

Victorian healthcare experience survey

Your chemotherapy experience

<Study ID>
<First Name> <Last Name>
<Address Line 1>
<SUBURB> <STATE> <POSTCODE>

<Date>

Dear <INSERT TITLE AND SURNAME FROM PATIENT FILE>,

Your feedback about your experience receiving chemotherapy treatment is important.

I invite you to participate in the Victorian Healthcare Experience Survey. You have been randomly selected following chemotherapy treatment recently received at a Victorian public hospital. Even if your experience was brief, your feedback will help improve services for future patients.

You may have had different hospital visits recently, please complete the survey in relation to this particular experience:


[NAME OF HOSPITAL], discharged in [INSERT DISCHARGE MONTH AND YEAR]

Information about the survey is provided on the next page. If you have any questions about the survey, please contact the toll-free Survey Helpline on:


1800 356 928

The survey will take about 20 minutes to complete. Taking part in the survey is voluntary. If you do not wish to participate, please disregard this survey and the following reminder letter. You can opt-out of the survey by calling the toll-free Survey Helpline using the details listed above. If you opt-out, you will not be invited to complete the survey again.

There are two ways to complete the survey:

 **Online:** Please visit www.vhes.com.au/survey and enter this password to access the survey: [INSERT PASSWORD]. Alternatively, scan the QR code at the bottom of this letter using your tablet or smartphone. Once you start the online survey your answers will be saved if you want to stop and return to complete it later.

OR

 **Pen and paper:** If you prefer to complete the attached paper survey, please remove this covering letter before placing the completed survey in the enclosed Reply Paid envelope. Removing the covering letter helps to ensure your privacy. If you have misplaced the Reply Paid envelope, please use a plain envelope (no stamp is necessary) and address to:

**Victorian Healthcare Experience Survey
Reply Paid 91979
Port Melbourne Vic 3207**

There are many safeguards in place to protect your privacy when answering this survey. All information that you provide in response to the survey will be treated confidentially. The hospital and staff who cared for you will not know whether you have completed the questionnaire and will not be able to see your individual responses.

Thank you for taking the time to provide your feedback.

Yours sincerely,

Kym Peake
Secretary
Victorian Department of Health and Human Services



Victorian
Agency for
**Health
Information**



Health
and Human
Services

PLEASE DETACH THIS OUTER COVER

Information Sheet

You are being invited to complete the enclosed questionnaire because you have attended a Victorian public hospital for chemotherapy related care in 2019. 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?

The Victorian healthcare experience survey is a Victoria wide survey that asks people how they felt about their experience with the Victorian public health system. The survey is managed by the Victorian Agency for Health Information (VAHI), an office of the Victorian Department of Health and Human Services, and conducted by Ipsos Australia, an independent research company.

What happens to my survey responses?

The information you provide in your survey responses will be de-identified and combined with responses from other people. The results will be used by Victorian public health services, the Department of Health and Human Services and Safer Care Victoria to identify ways to improve the care and services provided to patients.

You will be asked to provide some personal information, such as your year of birth and gender, and some sensitive information, including about your racial or ethnic origin or sexual orientation. This information helps us understand the experience of Victorians in our healthcare system, however it will not be used to identify you.

We use information about patients' experience with other health data to see what is working well in our healthcare system, and where there is opportunity for improvement.

How is my privacy and data protected?

VAHI and Ipsos are committed to protecting personal and sensitive information provided by you, in accordance with Australian Privacy Principles

(<https://www.oaic.gov.au/privacy/australian-privacy-principles/>), the Victorian Information Privacy Principles (<https://ovic.vic.gov.au/privacy/for-agencies/information-privacy-principles/>) and the Australian Market and Social Research Organisations privacy code (<https://www.legislation.gov.au/Details/F2014L01725>).

Who should complete the survey?

We have randomly selected a sample of people who have received chemotherapy treatment 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?

If you have a complaint, you should contact the health service where the issue occurred. Alternatively, if you feel the health service is not responding to your complaint you may contact the Office of the Health Services Commissioner on 1300 582 113.

If your survey responses contain information that we believe would be better addressed in a formal complaint to the health service or of serious concern, we may contact you confidentially to give you the opportunity to address these comments appropriately.

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).

Is there a number I can call if I require support?

Cancer Council is a free, confidential telephone information and support service. If you have a question about cancer, or if you're seeking emotional or practical support, call 13 11 20 to speak to specially trained staff.

How to complete the paper survey

For each question, please use a blue or black pen to cross the box next to the answer you choose, as shown below.



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, cannot remember or if they are not applicable to you, 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 cross 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.

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 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:

DIAGNOSIS AND TREATMENT
OVERALL: Page 4-5

CHEMOTHERAPY:
Pages 6-9

EMERGENCY DEPT
CARE: Page 10

YOUR HEALTH:
Page 11

YOUR BACKGROUND:
Page 12

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 treatment. Targeted therapies are drugs or other substances that block the growth and spread of cancer by interfering with specific molecules. Chemotherapy treatment 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.

DIAGNOSIS AND TREATMENT OVERALL

Q1 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.

- | | | |
|---|---|--|
| <input type="checkbox"/> Breast | <input type="checkbox"/> Uterus | <input type="checkbox"/> Ovarian |
| <input type="checkbox"/> Leukaemia | <input type="checkbox"/> Multiple myeloma | <input type="checkbox"/> Lymphoma |
| <input type="checkbox"/> Prostate | <input type="checkbox"/> Kidney | <input type="checkbox"/> Bladder cancer |
| <input type="checkbox"/> Colorectal/Bowel | <input type="checkbox"/> Stomach cancer | <input type="checkbox"/> Pancreatic cancer |
| <input type="checkbox"/> Lung | <input type="checkbox"/> Mesothelioma | <input type="checkbox"/> Throat/mouth |
| <input type="checkbox"/> Brain | <input type="checkbox"/> Central nervous system | |
| <input type="checkbox"/> Sarcoma | <input type="checkbox"/> Melanoma | |
| <input type="checkbox"/> Other cancer (<i>please specify</i>) | | |

Q2 Who provided you with your diagnosis?

- GP Medical Specialist (*Insert hospital name*) Other (*please specify*)

Q3 When was this cancer diagnosed? Please provide the month and year. If you cannot remember the month, please provide the year.

| | | | | | |
|---|---|---|---|---|---|
| M | M | Y | Y | Y | Y |
|---|---|---|---|---|---|

Q4 When you were told you had cancer:

| | Yes, definitely | Yes, I think so | No, I do not think so | No, definitely not | Not sure/ cannot remember |
|---|--------------------------|--------------------------|--------------------------|--------------------------|---------------------------|
| a. Were you given information about your cancer in a format that you were satisfied with (e.g. written information or being spoken with)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Were you given information about the treatment options for your cancer (e.g. written information or being spoken with)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Were you told how you could get more information (e.g. to go to a specific website, how to get booklets, to call the cancer helpline)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Were you given information about who you could contact for support (e.g. another health professional, support group, cancer helpline)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Q5 From the list below, could you please indicate the treatments you have had, or are having, other than chemotherapy, for your cancer and the hospital or clinic where you received this treatment.

- Surgery (*Hospital/Clinic Name*) Radiotherapy (*Hospital/Clinic Name*)

- Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®.)

Q6 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

Q7 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

Q8 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?

- Yes, there was at least one health professional I could contact throughout my treatment
- Yes, there was someone I could contact but not all the time
- No
- Not sure/cannot remember

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.

Q9 Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?

- Yes
- No [▶ Go to Q11](#)
- Not sure/can't remember [▶ Go to Q11](#)

Q10 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

Q11 How would you rate how well the doctors and nurses involved in your cancer care worked together?

- Excellent
- Very good
- Good
- Fair
- Poor

Q12 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
- No, my care was generally fine [▶ Go to Q14](#)
- No, my care was excellent [▶ Go to Q14](#)
- Not sure/cannot remember [▶ Go to Q14](#)

Q13 If yes, what was the issue you wanted to complain about?

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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.

Q14 At what stage of your chemotherapy treatment are you currently?

- Treatment has not yet started
- I am in the course of treatment and am unsure how my cancer has responded
- I am in the course of treatment and my cancer is in remission
- I have finished the course of treatment but my cancer is still present
- I have finished the course of treatment and I have no signs or symptoms of cancer

Q15 When did you start chemotherapy treatment 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

Q16 Who made the decision about where you would have your chemotherapy treatment? (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

Q17 Did you have any bills associated with your chemotherapy treatment 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 Q20**
- 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

Q18 What sort of bills did you have? (Please provide a brief description of the type of bills you had)

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Q19 Before you started your chemotherapy treatment, 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

Q20 Did you have to stay away from home while receiving chemotherapy treatment (e.g. at the home of a friend or relative, or in a hotel or hostel)?

- Yes
- No **Go to Q22**

Q21

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

Q22

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?

- 2 weeks or less ▶ Go to Q24
- More than two weeks, but within four weeks
- More than a month
- Not sure/cannot remember

Q23

If more than two weeks was this due to:

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

Q24

Before starting chemotherapy treatment for the first time were you given information, both written and verbal, about:

a How to prepare for chemotherapy treatment (e.g. changes to other medications)?

- Yes, I was given this information
- Yes, but I would have liked more
- No, I was not given this information
- Not sure/ cannot remember

b How to manage any anxiety or stress you might feel before your chemotherapy treatments (e.g. relaxation exercises etc.)?

- Yes, I was given this information
- Yes, but I would have liked more
- No, I was not given this information
- Not sure/ cannot remember

c How you would feel at the end of the chemotherapy treatment?

- Yes, I was given this information
- Yes, but I would have liked more
- No, I was not given this information
- Not sure/ cannot remember

d What side-effects you might experience from chemotherapy treatment?

- Yes, I was given this information
- Yes, but I would have liked more
- No, I was not given this information
- Not sure/ cannot remember

e How to manage any side-effects of chemotherapy treatment at home?

- Yes, I was given this information
- Yes, but I would have liked more
- No, I was not given this information
- Not sure/ cannot remember

f The possibility of going to the Emergency Department if you had a bad response to your chemotherapy treatment?

- Yes, I was given this information
- Yes, but I would have liked more
- No, I was not given this information
- Not sure/ cannot remember

Q25

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

- Yes
- No
- Not sure/cannot remember

Q26

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
- Not applicable



Q27

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 tablet form
- Not sure/cannot remember

Q28

While you were having chemotherapy treatment, 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

Q29

Do you think the health professionals involved in your chemotherapy treatment 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

Q30

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

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

Q31

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

- Yes
- No
- Not sure/cannot remember

Q32

Did the health professionals involved in your chemotherapy treatment 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

Q33

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

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

Q34

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

- Yes
- No
- Not sure/cannot remember

Q35

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

Q36

Did the health professionals involved in your chemotherapy treatment 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

Q37 How satisfied were you with the availability of car parking at the treatment centre where you had chemotherapy treatment?

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

Q38 Overall, how satisfied were you with the care you received during your chemotherapy treatment?

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

What were the most helpful things the chemotherapy treatment team did during your care?

SA
MPLE

What could the hospital that provided your chemotherapy treatment do to improve the care and services it provides to better meet your needs?

S

YOUR HEALTH

The next set of questions have been included here for the first time to inform clinical care and improvement activities. Your responses are anonymised before being provided to the health service that delivered your chemotherapy treatment. Your answers to the following questions will help us better understand treatment outcomes from your perspective. Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- Q45** I have no problems in walking about
 I have slight problems in walking about
 I have moderate problems in walking about
 I have severe problems in walking about
 I am unable to walk about

SELF-CARE

- Q46** I have no problems washing or dressing myself
 I have slight problems washing or dressing myself
 I have moderate problems washing or dressing myself
 I have severe problems washing or dressing myself
 I am unable to wash or dress myself

USUAL ACTIVITIES

- Q47** (e.g. work, study, housework, family or leisure activities)
 I have no problems doing my usual activities
 I have slight problems doing my usual activities
 I have moderate problems doing my usual activities
 I have severe problems doing my usual activities
 I am unable to do my usual activities

PAIN / DISCOMFORT

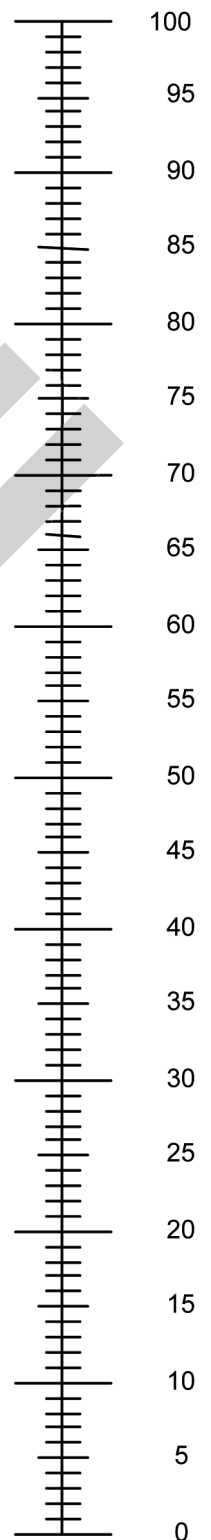
- Q48** I have no pain or discomfort
 I have slight pain or discomfort
 I have moderate pain or discomfort
 I have severe pain or discomfort
 I have extreme pain or discomfort

ANXIETY / DEPRESSION

- Q49** I am not anxious or depressed
 I am slightly anxious or depressed
 I am moderately anxious or depressed
 I am severely anxious or depressed
 I am extremely anxious or depressed

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from **0** to **100**.
- 100** means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an **X** on the scale to indicate how your health is **TODAY**.
- Now, please write the number you marked on the scale in the box below.

The best health you can imagine



The worst health you can imagine

YOUR HEALTH TODAY =

YOUR BACKGROUND

Your answers to the following questions will help us to describe the people taking part in the survey and to find out whether the care offered is the same regardless of a person's background or circumstances.

If you are responding for another person, please complete these questions about the person undergoing treatment.

Q50 What is your gender?

- Male
 Female

Q51 How old were you at your last birthday?

years

Q52 What is the name or postcode of the town/suburb where you currently live?

Town/Suburb

OR Postcode

Q53 Where were you living when you received your treatments for cancer?

- Same address as above
 Different address:

Town/Suburb

OR Postcode

Q54 What language do you mainly speak at home?

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

Q55 Are you of Aboriginal or Torres Strait Islander origin?

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

Q56 In general, how would you rate your health?

- Excellent
 Very good
 Good
 Fair
 Poor

Q57 Who completed this survey?

- The patient
 Someone on behalf of the patient

Thank you very much for completing the questionnaire. If you need help, or someone to talk to about concerns or worries about your condition, you may like to contact your general practitioner or the Cancer Council Information and Support Line on 13 11 20.

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