



Patient Survey

This questionnaire is about your care and treatment for cancer. Its purpose is to provide information which can help the NHS 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 who is helping.

Completing the questionnaire

For each question please tick clearly 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.

IMPORTANT INFORMATION

To make sure the information we collect is useful, we need to collect some personal details from you and to access information held about you in other NHS databases. The purpose of collecting this information is to generate aggregated statistics about the care and treatment people receive. These statistics will be used to compare the differences in care and treatment by different providers and to understand what may be causing these. The results will be used to measure and improve the quality of healthcare services.

By completing this questionnaire you are giving your consent for the information provided to be used for the above purposes. Specifically, you are agreeing that:

- Your personal details and relevant health information can be held and used by an organisation contracted to NHS England to analyse the data
- Other information about you held by the Patient Demographics Service, the Secondary Users Service and other NHS databases can be held and used by an organisation contracted to NHS England to analyse the data

Your personal information will be handled securely and anonymised after analysis and before any publication.

Your personal information will not be released by NHS England or third party organisations working on its behalf unless required by law or where there is a clear overriding public interest.

You can withdraw the information you give the NHS 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 FREEPHONE helpline number **on 0800 783 1775**

Taking part in this survey is voluntary

Published reports will not contain any personal details

NC14CORE-01

SEEING YOUR GP

These questions are about what happened before you went into hospital about 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 did not see my GP before going to hospital
 - 2 I saw my GP **once**
 - 3 I saw my GP **twice**
 - 4 I saw my GP **3 or 4** times
 - 5 I saw my GP **5 or more** times
 - 6 Don't know / can't say

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 hospital 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

4. Did your health get worse, get better or stay about the same while you were waiting for your first appointment with a hospital doctor?
 - 1 My health got worse
 - 2 My health got better
 - 3 My health stayed about the same

DIAGNOSTIC TESTS

5. In the last 12 months, have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan at one of the hospitals named in the covering letter?
 - 1 Yes → **Go to Q6**
 - 2 No → **Go to Q10**

*Thinking about the **LAST** time you had a diagnostic test for your cancer at one of the hospitals named in the covering letter*

6. Beforehand, did a member of staff explain the purpose of the test(s)?
 - 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No, but I would have liked an explanation
 - 4 I did not need an explanation
 - 5 Don't know / can't remember

7. Beforehand, did a member of staff explain what would be done during the test procedure(s)?
 - 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No, but I would have liked an explanation
 - 4 I did not need an explanation
 - 5 Don't know / can't remember

8. Beforehand, were you given **written** information about your test(s)?
 - 1 Yes, and it was **easy** to understand
 - 2 Yes, but it was **difficult** to understand
 - 3 No, but I would have liked written information about the test(s)
 - 4 I did not need written information
 - 5 Don't know / can't remember

9. Were the **results** of the test(s) explained 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
- 5 Don't know / can't remember

FINDING OUT WHAT WAS WRONG WITH YOU

10. Who first told you that you had cancer?

- 1 A hospital doctor
- 2 A hospital nurse
- 3 A GP (family doctor)
- 4 Another health professional
- 5 A friend or relative
- 6 Nobody – I worked it out for myself

11. 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 It was not necessary
- 4 I was told by phone or letter
- 5 Don't know / can't remember

12. 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

13. 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 Can't remember

14. 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 written information
- 5 Don't know / can't remember

DECIDING THE BEST TREATMENT FOR YOU

15. Before your cancer treatment started, were you given a choice of different types of treatment?

- 1 Yes
- 2 No, but I would have liked a choice
- 3 I was not given a choice because only one type of treatment was suitable for me
- 4 Not sure / can't remember

16. Do you think your views were taken into account when the team of doctors and nurses caring for you were discussing which treatment you should have?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, my views were not taken into account
- 4 I didn't know my treatment was being discussed by a team of doctors / nurses
- 5 Not sure / can't remember

17. 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 Not sure / can't remember

18. 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

19. Before you started your treatment, were you also told about any side effects of the treatment that could affect you in the future rather than straight away?

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

20. 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 Not sure / 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.

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

- 1 Yes → Go to Q22
- 2 No → Go to Q25
- 3 Don't know / not sure → Go to Q25

22. 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

23. 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

24. 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

SUPPORT FOR PEOPLE WITH CANCER

Thinking about when your cancer treatment first started...

25. 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
26. 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
27. 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
28. Did hospital staff tell you that you could get free prescriptions?
- 1 Yes
 - 2 No, but I would have liked information
 - 3 It was not necessary
 - 4 Don't know / can't remember

29. Have you seen information (such as leaflets, posters, information screens etc.) about cancer research in your hospital?
- 1 Yes
 - 2 No
30. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?
- 1 Yes → **Go to Q31**
 - 2 No → **Go to Q32**
 - 3 Don't know / can't remember → **Go to Q32**
31. **If yes**, did you then go on to take part in cancer research?
- 1 Yes
 - 2 No

OPERATIONS

32. During the last 12 months, have you **had an operation** (such as removal of a tumour or lump) at one of the hospitals named in the covering letter?
- 1 Yes → **Go to Q33**
 - 2 No → **Go to Q36**
- Thinking about the LAST time you went into one of the hospitals named in the covering letter for an operation for your cancer ...*
33. Before you had your operation, did a member of staff explain what would be done during the operation?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No, but I would have liked an explanation
 - 4 I did not need an explanation
 - 5 Don't know / can't remember

- 34.** Beforehand, were you given **written** information about your operation?
- 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 my operation
 - 4 Don't know / can't remember
- 35.** 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 DOCTORS

- 36.** During the last 12 months, have you had an operation or stayed overnight **for cancer care** at one of the hospitals named in the covering letter?
- 1 Yes → **Go to Q37**
 - 2 No → **Go to Q57**

Thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

- 37.** When you had important questions to ask a doctor, how often did you get answers that you could understand?
- 1 All or most of the time
 - 2 Some of the time
 - 3 Rarely or never
 - 4 I did not ask any questions

- 38.** Did you have confidence and trust in the doctors treating you?
- 1 In all of them
 - 2 In some of them
 - 3 In none of them
- 39.** Did doctors talk in front of you as if you weren't there?
- 1 Yes, often
 - 2 Yes, sometimes
 - 3 No
- 40.** If your family or someone else close to you wanted to talk to a doctor, did they have enough opportunity to do so?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 No family or friends were involved
 - 5 My family did not want or need information
 - 6 I did not want my family or friends to talk to a doctor

WARD NURSES

Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

- 41.** When you had important questions to ask a ward nurse, how often did you get answers you could understand?
- 1 All or most of the time
 - 2 Some of the time
 - 3 Rarely or never
 - 4 I did not ask any questions

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

- 1 In all of them
 2 In some of them
 3 In none of them

43. Did ward nurses talk in front of you as if you weren't there?

- 1 Yes, often
 2 Yes, sometimes
 3 No

44. 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

HOSPITAL CARE & TREATMENT

Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

45. While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?

- 1 Often
 2 Sometimes
 3 Only once
 4 Never

46. While you were in hospital, did it ever happen that one doctor or nurse said one thing about your condition or treatment, and another said something different?

- 1 Often
 2 Sometimes
 3 Only once
 4 Never

47. 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

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

- 1 Yes, always
 2 Yes, sometimes
 3 No

49. Were you given enough privacy when being examined or treated?

- 1 Yes, always
 2 Yes, sometimes
 3 No

50. Were you able to discuss any worries or fears with staff during your hospital visit?

- 1 As much as I wanted
 2 Most of the time
 3 Some of the time
 4 Not at all, but would have liked to
 5 I did not have any worries or fears

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

- 1 All of the time
 2 Some of the time
 3 Not at all
 4 I did not have any pain

52. Were you treated with respect and dignity by the doctors and nurses and other hospital staff?

- 1 Always
 2 Most of the time
 3 Some of the time
 4 Never

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

- 1 Yes
 2 No
 3 Can't remember

54. 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

HOME CARE AND SUPPORT

Still thinking about the LAST time you had an operation or stayed overnight for cancer care at one of the hospitals named in the covering letter...

55. 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 given information

56. After leaving hospital, were you given enough care and help 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

HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

57. Did hospital staff do everything possible to control the side effects of radiotherapy?

- 1 Yes, definitely
 2 Yes, to some extent
 3 No, they could have done more
 4 I have not had any side effects from radiotherapy
 5 I have not had radiotherapy

58. Did hospital staff do everything possible to control the side effects of chemotherapy?

- 1 Yes, definitely
 2 Yes, to some extent
 3 No, they could have done more
 4 I have not had any side effects from chemotherapy
 5 I have not had chemotherapy

59. While you were being treated as an outpatient or day case, did hospital staff do everything they could to help control your pain?

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

60. While you were being treated as an outpatient or day case, were you given enough emotional support from hospital staff?

- 1 Yes, definitely
 2 Yes, to some extent
 3 No, I would have liked more support
 4 I did not need emotional support from staff

OUTPATIENTS APPOINTMENTS WITH DOCTORS

61. In the last 12 months, have you had an outpatients appointment with a cancer doctor at one of the hospitals named in the covering letter?

- 1 Yes → Go to Q62
2 No → Go to Q63

62. The **last** time you had an 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 Don't know / can't remember

CARE FROM YOUR GENERAL PRACTICE

63. 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

64. 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 NHS CARE

65. 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

66. Have you had treatment from any of the following for your cancer? **(Tick all that apply)**

- 1 Physiotherapist
2 Occupational therapist (OT)
3 Dietician
4 Speech and language therapist
5 Lymphoedema specialist

67. How much information were you given about your condition and treatment?

- 1 Not enough
2 The right amount
3 Too much

68. Have you been offered a written assessment and care plan? *A 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 Don't know / can't remember

69. Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?

- 1 Yes, often
 2 Yes, sometimes
 3 No

70. Overall, how would you rate your care?

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

ABOUT YOU

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

71. What year were you born?

(Please write in) e.g.

1	9	4	4
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Y	Y	Y	Y

72. Are you male or female?

- 1 Male
 2 Female

73. Which of the following best describes your sexual orientation? **(Tick one box only)**

- 1 Heterosexual / straight (opposite sex)
 2 Bisexual (both sexes)
 3 Gay or Lesbian (same sex)
 4 Other
 5 Prefer not to answer

74. What is your **main** employment status? *(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

75. 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
 7 No, I do not have a longstanding condition

76. 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

77. Is this the **first time** you have been treated for cancer?

- 1 Yes, this is the first time I have been treated for cancer
- 2 No, I have been treated for the **same type of cancer** before but it has now come back
- 3 No, I have been treated for a **different type of cancer** before

78. How has your current cancer responded to treatment? (**Please tick ONE option that is closest to your situation**)

- 1 Treatment has not yet started for this cancer
- 2 I am in the course of treatment and I can't tell yet how my cancer has responded
- 3 The treatment has been effective and I have no signs or symptoms of cancer
- 4 I have finished the course of treatment but my cancer is still present
- 5 My cancer is being treated again because it has not responded fully to treatment
- 6 I am not in active treatment but I am on "Watch and Wait"
- 7 My cancer has not been treated at all

79. Could we send you a survey in the future to ask about your health and healthcare?

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

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

a. WHITE

- 1 English / Welsh / Scottish / Northern Irish / British
- 2 Irish
- 3 Gypsy or 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)

OTHER COMMENTS

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

Was there anything particularly good about your NHS cancer care?

Was there anything that could have been improved?

Any other comments?