

Experiences of Care Survey

Patient Experiences of Care Survey

Please remove this cover page prior to distributing to patients.

Experiences of Care Survey

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

Patient ₁

On behalf of patient ₂

This survey is about the care you received during your cancer treatment.

Taking part in this survey is voluntary. Your responses are confidential. They will be combined with the responses of others in reports.

Completing this survey:

For most questions there is a choice of answers. Pick the response that is true for you and tick the box next to it. Sometimes, more than one box may be ticked. If you make a mistake, scribble out the mistake and put a tick in the correct box.

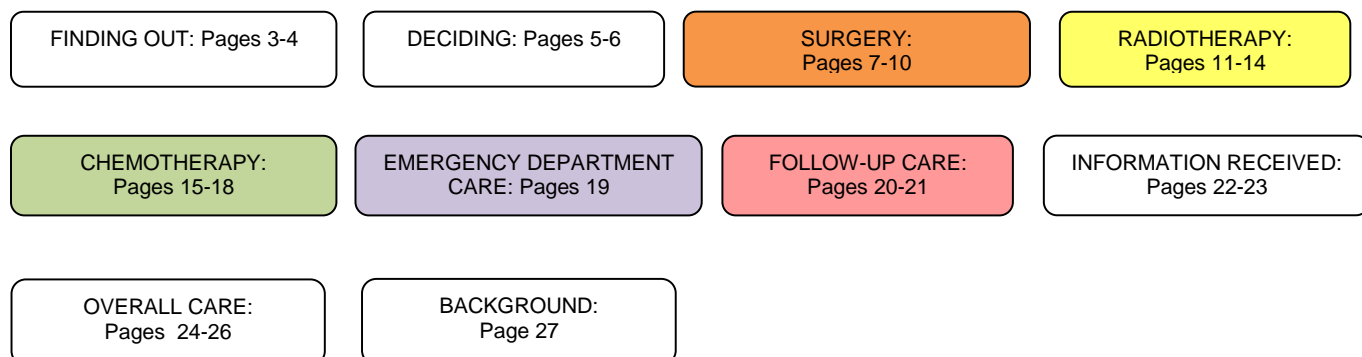
There is space throughout the survey for you to make any comments about your care. There is also space at the end of the survey for any comments you want to make.

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.

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

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



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.

1a. How long was it between when you were referred to a specialist doctor or hospital clinic and your first appointment?

- ₁ Less than two weeks
₂ More than two weeks, but within four weeks
₃ More than a month
₄ I stayed with my GP
₅ Not sure/cannot remember
₆ Other _____

1b. If more than two weeks, was this due to:

- ₁ Personal decision to wait
₂ Specialist waiting times
₃ Hospital waiting time
₄ 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.

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

- ₁ GP
₂ Surgeon
₃ Medical oncologist
₇ Other (please specify) _____
₄ Radiation oncologist
₅ Haematologist
₆ Hospital doctor

3. 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.

- ₁ Breast
₂ Leukaemia
₃ Prostate
₄ Colorectal
₅ Lung
₆ Brain
₇ Sarcoma
₂₀ Other cancer (please specify) _____
₈ Uterus
₉ Multiple myeloma
₁₀ Kidney
₁₁ Stomach cancer
₁₂ Mesothelioma
₁₃ Central nervous system
₁₄ Melanoma
₁₅ Ovarian
₁₆ Lymphoma
₁₇ Bladder cancer
₁₈ Pancreatic cancer
₁₉ Throat/mouth

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

- ₁ Yes, I understood it completely
₂ I understood most of it
₃ I understood some of it
₄ No, I did not understand it
₅ Not sure/cannot remember

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

- ₁ Yes
 ₂ No
 ₃ It wasn't necessary, I wanted to ask questions
 ₄ I did not want to ask questions
 ₅ Not sure/cannot remember

7. 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 happy with (e.g. written information or being spoken with)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b. Were you given information about the treatment options for your cancer (e.g. written information or being spoken with)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
d. Were you given information about who you could contact for support (e.g. another health professional, support group, cancer helpline)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

8. After getting your diagnosis, did a health professional go through the information about your cancer and your treatment options again?

- ₁ Yes, I had another appointment
 ₂ Yes, I spoke to someone over the phone
 ₃ Yes, but informally (e.g. when I saw them about something else)
 ₄ No, but I would have liked them to
 ₅ No, but it was not necessary
 ₆ Not sure/cannot remember

9. Did the health professionals involved in your diagnosis talk to you with respect and understanding?

- ₁ Yes, always
 ₂ Yes, sometimes
 ₃ No
 ₄ Not sure/cannot remember

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

- ₁ Yes, definitely
 ₂ Yes, I think so
 ₃ No, not at all
 ₄ No, my family/friends did not need this
 ₅ No, family or friends were not involved
 ₆ Not sure/cannot remember

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

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.

1. Were you involved as much as you wanted to be in decisions about your care and treatment?

- ₁ Yes, definitely
- ₂ Yes, to some extent
- ₃ No
- ₄ I was not well enough or did not want to be involved in these decisions
- ₅ Only one type of treatment/treatment option was suitable for me
- ₆ Not sure/cannot remember

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

- ₁ Yes
- ₂ No → PLEASE GO TO QUESTION 1 ON PAGE 28 (SECTION: BACKGROUND)

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

- ₁ Surgery
- ₁ Radiotherapy
- ₁ Chemotherapy or targeted therapies
- ₁ Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®.)

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?

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

- | | |
|---|--|
| <input type="checkbox"/> ₁ Yes, definitely | <input type="checkbox"/> ₄ No, but I researched this myself |
| <input type="checkbox"/> ₂ Yes, to some extent | <input type="checkbox"/> ₅ Not sure/cannot remember |
| <input type="checkbox"/> ₃ No, but I would have liked this information | |

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

- ₁ Yes, definitely
- ₂ Yes, to some extent
- ₃ No, but I would have liked this information
- ₄ No, but I researched this myself
- ₅ Not sure/cannot remember

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

- ₁ Yes, definitely
- ₂ Yes, to some extent
- ₃ No
- ₄ I did not receive this information
- ₅ Not sure/cannot remember

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

- ₁ Yes, definitely
- ₂ Yes, to some extent
- ₃ No
- ₄ Not sure/cannot remember

8. **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?**

- ₁ Yes, I was given this information and it was adequate
- ₂ Yes, I was given this information but it was **not** adequate
- ₃ No, I did not receive this information
- ₄ Not sure/cannot remember

9. **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?**

- ₁ Yes, I was referred to services before treatment
- ₂ No, but I would have liked to have been
- ₃ No, as I did not need anything
- ₄ Not sure/cannot remember

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.

1. Did you have surgery related to your cancer?

₁ Yes

₂ No → PLEASE GO TO QUESTION 1 ON PAGE 11 (SECTION: RADIOTHERAPY)

2. How long ago did you have this surgery?

₁ Within the last 3 months

₂ More than 3 months ago, but less than 6 months ago

₃ More than 6 months ago, but less than 12 months ago

₄ More than 12 months ago, but less than 2 years ago

₅ More than 2 years ago

₆ Not sure/cannot remember

3. 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 _____

4. Who made the decision to have your surgery at this hospital? (please choose one response)

₁ I made the decision with little or no input from my doctor

₂ I made the decision after considering my doctor's opinion

₃ My doctor and I made the decision together

₄ My doctor made the decision after considering my opinion

₅ My doctor made the decision with little or no input from me

₆ Other (please specify) _____

₇ Not sure/cannot remember

5. 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)?

₁ No, I did not have any bills associated with my surgery → GO TO QUESTION 7A

₂ Yes, and my health insurance covered these costs completely

₃ Yes, and my health insurance covered only some of these costs

₄ Yes, I had bills to pay

5a. What sort of bills did you have? (please provide a brief description of the bills you have to pay)

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

- ₁ Yes, I was fully informed of the costs I would have to pay
- ₂ Yes, I was informed, but not of the full amount
- ₃ No, I was not informed of the costs involved
- ₄ Not sure/cannot remember

7a. **Once you were told you were ready for surgery, how long did you wait until you actually had surgery?**

- ₁ Less than 2 weeks
- ₂ More than 2, but within 4 weeks
- ₃ More than a month
- ₄ Not sure/cannot remember
- ₅ Other _____

7b. **If more than two weeks was this due to:**

- ₁ Personal decision to wait
- ₂ Surgery waiting times. I was kept updated
- ₃ Surgery waiting times. I was **not** updated
- ₄ Other _____

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

- ₁ Yes, regularly
- ₄ No, as family or friends were not involved
- ₂ Yes, occasionally
- ₅ Not sure/cannot remember
- ₃ No, never

9. Before having surgery for cancer were you given information in a way that was acceptable to you 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. What it would be like after surgery (e.g. pain you may have, tubes that may be connected)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
10. 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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. Information about what would happen after your surgery (e.g. arrangements for follow-up, further treatments)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

11. **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?**

- ₁ All of the time
- ₄ Rarely
- ₂ Most of the time
- ₅ Never
- ₃ Some of the time
- ₆ Not sure/cannot remember

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

- ₁ Yes
- ₂ No → PLEASE GO TO QUESTION 14

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

- ₁ Yes, completely
- ₃ No
- ₂ Yes, to some extent
- ₄ Not sure/cannot remember

14. **When you were in the hospital for your surgery, were side-effects from surgery well managed (e.g. nausea, vomiting, pain etc.)?**
- ₁ Yes, completely ₄ I did not have any side-effects from surgery
₂ Yes, to some extent ₅ Not sure/cannot remember
₃ No
15. **Were you in pain while in hospital after your surgery for cancer?**
- ₁ Yes ₂ No → PLEASE GO TO QUESTION 17
16. **Do you think hospital staff did everything they could to help manage your pain?**
- ₁ Yes, definitely ₃ No
₂ Yes, to some extent ₄ Not sure/cannot remember
17. **If you needed assistance, were you able to get a member of staff to help you within a reasonable timeframe?**
- ₁ Yes, all of the time ₄ Never
₂ Yes, most of the time ₅ I did not need assistance
₃ Yes, some of the time ₆ Not sure/cannot remember
18. **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.)?**
- ₁ Yes, I saw all the services I needed ₄ I did not need any other services
₂ Yes, but I think I needed more ₅ Not sure/cannot remember
₃ No, but I think I needed to
19. **Did you feel you were treated with respect and dignity while you were in the hospital?**
- ₁ Yes, always ₃ No
₂ Yes, sometimes ₄ Not sure/cannot remember
20. **When you were discharged from hospital, were you given enough information about how to manage at home?**
- ₁ Yes, completely ₄ No, but I researched this myself
₂ Yes, to some extent ₅ Not sure/cannot remember
₃ No
21. **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?**
- ₁ I was only given my doctor's number
₂ I was given the name and number of someone at the hospital
₃ I was given a hospital number to call but didn't have anyone's name
₄ No I wasn't given any number to call
₅ Not sure/cannot remember
22. **Thinking about when you left hospital, were adequate arrangements made by the hospital staff for any services you needed (e.g. district nurse)?**
- ₁ Yes, completely ₄ I did not need assistance
₂ Yes, to some extent ₅ Not sure/cannot remember
₃ No

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

- | | |
|--|--|
| <input type="checkbox"/> ₁ Very clean | <input type="checkbox"/> ₄ Not at all clean |
| <input type="checkbox"/> ₂ Fairly clean | <input type="checkbox"/> ₅ Not sure/cannot remember |
| <input type="checkbox"/> ₃ Not very clean | |

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

- | | |
|---|---|
| <input type="checkbox"/> ₁ Very satisfied | <input type="checkbox"/> ₄ Dissatisfied |
| <input type="checkbox"/> ₂ Satisfied | <input type="checkbox"/> ₅ Very dissatisfied |
| <input type="checkbox"/> ₃ Neither satisfied or dissatisfied | |

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.

RADIOTHERAPY

1. Did you have radiotherapy treatment for cancer?

- ₁ Yes
- ₂ No → PLEASE GO TO QUESTION 1 ON PAGE 15 (SECTION: CHEMOTHERAPY)

2. When did you have your first radiotherapy treatment?

- ₁ Within the last 3 months
- ₂ More than 3 months ago, but less than 6 months ago
- ₃ More than 6 months ago, but less than 12 months ago
- ₄ More than 12 months ago, but less than 2 years ago
- ₅ More than 2 years ago
- ₆ Not sure/cannot remember

3. 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 _____

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

- ₁ I made the decision with little or no input from my doctor
- ₂ I made the decision after considering my doctor's opinion
- ₃ My doctor and I made the decision together
- ₄ My doctor made the decision after considering my opinion
- ₅ My doctor made the decision with little or no input from me
- ₆ Other (please specify) _____
- ₇ Not sure/cannot remember

5a. 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.)?

- ₁ No, I did not have any bills associated with my radiotherapy → GO TO QUESTION 7
- ₂ Yes, my health insurance covered these costs completely
- ₃ Yes, and my health insurance only covered some of these costs
- ₄ Yes, I had bills to pay

5b. What sort of bills did you have? (please provide a brief description of the type of bills you had)

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

- ₁ Yes, I was fully informed of the costs I would have to pay
- ₂ Yes, I was informed, but not of the full amount
- ₃ No, I was not informed of the costs involved
- ₄ Not sure/cannot remember

7. **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)?**

- ₁ Yes
- ₂ No

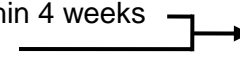


7b. **Who arranged this accommodation?**

- ₁ I did/my family or friends did
- ₂ Staff at the hospital
- ₃ Staff associated with my doctor
- ₄ Not sure/cannot remember
- ₅ Other _____

8a. **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?**

- ₁ Less than 2 weeks
- ₂ More than 2, but within 4 weeks
- ₃ More than a month
- ₄ Not sure/cannot remember
- ₅ Other _____



8b. **If more than two weeks was this due to:**

- ₁ Personal decision to wait
- ₂ Radiotherapy waiting times. I was kept updated.
- ₃ Radiotherapy waiting times. I was **not** updated.
- ₄ Other _____

9. Before starting radiotherapy for the <u>first</u> 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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. How to manage any anxiety or stress you might experience before your radiotherapy treatments?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. How you might manage side-effects from radiotherapy (e.g. apply ointments, change bandages, exercise etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
d. How you might feel at the end of treatment (e.g., fatigued or tired)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. How long it might take to recover from having radiotherapy?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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

- ₁ Yes
- ₂ No
- ₃ Not sure/cannot remember

11. **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)?**

- ₁ Yes, definitely
- ₂ Yes, as much as they could
- ₃ No, not at all
- ₄ Travel/other commitments were not a problem
- ₅ Not sure/cannot remember

12. **On average, how long did you have to wait at your radiotherapy appointments before you had your treatment?**
- ₁ I generally had treatment within 15 minutes of my appointment time
₂ I generally had treatment within 15-30 minutes of my appointment time
₃ I generally had treatment within 30-60 minutes of my appointment time
₄ I generally had treatment within 1-2 hours of my appointment time
₅ I generally waited longer than 2 hours for my appointment
₆ Not sure/cannot remember
13. **While you were having radiotherapy, did health professionals check if you had any side-effects or symptoms (e.g. skin problems, nausea, diarrhoea, tiredness)?**
- ₁ Yes ₃ No
₂ Yes, but not as often as I would have liked ₄ Not sure/cannot remember
14. **Do you think the health professionals involved in your care did everything they could to help you manage any side-effects you experienced?**
- ₁ Yes, definitely ₄ I did not have any side-effects
₂ Yes, to some extent ₅ Not sure/cannot remember
₃ No
15. **Did the health professionals involved in your radiotherapy treat you with respect and dignity?**
- ₁ Yes, always ₃ No
₂ Yes, sometimes ₄ Not sure/cannot remember
16. **Did the health professionals involved in your care check if you needed any help or assistance with things like your diet, eating, physical movements (e.g. raising your arm)?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
17. **Did health professionals involved in your care check if you needed any help or assistance with managing your emotional state (feeling stressed, anxious, feeling sad or down etc)?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
18. **Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
19. **Were you given a telephone number to contact if you had concerns or questions about your condition or treatment?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
20. **Did the health professionals involved in your radiotherapy ask if your family or friends needed any information or support?**
- ₁ Yes, regularly ₄ No, family or friends were not involved
₂ Yes, occasionally ₅ Not sure/cannot remember
₃ No, never

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.

1. **Did you have chemotherapy treatment for cancer?**

- ₁ Yes
- ₂ No → PLEASE GO TO QUESTION 1 PAGE 19 (EMERGENCY DEPARTMENT)

2. **When did you start chemotherapy for the first time?**

- ₁ Within the last 3 months
- ₂ More than 3 months ago, but less than 6 months ago
- ₃ More than 6 months ago, but less than 12 months ago
- ₄ More than 12 months ago, but less than 2 years ago
- ₅ More than 2 years ago
- ₆ Not sure/cannot remember

3. **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 _____

4. **Who made the decision to have your chemotherapy at this hospital/treatment centre? (please choose one response)**

- ₁ I made the decision with little or no input from my doctor
- ₂ I made the decision after considering my doctor's opinion
- ₃ My doctor and I made the decision together
- ₄ My doctor made the decision after considering my opinion
- ₅ My doctor made the decision with little or no input from me
- ₆ Other (please specify) _____
- ₇ Not sure/cannot remember

5a. **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.)?**

- ₁ No, I did not have any bills associated with my chemotherapy → GO TO QUESTION 7
- ₂ Yes, and my health insurance covered these costs completely
- ₃ Yes, and my health insurance covered only some of these costs
- ₄ Yes, I had bills to pay

5b. **What sort of bills did you have? (please provide a brief description of the type of bills you had)**

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

- ₁ Yes, I was fully informed of the costs I would have to pay
- ₂ Yes, I was informed, but not of the full amount
- ₃ No, I was not informed of the costs involved
- ₄ Not sure/cannot remember

7. 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)?

- ₁ Yes
- ₂ No

7b. Who arranged this accommodation?

- ₁ I did/my family or friends did
- ₂ Staff at the hospital
- ₃ Staff associated with my doctor
- ₄ Not sure/cannot remember
- ₅ Other _____

8. 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?

- ₁ Less than 2 weeks
- ₂ More than 2, but within 4 weeks
- ₃ More than a month
- ₄ Not sure/cannot remember
- ₅ Other _____

8b. If more than two weeks was this due to:

- ₁ Personal decision to wait
- ₂ Chemotherapy waiting times. I was kept updated.
- ₃ Chemotherapy waiting times. I was **not** updated.
- ₄ Other _____

9. Before starting chemotherapy for the <u>first</u> time were you given information about:	Yes, I was given this information	Yes, but I would have liked more	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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. How to manage any anxiety or stress you might feel before your chemotherapy treatments (e.g. relaxation exercises etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. How you would feel at the end of the chemotherapy treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
d. What side-effects you might experience from chemotherapy?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. How to manage any side-effects of chemotherapy at home?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
f. The possibility of going to the Emergency Department if you had a bad response to your chemotherapy?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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

- ₁ Yes
- ₂ No
- ₃ Not sure /cannot remember

11. 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)?

- ₁ Yes, definitely
- ₂ Yes, as much as they could
- ₃ No, not at all
- ₄ Travel/other commitments were not a problem
- ₅ Not sure/cannot remember

12. **On average, how long did you wait at your chemotherapy appointments before you had your treatment?**
- ₁ I generally had treatment within 15 minutes of my appointment time
₂ I generally had treatment within 15-30 minutes of my appointment time
₃ I generally had treatment within 30-60 minutes of my appointment time
₄ I generally had treatment within 1-2 hours of my appointment time
₅ I generally waited longer than 2 hours for my appointment
₆ My chemotherapy was given in a tablet form. This wasn't a problem for me
₇ Not sure/cannot remember
13. **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.)?**
- ₁ Yes ₃ No
₂ Yes, but not as often as I would have liked ₄ Not sure/cannot remember
14. **Do you think the health professionals involved in your chemotherapy did everything they could to help manage any side-effects you experienced?**
- ₁ Yes, definitely ₄ I did not have any side-effects
₂ Yes, to some extent ₅ Not sure/cannot remember
₃ No
15. **Did the health professionals involved in your chemotherapy treat you with respect and dignity?**
- ₁ Yes, always ₃ No
₂ Yes, sometimes ₄ Not sure/cannot remember
16. **Did the health professionals involved in your care check if you needed any help or assistance with things like your diet or eating, etc.?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
17. **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.)?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
18. **Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
19. **Were you given a telephone number to contact if you had concerns, questions or became unwell because of your treatment?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember
20. **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?**
- ₁ Yes ₂ No ₃ Not sure /cannot remember

EMERGENCY DEPARTMENT EXPERIENCES

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

1. **Have you felt so ill from your cancer or cancer treatment that you have had to go to an Emergency Department?**
 - ₁ Yes, only once
 - ₂ Yes, more than once
 - ₃ Yes, but it was before my cancer was properly diagnosed
 - ₄ No, never → *PLEASE GO TO QUESTION 1 ON PAGE 20 (SECTION: FOLLOW-UP CARE)*

2. **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 _____

3. **The last time you were at the Emergency Department, about how long did you have to wait before you saw the doctor?**
 - ₁ Less than 10 minutes
 - ₂ More than 10 minutes, but less than 30 minutes
 - ₃ More than 30 minutes, but less than 1 hour
 - ₄ Between 1-2 hours
 - ₅ Between 2-4 hours
 - ₆ More than 4 hours
 - ₇ Not sure/cannot remember

4. **Do you think that your condition was well managed while you were waiting to see an Emergency Department doctor?**
 - ₁ Yes, my condition was managed well
 - ₂ No, my condition was **not** managed well
 - ₃ Not sure/cannot remember

5. **Do you think that the health professionals in the Emergency Department had the knowledge and skills needed to look after you?**
 - ₁ Yes, all or most of them did
 - ₂ Only a few of them did
 - ₃ No
 - ₄ Not sure/cannot remember

6. **Were you admitted into hospital as a result of your consultation with doctors at the Emergency Department?**
 - ₁ Yes
 - ₂ No
 - ₃ Not sure /cannot remember

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.

FOLLOW-UP CARE

IF YOU ARE STILL UNDERGOING **CHEMOTHERAPY** OR **RADIOTHERAPY**, PLEASE GO TO QUESTION 1 ON PAGE 22 (SECTION: INFORMATION RECEIVED)

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

- | | |
|--|--|
| <input type="checkbox"/> ₁ Surgeon | <input type="checkbox"/> ₆ Other (<i>please specify</i>) _____ |
| <input type="checkbox"/> ₂ Haematologist | <input type="checkbox"/> ₇ Other medical doctor (e.g. urologist, gynaecologist, respiratory physician) (<i>please specify</i>)
_____ |
| <input type="checkbox"/> ₃ Radiation oncologist | |
| <input type="checkbox"/> ₄ GP | <input type="checkbox"/> ₈ I am not sure who is in charge |
| <input type="checkbox"/> ₅ Medical oncologist | |

2. **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 _____

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

- | | |
|--|---|
| <input type="checkbox"/> ₁ Yes, definitely | <input type="checkbox"/> ₄ Travel/other commitments were not a problem |
| <input type="checkbox"/> ₂ Yes, as much as they could | <input type="checkbox"/> ₅ Not sure/cannot remember |
| <input type="checkbox"/> ₃ No, not at all | |

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

- | | |
|---|--|
| <input type="checkbox"/> ₁ Yes, definitely | <input type="checkbox"/> ₃ No |
| <input type="checkbox"/> ₂ Yes, sometimes | <input type="checkbox"/> ₄ Not sure/cannot remember |

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

- | | |
|---|--|
| <input type="checkbox"/> ₁ Never | <input type="checkbox"/> ₄ Five or more times |
| <input type="checkbox"/> ₂ Once or twice | <input type="checkbox"/> ₅ Not sure/cannot remember |
| <input type="checkbox"/> ₃ Three or four times | |

6. 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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. Information about what follow-up tests you would need?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. Information about things you could do to stay healthy (e.g. exercise, diet, stopping smoking)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
d. Information about which new symptoms need investigation?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. Information about how people feel after finishing cancer treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
f. Information about how to get extra support if you or your family wanted it?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
g. Information about how often you would need to have tests or check-ups?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

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

- ₁ Yes, I was given this information
- ₂ Yes, but I would have liked more
- ₃ No
- ₄ I did not have any side-effects or ongoing symptoms
- ₅ Not sure/cannot remember

8. 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)?

- ₁ Yes
- ₃ I do not have a regular GP
- ₂ No
- ₄ Not sure/cannot remember

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.

INFORMATION RECEIVED

1. Did you get enough information from health professionals about:	Yes, I received 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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b. The possible changes in your energy level?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
c. What you could do to preserve your fertility?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

2. 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.)

- ₁ Yes, someone talked to me about financial support
₂ No, but I would have liked someone to
₃ No, I did not need any financial support services
₄ Not sure /cannot remember

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

- ₁ Yes, definitely
₂ Yes, to some extent
₃ No
₄ Not sure/cannot remember

4. 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"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. Psychologist	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. Dietitian	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
d. Speech Therapist	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. Occupational Therapist	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
f. Pain management specialist	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
g. Cancer Helpline	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
h. Financial planner/services	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

5. Did health professionals ask you if you needed any help or assistance with the following:	Yes	No, but I would have liked them to	I didn't need assistance with this	Not sure/ cannot remember
a. Domestic chores (e.g. cooking, cleaning, etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b. Family problems?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
c. Working out childcare while having treatment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
d. Your finances (accessing your superannuation, illness insurance, income protection etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
e. Finding support groups or other services that put people who have had cancer in contact?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

6. Did any member of your health care team discuss with you the possibility of you taking part in cancer research?

- ₁ Yes, and I was happy for them to do this
- ₂ Yes, but I was **not** happy for them to do this
- ₃ No, but I would have liked them to have done this
- ₄ No, and I am glad they did not do this
- ₅ Not sure /cannot remember

7. Did you feel you could talk with the health professionals involved in your care about complementary or alternative therapies?

- ₁ Yes, with all the health professionals
- ₂ Yes, with some health professionals
- ₃ No, not at all
- ₄ I didn't want to talk to staff about this issue
- ₅ I was not interested in complementary or alternative therapies
- ₆ Not sure /cannot remember

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.

OVERALL CARE

1. 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?

- ₁ Yes, there was at least one health professional I could contact throughout my treatment
- ₂ Yes, there was someone I could contact but not all the time
- ₃ No
- ₄ Not sure /cannot remember

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

- ₁ Surgeon
- ₁ Haematologist
- ₁ Medical oncologist
- ₁ Radiation oncologist
- ₁ GP
- ₁ Other medical doctor (*please specify*)

₁ Other (*please specify*)

₁ I am not sure who is/was in charge of my care

3. Throughout your cancer care, has there been a time when:	No, Never	Once	2-3 times	4 or more times	Not sure/cannot remember
a. You received conflicting information or advice from different doctors or health professionals?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b. You thought a health professional involved in your care was not fully informed about your treatment and/or your progress?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
c. You thought tests or other assessments were being repeated unnecessarily?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
d. The results of your tests, X-rays or scans were not available when they were needed for an appointment?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
e. You thought the health professionals involved in your care were not passing on information to one another?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

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.

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.

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

- ₁ Yes
₂ No → *PLEASE GO TO QUESTION 8*
₃ Not sure/ can't remember → *PLEASE GO TO QUESTION 8*

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

- ₁ Easy
₂ Sometimes easy, sometimes difficult
₃ Difficult
₄ I have not tried to contact her/him

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

- ₁ Yes, definitely
₂ Yes, to some extent
₃ No

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

- ₁ All or most of the time
₂ Some of the time
₃ Rarely or never
₄ I do not ask any questions

8. **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)?**
- ₁ Yes, they seemed well informed about the care I had received at other places
- ₂ Yes, although some information seemed to be missing
- ₃ No, there seemed to be little or no sharing of information
- ₄ I was only treated at one treatment centre
- ₅ Not sure/ can't remember
9. **If you needed an interpreter at your appointments, was a hospital/treatment centre interpreter available for you?**
- ₁ Yes, at most or all of my appointments
- ₂ Yes, at some of my appointments
- ₃ No, an interpreter was never available
- ₄ No one talked to me about getting an interpreter, but I needed one
- ₅ I did not need an interpreter
- ₆ Not sure/ can't remember
10. **As far as you know, was your GP kept informed about your condition and your treatment?**
- ₁ Yes, my GP seemed very well informed
- ₂ Yes, to some extent
- ₃ No, my GP did not know much about my cancer or the treatment I had
- ₄ I do not have a regular GP
- ₅ Not sure/ can't remember
11. **How would you rate how well the doctors and nurses involved in your cancer care worked together?**
- ₁ Excellent
- ₂ Very good
- ₃ Good
- ₄ Fair
- ₅ Poor
12. **How satisfied were you with the overall care you received from all health professionals involved in your treatment?**
- ₁ Very satisfied
- ₂ Satisfied
- ₃ Neither satisfied or dissatisfied
- ₄ Dissatisfied
- ₅ Very dissatisfied
13. **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)?**
- ₁ Yes, there was at least one time → **Go to Q13b**
- ₂ No, my care was generally fine
- ₃ No, my care was excellent
- ₄ Not sure/cannot remember

13b If yes, what was the issue you wanted to complain about?

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.

PTO

ABOUT YOU

1. What is your gender?

- ₁ Male
₂ Female

2. How old were you at your last birthday? _____ years

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

Town/Suburb _____ OR
Postcode _____

4. Where were you living when you received your treatments for cancer?

- ₁ Same address as above
₂ Different address: Town/Suburb _____ OR
Postcode _____

5. What language do you mainly speak at home?

- ₁ English
₂ Italian
₃ Greek
₄ Cantonese
₅ Arabic (including Lebanese)
₆ Vietnamese
₇ Mandarin
₈ Other (*please specify*) _____

6. Are you of Aboriginal or Torres Strait Islander origin?

- ₁ Yes, Aboriginal
₂ Yes, Torres Strait Islander
₃ Yes, both Aboriginal and Torres Strait Islander
₄ No

7. In general, how would you rate your health?

- ₁ Excellent
₂ Very good
₃ Good
₄ Fair
₅ Poor

