



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

MailDate

Dear <Title> <Last Name>,

We want to know about your care

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.

The Bureau of Health Information, established by the NSW government to independently report on the performance of the NSW health system, asks thousands of people each year to tell us about the care they received. Hearing about your recent outpatient experience helps us to understand the quality of care you received and it allows health services to see where they need to improve.

How do you take part?

There are two ways to complete the questionnaire:

 **Online:** Visit survey.ipsos.com.au/patientsurvey and enter your username [INS_UNAME] and password [INS_PWORD] when prompted

OR

 **Pen and paper:** Simply fill in the questionnaire. To ensure your anonymity, remove this covering letter before placing the completed questionnaire in the Reply Paid envelope.

Your information will be treated as confidential

You have been randomly selected to participate and there are many safeguards in place to protect your identity. The clinic staff who cared for you will not know if you have returned a completed questionnaire and will not be able to see your responses.

If you have any questions or need help with the questionnaire, please contact:

Toll-free Patient Survey Helpline
1800 220 936 (Monday to Friday, 4pm–8pm) OR
or leave a message to be called back

Email your questions to
NSWPatientSurvey@ipsos.com
(include your username [INS_UNAME] in the subject line)

For information about the NSW Patient Survey Program and to see how your local hospital is performing, visit the Bureau of Health Information's website at bhi.nsw.gov.au. Thank you very much for your time helping to improve NSW Health's services.

Yours sincerely

Dr Jean-Frédéric Lévesque
Chief Executive
Bureau of Health Information

How to complete the survey

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

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

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.

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

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 use in writing 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). You may also send an email to NSWPatientSurvey@ipsos.com (and write your username, provided on the previous page, in the 'subject' line).



ARRIVAL AT THE CLINIC

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

Q1 What was the purpose of this visit?
Please all 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
- 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 What was your main form of transport to the clinic?

- Please one box only
- By private car
 - Hospital or community transport... **Go to Q5**
 - Taxi..... **Go to Q5**
 - Public transport..... **Go to Q5**
 - On foot..... **Go to Q5**
 - Other..... **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

Thinking about your latest visit to this cancer clinic...

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
- Psychologist
- 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
- NoGo 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

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

Q26 Do you have a written care plan for your treatment?

- Yes
- NoGo to Q30
- I do not need one.....Go to Q30
- Don't know/can't rememberGo to Q30

Q27 Was your care plan developed by health professionals from this clinic?

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

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 latest 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 latest visit to this cancer clinic...

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

- Yes
- NoGo 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
- NoGo 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

- Your age
- Your sex
- Your ethnic background
- Your religion
- Your sexual orientation
- A disability that you have
- 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? (other than common side-effects from treatment)
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
- Severe anxiety or worry
- Any other complication or problem
- NoneGo 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

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 cancer clinic over the past six months...

Q48 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

Q49 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

Q50 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

COORDINATION OF CARE

Q51 How long have you been attending this cancer clinic?

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

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

- Once
- 2 to 3 times
- 4 to 8 times
- More than 8 times

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

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

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

- Yes
- No

OVERALL CARE

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

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

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

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

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

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

ABOUT YOUR CANCER

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

- Yes
 NoGo to Q67

Q59 Is this the **first time** you have had cancer?

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

Q60 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)
 Other (e.g. bladder, bone, eye, heart, kidney, mesothelioma, thyroid)

Q61 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

Q62 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 Q65
 I am in the course of treatment and I can't tell yet how my cancer has responded
 The treatment has been effective and I have no signs or symptoms of cancer
 I have finished the course of treatment but my cancer is still present
 My cancer is being treated again because it has not responded fully to treatment
 I am not in active treatment but I am on "Watch and Wait"Go to Q65
 My cancer has not been treated at allGo to Q65

Q63 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

Q64 In the **past three months**, what treatment have you received for your cancer?

Please **all 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

Q65 Please rate the following cancer symptoms for how severe each is for you right now (at the time of completing this survey).

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

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

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

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

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

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

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

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

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

i. 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. The 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 Helpline on 13 11 20.

COPING WITH CANCER

Q66 Select the answer that best describes how strongly you agree or disagree with each statement below.

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

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

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

ABOUT YOU

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

Q67 What year were you born?

WRITE IN (YYYY)

Q68 What is your gender?

- Male
 Female

Q69 What is the highest level of education you have completed?

- Still at secondary school
 Less than Year 12 or equivalent
 Completed Year 12 or equivalent
 Trade or technical certificate or diploma
 University degree
 Post graduate/higher degree

Q70 Which language do you mainly speak at home?

- EnglishGo to Q73
 A language other than English

Please write in the language:

Q71 Did you need, or would you have liked, to use an interpreter at any stage while you were at the clinic?

- Yes
 NoGo to Q73

Q72 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

Q73 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

Q74 Which, if any, of the following long-standing 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 long-standing illness (e.g. cancer, HIV, diabetes, chronic heart disease)
 A long-standing physical condition
 A learning disability
 A mental health condition (e.g. depression)
 A neurological condition (e.g. Alzheimer's, Parkinson's)
 None of these

Q75 Which of the following best describes your smoking status?

- I smoke daily
 I smoke occasionally
 I've tried it a few times but never smoked regularly
 I don't smoke now, but I used to
 I've never smokedGo to Q77
 Don't knowGo to Q77

Q76 Has a health professional at this clinic advised you to quit smoking?

- Yes
 No
 Don't know/can't remember
 Not applicable, as I have not smoked in this time

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?

- Yes
- No

YOUR COMMENTS

Q79

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

Q80

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 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

Barcode