

Outpatient Cancer Clinics Survey 2020

Development Report

March 2021

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Please note that there is the potential for minor revisions of this report.

Please check the online version at **bhi.nsw.gov.au** for any amendments or errata.

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The conclusions in this report are those of BHI and no official endorsement by the NSW Minister for Health, the NSW Ministry of Health or any other NSW public health organisation is intended or should be inferred.

Background

As part of the NSW Patient Survey Program Strategy 2019–22, the Bureau of Health Information (BHI) is currently undertaking reform of the survey program. This work aims to improve the timeliness, representativeness and usefulness of survey data for NSW stakeholders.

In 2021, BHI, in collaboration with the Cancer Institute NSW, reviewed the Outpatient Cancer Clinics Survey 2019 to ensure the questionnaire is still appropriate for the NSW context and all questions remain optimal.

This document summarises the changes to the 2019 version applied to the 2020 questionnaire. Please refer to the 2015–2019 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.

Review of the 2019 questionnaire

The review of the Outpatient Cancer Clinics Survey 2019 focused on ensuring that the questionnaire content remained relevant regardless of the mode of service delivery (in-person and virtual care appointments). The previous Outpatient Cancer Clinics Survey questionnaires were completed by respondents who had an in-person visit to an outpatient cancer clinic. The 2019 questionnaire has undergone minor updates to make questions and response options applicable to virtual care appointments, taking into account the increase of virtual care appointments since the COVID-19 pandemic started.

BHI and the Cancer Institute NSW agreed to make only minimal changes to the questionnaire to enable reporting of trend data over time.

Overview of changes

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

Modified questionnaire content

- Modified questions and/or response options:
 - Q1–2, Q8, Q11, Q14, Q16, Q29–30, Q34, Q37, Q39, Q44, Q46, Q49, Q51, Q53–56, Q67, Q73, Q79.
- Modified section preambles:
 - ARRIVAL AT THE CLINIC
 - YOUR CARE AND TREATMENT
 - PAYMENTS FOR YOUR CARE.

Details of changes

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q1	Q1	<p>What was the purpose of this appointment?</p> <p>Please x <u>all</u> the boxes that apply to you</p> <ul style="list-style-type: none"> • 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 	<p>Modified question</p> <p>Replaced 'visit' with 'appointment' in the question wording</p>	<p>This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>
Q2	Q2	<p>How long did it take you to travel to the clinic for this appointment?</p> <ul style="list-style-type: none"> • Less than 30 minutes • 30 to 59 minutes • 1 hour to under 2 hours • 2 hours or more • Don't know/can't remember • Not applicable, as I had a phone/video appointment.....Go to Q6 	<p>Modified response option and instruction</p> <p>Added the response option 'Not applicable, as I had a phone/video appointment' and the 'Go to Q6' instruction</p>	<p>The response option was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q8	Q8	How comfortable was the waiting room area? <ul style="list-style-type: none"> • Very comfortable • Fairly comfortable • Not very comfortable • Not at all comfortable • Not applicable, as I had a phone/video appointment.....Go to Q11 	Modified response option and instruction Added the response option 'Not applicable, as I had a phone/video appointment' and the 'Go to Q11' instruction	The response option was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q11	Q11	Who did you see during this appointment? Please x <u>all</u> the boxes that apply to you <ul style="list-style-type: none"> • Doctor/specialist • Nurse (including for chemotherapy) • Radiation therapist (for radiotherapy) • Radiographer (X-ray, ultrasound, MRI) • Dietician • Social worker • Lymphoedema therapist • Other healthcare professional 	Modified question Replaced 'visit' with 'appointment' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q14	Q14	During this appointment, did the health professionals know enough about your medical history? <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No 	Modified question Replaced 'visit' with 'appointment' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q16	Q16	<p>Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching you?</p> <ul style="list-style-type: none"> • Yes, always • Yes, sometimes • No, I did not see this • Not applicable • Can't remember 	<p>Modified response option</p> <p>Removed 'to my visit' from the response option 'Not applicable to my visit'</p>	<p>The response option was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>
Q29	Q29	<p>At your November appointment, did the health professionals review your care plan with you?</p> <ul style="list-style-type: none"> • Yes • No • Not applicable, as I did not have a care plan before this appointment • Don't know/can't remember 	<p>Modified question and response option</p> <p>Replaced 'visit' with 'appointment' in the question wording and response option wording</p>	<p>The response option was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>
Q30	Q30	<p>Did you receive any treatment during this appointment (chemotherapy, radiotherapy, surgery or other treatments)?</p> <p>Yes</p> <p>No.....Go to Q34</p>	<p>Modified question</p> <p>Replaced 'visit' with 'appointment' in the question wording</p>	<p>This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>
Q34	Q34	<p>During this appointment, were you given, or prescribed, any <u>new</u> medication to take at home?</p> <ul style="list-style-type: none"> • Yes • No.....Go to Q37 	<p>Modified question</p> <p>Replaced 'visit' with 'appointment' in the question wording</p>	<p>This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q37	Q37	Were you told who to contact if you were worried about your condition or treatment after your appointment? <ul style="list-style-type: none"> • Yes • No • I did not need this type of information • Don't know/can't remember 	Modified question Replaced 'you left the clinic' with 'your appointment' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q39	Q39	Were you treated with respect and dignity during your appointment? <ul style="list-style-type: none"> • Yes, always • Yes, sometimes • No 	Modified question Replaced 'while you were at the clinic' with 'during your appointment' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q44	Q44	During your appointment or soon afterwards, did you experience any of the following complications or problems? Please x <u>all</u> the boxes that apply to you <ul style="list-style-type: none"> • 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 	Modified question Replaced 'visit' with 'appointment' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q46	Q46	In your opinion, were the health professionals open with you about this complication or problem? <ul style="list-style-type: none"> • Yes, completely • Yes, to some extent • No • Not applicable, as it happened after my appointment 	Modified response option Replaced 'I left' with 'my appointment' in the response option	The response option was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q49	Q49	At the time of your appointment, 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 Replaced 'clinic visit' with 'appointment' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q51	Q51	Overall, how would you rate the care you received from the clinic? <ul style="list-style-type: none"> • Very good • Good • Neither good nor poor • Poor • Very poor 	Modified question Replaced 'at' with 'from' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q53	Q53	How well organised was the care you received from the clinic? <ul style="list-style-type: none"> • Very well organised • Fairly well organised • Not well organised 	Modified question Replaced 'at' with 'from' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q54	Q54	How much were your out-of-pocket expenses for <u>medication</u> related to these appointments? <ul style="list-style-type: none"> • 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 	Modified question Replaced 'visits' with 'appointments' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q55	Q55	How much were your out-of-pocket expenses for <u>consultations</u> , <u>tests</u> , <u>surgery</u> or <u>treatment</u> related to these appointments (excluding medication)? <ul style="list-style-type: none"> • 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 	Modified question Replaced 'visits' with 'appointments' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q56	Q56	How much were your out-of-pocket expenses for <u>other costs</u> related to these appointments (e.g. travel, petrol, parking, accommodation)? <ul style="list-style-type: none"> • 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 	Modified question Replaced 'visits' with 'appointments' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).
Q67	Q67	How do you describe your gender? Please x <u>one</u> option <ul style="list-style-type: none"> • Man or male • Woman or female • Non-binary • Prefer to use a different term...Please specify below • Prefer not to answer 	Modified question and response option Reworded the question and response options from 'What is your gender?' 'Male/female' to 'How do you describe your gender?' 'Man or male/Woman or female/Non-binary/Prefer to use a different term - Please specify below/ Prefer not to answer'	The question and response options were changed to align with the data standard on how to collect data on 'gender' provided by the Australian Bureau of Statistics.
Q73	Q73	Did you receive support, or the offer of support, from an Aboriginal Health Worker during your November appointment? <ul style="list-style-type: none"> • Yes • No • Don't know/can't remember 	Modified question Replaced 'visit' with 'appointment' and deleted 'to the clinic' in the question wording	This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).

Question # 2019	Question # 2020	Updated question (as it appears in 2020 questionnaire)	Change from 2019	Rationale
Q79	Q79	What was the best part of the care you received from this clinic?	<p>Modified question</p> <p>Replaced 'while at' with 'from' in the question wording</p>	<p>This question was changed to enable respondents to answer the question regardless of the mode of service delivery (in-person and virtual care appointments).</p>

Section 2019	Section 2020	Updated section (As it appears in 2020 questionnaire)	Change from 2019	Rationale
Q1–7	Q1–7	<p>ARRIVAL AT THE CLINIC</p> <p>When completing the questionnaire, please think about your appointment with the hospital named in the covering letter in November 2020.</p>	<p>Modified section preamble</p> <p>Replaced 'visit to the clinic at' with 'appointment with' in the preamble</p>	<p>The section preamble was changed to relate to different modes of service delivery (in-person and virtual care appointments).</p>
Q30–38	Q30–38	<p>YOUR CARE AND TREATMENT</p> <p>Thinking again about your <u>November appointment</u> with this clinic...</p>	<p>Modified section preamble</p> <p>Replaced 'visit to' with 'appointment with' in the preamble</p>	<p>The section preamble was changed to relate to different modes of service delivery (in-person and virtual care appointments).</p>
Q54–56	Q54–56	<p>PAYMENTS FOR YOUR CARE</p> <p>This section is about out-of-pocket expenses you may have to pay for clinic appointments. Out-of-pocket expenses are those that you don't get back from Medicare or a private health fund.</p> <p>Please think about your appointments with this clinic over the <u>past six months</u>...</p>	<p>Modified section preamble</p> <p>Replaced 'visits' with 'appointments' and 'visits to' with 'appointments with' in the preamble</p>	<p>The section preamble was changed to relate to different modes of service delivery (in-person and virtual care appointments).</p>