Outpatient Cancer Clinics Survey 2024

With cancer care module

Development Report

June 2024



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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 healthcare experiences and outcomes, using evidence-based, validated survey instruments.

The Outpatient Cancer Clinics Survey is an important component of the NSW Patient Survey Program, which provides essential system-wide intelligence about patients' healthcare experiences at outpatient cancer clinics. Since 2015, BHI has partnered with the Cancer Institute NSW to conduct this survey.

As part of the *BHI Strategic Plan 2023*–26, BHI regularly reviews and adapts the NSW Patient Survey Program survey materials to ensure the information remains relevant and useful. This involves galvanising our focus on helping health system managers make effective use of the survey results, and delivering high value insights that align with health system priorities and reflect the complexity of patients' healthcare journeys.

BHI developed a list of core questions, the Minimum Question Set, for surveys seeking patients' reflections on their experiences of care. The Minimum Question Set enables greater flexibility in the NSW Patient Survey Program by providing a consistent set of questions around which targeted measures and modules can be included as required to respond to health system needs. It is applicable across different patient cohorts and care settings, and has been incorporated in all BHI Patient Survey Program questionnaires. The Minimum Question Set also supports ongoing work across NSW Health to minimise the survey burden on patients, maximise the value of results and improve response rates.

BHI publishes survey results on the BHI website to help ensure patients' voices drive improvements in experiences and outcomes of care.

Review of the Outpatient Cancer Clinics Survey

In 2023 and early 2024, BHI completed a major review of the Outpatient Cancer Clinics Survey.

The purpose of this review was to develop a questionnaire based on the Minimum Question Set which was shorter and more focused, while preserving essential evidence-based content informed by what matters to patients, stakeholders across local health districts (LHDs) and users of patient survey data.

The outcome is a two-part questionnaire which continues to support the monitoring of the usefulness and relevance of key questions about care provided at facilities while collecting important system-level information. The first part of the questionnaire comprises questions asking about patients' experiences of care at their most recent appointment at the specific outpatient cancer clinic or hospital listed on their covering letter (the core content), and the second part collects patients' overall experiences of cancer care across all their interactions with the broader health system (the cancer care module).

Addition of a cancer care module

As part of the major review of the Outpatient Cancer Clinics Survey questionnaire, BHI developed a 20question module for patients who have, or have had, cancer. The cancer care module comprises questions asking patients about their overall experiences of cancer care, including care they received from a clinic or hospital, GP, and other services.

This module complements insights from the core questionnaire content and provides a unique insight into patients' overall experiences beyond the care received at a particular individual facility. It asks patients to reflect on their cancer diagnosis, their overall experiences of care with different services (e.g. GPs and

other hospitals), their use of cancer support services, how their diagnosis has impacted their financial situation, as well as the practical and emotional support they have received.

The questions from the cancer care module are outlined in the *Details of changes* table below.

The review aligns with priorities and principals of the *NSW Cancer Plan 2022*–27, focusing on optimal cancer treatment, care and support, and ensuring patients' feedback is routinely used to improve the delivery of care, service planning and quality improvement.

The BHI survey review included the following key steps in reviewing the questionnaire:

- literature scan
- · historical data review
- stakeholder engagement
- cognitive testing interviews.

Literature scan

BHI commissioned the Sax Institute to complete a literature scan exploring the healthcare experiences of patients who received inpatient or outpatient care for cancer treatment. The purpose of the review was to identify any issues or areas of unmet needs in inpatient and outpatient care settings, as well as provide recommendations for relevant new topics or questions for inclusion. The scope of this review considered Australian jurisdictions as well as other countries including the United Kingdom, Canada and Europe. The review also looked at grey literature including NSW Government policies which impact the provision of cancer care.

In total, 12 patient experience instruments were reviewed. The studies associated with these instruments were analysed. Questions in these instruments were mapped against the *NSW Cancer Plan 2022*–27 to identify key themes and system priorities. Each of the survey instruments was compared side-by-side with the previous iteration of the Outpatient Cancer Clinics Survey questionnaire to identify any overlap and areas that were missing.

The Sax Institute reviewed the following surveys (listed below in alphabetical order) as part of this process:

- Cancer Care Ontario, Ontario Health (Canada), Your Voice Matters (in-person and online survey), 2021
- Cancer Care Ontario, Ontario Health (Canada), Your Voice Matters (online), 2021
- Fernstrom et al (USA), Patient experience tool in patients with serious illness (survey items extracted from papers), 2019
- Jean-Pierre et al (USA), Patient Satisfaction with Cancer Care (survey items extracted from papers),
 2014
- Peipert et al (USA), Functional Assessment of Chronic Illness Therapy Treatment Satisfaction, 2018
- NHS England (UK), National Cancer Patient Experience Survey, 2019
- Shirk et al (USA), Consumer Assessment of Healthcare Providers and Systems (survey items extracted from papers), 2016
- The European Organisation for Research and Treatment of Cancer Quality of Life Group (Europe), Inpatient Satisfaction with Care Questionnaire (EORTC IN-PATSAT32), 2018
- The European Organisation for Research and Treatment of Cancer Quality of Life Group (Europe), QLQ INFO-25, 2018

- Tucker et al (USA), CSQ-8 (survey items extracted from papers), 2022
- Victorian Government (Australia), Victorian Cancer Patient Experiences of Care Survey, 2016
- Watson et al (Canada), Ambulatory Oncology Patient Satisfaction Survey, 2020.

The inclusion of pre-treatment, e.g. support from a GP diagnosis, and patients' involvement and decision-making about their treatment options was a key recommendation from the review. It was also recommended to include: inpatient experiences with a multidisciplinary care team; waiting time for appointments; participation in research opportunities; offer of financial support and other available services, e.g. social worker, psychologist, occupational therapist; timely access to information in each relevant aspect of care; easy to understand information about cancer screening; experiences with the emergency department; and follow-up care.

The report noted that the length of the surveys ranged from eight questions to 95 questions. Most of the surveys reviewed only included closed questions using Likert response scales, e.g. Strongly Agree/Agree; Poor/Fair; Never/Sometimes, and Yes or No responses. Several surveys included open-ended questions to describe care and treatment and how these could be improved.

In summary, the outcome of the literature scan demonstrated the usefulness and comprehensiveness of the existing Outpatient Cancer Clinics Survey questionnaire, with the main aspects of care, e.g. communication, involvement in decision-making, and clear information, already covered. The review provided recommendations around the inclusion of additional questions such as overall cancer care experiences in a broader context, e.g. from a GP, social worker, psychologist, financial support services offered, and whether the patient felt sufficiently informed about how treatment may impact work, daily activities, relationships, and emotional wellbeing.

Historical data review

BHI reviewed the results of previous Outpatient Cancer Clinic Survey questionnaires to look at response patterns for each question and identify any issues which may need to be addressed in the updated questionnaire. These include non-response items (missing responses), non-specific responses (don't know/can't remember), ceiling and floor effects (responses where almost all patients were very positive or very negative, with little variation between hospitals), correlations between questions, and any other sampling or analysis issues that have arisen in the past.

Patient comments made in response to the two free-text questions (what was the best part of care and what could be improved) also underwent a thematic analysis to identify topics of high relevance to patients attending outpatient cancer clinics that were not already captured in the questionnaire. The free-text responses allowed BHI to gain insights on each patient's journey through their own words and these informed the new questionnaire.

The historical data review also supported the removal of sections and questions that were no longer required, to reduce the length of the questionnaire and ease the burden on patients.

Stakeholder consultation

BHI reviewed the Outpatient Cancer Clinics Survey questionnaire in consultation with the Cancer Institute NSW, LHDs, stakeholders and consumers. This was an iterative process providing an opportunity for feedback and input at different stages throughout the development of the questionnaire. The purpose of this consultation was to provide context as to which of the existing survey questions were most useful for identifying and driving efforts to make healthcare improvements at facilities. It was also an opportunity to provide input on topics in line with system priorities, reflecting issues of high relevance to: patients attending outpatient cancer clinics: patients with cancer: and healthcare professionals providing cancer care.

The following key findings were noted during consultations with stakeholders:

- The right aspects of care were covered in the existing questionnaire, including coordination of care, information and communication and informed decision-making, which are all essential topics covering important measures of person-centred care.
- Sections such as 'complications', 'payments about your care', smoking behaviour' and 'about your health'
 provided good contextual information but results were not commonly used at facilities.
- Although the 'purpose of the appointment' and 'type of cancer' were useful contextual questions, stakeholders would like specific question responses to be analysed by grouping patients' cancer types.
- The survey is the primary source of data for virtual care services for outpatient cancer clinics, and is useful in informing assessment of virtual care service performance.
- Additional questions on coordination of care were requested given the increased use of multidisciplinary teams.
- Other themes of interest not previously covered included cancer research, journey of care, wait times, equity of outcomes and financial burden.
- Some information, e.g. hand washing, was locally available and therefore not required to be collected as part of a reflective survey program.
- The questionnaire could be shortened, and some questions combined.

Based on the stakeholder feedback, and together with the findings of the literature scan and historical data review, BHI revised the questionnaire into a two-part questionnaire, the first section being questions on patients' experiences of care at their most recent appointment at an outpatient cancer clinic or hospital (the core content), and a new cancer module for patients who have, or have had, cancer (the cancer care module).

The responses from the multiple rounds of stakeholder consultation were used to draft the Outpatient Cancer Clinics Survey 2024 questionnaire in preparation for cognitive testing.

Cognitive testing

BHI's survey vendor, Ipsos Public Affairs, completed cognitive testing with consumers to ensure the revised and new questions and response options would be interpreted consistently and as intended, and to identify any issues with question flow, skip logic and formatting.

All participants were patients who had attended an outpatient cancer clinic at a NSW public hospital in the past 12 months. The interviews were conducted with people of different genders, rurality and age.

Interviews were conducted virtually or face-to-face and continued for 45-60 minutes. Ipsos conducted 15 interviews across two rounds. This process ensured there was a 'review and revise' period to apply changes to the draft questions and response options and re-test during the second round.

The interviews generated valuable insights that helped to refine the questionnaire. Participants gave detailed feedback, including on wording, perceived question value and interpretation, sequencing, skip logic and suggestions for modifications.

The following findings were noted during cognitive testing:

- Participants had to be reminded to think back to their most recent appointments for some of the questions relating to their care and treatment with the clinic or hospital.
- There were sufficient questions on information, decision making and communication on different aspects of care, and the questions were not repetitious.

- Participants found that the questions were generally clear and easy to understand.
- Several questions were subjective and interpreted differently, e.g. safe high-quality care, confidence and trust, and kind and caring.
- Participants particularly liked new questions about navigation of care, emotional and practical support and decision making.

The final Outpatient Cancer Clinics 2024 questionnaire contains 65 questions, including 20 questions for patients who have, or had, cancer. Among these are 13 new questions drafted by BHI. The remaining questions are taken directly from the previous survey years, existing BHI surveys and/or are based on validated questions already in use in other related surveys. Minor amendments were made to some questions to tailor them to the context and align with them the BHI Minimum Question Set and the BHI Style Guide.

The Outpatient Cancer Clinics 2024 questionnaire is available on the BHI website.

Details of changes – core content

The core content section of the questionnaire comprises questions asking about patients' experiences of care at their most recent appointment at the specific outpatient cancer clinic or hospital listed on their covering letter.

Additional details, including changes from the 2023 questionnaire and rationale for each of the questions, can be found in the table below.

Questions that have been removed since the 2023 questionnaire are listed here.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q1-Q6	Appointment with the outpatient clinic For the questions in this section, please think about your most recent appointment at the clinic or hospital named in the covering letter.	Amended section Changed from 'When completing the questionnaire, please think about your appointment with the hospital named in the covering letter in January 2023.'	This preamble was amended to remind patients to think about their most recent appointment at the clinic or hospital named in the covering letter.
Q1	Were you able to get an appointment time that suited you?	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback.
	Yes, definitely		The question was clear and unambiguous to cognitive testing
	Yes, to some extent		participants and was found to work well as a first question in the questionnaire.
	• No		the questionnane.
Q2	Did you have any of the following issues getting to the clinic? Please X all the boxes that apply to you	New question	Previous questions about parking and issues with making an appointment were merged to reduce the questionnaire length. These concepts were regarded as important from a patient's
	Car park issues		perspective as elicited from the analysis of the free text
	Transport issues		comments.
	Finding the clinic		
	Other issue		
	I had <u>no</u> issues		

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q3	Were the staff you met on your arrival to the clinic polite and welcoming? • Yes, definitely • Yes, to some extent • No	Amended question Changed from 'Were the reception staff polite and courteous?'	This question was included, based on stakeholder and internal feedback, to shift the focus from reception staff to the staff met on arrival, and for consistency with other BHI patient survey questionnaires. Cognitive testing participants understood this question well. It was seen as referring to the first meeting of staff and patients on arrival at a clinic.
Q4	How long after the scheduled appointment time did your appointment actually start? On time, or early Go to X Less than 15 minutes 15 to 29 minutes 30 to 59 minutes 60 minutes or more Don't know/can't remember Go to X	Amended response option Removed 'I didn't have an appointment' from response options	Response options have been streamlined following historical data review. Cognitive testing participants felt the response options were appropriate and they understood the question well.
Q5	Were you told how long you had to wait? • Yes • No	Unchanged	
Q6	Were the areas of the clinic you used clean?Yes, definitelyYes, to some extentNo	New question	Questions about cleanliness and comfort of treatment and waiting areas were merged to reduce questionnaire length and take account of feedback from stakeholders who said it was more efficient to ask about these concepts together. This question was included for consistency with other BHI patient survey questionnaires.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q7-Q13	Health professionals For the questions in this section, please think about all the health professionals you saw at your most recent appointment at the clinic or hospital named in the covering letter.	Amended section heading and new preamble	Cognitive testing participants understood that the term 'health professionals' referred to doctors and nurses. The purpose of the preamble is to remind patients to think about their most recent appointment.
Q7	At your most recent appointment, did you have enough time to discuss your health issues with the health professionals? • Yes, definitely • Yes, to some extent • No	Amended question wording Question wording changed from 'Did you have enough time to discuss your health issues with the health professionals you saw?'	This question was amended to improve readability and ensure the patient would refer to their most recent appointment when answering the questions in part one of the questionnaire. As some patients skip reading the preamble, reference to 'most recent appointment' is repeated in the question wording to clarify what patients should think about.
Q8	Did the health professionals explain things in a way you could understand? • Yes, always • Yes, sometimes • No	Unchanged	This question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
Q9	Did the health professionals listen carefully to your views and concerns? • Yes, always • Yes, sometimes • No • Not applicable	New question	This question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys. It was highlighted during cognitive testing as an integral and important concept to ask about.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q10	Did you have confidence and trust in the health professionals?	Unchanged	This question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
	Yes, definitelyYes, to some extentNo		'Confidence and trust' were important concepts to cognitive testing participants. They spoke of confidence and trust in their medical team being vital. They had confidence and trust when feeling they were in 'the best hands' and that medical staff were knowledgeable and conducted themselves professionally.
Q11	Were the health professionals kind and caring? • Yes, always	Amended question wording Removed 'towards you' from question wording	This question was amended for consistency with other BHI patient survey questionnaires.
	Yes, sometimesNo		The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
			The question was well understood by cognitive testing participants. 'Kind and caring' was seen as more personal, less formal, empathic interactions. This aspect was particularly important to respondents who did not have support people with them.
Q12	Overall, how would you rate the health professionals?	Amended question wording Removed 'who treated you' from question	This question was amended for consistency with other BHI patient survey questionnaires.
	Very goodGoodNeither good nor poor	wording	The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
	PoorVery poor		

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q13	How would you rate how well the health professionals worked together as a team?	Amended question wording Added 'as a team' from question wording	This question was amended for consistency with other BHI patient survey questionnaires.
	Very goodGood		The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
	Neither good nor poorPoorVery poor		Cognitive testing participants understood this question well. Participants believed working well as a team was demonstrated by each member of the team knowing what they were doing and communicating well with one another.
Q14-Q23	Care and treatment For the questions in this section, please think about the care and treatment you received at your most recent appointment at the clinic or hospital named in the covering letter.	Amended section Section header changed from 'Your care and treatment' Preamble changed from 'Thinking again about your January appointment with this clinic'	This section header was amended for consistency with other BHI patient survey questionnaires. The preamble was included to refer patients back to their most recent appointment at the clinic or hospital named in the covering letter.
Q14	At your most recent appointment, did you feel confident to ask questions about your care and treatment? Yes, definitely Yes, to some extent	New question	This question was included following stakeholder feedback on the importance of this aspect of care. The question was guided by the <i>Future Health: Guiding the next decade of care in NSW 2022–2032</i> report to continue to empower people to manage and make decisions about their care with clinicians.
			Several cognitive testing participants spoke of their persistence in asking for more information and receiving clarification. They said the severity of their situation motivated them to be very active in gathering information about their condition.
			Confidence was consistently thought of in the frame of healthcare staff creating an approachable environment.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q15	Did the health professionals discuss what was important to you in managing your care and	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	treatment?Yes, definitelyYes, to some extentNo		The question was guided by the Future Health: Guiding the next decade of care in NSW 2022–2032 report to continue to empower people to manage and make decisions about their care with clinicians.
			While cognitive testing participants understood the question, it was interpreted in a number of ways e.g. referring to general needs rather than their personal and individual needs. As such, underlining of 'to you' was introduced to highlight the essence of this question.
Q16	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Amended response option Response option changed from 'I didn't want or	The response options were amended for consistency with other BHI patient survey questionnaires.
	Yes, definitelyYes, to some extentNoNot applicable	need to be involved' to 'Not applicable'	This question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
Q17	Did the health professionals explain the next steps of your care and treatment in a way you could understand? • Yes, definitely • Yes, to some extent	Amended question and response options Question wording changed from 'Did a health professional at the clinic explain the next steps of your care and treatment in a way you could understand?'	This question and the response options were amended to improve readability and consistency with other BHI patient survey questionnaires.
	• No	Response options changed from 'Yes, completely, Yes, to some extent, No'	

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q18	Were the possible side effects of your treatment explained in a way you could understand?	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	Yes, definitelyYes, to some extentNoNot applicable		The question was understood well by cognitive testing participants. In their feedback, participants said the positioning of Q18 and Q19 at this point of the questionnaire flowed well.
Q19	Were you given enough information about how to manage the possible side effects of your treatment? • Yes, definitely • Yes, to some extent • No • Not applicable	Amended question wording and response options Question wording changed from 'Were you given enough information about how to manage the side effects of your treatment?' Response options changed from 'Yes, completely, Yes to some extent, No'	This question was understood well by cognitive testing participants. They said the positioning of Q18 and Q19 at this point of the questionnaire flowed well. The question was guided by the <i>Future Health: Guiding the next decade of care in NSW 2022–2032</i> report, to continue to empower people to manage and make decisions about their care with clinicians.
Q20	Were you treated with respect and dignity?Yes, alwaysYes, sometimesNo	Amended question wording Question wording changed from 'Were you treated with respect and dignity during your appointment?'	This question was amended for consistency with other BHI patient survey questionnaires. The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys. The question was understood well by cognitive testing participants. This concept was seen as a more formal recognition of privacy and autonomy, acknowledgment of private space, politeness and the need for consent to touch. For some, it was seen as a minimum standard for professional care.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q21	Were your cultural or religious beliefs respected by the clinic staff?	Unchanged	This question is used routinely across NSW Patient Survey Program surveys.
	Yes, alwaysYes, sometimesNoNot applicable		The question was guided by the <i>NSW Cancer Plan 2022–2027</i> , to provide optimal cancer treatment, care and support.
Q22	Were you given enough information about how to manage your care at home? • Yes, definitely • Yes, to some extent • No	New question	Cognitive testing participants understood this question well. The question was guided by the <i>Future Health: Guiding the next decade of care in NSW 2022–2032</i> report, to continue to empower people to manage and make decisions about their care with clinicians. The question was also guided by the <i>NSW Cancer Plan 2022–2027</i> , to provide optimal cancer treatment, care and support.
Q23	Were you told who to contact if you were worried about your condition or treatment after your appointment? • Yes • No • Not applicable	Amended response option Response option changed from 'Don't know/can't remember' to 'Not applicable'	This question was amended for consistency with other BHI patient survey questionnaires. The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
Q24-Q27	Overall experience For the questions in this section, please think about your overall experiences of the care you received at your most recent appointment at the clinic or hospital named in the covering letter.	Amended section Changed section header from 'Overall care' and added preamble	This section header was amended for consistency with other BHI patient survey questionnaires. The preamble was included to refer patients back to their most recent appointment at the clinic or hospital named in the covering letter.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q24	Overall, how would you rate the care you received at the clinic?	Amended question wording Question wording changed from 'Overall, how	This question was amended for consistency with other BHI patient survey questionnaires.
	Very goodGood	would you rate the care you received from the clinic?'	The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
	Neither good nor poorPoor		
	Very poor		
Q25	How well organised was the care you received from the clinic?	Unchanged	This question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
	Very well organised		Cognitive testing participants understood that the question was about efficiency and teamwork and, as such, reflected the same considerations as those of Q13 – although participants did not identify this as repetitious.
	Fairly well organisedNot well organised		
Q26	Do you think you received safe, high-quality care from the clinic?	New question	This question is a patient reported measure relevant to patient safety and aspects of safety culture in organisations.
	Yes, definitely		
	Yes, to some extent		
	• No		
Q27	Did the care and treatment you received help you?	New question	This question was included for consistency with other BHI
	Yes, definitely		patient survey questionnaires.
	Yes, to some extent		The question is part of the BHI Minimum Question Set used
	• No		routinely across NSW Patient Survey Program surveys.

Question #	Question/section		
2024	(as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q28-Q31	Complications or problems For questions in this section, please think about any complication or problem that you may have experienced related to your most recent care and treatment at the clinic or hospital named in the covering letter.	Amended section	This section and subsequent questions (Q28-31) were amended for consistency with other BHI patient survey questionnaires.
Q28	Did you experience any complication or problem related to your most recent care and treatment?	Amended question and response options Changed question wording from 'During your	This question was amended for consistency with other BHI patient survey questionnaires.
	• Yes	appointment or soon afterwards, did you experience any of the following complications or	The previous breakdown of different complications and
	• No Go to X		problems as response options was not used deemed necessary by stakeholders.
		Removed from response options:	
		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	

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q29	Was the impact of this complication or problem? Very serious Fairly serious Not very serious Not at all serious	Unchanged	
Q30	Were the health professionals responsive in addressing this complication or problem? • Yes, definitely • Yes, to some extent • No	New question	This question was included for consistency with other BHI patient survey questionnaires.
Q31	In the <u>past three months</u> , have you gone to an <u>emergency department</u> because of complications or problems related to the care you received? • Yes • No	Amended question and response option Added 'or problems' to the question Removed 'Don't know/can't remember' from response options	This question and response option was amended for consistency with other BHI patient survey questionnaires.
Q52-63	About you The questions in this section will help us to see how experiences vary between different groups of the population	Amended section Changed from 'About You (The Patient)'	This section was amended for consistency with other BHI patient survey questionnaires.
Q52	What year were you born? Write in (YYYY)	Unchanged	This question was retained as it is necessary for the analysis of results.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q53	How do you describe your gender? Please X one option	Unchanged	This question was retained as it is necessary for the analysis of results.
	Man or male		
	Woman or female		
	Non-binary		
	 Prefer to use a different termPlease specify below. 		
	Prefer not to answer		
Q54	What is the highest level of education you have completed?	Unchanged	This question was retained as it is necessary for the analysis of results.
	Less than Year 12 or equivalent		
	Completed Year 12 or equivalent		
	Trade or technical certificate or diploma		
	University degree		
	Postgraduate/higher degree		
Q55	Which language do you mainly speak at home?	Unchanged	This question was retained as it is necessary for the analysis of
	• English		results.
	A language other than EnglishWhat is that language? Please write below.		
Q56	Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic?	Unchanged	This question was retained as it is necessary for the analysis of results.
	• Yes		
	• NoGo to X		

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q57	Did the clinic provide an interpreter when you needed one? • Yes, always • Yes, sometimes • No	Unchanged	This question was retained as it is necessary for the analysis of results for this subgroup.
Q58	 Are you of Aboriginal origin, Torres Strait Islander origin, or both? Yes, Aboriginal Yes, Torres Strait Islander Yes, both Aboriginal and Torres Strait Islander No <i>Go to X</i> 	Unchanged	This question was retained as it is necessary for the analysis of results for this subgroup.
Q59	Did you receive support, or the offer of support, from an Aboriginal Health Worker at the clinic? • Yes • No • Don't know/can't remember	Amended question wording Question wording changed from 'Did you receive support, or the offer of support, from an Aboriginal Health Worker during your January appointment?'	This question was amended as we are no longer referring to a particular appointment month.
Q60	In the past 12 months, did you have any virtual care appointments, over the telephone or by video call, with a hospital or outpatient clinic? • Yes • No • Don't know/can't remember	Unchanged	This question was retained to allow for analysis on prevalence of virtual care use among respondents.

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q61	Which, if any, of the following longstanding conditions do you have (including age-related conditions)? Please X all the boxes that apply to you	Amended response option Removed cancer from 'A longstanding illness (e.g. HIV, cancer, diabetes, chronic heart disease)' response option	The response option was modified to improve relevancy to patients with cancer.
	Deafness or severe hearing impairment		
	Blindness or severe vision impairment		
	 A longstanding illness (e.g. 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) 		
	• None of these Go to X		
Q62	Does this condition(s) cause you difficulties with your day-to-day activities?	Unchanged	This question was retained as it is necessary for the analysis of results for this subgroup.
	Yes, definitely		
	Yes, to some extent		
	• No		

Question # 2024	Question/section (as it appears in the 2024 questionnaire)	Changes from 2023	Rationale
Q63	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 (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.	Unchanged	This question was retained for linkage of patient results to patients' records, used routinely across NSW Patient Survey Program surveys.
	Your information will be treated in the strictest confidence. BHI will not report any results that may identify you as an individual. Your questionnaire responses will not be accessible to the health professionals who cared for you.		
	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)?		
	YesNo		
Q64	What was the <u>best part</u> of the care you received from this clinic?	Unchanged	This question provides insights into anything of importance to patients. It is routinely used across NSW Patient Survey Program surveys.
Q65	What most needs improving about the care you received from this clinic?	Unchanged	This question provides insights into anything of importance to patients. It is routinely used across NSW Patient Survey Program surveys.

Details of changes – cancer care module

For patients who have, or have had, cancer, the cancer care module comprises questions asking patients about their overall experiences of cancer care, including care they received from a clinic or hospital, GP, and other services.

Rationale for each question selected for this module can be found in the table below.

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q32-Q51	Cancer Care This section asks questions for people who have, or have had, cancer. If you received care for a condition other than cancer, please answer Q32.	New section	The cancer care module complements the core section of the survey, and provides a unique insight into overall experiences of patients with cancer beyond what is solely attributable to care received at a facility.
Q32	Did you attend this clinic or hospital because you have, or have had, cancer? • Yes • No Go to X	Unchanged	This is a necessary filter question for the cancer care module. Patients without cancer who answer 'No' skip this section.

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q33	 What is/was the main type of cancer? Please X one option Prostate Breast Bowel (e.g. colon, rectal, anal) Lung Skin/melanoma Upper gastrointestinal (e.g. oesophageal, 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. bladder, kidney, bone, mesothelioma, thyroid, sarcoma) The type of cancer is not known yet 	Amended question wording and response options Question wording changed from 'What was the main type of cancer you were receiving care for at this clinic?' Response option changed from: 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	The response options were amended based on consultation with the Cancer Institute NSW. This question was retained as it allows patients to share key information about their health characteristics, which may be used in analysis.
Q34	 When were you first diagnosed with this cancer? Less than 1 year 1 to 3 years 3 to 5 years More than 5 years 	New question	This question was included as it allows patients to share key information about their health characteristics, which may be used to support analysis.

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q35	Was the hospital named in the cover letter the main place where you received most of your care and treatment for this cancer? • Yes • No	New question	This question was included as it allows patients to share information about their cancer journey, which may be used to support analysis. It will also help BHI determine whether the results from this module are attributable to a facility/LHD.
Q36-Q43	All your cancer care For the questions in this section, please think about your <u>overall experiences</u> of your cancer care, including with this clinic or hospital, your general practitioner, and <u>other hospitals and services.</u>	New section	
Q36	When you were diagnosed with this cancer, were you told about different treatment options?	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	Yes, definitelyYes, to some extentNo		The question was guided by the <i>Future Health: Guiding the</i> next decade of care in NSW 2022–2032 report, to continue to empower people to manage and make decisions about their care with clinicians.
			Some cognitive testing participants spoke of 'definitely' being informed about mainstream treatment options, but not 'alternative' treatments. The question was deemed more difficult to answer for those who did not have a range of treatment options available.
Q37	How much information about your condition or treatment for this cancer was given to you when	New question	This question was included for consistency with other BHI patient survey questionnaires.
	you were diagnosed? Not enough		The question is part of the BHI Minimum Question Set used
	The right amount		routinely across NSW Patient Survey Program surveys.
	Too much		

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q38	Were the risks and benefits of your treatment explained in a way you could understand?	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	Yes, definitelyYes, to some extent		Cognitive testing participants confirmed the relevance of this question.
	• No		The question was guided by the <i>NSW Cancer Plan 2022–2027</i> , to provide optimal cancer treatment and support.
Q39	Did you feel confident you were making an informed decision about your treatment?	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	Yes, definitelyYes, to some extentNo		The question was guided by the Future Health: Guiding the next decade of care in NSW 2022–2032 report, to continue to empower people to manage and make decisions about their care with clinicians.
			It is a proxy measure for 'informed consent'.
Q40	Did you receive conflicting information about your condition or treatment from the health professionals?	Amended question wording and response options	This question and response options were amended for consistency with other BHI patient survey questionnaires.
	Yes, definitelyYes, to some extentNo	Removed 'ever' from question wording Changed response option from 'Yes, No'	The question is part of the BHI Minimum Question Set used routinely across NSW Patient Survey Program surveys.
Q41	Were you given information upfront about the costs of different treatment options for your cancer? • Yes, definitely	New question	This question was included following stakeholder feedback on the importance of this topic. Patients and their families should be empowered to make the best treatment choices based on their circumstances.
	Yes, to some extentNoNot applicable		The question was guided by Future Health: Guiding the next decade of care in NSW 2022–2032 report to continue to empower people to manage and make decisions about their care with clinicians.

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q42	Were health professionals you saw in your community (such as your general practitioner) up-	New question	This question was amended for consistency with other BHI patient survey questionnaires.
	to-date about the care you received?		The question is part of the BHI Minimum Question Set used
	Yes, definitely		routinely across NSW Patient Survey Program surveys.
	Yes, to some extent		
	• No		
	Not applicable		
Q43	Overall, how would you rate your experience of navigating the healthcare system (e.g. accessing	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	treatment, getting referrals to other services, and seeing different health professionals)?		It was guided by the NSW Cancer Plan 2022–2027, on navigating the health system as a key component of care.
	Very good		Cognitive testing participants understood this question well and
	• Good		said it referred to coordination of care for them, as a patient,
	Neither good nor poor		and the different appointments with various health
	• Poor		professionals.
	Very poor		
Q44-Q46	Cancer support services	New section	This section was guided by the NSW Cancer Plan 2022–2027,
	For the questions in this section, please think		to ensure people who experience cancer, their families and
	about any lifestyle choices and cancer support		carers are linked with supportive care and services such as psychosocial care, allied health care and financial counselling.
	services that were discussed with you.		psychosocial care, amed health care and imaricial couriseiling.

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q44	Did health professionals discuss any of the following lifestyle choices with you? Please X all that apply to you	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback on the importance of information and support around lifestyle changes/choices for
	Quitting smoking/vaping		patients with cancer.
	Nutrition		The question was included as an indicator relating to elements in the NSW Cancer Plan 2022–2027 and replaces several
	Exercise and leisure activity		questions previously included in the Outpatient Cancer Clinics
	Limiting drinking alcohol		Survey 2023 questionnaire.
	Sun safety/protection		The response option 'mindfulness and wellbeing' was included
	Mindfulness and wellbeing		following stakeholder feedback on the importance of this aspect
	Other lifestyle choice		of care.
	No lifestyle choices were discussedGo to X		
Q45	Were you given enough support to make the lifestyle changes recommended?	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback on the importance
	Yes, definitely		of support around lifestyle changes/choices for patients with
	Yes, to some extent		cancer.
	• No		
	Not applicable		
Q46	Were you given information about support programs (e.g. counselling, financial, mental health)?	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback on the importance of support around lifestyle changes/choices for patients with
	Yes, definitely		cancer.
	Yes, to some extent		Cognitive testing participants confirmed the relevance of this
	• No		question.

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q47-Q49	Your current situation For the questions in this section, please think about your work and financial situation. By 'work' we mean working in a job, at a business or volunteering (part time/full time).	New section	The next couple of questions were included to replace the payments for your care section previously included in the Outpatient Cancer Clinics Survey 2023 questionnaire. Financial burden is important to understand for this cohort as it impacts access to care.
Q47	Have you been able to return to work or continue work (including volunteering) in the same or a similar capacity as before your cancer diagnosis?	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback. It was well received during cognitive testing.
	Yes, definitely		
	Yes, to some extent		
	• No		
	Not applicable		
Q48	Have you experienced any loss of income or other financial burden (e.g. out of pocket medical costs) related to your cancer diagnosis? • Yes	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback. It was well received during cognitive testing.
	• NoGo to X		
Q49	What was the impact of this loss of income or financial burden?	New question	This question was included based on recommendations from the Sax Institute and stakeholder feedback. It was well received
	• High		during cognitive testing.
	Medium		
	• Low		
	No impact		

Question # 2024	Question/section (as it appears in 2024 questionnaire)	Changes from 2023	Rationale
Q50-Q51	For the following two questions, please think about how you feel <u>now</u> (at the time of completing this questionnaire).	New preamble	This section was guided by the <i>NSW Cancer Plan 2022–2027</i> , to ensure people who experience cancer, their families and carers are linked with supportive care and services such as psychosocial care, allied health care and financial counselling.
Q50	Do you have someone you can turn to for practical support (e.g. help with home duties, transport)?	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	Yes, definitely		Cognitive testing participants found this question important and
	Yes, to some extent		relevant to their experience of care.
	• No		
	Not applicable		
Q51	Do you have someone you can turn to for emotional support?	New question	This question was included following stakeholder feedback on the importance of this aspect of care.
	Yes, definitely		Cognitive testing participants found this question important and
	Yes, to some extent		relevant to their experience of care. Several participants felt
	• No		their healthcare team needed this information to care for them effectively.
	Not applicable		,
			A footnote with telephone details of the Cancer Council's information and support line is included for respondents who need help or someone to talk to.

Details of changes – deleted questions

As part of the major review process, the following questions were removed as a result of analyses of the literature review, cognitive testing, stakeholder consultation and feedback.

Question # 2023	Section	Question deleted
Q1	Appointment with the outpatient clinic	What was the purpose of this appointment?
Q2	Appointment with the outpatient clinic	How long did it take you to travel to the clinic for this appointment?
Q3	Appointment with the outpatient clinic	Did you need parking for your clinic visit?
Q4	Appointment with the outpatient clinic	Did you have any of the following issues with parking during this visit?
Q8	Appointment with the outpatient clinic	How comfortable was the waiting area?
Q9	Appointment with the outpatient clinic	How comfortable was the treatment area?
Q11	The health professionals	Who did you see during this appointment?
Q14	The health professionals	During this appointment, did the health professionals know enough about your medical history?
Q16	The health professionals	Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching you?
Q17	The health professionals	Did you have worries or fears about your condition or treatment?
Q18	The health professionals	Did a health professional discuss your worries or fears with you?

Question # 2023	Section	Question deleted
Q22	Planning your care	When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options?
Q23	Planning your care	Did a health professional at the clinic tell you about the risks and benefits of the treatment options?
Q27	Planning your care	Do you have a written care plan for your current or ongoing care?
Q28	Planning your care	Were you asked about your preferences for care and treatment when developing this plan?
Q29	Planning your care	At your January appointment, did the health professionals review your care plan with you?
Q30	Your care and treatment	Did you receive any treatment during this appointment (chemotherapy, radiotherapy, surgery or other treatments)?
Q31	Your care and treatment	Did a health professional at the clinic explain what would be done during your treatment in a way you could understand?
Q32	Your care and treatment	Did a health professional at the clinic tell you about possible side effects of your treatment?
Q34	Your care and treatment	During this appointment, were you given, or prescribed, any new medication to take at home?
Q35	Your care and treatment	Did a health professional at the clinic explain the purpose of this medication in a way you could understand?
Q36	Your care and treatment	Did a health professional at the clinic tell you about side effects of this medication to watch for?
Q38	Your care and treatment	Did a health professional at the clinic give your family or someone close to you enough information to help care for you at home?

Question # 2023	Section	Question deleted
Q40	Respectful care	Were you given enough privacy when being examined or treated?
Q41	Respectful care	Were you given enough privacy when discussing your condition or treatment?
Q42	Respectful care	Were you ever treated unfairly for any of the reasons below?
Q46	Complications	In your opinion, were the health professionals open with you about this complication or problem?
Q48	Smoking behaviour	Did a staff member at this clinic ask you if you smoked/used tobacco?
Q49	Smoking behaviour	At the time of your appointment, how often were you smoking/using tobacco?
Q50	Smoking behaviour	Has a staff member at this clinic done any of the following in the past year?
Q52	Overall care	If asked about your clinic experience by friends and family, how would you respond?
Q54	Payments for your care	How much were your out-of-pocket expenses for medication related to these appointments?
Q55	Payments for your care	How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these appointments (excluding medication)?
Q56	Payments for your care	How much were your out-of-pocket expenses for other costs related to these appointments (e.g. travel, petrol, parking, accommodation)?
Q58	About your health	Is this the first time you have had cancer?
Q60	About your health	Which of the following statements best describes how well you are able to carry out ordinary tasks and daily activities? In the past month I would generally rate my activity as

Question # 2023	Section	Question deleted
Q61	About your health	How has your current cancer responded to treatment?
Q62	About your health	How long has it been since you first received treatment for this cancer?
Q64	Virtual care with a hospital outpatient clinic	How many virtual care appointments have you had with a hospital or outpatient clinic in the past 12 months (not counting any appointments with your general practitioner/family doctor)?
Q65	Virtual care with a hospital outpatient clinic	Overall, how would you rate the virtual care you received?
Q66	Virtual care with a hospital outpatient clinic	Did the care and treatment received through virtual care help you?
Q67	Virtual care with a hospital outpatient clinic	Compared with in-person appointments, were your virtual care experiences?
Q68	Virtual care with a hospital outpatient clinic	If given the choice, would you use virtual care again?
Q69	Virtual care with a hospital outpatient clinic	Thinking about your experiences of virtual care, what have been the benefits for you?
Q70	Virtual care with a hospital outpatient clinic	How did you access your most recent virtual care appointment?
Q71	Virtual care with a general practitioner	In the past 12 months, did you have any virtual care appointments – over the telephone or by video call – with a general practitioner (GP)?
Q72	Virtual care with a general practitioner	How many virtual care appointments have you had with a GP in the past 12 months?
Q73	Virtual care with a general practitioner	Overall, how would you rate the virtual care you received from GPs?
Q74	Virtual care with a general practitioner	Did the care and treatment received from GPs through virtual care help you?

Question # 2023	Section	Question deleted
Q75	Virtual care with a general practitioner	Did the opportunity to use virtual care help ensure that your care was well coordinated between the hospital outpatient clinic and the GP?
Q86	About you (the patient)	Are you a participant of the National Disability Insurance Scheme (NDIS)?
Q87	About you (the patient)	Who completed this survey?