

Experiences of Care Survey

Surgery

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

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.

₁ Surgery → Hospital/Clinic Name: _____

₁ Radiotherapy → Hospital/Clinic Name: _____

₁ Chemotherapy → Hospital/Clinic Name: _____

₁ Hormonal therapy (e.g., Tamoxifen®, Arimidex®, Zoladex®, Lucrin®, Flutamin®)

₁ 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)?

₁ Yes, definitely

₄ No, but I researched this myself

₂ Yes, to some extent

₅ Not sure/cannot remember

₃ 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)?

₁ Yes, definitely

₄ No, but I researched this myself

₂ Yes, to some extent

₅ Not sure/cannot remember

₃ 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?

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

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?

₁ Yes

₂ No → **PLEASE GO TO THE QUESTION 10**

₃ Not sure/ can't remember → **PLEASE GO TO QUESTION 10**

9. 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

10. 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

11. 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

12. 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 Q12a**
- ₂ No, my care was generally fine
- ₃ No, my care was excellent
- ₄ Not sure/cannot remember

12a. If yes, what was the issue you wanted to complain about?

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.

13. Did you have surgery related to your cancer?

- ₁ Yes
₂ No → **PLEASE GO TO QUESTION 38**

14. 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

15. 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: _____

16. 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

17. 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 18A**
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

17a. What sort of bills did you have? (please provide a brief description of the bills you have to pay)?

18. 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

18a. 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: _____

18b. 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: _____

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

₁ Yes, regularly

₂ Yes, occasionally

₃ No, never

₄ No, as family or friends were not involved

₅ Not sure/cannot remember

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

21. 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
21a. 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

22. 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

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

- ₁ Yes ₂ No → **GO TO QUESTION 36**

24. 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

25. 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

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

- ₁ Yes ₂ No → **GO TO QUESTION 28**

27. 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

28. 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
29. 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
30. 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
31. 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
32. 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
33. 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
34. How clean were the toilets and bathrooms that you used while in hospital?
- ₁ Very clean ₄ Not at all clean
₂ Fairly clean ₅ Not sure/cannot remember
₃ Not very clean

YOUR BACKGROUND

36. What is your gender?

- ₁ Male
₂ 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?

- ₁ Same address as above
₂ Different address:

Town/Suburb: _____ **OR**

Postcode: _____

40. 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*)

41. 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

