



National Cancer Patient Experience Survey

This questionnaire is about your experience of cancer care in the NHS. Your views will help the NHS monitor and improve the quality of cancer services so that they better meet patient needs.

What to do

For each question please tick inside the box that is closest to your views using a black or blue pen. If you make a mistake; simply cross out the mistake and put a tick in the correct box. If you cannot answer a question, or do not want to answer it, just leave it blank and go to the next question. Please **do not** write your name or address anywhere on the questionnaire. If you would prefer, you can complete this survey online at www.ncpes.uk/.

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 NHS Trust that treated you. The details have been shared with Quality Health Ltd who are carrying out the survey on behalf of NHS England. **Your personal information will be handled securely, and the results will be presented in a form that does not allow your answers to be identified. Published reports will not contain any personal details.**

By completing this questionnaire you are agreeing for the information you provide, and the information from the NHS Trust to be used to carry out the survey. You are agreeing that your personal information can be held and used by NHS England and organisations acting under its instructions. Information that does not directly identify you may be made available to research organisations. Any research organisation analysing the data will be subject to strict obligations 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 shared with anyone else unless required by law or where there is a clear overriding public interest.

We send Public Health England the survey data to carry out further analysis by linking the data to the National Cancer Registration and Analysis Service. NHS Digital will use the survey data to carry out further analysis for bowel cancer patients by linking the data to the National Bowel Cancer Audit. They will NOT receive your name and address. Under data protection legislation NHS England is responsible for the processing of your personal data for the purposes of the survey.

We conduct the survey and process personal data in accordance with our statutory powers, and for data protection purposes, in the exercise of official authority. For the processing of special categories (health) data our basis is that it is necessary for the management of health systems. For information about how NHS England uses personal data and how you can contact us and invoke your rights as a data subject, please see our privacy notice: <https://www.england.nhs.uk/contact-us/privacy-notice/>. You can obtain a copy of this by contacting our Customer Contact Centre: Telephone: 0300 311 22 33; Email: england.contactus@nhs.net; Post: NHS England, PO Box 16738, Redditch, B97 9PT.

If you answer yes to question 67 in this questionnaire, the personal information used to identify you to take part in this survey and to analyse the results, including information about your cancer diagnosis will be kept so that you can be contacted again in the future. If you answer no, your name, address, date of birth and NHS number will be deleted by 31 August 2019. You can withdraw the information you give in this questionnaire upon request, up to the point at which data are analysed and personal details are removed (31 March 2019). **You still have the right to request deletion of your data at any time by contacting the helpline.**

If you have any queries about the questionnaire or how your information may be used, please call the FREEPHONE helpline number **on 0800 783 1775**.

Taking part in this survey is voluntary

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 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
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 at one of the hospitals named in the covering letter?
 - 1 Yes → **Go to Q5**
 - 2 No → **Go to Q8**

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

5. 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
6. 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
7. 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

8. 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 by phone or letter
 - 4 Don't know / can't remember
9. 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
10. 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
11. 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

12. 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
13. 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
14. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No, I was not offered any practical advice or support
 - 4 Don't know / can't remember

15. 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?

- 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

16. 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.

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

- 1 Yes → Go to Q18
- 2 No → Go to Q20
- 3 Don't know / can't remember → Go to Q20

18. 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

19. 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

20. 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
21. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, 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
22. 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
23. 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

OPERATIONS

24. 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 Q25
- 2 No → Go to Q27

Thinking about the LAST time you went into one of the hospitals named in the covering letter for an operation for your cancer ...

25. 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

26. 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

27. 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 Q28

2 No → Go to Q40

*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...*

28. 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

29. 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

30. 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

31. 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

32. 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

33. 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

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

1 Yes, always

2 Yes, sometimes

3 No

35. 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

36. 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

37. 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

38. 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

39. 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** at one of the hospitals named in the covering letter...*

40. During the last 12 months, have you been treated as an outpatient or day case for **cancer care** at one of the hospitals named in the covering letter?

- 1 Yes → **Go to Q41**
 2 No → **Go to Q49**

41. 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

42. 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

43. During the last 12 months, have you had radiotherapy at any of the hospitals named in the covering letter?

- 1 Yes → **Go to Q44**
 2 No → **Go to Q46**

44. 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

45. 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

46. During the last 12 months, have you had chemotherapy at any of the hospitals named in the covering letter?

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

47. 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

48. 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

49. 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

50. **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

51. 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

52. 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

53. 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

54. 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

55. Have you been given a 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 I do not know / understand what a care plan is
- 4 Don't know / can't remember

56. 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

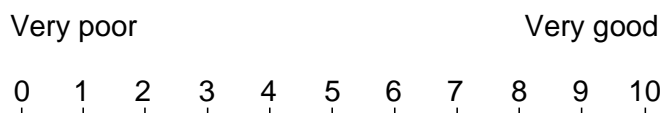
57. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?

- 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

58. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?

- 1 Yes
- 2 No
- 3 No, but I would have liked them to
- 4 Don't know / can't remember

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



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.

60. 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

61. 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 Q63**
- 2 No → **Go to Q62**
- 3 Don't know → **Go to Q63**
- 4 Does not apply to my type of cancer → **Go to Q63**

62. Which of the following applies?

- 1 My cancer has been taken out / treated, without any sign of further problem
- 2 My cancer was taken out / 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.

63. What year were you born?

(Please write in) e.g.

1	9	4	4
---	---	---	---

--	--	--	--

64. Are you male or female?

- 1 Male
- 2 Female

65. 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

66. 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

67. 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

68. Is English your first language?

- 1 Yes
- 2 No

69. 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

Thinking about the **hospital named in the covering letter**, if there is anything else you would like to tell us about your experience of NHS 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 NHS Trust, NHS England 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 NHS cancer care?

Was there anything that could have been improved?

Any other comments?