

Survey

Information for people with cancer

About the survey

Northern Ireland Cancer Network is carrying out this survey. We hope to learn what information people are being given. From this, we hope to see if there are ways that we can improve it.

You do not have to take part. If you choose not to take part, you do not have to give us a reason. Your healthcare and treatment will not be affected.

If you do wish to take part, you do not need to give us your name. All information will be kept strictly private and confidential. The doctors and other healthcare staff involved in your care **will not** see your answers.

Once everybody's answers have been collected together, we will write a report. This report will be used by hospitals and cancer charities to help them understand how best to meet patients' needs.

Please consider each question carefully and tick the boxes that best suit. Sometimes you might need to tick more than one box for a question.

At the end of some pages, the survey will ask you to write a few words to give us more information.

Your answers could be about information that you have been offered in hospital or by your GP/family doctor, charities here in NI or further afield.

Section 1: About you

1. What age are you?

- Under 35 35-49
 50-64 65 and over

2. Are you? male female

Section 2 : Before you were diagnosed with cancer

3. Did you already know possible symptoms for your type of cancer?

- Yes No Not sure

4. Who referred/sent you to hospital?

- GP
 Screening service
 Other (please tell us who)
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5. Were you offered information about the tests that would be done at hospital?

- Yes, this was written information
 Yes, I was told about them
 No, I didn't want/need any information
 No, but I would have liked some
 Don't know

6. Who gave you this information?

- GP
 Screening clinic
 Hospital
 Other

7. Were you offered information about how to get to the hospital?

- Yes, this was written information
 Yes, I was told
 No, I didn't want/need any information
 No, but I would have liked some
 Don't know

8. Were you told where you could get more information about your appointment and tests?

- Yes, this was written information
 Yes, I was told about it
 No, I didn't want/need any information
 No, but I would have liked some
 Don't know

Please use the space in this box to tell us

Was the information that you were given before you were diagnosed all that you needed?

Was it given at the right time?

Section 3 :
When your cancer was diagnosed

9. When you were diagnosed, were you offered information about the type of cancer that you have?

- Yes, this was written information
- Yes, I was told about it
- No, I didn't want/need any information
- No, but I would have liked some
- Don't know

10. At the time you were told you had cancer, were you offered information about your treatment options?

- Yes, this was written information
- Yes, I was told about the options
- No, I didn't want/need any information
- No, but I would have liked some
- Don't know

11. Were you given information about your prognosis (the likely effect your illness would have on your life)?

- Yes, this was written information
- Yes, I was told this
- No, I didn't want to be told
- No, but I would have liked to be told
- Don't know

12. At the time you were diagnosed, were you offered information about where you could get support or more information?

- Yes, this was written information
- Yes, I was told
- No, I didn't want/need any information
- No, but I would have liked some
- Don't know

13. Do you have a nurse to contact if you need more information?

- Yes
- No
- Not sure

If yes, have you been given their contact details?

- Yes
- No
- Not sure

If yes, what type of nurse do you have?

- Nurse
- Specialist nurse e.g. stoma nurse, colorectal clinical nurse specialist, coloproctology nurse specialist
- Chemotherapy nurse
- Palliative care nurse
- Don't know
- Other

If no, would you have you liked to have one?

- Yes
- No
- Not sure

Please use the space in this box to tell us
Was the information that you were given when your cancer was diagnosed all that you needed?

Was it given at the right time?

14. Did you have to have more tests after your diagnosis, so your doctors could understand more about your cancer?

- Yes
- No
- Not sure

If yes, were you given information about those tests before you had them?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked this information
- Don't know

If yes, did the surgery information include:

The benefits of surgery?

- Yes
- No
- Not sure

Any risks?

- Yes
- No
- Not sure

Any side effects?

- Yes
- No
- Not sure

Any other treatments that are available?

- Yes
- No
- Not sure

Please use the space below if you wish to add any comments about Question 15.

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17. Were you offered information about the aim of your surgery?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need to know
- No, but I would have liked to know
- Don't know

18. Were you offered information about how your surgery works?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need to know
- No, but I would have liked to know
- Don't know

Section 4 : Treatment(s)

15. Which treatments have you had?

- Chemotherapy
- Radiotherapy
- Surgery (operation)
- Hormonal treatment
- Other (please specify)

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Questions 16 – 23 are about SURGERY only. If you have not had surgery, please go straight to Question 24.

16. Were you given information about your surgery?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked this information
- Don't know

19. Were you offered information about how likely it is that the surgery would work in your case? (its effectiveness)

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need to know
- No, but I would have liked to know
- Don't know

20. Were you offered information about how your appearance might be affected by your surgery?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't need any
- No, but I would have liked some information
- Don't know

If yes, were you offered information about emotional support with this?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some information
- Don't know

21. Were you offered information about practical help? For example, prosthesis (artificial replacement), clothing ranges.

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some
- Don't know

22. Were you offered information about how to get to the hospital for your surgery?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some information
- Don't know

23. Were you offered any information about what to expect when you got there? For example, how long you would be there and whether you would actually have your operation on that day.

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some information
- Don't know

Please use the space in this box to tell us

Was the information that you were given about your surgery all that you needed?

Was it given at the right time?

24. Were you given information about chemotherapy?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked this information
- Don't know

If yes, did the chemotherapy information include:

The benefits of it?

- Yes
- No
- Not sure

Any risks?

- Yes
- No
- Not sure

Any side effects?

- Yes
- No
- Not sure

Any other treatments that are available?

- Yes
- No
- Not sure

Please use the space below if you wish to add any comments about Question 15.

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25. Were you offered information about the aim of the chemotherapy?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need to know
- No, but I would have liked to know
- Don't know

26. Were you offered information about how chemotherapy works?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need to know
- No, but I would have liked to know
- Don't know

27. Were you offered information about how likely it is that the chemotherapy would work in your case? (its effectiveness)

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need to know
- No, but I would have liked to know
- Don't know

28. Were you offered information about how your appearance might be affected by chemotherapy?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't need any
- No, but I would have liked some information
- Don't know

If yes, were you offered information about emotional support with this?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some information
- Don't know

29. Were you offered information about practical help? For example, wig fitting, headwear.

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some
- Don't know

30. Were you offered information about how to get to the hospital for chemotherapy?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some
- Don't know

31. Were you offered any information about what to expect when you got there? For example, how long you would be there and whether you would actually be given chemotherapy on that day.

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked some information
- Don't know

Please use the space in this box to tell us

Was the information that you were given about chemotherapy all that you needed?

Was it given at the right time?

**Section 5 :
Supportive care and practical help**

32. Have you been offered information about the financial help that you may be entitled to?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need this information
- No, but I would have liked to know this
- Don't know

If yes, when was this given to you?

- At diagnosis During treatment
- At another time (please specify)

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Was this the right time? Yes No

If not, when would have been the best time?

.....

Do you know that there are services that can help you with financial help you may be entitled to?

- Yes No Not sure

33. Have you been offered information about how a Social Worker can help you?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need this information
- No, but I would have liked to know this
- Don't know

If yes, when did you get this information?

.....

Was this the right time? Yes No

If no, when would have been the best time?

.....

34. Have you been offered information about spiritual support? This might be the hospital Chaplain's details or information about how a Social Worker can help you.

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any
- No, but I would have liked this information
- Don't know

35. Have you been offered information about support services from voluntary organisations / charities?

- Yes, this was written information
- Yes, it was described to me
- No, I didn't want/need any information
- No, but I would have liked to know this
- Don't know

36. Have you been offered a copy of the pocket-sized book "Cancer Services for patients, carers, families and friends"

- Yes No Not sure

If yes, when was it given to you?

- At diagnosis During treatment
- At another time (please specify)

.....

Was this the right time? Yes No

If no, when would have been the best time?

.....

Please use the space in this box to tell us

Was the information that you were given about help and support all that you needed?

Was it given at the right time?

Thank you for completing this survey.

We are planning a 'focus group'. This is a small group of people talking about this in more detail. If you are interested, please complete the blue slip and post it back to us with your questionnaire. They will be processed separately so this is kept anonymous.

Even if you complete the blue slip today, this doesn't mean you have to take part. We will write out to you with the details and you can decide then.