

# Outpatient Cancer Clinics Survey 2021

Development Report

May 2022

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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

The Bureau of Health Information (BHI) is the statutory agency responsible for reporting on the performance of the NSW public health system. BHI manages the NSW Patient Survey Program on behalf of NSW Health. Every year this statewide program gives thousands of patients the opportunity to provide feedback about their experiences of care in the healthcare system and subsequent outcomes, using evidence-based, validated survey instruments.

As part of the *NSW Patient Survey Program Strategy 2019–2022*, BHI is reforming the survey program. As well as addressing the timeliness and usefulness of results to inform improvements, BHI is reviewing survey length and structure to minimise the burden on patients, maximise the value of results and improve response rates to the survey.

Since 2015, the Cancer Institute NSW (CINSW) has partnered with BHI to conduct the Outpatient Cancer Clinics Survey. The results, which reflect the experiences of patients who visit outpatient cancer clinics in NSW, are reported annually in the Reporting for Better Cancer Outcomes program. BHI also reports the results publicly in annual Snapshot reports and on the BHI Data Portal.

This document summarises the changes to the Outpatient Cancer Clinics Survey 2020 questionnaire for the 2021 questionnaire. Please refer to the 2015–2020 Outpatient Cancer Clinics Survey development reports available at [bhi.nsw.gov.au](http://bhi.nsw.gov.au) for information about how previous questionnaires were developed. These reports include information about stakeholder consultation and engagement, questionnaire development and sampling methodology, and more development notes.

## Review of the Outpatient Cancer Clinics Survey

BHI undertook a review of the Outpatient Cancer Clinics Survey 2020 questionnaire to inform the development of the 2021 questionnaire. The aim of reviewing the Outpatient Cancer Clinics Survey 2020 questionnaire was to identify questions that mattered most to patients. A module consisting of seven questions about patients' experiences with virtual care outpatient appointments was added, in response to the increased and ongoing use of virtual care. This module is detailed further in the section below. The Edmonton Symptom Assessment System (ESAS) and the Communication and Attitudinal Self Efficacy scale for cancer (CASE-Cancer) were removed following stakeholder consultation and feedback regarding the length of the survey.

### Addition of a new module

In response to the COVID-19 pandemic, models of outpatient hospital and primary healthcare across NSW have increasingly involved a mix of in-person and virtual care.

A module consisting of seven questions about virtual care appointments with a hospital or outpatient clinic was added to the Outpatient Cancer Clinics Survey 2021. The module asks any patients who had appointments over the telephone or by video call, rather than in person, to complete it.

Through this module, the 2021 survey will provide insights in relation to patients' virtual encounters with a hospital or outpatient clinic, including all their experiences of virtual care over the past 12 months. This new reporting area will complement insights from the core section of the survey, as well as other BHI surveys, regarding experiences with virtual care appointments with NSW public hospitals.

The [Outpatient Cancer Clinics Survey 2021 questionnaire](#) is available on the BHI website.

## Overview of changes

A short summary of amended questions and sections is outlined below. Details of these changes are explained in the following section. Changes to question numbers used in instructional text (e.g. 'Go to Q10') are not included.

### **New questionnaire content (in 2021 questionnaire)**

- New section:
  - VIRTUAL CARE (Q63–69).

### **Modified questionnaire content (in 2021 questionnaire)**

- Modified questions and/or response options:
  - Q2, Q8, Q9, Q16, Q24, Q27, Q29, Q37, Q41, Q43, Q47, Q50, Q83, Q84.
- Modified section and/or section title:
  - APPOINTMENT AT THE CLINIC
  - COMMENTS.

### **Deleted questionnaire content (from 2020 questionnaire)**

- Deleted questions (from 2020 questionnaire):
  - Q63–65.

## Details of changes

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q1–7	Q1–7	<b>APPOINTMENT AT THE CLINIC</b> When completing the questionnaire, please think about your appointment with the hospital named in the covering letter in November 2021.	<b>Modified section title</b> Changed 'Arrival at the clinic' to 'Appointment at the clinic'	The section title was changed to accommodate different modes of service delivery (in-person and virtual care appointments).
Q2	Q2	How long did it take you to travel to the clinic for this appointment? <ul style="list-style-type: none"> <li>• Less than 30 minutes</li> <li>• 30 to 59 minutes</li> <li>• 1 hour to under 2 hours</li> <li>• 2 hours or more</li> <li>• Don't know/can't remember</li> <li>• Not applicable...Go to Q6</li> </ul>	<b>Modified response option</b> Changed 'Not applicable, as I had a phone/video appointment' to 'Not applicable'	The response option was modified for consistency with other BHI patient questionnaires.
Q8	Q8	How comfortable was the waiting room area? <ul style="list-style-type: none"> <li>• Very comfortable</li> <li>• Fairly comfortable</li> <li>• Not very comfortable</li> <li>• Not at all comfortable</li> <li>• Not applicable</li> </ul>	<b>Modified response option</b> Changed 'Not applicable, as I had a phone/video appointment' to 'Not applicable'	The response option was modified for consistency with other BHI patient questionnaires.
Q9	Q9	How comfortable was the treatment area? <ul style="list-style-type: none"> <li>• Very comfortable</li> <li>• Fairly comfortable</li> <li>• Not very comfortable</li> <li>• Not at all comfortable</li> <li>• Not applicable...Go to Q11</li> </ul>	<b>Modified response option</b> Changed 'I did not go to a treatment area at the clinic' to 'Not applicable'	The response option was modified for consistency with other BHI patient questionnaires.

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	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"> <li>• Yes, always</li> <li>• Yes, sometimes</li> <li>• No, I didn't see this</li> <li>• Not applicable</li> <li>• Can't remember</li> </ul>	<p><b>Modified response option</b></p> <p>Changed 'did not' to 'didn't' in third response option</p>	<p>The response option was modified to align with the BHI style guide.</p>
Q24	Q24	<p>Were you involved, as much as you wanted to be, in decisions about your care and treatment?</p> <ul style="list-style-type: none"> <li>• Yes, definitely</li> <li>• Yes, to some extent</li> <li>• No</li> <li>• I didn't want or need to be involved</li> </ul>	<p><b>Modified response option</b></p> <p>Changed 'did not' to 'didn't' in fourth response option</p>	<p>The response option was modified to align with the BHI style guide.</p>
Q27	Q27	<p>Do you have a <u>written</u> care plan for your current or ongoing care?</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No...Go to Q30</li> <li>• I don't need one...Go to Q30</li> <li>• Don't know/can't remember...Go to Q30</li> </ul>	<p><b>Modified response option</b></p> <p>Changed 'do not' to 'don't' in third response option</p>	<p>The response option was modified to align with the BHI style guide.</p>

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q29	Q29	At your November appointment, did the health professionals review your care plan with you? <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Not applicable, as I didn't have a care plan before this appointment</li> <li>• Don't know/can't remember</li> </ul>	<b>Modified response option</b> Changed 'did not' to 'didn't' in third response option	The response option was modified for consistency with other BHI patient questionnaires.
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"> <li>• Yes</li> <li>• No</li> <li>• Don't know/can't remember</li> </ul>	<b>Deleted response option</b> Deleted 'I did not need this type of information' from the response options	The response option was deleted for consistency with other BHI patient questionnaires.
Q40	Q40	Were you given enough privacy when being <u>examined or treated</u> ? <ul style="list-style-type: none"> <li>• Yes, always</li> <li>• Yes, sometimes</li> <li>• No</li> </ul>	<b>Modified response options</b> Response options changed from: <ul style="list-style-type: none"> <li>• Yes, definitely</li> <li>• Yes, to some extent</li> <li>• No</li> </ul>	The response options were modified for consistency with other BHI patient questionnaires.
Q41	Q41	Were you given enough privacy when <u>discussing</u> your condition or treatment? <ul style="list-style-type: none"> <li>• Yes, always</li> <li>• Yes, sometimes</li> <li>• No</li> </ul>	<b>Modified response options</b> Response options changed from: <ul style="list-style-type: none"> <li>• Yes, definitely</li> <li>• Yes, to some extent</li> <li>• No</li> </ul>	The response options were modified for consistency with other BHI patient questionnaires.

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q43	Q43	<p>Were your cultural or religious beliefs respected by the clinic staff?</p> <ul style="list-style-type: none"> <li>• Yes, always</li> <li>• Yes, sometimes</li> <li>• No</li> <li>• Not applicable</li> </ul>	<p><b>Modified response options</b></p> <p>Changed 'My beliefs were not an issue' to 'Not applicable' and 'No, my beliefs were not respected' to 'No'</p>	<p>The response options were modified for consistency with other BHI patient questionnaires.</p>
Q47	Q47	<p>In the <u>past three months</u>, have you gone to an <u>emergency department</u> because of complications related to the care you received?</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Don't know/can't remember</li> </ul>	<p><b>Modified formatting</b></p> <p>Underlined 'past three months' in question</p>	<p>The question formatting was amended to emphasise the time frame being asked about.</p>
Q50	Q50	<p>Has a staff member at this clinic done any of the following in the <u>past year</u>?</p> <p>Please (tick) <u>all</u> the boxes that apply to you</p> <ul style="list-style-type: none"> <li>• Advised you to quit smoking</li> <li>• Offered to refer you to the Quitline or a smoking support service/professional</li> <li>• Offered you nicotine replacement therapy (e.g. patches, gum)</li> <li>• Provided other help to quit smoking</li> <li>• Don't know/can't remember</li> <li>• <u>None</u> of the above</li> </ul>	<p><b>Modified formatting</b></p> <p>Underlined 'past year' in question</p>	<p>The question formatting was amended to emphasise the time frame being asked about.</p>



Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q63–69	N/A	<b>VIRTUAL CARE</b> Virtual care appointments are held over the telephone or by video call, rather than in person. For the following questions, please think about <u>all your experiences</u> of virtual care provided by a hospital or outpatient clinic <u>over the past 12 months</u> , not with your general practitioner/family doctor.	<b>New section</b>	The virtual care module was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.
Q63	N/A	In the <u>past 12 months</u> , did you have <u>any</u> virtual care appointments – over the telephone or by video call – with a hospital or outpatient clinic? <ul style="list-style-type: none"> <li>• Yes</li> <li>• No...Go to Q70</li> <li>• Don't know/can't remember...Go to Q70</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.
Q64	N/A	How many virtual care appointments have you had with a hospital or outpatient clinic over the <u>past 12 months</u> (not counting any appointments with your general practitioner/family doctor)? <ul style="list-style-type: none"> <li>• 1 to 2</li> <li>• 3 to 5</li> <li>• More than 5</li> <li>• Don't know/can't remember</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q65	N/A	Overall, how would you rate the virtual care you received? <ul style="list-style-type: none"> <li>• Very good</li> <li>• Good</li> <li>• Neither good nor poor</li> <li>• Poor</li> <li>• Very poor</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.
Q66	N/A	Did the care and treatment received through virtual care help you? <ul style="list-style-type: none"> <li>• Yes, definitely</li> <li>• Yes, to some extent</li> <li>• No</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.
Q67	N/A	Compared with in-person appointments, was your virtual care experience...? <ul style="list-style-type: none"> <li>• Better</li> <li>• About the same</li> <li>• Not as good</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.
Q68	N/A	If given the choice, would you use virtual care again? <ul style="list-style-type: none"> <li>• Yes, definitely</li> <li>• Yes, in some circumstances</li> <li>• No</li> <li>• Don't know</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q69	N/A	<p>Thinking about your experiences of virtual care, what have been the benefits for you?</p> <p>Please (tick) <u>all</u> the boxes that apply to you</p> <ul style="list-style-type: none"> <li>• I thought it was convenient</li> <li>• I saved time</li> <li>• I saved money</li> <li>• I felt that I received the right care at the right time</li> <li>• I felt that I received safe, high quality care</li> <li>• I felt at ease being in my own home/surroundings</li> <li>• I didn't have to take as much time off work as I would have with an in-person appointment</li> <li>• I didn't need to arrange care for children or dependants</li> <li>• I was able to have others join the appointment (my family, other members of my healthcare team)</li> <li>• I thought it benefitted me in other ways</li> <li>• I had <u>no</u> benefits</li> </ul>	<b>New question</b>	The question was added to gain insights into experiences of virtual care appointments with a hospital or outpatient clinic.
Q75	Q71	<p>Did the clinic provide an interpreter when you needed one?</p> <ul style="list-style-type: none"> <li>• Yes, always</li> <li>• Yes, sometimes</li> <li>• No</li> </ul>	<b>Deleted response option</b> Deleted 'I did not need the clinic to provide a professional interpreter' from the response options	The response option essentially has the same meaning as 'No' in the previous question (Q74) and is therefore not needed.

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q82	Q78	<p><b>BHI would like your permission to link your questionnaire responses to other information from health records relating to you which are maintained by NSW Government and Commonwealth agencies</b> (including your hospitalisations or health registry information). Linking to your health information will allow us to better understand how the care provided by health services is related to the health of their patients.</p> <p><b>Your information will be treated in the strictest confidence.</b> BHI will not report any results that may identify you as an individual. Your questionnaire responses will not be accessible to the hospital staff who cared for 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"> <li>• Yes</li> <li>• No</li> </ul>	<b>Modified preamble</b>	The preamble to the linkage question was modified to clarify the intent of linkage.
Q83–84	Q79–80	<b>COMMENTS</b>	<b>Modified section title</b> Changed 'YOUR COMMENTS' to 'COMMENTS'	The section title was modified for consistency with other BHI patient questionnaires.
Q83	Q79	<p>What was the <u>best part</u> of the care you received from this clinic?</p> <p>Please don't include your name, address or any personal information about yourself or the health professionals who treated you</p>	<p><b>Modified question</b></p> <p>Added 'Please don't include your name, address or any personal information about yourself or the health professionals who treated you'</p> <p>Underlined 'best part' in question</p>	<p>The instruction was added to reduce the amount of personal information respondents include in their free-text comments.</p> <p>The question formatting was amended to emphasise the purpose of the question.</p>

Question # 2021	Question # 2020	Updated question/section (as it appears in 2021 questionnaire)	Change from 2020	Rationale
Q84	Q80	What part of your care provided by this clinic <u>most needs improving</u> ? Please don't include your name, address or any personal information about yourself or the health professionals who treated you	<b>Modified question</b> Added 'Please don't include your name, address or any personal information about yourself or the health professionals who treated you' Underlined 'most needs improving' in question	The instruction was added to reduce the amount of personal information respondents include in their free-text comments. The question formatting was amended to emphasise the purpose of the question.

## Deleted questions (from 2020 questionnaire)

Question # 2020	Question wording	Rationale
Q63	In the <u>past three months</u> , what treatment have you received for your cancer? Please (tick) <u>all</u> the boxes that apply to you	The question was added to provide 'treatment' context to questions 64 and 65. As questions 64 and 65 are now deleted, this question is not required anymore.
Q64	Please rate the following cancer symptoms for how severe each is for you <u>right now</u> (at the time of completing this survey)? Please (tick) the box that corresponds to your rating on a scale of 0 (no problem) to 10 (worst possible problem).	This question was deleted following stakeholder consultation and feedback regarding the length of the survey.
Q65	Please select the answer that best describes how strongly you agree or disagree with each statement below. Please answer for how you feel <u>right now</u> (at the time of completing this survey). If a statement doesn't apply to you, just skip it and move to the next one.	This question was deleted following stakeholder consultation and feedback regarding the length of the survey.