



Victorian healthcare experience survey

Your cancer experience

BSP: 0000-1
Jo Blogs
12 Smith Street
Melbourne VIC 3000

<Date>

Dear <INSERT TITLE AND SURNAME FROM PATIENT FILE>,


[INSERT HOSPITAL FROM DATA FILE] is working to make sure that everyone treated for cancer at our service receives the best care possible. To help achieve this, we need to find out what people think about the care they have received so we can identify what is being done well and what areas need to be improved.

We are contacting you because you have recently been a patient at [INSERT HOSPITAL FROM DATA FILE]. We are hoping that you could take the time to tell us about your experiences by completing the attached survey and returning it in the enclosed Reply Paid envelope by 31st May 2019.


Further information explaining why the survey is being done and how the information collected will be used can be found overleaf. If you have any questions about the survey, please contact the toll-free Survey Helpline on:

1800 356 928

There are two ways to complete the survey:

 **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.

OR

 **Online:** visit www.vhes.com.au/survey and enter this password when prompted: [INSERT PASSWORD]. Alternatively, scan the QR code at the bottom of this letter using your tablet or smartphone.

If you believe that you have been sent this survey in error, or you do not wish to participate, please call our toll-free Survey Helpline on the number above to let us know if this is the case, or simply discard this survey and any reminders you receive.

Thank you for considering this request.

Yours sincerely,

Kym Peake
Secretary
Department of Health and Human Services



Health
and Human
Services

Information Sheet

You are being invited to complete the enclosed questionnaire because you have attended a Victorian public hospital for cancer related treatment in 2018. Completing the survey is voluntary. You don't have to complete the survey if you don't want to, and this will have no impact on any health services that may be provided to you.

If you decide to take part in the survey, please complete the enclosed questionnaire and return it in the Reply Paid envelope provided. If you do not wish to participate, please call our toll-free Survey Helpline on: 1800 356 928 to let us know if this is the case, or simply discard this survey and any reminders you receive.

What is the Victorian healthcare experience survey?

It is a state-wide survey that asks people how they felt about their experience with the Victorian public health system. Results from this survey are used by health services to identify ways that they can improve.

What happens to my survey responses?

Your survey responses will be made anonymous and combined with responses from others to form a report. These reports will then be provided to health services and the Department of Health & Human Services.

Your responses will be treated in the strictest confidence and no identifying information will be given to the health service you attended, your doctor or any other health provider, or the Department of Health & Human Services.

Your responses will not affect any health services that may be provided to you.

How is my privacy protected?

There are many safeguards in place to protect your privacy. Ipsos Australia, an independent research company, conducts this survey for the Victorian Department of Health and Human Services.

Your privacy is protected by legislation. Ipsos has been provided with your name and address only for the purpose of sending you this survey, and will keep your information confidential.

To make sure that you are not sent another survey too soon, we will keep your information for six months. After this time, your identifying information will be destroyed. 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 Survey Helpline to request that some, or all, of your information be deleted.

Who should complete the survey?

We have randomly selected a sample of people who have been treated for cancer within the Victorian public health system to complete the survey. If you have been satisfied with your care we would like to hear about your experiences. If you have not been satisfied with your care we would like to hear about your experiences.

We acknowledge that you may not have had all your treatment at one hospital therefore the survey asks you to indicate where you had different treatments so you can let us know which part/s of your care were at the hospital mentioned on the letter.

Can I use the survey to make a formal complaint?

As the survey is anonymous, you can't use it to make a formal complaint. If you have a complaint, it should be to the health service where the issue occurred. Alternatively, if you feel the health service is not responding to your complaint you may contact the Health Complaints Commissioner on 1300 582 113.

How do I get more information about the survey?

Please contact the Survey Helpline on 1800 356 928 (Monday to Friday, 4pm–8pm, excluding public holidays). If you are hearing impaired you can contact us via the National Relay Service on 1300 555 727 or e-mail survey@vhes.com.au

What if I would like the survey in a different language?

If you prefer a language other than English, please contact the Survey Helpline on 1800 356 928 (Monday to Friday, 4pm–8pm, excluding public holidays).

How to complete the paper survey

For most questions there is a choice of answers. Pick the response that is true for you and cross the box next to it, as shown below.



Sometimes, more than one box may be crossed. If you make a mistake, scribble out the mistake and put a cross in the correct box.



There is space throughout the survey for you to make any comments about your care. There is also space at the end of the survey for any comments you want to make.

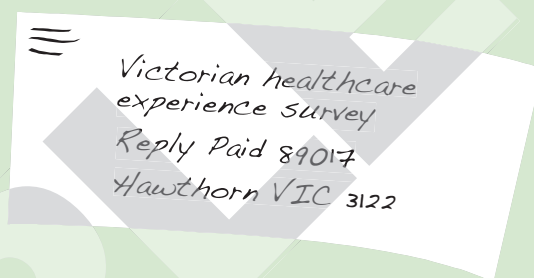
The instructions before the questions will tell you who should answer the questions. You may be able to skip questions if you haven't had particular treatments (e.g. radiotherapy, chemotherapy). You may not have had treatment in the order presented in the survey.

If you would prefer not to answer individual questions, cannot remember or they are not relevant to you, leave them blank but please complete the rest of the survey.

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

The survey may take 30 minutes to complete, depending on what treatment you have had.

Once complete, please place the survey in the Reply Paid envelope and post it. You do not have to use a stamp. If you have misplaced the Reply Paid envelope, please use a plain envelope (no stamp is necessary) and address it to:



A tab on the top outside corner of each page tells you what section of the survey you are in. Sections with tabs displaying different pictures are about different treatments. The pictures for the different sections are shown below:

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EMERGENCY DEPT
CARE Page 20



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Words used in the survey:

We have used certain words or terms throughout the survey. The following may help to explain what we mean by these terms.

Health professionals: includes doctors, nurses, radiologists, radiotherapists, care coordinators, physiotherapists, dietitians, speech pathologists, social workers and other professions that you may have had contact with during your treatment.

Chemotherapy: is the use of drugs that aim to destroy cancer cells in the body, or to stop them from multiplying and spreading. For this survey, **targeted therapies** are included with chemotherapy. Targeted therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules. Chemotherapy and targeted therapies can be given through a drip that goes into a vein via a needle, as a tablet that you swallow, or as cream that's put on the surface of the skin.

Radiotherapy: is the use of radiation to destroy cancer cells in the body, to slow the growth of cancer, or to reduce the symptoms of cancer. External beam radiotherapy is given using a machine that directs radiation onto the body. Radiotherapy can also be given internally using radioactive implants, which is known as brachytherapy.

Hormonal therapy: aims to control a cancer by changing the hormonal environment in which it is growing. This treatment is used most commonly for breast, ovarian, endometrial and prostate cancer but can be used for some other cancers as well. Treatments can be given by injections into a vein or as a tablet.

Lymphoedema: is a swelling (oedema) due to an accumulation of lymphatic fluid in the body's tissues. It usually affects the arm(s) or leg(s) but can also occur in other parts of the body. Lymphoedema can occur following some cancer treatments.

FINDING OUT WHAT WAS WRONG

When cancer is suspected or diagnosed, most people are referred to see a specialist doctor either directly (privately) or through a referral to a clinic at a public hospital.

Q1a How long was it between when you were referred to a specialist doctor or hospital clinic and your first appointment?

- ☐ Less than two weeks
- ☐ More than two weeks, but within four weeks
- ☐ More than a month
- ☐ I stayed with my GP
- ☐ Not sure/cannot remember
- ☐ Other

Go to Q1b

Go to Q1b

Q1b If more than two weeks, was this due to:

- ☐ Personal decision to wait
- ☐ Specialist waiting times
- ☐ Hospital waiting time
- ☐ Other

Sometimes people will have several tests before a diagnosis of cancer is given. This is to find out whether somebody definitely has cancer. Tests may include a biopsy, which involves a doctor taking a sample of tissue if you have a solid tumour (e.g. a lump, a cyst, a swelling), or a sample of blood or bone marrow if you have a blood cancer like leukaemia. It may also include an ultrasound, x-ray or scan.

Q2 Who gave you the result of the test that showed that you definitely had cancer?

- ☐ GP
- ☐ Surgeon
- ☐ Medical oncologist
- ☐ Radiation oncologist
- ☐ Haematologist
- ☐ Hospital doctor
- ☐ Other (please specify)

Q3

What cancer were you diagnosed with? If you have been diagnosed with more than one cancer, please indicate the cancer that was diagnosed most recently.

- ☐ Breast
- ☐ Leukaemia
- ☐ Prostate
- ☐ Colorectal
- ☐ Lung
- ☐ Brain
- ☐ Sarcoma
- ☐ Uterus
- ☐ Multiple myeloma
- ☐ Kidney
- ☐ Stomach cancer
- ☐ Mesothelioma
- ☐ Central nervous system
- ☐ Melanoma
- ☐ Ovarian
- ☐ Lymphoma
- ☐ Bladder cancer
- ☐ Pancreatic cancer
- ☐ Throat/mouth
- ☐ Other cancer (please specify)

Q4

When was this cancer diagnosed? Please provide the day, month and year. If you cannot remember the day, please provide the month and year. If you cannot remember the month, please provide the year.

D	D	M	M	Y	Y	Y	Y
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Q5

When you were told you had cancer, did you understand the doctor's explanation of what was wrong with you?

- ☐ Yes, I understood it completely
- ☐ I understood most of it
- ☐ I understood some of it
- ☐ No, I did not understand it
- ☐ Not sure/cannot remember

Q6

When you were told you had cancer, did your doctor encourage you to ask questions?

- ☐ Yes
- ☐ No
- ☐ It wasn't necessary, I wanted to ask questions
- ☐ I did not want to ask questions
- ☐ Not sure/cannot remember

DECIDING ON TREATMENT

For some cancers and for some people there is only one recommended treatment, while for others there might be several treatment options. Some cancers may not require treatment straight away, such as some prostate cancers etc.

Q12 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 was not well enough or did not want to be involved in these decisions
- ☐ Only one type of treatment/treatment option was suitable for me
- ☐ Not sure/cannot remember

Q13 Did you have any treatment for your cancer (e.g. surgery, chemotherapy, radiotherapy or hormonal therapy)?

- ☐ Yes
- ☐ No

Go to Q134 on page 28
(Section: About You)

Q14 What treatment/s have you had, or are you currently having, for your cancer (tick all that apply)?

- ☐ Surgery
- ☐ Radiotherapy
- ☐ Chemotherapy or targeted therapies
- ☐ Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®.)

Q15 If you had hormonal therapy, please think about the care you have received while having hormonal therapy and the information you received. What could be done better to help improve care?

Q16 Were possible short-term side-effects of treatment explained to you before your cancer treatment started (e.g. nausea, pain, fatigue)?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, but I would have liked this information
- ☐ No, but I researched this myself
- ☐ Not sure/cannot remember

Q17 Were possible long-term side-effects of treatment explained to you before your cancer treatment started (e.g. reduced fertility, lymphoedema)?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No, but I would have liked this information
- ☐ No, but I researched this myself
- ☐ Not sure/cannot remember

Q18

Did the health professionals involved in your care check that you understood the information provided to you about the side-effects of treatment?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ I did not receive this information
- ☐ Not sure/cannot remember

Q19

Did the health professionals encourage you to ask questions about your treatment options?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ Not sure/cannot remember

Q20

Once your treatment was decided on, did a health professional give you information regarding what treatment would involve, how long it would take to complete all treatment and how long it might take to recover?

- ☐ Yes, I was given this information and it was adequate
- ☐ Yes, I was given this information but it was **not** adequate
- ☐ No, I did not receive this information
- ☐ Not sure/cannot remember

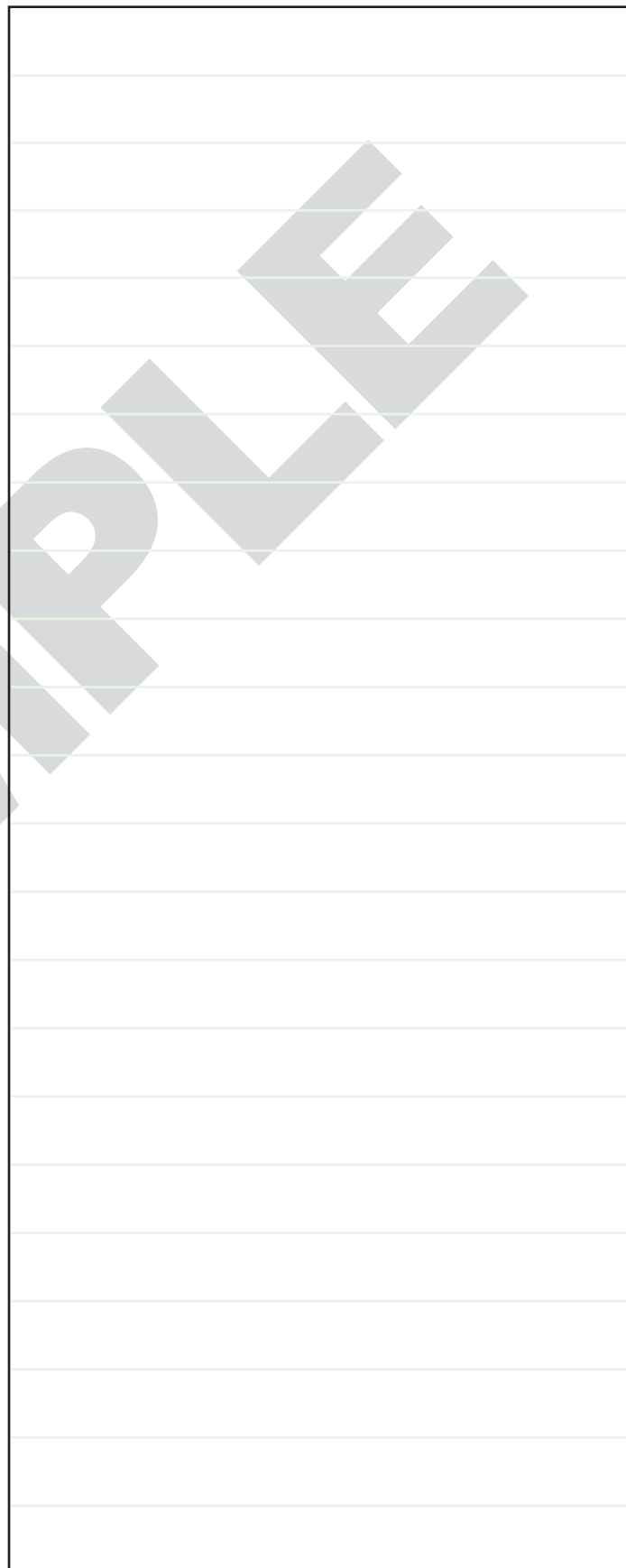
Q21

Before you started any treatment, did a health professional organise for you to see any other health professionals who may have been able to help with issues that may arise from your treatment, such as reduced fertility or incontinence?

- ☐ Yes, I was referred to services before treatment
- ☐ No, but I would have liked to have been
- ☐ No, as I did not need anything
- ☐ Not sure/cannot remember

Q22

If you would like to make any other comments about your experiences regarding treatment decisions please use the space below. We would like to know about them.





SURGERY

Surgery to treat cancer usually involves an operation to remove some or all of the cancer. If you have had more than one surgery to treat cancer, please think about the first surgical treatment that you had for your current cancer when answering the questions.

Did you have surgery related to your cancer?

Q23 ☐ Yes

☐ No

**Go to Q48 on page 12
(Section: Radiotherapy)**

How long ago did you have this surgery?

Q24 ☐ Within the last 3 months

☐ More than 3 months ago, but less than 6 months ago

☐ More than 6 months ago, but less than 12 months ago

☐ More than 12 months ago, but less than 2 years ago

☐ More than 2 years ago☐ Not sure/cannot remember

Q25 Where did you have your surgical treatment?
(Please indicate name of hospital/clinic and the town/suburb or postcode of where the hospital/clinic is located)

Name of hospital

AND Town/suburb/postcode

Q26 Who made the decision to have your surgery at this hospital? (Please choose one response)

☐ I made the decision with little or no input from my doctor

☐ I made the decision after considering my doctor's opinion

☐ My doctor and I made the decision together

☐ My doctor made the decision after considering my opinion

☐ My doctor made the decision with little or no input from me

☐ Other (*please specify*)

☐ Not sure/cannot remember

Q27a

Did you have any bills associated with your surgery that you had to pay (e.g. bills from the surgeon, anaesthetist, the hospital, bills for pathology tests or medications etc)?


☐ No, I did not have any bills associated with my surgery

☐ Yes, and my health insurance covered these costs completely

☐ Yes, and my health insurance covered only some of these costs☐ Yes, I had bills to pay

Q27b

What sort of bills did you have? (Please provide a brief description of the bills you have to pay)



Q28

Before you had your surgery, were you told or given information about the costs you would have to pay?

☐ Yes, I was fully informed of the costs I would have to pay

☐ Yes, I was informed, but not of the full amount

☐ No, I was not informed of the costs involved

☐ Not sure/cannot remember

Q29a

Once you were told you were ready for surgery, how long did you wait until you actually had surgery?

☐ Less than 2 weeks
 ☐ More than two weeks, but within four weeks
 ☐ More than a month
 ☐ Not sure/cannot remember
 ☐ Other

Go to Q29b

Go to Q29b

Q29b

If more than two weeks was this due to:

☐ Personal decision to wait
 ☐ Surgery waiting times. I was kept updated
 ☐ Surgery waiting times. I was **not** updated
 ☐ Other

Q30

Did the health professionals involved in your surgery ask if your family or friends needed any information or support?

☐ Yes, regularly
 ☐ Yes, occasionally
 ☐ No, never
 ☐ No, as family or friends were not involved
 ☐ Not sure/cannot remember

Q31

Before having surgery for cancer were you given information in a way that was acceptable to you about:

a. What it would be like after surgery (e.g. pain you may have, tubes that may be connected)?

Q32	Were you given:	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure/ cannot remember
a.	Information about how to manage any potential side-effects of surgery?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Information about what would happen after your surgery (e.g. arrangements for follow-up, further treatments)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q33

During your hospital stay, how often did the doctors, nurses and other health professionals caring for you explain things in a way you could understand?

☐ All of the time
 ☐ Most of the time
 ☐ Some of the time
 ☐ Rarely
 ☐ Never
 ☐ Not sure/cannot remember

Q34

Did you have worries or fears about your condition or treatment while you were in hospital?

☐ Yes
 ☐ No

Go to Q36

Q35

Did a health professional discuss these worries or concerns with you?

☐ Yes, completely
 ☐ Yes, to some extent
 ☐ No
 ☐ Not sure/cannot remember

Q36

When you were in the hospital for your surgery, were side-effects from surgery well managed (e.g. nausea, vomiting, pain etc.)?

☐ Yes, completely
 ☐ Yes, to some extent
 ☐ No
 ☐ I did not have any side-effects from surgery
 ☐ Not sure/cannot remember



Q37

Were you in pain while in hospital after your surgery for cancer?

☐ Yes

☐ No

Go to Q39

Q38

Do you think hospital staff did everything they could to help manage your pain?

☐ Yes, definitely

☐ Yes, to some extent

☐ No

☐ Not sure/cannot remember

Q39

If you needed assistance, were you able to get a member of staff to help you within a reasonable timeframe?

☐ Yes, all of the time

☐ Yes, most of the time

☐ Yes, some of the time

☐ Never

☐ I did not need assistance

☐ Not sure/cannot remember

Q40

While you were in hospital for your surgery, did a health professional organise other services you may have needed to help with your recovery (e.g. someone to help you with walking or other movements, mood, anxiety, eating, finances etc.)?

☐ Yes, I saw all the services I needed

☐ Yes, but I think I needed more

☐ No, but I think I needed to

☐ I did not need any other services

☐ Not sure/cannot remember

Q41

Did you feel you were treated with respect and dignity while you were in the hospital?

☐ Yes, always

☐ Yes, sometimes

☐ No

☐ Not sure/cannot remember

Q42

When you were discharged from hospital, were you given enough information about how to manage at home?

☐ Yes, completely

☐ Yes, to some extent

☐ No

☐ No, but I researched this myself

☐ Not sure/cannot remember

Q43

When you were discharged from hospital, were you given a telephone number of someone at the hospital to contact if you had concerns or questions about your condition or treatment?

☐ I was only given my doctor's number

☐ I was given the name and number of someone at the hospital

☐ I was given a hospital number to call but didn't have anyone's name

☐ No I wasn't given any number to call

☐ Not sure/cannot remember

Q44

Thinking about when you left hospital, were adequate arrangements made by the hospital staff for any services you needed (e.g. district nurse)?

☐ Yes, completely

☐ Yes, to some extent

☐ No

☐ I did not need assistance

☐ Not sure/cannot remember

Q45

How clean were the toilets and bathrooms that you used while in hospital?

☐ Very clean

☐ Fairly clean

☐ Not very clean

☐ Not at all clean

☐ Not sure/cannot remember

Q46

Overall how satisfied were you with the treatment you received from all health professionals involved in your surgery?

☐ Very satisfied

☐ Satisfied

☐ Neither satisfied or dissatisfied

☐ Dissatisfied

☐ Very dissatisfied

Q47 If you would like to make any other comments about your experiences with surgery, please use the space below. We would like to know about them.

SAMPLE

RADIOTHERAPY

Q48 Did you have radiotherapy treatment for cancer?

- ☐ Yes
☐ No

**Go to Q71 on page 16
(Section: Chemotherapy)**

Q49 When did you have your first radiotherapy treatment?

- ☐ Within the last 3 months
☐ More than 3 months ago, but less than 6 months ago
☐ More than 6 months ago, but less than 12 months ago
☐ More than 12 months ago, but less than 2 years ago
☐ More than 2 years ago
☐ Not sure/cannot remember

Q50 Where did you have your radiotherapy treatment? (Please indicate name of hospital/treatment centre and the town/suburb or postcode of where the hospital/treatment centre is located)

Name of hospital

AND Town/suburb/postcode

Q51 Who made the decision to have your radiotherapy at this hospital/treatment centre? (Please choose one response)

- ☐ I made the decision with little or no input from my doctor
☐ I made the decision after considering my doctor's opinion
☐ My doctor and I made the decision together
☐ My doctor made the decision after considering my opinion
☐ My doctor made the decision with little or no input from me
☐ Other (please specify)

- ☐ Not sure/cannot remember

Q52a

Did you have any bills associated with your radiotherapy that you had to pay (e.g. bills from your doctor, the hospital, bills for tests or medications etc.)?

- ☐ No, I did not have any bills associated with my radiotherapy
☐ Yes, and my health insurance covered these costs completely
☐ Yes, and my health insurance covered only some of these costs
☐ Yes, I had bills to pay

Go to Q54a

Q52b

What sort of bills did you have? (Please provide a brief description of the type of bills you had)

Q53

Before your radiotherapy treatment started, were you told or given information about the costs you would have to pay?

- ☐ Yes, I was fully informed of the costs I would have to pay
☐ Yes, I was informed, but not of the full amount
☐ No, I was not informed of the costs involved
☐ Not sure/cannot remember

Q54a



Did you have to stay away from home while receiving radiotherapy (e.g. at the home of a friend or relative, or in a hotel or hostel)?

- ☐ Yes **Go to Q54b**
☐ No

Q54b Who arranged this accommodation?

- ☐ I did/my family or friends did
- ☐ Staff at the hospital
- ☐ Staff associated with my doctor
- ☐ Not sure/cannot remember
- ☐ Other

Q55a Once you had your radiotherapy planning or mapping appointment (to scan or measure your body and mark the area to treat), how long did you wait before your first radiotherapy treatment?

- ☐ Less than 2 weeks
- ☐ More than two weeks,  **Go to Q55b**
- ☐ More than a month  **Go to Q55b**
- ☐ Not sure/cannot remember
- ☐ Other

Q55b If more than two weeks was this due to:

- ☐ Personal decision to wait
- ☐ Radiotherapy waiting times. I was kept updated
- ☐ Radiotherapy waiting times. I was **not** updated
- ☐ Other

Q56 Before starting radiotherapy for the first time were you given information about:

	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure/cannot remember
a. How to prepare for radiotherapy (e.g. any changes to other medications, not to use moisturisers etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. How to manage any anxiety or stress you might experience before your radiotherapy treatments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. How you might manage side-effects from radiotherapy (e.g. apply ointments, change bandages, exercise etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. How you might feel at the end of treatment (e.g. fatigued or tired)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. How long it might take to recover from having radiotherapy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q57 Did a health professional check that you understood the information provided to you?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q58 Did staff take into account how far you had to travel or other commitments when arranging your appointment times (e.g. work, caring for family members)?

- ☐ Yes, definitely
- ☐ Yes, as much as they could
- ☐ No, not at all
- ☐ Travel/other commitments were not a problem
- ☐ Not sure/cannot remember

Q59 On average, how long did you have to wait at your radiotherapy appointments before you had your treatment?

- ☐ I generally had treatment within 15 minutes of my appointment time
- ☐ I generally had treatment within 15-30 minutes of my appointment time
- ☐ I generally had treatment within 30-60 minutes of my appointment time
- ☐ I generally had treatment within 1-2 hours of my appointment time
- ☐ I generally waited longer than 2 hours for my appointment
- ☐ Not sure/cannot remember

Q70 If you would like to make any other comments about your experiences with radiotherapy, please use the space below. We would like to know about them.

SAMPLE

CHEMOTHERAPY

Please Note: Targeted therapies are included in chemotherapy. If you have had chemotherapy and targeted therapies please think about your chemotherapy when you answer these questions.

Q71 Did you have chemotherapy treatment for cancer?

- ☐ Yes
- ☐ No

Go to Q95 on page 20
(Section: Emergency Department)

Q72 When did you start chemotherapy for the first time?

- ☐ Within the last 3 months
- ☐ More than 3 months ago, but less than 6 months ago
- ☐ More than 6 months ago, but less than 12 months ago
- ☐ More than 12 months ago, but less than 2 years ago
- ☐ More than 2 years ago
- ☐ Not sure/cannot remember

Q73 Where did you have your chemotherapy treatment? (Please indicate name of hospital/treatment centre and the town/suburb or postcode of where the hospital/treatment centre is located)

Name of hospital

AND Town/suburb/postcode

Q74 Who made the decision to have your chemotherapy at this hospital/treatment centre? (Please choose one response)

- ☐ I made the decision with little or no input from my doctor
- ☐ I made the decision after considering my doctor's opinion
- ☐ My doctor and I made the decision together
- ☐ My doctor made the decision after considering my opinion
- ☐ My doctor made the decision with little or no input from me
- ☐ Other (*please specify*)

- ☐
- Not sure/cannot remember

Q75a

Did you have any bills associated with your chemotherapy that you had to pay (e.g. bills from the doctor, the hospital, for tests or medications you may have had etc.)?

- ☐ No, I did not have any bills associated with my chemotherapy. [Go to Q77a](#)
- ☐ Yes, and my health insurance covered these costs completely
- ☐ Yes, and my health insurance covered only some of these costs
- ☐ Yes, I had bills to pay

Go to Q77a

Q75b

What sort of bills did you have? (Please provide a brief description of the type of bills you had)

PROV

Q76

Before you started your chemotherapy, were you told or given information about the out-of-pocket costs you might have to pay?

- ☐ Yes, I was fully informed of the costs I would have to pay
- ☐ Yes, I was informed, but not of the full amount
- ☐ No, I was not informed of the costs involved
- ☐ Not sure/cannot remember

Q77a

Did you have to stay away from home while receiving chemotherapy (e.g. at the home of a friend or relative, or in a hotel or hostel)?

- ☐ Yes  **Go to Q77b**
- ☐ No

Go to Q77b

Q77b Who arranged this accommodation?

- ☐ I did/my family or friends did
☐ Staff at the hospital
☐ Staff associated with my doctor
☐ Not sure/cannot remember
☐ Other

Q78a Sometimes other treatments or tests need to be completed before a person is ready to start chemotherapy treatment. Once you were ready to begin chemotherapy, how long did you wait until you had your first chemotherapy treatment?

- ☐ Less than 2 weeks
☐ More than two weeks, **Go to Q78b**
but within four weeks
☐ More than a month **Go to Q78b**
☐ Not sure/cannot remember
☐ Other

Q78b If more than two weeks was this due to:

- ☐ Personal decision to wait
☐ Chemotherapy waiting times. I was kept updated
☐ Chemotherapy waiting times. I was **not** updated
☐ Other

Q79 Before starting chemotherapy for the first time were you given information about:

	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	Not sure/cannot remember
a. How to prepare for chemotherapy (e.g. changes to other medications)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. How to manage any anxiety or stress you might feel before your chemotherapy treatments (e.g. relaxation exercises etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. How you would feel at the end of the chemotherapy treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. What side-effects you might experience from chemotherapy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. How to manage any side-effects of chemotherapy at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. The possibility of going to the Emergency Department if you had a bad response to your chemotherapy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q80 Did a health professional check that you understood the information provided to you?

- ☐ Yes
☐ No
☐ Not sure/cannot remember

Q81 Did staff take into account how far you had to travel or other commitments when arranging your appointment times (e.g. work, caring for family members)?

- ☐ Yes, definitely
☐ Yes, as much as they could
☐ No, not at all
☐ Travel/other commitments were not a problem
☐ Not sure/cannot remember

Q82 On average, how long did you wait at your chemotherapy appointments before you had your treatment?

- ☐ I generally had treatment within 15 minutes of my appointment time
☐ I generally had treatment within 15-30 minutes of my appointment time
☐ I generally had treatment within 30-60 minutes of my appointment time
☐ I generally had treatment within 1-2 hours of my appointment time
☐ I generally waited longer than 2 hours for my appointment
☐ My chemotherapy was given in a tablet form. This wasn't a problem for me
☐ Not sure/cannot remember



Q83

While you were having chemotherapy, did health professionals check if you had any side-effects or symptoms (e.g. pain, vomiting, constipation or diarrhoea, hair loss, tiredness, tingling or loss of feeling in the fingers and toes etc.)?

- ☐ Yes
- ☐ Yes, but not as often as I would have liked
- ☐ No
- ☐ Not sure/cannot remember

Q84

Do you think the health professionals involved in your chemotherapy did everything they could to help manage any side-effects you experienced?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ I did not have any side-effects
- ☐ Not sure/cannot remember

Q85

Did the health professionals involved in your chemotherapy treat you with respect and dignity?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No
- ☐ Not sure/cannot remember

Q86

Did the health professionals involved in your care check if you needed any help or assistance with things like your diet or eating, etc.?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q87

Did the health professionals involved in your care check if you needed any help or assistance with managing your emotional state (e.g. feeling stressed or anxious, feeling sad or down etc.)?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q88

Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q89

Were you given a telephone number to contact if you had concerns, questions or became unwell because of your treatment?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q90

Were you given a card or some other document that explained your chemotherapy treatment to show if you needed to go to the Emergency Department?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q91

Did the health professionals involved in your chemotherapy ask if your family or friends needed any information or support?

- ☐ Yes, regularly
- ☐ Yes, occasionally
- ☐ No, never
- ☐ No, family or friends were not involved
- ☐ Not sure/cannot remember

Q92

How satisfied were you with the availability of car parking at the treatment centre where you had chemotherapy?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied or dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied
- ☐ Not applicable

Q93

Overall, how satisfied were you with the treatment you received from all health professionals involved in your chemotherapy?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied or dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied

Q94

If you would like to make any other comments about your experiences regarding chemotherapy, please use the space below. We would like to know about them.

SAMPLE

Sometimes people become very unwell during their cancer treatment and need to go to an Emergency Department.

Q95 Have you felt so ill from your cancer or cancer treatment that you have had to go to an Emergency Department?

- ☐ Yes, only once
- ☐ Yes, more than once
- ☐ Yes, but it was before my cancer was properly diagnosed
- ☐ No, never
- Go to Q102 on page 21**
(Section: Follow up Care)

Go to Q102 on page 21
(Section: Follow-up Care)

Q96 Which hospital Emergency Department did you last go to? (Please indicate name of the hospital and the town/suburb or postcode of where this hospital is located)

Name of hospital

--

AND Town/suburb/postcode

Q97 The last time you were at the Emergency Department, about how long did you have to wait before you saw the doctor?

- ☐ Less than 10 minutes
- ☐ More than 10 minutes, but less than 30 minutes
- ☐ More than 30 minutes, but less than 1 hour
- ☐ Between 1-2 hours
- ☐ Between 2-4 hours
- ☐ More than 4 hours
- ☐ Not sure/cannot remember

Q98 Do you think that your condition was well managed while you were waiting to see an Emergency Department doctor?

- ☐ Yes, my condition was managed well
- ☐ No, my condition was **not** managed well
- ☐ Not sure/cannot remember

Q99 Do you think that the health professionals in the Emergency Department had the knowledge and skills needed to look after you?

- ☐ Yes, all or most of them did
- ☐ Only a few of them did
- ☐ No
- ☐ Not sure/cannot remember

Q100 Were you admitted into hospital as a result of your consultation with doctors at the Emergency Department?

- ☐ Yes
- ☐ No
- ☐ Not sure/cannot remember

Q101 If you would like to make any other comments about your experiences with the Emergency Department, please use the space below. We would like to know about them.

[illegible]

FOLLOW-UP CARE

**IF YOU ARE STILL UNDERGOING
CHEMOTHERAPY OR RADIOTHERAPY,
PLEASE GO TO QUESTION 111 ON PAGE 23
(SECTION: INFORMATION RECEIVED)**

Q102 Which doctor is mainly in charge of your follow-up care (if there is more than one doctor please tick all that apply)?

- ☐ Surgeon
- ☐ Haematologist
- ☐ Radiation oncologist
- ☐ GP
- ☐ Medical oncologist
- ☐ Other (please specify)

- ☐ Other medical doctor (e.g. urologist, gynaecologist, respiratory physician) (please specify)

- ☐ I am not sure who is in charge

Q103 Which hospital or clinic has the most involvement in your follow-up care? (This could be the location of the doctor in charge of your follow-up care, or the hospital/clinic where you have most of your follow-up appointments)

Name of hospital/clinic

AND Town/suburb/postcode

Q104

When scheduling your follow-up appointments, was work or other commitments, or how far you had to travel taken into consideration?

- ☐ Yes, definitely
- ☐ Yes, as much as they could
- ☐ No, not at all
- ☐ Travel/other commitments were not a problem
- ☐ Not sure/cannot remember

Q105

Were your appointments and tests coordinated by health professionals to reduce the time you would spend going to and from your medical appointments?

- ☐ Yes, definitely
- ☐ Yes, sometimes
- ☐ No
- ☐ Not sure/cannot remember

Q106

When you have seen your doctor, how often have test results or other information needed for your appointment not been available to your doctor?

- ☐ Never
- ☐ Once or twice
- ☐ Three or four times
- ☐ Five or more times
- ☐ Not sure/cannot remember

When you had finished your cancer treatment were you given:

Yes, I was given this information

Yes, but I would have liked more

No, I was not given this information

Not sure/
cannot
remember

a. A written plan that included information about your follow-up care over the next 12 months? (This should be more than a list of medical appointments)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Information about what follow-up tests you would need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Information about things you could do to stay healthy (e.g. exercise, diet, stopping smoking)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Information about which new symptoms need investigation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Information about how people feel after finishing cancer treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Information about how to get extra support if you or your family wanted it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Information about how often you would need to have tests or check-ups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q108

When you had finished your cancer treatment were you given information about how to manage any ongoing symptoms or side-effects?

- ☐ Yes, I was given this information
- ☐ Yes, but I would have liked more
- ☐ No
- ☐ I did not have any side-effects or ongoing symptoms
- ☐ Not sure/cannot remember

Q109

As far as you know, does your GP have a good understanding of the follow-up care you need (e.g. how to manage any ongoing symptoms or side-effects like lymphoedema, fertility or fatigue)?

- ☐ Yes
- ☐ No
- ☐ I do not have a regular GP
- ☐ Not sure/cannot remember

Q110

If you would like to make any other comments about your experiences with follow-up care, please use the space below. We would like to know about them.

This image shows a single sheet of white paper with horizontal blue or green ruling lines. The lines are evenly spaced and run across the width of the page. On the left side, there is a vertical margin line. In the top-left corner, there is a small, dark grey tab-like shape protruding from the edge. The overall appearance is that of a clean, unused piece of stationery or notebook paper.

INFORMATION RECEIVED

Q111 Did you get enough information from health professionals about:	Yes, I was given this information	Yes, but I would have liked more	No, I was not given this information	I did not need this information	Not sure/ cannot remember
a. The possible impact of treatment on your capacity to work or do activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The possible changes in your energy level?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. What you could do to preserve your fertility?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q112 Did any health professionals talk to you about any financial support programs you might have been able to use? (e.g. this could be to help with the cost of travelling to your treatment if you lived far away, or payments through Centrelink etc.)

- ☐ Yes, someone talked to me about financial support
- ☐ No, but I would have liked someone to
- ☐ No, I did not need any financial support services
- ☐ Not sure/cannot remember

Q113 Did you feel like you could ask the health professionals involved in your care any questions that you had?

- ☐ Yes, definitely
- ☐ Yes, to some extent
- ☐ No
- ☐ Not sure/cannot remember

Q114 Below are some services or health professionals that some people use during their cancer treatments. We would like to know if a health professional talked to you about any of the following services.

Did a health professional talk to you about this service?	Yes	No, but I would have liked them to	No, but I didn't need them to	Not sure/ cannot remember
a. Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Dietitian	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Speech Therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Occupational Therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Pain management specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Cancer Helpline	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Financial planner/services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Would you like to make any other comments or share your own care experiences regarding the care you received or would like to receive? Please use the space below.

Q118 If you would like to make any other comments about your care experiences regarding information you received or would like to have received, please use the space below. We would like to know about them.

[illegible]

OVERALL CARE

Throughout your cancer care and treatment, has there been a health professional or a team of health professionals you could contact if you had any questions about your care or if you needed help or advice?

- Which doctor/s were in charge of your care (tick all that apply)?**

- _____

- _____

- Throughout your cancer care, has there been a time when:**

If you experienced any of the things listed in question 3, could you please provide us with information about what happened and when it happened.

PROVE

Throughout your cancer care, here are some things to keep in mind in a time when:

A Clinical Nurse Specialist is a specialist cancer nurse (e.g. breast care nurse, urology/prostate care nurse) who makes sure you get the right care and gives you help and advice on coping with cancer.

Q123 Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

- ☐ Yes
☐ No **Go to Q127**
☐ Not sure/can't remember **Go to Q127**

Q124 How easy is it for you to contact your Clinical Nurse Specialist?

- ☐ Easy
☐ Sometimes easy, sometimes difficult
☐ Difficult
☐ I have not tried to contact her/him

Q125 The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?

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

Q126 When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?

- ☐ All or most of the time
☐ Some of the time
☐ Rarely or never
☐ I do not ask any questions

Q127 Were the different treatment centres involved in your care informed about the care you had received at the other centres (e.g. different hospitals or radiotherapy and chemotherapy departments at the same hospital)?

- ☐ Yes, they seemed well informed about the care I had received at other places
☐ Yes, although some information seemed to be missing
☐ No, there seemed to be little or no sharing of information
☐ I was only treated at one treatment centre
☐ Not sure/ can't remember

Q128 If you needed an interpreter at your appointments, was a hospital/treatment centre interpreter available for you?

- ☐ Yes, at most or all of my appointments
☐ Yes, at some of my appointments
☐ No, an interpreter was never available
☐ No one talked to me about getting an interpreter, but I needed one
☐ I did not need an interpreter
☐ Not sure/ can't remember

Q129 As far as you know, was your GP kept informed about your condition and your treatment?

- ☐ Yes, my GP seemed very well informed
☐ Yes, to some extent
☐ No, my GP did not know much about my cancer or the treatment I had
☐ I do not have a regular GP
☐ Not sure/ can't remember

Q130 How would you rate how well the doctors and nurses involved in your cancer care worked together?

- ☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

Q131 How satisfied were you with the overall care you received from all health professionals involved in your treatment?

- ☐ Very satisfied
☐ Satisfied
☐ Neither satisfied or dissatisfied
☐ Dissatisfied
☐ Very dissatisfied

Q132a Was there a time when you were so unhappy with your treatment that you wanted to or did complain about it (this includes medical treatment, the way you were treated personally and the way that healthcare professionals communicated with you)?

- ☐ Yes, there was at least one time **Go to Q132b**
☐ No, my care was generally fine
☐ No, my care was excellent
☐ Not sure/cannot remember

Q132b

If yes, what was the issue you wanted to complain about?

Q133

If you would like to make any other comments about your overall care experiences please use the space below. We would like to know about them.

ABOUT YOU

Q134 Are you completing this questionnaire as the patient or on behalf of the patient?

- ☐ Patient
☐ On behalf of patient

Q135 What is your gender?

- ☐ Male
☐ Female

Q136 How old were you at your last birthday?

years

Q137 What is the name or postcode of the town/suburb where you currently live?

Town/Suburb

OR Postcode

Q138 Where were you living when you received your treatments for cancer?

- ☐ Same address as above
☐ Different address:

Town/Suburb

OR Postcode

Q139

What language do you mainly speak at home?

- ☐ English
☐ Italian
☐ Greek
☐ Cantonese
☐ Arabic (including Lebanese)
☐ Vietnamese
☐ Mandarin
☐ Other (*please specify*)

Q140

Are you of Aboriginal or Torres Strait Islander origin?

- ☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, both Aboriginal and Torres Strait Islander
☐ No

Q141

In general, how would you rate your health?

- ☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

Thank you very much for completing the questionnaire.

If you would like to make any other comments about your care experiences during your treatment, please use the space below. We would like to know about them.

Barcode