

Outpatient Cancer Clinics Survey 2017

Development Report

December 2018

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Please note that there is the potential for minor revisions of data in this report. Please check the online version at bhi.nsw.gov.au for any amendments.

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Background

In 2017, the Bureau of Health Information (BHI) collaborated with the Cancer Institute NSW (CINSW) to review the questionnaire used in the *Outpatient Cancer Clinics Survey 2016* for implementation with November 2017 patients.

BHI undertakes reviews of all recurrent surveys before the surveys are repeated. The purpose of the review is to ensure the questionnaire is still appropriate for the NSW context and that all questions remain optimal. This document summarises the changes to the Outpatient Cancer Clinics Survey questionnaire made in 2017 to the 2016 version. Please refer to the 2015 and 2016 Outpatient Cancer Clinics Survey development reports, available at bhi.nsw.gov.au, for information about how those questionnaires were developed, including details on stakeholder consultation and engagement, questionnaire development, sampling methodology, and additional development notes.

Method

The review of the questionnaire focused on a methodological analysis of the 2016 data, as well as a review of the use of the survey data for reporting cancer clinics' performance. The changes and rationales are presented in this document.

The following stages were undertaken in the analysis of the Outpatient Cancer Clinics Survey 2016 data to test the quality of question and questionnaire design:

- 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 facilities) using the scored mean, standard deviation and skew of responses
- Correlations between questions (using the most positive response option) to understand if any questions appear to be duplicating the same aspect of care (using the Pearson method).

Following the analysis of the questionnaire content and data, BHI and CINSW met to discuss and agree on proposed changes. The final versions of the questionnaires were reviewed and signed off by the chief executives of BHI and CINSW.

Overview of changes to the Outpatient Cancer Clinics Survey

NEW Questions

- **Question 3.** Did you need parking for your clinic visit?
- **Question 48.** At the time of your clinic visit, how often were you smoking cigarettes?
- **Question 49.** Has a staff member at this clinic done any of the following in the past year? Please x all boxes that apply to you
- **Question 73.** Did you see an Aboriginal Health Worker during your November visit to the clinic?
- **Question 75.** Does this condition(s) cause you difficulties with your day-to-day activities?
- **Question 76.** Are you a participant of the National Disability Insurance Scheme (NDIS)?

DELETED Questions

- **Previous Question 3.** What was your main form of transport to the clinic? Please x one box only
- **Previous Question 27.** Was your care plan developed by health professionals from this clinic?
- **Previous Question 51.** How long have you been attending this cancer clinic?
- **Previous Question 52.** In the last 12 months, how many times have you visited this cancer clinic?
- **Previous Question 75.** Which of the following best describes your smoking status?
- **Previous Question 76.** Has a health professional at this clinic advised you to quit smoking?

MODIFIED Questions and questionnaire content

- **Survey title (see page 8)**
- **Cover letter (see page 8-9)**
- **Some sections within the questionnaire were reworded and restructured to assist to improve the navigation through the questionnaire.** Four questions (Q26, Q51, Q52, Q53) were moved to other sections of the questionnaire in this process
- **The wording of seven questions was amended for grammatical/formatting reasons (Q2, Q54, Q55, Q56, Q64, Q65, Q74)**
- **Three questions were slightly reworded in light of changes to the survey cover letter specifying the date of the outpatient visit (Q29, Q79, Q80)**
- **Two questions were amended to align with other BHI questionnaires (Q42, Q68)**
- **The question wording and/or response options were substantially amended for the following questions:**
 - **Question 1.** (previous Q1) What was the purpose of this visit? Please x all boxes that apply to you
 - **Question 11.** (previous Q11) Who did you see during this visit? Please x all boxes that apply to you
 - **Question 27.** (previous Q26) Do you have a written care plan for your current or ongoing care?
 - **Question 44.** (previous Q44) During your visit or soon afterwards, did you experience any of the following complications or problems? Please x all boxes that apply to you
 - **Question 59.** (previous Q60) What type of cancer were you receiving care for at this clinic? Please x one box only
 - **Question 62.** (previous Q63) How long has it been since you first received treatment for this cancer?

Details of changes

New questions

Question 3.

Did you need parking for your clinic visit?

- Yes
- NoGo to Q5

Rationale

This question was added to provide a better filter to Question 4 ('Issues with parking'). It replaces and simplifies the 2016 question about the main form of transport to the clinic, which had six response options. In addition, it addresses issues where many of those who should have answered the subsequent parking questions could not find a response option that suited their situation. For more detail on the removal of the former question, please refer to the rationale provided for the deletion of the previous Question 3 on page 6.

Question 48.

At the time of your clinic visit, how often were you smoking cigarettes?

- I've never smoked
- Not at all, I've quit smoking
- Some days
- Every day
- Don't want to say

AND Question 49.

Has a staff member at this clinic done any of the following in the past year?

Please x all the boxes that apply to you

- Asked if you smoke
- Advised you to quit smoking
- Offered to refer you to the Quitline or a smoking support service/professional
- Offered you nicotine replacement therapy (e.g. patches, gum)
- Provided other help to quit smoking
- Don't know/can't remember

Rationale

The two questions focused on smoking habits and quitting support offered at the time of the clinic visit were added to replace the two 2016 questions. These questions form a new section entitled 'Smoking Behaviour' and were designed to elicit exactly the type of support offered to allow for targeted improvement.

Question 73.

Did you see an Aboriginal Health Worker during your November visit to the clinic?

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

Rationale

BHI was requested by a stakeholder to add 'Aboriginal Health Worker' as another response option to Question 11 'Who did you see during this visit?'. However, given this question only applies to Aboriginal respondents, this new question was designed to be included immediately following the question about Aboriginal status. This question has also been added to most other BHI questionnaires.

Question 75.

Does this condition(s) cause you difficulties with your day-to-day activities?

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

Rationale

This question was added to align with other BHI surveys. It provides more context to Question 74 ('longstanding health conditions') as it assesses the burden of longstanding health conditions.

Question 76.

Are you a participant of the National Disability Insurance Scheme (NDIS)?

- Yes
- No
- Don't know

Rationale

This question was added to align with other BHI surveys. It provides an additional proxy measure for analyses by a 'disability' cohort, in combination with questions 74 and 75.

Deleted questions

Previous Question 3.

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

Rationale

In 2016, 83% of respondents reported that they arrived 'by private car'. In the 2016 survey, the subsequent question (Q4 'Issues with parking') had a high rate (19%) of missing responses. This identified issues with the previous Question 3 in that having a private car as your 'main form of transport' to the clinics does not mean that the respondent needed to park, they could have been dropped off. To reduce the missing response rate, a new Question 3 was designed to simply ask if parking at the clinic was required and the former question on mode of transport was deleted.

Previous Question 27.

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

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

Rationale

This question was not used in the reporting of the Outpatient Cancer Clinics Survey 2016. It does not provide information about the experiences of care received and does not imply that the care plan was developed in partnership with clinic staff. For these reasons, it was removed from the 2017 questionnaire.

Previous Question 51.

How long have you been attending this cancer clinic?

- Less than 6 months
- 6 to 12 months
- More than 1 year but less than 2 years
- 2 years or more

Rationale

This question was not used in the reporting of the Outpatient Cancer Clinics Survey 2016 results. It does not provide information about the experience of care received and has poor attribution to a hospital. It is not uncommon for patients attending cancer clinics to visit different clinics/hospitals depending on their treatment modality. Because of these reasons, it was removed from the 2017 questionnaire.

Previous Question 52.

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

Rationale

This question was not used in the reporting of the Outpatient Cancer Clinics Survey 2016 results. It does not provide information about the experience of care received and has poor attribution to a hospital. It is not uncommon for patients attending cancer clinics to visit different clinics/hospitals depending on their treatment modality. For these reasons, it was removed from the 2017 questionnaire.

Previous Question 75.

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.....Go to Q77

- Don't know.....Go to Q77

AND Previous Question 76.

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

Rationale

These two questions were replaced with two new smoking questions (Q48/49) which form a new questionnaire section entitled 'Smoking Behaviour'. The new questions focus on the smoking status and specific support offered at the time of the clinic visit.

Modified questions and questionnaire content changes

Survey title

NSW Patient Survey: Outpatient Clinics

Action

Deleted 'cancer' from the title of the survey

Rationale

Patients attend outpatient cancer clinics for a range of diagnostic, therapeutic and consultation services, including some patients treated for conditions other than cancer, such as rheumatoid arthritis and lupus. In 2016, 11% of respondents were non-cancer patients. To alleviate any potential stress or anxiety associated with receiving a 'cancer' questionnaire, the word 'cancer' was removed from the title of the survey and any question wording. The questionnaire was still sent to patients who attended a clinic designated by NSW Health organisations as an 'outpatient cancer clinic'.

Cover letter and information page

Action

Two main changes to the cover letter were made:

- Included text to acknowledge the delay in respondents receiving the survey
- Added text to highlight that while the survey is predominantly looking at feedback from patients with cancer, input from non-cancer patients is very much valued.

The instruction page was amended to align with other BHI surveys.

Rationale

Due to a complex and unique sampling process that is in place for the Outpatient Cancer Clinics Survey, patients received the questionnaire four to five months after their actual clinic visit in November. The cover letter was amended to acknowledge this upfront and to remind respondents to think about their November clinic visit as much as possible.

The survey is trying to capture feedback about the performance of outpatient cancer clinics regardless of the 'types' of patients they are treating (cancer or non-cancer patients). To

encourage patients who have visited the clinics for non-cancer related illnesses to complete the questionnaire, the covering letter was amended to specifically highlight that their feedback is important, too.

Sections of the questionnaire

In particular, changes to the following sections were made:

ARRIVAL AT THE CLINIC

When completing the survey, please think about your visit to the clinic at the hospital named on the covering letter, in November 2017

Action

Deleted 'this part of', 'latest', 'cancer', 'cover of this booklet' and underline from 'visit'
Added 'covering letter' and 'in November 2017'

SMOKING BEHAVIOUR

Action

Added new section heading with two new questions related to smoking

ABOUT YOUR CANCER

Action

Replaced with **ABOUT YOUR HEALTH**

ABOUT YOUR HEALTH

Action

The following text was added to the questionnaire section heading:

'This section asks questions for people who have or have had cancer. If you receive care for a condition other than cancer, please answer Q57 and then go to Q66.'

COORDINATION OF CARE

Action

Deleted section heading. Questions were either deleted or moved to other sections of the questionnaire.

THE PHYSICAL ENVIRONMENT

Action

Deleted instruction text 'Thinking about your latest visit to this cancer clinic'.

- \$1,000 or more
- Don't know/can't remember

YOUR CARE AND TREATMENT

Thinking again about your November visit to this clinic...

Action

Deleted 'latest' and 'cancer'. Added 'November' and underline to 'visit'.

YOUR FINAL COMMENTS

Action

Added FINAL to section heading to align with other BHI questionnaires.

Rationale

Some sections of the questionnaire were re-arranged/re-worded to assist with the flow of the questions. The survey is sent to people who may or may not have cancer, it is important for all patients to feel that the survey is relevant to them. Deletion of the word 'cancer' to alleviate any stress or anxiety associated with receiving the questionnaire for patients without cancer. To assist respondents with re-calling their clinic visit, the month 'November' was added.

Question wording changes for grammatical/formatting reasons

Question 2. (previous Q2) 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 or more
- Don't know/can't remember

Action

Underlining of 'for this appointment' removed.

Question 54. (previous Q48)

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

Question 55. (previous Q49)

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

Question 56. (previous Q50)

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

'Out of pocket' was changed to 'out-of-pocket'.

Question 64. (previous Q65)

Please rate the following cancer symptoms for how severe each is for you right now (at the time of completing this survey).

Question 65. (previous Q66)

Please select the answer that best describes how strongly you agree or disagree with each statement below.

Action

Deleted alphabetical 'numbering' from both questions

Added 'Please' to Question 65.

Question 74. (previous Q74)

Which, if any, of the following longstanding conditions do you have (including age related conditions)?

- Deafness or severe hearing impairment
- Blindness or severe vision impairment
- A longstanding illness (e.g. cancer, HIV, diabetes, chronic heart disease)
- A longstanding physical condition (e.g. arthritis, spinal injury or multiple sclerosis)
- An intellectual disability
- A mental health condition (e.g. depression)
- A neurological condition (e.g. Alzheimer's, Parkinson's)
- None of these.....Go to Q77

Action

Deleted hyphen in 'longstanding'.

Changed 'A learning disability' to 'An intellectual disability'.

Added (*e.g. arthritis, spinal injury or multiple sclerosis*) to 'A longstanding physical condition'.

Added *Go to Q77* for 'None of these' response option and arrows from all other response options to Question 75.

Rationale

These changes were made to align with other BHI surveys and to conform with formatting and grammatical principles.

Questions were moved to other sections of the questionnaire

Question 26. (previous Q54)

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

- Yes
- No

Action

Deleted from the COORDINATION OF CARE section and moved to the PLANNING YOUR CARE section.

Rationale

The questionnaire section 'COORDINATION OF CARE' was deleted and subsequently the questions that were grouped under this section were moved to other sections.

Question 51. (previous Q57)

If asked about your clinic experience by friends and family, how would you respond?

- I would speak highly of the clinic
- I would neither speak highly nor be critical
- I would be critical of the clinic

Question 52. (previous Q56)

How well organised was the care you received in the clinic?

- Very well organised
- Fairly well organised
- Not well organised

Question 53. (previous Q53)

Was there any time when the health professionals needed access to your health records and they were not available?

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

Rationale

The question order of the OVERALL CARE section was modified and incorporated Question 53 from the COORDINATION OF CARE section to assist with better question flow.

Questions were slightly reworded in light of changes made to survey title/covering letter

Question 29.

At your November 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

Deleted 'latest' and replaced with 'November'.

Rationale

The questionnaire asks the respondents to think about their visit to a clinic in November. However, respondents receive the questionnaire a few months after their actual November visit and therefore the reference to 'latest' visit was confusing (as the respondents could have had a later visit to the clinic than November). 'November' was added to specify that this is the visit respondents are asked to recall.

Question 79.

What part of the care provided by this clinic most needs improving?

Action

Deleted 'cancer' as not all respondents to the survey have cancer.

Question 80. What part of your care provided by this clinic most needs improving?

Action

Deleted 'cancer' as not all respondents to the survey have cancer. Replace 'the' with 'your'.

Rationale

To ensure consistency throughout the survey by deleting the reference to 'cancer' to reduce anxiety for participants.

Questions were amended to align with other BHI questionnaires

Question 42.

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

- Age
- Sex
- Aboriginal background
- Ethnic background
- Religion
- Sexual orientation
- Disability
- Marital status
- Something else
- I was not treated unfairly

Action

Added response option 'Aboriginal background'. Deleted 'Your' from Age, Sex, Ethnic background, Religion, Sexual orientation. Modified 'A disability you have' to 'Disability'.

AND

Question 68. (previous Q69)

What is the highest level of education you have completed?

- Less than Year 12 or equivalent
- Completed Year 12 or equivalent
- Trade or technical certificate or diploma
- University degree
- Post graduate/higher degree

Action

Deleted response option

- Still at secondary school

Rationale

The changes were made to align with other BHI surveys.

Modified questions and response options

Question 1. (previous Q1)

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

- Have tests, X-rays or scans
- Receive test, X-ray or scan results
- Medical diagnosis or advice
- Chemotherapy
- Radiotherapy
- Immunotherapy or hormone therapy
- Transfusion
- Surgical procedure
- Follow-up after surgery
- Treatment review
- Regular check-up/long-term follow-up
- Other reason

Action

Added a new response option

- Transfusion

Rationale

A proportion of respondents are haematology patients (some of which are not cancer patients) and there was no specific answer option for this cohort. The answer option 'Transfusion' was added to assist haematology patients identifying the purpose of their visit. The addition of this new response option also aimed at reducing the percentage to the response option 'other reason' (5.8% in 2016).

Question 11. (previous Q11)

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

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

Action

Deleted response option

- Psychologist

Rationale

The response option 'Psychologist' was added and piloted in 2016 to investigate if the percentage to the 'other healthcare professional' response option could be reduced. However, only 1% reported seeing a psychologist and the 'other' percentage remained high (6.1% in 2016). The response option was therefore deleted from the questionnaire in 2017.

Question 27. (previous Q26)

Do you have a written care plan for your current or ongoing care?

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

Action

Deleted 'treatment' and added 'current or ongoing care' to the question.

Rationale

The previous wording of the question restricted the care plan to the 'treatment' phase. However, a proportion of respondents are in the 'follow-up phase' and might not receive treatment but a care plan might still be applicable for their ongoing care. The new wording is specific to both current and ongoing care phases.

Question 44. (previous Q44)

During your visit or soon afterwards, did you experience any of the following complications or problems? 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
- Lymphoedema (chronic excessive swelling)
- Severe anxiety or worry
- Any other complication or problem
- None

Action

Deleted '(other than common side-effects from treatment)' from the question.

Added response option:

- Lymphoedema (chronic excessive swelling)

Rationale

This response option was added at the request of one of the survey's stakeholders. BHI agreed as it was hoped that addition of 'Lymphoedema' would reduce the percentage of respondents selecting the non-specific response option 'Any other complication or problem' (2.6% in 2016) and/or the 'missing' response rates (4.3% in 2016).

Question 59. (previous Q60)

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 etc.)
- Other (bone, mesothelioma, thyroid etc.)

Deleted 'e.g.', 'bladder', 'eye', 'heart' and 'kidney' from response option 'Other'. Added 'etc.' to response options 'Blood' and 'Other'.

Rationale

To specify that the response options 'blood' and 'other' list a few examples but the lists are not complete.

Question 62. (previous Q63) How long has it been since you first received treatment for this cancer?

- Less than 3 months
- 3 to 6 months
- More than 6 months but less than 1 year
- 1 to 5 years
- More than 5 years
- Don't know/can't remember
- I have not received any treatment

Additional response option

- I have not received any treatment

Rationale

The filter from the response option ('*I am not in active treatment but I am on "Watch and Wait"*') to question 61 was changed. These respondents also now answer Q62. It is possible that the 'Watch and Wait' respondents have not received any treatment which is why this was added as a response option to Q62.