



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

Date

Dear <First Name> <Last Name>,

Your feedback about your experience will help improve healthcare services

I invite you to complete a questionnaire about your outpatient appointment with [HOSPITAL NAME] in November 2020. 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 help improve healthcare experiences and outcomes for patients across NSW. Any information you provide will be treated confidentially, and the hospital staff who cared for you will not be able to see your responses.

It is also easy to take part using your smartphone, tablet or computer:



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

For further information about patient experience across hospitals in NSW, including results from previous surveys, visit **bhi.nsw.gov.au**

Thank you for taking the time to help improve NSW Health services.

Yours sincerely

Dr Diane Watson

Chief Executive
Bureau of Health Information

COMPLETING THE PAPER QUESTIONNAIRE

If you complete the paper questionnaire, please use a blue or black pen to mark an X in the box next to your answer.

Sometimes response options have a 'Go to...' instruction which direct you to skip any questions that do not apply to you:

Q30	Did you receive any treatment during this visit (chemotherapy, radiotherapy,
	surgery or other treatments)?
	Yes
\	No

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



Were you told how long you had to wait?



Yes



X No

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

To return the paper questionnaire, remove the covering letter before placing the completed copy in the enclosed reply paid envelope.

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. 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.

You can find more information about privacy and confidentiality on the BHI website at bhi.nsw. gov.au/nsw_patient_ survey_program/privacy

More information about the NSW Patient Survey Program can be found at bhi.nsw.gov.au/nsw patient_survey_program

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 had an appointment with 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 appointment with the hospital named in the covering letter in November 2020.	Yes, definitely Yes, to some extent No
What was the purpose of this appointment? 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	How long after the scheduled appointment time did your appointment actually start? On time, or early
Regular check-up/long-term follow-up Other reason	L No
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 Not applicable, as I had a phone/video appointment	How comfortable was the waiting area? Very comfortable Fairly comfortable Not very comfortable Not at all comfortable Not applicable, as I had a phone/video appointment
Did you need parking for your clinic visit?	How comfortable was the treatment area?
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	Very comfortable Fairly comfortable Not very comfortable Not at all comfortable I did not go to a treatment area at the clinic

THE HEALTH PROFESSIONALS	condition or treatment?
Who did you see during this appointment? 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 Did you have enough time to discuss your health issues with the health professionals	Yes No
you saw? Yes, definitely Yes, to some extent No	Were the health professionals kind and caring towards you? Yes, always Yes, sometimes
Did the health professionals explain things in a way you could understand? Yes, always Yes, sometimes No	Overall, how would you rate the health professionals who treated you? Very good
During this appointment, did the health professionals know enough about your medical history? Yes, definitely Yes, to some extent No	Good Neither good nor poor Poor Very poor PLANNING YOUR CARE
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	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 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 Can't remember	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	YOUR CARE AND TREATMENT
and treatment?	
Yes, definitely	Thinking again about your November appointment
Yes, to some extent	with this clinic
□ No	
I did not want or need to be involved	Did you receive any treatment during this appointment (chemotherapy, radiotherapy,
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	surgery or other treatments)? Yes No
Did you ever receive conflicting information about your condition or treatment from the health professionals?	Yes, completely Yes, to some extent No
Yes No	Did a health professional at the clinic tell you about possible side effects of your treatment?
The following questions ask about care plans. Care plans are written documents that outline the steps and goals in managing your medical condition.	Yes, completely Yes, to some extent No
Do you have a written care plan for your current or ongoing care? Yes No	Were you given enough information about how to manage the side effects of your treatment? Yes, completely Yes, to some extent No During this appointment, were you given, or prescribed, any new medication to take at home? Yes No

Were you told who to contact if you were worried about your condition or treatment after your appointment? 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
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 appointment 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
Were you treated with respect and dignity during your appointment? Yes, always Yes, sometimes No Were you given enough privacy when being examined or treated?	A complication as a result of tests or procedures Severe pain due to the treatment Lymphoedema (chronic excessive swelling) Severe anxiety or worry Any other complication or problem None
examined or treated? Yes, definitely Yes, to some extent No Were you given enough privacy when discussing your condition or treatment? Yes, definitely Yes, to some extent No	Was the impact of this complication or problem? Very serious Fairly serious Not very serious Not at all serious In your opinion, were the health
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	complication or problem? Yes, completely Yes, to some extent No Not applicable, as it happened after my appointment 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	How well organised was the care you received from the clinic?
Did a staff member at this clinic ask you if you smoked/used tobacco? Yes No Can't remember At the time of your appointment, how often	☐ Very well organised ☐ Fairly well organised ☐ Not well organised PAYMENTS FOR YOUR CARE This section is about out-of-pocket expenses you
were you smoking/using tobacco? I've never smoked Go to Q51 Not at all, I've quit smoking Go to Q51 Some days	may have to pay for clinic appointments. Out-of- pocket expenses are those that you don't get back from Medicare or a private health fund.
Every day Don't want to say	Please think about your appointments with this clinic over the <u>past six months</u>
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 appointments? 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	appointments (excluding medication)? Zero (\$0)
Overall, how would you rate the care you received from 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
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 appointments (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
be critical	\$500 to less than \$1,000

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. Did you attend this clinic because you have or have had cancer? Yes 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 What was the main type of cancer you were Q59 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 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 | X | 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		v nas your current cancer responded
		reatment? ase 🗷 one option that is closest to
		r situation
		Treatment has not yet started for this cancer
		I am in the course of treatment and I
		can't tell yet how my cancer has responded
	Ш	The treatment has been effective and I have no signs or symptoms of cancer
上		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
F		I am not in active treatment but I am on "Watch and Wait"
\		My cancer has not been treated at all
		at all
Q62		v long has it been since you <u>first</u> eived treatment for this cancer?
	П	Less than 3 months
	一	3 to 6 months
	Ħ	More than 6 months but less than 1 year
	H	1 to 5 years
	H	More than 5 years
	H	Don't know/can't remember
		I have not received any treatment
Q63		ne <u>past three months</u> , what treatment e you received for your cancer?
		ase X all the boxes that apply to you
		Radiotherapy
	同	Chemotherapy (including hormone
	_	therapy, immunotherapy, targeted drug therapy)
		Surgery
	同	Other treatment
		(e.g. bone marrow transplant)
	П	I have not 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 X 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 during your November appointment? Yes No Don't know/can't remember Which, if any, of the following longstanding conditions do you have (including age-
Prefer not to answer What is the highest level of education you	related conditions)? Please all the boxes that apply to you Deafness or severe hearing impairment Blindness or severe vision impairment
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	A longstanding illness (e.g. cancer, HIV, diabetes, chronic heart disease) A longstanding physical condition (e.g. arthritis, spinal injury, multiple sclerosis) An intellectual disability A mental health condition (e.g. depression)
Which language do you mainly speak at home? English	A neurological condition (e.g. Alzheimer's, Parkinson's) None of these
What is that language? Please write below.	Does this condition(s) cause you difficulties with your day-to-day activities? Yes, definitely Yes, to some extent
Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic? Yes No	Are you a participant of the National Disability Insurance Scheme (NDIS)? Yes
Did the clinic provide an interpreter when you needed one? Yes, always	☐ No ☐ Don't know
Yes, sometimes No I did not need the clinic to provide a professional interpreter	Who completed this survey? The patient The patient with help from someone else Someone else on behalf of the patient

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

What was the best part of the care you received from this clinic?

What part of	your care provided	by this clinic m	ost needs impro	ving?	

Q80

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