



<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 2019. 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. Your feedback will be used to improve health services.

We understand that this questionnaire reaches you some time after your November 2019 clinic visit, but we would greatly appreciate it if you can complete it to the best of your recollection. If you have been affected by the bushfires and are unable to fill out the questionnaire, we understand.

The questionnaire can also be completed 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 questionnaire, please remove this covering letter before placing the completed copy in the enclosed reply paid envelope.

Your information will be treated confidentially. The 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 taking the time to help improve NSW Health services.

Yours sincerely

Dr Diane Watson Chief Executive Bureau of Health Information





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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 to you.

	Did you need parking for your clinic visit?
	X Yes
\	Yes No. Go 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?

X

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 NSW Patient Survey Program on behalf of NSW Health. Your name and address is provided to Ipsos 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 questionnaire, 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 find more information about privacy and confidentiality at bhi.nsw.gov.au/nsw_patient_survey_program/privacy

The results of all patient surveys in the program 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	Were the reception staff polite and courteous?
When completing the questionnaire, please think about your visit to the clinic at the hospital named in the covering letter, in November 2019.	Yes, definitely Yes, to some extent No
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	How long after the scheduled appointment time did your appointment actually start? On time, or early
Surgical procedure Follow-up after surgery Treatment review Regular check-up/long-term follow-up Other reason	Were you told how long you had to wait? Yes No THE PHYSICAL ENVIRONMENT
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	How comfortable was the waiting area? Very comfortable Fairly comfortable Not very comfortable Not at all comfortable
Did you need parking for your clinic visit? Yes No	How comfortable was the treatment area? Very comfortable Fairly comfortable Not very comfortable
Did you have any of the following issues with parking during this visit? Please all the boxes that apply to you	Not at all comfortable I did not go to a treatment area at the clinic
 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 	How clean was the treatment area? Very clean Fairly clean Not very clean Not at all clean







condition or treatment?
Did a health professional discuss your worries or fears with you? Yes, completely Yes, to some extent No Did you have confidence and trust in the health professionals? Yes, definitely Yes, to some extent No Were the health professionals kind and caring towards you? Yes, always
Yes, sometimes No Overall, how would you rate the health professionals who treated you? Very good Good Neither good nor poor Poor Very poor
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 Did a health professional at the clinic tell you about the risks and benefits of the treatment options? Yes, always Yes, sometimes No

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Were you involved, as much as you	
wanted to be, in decisions about your care and treatment?	YOUR CARE AND TREATMENT
Yes, definitely	Thinking again about your November visit to this clinic
Yes, to some extent	tilis cililic
□ No	Did you receive any treatment during this
I did not want or need to be involved	visit (chemotherapy, radiotherapy, surgery or other treatments)?
Did a health professional at the clinic	
explain the next steps of your care and	Yes
treatment in a way you could understand?	
	Did a health professional at the alinia
Yes, completely	Did a health professional at the clinic
Yes, to some extent	explain what would be done during your
☐ No	treatment in a way you could understand?
	Yes, completely
Did you ever receive conflicting information	Yes, to some extent
about your condition or treatment from the	□ No
health professionals?	
Yes	Did a health professional at the clinic tell
□ No	you about possible side effects of your
_	treatment?
The following questions ask about care plans.	Yes, completely
Care plans are written documents that outline the	Yes, to some extent
steps and goals in managing your	No
medical condition.	
	Were you given enough information about
Do you have a written care plan for your	how to manage the side effects of your
current or ongoing care?	treatment?
Yes	Yes, completely
No	Yes, to some extent
I do not need one Go to Q30	
Don't know/can't rememberGo to Q30	∐ No
Were you asked about your preferences for	During this visit, were you given, or
care and treatment when developing this	prescribed, any <u>new</u> medication to take at home?
plan?	
☐ Yes	Yes
□ No	
Don't know/can't remember	Did a health professional at the clinic
Don't know/can't remember	Did a health professional at the clinic
At your November visit, did the health	explain the <u>purpose</u> of this medication in a way you could understand?
professionals review your care plan	
with you?	Yes, completely
☐ Yes	Yes, to some extent
	No
∐ No	Did a health professional at the clinic tell
Not applicable as I did not have a care plan before this visit	you about side effects of this medication to
☐ Don't know/can't remember	watch for?
_	Yes, completely
	Yes, to some extent
	□ No

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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	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
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	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
	RESPECTFUL CARE	to medication A complication as a result of tests
Q40 Q41	Were you treated with respect and dignity while you were at the clinic? Yes, always Yes, sometimes No Were you given enough privacy when being examined or treated? Yes, definitely Yes, to some extent No Were you given enough privacy when discussing your condition or treatment? Yes, definitely	or procedures Severe pain due to the treatment Lymphoedema (chronic excessive swelling) Severe anxiety or worry Any other complication or problem None
Q42	 Yes, to some extent No 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 	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 In the past three months, have you gone to an emergency department because of complications related to the care you received? Yes
	Something else I was not treated unfairly	No□ Don't know/can't remember

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SMOKING BEHAVIOUR	received at the clinic?
Did a staff member at this clinic ask you if you smoked/used tobacco? Yes	Very well organised Fairly well organised Not well organised
☐ No☐ Can't remember	PAYMENTS FOR YOUR CARE
At the time of your clinic visit, how often were you smoking/using tobacco? I've never smoked	This section is about out-of-pocket expenses you may 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
Has a staff member at this clinic done any of the following in the past year? Please all the boxes that apply to you 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 None of the above	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 How much were your out-of-pocket expenses for consultations, tests, surgery or treatment related to these
OVERALL CARE	visits (excluding medication)? Zero (\$0)
Overall, how would you rate the care you received at the clinic? Very good Good Neither good nor poor	\$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
Poor Very poor 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	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.

	ition other than cancer, please answer Q57 hen go to Q66.
Q57	Did you attend this clinic because you have or have had cancer?
	Yes
V	No
Q58	Is this the <u>first time</u> 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 was the main type of cancer you were receiving care for at this clinic? Please X 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 (e.g. lymphoma, leukaemia,
	marrow, lymph nodes) Other (e.g. bone, mesothelioma, thyroid)
	The type of cancer is not known yet
000	Which of the following statements best
Q60	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	now has your current cancer responded
	to treatment? Please X 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
Q62	How long has it been since you <u>first</u> 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 X all the boxes that apply to you
	Radiotherapy Chemotherapy (including hormone
	therapy, immunotherapy, targeted drug therapy)
	Surgery
	Other treatment
	(e.g. bone marrow transplant)
	I have <u>not</u> received treatment in the past three months

ABOUT YOUR CANCER SYMPTOMS

Please rate the following cancer symptoms for how severe each is for you <u>right now</u> (at the time of completing this survey)?

Please ** 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, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. Journal of Palliative Care 1991; 7(2):6-9 (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 <u>right now</u> (at the time of completing this survey). If a statement doesn't apply to you, just skip it and move to the next one.

	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree
I know that I will be able to deal with any unexpected health problems				
I am confident in my ability to understand written information about cancer				
I am confident in my ability to understand my doctor's instructions				
It is easy for me to actively participate in decisions about my treatment				
I won't let cancer get me down				
It is easy for me to keep a positive attitude				
It is easy for me to maintain a sense of humour				
I am confident that I can control my negative feelings about cancer				
If I don't understand something, it is easy for me to ask for help				
It is easy for me to ask nurses questions				
It is easy for me to ask my doctor questions				
It is easy for me to get information about cancer				
	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree

Source: Wolf S, Chang CH, Davis T, Makoul G. Development and validation of the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). Patient Education and Counseling 2005; 57(3):333-41 (modified).



ABOUT YOU	Are you of Aboriginal origin, Torres Strait Islander origin, or both?
The following questions will help us to see how experiences vary between different groups of the population.	Yes, Aboriginal Yes, Torres Strait Islander Yes, both Aboriginal and Torres Strait Islander
What year were you born? Write in (YYYY)	Did you receive support, or the offer of support, from an Aboriginal Health Worker
What is your gender? Male Female	during your November visit to the clinic? Yes No Don't know/can't remember
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	Which, if any, of the following longstanding conditions do you have (including agerelated conditions)? Please X all the boxes that apply to you Deafness or severe hearing impairment Blindness or severe vision impairment A longstanding illness (e.g. cancer, HIV,
Which language do you mainly speak at home? English	diabetes, chronic heart disease) A longstanding physical condition (e.g. arthritis, spinal injury, multiple sclerosis) An intellectual disability A mental health condition (e.g. depression) A neurological condition
Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic? Yes No	(e.g. Alzheimer's, Parkinson's) None of these
Did the clinic provide an interpreter when you needed one? Yes, always Yes, sometimes No I did not need the clinic to provide a	Yes, definitely Yes, to some extent No Are you a participant of the National Disability Insurance Scheme (NDIS)? Yes No
professional interpreter	Don't know Who completed this survey? The patient The patient with help from someone else Someone else on behalf of the patient

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Please go to the next page to complete the final questions

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 healthcare information will allow us to better understand how different aspects of the care provided by health facilities are related to the health of, and use of health services by, 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 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 91752, Port Melbourne VIC 3207

Some questions asked in this questionnaire are sourced from: the NHS Patient Survey Programme (courtesy of the NHS Care Quality Commission); the National Research Corporation (USA), the Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer) tool and; the Edmonton Symptom Assessment System (ESAS) tool. Questions are used with the permission of each organisation.

Barcode