

Development of the Outpatient Cancer Clinics Survey 2016

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Background

The Bureau of Health Information (BHI) undertakes reviews of all recurrent surveys before repeating them. The purpose is to ensure the questionnaire is still appropriate for the NSW context and that all questions remain optimal. From October to December 2016, BHI reviewed the questionnaire used in the 2015 Outpatient Cancer Clinics Survey (COPS) to prepare for the collection of experience data from patients visiting a cancer outpatient clinic during November 2016. This document summarises the changes to the COPS questionnaire from the 2015 to 2016 survey years.

Methods

Analysis of historic COPS data

An analysis of the 2015 COPS survey data was undertaken to support the questionnaire review. This analysis determined the following for each question:

- response patterns for each question, including rates of item non-response (not answering a question when they should have), invalid responses (selecting more than one answer to a single response question or answering a question they should have skipped past) and non-specific responses, such as 'don't know', 'can't remember' or 'not applicable to me'
- ceiling and floor effects of response categories (responses where almost all patients are very positive or very negative, with little variation between hospitals) using the scored mean, standard deviation and skewness of responses
- correlations between questions (using the most positive response category) to understand if any questions appear to be duplicating the same aspect of care (using the Pearson method).

Feedback from stakeholders

A pro forma spreadsheet containing questions and response options from the 2015 COPS was circulated to relevant stakeholders, including the Cancer Institute NSW, the Directors of Area Cancer Services and to Cancer Services Innovation Managers and their staff in the NSW local health districts (LHDs). Consumer representatives from the Cancer Institute NSW consumer panel were also invited to participate in the review. Stakeholders were asked to:

- indicate whether they thought the question should be included in the updated survey
- rate the priority for inclusion of each question as either low, medium or high
- suggest new questions or question topics for development
- provide a rationale for any questions they thought should be removed, or have wording changed.

Responses were collated and reviewed by BHI and Cancer Institute NSW staff. Based on the feedback provided, an updated version of the questionnaire was drafted and circulated for comments. This was an iterative process. As a final step, BHI undertook cognitive testing with consumer representatives. The questionnaire was modified based on the findings of this cognitive interviewing.

Approval of changes

A final version of the draft questionnaire was approved by BHI's Acting Chief Executive, BHI and the Cancer Institute NSW's Chief Cancer Officer. The questionnaire was sent to design for layout prior to printing and scanning. Following review of the design file, the Chief Executives gave final approval to the questionnaire and for the survey to begin. The questionnaire was then provided to the external contractor for printing and mailing.

Summary of changes to the Outpatient Cancer Clinics Survey

The following is a list of the changes. The rationale and evidence can be found in the following section.

Q number (2015)	Question	Change
Cover	Changes to cover letter	Addition of new logo and extra sentence directing respondents to view results on Healthcare Observer. Use of BHI acronym. Reordering of some paragraphs.
1	What was the purpose of this visit?	Added new response option and changes to some existing response options and order of responses
2	Were you able to get an appointment time that suited you?	Removed question
3	Did you have any of the following difficulties when making this appointment?	Removed question
4	From the time you booked this appointment to the time you went to the clinic, how long did you wait?	Removed question
5	Do you think the amount of time you waited was...?	Removed question
6	How much did your symptoms or condition stop you from carrying out your normal daily activities (for example, eating, dressing or using the bathroom) while you waited for this appointment?	Removed question
7	While you were waiting for this appointment, did your symptoms or condition...?	Removed question
8	How long did it take you to travel to the clinic for this appointment?	Added underline to ' <u>for this appointment</u> ' Combined responses '2 hours to under 3 hours' and '3 hours or more' to '2 hours or more'
9	What was your main form of transport to the clinic?	Removed the word 'by' in some response options
10	Was there a problem finding parking near the clinic?	Replaced with: Did you have any of the following issues with parking during this visit? Please x <u>all</u> the boxes that apply to you. Response options all new
11	At the hospital, was it easy to find your way to the clinic?	Removed question
12	Did any of the following cause you difficulties when entering and moving around the clinic?	Removed question

Q number (2015)	Question	Change
14	Did you feel you had enough privacy when talking with the receptionist?	Removed question
16	Did you experience any inconvenience or problems as a result of the wait?	Removed question
18	Were you told why you had to wait?	Removed question
New	How comfortable was the treatment area?	Added to 'The Physical Environment'
20	How clean was the clinic?	Changed 'clinic' to 'treatment area'
21	Were you given enough privacy when being <u>examined or treated</u> ?	Changed from 'Your Treatment and Care' to 'Respectful Care' section
22	Were you given enough privacy when <u>discussing</u> your condition or treatment?	Changed from 'Your Treatment and Care' to 'Respectful Care' section
23	Who did you see during this visit?	Change in order of response options. Removed response option for Physiotherapist and added response option of Psychologist
New	When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options?	Added to 'Planning your Care'
New	Did a health professional at the clinic tell you about risks and benefits of the treatment options?	Added to 'Planning your Care'
New	Did a health professional at the clinic explain the next steps of your care and treatment in a way you could understand?	Added to 'Planning your Care'
34	Do you have a care plan for your cancer treatment? A care plan is a document that sets out your needs and goals for the treatment and management of your cancer.	<p>Changed explanation text to:</p> <p>The following questions ask about care plans. Care plans are written documents that outline the steps and goals in managing your medical condition.</p> <p>Explanation text changed to proceed question.</p> <p>Question changed to included 'written' and remove 'cancer'</p>
35	Was your care plan developed by health professionals from this clinic?	Added response 'Don't know/can't remember'

Q number (2015)	Question	Change
36	Were you asked for your ideas and preferences when developing this plan?	Removed 'your ideas' and included 'care and treatment' in the question. Combined two 'yes' responses to only one 'yes' response
37	At your most recent visit, did the health professionals review your care plan with you?	Changed 'most recent' to 'latest'
38	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Moved from 'Your Treatment and Care' to 'Planning Your Care' section
39	Were you treated with respect and dignity while you were at the clinic?	Moved from 'Your Treatment and Care' to 'Respectful Care' section
40	Were your cultural or religious beliefs respected by the clinic staff?	Moved from 'Your Treatment and Care' to 'Respectful Care' section
New	Did you receive any treatment during this visit? (e.g. chemotherapy, radiotherapy, surgery or other treatments)	Added to 'Your Care and Treatment' section
New	Did a health professional at the clinic explain what would be done during your treatment in a way you could understand?	Added to 'Your Care and Treatment' section
New	Did a health professional at the clinic tell you about possible side effects of your treatment?	Added to 'Your Care and Treatment' section
41	Were you given, or prescribed, any new medication to take at home?	Added 'During this visit' to the question
43	Did a health professional at the clinic tell you about medication side effects to watch for?	Rewording of the question to 'side effects of this medication'
44	Were you given enough information about how to manage the side effects of any other treatment you received during this visit?	Removed 'any other' and 'received during this visit' Removed the response 'I did not need this type of information' Moved earlier in section to be collocated with treatment effects questions
46	While in the clinic, did you receive or see any information about how to comment or complain about your case?	Removed question
New	Did a health professional at the clinic give your family or someone close to you enough information to help care for you at home?	Added to 'Your Care and Treatment'

Q number (2015)	Question	Change
New	Were you ever treated unfairly for any of the reasons below? Please x <u>all</u> boxes that apply to you.	Added to 'Respectful Care' section
47	During your visit or soon afterwards, did you experience any of the following complications or problems related to the care you received at the clinic?	Moved from 'After Your Visit' to 'Complications' section Removed 'related to the care you received at the clinic' Added '(other than common side effects from treatment)' Change the response ' <u>None</u> of these' to 'None'
49	In your opinion, were the clinic staff open with you about this complication or problem?	'Clinic staff' changed to 'health professionals'
50	Did you have to pay any of the following out-of-pocket expenses in relation to this visit? Out-of-pocket expenses are those that you don't get back from Medicare or a private health fund	Expanded to a 'Payments for your care' section Removed question
New	This section is about out-of-pocket expenses you might have to pay for clinic visits. Out-of-pocket expenses are those that you don't get back from Medicare or a private health fund. Please think about your visits to this cancer clinic over the <u>past six months</u> ... How much were your out pocket expenses for <u>medication</u> related to these visits?	Added to 'Payments For Your Care' section
New	How much were your out-of-pocket expenses for <u>consultations, tests, surgery or treatment</u> related to these visits (excluding medication)?	Added to 'Payments For Your Care' section
New	How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)?	Added to 'Payments For Your Care' section
51	How long have you been attending this cancer clinic?	Moved from 'Number of Visits' to 'Coordination of Care' section
52	In the last 12 months, how many times have you visited this cancer clinic?	Moved from 'Number of Visits' to 'Coordination of Care' section Removed skip option from response
53	Was there any time when the health professionals needed access to your health records and they were not available?	Moved from 'Number of Visits' to 'Coordination of Care' section

Q number (2015)	Question	Change
54	Did you ever receive conflicting information about your condition or treatment from the health professionals?	Moved from Number of Visits to 'Coordination of Care' section Removed response 'Not applicable – I was always treated by the same person'
58	Did you attend this clinic because you have or have had cancer?	'Treatment Needs and Outcomes' section changed to 'About Your Cancer' section
59	Is this the first time you have had cancer?	'Treatment Needs and Outcomes' section changed to 'About Your Cancer' section
New	What type of cancer were you receiving care for at this clinic? Please x <u>one</u> box only.	Added to 'About Your Cancer' section
New	Which of the following statements best describes how well you are able to carry out ordinary tasks and daily activities? Over the past month I would generally rate my activity as... Please x <u>one</u> box only.	Added to 'About Your Cancer' section
60	How has your current cancer responded to treatment?	'Treatment Needs and Outcomes' section changed to 'About Your Cancer'
61	How long has it been since you first received treatment for this cancer?	'Treatment Needs and Outcomes' section changed to 'About Your Cancer'
62	What treatment have you received for your cancer?	'Treatment Needs and Outcomes' section changed to 'About Your Cancer' Added 'In the <u>past three months</u> ' to the question and 'boxes' added to response instructions Added new response option and changes to some existing response options
63	In the past three months, have you gone to an emergency department because of your cancer or cancer complications?	Moved from 'Treatment Needs and Outcomes' to 'Complications' section Changed to: In the past three months, have you gone to an emergency department because of complications related to the care you received?'
65	Please rate the following cancer symptoms for how severe each is for you right now (at the time of completing this survey).	Changed from 'Assessing your Health' to 'About Your Cancer Symptoms' section
70	Did you need, or would you have liked, to use a professional interpreter at any stage while you were at the clinic?	Removed 'professional' from the question

Q number (2015)	Question	Change
71	Was a professional interpreter provided when you needed one?	<p>Changed question to ask about hospital-provided interpreters, removed 'professional'</p> <p>Added response option 'I did not need the hospital to provide a professional interpreter'</p>
New	Which of the following best describes your smoking status?	Added to 'About You' section
New	Has a health professional at this clinic advised you to quit smoking?	Added to 'About You' section

Details of changes

The rationale and evidence

This section presents changes made to the 2015 questionnaire for the production of a 2016 version. 'Current question' therefore refers to the 2015 questionnaire and the 'action' is the change made to arrive at the 2016 questionnaire.

Cover page

Action

Addition of new logo and extra sentence directing respondents to view results on Healthcare Observer. Use of BHI acronym. Reordering of some paragraphs.

Rationale

- The cover page was changed to ensure comparability across BHI surveys and to provide links for more information. There was additional restructuring to simplify the presentation of information to survey participants and to clarify that some participants are included who do not have cancer.

Question 1

Current question

What was the purpose of this visit? Please x all the boxes that apply to you

- Have tests, X-rays or scans
- Receive test, X-ray or scan results
- Medical diagnosis or advice
- Regular check-up
- Chemotherapy
- Radiotherapy
- Review of treatment
- Surgical procedure
- Follow-up after surgery
- Other reason

Action

Addition of Immunotherapy or hormone therapy response.

Change to 'Treatment review' from 'Review of treatment'.

Change in response order.

Rationale

Testing of the 2015 question showed sufficient item non-response rate to suggest that there were missing response options. 'Immunotherapy or hormone therapy' were identified as one item that was missing. The order was restructured to group treatment types together and to have reviews of treatment following on from the treatment types as these could provide a prompt for this type of care.

Question 2

Current question

Were you able to get an appointment time that suited you?

- Yes
- No
- I didn't have an appointment arranged in advance

Action

Removed question.

Rationale

This question had clear ceiling effect as almost all patients were able to get an appointment time that suited them.

Question 3

Current question

Did you have any of the following difficulties when making this appointment? Please x all that apply to you

- I didn't know how to make an appointment
- I didn't know which clinic to call
- The contact details were hard to find
- My call was not answered
- I had to wait on hold for a long time
- The appointment was previously cancelled/postponed
- Some other difficulty
- None - I had no difficulties

Action

Removed question.

Rationale

This question was filtered by Q2 above – due to the very small number of patients saying they had difficulties, this question was also removed from the survey.

Question 4

Current question

From the time you booked this appointment to the time you went to the clinic, how long did you wait?

- Less than 15 days
- 15 days to less than 1 month
- 1 to 3 months
- 4 to 6 months
- 7 to 12 months
- More than 1 year
- Don't know/can't remember

Action

Removed question.

Rationale

This question does not reflect the initial purpose which was to assess how quickly patients could access services. People on long-term follow-up had long waits which could incorrectly be inferred as poor performance. When filtered for first time attendees, numbers were too small at many clinics to be useful.

Question 5

Current question

Do you think the amount of time you waited was...?

- About right
- Slightly too long
- Much too long
- Don't know/can't remember

Action

Removed question.

Rationale

Question was deemed not to be relevant in the absence of Q4 on how long they waited.

Question 6

Current question

How much did your symptoms or condition stop you from carrying out your normal daily activities (for example, eating, dressing or using the bathroom) while you waited for this appointment?

- Not at all
- Only a little
- Somewhat
- Very much
- I was not able to at all I had no symptoms

Action

Removed question.

Rationale

This question cannot be attributed to the waiting time at the clinic and was complicated by the very high number of patients in long-term follow-up.

Question 7

Current question

While you were waiting for this appointment, did your symptoms or condition...?

- Get much better
- Get a little better
- Stay about the same
- Get a little worse
- Get much worse
- Don't know/can't remember

Action

Removed question.

Rationale

This question cannot be attributed to the waiting time at the clinic and was complicated by the very high number of patients in long-term follow-up.

Question 8

Current question

How long did it take you to travel to the clinic for this appointment?

- Less than 30 minutes
- 30 to 59 minutes
- 1 hour to under 2 hours
- 2 hours to under 3 hours
- 3 hours or more
- Don't know/can't remember

Action

Added underline to 'for this appointment'.

Combined responses '2 hours to under 3 hours' and '3 hours or more' to '2 hours or more'.

Rationale

Distribution of responses in the 2015 questionnaire showed very few patients travelled for '3 hours or more' so this category was combined with '2 hours to under 3 hours'. We added underlining to stress that we are asking only about the most recent appointment.

Question 9

Current question

What was your main form of transport to the clinic? Please x one box only

- By private car
- By a hospital or community transport service
- By taxi
- By public transport
- On foot
- Other

Action

Removed the word 'by' in some response options.

Rationale

By removing the preposition ('by'), the subject of response option is made more prominent and the cognitive demand in answering the question is slightly reduced. We hypothesise that this should also reduce error in following the question skips.

Question 10

Current question

Was there a problem finding parking near the clinic?

- Yes, a big problem
- Yes, a small problem
- No problem
- I did not need parking

Action

Replaced question with:

Did you have any of the following issues with parking during this visit? Please x all the boxes that apply to you

- No car park at the clinic
- The car park was full
- Too few disabled parking spaces
- Expensive parking fees
- Had to walk a long way from the car park
- None of these issues

Rationale

The new question is much more specific about what the parking issue was, allowing services to target improvements more effectively.

Question 11

Current question

At the hospital, was it easy to find your way to the clinic?

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

Action

Removed question.

Rationale

This question demonstrated a high ceiling effect and was removed to make space for new questions.

Question 12

Current question

Did any of the following cause you difficulties when entering and moving around the clinic? Please x all that apply to you

- A long walk
- No ramp/only stairs
- No lift/elevator
- Narrow walkways/halls/doorways
- No accessible toilets
- Some other difficulty
- None - I had no difficulties

Action

Removed question.

Rationale

This question demonstrated a high ceiling effect and was removed to make space for new questions.

Question 14

Current question

Did you feel you had enough privacy when talking with the receptionist?

- Yes
- No
- I did not talk to the receptionist

Action

Removed question.

Rationale

This question was scored relative low on the engagement with stakeholders and demonstrated a ceiling effect in the 2015 survey.

Question 16

Current question

Did you experience any inconvenience or problems as a result of the wait?

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

Action

Removed question.

Rationale

This question was scored low during the engagement with stakeholders and was removed to make space for questions with higher priority.

Question 18

Current question

Were you told why you had to wait?

- Yes
- No
- Don't know/can't remember

Action

Removed question.

Rationale

This question was removed to make space for new questions. The matched question on being told how long they had to wait was retained as this was seen as a more crucial question.

New question

How comfortable was the treatment area?

- Very comfortable
- Fairly comfortable
- Not very comfortable
- Not at all comfortable
- I did not go to a treatment area at the clinic

Action

New question.

Rationale

This question was added to provide information about the treatment areas and to compliment the question on comfort of the waiting area.

Question 20

Current question

How clean was the clinic?

- Very clean
- Fairly clean
- Not very clean
- Not at all clean

Action

Changed 'clinic' to 'treatment area'.

Rationale

With limited questionnaire space available, it was agreed that the cleanliness of the treatment area was the highest priority so this question was made specific to that (clinic was understood to mean the waiting AND treatment areas).

Questions 21 and 22

Current question

Were you given enough privacy when being examined or treated?

- Yes, completely
- Yes, to some extent
- No

Were you given enough privacy when discussing your condition or treatment?

- Yes, completely
- Yes, to some extent
- No

Action

Questions moved from 'The physical environment' to 'Respectful care' section

Rationale

The 2016 questionnaire focused the physical environment section on comfort and cleanliness. Privacy, as an aspect of dignity, was moved to the respectful care section instead.

Question 23

Current question

Who did you see during this visit? Please x all the boxes that apply to you

- Doctor/Specialist
- Nurse (including for chemotherapy)
- Radiation therapist (for radiotherapy)
- Radiographer (X-ray, ultrasound, MRI)
- Lymphoedema therapist
- Physiotherapist
- Dietician
- Social worker
- Other healthcare professional

Action

Change in order of response options.

Removed response option for Physiotherapist and added response option of Psychologist.

Rationale

Only 1% of respondents said they saw a physiotherapist so this option was removed. Psychologists were identified as a specialist group that was not represented so this was added. The order was changed to reflect the results of the 2015 survey – these are now in descending order of the most commonly seen health professionals in cancer clinics.

New questions

When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options?

- Yes, always
- Yes, sometimes
- No, treatment options were not discussed
- Not applicable to my situation.

Did a health professional at the clinic tell you about the risks and benefits of the treatment options?

- Yes, always
- Yes, sometimes
- No

Did a health professional at the clinic explain the next steps of your care and treatment in a way you could understand?

- Yes, completely
- Yes, to some extent
- No

Action

New questions.

Rationale

These new additions to this section explore treatment choice, information and planning care.

Question 34

Current question

Do you have a care plan for your cancer treatment? *A care plan is a document that sets out your needs and goals for the treatment and management of your cancer.*

- Yes
- No
- I do not need one
- Don't know/can't remember

Action

Changed explanation text to the following and moved text to proceed question:

The following questions ask about care plans. Care plans are written documents that outline the steps and goals in managing your medical condition.

Question changed to included 'written' and remove 'cancer'.

Rationale

The focus for future cancer care in NSW is for written care plans to better manage care, provide continuity and to be transparent to patients. This question has changed to focus on written care plans specifically.

Question 35

Current question

Was your care plan developed by health professionals from this clinic?

- Yes
- No

Action

Added response 'Don't know/can't remember'.

Rationale

This question attracted a higher than expected rate of missing responses indicating another response option was needed for some participants – the consensus of the development team was that a non-specific response ('don't know/can't remember') was more appropriate than increasing the range of response options (i.e. to 'yes, always', 'yes sometimes' and 'no').

Question 36

Current question

Were you asked for your ideas and preferences when developing this plan?

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

Action

Removed 'your ideas' and included 'care and treatment' in the question.

Combined the 'yes, definitely' and 'yes, to some extent' responses into a single 'yes' response.

Rationale

On review of response patterns for this question, it was evident that two options (yes and no) were more appropriate for this question than an expanded range. In addition, the focus of the question moved to preferences for care and treatment rather than the patient contributing treatment possibilities.

Question 37

Current question

At your most recent visit, did the health professionals review your care plan with you?

- Yes
- No
- Not applicable as I did not have a care plan before this visit
- Don't know/can't remember

Action

Changed 'most recent' to 'latest'.

Rationale

This change was made to improve sentence flow.

Question 38

Current question

Were you involved, as much as you wanted to be, in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No
- I did not want or need to be involved

Action

Moved from 'Your Treatment and Care' section to 'Planning Your Care'.

Rationale

This question was grouped with questions relating to involvement and engagement in decisions about care.

Questions 39 and 40

Current question

Were you treated with respect and dignity while you were at the clinic?

- Yes, always
- Yes, sometimes
- No

Were your cultural or religious beliefs respected by the clinic staff?

- Yes, always
- Yes, sometimes
- No, my beliefs were not respected
- My beliefs were not an issue

Action

Questions moved from 'Your Treatment and Care' to 'Respectful Care' section.

Rationale

Due to restructuring of the questionnaire, these questions were moved to a section specifically dealing with respectful care.

Redesign of the 'Treatment and Care' section

Current name of section

Your Treatment and Care

Action

'Your Treatment and Care' section was changed to 'Your Care and Treatment'.

Rationale

The Treatment and Care section of the 2015 questionnaire was completely rearranged for 2016, including additional questions to allow distinction between treatments and new medication. The heading of the section was specifically changed to improve readability.

New questions

Did you receive any treatment during this visit? (e.g. chemotherapy, radiotherapy, surgery or other treatments)

- Yes
- No

Did a health professional at the clinic explain what would be done during your treatment in a way you could understand?

- Yes, completely
- Yes, to some extent
- No

Did a health professional at the clinic tell you about possible side effects of your treatment?

- Yes, completely
- Yes, to some extent
- No

Action

New questions.

Rationale

The first question was added to assess if treatment had been delivered and then to filter past these questions if no treatment had been delivered. The following new questions were added to expand on the information provision related to treatment.

Question 41

Current question

Were you given, or prescribed, any new medication to take at home?

- Yes
- No

Action

Added 'During this visit' to the beginning of the question.

Rationale

Text was added to clarify that the new medication (and following questions) related to this visit only.

Question 43

Current question

Did a health professional at the clinic tell you about medication side effects to watch for?

- Yes, completely
- Yes, to some extent
- No

Action

Rewording of the question to 'side effects of this medication'.

Rationale

Wording changed to improve readability and align with new questions on side effects of treatment.

Question 44

Current question

Were you given enough information about how to manage the side effects of any other treatment you received during this visit?

- Yes, completely
- Yes, to some extent
- No
- I did not need this type of information

Action

Removed 'any other' and 'received during this visit'.

Removed the response 'I did not need this type of information'.

Moved earlier in section to be collocated with treatment side effect questions.

Rationale

The rebuild of this part of the questionnaire necessitated rewriting and repositioning this question on management of treatment side effects.

Question 46

Current question

While in the clinic, did you receive or see any information about how to comment or complain about your case?

- Yes
- No
- Don't know/can't remember

Action

Removed question.

Rationale

This question was removed to make space for new questions and for consistency across the BHI surveys.

New question

Did a health professional at the clinic give your family or someone close to you enough information to help care for you at home?

- Yes, completely
- Yes, to some extent
- No
- Not applicable to my situation
- Don't know/can't remember

Action

New question.

Rationale

This question was added to collect information about how staff interact with carers and family members that attend the clinic.

New question

Were you ever treated unfairly for any of the reasons below? Please x all the boxes that apply to you

- Your age
- Your sex
- Your ethnic background
- Your religion
- Your sexual orientation
- A disability that you have
- Marital status

Action

Added to 'Respectful Care' section.

Rationale

This question has been added to align the questionnaire with those in other BHI surveys. In addition, it was seen as a priority by Cancer Institute NSW (CINSW) representatives.

Question 47**Current question**

During your visit or soon afterwards, did you experience any of the following complications or problems related to the care you received at the clinic? Please x all the boxes that apply to you

- An infection
- Uncontrolled bleeding
- An unexpected negative reaction to medication
- Complications as a result of tests or procedures
- Severe pain due to the treatment
- Severe anxiety or worry
- Any other complication or problem (other than common side-effects from treatment)
- None of these

Action

Changed from 'After Your Visit' to 'Complications' section.

Removed 'related to the care you received at the clinic'.

Added '(other than common side-effects from treatment)'.

Change the response 'None of these' to 'None'.

Rationale

The question text was modified to improve readability.

Question 49**Current question**

In your opinion, were the clinic staff open with you about this complication or problem?

- Yes, completely
- Yes, to some extent
- No
- Not applicable, as it happened after I left

Action

'Clinic staff' changed to 'health professionals'.

Rationale

Changed to improve consistency across the questionnaire.

Inserting new section on payments

Name of new section

Payments for your care

Action

New section and questions added.

Rationale

This section was added to replace the former single question on out-of-pocket expenses with three more specific questions.

New questions

How much were your out-of-pocket expenses for medication related to these visits?

- Zero (\$0)
- \$1 to less than \$100
- \$100 to less than \$500
- \$500 to less than \$1,000
- \$1,000 or more
- Don't know/can't remember

How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these visits (excluding medication)?

- Zero (\$0)
- \$1 to less than \$100
- \$100 to less than \$500
- \$500 to less than \$1,000
- \$1,000 or more
- Don't know/can't remember

How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)?

- Zero (\$0)
- \$1 to less than \$100
- \$100 to less than \$500
- \$500 to less than \$1,000
- \$1,000 or more
- Don't know/can't remember

Action

New questions.

Rationale

Questions added to provide information on three types of out-of-pocket costs and the level of cost. These questions were considered a high priority by stakeholders and the Cancer Institute NSW.

Question 50**Current question**

Did you have to pay any of the following out-of-pocket expenses in relation to this visit? *Out-of-pocket expenses are those that you don't get back from Medicare or a private health fund.* Please x all that apply to you

- Consultation fees
- Medication
- Treatment/surgery costs
- Travel
- Parking
- Accommodation
- Other related expenses
- None of these – I had no expenses
- Don't know/can't remember

Action

Removed question.

Rationale

This question was replaced by three more specific questions.

Redesign of the 'Number of visits' section**Current name of section**

Number of visits

Action

'Number of visits' section changed to 'Coordination of care'.

Rationale

The title of this section was changed because two of the questions (access to medical records and contradictory information) are not specific to the number of visits.

Question 52

Current question

In the last 12 months, how many times have you visited this cancer clinic?

- Once
- 2 to 3 times
- 4 to 8 times
- More than 8 times

Action

Removed question filter than skips past the next two questions.

Rationale

It is possible that patients could have received contradictory information from clinic staff longer than just the 12 month period or through other mechanisms such as phone calls or prescriptions. The consensus was to remove the filter from the question.

Question 54

Current question

Did you ever receive conflicting information about your condition or treatment from the health professionals?

- Yes
- No
- Not applicable – I was always treated by the same person

Action

Removed third response option of 'Not applicable – I was always treated by the same person'.

Rationale

The response option of 'Not applicable – I was always treated by the same person' was removed because it is possible to receive contradictory information from the same health professional.

Redesign of the 'Treatment needs and outcomes' section

Current name of section

Treatment needs and outcomes

Action

'Treatment needs and outcomes' section changed to 'About your cancer'.

Rationale

The title of this section was changed to clarify that this was referring to cancer information and care.

New question

What type of cancer were you receiving care for at this clinic? Please x one box only.

- Prostate
- Breast
- Bowel (colon, rectal, anus)
- Lung
- Skin/melanoma
- Upper gastrointestinal (oesophagus, stomach, liver, pancreatic, bile ducts)
- Gynaecological (e.g. ovarian, endometrial, cervical)
- Brain or spinal column
- Head and neck
- Blood (lymphoma, leukaemia, marrow, lymph nodes)
- Other (e.g. bladder, bone, eye, heart, kidney, mesothelioma, thyroid)

Action

New question.

Rationale

Having information about the type of cancer patients have provides much more targeted insights into service delivery, however, the non-admitted patient datasets do not contain this information. This question was designed by the CINSW and recommended for inclusion.

New question

Which of the following statements best describes how well you are able to carry out ordinary tasks and daily activities? Over the past month I would generally rate my activity as... Please x one box only.

- normal with no limitations
- not my normal self, but able to be up and about with fairly normal activities
- not feeling up to most things, but in bed or chair less than half the day
- able to do little activity and spend most of the day in bed or chair
- pretty much bedridden, rarely out of bed

Action

New question.

Rationale

This question was included at the request of the CINSW as an additional outcome measure.

Question 62

Current question

What treatment have you received for your cancer? Please x all that apply to you

- Radiotherapy
- Chemotherapy
- Surgery
- Other treatment (e.g. hormone therapy)

Action

Added 'In the past three months' to the start of the question.

Added new response option 'I have not received treatment in the past three months'.

Additional information added to chemotherapy response – '(including hormone therapy, immunotherapy and targeted drug therapy)'.

Changed 'Other treatment (e.g. hormone therapy)' to 'Other treatment (e.g. bone marrow transplant)'.

Rationale

This question was rebuilt to provide information about what treatment was received in the three months since their outpatient appointment. It was conceived that the amended question would provide a better estimate of active treatment than the current question did.

Question 63

Current question

In the past three months, have you gone to an emergency department because of your cancer or cancer complications?

- Yes
- No
- Don't know/can't remember

Action

Moved from 'Treatment Needs and Outcomes' to 'Complications' section.

Wording change to 'complications related to the care you received'.

Rationale

This question was seen to be a better match for the complications questions.

Redesign of the 'Assessing your health' section

Current name of section

Assessing your health

Action

'Assessing your health' section changed to 'About your cancer symptoms'.

Rationale

The title of this section was changed to identify that it is cancer symptom severity that is of interest rather than overall health.

Question 70

Current question

Did you need, or would you have liked, to use a professional interpreter at any stage while you were at the clinic?

- Yes
- No

Action

Removed 'professional' from the question.

Rationale

The use of professional when referring to the interpreter suggested to some that this was an external interpreter brought by the patient. This was removed and the following question modified so it is clear that this is interpreters provided by the hospital.

Question 71

Current question

Was a professional interpreter provided when you needed one?

- Yes, always
- Yes, sometimes
- No

Action

Changed question to ask about hospital-provided interpreters, removed 'professional'.

Added response option 'I did not need the hospital to provide a professional interpreter'.

Rationale

This question was modified to ensure people understood it was the hospital providing the interpreter and to bring these questions in line with other BHI surveys.

New question

Which of the following best describes your smoking status?

- I smoke daily
- I smoke occasionally
- I've tried it a few times but never smoked regularly
- I don't smoke now, but I used to
- I've never smoked
- Don't know

Action

New question.

Rationale

This question was included at the request of the CINSW and designed by the Ministry of Health.

New question

Has a health professional at this clinic advised you to quit smoking?

- Yes
- No
- Don't know/can't remember
- Not applicable, as I have not smoked in this time

Action

New question.

Rationale

This question was included at the request of the CINSW and designed by the Ministry of Health.