"/> Don't know/Can't remember	Simpler language. Length of longest wait reduced to reflect shorter wait times

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C3	Did your condition get worse, get better or stay about the same during the time you were waiting for your first appointment with a hospital doctor? (My condition got worse/ My condition got better/My condition stayed about the same)	Slightly revised	5	Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor? 1 <input type="checkbox"/> I got worse 2 <input type="checkbox"/> I got better 3 <input type="checkbox"/> I stayed about the same	Simpler language
C4	Overall how would you rate the quality of care provided by your GP during this stage of	Removed			Too vague to be useful for quality improvement
C5	If you rated the quality of care as poor or very poor, what are your reasons for this rating? (PLEASE WRITE IN THE BOX BELOW)	Removed			Impractical to analyse open responses in large-scale survey.
C6	During your first hospital appointment, did the hospital doctors or nurses explain the purpose of any tests to you?	Removed		<i>Thinking about the LAST time you had a test procedure....</i> Beforehand, did a member of staff explain the purpose of the test? 1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember	Covered by Q45 in tests section. Better to ask patients to focus on more recent experience.
C7	Were you first told what was wrong with you in person, over the telephone, or in a letter?	Removed			Not sure if mode of communication is an issue. Aren't most people told in person? If not, have people complained about being told over the phone or by letter?

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C8	At the time you were first told, who told you what was wrong with you?	Revised	6	Who first told you that you had cancer? 1 <input type="checkbox"/> A hospital doctor 2 <input type="checkbox"/> A hospital nurse 2 <input type="checkbox"/> A GP (family doctor) 4 <input type="checkbox"/> Another health professional 5 <input type="checkbox"/> A friend or relative 6 <input type="checkbox"/> Nobody – I worked it out for myself	
C9	Who else was present when you were told what was wrong with you, not including the person who told you?	Revised	7	When you were first told you that you had cancer, did you have a family member or friend with you? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	Simpler wording.
C10	At the time, did you want somebody else to be present when you were told what was wrong with you? Tick ALL that apply (Yes, I wanted to have a family member or friend present /Yes, I wanted to have a nurse present / Yes, I wanted to have a doctor present/ No, I didn't want anybody else to be present)	Revised	8	When you were first told you that you had cancer, did you want a family member or friend to be with you? 1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 3 <input type="checkbox"/> I did not mind	Simpler wording. "Tick all that apply" questions don't work well.
C11	Did you understand the explanation of what was wrong with you?(Yes I completely understood what was said/ Yes, I understood some of what was said/ No, I did not understand what was said/ Can't remember)	Kept same	10	Did you understand the explanation of what was wrong with you? 1 <input type="checkbox"/> Yes I completely understood what was said 2 <input type="checkbox"/> Yes, I understood some of what was said 3 <input type="checkbox"/> No, I did not understand what was said 4 <input type="checkbox"/> Can't remember	
C12	Did you find that the person who told you what was wrong with you was easy to talk to?	Removed			Covered by question about it being done sensitively

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C13	Did you find that the person who told you what was wrong with you did so with sufficient sensitivity and care?	Revised	9	How do you feel about the way you were told you had cancer? 1 <input type="checkbox"/> It was done sensitively 2 <input type="checkbox"/> It should have been done a bit more sensitively 3 <input type="checkbox"/> It should have been done a lot more sensitively	Simpler language
C14	If you asked any questions, were they answered in a way that you could understand?	Removed			Already covered by "did you understand the explanation...?"
C15	How much time was spent telling you what was wrong with you?	Removed			Length of time spent not the most important factor and not useful for quality improvements
C16	Do you feel that the time spent telling you what was wrong with you was too long, too short, or about right?	Removed			Length of time spent not the most important factor and not useful for quality improvements

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C17	When you were told what was wrong with you, did anyone explain the different types of treatment you could have for your condition?	Revised	13, 14	<p>Before your cancer treatment started, were the risks and benefits of different types of treatment explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, different treatments were not properly explained 4 <input type="checkbox"/> I was told there was only one type of treatment for my cancer 5 <input type="checkbox"/> Not sure/ Can't remember</p> <p>Were the possible side effects of different treatments explained in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, side effects were not properly explained 5 <input type="checkbox"/> Not sure/ Can't remember</p>	Two questions covering getting explanations about different treatment options
C18	Were you given a record of your discussion?	Revised	11	<p>When you were told you had cancer, were you also given this information in writing?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand 2 <input type="checkbox"/> Yes, but it was difficult to understand 3 <input type="checkbox"/> No, I was not given anything in writing 4 <input type="checkbox"/> Don't know / Can't remember</p>	

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C19	When you were told what was wrong with you, were you given any written or printed information about your treatment or condition?	Revised	12	When you were told you had cancer, were you given clear written information about the type of cancer you had? 1 <input type="checkbox"/> Yes, and it was easy to understand 2 <input type="checkbox"/> Yes, but it was difficult to understand 3 <input type="checkbox"/> No, I was not given written information about the type of cancer I had 4 <input type="checkbox"/> Don't know / Can't remember	Requested by Cancer team
C20	Was the written or printed information you were given easily understandable?	Removed			Covered by the response options to "Were you given a record..."
C21	Did the written or printed information you were given cover all the areas you needed it to cover?	Removed			Mostly covered by the response options to "Were you given a record..."
C22	If no, what information was missing from the written or printed information? (PLEASE WRITE IN BOX BELOW)	Removed			Impractical to analyse open responses in large-scale survey.
C23	Were you given any information about complementary therapies such as massage, aromatherapy etc?	Removed			Purpose of question unclear - not useful for quality improvement. Advisory group feedback suggests removing.
C24	Have you tried any complementary therapies for your condition?	Removed			Purpose of question unclear - not useful for quality improvement. Advisory group feedback suggests removing.

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
C25	How useful did you find them in helping you with your condition?	Removed			Purpose of question unclear - not useful for quality improvement, Advisory group feedback suggests removing.
D1	Have you had an out-patient appointment for this condition, at any hospital, in the last 2 years?	Revised	64	During the last 12 months, have you had an outpatients appointment at any hospital to get treatment for your cancer or to see a specialist? 1 <input type="checkbox"/> Yes → Go to Q0 2 <input type="checkbox"/> No → Go to Q	Better to ask about last 12 months so results are owned as recent. Simpler question.
D2	Was this most recent out-patient appointment ever cancelled or postponed by the hospital?	Removed			Probably not needed - are outpatients appointments often cancelled?
D3	How long did you wait, after your appointment time, before seeing a doctor at the out-patient clinic on this occasion? (Less than 10 minutes/ 10 minutes or more, but less than 20 minutes/ 20 minutes or more, but less than 30 minutes/ 30 minutes or more, but less than 1 hour/ 1 hour or more/ Can't remember/ Did not see a doctor)	Revised	66	How long after the stated appointment time did the appointment start? 1 <input type="checkbox"/> Seen on time, or early 2 <input type="checkbox"/> Waited up to 5 minutes 3 <input type="checkbox"/> Waited 6 - 15 minutes 4 <input type="checkbox"/> Waited 16 - 30 minutes 5 <input type="checkbox"/> Waited 31 - 60 minutes 6 <input type="checkbox"/> Waited 1 to 2 hours 7 <input type="checkbox"/> Waited more than 2 hours 8 <input type="checkbox"/> Don't know/Can't remember	Simpler response options, allowing for longer waits. Not just doctor appointments but most recent appointment.
D4	How much time did the doctor spend with you during this most recent out-patient appointment?	Removed			Length of time spent not the most important factor and not useful for quality improvements. Advisory group feedback to omit this question.

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
D5	Do you feel that the time the doctor spent with you on this occasion was too long, too short or about right?	Revised	67	Do you feel that the time you spent with the main person you saw was too long, too short or about right? 1 <input type="checkbox"/> Too short 2 <input type="checkbox"/> About right 3 <input type="checkbox"/> Too long	? Will it be OK to ask this about last professional you saw, not just doctors? We could still compare longitudinally by taking only those who say the main reason for their visit was to see a doctor.
D6	Did you have confidence and trust in the hospital doctor who saw you as an out-patient on this occasion? (Yes, completely/ Yes, to some extent/ Not very much/ None at all/ Can't say)	Revised	68	Did you have confidence and trust in main person you saw in the outpatients department? 1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No	Simpler wording, not just doctor appointments but most recent appointment
D7	Did you have enough privacy while the doctor was examining you as an out-patient on this occasion?(Yes, completely/ Yes, to some extent/ No/ I was not examined)	Revised	69	Were you given enough privacy during your most recent outpatients appointment? 1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> It was not necessary	Two questions about privacy combined into one, based on advisory group feedback. Simpler wording, not just doctor appointments but most recent appointment
D8	Did you have enough privacy when discussing your condition or treatment with the doctors or nurses as an outpatient on this occasion?	Combined into previous question			See above
D9	During this most recent out- patient appointment, did the doctor or nurse involve your family or friends in discussing your care or treatment?	Removed			A complex issue (some might not have wanted this) so difficult to use the question for quality improvement

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
D10	Were you treated with respect and dignity by the doctors or nurses as an out-patient on this occasion?	Removed			Quite vague so not very useful for quality improvement.
D11	Since the very first hospital visit you had for this condition, have your appointments as an out-patient been too frequent, not frequent enough or about right?	Removed			A complex issue so difficult to use the question for quality improvement
E1	Did you feel that the different people treating and caring for you (e.g. GP, hospital doctor, hospital nurses, community nurses) were working closely together to provide you with the best possible care? (Yes, always/ Yes, most of the time/Yes, some of the time/No, never /Don't know	Slightly revised	76	Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, community nurses) work well together to give you the best possible care? 1 <input type="checkbox"/> Yes, always 2 <input type="checkbox"/> Yes, most of the time 3 <input type="checkbox"/> Yes, some of the time 3 <input type="checkbox"/> No, never 4 <input type="checkbox"/> Don't know	Simpler wording.
E2	Overall, how would you rate the quality of the information provided to you about your condition and treatment?	Removed			Too vague to be useful for quality improvement
E3	Overall, how would you rate the quantity of the information provided to you about your condition and treatment	Removed			Too vague to be useful for quality improvement
E4	Did you feel that you were given enough emotional support during your treatment?	Removed			Too vague to be useful for quality improvement

2004 number	2004 wording	Action	2010 number	2010 wording	Reason
E5	Did you feel that you were generally provided with enough support for your religious beliefs during your treatment?	Removed			Not important to patients
E6	Over the course of your treatment for this condition, roughly how many hospital visits have you made?	Removed			Purpose of question not clear
F1	Are you male or female?	Kept same	78		
F2	To which of the following ethnic groups would you say you belong? (White/Black/Caribbean/Black – African/Black – Other Black Groups/Indian/Pakistani/Bangladeshi/Chinese/ Other (please write in box below)	Kept same	80		*We've been using a longer version of this question for several years but it doesn't work well and the detail it asks for is never used so I think this question is fine.
F3	What language do you speak most often at home?	Removed			Not useful for comparing groups
F4	What was your year of birth?	Slightly revised	77	What year were you born?	
F5	Did you complete this form by yourself, or did someone help you with any of it?	Removed			Purpose of question not clear
F6	If at some future date we wanted to ask you more questions about your health or health care, may we contact you again?	Removed			Not necessary
	Was there anything particularly good about your NHS healthcare?	Kept same			
	Was there anything that could have been improved?	Kept same			
	Any other comments?	Kept same			

3 New questions

Table 2 lists the new questions added to the 2010 cancer questionnaire.

Table 2: New questions added for 2010 survey

2010 number	New 2010 question	Reason
3	<p>How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?</p> <p>1 <input type="checkbox"/> I was seen as soon as I thought was necessary 2 <input type="checkbox"/> I should have been seen a bit sooner 3 <input type="checkbox"/> I should have been seen a lot sooner</p>	Useful to know how patient feels about wait
4	<p>How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?</p> <p>1 <input type="checkbox"/> Less than 3 months 2 <input type="checkbox"/> 3-6 months 3 <input type="checkbox"/> 6-12 months 4 <input type="checkbox"/> More than 12 months</p>	<p>Requested by Cancer team. I'm not confident this question will work well. I've tried to make it simple but it's still a complex idea. Also, there probably isn't a single day when people realise there might be something wrong. They probably only realise there were earlier symptoms retrospectively. What will we do with these findings? How will they help improve quality?</p>
15	<p>Before you started your treatment, were you given clear written information about the side effects of different treatments?</p> <p>1 <input type="checkbox"/> Yes, and it was easy to understand 2 <input type="checkbox"/> Yes, but it was difficult to understand 3 <input type="checkbox"/> No, I was not given anything in writing 4 <input type="checkbox"/> Don't know / Can't remember</p>	Requested by Cancer team to monitor "Information Prescription".
20	<p>Do you think the doctors treating you knew enough about your condition and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know/ Not sure</p>	Patients give clinical competence very high importance ranking.

2010 number	New 2010 question	Reason
25-28 (Questions 23 and 24 in this section replace 2004 questions)	<p>The last time you saw your Clinical Nurse Specialist, did she/he spend enough time with you?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p> <p>The last time you saw your Clinical Nurse Specialist, did she/he listen carefully to you?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No</p> <p>When you had important questions to ask your Clinical Nurse Specialist, did you get answers that you could understand?</p> <p>1 <input type="checkbox"/> Yes, always 2 <input type="checkbox"/> Yes, sometimes 3 <input type="checkbox"/> No 4 <input type="checkbox"/> I had no need to ask questions</p> <p>Do you think your Clinical Nurse Specialist knew enough about your cancer and its treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know/ Not sure</p>	New section about clinical nurse specialist.
31	<p>Do you think the hospital nurses knew enough about your condition and treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know/ Not sure</p>	Patients give clinical competence very high importance ranking.
41	<p>Do you think the hospital staff did everything they could to help control the side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, they could have done more 4 <input type="checkbox"/> I did not have any side effects</p>	Requested by Cancer team.
43-49 (Question 45 in this section replaces a 2004 question)	<p>TEST PROCEDURES</p> <p>During the last 12 months, have you had a test procedure (such as a biopsy, endoscopy, x-ray or scan) at this hospital?</p> <p>1 <input type="checkbox"/> Yes → Go to [next question] 2 <input type="checkbox"/> No → Go to [next section]</p> <p>The last time you had a test procedure, what was it?</p> <p>1 <input type="checkbox"/> Biopsy 2 <input type="checkbox"/> Endoscopy 3 <input type="checkbox"/> Scan (e.g. MRI) or ultrasound 3 <input type="checkbox"/> X-ray 4 <input type="checkbox"/> Something else</p> <p><i>Thinking about the LAST time you had a test</i></p>	New section with more specific questions about patients' experiences of tests, kept separate from a section about operations. *Check with clinicians: does this list cover the most common ones? *Should X-rays be included here? Maybe it would be more useful to focus on the more invasive tests?

2010 number	New 2010 question	Reason
	<p><i>procedure....</i></p> <p>Beforehand, did a member of staff explain what would be done during the test procedure?</p> <p>1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember</p> <p>Beforehand, were you given clear written information about your test?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, the test was not properly explained 4 <input type="checkbox"/> Don't know / Can't remember</p> <p>During the procedure, do you think the hospital staff did everything they could to make you comfortable?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, they could have done more</p> <p>Afterwards, did a member of staff explain the results of the test in a way you could understand?</p> <p>1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember</p>	
<p>50, 51 (Questions 52 and 53 in this section replace 2004 questions.)</p>	<p>During the last 12 months, have you had an operation (such as removal of a tumour or lump) at this hospital?</p> <p>1 <input type="checkbox"/> Yes → Go to [next question] 2 <input type="checkbox"/> No → Go to [next section]</p> <p><i>Thinking about the LAST time you had an operation</i></p> <p>Beforehand, did a member of staff explain what would be done during the operation?</p> <p>1 <input type="checkbox"/> Yes, completely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No, but I would have liked an explanation 4 <input type="checkbox"/> I did not need an explanation 5 <input type="checkbox"/> Don't know / Can't remember</p>	<p>New section focusing on operations.</p>
<p>54</p>	<p>Before you left hospital, were you given clear written information about your medicines?</p> <p>1 <input type="checkbox"/> Yes, definitely 2 <input type="checkbox"/> Yes, to some extent 3 <input type="checkbox"/> No 4 <input type="checkbox"/> Don't know / Can't remember</p>	<p>Requested by Cancer team to monitor "Information Prescription".</p>

2010 number	New 2010 question	Reason
57	<p>Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> No family or friends were involved</p> <p>5 <input type="checkbox"/> My family or friends did not want or need information</p>	Simpler question from inpatient survey - replaces some of the removed questions about family involvement.
61	<p>Were you told that you could get free prescriptions?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No, but I would have liked information</p> <p>3 <input type="checkbox"/> It was not necessary</p> <p>4 <input type="checkbox"/> Don't know/ Can't remember</p>	New policy
65	<p>What was the main reason for your most recent outpatients appointment?</p> <p>1 <input type="checkbox"/> To have radiotherapy</p> <p>2 <input type="checkbox"/> To have chemotherapy</p> <p>3 <input type="checkbox"/> To see a doctor</p> <p>4 <input type="checkbox"/> To see a nurse</p> <p>5 <input type="checkbox"/> Something else</p>	Responses can be used to focus responses to subsequent questions. *However, we don't know how many people will fall into each category so we might not get enough of some types of appointment to be able to say useful things about them.
70	<p>The last 2 times you had an outpatients appointment with a hospital doctor, was it...?</p> <p>1 <input type="checkbox"/> With the same doctor both times</p> <p>2 <input type="checkbox"/> With two different doctors</p> <p>3 <input type="checkbox"/> I have only had one appointment with a doctor</p>	Requested by Cancer team but I'm not sure it will work because this section is about all outpatients appointments, not just doctors.
71	<p>Did you receive copies of letters sent between hospital doctors and your family doctor (GP)?</p> <p>1 <input type="checkbox"/> Yes, I received copies</p> <p>2 <input type="checkbox"/> No, I did not receive copies</p> <p>3 <input type="checkbox"/> Not sure / Don't know</p>	Copying letters to patients a relatively new policy and, arguably, particularly important to cancer patients.
74	<p>Do you think your GP and practice nurses did everything they could to help control the side effects of your treatment?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No, they could have done more</p> <p>4 <input type="checkbox"/> I did not have any side effects</p>	Requested by Cancer team

2010 number	New 2010 question	Reason
79	Do you have any of the following longstanding conditions? (Tick ALL that apply) 1 <input type="checkbox"/> Deafness or severe hearing impairment 2 <input type="checkbox"/> Blindness or partially sighted 3 <input type="checkbox"/> A long-standing physical condition 4 <input type="checkbox"/> A learning disability 5 <input type="checkbox"/> A mental health condition 6 <input type="checkbox"/> A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy 7 <input type="checkbox"/> No, I do not have a long-standing condition	Adapted from the current inpatient survey.
81	Which of the following best describes your sexual orientation? (Tick one box only) 1 <input type="checkbox"/> Heterosexual (opposite sex) 2 <input type="checkbox"/> Bisexual (both sexes) 3 <input type="checkbox"/> Gay or Lesbian (same sex) 4 <input type="checkbox"/> Other 5 <input type="checkbox"/> Prefer not to answer	To save space, we could leave out this question because it's unlikely we'll do anything with the results: very few will indentify themselves as non-heterosexual - perhaps not enough for national-level analyses, certainly not trust-level.

4 Questions with longitudinal comparability

The following 13 questions are identical or may be judged to be almost identical to those used in the 2004 survey, and therefore could provide direct longitudinal comparisons.

Q5. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?

Q10. Did you understand the explanation of what was wrong with you?

Q18. When you had important questions to ask a doctor, how often did you get answers that you could understand?

Q19. Did you have confidence and trust in the doctors treating you?

Q30. When you had important questions to ask a hospital nurse, how often did you get answers you could understand?

Q31. Did you have confidence and trust in the hospital nurses treating you?

Q34. In your opinion, were there enough nurses on duty to care for you in hospital?

Q35. While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?

Q36. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?

Q41. Do you think the hospital staff did everything they could to help control your pain?

Q57. Were you given clear written information about what you should or should not do after leaving hospital?

Q73. As far as you know, was your GP given enough information about your condition and the treatment given by the hospital?

Q77. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, community nurses) work well together to give you the best possible care?

Three demographic questions on age, sex and ethnic group are also the same as those used in the 2004 survey.

5 Recommended questions to remove

To fit the questionnaire on to 12 pages, we need to remove at least one question. If more questions can be removed, this is likely to improve the acceptability of the questionnaire and could improve response rates. The following are my recommendations, in priority order.

Question	Reason
<p>Q4. How long was it from the time you first thought something might be wrong with you until you first saw a hospital doctor?</p>	<p>I'm not confident this question will work well. I've tried to make it simple but it's still a complex idea.</p> <p>There probably isn't a single day when people realise there might be something wrong. They probably only realise there were earlier symptoms retrospectively.</p> <p>What will we do with these findings? How will they help improve quality?</p>
<p>Q68. Did you have confidence and trust in main person you saw in the outpatients department?</p>	<p>This issue is covered by other questions and it's not very useful for quality improvement because people don't know what they need to do to inspire confidence and trust.</p> <p>It has had to be revised to fit with the new questionnaire structure so longitudinal comparison will be less straightforward.</p>
<p>Q67. Do you feel that the time you spent with the main person you saw [in the outpatients department] was too long, too short or about right?</p>	<p>Cancer team say this is not one of the most important issues.</p> <p>It has had to be revised to fit with the new questionnaire structure so longitudinal comparison will be less straightforward.</p>
<p>Q70. The last 2 times you had an outpatients appointment with a hospital doctor, was it...?</p> <p>1 <input type="checkbox"/> With the same doctor both times</p> <p>2 <input type="checkbox"/> With two different doctors</p> <p>3 <input type="checkbox"/> I have only had one appointment with a doctor</p>	

Question	Reason
<p>Q19. Did you have confidence and trust in the doctors treating you?</p> <p>Q30. Did you have confidence and trust in the hospital nurses treating you?</p>	<p>These issues are covered by other questions and the questions are not very useful for quality improvement because people don't know what they need to do to inspire confidence and trust.</p> <p>However, these are two of the longitudinal comparison questions so they may need to be kept for that reason.</p>
<p>Q81. Which of the following best describes your sexual orientation? (Tick one box only)</p>	<p>It's unlikely we'll do anything with the results: very few will identify themselves as non-heterosexual - perhaps not enough for national-level analyses, certainly not trust-level.</p>
<p>Q15. Before you started your treatment, were you given clear written information about the side effects of different treatments?</p>	<p>Questions 14 and 46 also ask about information about side effects.</p>