



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

Date

Dear <First Name> <Last Name>

Your feedback about your hospital experience is important

I am writing to invite you to provide feedback about your outpatient visit to [Hospital Name] in November 2017. This questionnaire asks about outpatient clinics that mainly provide care to patients with cancer, but also provide care to patients without cancer, who were treated for other conditions. We would like to hear from all patients so your feedback can be used to improve health services. We understand that this questionnaire reaches you some time after your November 2017 clinic visit, but we would greatly appreciate it if you can complete it to the best of your recollection.

The questionnaire is easiest to complete online. Once you start the online questionnaire, it is possible to return later to complete it. Please visit the web address below and log in with the following unique username and password.



Visit survey.ipsos.com.au/patientsurvey

Username [INS_UNAME]

Password [INS_PWORD]

If you prefer to complete the attached paper questionnaire, please remove this covering letter before placing the completed questionnaire in the enclosed Reply Paid envelope.

Your information will be treated confidentially. The hospital staff who cared for you will not know whether you have completed the questionnaire and will not be able to see your responses.

If you have any questions or need help filling in the questionnaire, please contact the toll-free Patient Survey Helpline on **1800 220 936** (Monday to Friday, 9am–8pm), or email your questions to **NSWPatientSurvey@ipsos.com** (include your username [INS_UNAME] in the subject line).

For further information about the survey program and to see how your local hospital is performing, visit the Bureau of Health Information website at **bhi.nsw.gov.au**

Thank you very much for your time helping to improve NSW Health services.

Yours sincerely

Dr Diane Watson

Chief Executive
Bureau of Health Information



HOW TO COMPLETE THE PAPER QUESTIONNAIRE

Please use a blue or black pen to mark an **X** in the box next to the answer you choose.

Sometimes the box you have marked has a 'Go to...' instruction. By following the 'Go to...' instruction you will be able to move past any questions that do not apply.

Q3

Did you need parking for your clinic visit?

Yes

NoGo to Q5

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

Q7

Were you told how long you had to wait?

Yes

No

If you prefer not to answer a question, leave it blank and continue to the next question.

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

PRIVACY INFORMATION

Your privacy is protected by legislation

The Bureau of Health Information (BHI) works with Ipsos to manage the patient survey program on behalf of NSW Health. NSW Health provides Ipsos with your name and address for the purpose of sending you this questionnaire only. Ipsos will keep your contact details confidential.

Your questionnaire responses will be treated in the strictest confidence. Once you have completed the survey, your contact details are removed from the survey results. No identifying information will be given to NSW Health, the hospital or health service you attended, your doctor or any other health professionals unless required by law.

Your answers will be analysed along with the responses from other people who completed the questionnaire. The results will be provided to your local hospital and to NSW Health to help improve services.

You can get more information about privacy and confidentiality at www.bhi.nsw.gov.au/nsw_patient_survey_program/privacy

The results of all NSW patient surveys are reported publicly on the BHI website at bhi.nsw.gov.au

MORE INFORMATION

This questionnaire asks about outpatient clinics that mainly provide care to patients with cancer, but also provide care to patients without cancer. Therefore this questionnaire will also have been received by patients who were treated for other conditions.

Some of the questions relate to people who visited the outpatient clinic because they have or had cancer. We appreciate that this questionnaire 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 any concerns or worries you might have, you may like to contact your general practitioner or specially trained staff at the Cancer Council Information and Support Line on **13 11 20**.

The Cancer Council Information and Support Line is a free, confidential phone information and support service.



ARRIVAL AT THE CLINIC

When completing the survey, please think about your visit to the clinic at the hospital named in the covering letter, in November 2017.

Q1 What was the purpose of this visit?

Please all the boxes that apply to you

- Have tests, X-rays or scans
- Receive test, X-ray or scan results
- Medical diagnosis or advice
- Chemotherapy
- Radiotherapy
- Immunotherapy or hormone therapy
- Transfusion
- Surgical procedure
- Follow-up after surgery
- Treatment review
- Regular check-up/long-term follow-up
- Other reason

Q2 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 or more
- Don't know/can't remember

Q3 Did you need parking for your clinic visit?

- Yes
- No Go to Q5

Q4 Did you have any of the following issues with parking during this visit?

Please all the boxes that apply to you

- No car park at the clinic
- The car park was full
- Too few disabled parking spaces
- Expensive parking fees
- Had to walk a long way from the car park
- None of these issues

Q5 Were the reception staff polite and courteous?

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

Q6 How long after the scheduled appointment time did your appointment actually start?

- On time, or early Go to Q8
- 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 Q8
- Don't know/can't remember Go to Q8

Q7 Were you told how long you had to wait?

- Yes
- No

THE PHYSICAL ENVIRONMENT

Q8 How comfortable was the waiting area?

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

Q9 How comfortable was the treatment area?

- Very comfortable
- Fairly comfortable
- Not very comfortable
- Not at all comfortable
- I did not go to a treatment area at the clinic Go to Q11

Q10 How clean was the treatment area?

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

THE HEALTH PROFESSIONALS

Q11 Who did you see during this visit?

Please all the boxes that apply to you

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

Q12 Did you have enough time to discuss your health issues with the health professionals you saw?

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

Q13 Did the health professionals explain things in a way you could understand?

- Yes, always
- Yes, sometimes
- No

Q14 During this visit, did the health professionals know enough about your medical history?

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

Q15 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

Q16 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

Q17 Did you have worries or fears about your condition or treatment?

- Yes
- No.....Go to Q19

Q18 Did a health professional discuss your worries or fears with you?

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

Q19 Did you have confidence and trust in the health professionals?

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

Q20 Were the health professionals kind and caring towards you?

- Yes, always
- Yes, sometimes
- No

Q21 Overall, how would you rate the health professionals who treated you?

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

PLANNING YOUR CARE

Q22 When making decisions about your treatment, did a health professional at the clinic inform you about different treatment options?

- Yes, always
- Yes, sometimes
- No, treatment options were not discussed
- Not applicable to my situation... Go to Q24

Q23 Did a health professional at the clinic tell you about the risks and benefits of the treatment options?

- Yes, always
- Yes, sometimes
- No

Q24 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

Q25 Did a health professional at the clinic explain the next steps of your care and treatment in a way you could understand?

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

Q26 Did you ever receive conflicting information about your condition or treatment from the health professionals?

- Yes
- No

The following questions ask about care plans. Care plans are written documents that outline the steps and goals in managing your medical condition.

Q27 Do you have a written care plan for your current or ongoing care?

- Yes
- No..... Go to Q30
- I do not need one..... Go to Q30
- Don't know/can't remember Go to Q30

Q28 Were you asked about your preferences for care and treatment when developing this plan?

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

Q29 At your November 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 CARE AND TREATMENT

Thinking again about your November visit to this clinic...

Q30 Did you receive any treatment during this visit? (e.g. chemotherapy, radiotherapy, surgery or other treatments)

- Yes
- No..... Go to Q34

Q31 Did a health professional at the clinic explain what would be done during your treatment in a way you could understand?

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

Q32 Did a health professional at the clinic tell you about possible side effects of your treatment?

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

Q33 Were you given enough information about how to manage the side effects of your treatment?

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

Q34 During this visit, were you given, or prescribed, any new medication to take at home?

- Yes
- No..... Go to Q37

Q35 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

Q36 Did a health professional at the clinic tell you about side effects of this medication to watch for?

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

Q37 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

Q38 Did a health professional at the clinic give your family or someone close to you enough information to help care for you at home?

- Yes, completely
- Yes, to some extent
- No
- Not applicable to my situation
- Don't know/can't remember

RESPECTFUL CARE

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

- Yes, always
- Yes, sometimes
- No

Q40 Were you given enough privacy when being examined or treated?

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

Q41 Were you given enough privacy when discussing your condition or treatment?

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

Q42 Were you ever treated unfairly for any of the reasons below?

Please all the boxes that apply to you

- Age
- Sex
- Aboriginal background
- Ethnic background
- Religion
- Sexual orientation
- Disability
- Marital status
- Something else
- I was not treated unfairly

Q43 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

COMPLICATIONS

Q44 During your visit or soon afterwards, did you experience any of the following complications or problems?

Please all the boxes 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
- Lymphoedema (chronic excessive swelling)
- Severe anxiety or worry
- Any other complication or problem
- None..... Go to Q47

Q45 Was the impact of this complication or problem...?

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

Q46 In your opinion, were the health professionals open with you about this complication or problem?

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

Q47 In the past three months, have you gone to an emergency department because of complications related to the care you received?

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

SMOKING BEHAVIOUR

Q48 At the time of your clinic visit, how often were you smoking cigarettes?

- I've never smoked
- Not at all, I've quit smoking
- Some days
- Every day
- Don't want to say

Q49 Has a staff member at this clinic done any of the following in the past year?

Please all the boxes that apply to you

- Asked if you smoke
- Advised you to quit smoking
- Offered to refer you to the Quitline or a smoking support service/professional
- Offered you nicotine replacement therapy (e.g. patches, gum)
- Provided other help to quit smoking
- Don't know/can't remember

OVERALL CARE

Q50 Overall, how would you rate the care you received in the clinic?

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

Q51 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

Q52 How well organised was the care you received in the clinic?

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

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

PAYMENTS FOR YOUR CARE

This section is about out-of-pocket expenses you might have to pay for clinic visits. Out-of-pocket expenses are those that you don't get back from Medicare or a private health fund.

Please think about your visits to this clinic over the past six months...

Q54 How much were your out-of-pocket expenses for medication related to these visits?

- Zero (\$0)
- \$1 to less than \$100
- \$100 to less than \$500
- \$500 to less than \$1,000
- \$1,000 or more
- Don't know/can't remember

Q55 How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these visits (excluding medication)?

- Zero (\$0)
- \$1 to less than \$100
- \$100 to less than \$500
- \$500 to less than \$1,000
- \$1,000 or more
- Don't know/can't remember

Q56 How much were your out-of-pocket expenses for other costs related to these visits (e.g. travel, petrol, parking, accommodation)?

- Zero (\$0)
- \$1 to less than \$100
- \$100 to less than \$500
- \$500 to less than \$1,000
- \$1,000 or more
- Don't know/can't remember

ABOUT YOUR HEALTH

This section asks questions for people who have or have had cancer. If you received care for a condition other than cancer, please answer Q57 and then go to Q66.

Q57 Did you attend this clinic because you have or have had cancer?

- Yes
 No..... Go to Q66

Q58 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**

Q59 What type of cancer were you receiving care for at this clinic?

Please one box only

- 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 (lymphoma, leukaemia, marrow, lymph nodes etc.)
 Other (bone, mesothelioma, thyroid etc.)

Q60 Which of the following statements best describes how well you are able to carry out ordinary tasks and daily activities?

Over the past month I would generally rate my activity as...

Please one box only

- Normal with no limitations
 Not my normal self, but able to be up and about with fairly normal activities
 Not feeling up to most things, but in bed or chair less than half the day
 Able to do little activity and spend most of the day in bed or chair
 Pretty much bedridden, rarely out of bed

Q61 How has your current cancer responded to treatment?

Please one option that is closest to your situation

- Treatment has not yet started for this cancer..... Go to Q64
 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"
 My cancer has not been treated at all..... Go to Q64

Q62 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
 I have not received any treatment

Q63 In the past three months, what treatment have you received for your cancer?

Please all the boxes that apply to you

- Radiotherapy
 Chemotherapy (including hormone therapy, immunotherapy and targeted drug therapy)
 Surgery
 Other treatment (e.g. bone marrow transplant)
 I have not received treatment in the past three months

ABOUT YOUR CANCER SYMPTOMS

Q64 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).

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible tiredness

Not nauseated 0 1 2 3 4 5 6 7 8 9 10 Worst possible nausea

Not depressed 0 1 2 3 4 5 6 7 8 9 10 Worst possible depression

Not anxious 0 1 2 3 4 5 6 7 8 9 10 Worst possible anxiety

Not drowsy 0 1 2 3 4 5 6 7 8 9 10 Worst possible drowsiness

Best appetite 0 1 2 3 4 5 6 7 8 9 10 Worst possible appetite

Best feeling of wellbeing 0 1 2 3 4 5 6 7 8 9 10 Worst possible feeling of wellbeing

No shortness of breath 0 1 2 3 4 5 6 7 8 9 10 Worst possible shortness of breath

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

Please note that this survey is anonymous. If you need help, or someone to talk to about concerns or worries about your condition, you may like to contact your General Practitioner or The Cancer Council Information and Support Line on 13 11 20.

COPING WITH CANCER

Q65 Please 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
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"/>
I am confident in my ability to understand written information about cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident in my ability to understand my doctor's instructions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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"/>
I won't let cancer get me down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is easy for me to keep a positive attitude	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is easy for me to maintain a sense of humour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am confident that I can control my negative feelings about cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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"/>
It is easy for me to ask nurses questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It is easy for me to ask my doctor questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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).

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?

- 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?

- English Go to Q72
 A language other than English

Please write in the language

Q70 Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic?

- Yes
 No Go to Q72

Q71 Did the hospital provide an interpreter when you needed one?

- Yes, always
 Yes, sometimes
 No
 I did not need the hospital to provide a professional interpreter

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 Go to Q74

Q73 Did you see an Aboriginal Health Worker during your November visit to the clinic?

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

Q74 Which, if any, of the following longstanding conditions do you have (including age related conditions)?

Please all the boxes that apply to you

- Deafness or severe hearing impairment
 Blindness or severe vision impairment
 A longstanding illness (e.g. cancer, HIV, diabetes, chronic heart disease)
 A longstanding physical condition (e.g. arthritis, spinal injury or 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 Q77

Q75 Does this condition(s) cause you difficulties with your day-to-day activities?

- Yes, definitely
 Yes, to some extent
 No

Q76 Are you a participant of the National Disability Insurance Scheme (NDIS)?

- Yes
 No
 Don't know

Q77 Who completed this survey?

- The patient
 The patient with help from someone else
 Someone else on behalf of the patient

Q78 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 (the patient)?

- Yes
- No

YOUR FINAL COMMENTS

Q79 What was the best part of the care you received while at this clinic?

Q80 What part of your care provided by this clinic most needs improving?

THANK YOU FOR YOUR TIME

Please remove the covering letter by tearing along the perforated line.
 Return the questionnaire in the reply paid envelope provided or send it in an envelope addressed to our survey processing centre (no stamp needed):
 NSW Patient Survey, Ipsos Social Research Institute
 Reply Paid 84599, Hawthorn VIC 3122

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 Counselling) and 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 ECOG Performance Status Scale (reference 'Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group', Oken, MM et al, 1982. Am J Clin Oncol). Questions are used with the permission of each organisation.

