

# Experiences of Care Survey

Radiotherapy

\*Remove this coversheet before distributing to patient.



# Experiences of Care Survey

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

Patient <sub>1</sub>

On behalf of patient <sub>2</sub>

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 for you to make any comments about your care.

The instructions before the questions will tell you who should answer the questions. You may be able to skip questions.

**The survey may take around 15 minutes to complete.**

### **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.

# Diagnosis and treatment overall

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

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

DECIDING

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

- <sub>1</sub> Surgery       $\longrightarrow$       Hospital/Clinic Name \_\_\_\_\_
- <sub>1</sub> Radiotherapy       $\longrightarrow$       Hospital/Clinic Name \_\_\_\_\_
- <sub>1</sub> Chemotherapy       $\longrightarrow$       Hospital/Clinic Name \_\_\_\_\_
- <sub>1</sub> Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrein®, Flutamin®)
- <sub>1</sub> Other (please specify)

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

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

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

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

7. 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?

- <sub>1</sub> Yes, there was at least one health professional I could contact throughout my treatment
- <sub>2</sub> Yes, there was someone I could contact but not all the time
- <sub>3</sub> No
- <sub>4</sub> 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.

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

- <sub>1</sub> Yes
- <sub>2</sub> No → **PLEASE GO TO THE QUESTION 10**
- <sub>3</sub> Not sure/ can't remember → **PLEASE GO TO QUESTION 10**



# RADIOTHERAPY

13. Did you have radiotherapy treatment for cancer?

<sub>1</sub> Yes

<sub>2</sub> No → **PLEASE GO TO QUESTION 36**

14. When did you have your first radiotherapy treatment?

<sub>1</sub> Within the last 3 months

<sub>2</sub> More than 3 months ago, but less than 6 months ago

<sub>3</sub> More than 6 months ago, but less than 12 months ago

<sub>4</sub> More than 12 months ago, but less than 2 years ago

<sub>5</sub> More than 2 years ago

<sub>6</sub> Not sure/cannot remember

15. 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 \_\_\_\_\_

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

<sub>1</sub> I made the decision with little or no input from my doctor

<sub>2</sub> I made the decision after considering my doctor's opinion

<sub>3</sub> My doctor and I made the decision together

<sub>4</sub> My doctor made the decision after considering my opinion

<sub>5</sub> My doctor made the decision with little or no input from me

<sub>6</sub> Other (please specify) \_\_\_\_\_

<sub>7</sub> Not sure/cannot remember

17. 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.)?

<sub>1</sub> No, I did not have any bills associated with my radiotherapy → **GO TO QUESTION 20**

<sub>2</sub> Yes, my health insurance covered these costs completely

<sub>3</sub> Yes, and my health insurance only covered some of these costs

<sub>4</sub> Yes, I had bills to pay

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

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

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

20. 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)?

- <sub>1</sub> Yes →
- <sub>2</sub> No

**20b. Who arranged this accommodation?**

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

21. 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?

- <sub>1</sub> Less than 2 weeks
- <sub>2</sub> More than 2, but within 4 weeks } →
- <sub>3</sub> More than a month
- <sub>4</sub> Not sure/cannot remember
- <sub>5</sub> Other \_\_\_\_\_

**21b. If more than two weeks was this due to:**

- <sub>1</sub> Personal decision to wait
- <sub>2</sub> Radiotherapy waiting times. I was kept updated.
- <sub>3</sub> Radiotherapy waiting times. I was **not** updated.
- <sub>4</sub> Other \_\_\_\_\_

<b>22. Before starting radiotherapy for the <u>first</u> time were you given information about:</b>	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"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
b. How to manage any anxiety or stress you might experience before your radiotherapy treatments?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
c. How you might manage side-effects from radiotherapy (e.g. apply ointments, change bandages, exercise etc.)?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
d. How you might feel at the end of treatment (e.g., fatigued or tired)?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>
e. How long it might take to recover from having radiotherapy?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>

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

- <sub>1</sub> Yes
- <sub>2</sub> No
- <sub>3</sub> Not sure/cannot remember

24. 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)?

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

25. On average, how long did you have to wait at your radiotherapy appointments before you had your treatment?
- <sub>1</sub> I generally had treatment within 15 minutes of my appointment time  
<sub>2</sub> I generally had treatment within 15-30 minutes of my appointment time  
<sub>3</sub> I generally had treatment within 30-60 minutes of my appointment time  
<sub>4</sub> I generally had treatment within 1-2 hours of my appointment time  
<sub>5</sub> I generally waited longer than 2 hours for my appointment  
<sub>6</sub> Not sure/cannot remember
26. While you were having radiotherapy, did health professionals check if you had any side-effects or symptoms (e.g. skin problems, nausea, diarrhoea, tiredness)?
- <sub>1</sub> Yes <sub>3</sub> No  
<sub>2</sub> Yes, but not as often as I would have liked <sub>4</sub> Not sure/cannot remember
27. Do you think the health professionals involved in your care did everything they could to help you manage any side-effects you experienced?
- <sub>1</sub> Yes, definitely <sub>4</sub> I did not have any side-effects  
<sub>2</sub> Yes, to some extent <sub>5</sub> Not sure/cannot remember  
<sub>3</sub> No
28. Did the health professionals involved in your radiotherapy treat you with respect and dignity?
- <sub>1</sub> Yes, always <sub>3</sub> No  
<sub>2</sub> Yes, sometimes <sub>4</sub> Not sure/cannot remember
29. 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)?
- <sub>1</sub> Yes <sub>2</sub> No <sub>3</sub> Not sure /cannot remember
30. 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)?
- <sub>1</sub> Yes <sub>2</sub> No <sub>3</sub> Not sure /cannot remember
31. Did the health professionals involved in your care check if you needed any help or assistance with travelling to or from your appointments?
- <sub>1</sub> Yes <sub>2</sub> No <sub>3</sub> Not sure /cannot remember
32. Were you given a telephone number to contact if you had concerns or questions about your condition or treatment?
- <sub>1</sub> Yes <sub>2</sub> No <sub>3</sub> Not sure /cannot remember
33. Did the health professionals involved in your radiotherapy ask if your family or friends needed any information or support?
- <sub>1</sub> Yes, regularly <sub>4</sub> No, family or friends were not involved  
<sub>2</sub> Yes, occasionally <sub>5</sub> Not sure/cannot remember  
<sub>3</sub> No, never
34. How satisfied were you with the availability of car parking at the treatment centre where you had radiotherapy?
- <sub>1</sub> Very satisfied <sub>4</sub> Dissatisfied  
<sub>2</sub> Satisfied <sub>5</sub> Very dissatisfied  
<sub>3</sub> Neither satisfied or dissatisfied <sub>6</sub> Not applicable



# YOUR BACKGROUND

36. What is your gender?

- <sub>1</sub> Male  
<sub>2</sub> Female

37. How old were you at your last birthday? \_\_\_\_\_ years

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

Town/Suburb \_\_\_\_\_ **OR**  
Postcode \_\_\_\_\_

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

- <sub>1</sub> Same address as above  
<sub>2</sub> Different address: Town/Suburb \_\_\_\_\_ **OR**  
Postcode \_\_\_\_\_

40. What language do you mainly speak at home?

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

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

- <sub>1</sub> Yes, Aboriginal  
<sub>2</sub> Yes, Torres Strait Islander  
<sub>3</sub> Yes, both Aboriginal and Torres Strait Islander  
<sub>4</sub> No

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

- <sub>1</sub> Excellent  
<sub>2</sub> Very good  
<sub>3</sub> Good  
<sub>4</sub> Fair  
<sub>5</sub> Poor

