

Development Report: Outpatient Cancer Clinics Survey 2015

July 2016

Revision History

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Table of Contents

Development of the Outpatient Cancer Clinics Survey 2015	1
NSW Patient Survey Program	1
What is survey development?	1
Summary of content in the COPS 2015	2
COPS 2015 sampling summary	3
Questionnaire design	3
Review of key literature	3
Stakeholder engagement	4
Statistical analysis of the OPS 2014 results	4
Missing response analysis	5
Ceiling and floor effects	5
Invalid responses	6
High correlation between questions	7
Cognitive interviews	7
Questionnaire refinement	7
Appendix 1: COPS 2015 – question source and development notes	9
Appendix 2: Item non-response rate	17
Appendix 3: Cancer Outpatients Survey 2015	20

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

Development of the Outpatient Cancer Clinics Survey 2015

This document outlines the development of the 2015 Outpatient Cancer Clinics Survey (COPS). This survey was developed as part of the NSW Patient Survey Program run by the Bureau of Health Information (BHI). This document covers the questionnaire design and sampling methodology of the COPS 2015 but does not contain the results of the survey or technical details on how it was analysed. Survey results can be found in the COPS Patient Perspective report. Technical details can be found *Technical Supplement: Outpatient Cancer Clinics Survey 2015* on BHI's website at bhi.nsw.gov.au

NSW Patient Survey Program

The NSW Patient Survey Program began sampling patients in NSW public facilities from 2007. Up to mid-2012, the program was coordinated by the NSW Ministry of Health (Ministry) using questionnaires obtained under license from NRC Picker. Ipsos Social Research Institute (Ipsos) was contracted to manage the logistics of the survey program. Responsibility for the NSW Patient Survey Program was transferred from the Ministry to BHI in July 2012, with Ipsos continuing as the contracted partner to manage logistics.

The aim of the program is to measure and report on patients' experiences of care in public healthcare facilities in NSW, on behalf of the Ministry and local health districts (LHDs). Results are also used for performance measurement of hospitals, LHDs and the NSW healthcare system.

What is survey development?

Survey development is the process BHI undertakes to create a new survey focussing on a specific service or groups of patients. This work includes review of the sampling methodology, engagement of stakeholders and development of the questionnaire. This process is designed to ensure that the content of the survey is specifically tailored to the NSW healthcare environment and addresses the needs of our stakeholders, while allowing patients to reflect and report on the care they received.

The development uses information from a number of sources to identify questionnaire content, including:

- Patient focus groups
- Patient comments provided for previous surveys
- Literature reviews
- Stakeholder engagement
- Advisory committees of experts
- Consultation with partner organisations.

Topics arising from these sources are developed into questions and revised through testing with patients (cognitive interviewing). These processes are designed to ensure that the final survey provides feedback that:

- Is relevant to the current and future NSW policy context
- Is important to patients
- Will help inform quality improvement efforts of health services and policy makers.

Summary of content in the COPS 2015

The COPS 2015 was an evolution of the existing BHI questionnaire for the Outpatients Survey (OPS) 2014. This list summarises the changes from the OPS 2014, while subsequent sections provide greater detail:

- The invitation letter was changed to specify the patient's 'recent outpatient visit to a cancer clinic at xxx hospital', due to confusion in the OPS 2014 regarding which outpatient visit to answer about
- Revision of Q1 about the purpose of the outpatient visit (10 response options) to include specific cancer therapies of chemotherapy, radiotherapy and surgery
- Revision of Q4 to split the first response option because patients at cancer clinics had shorter waits
- Separation of a question about if the patient was told how and why an appointment was late into two questions (Q17 and Q18) to better understand each issue
- Revision of Q23 on health professionals seen during the visit to include those specific to cancer care, including radiation therapists and lymphoedema therapists
- Addition of a section called 'Planning Your Care' which includes whether the patient had a treatment plan, whether it was developed at this clinic, whether they were asked for their ideas and preferences in developing the plan, and whether it was reviewed at the last appointment
- Addition of Q42 on whether they received an explanation about the purpose of new medication to take at home, given the increased likelihood of cancer patients being given new medication
- Addition of Q44 on whether they were given enough information on how to manage side effects of treatments other than medication, given their higher likelihood of experiencing treatment side effects
- Addition of a new response option to the list of possible complications (Q47) – 'severe anxiety or worry' to account for this possibility as raised by the project's advisory committee
- Expansion of the question on out-of-pocket expenses (Q50) to provide details on what they had to pay for (e.g. parking, consultation, medication, accommodation, travel). For space reasons, the question on whether they skipped any follow-up medication, tests or treatment due to cost was removed, with the intent that this could be added back into future questionnaires.
- The section on children was removed as young patients were outside the scope of this survey
- Revising the 'Number Of Visits' section, to include questions on how long the patient had been attending the clinic (moved from a different section), whether health professionals always had access to their medical records, and whether they ever received conflicting information from staff
- Removal of the question asking if they were given enough information about managing their care after they left the outpatient clinic
- Removal of a question about whether the clinic gave the patient's GP enough information about their condition or treatment, as patients are at many different stages of their cancer journey
- Removal of the questions about making a complaint due to low numbers in the OPS 2014
- Addition of a new section 'Treatment Needs and Outcomes', sourced from the English Cancer Patient Experience Survey asking:
 - Whether they attended the clinic for cancer (as some clinic attendances can be for treatments delivered to patients without cancer)
 - Whether this is the first time they have had cancer
 - What stage of their cancer journey they are up to
 - How long ago they started treatment
 - What treatments they have had
- Addition of a question on whether they attended an emergency department due to their cancer or cancer complications
- The addition of two validated international tools for assessing cancer:
 - The Edmonton Symptom Assessment System (ESAS)
 - The Communication and Attitudinal Self-Efficacy scale for Cancer (CASE-Cancer).

The net effect of these changes on the questionnaire was a decrease in the number of questions from 80 (OPS 2014) to 77 (COPS 2015).

COPS 2015 sampling summary

The survey was sent to a random sample of 6,467 people aged 18+ years who attended an outpatient cancer clinic¹ at a NSW public hospital during February and March 2015. Sampling was conducted using the WebNAP system, operated by the Ministry. At the time the survey was conducted, there were 26 hospitals with sufficient numbers of patients for sampling.

Because essential data variables were not available to BHI from WebNAP at the time of sampling, it was not possible to stratify the sampling, for example, by age. Likewise, it was not possible to know the coverage of the sampling frame, for example, whether hospitals were unavailable because they had no clinics or because they were not supplying data. For example, there was no patient-level data for cancer outpatients in Far West, Murrumbidgee or Southern NSW LHDs.

In addition, at the time of sampling for this survey, there was no data in WebNAP for any hospital in the Hunter New England LHD, including the major cancer treatment centres of John Hunter Hospital and the Calvary Mater Newcastle. This was unexpected as data was observed for these hospitals in early versions of the sampling frame and, due to the short lead time for this survey, the sampling had to continue without these facilities being included.

Questionnaire design

The questionnaire development phase for this survey differed from standard BHI practices because of the tighter timetable. Patient focus groups and cognitive testing were not conducted. Instead, researchers in BHI and Cancer Institute NSW selected questions that had been tested in other BHI surveys, in surveys from other jurisdictions (primarily the NHS Cancer Patient Experience Survey), and validated question tools to provide questionnaire content.

The survey went through the following development stages:

1. Review of key literature (including policy documents and quality standards)
2. Stakeholder engagement
3. Statistical analysis of the OPS 2014
4. Questionnaire refinement, between staff at BHI, Ipsos and Cancer Institute NSW.

Review of key literature

The rapid literature review was performed to provide context and to inform the content of the COPS 2015 questionnaire. The aims of the review were as follows:

1. Identify and compare the core domains of treatment and care for outpatients in cancer clinics
2. Identify the most important current policies and quality standards relevant to outpatients in cancer clinics
3. Identify the key drivers of outpatient experience identified in other jurisdictions' surveys
4. Briefly describe and compare the format, content and questionnaire-related methodological issues associated with other jurisdictions' surveys of people with cancer.

¹ Including the Chris O'Brien Lifehouse – a not-for-profit integrated cancer treatment centre

This review identified research papers and 'grey' literature relevant to this work – the following terms and combinations of terms were investigated:

- 1) 'Patient satisfaction', 'patient experience', 'patient experience surveys', 'outpatient survey', 'questionnaire', 'quality improvement', 'patient views', 'quality of patient care'

AND

- 2) 'Hospital performance', 'hospital benchmarking', 'hospital profiling', 'hospital care'

AND

- 3) 'Outpatient', 'out-patient', 'ambulant'.

The search was restricted to original English-language papers, articles and reviews published in the last two decades. Furthermore, BHI consulted with Cancer Institute NSW to identify relevant NSW and national policy documents for inclusion in the review.

These sources were synthesised to form the basis of the rapid literature review.

Stakeholder engagement

To facilitate timely development of this survey, BHI engaged a small number of key stakeholders and experts in identifying question topics for the COPS 2015. These stakeholders formed the project's advisory committee and were involved in the construction of the questionnaire and advised on reporting. Membership of the committee changed at different stages of the project, but included:

- Nicole Cook, Project Manager, Cancer Institute NSW
- Tina Chen, Medical and Scientific Advisor, Cancer Institute NSW
- Deb Baker, Analyst, Cancer Institute NSW
- Sanchia Aranda, CEO, Cancer Council
- Afaf Girgis, Director, Centre for Oncology Education and Research Translation, Ingham Institute for Applied Medical Research.

BHI worked with this expert panel to redevelop the OPS 2014 questionnaire into the COPS 2015 questionnaire. Experts within this group advised on the inclusion of the ESAS and CASE-Cancer as validated outcome tools. Additional question topics were raised regarding greater detail about the patient's progress through their cancer journey, greater insight into outpatient treatments and therapies used, and which health professionals were most likely to be seen.

Statistical analysis of the OPS 2014 results

Survey results from the 2014 OPS were analysed for the following:

- Rates of item non-response – to show where patients have not answered a question, often because the response option they need isn't included but also due to the structure of the questionnaire
- Floor and ceiling effects – where the question shows overwhelmingly positive or negative results, with little variation across facilities
- Rates of invalid or ineligible responses – which typically demonstrate questionnaire design issues, including those around question filters/skips and formatting
- Question correlation rates – to identify questions that may be measuring the same topic construct and which could be combined or removed.

Missing response analysis

Analysis of item non-response rates ('% missing') was performed on the OPS 2014 data to determine whether particular questions in the survey were prone to participants' non-response (see Appendix 2).

A threshold of 5.0% is used to determine when the percentage missing is high enough to investigate. With regards to the OPS 2014, there were seven questions identified by this flag (Table 1).

Table 1: Item non-response rates, highest rates in OPS 2014

OPS 2014 question	OPS 2014 question wording	% missing
Q70	What is the highest level of education you (the patient) have completed?	7.5
Q53	Did the health professionals at this clinic provide you with a treatment plan for your ongoing care?	6.5
Q73	Which language do you (the patient) mainly speak at home?	5.3
Q78	Do you give permission for the Bureau of Health Information to link you answers from this survey to health records related to you (the patient)?	5.3
Q43	Were there things for your child to do (such as books, games and toys)?	5.0
Q44	Was the area in which your child was treated suitable for someone of their age group?	5.0
Q45	Did the clinic staff provide care and understanding appropriate to the needs of your child?	5.0

The highest rate of non-response (7.5%) was for the question on education level of the patient. This high rate is seen across all BHI surveys as we use a standardised question for this patient demographic sourced from the Australian Bureau of Statistics. BHI is reviewing other question formats to understand if this can be improved but, for now, the question will be continue to be used to allow comparisons between surveys.

The next highest rate (6.5%) of item non-response related to Q53 (was the patient provided with treatment plan). There were additional issues with this question in that the response options were not mutually exclusive, for example, the respondent could select response option 1 ('yes, I was given a written plan') and response option 2 ('yes, I was given a plan verbally'), that no definition of a treatment plan was included, and that the questions did not adequately capture the partnership component of developing the care plan. This question was revised for the COPS 2015.

Questions 73 (language spoken at home) and 78 (permission to link) were borderline high but comparability over time was seen to be more important here than rebuilding these questions.

All questions about children attending outpatient clinics were borderline high. As the COPS 2015 excludes children in the sampling, this was not an issue for the questionnaire development.

Ceiling and floor effects

A ceiling effect is present for a measurement variable when the majority of scores are at or close to the highest possible score, indicating a loss of sensitivity in the upper register of responses. Conversely, a floor effect is present when the majority of scores are at or close to the lowest possible score.

In order to determine the occurrence of true ceiling or floor effects, several criteria were used, including:

- sufficiently small standard deviation (25 or less),
- skewness statistic exceeding 1.5 or below -1.5
- mean greater than 85 or less than 15.

These criteria represent characteristics of a probability distribution that exhibits a ceiling or floor effect. The skewness statistic, in particular, has been demonstrated as a robust measure of test score ceiling and floor severity.

Dichotomous variables were excluded from the analysis because of the inherent response constraints of these questions.

Responses to the OPS 2014 were generally very positive and more so for the oncology and chemotherapy group. Because of this, many questions (20 out of 80) met the criteria of a ceiling effect and no questions met the criteria of a floor effect. The following questions met the criteria for ceiling effect:

- Q4 'Were you able to get an appointment time that suited you?'
- Q6 'From the time you booked this appointment to the time you went to the clinic, how long did you wait?'
- Q7 'Do you think the amount of time you waited was...?'
- Q10 'How long did it take you to travel to the clinic for this appointment?'
- Q15 'Were the reception staff polite and courteous?'
- Q23 'Were you given enough privacy when being examined or treated?'
- Q24 'Were you given enough privacy when discussing your condition or treatment?'
- Q26 'Did you have enough time to discuss your health issue with the health professionals you saw?'
- Q27 'Did the health professionals explain things in a way you could understand?'
- Q29 'Did you have confidence and trust in the health professionals?'
- Q30 'Were the health professionals polite and courteous?'
- Q31 'Were the health professionals kind and caring towards you?'
- Q32 'Overall, how would you rate the health professionals who treated you?'
- Q36 'How would you rate how well the health professionals worked together?'
- Q37 'Were you treated with respect and dignity while you were at the clinic?'
- Q38 'Were your cultural or religious beliefs respected by the clinic staff?'
- Q49 'Were you given enough information about this medication?'
- Q56 'Did you skip any follow-up medication, tests, or treatment recommended at this visit because of their cost?'
- Q61 'Overall, how would you rate the care you received in the clinic?'
- Q63 'If asked about your clinic experience by friends and family, how would you respond?'

The identification of ceiling effects for these questions indicates that they might be less useful in terms of informing service improvement and investigating variation in performance. However, these questions were not automatically excluded from the survey based on ceiling effects and were desirable to retain for other reasons.

Invalid responses

Invalid responses occur when patients answered questions they should not have, or answered the question in an incorrect way (e.g. selecting two options for a single response question). The only question with a high proportion (8.5%) of invalid responses in the OPS 2014 was Q1 'Which type of outpatient clinic did you attend?'. In this case, most of the responses coded as invalid arose from respondents selecting more than one outpatient clinic from the list. As this question does not appear in the COPS 2015, this was not an issue for questionnaire development.

The next highest invalid proportion was below the threshold of concern at 1.9% of respondents for Q76 'Are you (the patient) of Aboriginal origin, Torres Strait Islander origin, or both?'

High correlation between questions

Inter-item Pearson correlations were examined to establish if any questions were measuring the same construct, and may therefore be redundant. A correlation coefficient of 0.7 or higher is considered to represent a strong relationship between two variables.

The following pairs of questions exhibited a correlation of 0.7 or higher:

- Q23 'Were you given enough privacy when being examined or treated?' and Q24 'Were you given enough privacy when discussing your condition or treatment?'
- Q30 'Were the health professionals polite and courteous?' and Q31 'Were the health professionals kind and caring towards you?'
- Q32 'Overall, how would you rate the health professionals that treated you?' and Q61 'Overall, how would you rate the care you received in the clinic?'

Upon review with stakeholders, Q23 and Q24 were seen to be addressing different constructs, specifically, visual privacy and auditory privacy. Because of this, it was decided to retain both questions. Similarly, while Q32 and Q61 were highly correlated, one addressed rating of staff while the other was rating the entire experience – hence, as different constructs, both questions were retained.

However, reviewers thought there was good cause to remove one of Q30 and Q31 based on their experience of cancer outpatient clinics. Reviewers said that early contact was principally polite and courteous, developing into a more collegial relationship with staff expressing kindness and caring towards the outpatients. For this reason, Q30 on the politeness and courtesy of staff was removed, as this constituted a smaller part of the patient journey.

Cognitive interviews

No cognitive interviews were undertaken before this survey was implemented. This was due to the constricted timeframe to complete the survey before the end of the financial year. BHI minimised the impact of this by prioritising the inclusion of questions already tested in existing surveys and confirmed that the base questions had tested well in this population through analysis of data for oncology patient data from the Outpatient Survey 2014 (i.e. there were few questions with high item non-response rates, minimal examples of floor or ceiling effects, and little indication from factor analysis that large numbers of questions were highly correlated).

Questionnaire refinement

Throughout the development process, BHI and Ipsos were in regular contact with the advisory committee. This involved ad-hoc discussions, as well as series of meetings held at the key stages of development. Following the review of key literature and the statistical analysis of the OPS 2014, BHI met with Ipsos and the advisory committee to review and finalise the questionnaire for the COPS 2015.

The final content was developed depending on these design principles:

- The patient must be able to describe their experience with outpatient cancer services through answering the closed response questions in the survey
- Priority is given to questions that describe the experience and what occurred, rather than rating aspects of care or reporting satisfaction

- Validated questions are used in preference to non-validated questions, if they address the same construct (ideally, using the same question used in other BHI surveys)
- Double-barrelled questions are avoided
- Question wording must be clear, balanced and unbiased, i.e. leading questions are avoided
- Reading age must be no higher than 10 years
- 'Don't know' and 'not applicable' options are used only where essential
- Where relevant, the surveys include questions from a set of nationally-agreed core, common questions. These core questions were developed by the Patient Experience Information Development Working Group on behalf of the National Health Information Standards and Statistics Committee and have been tested by BHI across all of its surveys.

At each meeting, questionnaire inclusions and exclusions were discussed, with decisions made in light of the results of the development components, BHI's expert knowledge of the NSW healthcare system, survey design, data analysis and reporting needs and Ipsos' research expertise. Further, upon the drafting of the penultimate version of the questionnaire, it was presented to BHI's Strategic Advisory Committee for final review. Feedback from the committee was subsequently incorporated into the final version of the questionnaire.

Appendix 1: COPS 2015 – question source and development notes

The following table outlines the source of each question in the COPS 2015 and any relevant development notes. The following acronyms are used for questions which were developed for other surveys:

- **Original COPS 2015 question** – designed for the COPS 2015 questionnaire
- **Original OPS 2014 question (modified for COPS 2015)** – Designed for the NSW Outpatient Survey 2014, but modified for the COPS 2015
- **Original OPS 2014 question** – Designed for the NSW Outpatient Survey 2014
- **Original NSW PSP question** – designed for non-outpatient questionnaires from the NSW Patient Survey Program
- **CPES** – 2014 National Cancer Patient Experience Survey questionnaire
- **NHS Outpatients** - NHS Outpatient questionnaire 2011
- **NCCQ** – National set of Core, Common Patient Experience questions
- **AHQ** – the Acute Hospital Food Service Patient Satisfaction questionnaire
- **CQI** – the ‘Consumer Quality Index (CQ-Index) in an accident and emergency department: development and first evaluation’ BMC Health Services Research 2012.

Appendix Table 1: Question source and notes on modifications, COPS 2015

Question (COPS 2015)	Question source	Development notes
Q1 'What was the purpose of this visit?'	Original OPS 2014 question (modified for COPS 2015)	Treatments modified to include chemotherapy, radiotherapy and surgery.
Q2 'Were you able to get an appointment time that suited you?'	Original OPS 2014 question	Early development of this question was influenced by a similar question in the NHS Outpatient questionnaire. The purpose of the question changed to emphasise convenience of access rather than just being given a choice of appointments.
Q3 'Did you have any of the following difficulties when making this appointment?'	Original OPS 2014 question	
Q4 'From the time you booked this appointment to the time you went to the clinic, how long did you wait?'	Original OPS 2014 question (modified for COPS 2015)	Based on data from OPS 2014 for oncology and chemotherapy, the first response option ('less than one month') was split into 'less than 15 days' and '15 days to less than 1 month' to allow better discrimination of waiting time.
Q5 'Do you think the amount of time you waited was...?'	Original NSW PSP question	
Q6 'How much did your symptoms or condition stop you from carrying out your normal daily activities (for example, eating, dressing or using the bathroom) while you waited for this appointment?'	Original OPS 2014 question (modified for COPS 2015)	Added examples of activities to clarify the question and added option of 'I had no symptoms' to make it all inclusive.
Q7 'While you were waiting for this appointment, did your symptoms or condition...?'	Original OPS 2014 question	Early development of this question was influenced by a similar question in the NHS Outpatient questionnaire. The question changed to cover the full range of getting much better to getting much worse, moving from three items to five.
Q8 'How long did it take you to travel to the clinic for this appointment?'	NHS Outpatients	The question was re-phrased to refer to 'clinic' rather than 'the Outpatients Department'.
Q9 'What was your <u>main</u> form of transport to the clinic?'	NHS Outpatients	The reference to 'most recent' was removed from the OPS 2014 version. The answer category was changed to 'by a hospital or community transport service' for brevity and clarity.
Q10 'Was there a problem finding parking near the clinic?'	CQI A&E Survey	The question wording was adapted to refer to the 'clinic', and the same answer scale was used as adapted for the NSW Emergency Department Patient Survey.
Q11 'At the hospital, was it easy to find your way to the clinic?'	NHS Outpatients	The question wording was re-phrased from 'Outpatients Department' to the 'clinic'. The answer categories were revised to use the same scale as used elsewhere in the NSW Patient

Question (COPS 2015)	Question source	Development notes
		Surveys.
Q12 'Did any of the following cause you difficulties when entering and moving around the clinic?'	Original OPS 2014 question	Early development of this question was influenced by a similar question in the NHS Outpatient questionnaire. The question was changed to understand the range of difficulties in accessing the clinic, rather than the scale of difficulty.
Q13 'Were the reception staff polite and courteous?'	Original NSW PSP question	Early development of this question was influenced by a similar question in the NHS Inpatient questionnaire but the response options were changed from a five item rating scale to a three item scale.
Q14 'Did you feel you had enough privacy when talking with the receptionist?'	Original NSW PSP question	Early development of this question was influenced by a similar question in the NHS Outpatient questionnaire. Both question wording and answers were revised to be similar to other privacy questions used in the NSW Patient Surveys.
Q15 'How long after the scheduled <u>appointment time</u> did your appointment actually start?'	NHS Outpatients	The word 'stated' was removed from the question as it was considered redundant. The answer categories were reduced as the shorter waiting times (of less than 15 minutes) were not relevant.
Q16 'Did you experience any inconvenience or problems as a result of the wait?'	Original NSW PSP question	
Q17 'Were you told how long you had to wait?'	NHS Outpatients	
Q18 'Were you told why you had to wait?'	NHS Outpatients	
Q19 'How comfortable was the waiting area?'	Original OPS 2014 question	
Q20 'How clean was the clinic?'	NCCQ	The question wording was re-phrased to refer to the clinic generally, not the toilets and bathrooms.
Q21 'Were you given enough privacy when being <u>examined or treated</u> ?'	NHS Outpatients	

Question (COPS 2015)	Question source	Development notes
Q22 'Were you given enough privacy when discussing your condition or treatment?'	NHS Outpatients	
Q23 'Who did you see during this visit?'	Original OPS 2014 question	Modified for COPS 2015 to be specific to cancer, including a radiation therapist and lymphedema therapist, and being reordered by likely rate of seeing professionals.
Q24 'Did you have enough time to discuss your health issue with the health professionals you saw?'	NHS Outpatients	'Medical problem' was removed to simplify the question wording, and 'doctor' was replaced with 'health professional' to include the full range of staff caring for and treating them, during their visit to the clinic.
Q25 'Did the health professionals explain things in a way you could understand?'	NCCQ	
Q26 'During this visit, did the health professionals know enough about your medical history?'	NHS Outpatients	The question was changed to include the phrase 'during this visit' so that those patients making multiple visits to the clinic had clarity about which occasion they should be referring to. Also changed to refer to 'medical history' rather than 'condition or treatment'.
Q27 'How would you rate how well the health professionals worked together?'	NCCQ	The question wording was re-phrased so that 'doctors and nurses' was replaced with 'health professionals'.
Q28 'Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?'	Original NSW PSP question	Based on the UK question but heavily modified for NSW.
Q29 'Did you have worries or fears about your condition or treatment?'	NCCQ	The phrase 'while in hospital' was removed as it implied in-patient treatment.
Q30 'Did a health professional discuss your worries or fears with you?'	NCCQ	
Q31 'Did you have confidence and trust in the health professionals?'	NHS Outpatients	Modified to include all health professionals.
Q32 'Were the health professionals kind and caring towards you?'	Original NSW PSP question (modified)	The question was re-phrased to refer to 'health professionals' rather than doctors or nurses.
Q33 'Overall, how would you rate the health professionals who treated you?'	Original NSW PSP question (modified)	The question was re-phrased to refer to 'health professionals' rather than doctors or nurses.

Question (COPS 2015)	Question source	Development notes
Q34 'Do you have a care plan for your cancer treatment?'	Original OPS 2014 question (modified for COPS 2015)	Changed to work as a filter question for the following questions and to be more specific to cancer treatment. A definition of care plan was also added to clarify this with respondents.
Q35 'Was your care plan developed by health professionals from this clinic?'	Original OPS 2014 question (modified for COPS 2015)	Changed to be more direct.
Q36 'Were you asked for your ideas and preferences when developing this plan?'	Original OPS 2014 question	
Q37 'At your most recent visit, did the health professionals review your care plan with you?'	Original COPS 2015 question	
Q38 'Were you involved, as much as you wanted to be, NCCQ in decisions about your care and treatment?'		
Q39 'Were you treated with respect and dignity while you were at the clinic?'	NCCQ	'While in hospital' was replaced with 'while you were at the clinic' to be more appropriate. 'Did you feel' was removed from the question wording.
Q40 'Were your cultural or religious beliefs respected by the clinic staff?'	NHS Outpatients	Modified to ask about 'clinic staff' and to refer to cultural beliefs as well as religious beliefs.
Q41 'Were you given, or prescribed, any new medication to take at home?'	Original NSW PSP question	
Q42 'Did a health professional at the clinic explain the <u>purpose</u> of this medication in a way you could understand?'	Original NSW PSP question	This question was influenced by the NCCQ but was altered for comparability with other NSW PSP questionnaires.
Q43 'Did a health professional at the clinic tell you about medication <u>side effects</u> to watch for?'	NHS Outpatients	The question wording was re-phrased for clarity.
Q44 'Were you given enough information about how to manage the side effects of <u>any other treatment</u> you received during this visit?'	Original COPS 2015 question	
Q45 'Were you told who to contact if you were worried about your condition or treatment after you left the clinic?'	NHS Outpatients	The beginning of the question was changed to simplify the question.

Question (COPS 2015)	Question source	Development notes
Q46 'While in the clinic, did you receive, or see, any information about how to comment or complain about your case?'	Original NSW PSP question (modified)	Although influenced by the NHS Inpatient question, this question emphasised rights of the patient rather than information on how to complain. It was also altered to change from 'While in hospital' to 'while in the clinic'.
Q47 'During your visit or soon afterwards, did you experience any of the following complications or problems related to the care you received at the clinic?'	Original NSW PSP question (modified)	The question wording was re-phrased to refer to 'clinic' rather than 'hospital', and 'visit' rather than 'hospital stay'. The response option 'sever anxiety or worry' was added on the advice of the advisory committee.
Q48 'Was the impact of this complication or problem ...?'	Original NSW PSP question	
Q49 'In your opinion, were the clinic staff open with you about this complication or problem?'	Original NSW PSP question (modified)	The question wording was adapted to refer to 'clinic staff', not 'members of hospital staff'. 'Not applicable, as it happened after I left' was added to account for this scenario.
Q50 'Did you have to pay any of the following out of pocket expenses in relation to this visit?'	Original OPS 2014 question (modified for COPS 2015)	Question changed to identify what people had to pay for.
Q51 'How long have you been attending this cancer clinic?'	Original OPS 2014 question (modified for COPS 2015)	Early development of this question was influenced by a similar question in the NHS Outpatient questionnaire. The purpose of the question changed from the number of visits to the clinic, to the length of time they have attended the clinic.
Q52 'In the last 12 months, how many times have you visited this cancer clinic?'	NHS Outpatients	The question wording was simplified and 'Outpatient Department' changed to 'cancer clinic'.
Q53 'Was there any time when the health professionals needed access to your health records and they were not available?'	COPS 2015	
Q54 'Did you ever receive conflicting information about your condition or treatment from the health professionals?'	COPS 2015	
Q55 'Overall, how would you rate the care you received in the clinic?'	NCCQ	The question was re-phrased to refer to 'clinic' rather than 'hospital'.
Q56 'How well organised was the care you received in the clinic?'	NHS Outpatients	The question was altered to talk about how organised the care they received was (compared to how organised the outpatient department was) and response options were inverted.
Q57 'If asked about your clinic experience by friends and family, how would you respond?'	Original NSW PSP question (modified)	The word 'hospital' was replaced with 'clinic'.

Question (COPS 2015)	Question source	Development notes
Q58 'Did you attend this clinic because you have or have had cancer?'	COPS 2015	Question required as not all patients attending Cancer Outpatient Clinics in NSW are being seen for cancer – some conditions such as rheumatoid arthritis or lupus are treated by chemotherapy at these clinics.
Q59 'Is this the first time you have had cancer?'	CPES	Question modified to as if this is the first time they have 'had cancer' rather than 'been treated for cancer'.
Q60 'How has your current cancer responded to treatment?'	CPES	
Q61 'How long has it been since you first received treatment for this cancer?'	CPES	Changed to say 'first received treatment' rather than 'were first treated'. The timeframes in the responses were broken down into more parts to aid analysis.
Q62 'What treatment have you received for your cancer?'	Original COPS 2015 question	
Q63 'In the past three months, have you gone to an emergency department because of your cancer or cancer complications?'	Original NSW PSP question (modified)	Originally used in Small and Rural Hospitals Survey and modified for COPS 2015.
Q64 'Communication and Attitudinal Self-Efficacy Scale for Cancer (CASE-Cancer)'	Wolf MS et al, 2005. CASE-cancer survey (modified)	Small adjustments to question layout made.
Q65 'Edmonton Symptom Assessment System (ESAS)'	Bruera E et al, 1991. The Edmonton Symptom Assessment System (modified)	Set to nine items rather than the original 10, which included a non-specific response (an 'insert another symptom' option).
Q66 'What year were you born?'	NCCQ	
Q67 'What is your gender?'	AHQ	
Q68 'What is the highest level of education you have completed?'	Original NSW PSP question	
Q69 'What language do you mainly speak at home?'	NCCQ	
Q70 'Did you need, or would you have liked, to use a professional interpreter at any stage while you were at the clinic?'	Original NSW PSP question	

Question (COPS 2015)	Question source	Development notes
Q71 'Was a professional interpreter provided when you needed one?'	Original NSW PSP question (modified)	Question changed to specify a 'professional interpreter'.
Q72 'Are you of Aboriginal origin, Torres Strait Islander origin, or both?'		
Q73 'Which, if any, of the following long-standing conditions do you have (including age related conditions)?'	NHS Outpatients	Question and categories slightly modified.
Q74 'Who completed this survey?'	NHS Outpatients	
<p>Q75 'The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to you which are maintained by various NSW and Commonwealth agencies (including your hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your health care information for the two years before and after your visit will allow us to better understand how different aspects of the care provided by health facilities are related to the health and use of health services of their patients. Your information will be treated in the strictest confidence. We will receive the linked information after your name and address have been removed. We will not report any results which may identify you as an individual and your responses will not be accessible to the people who looked after you. Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you?'</p>	Original NSW PSP question	
Q76 'What was the best part of the care you received while at this cancer clinic?' (free text question)	Original NSW PSP question (modified)	Modified to be relevant to cancer clinics.
Q77 'What part of the care provided by this cancer clinic most needs improving?' (free text question)	Original NSW PSP question (modified)	Modified to be relevant to cancer clinics.

Appendix 2: Item non-response rate

Appendix Table 2: Rates of item non-response for COPS 2015, descending order

OPS 2014 question	OPS 2014 question wording	% missing
Q70	What is the highest level of education you (the patient) have completed?	7.5
Q53	Did the health professionals at this clinic provide you with a treatment plan for your ongoing care?	6.5
Q73	Which language do you (the patient) mainly speak at home?	5.3
Q78	Do you give permission for the Bureau of Health Information to link you answers from this survey to health records related to you (the patient)?	5.3
Q43	Were there things for your child to do (such as books, games and toys)?	5.0
Q44	Was the area in which your child was treated suitable for someone of their age group?	5.0
Q45	Did the clinic staff provide care and understanding appropriate to the needs of your child?	5.0
Q67	Is the problem you went to the clinic for...?	4.9
Q1	Which type of outpatient clinic did you attend?	4.8
Q50	Were you told about medication side effects to watch for?	4.8
Q9	While you were waiting for this appointment, did your symptoms or condition...?	4.5
Q52	Was this visit related to a long-standing or chronic health condition?	4.5
Q42	In your opinion, were the clinic staff open with you about this complication or problem?	4.3
Q76	Are you (the patient) of Aboriginal origin, Torres Strait Islander origin, or both?	4.2
Q6	From the time you booked this appointment to the time you went to the clinic, how long did you wait?	3.7
Q64	Did you want to make a complaint about something that happened in the clinic?	3.7
Q5	Did you have any of the following difficulties when making this appointment?	3.6
Q51	Did the clinic give your GP enough information about your condition or the treatment you received?	3.6
Q60	In your opinion, did the different health professionals you've seen know enough about your medical history?	3.6
Q75	Was an interpreter provided when you (the patient) needed one?	3.4
Q49	Were you given enough information about this medication?	3.3
Q7	Do you think the amount of time you waited was...?	3.2
Q8	How much did your symptoms or condition stop you from carrying out your normal daily activities while you waited for this appointment?	3.2
Q56	Did you skip any follow-up medication, tests, or treatment recommended at this visit because of their cost?	3.1
Q71	Which, if any, of the following long-standing conditions do you (the patient) have (including age related conditions)?	3.1
Q48	Were you given, or prescribed, any new medication to take at home?	3.0
Q57	In the last 12 months, how many times have you visited this outpatient clinic?	3.0
Q55	Did you have to pay any out of pocket expenses for this visit (i.e. a payment that you would not get back from Medicare or private health fund)?	2.9

OPS 2014 question	OPS 2014 question wording	% missing
Q66	Did the care and treatment received at the clinic help you?	2.9
Q59	Did the health professionals you've seen change from one visit to another?	2.8
Q65	Why didn't you make a complaint?	2.8
Q12	Was there a problem finding parking near the clinic?	2.6
Q40	Not including the reason you came to the clinic, during your visit, or soon afterwards, did you experience any of the following complications or problems?	2.6
Q41	Was the impact of this complication or problem...?	2.5
Q47	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?	2.5
Q63	If asked about your clinic experience by friends and family, how would you respond?	2.5
Q2	How long have you been attending this outpatient clinic?	2.3
Q46	When you left the clinic, were you given enough information about how to manage your care at home?	2.3
Q3	What was the purpose of this visit?	2.2
Q62	How well organised was the care you received in the clinic?	2.2
Q19	Were you told why and how long you had to wait?	2.1
Q33	Did you have worries or fears about your condition or treatment?	2.1
Q77	Who completed this survey?	2.1
Q20	How comfortable was the waiting area?	2.0
Q54	Were you asked for your ideas and preferences when developing this plan?	2.0
Q61	Overall, how would you rate the care you received in the clinic?	2.0
Q4	Were you able to get an appointment time that suited you?	1.9
Q72	In general, how would you rate your (the patient's) health?	1.9
Q58	Did you receive care or treatment from more than one health professional at this clinic?	1.8
Q14	Did any of the following cause you difficulties when entering and moving around the clinic?	1.7
Q24	Were you given enough privacy when discussing your condition or treatment?	1.7
Q35	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	1.6
Q17	How long after the appointment time did your appointment start?	1.5
Q28	During this visit, did the health professionals know enough about your medical history?	1.5
Q38	Were your cultural or religious beliefs respected by the clinic staff?	1.5
Q39	While in the clinic, did you receive, or see, any information about your rights as a patient, including how to comment or complain?	1.5
Q69	What is your (the patient's) gender?	1.5
Q10	How long did it take you to travel to the clinic for this appointment?	1.4
Q18	Did you experience any inconvenience or problems as a result of the wait?	1.4
Q13	At the hospital, was it easy to find your way to the clinic?	1.3
Q15	Were the reception staff polite and courteous?	1.3
Q21	How clean was the clinic?	1.3
Q23	Were you given enough privacy when being examined or treated?	1.3

OPS 2014 question	OPS 2014 question wording	% missing
Q26	Did you have enough time to discuss your health issue with the health professionals you saw?	1.3
Q16	Did you feel you had enough privacy when talking with the receptionist?	1.2
Q27	Did the health professionals explain things in a way you could understand?	1.2
Q29	Did you have confidence and trust in the health professionals?	1.1
Q30	Were the health professionals polite and courteous?	1.1
Q31	Were the health professionals kind and caring towards you?	1.1
Q32	Overall, how would you rate the health professionals who treated you?	1.1
Q11	What was your main form of transport to the clinic?	1.0
Q25	Who did you see during this visit?	1.0
Q22	Did you see health professionals wash their hands, or use hand gel to clean their hands, before touching you?	0.9
Q36	How would you rate how well the health professionals worked together?	0.9
Q37	Were you treated with respect and dignity while you were at the clinic?	0.8
Q74	Did you need, or would you have liked, to use an interpreter at any stage while you (the patient) were at the clinic?	0.8
Q34	Did a health professional discuss your worries or fears with you?	0.6
Q68	What year were you (the patient) born?	0.0

Appendix 3: Cancer Outpatients Survey 2015



NSW Patient Survey: Outpatient Cancer Clinics

<Barcode>
<Title> <First Name> <Last Name>
<Address Line 1>
<SUBURB> <STATE> <POSTCODE>

Date

Dear <TITLE> <LAST NAME>,

Your experience of healthcare in NSW is very important to us

I am writing to ask you to take part in the NSW Patient Survey by telling us about your recent outpatient visit to a cancer clinic at [HOSPITAL NAME] during [MONTH]. Outpatient cancer clinics provide oncology and chemotherapy services to people with cancer, people being tested for cancer and sometimes for people with non-cancer conditions.

Your experience at this clinic is important as it helps us understand the quality of care you received and allows clinics to see where they need to improve.

The survey is easiest to complete online. Please visit the web address below and log in with the following username and password. It is possible to partially complete the survey online and then return to it later to complete the remainder



Web address: [INS_URL]

Username: [INS_UNAME]

Password: [INS_PWORD]

If you prefer to complete the attached paper survey, please use the included reply-paid envelope to mail it back to us.

Taking part in the survey is voluntary. You have been randomly selected to participate and there are many safeguards in place to protect your identity. The staff who provided your care or treatment will not know if you have returned a completed survey and will not be able to see your responses to the survey. At no point will we report any information that identifies you as an individual.

The Bureau of Health Information (BHI) runs the survey along with Ipsos Social Research Institute, who is sending you this survey on BHI's behalf. BHI was established by the NSW Government to independently report on the performance of the public health system in NSW, including the healthcare experiences of patients. Results for the NSW Patient Survey are reported in *Healthcare Observer*, found on our website www.bhi.nsw.gov.au

If you have any queries regarding the survey, please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm).

Thank you for taking part in the survey.

Yours sincerely

Jean-Frédéric Lévesque
Chief Executive
Bureau of Health Information

How to complete the survey

This survey is about your recent experience as an outpatient in the cancer clinic at the hospital referred to on the previous page. If you have been to more than one cancer clinic recently, please answer about your most recent visit to this clinic.

For each question, please use a blue or black pen to mark the box next to the answer you choose.

Please do not write your name or address on the survey.

Sometimes you will find the box you have marked has an instruction to go to another question.

By following the instructions carefully you will be able to move past questions that do not apply to you.

If you would prefer not to answer individual questions, leave them blank but please complete the rest of the survey.

If you make a mistake or wish to change a response, simply fill in that box and mark the correct box like this:

If someone is helping you to complete this survey, please ensure the answers given are from your point of view, and not the opinion of the person helping you.

Some questions and answers

Why are you carrying out the survey?

The NSW Patient Survey gathers information about your experience of health services.

This survey will help us to understand people's experience with outpatient cancer clinics. It will assist us to identify ways to improve services, so that the health care system in NSW can better meet the needs of people using these services now and in the future.

How do I make a formal complaint about my experience at the outpatient clinic?

Please contact the clinic directly.

Alternatively, you can get more information about your options at the following website:

www.health.nsw.gov.au/patientconcerns

Why have I been sent a survey?

You have been sent this survey because you recently attended a cancer clinic at the hospital referred to on the cover of the survey.

People attend cancer clinics for a variety of reasons. While some do not have a diagnosis of cancer, unfortunately many do. We appreciate that for some people, this survey may be difficult to complete and we respect your decision about whether or not to do so.

If you need help, or someone to talk to about concerns or worries about your condition, you may like to contact:

- Your General Practitioner
- The Cancer Council helpline on 13 11 20

The Cancer Council helpline is a free, confidential phone information and support service. Specially trained staff are available to answer your questions about cancer and offer emotional or practical support.

What happens to my survey responses?

Your survey responses will be de-identified and then processed with responses from other people who completed the survey to form a report. These reports will then be provided to NSW Health and local hospitals to help them to improve health services.

Your responses will be treated in the strictest confidence and no identifying information will be given to NSW Health, the hospital or health service you attended, your doctor or other health provider unless required by law. Your responses will not affect any future health services that may be provided to you.

How is my privacy protected?

Your privacy is protected by legislation. Ipsos has been provided with your name and address by NSW Health for the purpose of sending you this survey only, and will keep your contact details confidential.

After all surveys are processed, identifying information will be destroyed and Ipsos will then no longer be able to identify the responses you provided. However, for the period that identifiable details remain, you will be able to contact Ipsos through the toll-free Patient Survey Helpline to ask to see your responses, or to request that some or all of your information be deleted.

You can get more information about privacy and confidentiality by calling the toll-free Patient Survey Helpline or at the following website:

www.bhi.nsw.gov.au/nsw_patient_survey_program/privacy

How do I get more information about the survey?

Please contact the toll-free Patient Survey Helpline on 1800 220 936 (Monday to Friday, 4pm–8pm, excluding public holidays).

NSW Patient Survey: Outpatient Cancer Clinics

BEFORE ARRIVING AT THE CLINIC

When completing this part of the survey, please think about your **latest visit** to the cancer clinic at the hospital named on the cover of this booklet.

Q1 What was the purpose of this visit?

Please all that apply to you

- Have tests, X-rays or scans
- Receive test, X-ray or scan results
- Medical diagnosis or advice
- Regular check-up
- Chemotherapy
- Radiotherapy
- Review of treatment
- Surgical procedure
- Follow-up after surgery
- Other reason

Q2 Were you able to get an appointment time that suited you?

- Yes
- No
- I didn't have an appointment arranged in advanceGo to Q8

Q3 Did you have any of the following difficulties when making this appointment?

Please all that apply to you

- I didn't know how to make an appointment
- I didn't know which clinic to call
- The contact details were hard to find
- My call was not answered
- I had to wait on hold for a long time
- The appointment was previously cancelled/postponed
- Some other difficulty
- None - I had no difficulties

Q4 From the time you booked this appointment to the time you went to the clinic, how long did you wait?

- Less than 15 days
- 15 days to less than 1 month
- 1 to 3 months
- 4 to 6 months
- 7 to 12 months
- More than 1 year
- Don't know/can't remember

Q5 Do you think the amount of time you waited was...?

- About right
- Slightly too long
- Much too long
- Don't know/can't remember

Q6 How much did your symptoms or condition stop you from carrying out your normal daily activities (for example, eating, dressing or using the bathroom) while you waited for this appointment?

- Not at all
- Only a little
- Somewhat
- Very much
- I was not able to at all
- I had no symptoms.....Go to Q8

Q7 While you were waiting for this appointment, did your symptoms or condition...?

- Get much better
- Get a little better
- Stay about the same
- Get a little worse
- Get much worse
- Don't know/can't remember

ARRIVAL AT THE CLINIC

Still thinking about your latest visit to this cancer clinic...

Q8 How long did it take you to travel to the clinic for this appointment?

- Less than 30 minutes
- 30 to 59 minutes
- 1 hour to under 2 hours
- 2 hours to under 3 hours
- 3 hours or more
- Don't know/can't remember

Q9 What was your main form of transport to the clinic?

Please one only

- By private car
- By a hospital or community transport serviceGo to Q11
- By taxiGo to Q11
- By public transportGo to Q11
- On footGo to Q11
- OtherGo to Q11

Q10 Was there a problem finding parking near the clinic?

- Yes, a big problem
- Yes, a small problem
- No problem
- I did not need parking

Q11 At the hospital, was it easy to find your way to the clinic?

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

Q12 Did any of the following cause you difficulties when entering and moving around the clinic?

Please all that apply to you

- A long walk
- No ramp/only stairs
- No lift/elevator
- Narrow walkways/halls/doorways
- No accessible toilets
- Some other difficulty
- None - I had no difficulties

Q13 Were the reception staff polite and courteous?

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

Q14 Did you feel you had enough privacy when talking with the receptionist?

- Yes
- No
- I did not talk to the receptionist

WAITING IN THE CLINIC

Q15 How long after the scheduled appointment time did your appointment actually start?

- On time, or earlyGo to Q19
- Less than 15 minutes
- 15 to 29 minutes
- 30 to 59 minutes
- 1 hour to under 2 hours
- 2 hours or more
- I didn't have an appointment.....Go to Q19
- Don't know/can't rememberGo to Q19

Q16 Did you experience any inconvenience or problems as a result of the wait?

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

Q17 Were you told how long you had to wait?

- Yes
- No

Q18 Were you told why you had to wait?

- Yes
- No

Q19 How comfortable was the waiting area?

- Very comfortable
- Fairly comfortable
- Not very comfortable
- Not at all comfortable

THE PHYSICAL ENVIRONMENT

Still thinking about your latest visit to this cancer clinic...

Q20 How clean was the clinic?

- Very clean
- Fairly clean
- Not very clean
- Not at all clean

Q21 Were you given enough privacy when being examined or treated?

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

Q22 Were you given enough privacy when discussing your condition or treatment?

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

THE HEALTH PROFESSIONALS

Q23 Who did you see during this visit?
Please all that apply to you

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

Q24 Did you have enough time to discuss your health issues with the health professionals you saw?

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

Q25 Did the health professionals explain things in a way you could understand?

- Yes, always
- Yes, sometimes
- No

Q26 During this visit, did the health professionals know enough about your medical history?

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

Q27 How would you rate how well the health professionals worked together?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor
- Not applicable – only saw one

Q28 Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching you?

- Yes, always
- Yes, sometimes
- No, I did not see this
- Not applicable to my visit
- Can't remember

Q29 Did you have worries or fears about your condition or treatment?

- Yes
- NoGo to Q31

Q30 Did a health professional discuss your worries or fears with you?

- Yes, completely
- Yes, to some extent
- No

Q31 Did you have confidence and trust in the health professionals?

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

Q32 Were the health professionals kind and caring towards you?

- Yes, always
- Yes, sometimes
- No

Q33 Overall, how would you rate the health professionals who treated you?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

PLANNING YOUR CARE

Q34 Do you have a care plan for your cancer treatment?

A care plan is a document that sets out your needs and goals for the treatment and management of your cancer.

- Yes
- NoGo to Q38
- I do not need oneGo to Q38
- Don't know/can't rememberGo to Q38

Q35 Was your care plan developed by health professionals from this clinic?

- Yes
- No

Q36 Were you asked for your ideas and preferences when developing this plan?

- Yes, definitely
- Yes, to some extent
- No
- Don't know/can't remember

Q37 At your most recent visit, did the health professionals review your care plan with you?

- Yes
- No
- Not applicable as I did not have a care plan before this visit
- Don't know/can't remember

YOUR TREATMENT AND CARE

Q38 Were you involved, as much as you wanted to be, in decisions about your care and treatment?

- Yes, definitely
- Yes, to some extent
- No
- I did not want or need to be involved

Q39 Were you treated with respect and dignity while you were at the clinic?

- Yes, always
- Yes, sometimes
- No

Q40 Were your cultural or religious beliefs respected by the clinic staff?

- Yes, always
- Yes, sometimes
- No, my beliefs were not respected
- My beliefs were not an issue

Q41 Were you given, or prescribed, any new medication to take at home?

- Yes
- NoGo to Q44

Q42 Did a health professional at the clinic explain the purpose of this medication in a way you could understand?

- Yes, completely
- Yes, to some extent
- No

Q43 Did a health professional at the clinic tell you about medication side effects to watch for?

- Yes, completely
- Yes, to some extent
- No

Q44 Were you given enough information about how to manage the side effects of any other treatment you received during this visit?

- Yes, completely
- Yes, to some extent
- No
- I did not need this type of information

Q45 Were you told who to contact if you were worried about your condition or treatment after you left the clinic?

- Yes
- No
- I did not need this type of information
- Don't know/can't remember

Q46 While in the clinic, did you receive or see any information about how to comment or complain about your case?

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

AFTER YOUR VISIT

Q47 During your visit or soon afterwards, did you experience any of the following complications or problems related to the care you received at the clinic?

Please all that apply to you

- An infection
- Uncontrolled bleeding
- An unexpected negative reaction to medication
- Complications as a result of tests or procedures
- Severe pain due to the treatment
- Severe anxiety or worry
- Any other complication or problem (other than common side-effects from treatment)
- None of theseGo to Q50

Q48 Was the impact of this complication or problem...?

- Very serious
- Fairly serious
- Not very serious
- Not at all serious

Q49 In your opinion, were the clinic staff open with you about this complication or problem?

- Yes, completely
- Yes, to some extent
- No
- Not applicable, as it happened after I left

Q50 Did you have to pay any of the following out of pocket expenses in relation to this visit?

Out of pocket expenses are those that you don't get back from Medicare or a private health fund.

Please all that apply to you

- Consultation fees
- Medication
- Treatment/surgery costs
- Travel
- Parking
- Accommodation
- Other related expenses
- None of these – I had no expenses
- Don't know/can't remember

NUMBER OF VISITS

Q51 How long have you been attending this cancer clinic?

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

Q52 In the last 12 months, how many times have you visited this cancer clinic?

- OnceGo to Q55
- 2 to 3 times
- 4 to 8 times
- More than 8 times

Q53 Was there any time when the health professionals needed access to your health records and they were not available?

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

Q54 Did you ever receive conflicting information about your condition or treatment from the health professionals?

- Yes
- No
- Not applicable - I was always treated by the same person

OVERALL CARE

Q55 Overall, how would you rate the care you received in the clinic?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

Q56 How well organised was the care you received in the clinic?

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

Q57 If asked about your clinic experience by friends and family, how would you respond?

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

TREATMENT NEEDS AND OUTCOMES

Q58 Did you attend this clinic because you have or have had cancer?

- Yes
- NoGo to Q66

Q59 Is this the first time you have had cancer?

- Yes, this is the first time I have had cancer
- No, I have had the same type of cancer before but it has now come back
- No, I have had a different type of cancer before

Q60 How has your current cancer responded to treatment?

Please ONE option that is closest to your situation

- Treatment has not yet started for this cancerGo to Q63
- I am in the course of treatment and I can't tell yet how my cancer has responded
- The treatment has been effective and I have no signs or symptoms of cancer
- I have finished the course of treatment but my cancer is still present
- My cancer is being treated again because it has not responded fully to treatment
- I am not in active treatment but I am on "Watch and Wait"Go to Q63
- My cancer has not been treated at allGo to Q63

Q61 How long has it been since you first received treatment for this cancer?

- Less than 3 months
- 3 to 6 months
- More than 6 months but less than 1 year
- 1 to 5 years
- More than 5 years
- Don't know/can't remember

Q62 What treatment have you received for your cancer?

Please all that apply to you

- Radiotherapy
- Chemotherapy
- Surgery
- Other treatment (e.g. hormone therapy)

Q63 In the past three months, have you gone to an emergency department because of your cancer or cancer complications?

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

COPING WITH CANCER

Q64

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

Please answer for how you feel **right now** (at the time of completing this survey). If a statement doesn't apply to you, just skip it and move to the next one.

	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree
a. I know that I will be able to deal with any unexpected health problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. I am confident in my ability to understand written information about cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. I am confident in my ability to understand my doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. It is easy for me to actively participate in decisions about my treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. I won't let cancer get me down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. It is easy for me to keep a positive attitude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. It is easy for me to maintain a sense of humour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. I am confident that I can control my negative feelings about cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. If I don't understand something, it is easy for me to ask for help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. It is easy for me to ask nurses questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. It is easy for me to ask my doctor questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. It is easy for me to get information about cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree

Source: Wolf MS et al, 2005. CASE-cancer survey (modified)

ASSESSING YOUR HEALTH

Q65

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

Please the box that corresponds to your rating on a scale of 0 (no problem) to 10 (worst possible problem).

a. No pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible pain
	0	1	2	3	4	5	6	7	8	9	10	
b. Not tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible tiredness
	0	1	2	3	4	5	6	7	8	9	10	
c. Not nauseated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible nausea
	0	1	2	3	4	5	6	7	8	9	10	
d. Not depressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible depression
	0	1	2	3	4	5	6	7	8	9	10	
e. Not anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible anxiety
	0	1	2	3	4	5	6	7	8	9	10	
f. Not drowsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible drowsiness
	0	1	2	3	4	5	6	7	8	9	10	
g. Best appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible appetite
	0	1	2	3	4	5	6	7	8	9	10	
h. Best feeling of wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible feeling of wellbeing
	0	1	2	3	4	5	6	7	8	9	10	
i. No shortness of breath	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Worst possible shortness of breath
	0	1	2	3	4	5	6	7	8	9	10	

Source: Bruera E et al, 1991. The Edmonton Symptom Assessment System (modified)

ABOUT YOU

The following questions will help us to see how experiences vary between different groups of the population.

Q66 What year were you born?
WRITE IN (YYYY)

Q67 What is your gender?
 Male
 Female

Q68 What is the highest level of education you have completed?
 Still at secondary school
 Less than Year 12 or equivalent
 Completed Year 12 or equivalent
 Trade or technical certificate or diploma
 University degree
 Post graduate/higher degree

Q69 Which language do you mainly speak at home?
 EnglishGo to Q72
 A language other than English
Please write in the language:

Q70 Did you need, or would you have liked, to use a professional interpreter at any stage while you were at the clinic?
 Yes
 NoGo to Q72

Q71 Was a professional interpreter provided when you needed one?
 Yes, always
 Yes, sometimes
 No

Q72 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

Q73 Which, if any, of the following long-standing conditions do you have (including age related conditions)?

Please all that apply to you

- Deafness or severe hearing impairment
- Blindness or severe vision impairment
- A long-standing illness (e.g. cancer, HIV, diabetes, chronic heart disease)
- A long-standing physical condition
- A learning disability
- A mental health condition (e.g. depression)
- A neurological condition (e.g. Alzheimer's, Parkinson's)
- None of these

Q74 Who completed this survey?
 The patient
 The patient with help from someone else
 Someone else on behalf of the patient

Q75 The Bureau of Health Information would like your permission to link your survey answers to other information from health records relating to you which are maintained by various NSW and Commonwealth agencies (including your hospitalisations, medical visits, ambulance transportation, medication or health registry information). Linking to your health care information for the two years before and after your visit will allow us to better understand how different aspects of the care provided by health facilities are related to the health and use of health services of their patients.

Your information will be treated in the strictest confidence. We will receive the linked information after your name and address have been removed. We will not report any results which may identify you as an individual and your responses will not be accessible to the people who looked after you.

Do you give permission for the Bureau of Health Information to link your answers from this survey to health records related to you?

- Yes
- No

YOUR COMMENTS

Q76 What was the best part of the care you received while at this cancer clinic?

Q77 What part of the care provided by this cancer clinic most needs improving?

**Thank you for your time.
Please remove the covering letter by tearing along the perforated line.
Return the survey in the reply paid envelope provided
or send it in an envelope addressed to
NSW Patient Survey, Ipsos Social Research Institute,
Reply Paid 84599, Hawthorn, VIC 3122 (no stamp is needed)**

Some of the questions asked in this survey are sourced from the NHS patient survey programme (courtesy of the NHS Care Quality Commission and the National Research Corporation (USA)), the CASE-cancer survey (reference 'Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer)', Wolf MS et al, 2005. Patient Education and Counseling), the ESAS survey (reference 'The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients', Bruera E et al, 1991. Journal of Palliative Care), and the Australian Patient Experience Indicator Development Working Group (PEIDWG) national set of core, common patient experience questions. Questions are used with the permission of each organisation.

Barcode