

National Cancer Patient Experience Survey

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

What to do

For each question please cross inside the box that is closest to your views using a black or blue pen. If you make a mistake; fill in that box and cross the correct box. If you cannot, or do not want to, answer a question, leave it blank and continue. Please do not put your name or address anywhere on the questionnaire. If you 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 for this survey and will be used to analyse the results. These details were provided by the NHS trust that treated you. The details have been shared with Picker, who are carrying out the survey on behalf of NHS England. Under data protection legislation NHS England is the controller responsible for the processing of your personal data to conduct the survey. **Your personal information will be handled securely, and the results published will not identify you.**

By completing this questionnaire you are agreeing that the information you provide, and the information from the NHS trust, can be used for 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 rules for the security and confidentiality of your information. They will **not** use your details for other purposes. Your personal information will not be shared with others unless required by law or where there is a clear overriding public interest.

We will send the survey data – with NHS Number, postcode and date of birth, but not name and address - to Public Health England for further analysis linked to the National Cancer Registration and Analysis Service database. We will send similar data about bowel cancer patients to NHS Digital to link to the National Bowel Cancer Audit. We will send this data regardless of whether you have answered *yes* or *no* to question 70. If you answer *yes* to question 70, we will keep your personal details for up to 20 years and then review the need to retain further. If you answer *no* to question 70 your name, address, date of birth and NHS number will be deleted by 31 August 2021 by Picker. We will keep survey data in anonymous form for up to 20 years after the completion of the analysis if you answer *no* to question 70 and then review the need to retain it.

NHS England conducts the survey and processes 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 also obtain a copy via our Customer Contact Centre: telephone 0300 311 22 33; email england.contactus@nhs.net; post to NHS England, PO Box 16738, Redditch, B97 9PT.

You can withdraw the information you give in this questionnaire upon request – up to the point at which personal details are removed if you answered *no* to question 70 (17 January 2020). **If you would like to discuss deletion of your data, please contact the survey helpline.**

If you have any queries about the questionnaire or how your information may be used, please call the Picker FREEPHONE helpline number on **0800 103 2804**. If you would prefer to opt out of this survey please email our helpline PickerSurveys@PickerEurope.ac.uk.

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 No, I did not need any information
 - 4 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. How long ago were you told that you had cancer?
- 1 Less than 6 months ago
 - 2 At least 6 months ago but not more than twelve months ago
 - 3 More than twelve months ago
 - 4 Don't know / can't remember
9. Who told you that you had cancer?
(Cross ALL that apply)
- 1 A specialist doctor or consultant at hospital
 - 2 My GP
 - 3 A Clinical Nurse Specialist (CNS)
 - 4 Someone else
 - 5 Don't know / can't remember
10. 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
11. 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

12. 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
13. 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

14. 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

15. 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

16. 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

17. 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

18. 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

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.

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

- 1 Yes → Go to Q20
- 2 No → Go to Q22
- 3 Don't know / can't remember → Go to Q22

20. 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

21. 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

22. 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
23. 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
24. 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
25. 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

26. 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 Q27**
 - 2 No → **Go to Q29**

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

27. 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
28. 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

29. During the last 12 months, have you stayed overnight **for cancer care** at one of the hospitals named in the covering letter?

1 Yes → Go to Q30

2 No → Go to Q42

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

30. Did **hospital staff** 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 **hospital staff** 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 at one of the hospitals named in the covering letter...

42. 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 Q43**
- 2 No → **Go to Q51**

43. 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

44. 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 did not have an appointment with a cancer doctor
- 4 Don't know / can't remember

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

- 1 Yes → **Go to Q46**
- 2 No → **Go to Q48**

46. 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

47. 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

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

- 1 Yes → **Go to Q49**
- 2 No → **Go to Q51**

49. 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

50. 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

51. 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

52. 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

53. 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

54. 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

55. 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

56. 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, some of the time
- 3 No, never
- 4 Don't know / can't remember

57. 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

58. 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

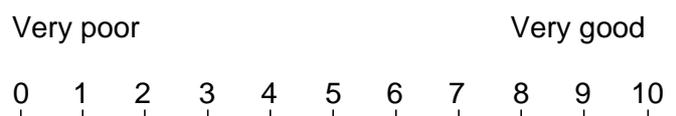
59. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?

- 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

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

- 1 Yes
- 2 Yes, but I was not eligible to take part
- 3 No
- 4 No, but I would have liked them to
- 5 Don't know / can't remember

61. 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.

62. 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

63. 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 Q65**
- 2 No → **Go to Q64**
- 3 Don't know → **Go to Q65**
- 4 Does not apply to my type of cancer → **Go to Q65**

64. 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.

65. What year were you born?

(Please write in) e.g.

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

- 1 Male
- 2 Female

67. 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
- 6 Don't know / not sure

68. Do you have any of the following?

Select **ALL** conditions you have that have lasted or are expected to last for 12 months or more.

- 1 Breathing problem, such as asthma
- 2 Blindness or partial sight
- 3 Dementia or Alzheimer's disease
- 4 Deafness or hearing loss
- 5 Diabetes
- 6 Heart problem, such as angina
- 7 Joint problem, such as arthritis
- 8 Kidney or liver disease
- 9 Learning disability
- 10 Mental health condition
- 11 Neurological condition
- 12 I do not have any of these conditions

→ **Go to Q70**

69. Do any of these reduce your ability to carry out day-to-day activities?

- 1 Yes, a lot
- 2 Yes, a little
- 3 No, not at all

70. 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

71. Is English your first language?

- 1 Yes
- 2 No

72. 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. Any information you give that could identify anyone will only be used if there are areas of concern. 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?