

Northern Ireland Cancer Patient Experience Survey

This questionnaire is about your cancer care and treatment. Its purpose is to provide information which can help Health and Social Care (HSC) Northern Ireland monitor and improve the quality of health services for future patients.

Who should complete the questionnaire?

The questions should be answered by the person named in the letter enclosed with this questionnaire. If that person needs help to complete the questionnaire, the answers should be given from their point of view - not the point of view of the person helping.

Completing the questionnaire

For each question please tick inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. Please **do not** write your name or address anywhere on the questionnaire.

If you would prefer, you may also complete this survey online. To do this, please refer to the login information which can be found in the letter accompanying this survey.

Important Information

Your personal details and some information about your cancer treatment have been used to identify you to take part in this survey and will be used to analyse the survey results. These details were provided by the HSC Trust that treated you.

Your personal information will be handled securely, anonymised after analysis and before any publication in line with the General Data Protection Regulation and Data Protection Act 2018.

Consent

By completing this questionnaire you are giving your consent for the information you provide, and the information from the HSC Trust to be used for the above purposes. You are agreeing that your personal information can be held and used by HSC. Information that does not directly identify you may be made available to approved research organisations. Organisations analysing the response data will be subject to strict data protection regulations regarding the security and confidentiality of your information, and will not be allowed to use your details for any other purpose. Your personal information will not be released without your explicit consent (see Question 74) unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give in this questionnaire upon request, up to the point at which data are analysed and personal details removed.

If you have any queries about the questionnaire, please call the Quality Health FREEPHONE helpline number on 0800 783 1775.

Taking part in this survey is voluntary

Published reports will not contain any personal details

**Your personal data will always be managed in line with the
General Data Protection Regulation (GDPR) 2018**

BEFORE YOUR DIAGNOSIS

These questions are about what happened before you found out you had cancer.

1. Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?
 - 1 **None** – I went straight to hospital
 - 2 **None** – I went to hospital following a cancer screening appointment
 - 3 I saw my GP **once**
 - 4 I saw my GP **twice**
 - 5 I saw my GP **3 or 4** times
 - 6 I saw my GP **5 or more** times
 - 7 Don't know / can't remember
 - 8 Other

2. How do you feel about the length of time you had to wait before your **first appointment with a hospital doctor**?
 - 1 I was seen as soon as I thought was necessary
 - 2 I should have been seen a bit sooner
 - 3 I should have been seen a lot sooner

3. How long was it from the time you first thought something might be wrong with you until you first saw a GP or other doctor?
 - 1 Less than 3 months
 - 2 3-6 months
 - 3 6-12 months
 - 4 More than 12 months
 - 5 Don't know / can't remember

DIAGNOSTIC TESTS

4. In the last 12 months, have you had a diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?
 - 1 Yes → **Go to Q5**
 - 2 No → **Go to Q9**

5. Did the test(s) take place at the hospital named on the letter that came with this questionnaire?
 - 1 Yes
 - 2 No, at another NHS hospital in Northern Ireland
 - 3 No, at a private hospital / centre in Northern Ireland
 - 4 No, somewhere outside Northern Ireland
 - 5 Don't know / can't remember

*Thinking about the **LAST** time you had a diagnostic test for your cancer...*

6. Beforehand, did you have all the information you needed about your test?
 - 1 Yes
 - 2 No, I would have liked more information
 - 3 Don't know / can't remember

7. Overall, how did you feel about the length of time you had to wait for your test to be done?
 - 1 It was about right
 - 2 It was a little too long
 - 3 It was much too long
 - 4 Don't know / can't remember

8. Were the results of the test explained in a way you could understand?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, I did not understand the explanation
- 4 I did not have an explanation but would have liked one
- 5 I did not need an explanation
- 6 Don't know / can't remember

FINDING OUT WHAT WAS WRONG WITH YOU

9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?

- 1 Yes
- 2 No
- 3 I was told I had cancer by phone or letter
- 4 Don't know / can't remember

10. How do you feel about the way you were told you had cancer?

- 1 It was done sensitively
- 2 It should have been done **a bit** more sensitively
- 3 It should have been done **a lot** more sensitively

11. Did you understand the explanation of what was wrong with you?

- 1 Yes, I completely understood it
- 2 Yes, I understood some of it
- 3 No, I did not understand it
- 4 Don't know / can't remember

12. When you were told you had cancer, were you given **written** information about the type of cancer you had?

- 1 Yes, and it was **easy** to understand
- 2 Yes, but it was **difficult** to understand
- 3 No, I was not given written information about the type of cancer I had
- 4 I did not need / want written information
- 5 Don't know / can't remember

DECIDING THE BEST TREATMENT FOR YOU

13. Before your cancer treatment started, were your treatment options explained to you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 There was only one type of treatment that was suitable for me
- 5 Don't know / can't remember

14. Were the possible side effects of treatment(s) explained in a way you could understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, side effects were not explained
- 4 I did not need an explanation
- 5 Don't know / can't remember

15. Before you started your treatment, were you given **written** information about the side effects of treatment(s)?

- 1 Yes, and it was **easy** to understand
- 2 Yes, but it was **difficult** to understand
- 3 No, I was not given written information about side effects
- 4 Don't know / can't remember

16. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away e.g. late effects?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, future side effects were not explained
- 4 I did not need an explanation
- 5 Don't know / can't remember

17. 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, but I would like to have been more involved
- 4 Don't know / can't remember

CLINICAL NURSE SPECIALIST

A Clinical Nurse Specialist is a specialist cancer nurse who makes sure you get the right care and gives you help and advice on coping with cancer.

18. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?

- 1 Yes → Go to Q19
- 2 No → Go to Q21
- 3 Don't know / can't remember → Go to Q21

19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?

- 1 Very easy
- 2 Quite easy
- 3 Neither easy nor difficult
- 4 Quite difficult
- 5 Very difficult
- 6 I have not tried to contact my Clinical Nurse Specialist

20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?

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

SUPPORT FOR PEOPLE WITH CANCER

21. Did hospital staff give you information about support or self-help groups for people with cancer?

- 1 Yes
- 2 No, but I would have liked information
- 3 It was not necessary
- 4 Don't know / can't remember

22. Did hospital staff discuss with you or give you information about the impact cancer could have on your work-life or education?

- 1 Yes
- 2 No, but I would have liked a discussion or information
- 3 It was not necessary / relevant to me
- 4 Don't know / can't remember

23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?

- 1 Yes
- 2 No, but I would have liked information
- 3 It was not necessary
- 4 Don't know / can't remember

OPERATIONS

24. During the last 12 months, have you had an operation (such as removal of a tumour or lump)?

- 1 Yes → Go to Q25
- 2 No → Go to Q28

25. Did the operation take place at the hospital named on the letter that came with this questionnaire?

- 1 Yes
- 2 No, at another NHS hospital in Northern Ireland
- 3 No, at a private hospital / centre in Northern Ireland
- 4 No, somewhere outside Northern Ireland
- 5 Don't know / can't remember

Thinking about the LAST time you went into hospital for an operation for your cancer...

26. Beforehand, did you have all the information you needed about your operation?

- 1 Yes
- 2 No, I would have liked more information
- 3 Don't know / can't remember

27. After the operation, did a member of staff explain how it had gone in a way you could understand?

- 1 Yes, **completely**
- 2 Yes, to some extent
- 3 No, but I would have liked an explanation
- 4 I did not need an explanation

HOSPITAL CARE AS AN INPATIENT

28. During the last 12 months, have you had an operation or stayed overnight for cancer care?

- 1 Yes → Go to Q29
- 2 No → Go to Q42

29. Did the overnight stay take place at the hospital named on the letter that came with this questionnaire?

- 1 Yes
- 2 No, at another NHS hospital in Northern Ireland
- 3 No, at a private hospital / centre in Northern Ireland
- 4 No, somewhere outside Northern Ireland
- 5 Don't know / can't remember

Thinking about the LAST time you had an operation or stayed overnight for cancer care ...

30. Did groups of **doctors and nurses** talk in front of you as if you weren't there?

- 1 Yes, often
2 Yes, sometimes
3 No

31. Did you have confidence and trust in the **doctors** treating you?

- 1 Yes, in all of them
2 Yes, in some of them
3 No, in none of them

32. If your family or someone else close to you wanted to talk to a **doctor**, were they able to?

- 1 Yes, definitely
2 Yes, to some extent
3 No
4 No family or friends were involved
5 My family did not want to talk to a doctor
6 I did not want my family or friends to talk to a doctor

33. Did you have confidence and trust in the ward **nurses** treating you?

- 1 Yes, in all of them
2 Yes, in some of them
3 No, in none of them

34. In your opinion, were there enough **nurses** on duty to care for you in hospital?

- 1 There were always or nearly always enough on duty
2 There were sometimes enough on duty
3 There were rarely or never enough on duty

35. While you were in hospital did the **doctors and nurses** ask you what name you prefer to be called by?

- 1 Yes, all of them did
2 Only some of them did
3 None of them did

36. Were you given enough privacy when discussing your condition or treatment?

- 1 Yes, always
2 Yes, sometimes
3 No

37. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?

- 1 Yes, definitely
2 Yes, to some extent
3 No
4 I had no worries or fears

38. Do you think the hospital staff did everything they could to help control your pain?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I did not have any pain

39. Overall, did you feel you were treated with respect and dignity while you were in the hospital?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

40. Were you given clear **written** information about what you should or should not do after leaving hospital?

- 1 Yes
- 2 No
- 3 Don't know / can't remember

41. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

- 1 Yes
- 2 No
- 3 Don't know / can't remember

HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

Thinking about the LAST time you attended hospital as a day patient or outpatient for cancer care...

42. During the last 12 months, have you been treated as an outpatient or day case **for cancer care**?

- 1 Yes → **Go to Q43**
- 2 No → **Go to Q52**

43. Was this at the hospital named on the letter that came with this questionnaire?

- 1 Yes
- 2 No, at another NHS hospital in Northern Ireland
- 3 No, at a private hospital / centre in Northern Ireland
- 4 No, somewhere outside Northern Ireland
- 5 Don't know / can't remember

44. While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I did not have any worries or fears

45. The **last** time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?

- 1 Yes
- 2 No
- 3 I didn't have an appointment with a cancer doctor
- 4 Don't know / can't remember

46. During the last 12 months, have you had radiotherapy?

- 1 Yes → **Go to Q47**
- 2 No → **Go to Q49**

47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?

- 1 Yes, completely
 2 Yes, to some extent
 3 No
 4 I did not need any information

48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?

- 1 Yes, completely
 2 Yes, to some extent
 3 No
 4 It is too early to know if my radiotherapy is working
 5 I did not need any information

49. During the last 12 months, have you had chemotherapy?

- 1 Yes → **Go to Q50**
 2 No → **Go to Q52**

50. Beforehand, did you have all of the information you needed about your chemotherapy treatment?

- 1 Yes, completely
 2 Yes, to some extent
 3 No
 4 I did not need any information

51. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?

- 1 Yes, completely
 2 Yes, to some extent
 3 No
 4 It is too early to know if my chemotherapy is working
 5 I did not need any information

HOME CARE AND SUPPORT

52. Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?

- 1 Yes, definitely
 2 Yes, to some extent
 3 No
 4 No family or friends were involved
 5 My family or friends did not want or need information
 6 I did not want my family or friends to be involved

53. **During** your cancer treatment, were you given enough care and support from **health** or social services (for example, district nurses, home helps or physiotherapists)?

- 1 Yes, definitely
 2 Yes, to some extent
 3 No
 4 I did not need help from health or social services
 5 Don't know / can't remember

54. Once your cancer treatment **finished**, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?

- 1 Yes, definitely
 2 Yes, to some extent
 3 No
 4 I did not need help from health or social services
 5 I am still having treatment
 6 Don't know / can't remember

CARE FROM YOUR GENERAL PRACTICE

55. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?

- 1 Yes
- 2 No
- 3 Don't know / can't remember

56. Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, they could have done more
- 4 My general practice was not involved

YOUR OVERALL CARE

57. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?

- 1 Yes, always
- 2 Yes, most of the time
- 3 Yes, some of the time
- 4 No, never
- 5 Don't know / can't remember

58. Have you been offered a needs assessment and care plan? *A needs assessment and care plan is a document that sets out your needs and goals for caring for your cancer. It is an agreement or plan between you and your health professional to help meet those goals.*

- 1 Yes
- 2 No
- 3 I do not know / understand what a needs assessment or care plan is
- 4 Don't know / can't remember

59. Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc.)?

- 1 Very good
- 2 Good
- 3 Neither good nor bad
- 4 Quite bad
- 5 Very bad
- 6 Don't know / can't remember

60. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?

- 1 It was much too long
- 2 It was a little too long
- 3 It was about right
- 4 Don't know / can't remember

61. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research for example, clinical trials?

- 1 Yes
- 2 No
- 4 Don't know / can't remember

62. Overall, how would you rate your care?
(Please circle a number)

Very poor Very good

0 1 2 3 4 5 6 7 8 9 10

YOUR CONDITION

We would like to understand a little bit more about your cancer and how you are now. Please answer these questions about the cancer that was treated at the hospital(s) named in the covering letter.

63. How long is it since you were first treated for **this cancer**?
- 1 Less than 1 year
 - 2 1 to 5 years
 - 3 More than 5 years
 - 4 Don't know / can't remember
64. Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?
- 1 Yes → **Go to Q66**
 - 2 No → **Go to Q65**
 - 3 Don't know → **Go to Q66**
 - 4 Does not apply to my type of cancer → **Go to Q66**
65. Which of the following applies?
- 1 My cancer has been removed / treated, without any sign of further problem
 - 2 My cancer was removed / treated without any sign of further problem, but has since come back / spread to other parts of my body
 - 3 None of the above options apply to my type of cancer
 - 4 I would prefer not to say
 - 5 I don't know

ABOUT YOU

If you are helping someone to complete this questionnaire, please make sure this information is the patient's not your own.

66. What year were you born?

(Please write in) e.g.

1	9	4	4
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67. Are you male or female?

- 1 Male
- 2 Female

68. Which of the following options best describes how you think of yourself?

- 1 Heterosexual or Straight
- 2 Gay or Lesbian
- 3 Bisexual
- 4 Other
- 5 Prefer not to say

69. Do you have any of the following long-standing conditions? (**Tick ALL that apply**)

- 1 Deafness or severe hearing impairment
- 2 Blindness or partially sighted
- 3 A long-standing physical condition
- 4 A learning disability
- 5 A mental health condition
- 6 A long-standing illness, such as HIV, diabetes, chronic heart disease, or epilepsy

70. What was your **main** employment status when you were diagnosed with cancer? *(If on maternity or sick leave answer in relation to your **usual** employment status)*

- 1 Full time employment
- 2 Part time employment
- 3 Homemaker
- 4 Student (in education)
- 5 Retired
- 6 Unemployed - and seeking work
- 7 Unemployed - unable to work for health reasons
- 8 Other

71. What is your **main** employment status now? *(If on maternity or sick leave answer in relation to your **usual** employment status)*

- 1 Full time employment
- 2 Part time employment
- 3 Homemaker
- 4 Student (in education)
- 5 Retired
- 6 Unemployed - and seeking work
- 7 Unemployed - unable to work for health reasons
- 8 Other

71a. If your **main** employment status changed between Q70 and Q71, was this due to your cancer diagnosis / treatment?

- 1 Yes
- 2 No
- 3 Don't know / can't remember
- 4 Not applicable

72. Is English your first language?

- 1 Yes
- 2 No

73. What is your ethnic group? **(Tick ONE only)**

a. WHITE

- 1 English / Welsh / Scottish / Northern Irish / British
- 2 Irish
- 3 Irish Traveller
- 4 Any other White background *(Please write in box)*

b. MIXED / MULTIPLE ETHNIC GROUPS

- 5 White and Black Caribbean
- 6 White and Black African
- 7 White and Asian
- 8 Any other Mixed / multiple ethnic background *(Please write in box)*

c. ASIAN OR ASIAN BRITISH

- 9 Indian
- 10 Pakistani
- 11 Bangladeshi
- 12 Chinese
- 13 Any other Asian background *(Please write in box)*

d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

- 14 African
- 15 Caribbean
- 16 Any other Black / African / Caribbean background *(Please write in box)*

e. OTHER ETHNIC GROUP

- 17 Arab
- 18 Any other ethnic group *(Please write in box)*

74. Could we send you a survey in the future to ask about your experience of cancer healthcare?

If you answer 'Yes', your contact details will be securely retained by the Business Services Organisation* (BSO) for two years and then destroyed, unless you wish to have them removed before this time, in which case you should contact your local HSC Trust using the details on page 2 of the covering letter. During this two-year period, your contact details may be shared with appropriate organisations who are approved by your Trust, and who may then contact you to ask you about your experience of cancer care. If contacted, you do not have to participate in any survey or other study.

*The Business Services Organisation is part of HSC in Northern Ireland and was established to provide a broad range of regional business support functions and specialist professional services to the Health and Social Care sector.

- 1 Yes, and I understand that this does **NOT** mean that I would have to take part in any survey or other study
- 2 No, I would prefer you not to contact me again

OTHER COMMENTS

If there is anything else you would like to tell us about your experience of cancer care, please do so here.

Please note that the comments you provide in the box below will be looked at in full by the HSC Trust, HSC and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback.

Was there anything particularly good about your cancer care in Northern Ireland?

Was there anything that could have been improved?

Do you have any other comments you wish to make?