

# 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

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.

Web address: [INS URL]

Yours sincerely

Jean-Frédéric Lévesque Chief Executive Bureau of Health Information

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# 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

Q4

did you wait?

Less than 15 days

From the time you booked this appointment

to the time you went to the clinic, how long

## **BEFORE ARRIVING AT THE CLINIC**

When completing this part of the survey, please think about your latest visit to the cancer clinic at

	about your <u>latest visit</u> to the cancer clinic at ospital named on the cover of this booklet.	<ul><li>15 days to less than 1 month</li><li>1 to 3 months</li></ul>
	What was the purpose of this visit?	4 to 6 months
Q1	Please 🗶 <u>all</u> that apply to you	7 to 12 months
	Have tests, X-rays or scans	More than 1 year
	Receive test, X-ray or scan results	Don't know/can't remember
	Medical diagnosis or advice	
	Regular check-up	Do you think the amount of time you waited was?
	Chemotherapy	About right
	Radiotherapy	Slightly too long
	Review of treatment	Much too long
	Surgical procedure	Don't know/can't remember
	Follow-up after surgery	
	Other reason	How much did your symptoms or condition stop you from carrying out your normal
Q2	Were you able to get an appointment time that suited you?	daily activities (for example, eating, dressing or using the bathroom) while you waited for this appointment?
		Not at all
	No	Only a little
	I didn't have an appointment	Somewhat
↓	arranged in advanceGo to Q8	Very much
	Did you have any of the following	I was not able to at all
Q3	difficulties when making this appointment?	I had no symptomsGo to Q8
	Please X all that apply to you	↓
	I didn't know how to make an appointment	While you were waiting for this
	I didn't know which clinic to call	Q7 appointment, did your symptoms or condition?
	The contact details were hard to find	
	My call was not answered	Get much better
	I had to wait on hold for a long time	Get a little better
	The appointment was previously	Stay about the same
	cancelled/postponed	Get a little worse
	Some other difficulty	Get much worse
	None - I had no difficulties	Don't know/can't remember

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ARRIVAL AT THE CLINIC	Q13 Were the reception staff polite and courteous?
Still thinking about your latest visit to this	Yes, definitely
	Yes, to some extent
Q8 clinic for this appointment?	
cancer clinic         Q8       How long did it take you to travel to the clinic for this appointment?	
Narrow walkways/halls/doorways No accessible toilets	Not very comfortable
Some other difficulty	Not at all comfortable
None - I had no difficulties	
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THE PHYSICAL ENVIRONMENT	Q26 During this visit, did the health professionals know enough about your medical history?
Still thinking about your latest visit to this	Yes, definitely
cancer clinic	Yes, to some extent
Q20 How clean was the clinic?	No
Very clean	How would you rate how well the health
Fairly clean	Q27 professionals worked together?
<ul> <li>Not very clean</li> <li>Not at all clean</li> </ul>	Very good
	Good Good
Q21 Were you given enough privacy when being examined or treated?	Neither good nor poor
Yes, definitely	Poor Poor
Yes, to some extent	Very poor
	Not applicable – only saw one
Q22 Were you given enough privacy when discussing your condition or treatment?	Q28 Did you see the health professionals wash their hands, or use hand gel to clean their hands, before touching you?
Yes, definitely	
Yes, to some extent	Yes, always Yes, sometimes
L No	No, I did not see this
THE HEALTH PROFESSIONALS	Not applicable to my visit
	Can't remember
Q23 Please X all that apply to you	
Doctor/Specialist	Did you have worries or fears about your condition or treatment?
Nurse (including for chemotherapy)	Yes
Radiation therapist (for radiotherapy)	□ No
Radiographer (X-ray, ultrasound, MRI)	
<ul><li>Lymphoedema therapist</li><li>Physiotherapist</li></ul>	Q30 Did a health professional discuss your worries or fears with you?
Dietician	Yes, completely
Social worker	Yes, to some extent
Other healthcare professional	L No
Did you have enough time to discuss your health issues with the health professionals you saw?	Did you have confidence and trust in the Q31 health professionals?
Yes, definitely	Yes, definitely
Yes, to some extent	Yes, to some extent
	□ No
Q25 Did the health professionals explain things in a way you could understand?	Were the health professionals kind and Q32 caring towards you?
Yes, always	Yes, always
Yes, sometimes	Yes, sometimes
No	□ No
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Q33	Overall, how would you rate the health professionals who treated you?	Q39	Were you treated with respect and dignity while you were at the clinic?
	Very good		Yes, always
	Good		Yes, sometimes
	Neither good nor poor		
	Poor Poor		—
	Very poor	Q40	Were your cultural or religious beliefs respected by the clinic staff?
	PLANNING YOUR CARE		Yes, always
Q34	Do you have a care plan for your cancer treatment?		<ul> <li>Yes, sometimes</li> <li>No, my beliefs were not respected</li> </ul>
	A care plan is a document that sets out your needs and goals for the treatment and		My beliefs were not an issue
_	management of your cancer.	Q41	Were you given, or prescribed, any <u>new</u> medication to take at home?
	☐ NoGo to Q38	_	Yes
	I do not need oneGo to Q38		NoGo to Q44
	Don't know/can't rememberGo to Q38	<u>+</u>	
Q35	Was your care plan developed by health professionals from this clinic?	Q42	Did a health professional at the clinic explain the <u>purpose</u> of this medication in a way you could understand?
	☐ Yes		Yes, completely
	No No		Yes, to some extent
Q36	Were you asked for your ideas and preferences when developing this plan?		No
	<ul><li>Yes, definitely</li><li>Yes, to some extent</li></ul>	Q43	Did a health professional at the clinic tell you about medication <u>side effects</u> to watch for?
			Yes, completely
	Don't know/can't remember		Yes, to some extent
Q37	At your most recent visit, did the health professionals review your care plan with you?		No No
	Yes No	Q44	Were you given enough information about how to manage the side effects of <u>any other</u> <u>treatment</u> you received during this visit?
	Not applicable as I did not have a care		Yes, completely
	plan before this visit		Yes, to some extent
	Don't know/can't remember		
Υ	OUR TREATMENT AND CARE		I did not need this type of information
Q38	Were you involved, as much as you wanted to be, in decisions about your care and treatment?	Q45	Were you told who to contact if you were worried about your condition or treatment after you left the clinic?
	Yes, definitely		Yes
	Yes, to some extent		No No
			I did not need this type of information
	I did not want or need to be involved		Don't know/can't remember
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<ul> <li>While in the clinic, did you receive or see any information about how to comment or complain about your case?</li> <li>Yes</li> <li>No</li> <li>Don't know/can't remember</li> </ul>	<ul> <li>Q50</li> <li>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.</li> <li>Please X all that apply to you</li> <li>Consultation fees</li> <li>Medication</li> <li>Treatment/surgery costs</li> </ul>
AFTER YOUR VISIT	Travel
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 X all that apply to you	<ul> <li>Parking</li> <li>Accommodation</li> <li>Other related expenses</li> <li><u>None</u> of these – I had no expenses</li> <li>Don't know/can't remember</li> </ul>
An infection	NUMBER OF VISITS
<ul> <li>Uncontrolled bleeding</li> <li>An unexpected negative reaction to medication</li> <li>Complications as a result of tests or procedures</li> <li>Severe pain due to the treatment</li> <li>Severe anxiety or worry</li> <li>Any other complication or problem (other than common side-effects from treatment)</li> <li>None of these</li></ul>	Understanding the set of
Q48 problem?	More than 8 times
<ul> <li>Very serious</li> <li>Fairly serious</li> <li>Not very serious</li> <li>Not at all serious</li> </ul>	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
<ul> <li>Q49</li> <li>In your opinion, were the clinic staff open with you about this complication or problem?</li> <li>Yes, completely</li> <li>Yes, to some extent</li> <li>No</li> <li>Not applicable, as it happened after I left</li> </ul>	<ul> <li>Did you ever receive conflicting information about your condition or treatment from the health professionals?</li> <li>Yes</li> <li>No</li> <li>Not applicable - I was always treated by the same person</li> </ul>

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OVERALL CARE	How has your current cancer responded to Q60 treatment?
	Please X ONE option that is closest to
Overall, how would you rate the care you	your situation
Q55 received in the clinic?	Treatment has not yet started for
Very good	this cancerGo to Q63
Good	I am in the course of treatment and I can't
Neither good nor poor	tell yet how my cancer has responded
Poor	The treatment has been effective and I
Very poor	have no signs or symptoms of cancer
	I have finished the course of treatment
How well organised was the care you	but my cancer is still present
Q56 received in the clinic?	— My cancer is being treated again because
Very well organised	it has not responded fully to treatment
Fairly well organised	I am not in active treatment but I am on
Not well organised	"Watch and Wait"Go to Q63
	My cancer has not been treated
If asked about your clinic experience by	at allGo to Q63
Q57 friends and family, how would you respond?	
<ul> <li>I would speak highly of the clinic</li> <li>I would neither speak highly nor be critical</li> </ul>	<b>Q61</b> How long has it been since you <u>first</u> received treatment for this cancer?
I would be critical of the clinic	Less than 3 months
	3 to 6 months
TREATMENT NEEDS	More than 6 months but less than 1 year
AND OUTCOMES	1 to 5 years
	More than 5 years
Did you attend this clinic because you have	Don't know/can't remember
Q58 or have had cancer?	
└ Yes	What treatment have you received for your Q62 cancer?
☐ No	Please X all that apply to you
	Radiotherapy
Is this the <u>first time</u> you have had cancer?	Chemotherapy
Q59 Yes, this is the first time I have had cancer	
No, I have had the same type of cancer	Other treatment (e.g. hormone therapy)
before but it has now come back	
No, I have had a <b>different type of</b>	In the past three months, have you gone to an
cancer before	Q63 emergency department because of your
	cancer or cancer complications?
	Yes
	□ No
	Don't know/can't remember

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# **COPING WITH CANCER**

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

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

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# **ASSESSING YOUR HEALTH**

Please rate the following cancer symptoms for how severe each is for you right now (at the time Q65 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	0	□ 1	 2	□ 3	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	□ 10	Worst possible pain
b. Not tired	0	□ 1	2	□ 3	4	<b>5</b>	<b>6</b>	 7	8	□ 9	□ 10	Worst possible tiredness
c. Not nauseated	0	 1	 2	3	<b>4</b>	<b>5</b>	6	7	8	9	10	Worst possible nausea
d. Not depressed	0	□ 1	 2	□ 3	4	5	6	<b>7</b>	8	9	10	Worst possible depression
e. Not anxious	0	□ 1	2	3	4	5	<b>6</b>	7	8	<b>9</b>	 10	Worst possible anxiety
f. Not drowsy	0	1	2	3	4	5	6	<b>7</b>	8	9	 10	Worst possible drowsiness
g. Best appetite	0	1	2	3	4	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	 10	Worst possible appetite
			$\sim$									
h. Best feeling of wellbeing	0	1	2	□ 3	□ 4	<b>5</b>	□ 6	 7	8	 9	□ 10	Worst possible feeling of wellbeing
i. No shortness												Morat pageible
of breath	0	1	2	3	4	5	6	7	8	9	L 10	Worst possible shortness of breath

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

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ABOUT YOU	Q73 Which, if any, of the following long-standing conditions do you have (including age
The following questions will help us to see how	related conditions)? Please X <u>all</u> that apply to you
experiences vary between different groups of	
the population.	Deafness or severe hearing impairment
What year were you born?	Blindness or severe vision impairment
	A long-standing illness (e.g. cancer, HIV, diabetes, chronic heart disease)
	A long-standing physical condition
What is your gender?	A learning disability
	A mental health condition (e.g. depression)
☐ Female	A neurological condition (e.g. Alzheimer's,
	Parkinson's)
What is the highest level of education Q68 you have <u>completed</u> ?	None of these
Still at secondary school	
Less than Year 12 or equivalent	Q74 Who completed this survey?
Completed Year 12 or equivalent	The patient
<ul> <li>Trade or technical certificate or diploma</li> <li>University degree</li> </ul>	The patient with help from someone else
Post graduate/higher degree	Someone else on behalf of the patient
Which language do you mainly speak Q69 at home?	The Bureau of Health Information would
	Q75 like your permission to link your survey answers to other information from health
English	records relating to you which are maintained
A language other than English	by various NSW and Commonwealth agencies (including your hospitalisations, medical
Please write in	visits, ambulance transportation, medication
the language:	or health registry information). Linking to your health care information for the two
Did you need, or would you have liked, to	years before and after your visit will allow us
Q70 use a professional interpreter at any stage while you were at the clinic?	to better understand how different aspects of the care provided by health facilities are
	related to the health and use of health
Go to Q72	services of their patients.
	Your information will be treated in the strictest confidence. We will receive the
Was a professional interpreter provided	linked information after your name and
Q71 when you needed one?	address have been removed. We will not
Yes, always	report any results which may identify you as an individual and your responses will not
Yes, sometimes	be accessible to the people who looked
No	after you.
Are you of Aboriginal origin, Torres Strait	Do you give permission for the Bureau of Health Information to link your answers from
Q72 Islander origin, or both?	this survey to health records related to you?
Yes, Aboriginal	Yes
Yes, Torres Strait Islander	□ No
Yes, both Aboriginal and Torres Strait Islander	
No	

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Please turn over @

## **YOUR COMMENTS**

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

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

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