

Outpatient Cancer Clinics Survey 2018

Development Report

October 2019

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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

Background

In 2018, the Bureau of Health Information (BHI) collaborated with the Cancer Institute NSW (CINSW) to review the Outpatient Cancer Clinics Survey 2017 questionnaire, to inform any content changes required for the 2018 survey.

BHI reviews all recurrent surveys before they are repeated to ensure the questionnaire is still appropriate for the NSW context and all questions remain optimal. This document summarises the changes made to the 2017 version, in developing the 2018 questionnaire. Please refer to the 2015, 2016 and 2017 Outpatient Cancer Clinics Survey Development Reports available at bhi.nsw.gov.au for information about how those questionnaires were developed. These reports include details such as 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 2017 data, as well as an evaluation of the use of the survey data for reporting on the performance of outpatient cancer clinics. The resulting changes and rationales are presented in this document.

BHI's analysis of the Outpatient Cancer Clinics Survey 2017 data to test the quality of questions and questionnaire design included an examination of the following:

- 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) 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 were very positive or very negative, with little variation between facilities) using the scored means, 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 discussed and agreed upon proposed changes. The final version of the questionnaire was reviewed and signed off by the chief executives of BHI and CINSW.

Overview of changes

A short summary of amended questions and sections is below. Details of changes are explained in the following section.

New question

- Q48

Deleted question

- Q53 (in 2017 questionnaire)

Modified questionnaire content

- Modified questions and/or response options:
 - Q6, Q30, Q44, Q49, Q50, Q51, Q53, Q59, Q63, Q69, Q71, Q73, Q78
- Modified formatting to questions and/or response options:
 - Q58, Q66, Q74
- Modified referencing:
 - Q64, Q65
- Modified sections:
 - Your Comments
 - Arrival at the clinic
 - Payments for your care

Details of changes

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q6	Q6	How long after the scheduled <u>appointment time</u> did your appointment actually start? <ul style="list-style-type: none"> • On time, or early..... Go to Q8 • Less than 15 minutes • 15 to 29 minutes • 30 to 59 minutes • 60 minutes or more • I didn't have an appointment Go to Q8 • Don't know/can't remember..... Go to Q8 	Modified response option Collapsed the former response options 5 and 6 to '60 minutes or more'	In 2017, only 2% of respondents indicated they waited two hours or more. Therefore, two answer options were collapsed to form the new answer option of '60 minutes or more'.
Q30	Q30	Did you receive any treatment during this visit (chemotherapy, radiotherapy, surgery or other treatments)?	Modified question Moved the content in the brackets to inside the question mark Deleted 'e.g.' from the list of treatment examples	The wording was modified for increased clarity and readability.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q44	Q44	<p>During your visit or soon afterwards, did you experience any of the following complications or problems?</p> <ul style="list-style-type: none"> • Please X <u>all</u> the boxes that apply to you • An infection • Uncontrolled bleeding • An unexpected negative reaction to medication • A complication 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..... Go to Q47 	<p>Modified response option</p> <p>Reworded the original response option 'Complications as a result of tests or procedures' to refer to a single event, 'A complication as a result of tests or procedures'</p>	<p>The wording of this response option was modified to be consistent with the other response options, which all referred to single events.</p>
n/a	Q48	<p>Did a staff member at this clinic ask you if you smoked/used tobacco?</p> <ul style="list-style-type: none"> • Yes • No • Can't remember 	<p>New</p>	<p>As a pilot, two smoking behaviour questions were included in the 2017 questionnaire. The 2017 results showed that the questions were not working well. In particular, there seemed to be an issue with Q49 ('Has a staff member at this clinic done any of the following in the past year?'). A total of 28.7% of respondents did not answer this question and a further 19.3% ticked the answer option 'Don't know/can't remember', indicating that perhaps there was a response option missing and/or the question was not applicable to the whole cohort. To rectify this issue, this additional smoking behaviour question was included and the other two previous smoking behaviour questions were amended (refer to the section 'Modified questionnaire content').</p>

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q48	Q49	At the time of your clinic visit, how often were you smoking/using tobacco? <ul style="list-style-type: none"> • I've never smoked Go to Q51 • Not at all, I've quit smoking Go to Q51 • Some days • Every day • Don't want to say..... Go to Q51 	Modified question and response options Changed 'smoking cigarettes' to 'smoking/using tobacco' 'Go to' directions were introduced	The wording of the question was slightly changed to include 'using tobacco', as 'smoking cigarettes' by itself is too specific and not inclusive of other means of using tobacco. 'Go to' directions were introduced as the following Q50 is only applicable to the cohort of respondents who were smoking/using tobacco at the time of their clinic visit. The 'Go to' options were introduced as a total of 28.7% of respondents did not answer the follow-up question, and a further 19.3% ticked 'Don't know/can't remember'.
Q49	Q50	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 <ul style="list-style-type: none"> • 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 • <u>None</u> of the above 	Modified response option Deleted 'Asked if you smoke' Added 'None of the above'	As a pilot, two smoking behaviour questions were included in the 2017 questionnaire. The 2017 results showed that the questions were not working well. In particular, there seemed to be an issue with the previous Q49. A total of 28.7% did not answer this question and a further 19.3% ticked the answer option 'Don't know/can't remember', indicating that perhaps there was a response option missing and/or the question was not applicable to the whole cohort. To rectify this issue, an additional smoking behaviour question was included (see new question 48). As a consequence, the response option 'Asked if you smoke' was no longer needed and deleted. Further to this, the additional response option ' <u>None</u> of the above' was added.
Q50	Q51	Overall, how would you rate the care you received at the clinic?	Modified question Replaced 'in' with 'at'	The question wording was changed for grammatical reasons and to align with the BHI style guide.
Q52	Q53	How well organised was the care you received at the clinic?		

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q53	n/a	Was there any time when the health professionals needed access to your health records and they were not available?	Deleted	This question was removed to make space for the new smoking behaviour question. This question was selected as it was highly correlated with Q14 ('During this visit, did the health professionals know enough about your medical history?').
Q58	Q58	Is this the <u>first time</u> you have had cancer? <ul style="list-style-type: none"> • Yes, this is the first time I have had cancer • No, I have had the <u>same type of cancer</u> before but it has now come back • No, I have had a <u>different type of cancer</u> before 	Modified response options Changed formatting of 'same type of cancer' and 'different type of cancer before' from bold to underline	This change was made for formatting consistency across the questionnaire.
Q59	Q59	What was the main type of cancer you were receiving care for at this clinic? Please X <u>one</u> box only <ul style="list-style-type: none"> • 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 (e.g. lymphoma, leukaemia, marrow, lymph nodes) • Other (e.g. bone, mesothelioma, thyroid) • The type of cancer is not known yet 	Modified question and response options Added 'was the main' in front of 'type of cancer' and changed 'you were' order Removed 'etc.' and added 'e.g.' for the examples in 'Blood' and 'Other' Added response option 'The type of cancer is not known yet'	The wording was slightly changed to clarify that respondents should indicate their 'main' type of cancer as opposed to their secondary or metastatic cancer. The grammatical changes were introduced to align with the BHI style guide. The additional response option was added in an attempt to reduce the 6% of respondents who selected 'Other' as a response option in 2017.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q63	Q63	In the <u>past three months</u> , what treatment have you received for your cancer? Please X <u>all</u> the boxes that apply to you <ul style="list-style-type: none"> • Radiotherapy • Chemotherapy (including hormone therapy, immunotherapy, targeted drug therapy) • Surgery • Other treatment (e.g. bone marrow transplant) • I have <u>not</u> received treatment in the past three months 	Modified response option Deleted 'and' from the example list of chemotherapy treatments	This was changed for grammatical reasons and to align with the BHI style guide.
Q64	Q64	Source: Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. Journal of Palliative Care 1991; 7(2):6-9 (modified). Please note that this survey is anonymous. If you need help, or someone to talk to about concerns or worries about your condition, you may like to contact your general practitioner or the Cancer Council Information and Support Line on 13 11 20.	Modified reference and text regarding assistance Full reference added Amended the text box underneath the question regarding assistance – lower case 'general practitioner' and 'the' added before Cancer Council	The full reference was added to align with BHI's reference style and to facilitate easier access to the source paper. The text was amended to align with the BHI style guide.
Q65	Q65	Source: Wolf S, Chang CH, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). Patient Education and Counseling 2005; 57(3):333-41 (modified).	Modified reference Full reference added	The full reference was added to align with BHI's reference style and to facilitate easier access to the source paper.
Q66	Q66	What year were you born? Write in (YYYY)	Modified response option Changed all upper case of 'Write in' to lower case	The text was amended to align with the BHI style guide.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q69	Q69	Which language do you mainly speak at home? <ul style="list-style-type: none"> English Go to Q72 A language other than English What is that language? Please write below.	Modified response option Changed instructions from 'Please write in the language' to 'What is that language? Please write below'	This change was introduced to clarify the instruction.
Q71	Q71	Did the clinic provide an interpreter when you needed one? <ul style="list-style-type: none"> Yes, always Yes, sometimes No I did not need the clinic to provide a professional interpreter 	Modified question and response options Replaced 'hospital' with 'clinic' in both the question and fourth response option	Throughout the questionnaire, the term 'clinic' is used. Therefore this change was made for consistency.
Q73	Q73	Did you receive support, or the offer of support, from an Aboriginal Health Worker during your November visit to the clinic?	Modified question Added 'receive support, or the offer of support, from...' to the question	This question was first trialled in 2017. Feedback from stakeholders indicated that 'seeing' a person does not necessarily mean that they have spoken with the person or received any support. The wording was changed to clarify the intent of this question for respondents.

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q74	Q74	<p>Which, if any, of the following longstanding conditions do you have (including age-related conditions)?</p> <p>Please X <u>all</u> the boxes that apply to you</p> <ul style="list-style-type: none"> • 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, multiple sclerosis) • An intellectual disability • A mental health condition (e.g. depression) • A neurological condition (e.g. Alzheimer's, Parkinson's) • <u>None</u> of these..... Go to Q77 	<p>Modified question Added a dash in between 'age' and 'related'</p>	<p>This change was made to align with the BHI style guide.</p>

Question # 2017	Question # 2018	Updated question (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Q78	Q78	<p>The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to you which are maintained by various NSW and Commonwealth agencies (including your hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your healthcare information will allow us to better understand how different aspects of the care provided by health facilities are related to the health of, and use of health services by, their patients.</p> <p>Your information will be treated in the strictest confidence. We will receive the linked information after your name and address have been removed. We will not report any results which may identify you as an individual and your responses will not be accessible to the people who looked after you.</p> <p>Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you (the patient)?</p> <ul style="list-style-type: none"> • Yes • No 	<p>Modified question</p> <p>The question was revised to emphasise key information points</p> <p>Amended 'health care' to be one word in the first paragraph</p> <p>Removed 'for the two years before and after your visit' from between 'information' and 'will' in the first paragraph</p> <p>Added 'of' after 'health' and 'by' after 'health services' in the first paragraph</p>	<p>This question was simplified to make it clearer and consistent with the text now used across the BHI survey program.</p> <p>This wording change was made to align with the BHI style guide.</p>

Section 2017	Updated section (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Section heading	Your Comments	<p>Modified section heading</p> <p>Changed 'Your Final Comments' to 'Your Comments'</p>	Asking respondents to provide comments determined to be more appropriate than asking for 'final' comments.

Section 2017	Updated section (as it appears in 2018 questionnaire)	Change from 2017	Rationale
Section description	<p>Arrival at the clinic</p> <p>When completing the questionnaire, please think about your visit to the clinic at the hospital named in the covering letter, in November 2018.</p>	<p>Modified section description</p> <p>Changed 'survey' to 'questionnaire'</p> <p>Updated '2017' to '2018'</p>	<p>This wording was changed for consistency across the questionnaire.</p>
Section description	<p>Payments for your care</p> <p>This section is about out-of-pocket expenses you may 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.</p>	<p>Modified section description</p> <p>Changed 'might' to 'may'</p>	<p>This change was made for grammatical reasons.</p>