

National Cancer Patient Experience Survey

Your chance to tell us about your experience of cancer care in the NHS

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

What to do

For each question please cross clearly inside one box using a black or blue pen.

For some questions you will be instructed that you may cross more than one box. Sometimes you will find the box you have crossed has an instruction to go to another question. By following the instructions carefully you will skip questions that do not apply to you.

Don't worry if you make a mistake; simply fill in the box and put a cross in the correct box.

Please **do not** write your name or address anywhere on the questionnaire.

You can provide your own comments about the cancer care you have received at the end of the questionnaire if you wish.

If you would like someone to help you complete the survey it's fine to ask a friend or relative to help, but please make sure the answers are only about your experiences.

Want to complete the survey online?

If you would prefer, you can complete this survey online at www.ncpes.co.uk by entering the code given to you in the letter we sent you with this questionnaire. If you have any problems contact the Freephone helpline on 0800 103 2804.

Consent

By completing and returning 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, and**
- **that your personal information can be held and used by NHS England and organisations acting under its instructions.**

The letter sent to you with this questionnaire includes how your information is used, or go to www.ncpes.co.uk/help-support

You can call the Picker Freephone helpline on 0800 103 2804 (9am to 5pm Monday to Friday) and we will do our best to help you. There is an answerphone at all times and someone will get back to you as soon as possible.

Taking part in this survey is voluntary

Support from your GP practice

These questions are about what happened before you knew you had cancer.

- 1 How long was it from the time you first thought something might be wrong with you until you first contacted your GP practice to talk about it?
- 1 Not applicable - I didn't contact my GP practice [Go to Question 4](#)
 - 2 Not applicable - The GP first identified that something could be wrong [Go to Question 3](#)
 - 3 Less than 3 months [Go to Question 2](#)
 - 4 3-6 months [Go to Question 2](#)
 - 5 6-12 months [Go to Question 2](#)
 - 6 More than 12 months [Go to Question 2](#)
 - 7 Don't know / can't remember [Go to Question 2](#)

- 2 Before you were diagnosed, how many times did you speak to a healthcare professional at your GP practice about health problems caused by cancer?
- 1 Once
 - 2 Twice
 - 3 Three or four times
 - 4 Five or more times
 - 5 Don't know / can't remember

- 3 When you were referred for diagnostic tests, did staff at your GP practice explain why you were being referred in a way that you could understand?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 I wasn't referred by my GP practice
 - 5 Don't know / can't remember

Diagnostic tests

- 4 In the last 12 months have you had any tests that helped to diagnose your cancer at one of the hospitals named in the covering letter? This could have been an endoscopy, biopsy, blood test or a scan.
- 1 Yes [Go to Question 5](#)
 - 2 No [Go to Question 10](#)

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

- 5 Before you went for your test(s), were you given all the information you needed about the test(s) you were having, including where they would be and how long you would be waiting?
- 1 Yes
 - 2 No, I would have liked more information
 - 3 No, but I didn't need any information
 - 4 Don't know / can't remember
- 6 When you went for your test(s) did the healthcare staff that you saw appear to have all the information that they needed about you?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

- 7 Overall, how did you feel about the length of time you had to wait for your test results to be shared with you?
- 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

Thinking more generally about your diagnostic tests for cancer...

- 8 Were the results of the tests explained in a way you could understand?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No, I didn't understand the explanation
 - 4 I didn't have an explanation but would have liked one
 - 5 I didn't need an explanation
 - 6 I haven't had the results yet
 - 7 Don't know / can't remember

- 9 Were you given enough privacy when receiving the results of your tests?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No
 - 4 Don't know / can't remember

Finding out that you had cancer

- 10 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 12 months ago
 - 3 At least 12 months ago but not more than 2 years ago
 - 4 At least 2 years ago but not more than 5 years ago
 - 5 At least 5 years ago
 - 6 Don't know / can't remember

- 11 Who told you that you had cancer?
- 1 A specialist doctor or consultant
 - 2 A specialist cancer nurse
 - 3 Another member of the team that looked after you at the hospital
 - 4 Someone at your GP practice
 - 5 Someone else
 - 6 Don't know / can't remember

- 12 When you were first told that you had cancer, had you been given the option of having a family member, carer or friend with you while being told?
- 1 Yes, I was told I could have someone with me
 - 2 No, I was not given the option to have someone with me
 - 3 No, I was specifically told I could not have someone with me
 - 4 No, I was told by letter or email
 - 5 Don't know / can't remember

When you were told you had cancer...

- 13 Were you told in a sensitive way?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

- 14 Was it explained to you in a way that you could understand?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

- 15 Were you told in a place that was appropriate for you?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / not applicable

- 16 Were you told that you could go back for more information after you had time to reflect on what it meant?
- 1 Yes
 - 2 No
 - 3 Don't know / can't remember

Support from a main contact person

- 17 Did you have a **main** contact person within the team looking after you, such as a clinical nurse specialist, who would support you through your treatment?
- 1 Yes, it was a specialist nurse
Go to Question 18
 - 2 Yes, it was another member of the team
Go to Question 18
 - 3 No
Go to Question 20
 - 4 Don't know / can't remember
Go to Question 20

- 18 How easy has it been to contact your main contact person?
- 1 Very easy
 - 2 Quite easy
 - 3 Neither easy nor difficult
 - 4 Quite difficult
 - 5 Very difficult
 - 6 I haven't needed to contact this person

- 19 Overall, how helpful was the advice you received from your main contact person?
- 1 Very helpful
 - 2 Quite helpful
 - 3 Neither helpful nor unhelpful
 - 4 Quite unhelpful
 - 5 Very unhelpful
 - 6 I haven't needed to ask for advice

Deciding on the best treatment

- 20 Before your cancer treatment started, were your treatment options explained to you in a way that you could understand?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 There was only one type of treatment
 - 5 Don't know / can't remember

- 21 Were you involved as much as you wanted to be in decisions about your treatment options?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

- 22 Were your family and/or carers able to be involved as much as you wanted them to be in decisions about your treatment options?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No, and I wanted them to be
 - 4 No, but I didn't want them to be
 - 5 Not applicable
 - 6 Don't know / can't remember

- 23 If you wanted further advice from a different healthcare professional before making decisions, were you able to get it?
- 1 Yes
 - 2 No
 - 3 I didn't want this
 - 4 I wasn't aware I could get this
 - 5 Don't know / can't remember

Care planning

These questions are about how you were supported with any worries, needs or goals during your cancer care. These might have been your physical health, practical, psychological or social needs.

- 24 Before your treatment started, did you have a discussion with a member of the team looking after you about your needs or concerns?
- 1 Yes, definitely
Go to Question 25
 - 2 Yes, to some extent
Go to Question 25
 - 3 No, and I wanted this
Go to Question 27
 - 4 No, but I didn't want this
Go to Question 27
 - 5 Don't know / can't remember
Go to Question 27

25 Has a member of the team looking after you helped you in creating a plan to address those needs or concerns?

1 Yes [Go to Question 26](#)

2 No, and I wanted this

[Go to Question 27](#)

3 No, but this was not needed

[Go to Question 27](#)

4 Don't know / can't remember

[Go to Question 27](#)

26 Did a member of the team looking after you review the plan with you to make sure it continued to reflect your needs or concerns? (E.g. soon after treatment started or at a follow up appointment).

1 Yes

2 No, it didn't need to be reviewed

3 No, it should have been reviewed but it wasn't

4 Don't know / can't remember

Support from hospital staff

27 Did hospital staff give you information that was relevant to you about support or self-help groups, events or resources for people with cancer?

1 Yes

2 No, but I would have liked information

3 No, I did not need information

4 Don't know / can't remember

28 Do you feel you got the right amount of support with your overall health and well being from hospital staff?

1 Yes, definitely

2 Yes, to some extent

3 No

4 Don't know / not applicable

29 Were you offered 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 No, I didn't need information

4 Don't know / can't remember

Hospital care

30 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 Question 31](#)

2 No [Go to Question 39](#)

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

31 Did you have confidence and trust in the team looking after you?

1 Yes, in all of them

2 Yes, in some of them

3 No

4 Don't know / can't remember

32 If a member of your family or someone close to you wanted to talk to someone in the team looking after you during your stay in hospital, were they able to?

1 Yes, definitely

2 Yes, to some extent

3 No

4 My family or friends were not involved

5 My family or friends did not want to talk to a member of the team

6 I did not want my family or friends to talk to a member of the team

7 Don't know / can't remember

33 Did you feel you were involved in decisions about your care and treatment while you were in hospital?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know / can't remember

34 Could you get help from staff on the ward when you needed it?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 I didn't need any help
- 5 Don't know / can't remember

35 During your hospital stay, could you talk with hospital staff about your worries and fears if you needed to?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know / can't remember

36 Did the hospital staff do everything you wanted to help control your pain?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 I didn't have any pain
- 5 Don't know / can't remember

37 Were you treated with respect and dignity during your stay in the hospital?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 Don't know / can't remember

38 Did hospital staff give you information about what you should or should not do after leaving hospital?

- 1 Yes, and it was easy to understand
- 2 Yes, but it was difficult to understand
- 3 No
- 4 Don't know / can't remember

Thinking about outpatient or day case appointments...

39 If you were treated as an outpatient or day case, were you able to talk to hospital staff about your worries or fears if you needed to?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No
- 4 I didn't have an outpatient or day case appointment
- 5 Don't know / can't remember

Your treatment

40 During the last 12 months, have you had...? **Cross ALL that apply**

- 1 Surgery [Go to Question 41](#)
- 2 Chemotherapy [Go to Question 41](#)
- 3 Radiotherapy [Go to Question 41](#)
- 4 Hormone Therapy [Go to Question 41](#)
- 5 Immunotherapy [Go to Question 41](#)
- 6 None of these [Go to Question 43](#)

41 Before your treatment started were you given all the information you needed about the treatment in a way that you could understand? **Please answer for each treatment you crossed in Q40.**

	Yes, completely	Yes, to some extent	No	Don't know / can't remember
Surgery	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Chemotherapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Radiotherapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Hormone Therapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Immunotherapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

42 Once your treatment had started, were you given enough information about your response to treatment in a way that you could understand? **Please answer for each treatment you crossed in Q40.**

	Yes, completely	Yes, to some extent	No	Don't know / can't remember
Surgery	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Chemotherapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Radiotherapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Hormone Therapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
Immunotherapy	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

43 Overall, how do you feel about the length of time you generally had to wait when you arrived at the clinic or day unit for your cancer treatments?

- 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

Immediate and long term side effects

44 Before you started your treatment(s), were the possible side effects of your treatment(s) explained in a way you could understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I didn't need an explanation
- 5 Don't know / can't remember

45 Were you offered practical advice and support in dealing with the immediate side effects of your treatment(s)?

- 1 Yes, always
- 2 Yes, to some extent
- 3 No, but I needed it
- 4 No, I didn't need it
- 5 Don't know / can't remember

46 Were you given information about where you could access other advice and support in dealing with the immediate side effects of your treatment?

- 1 Yes, and I was able to access it
- 2 Yes, but I wasn't able to access it
- 3 No, but I needed it
- 4 No, but I didn't need it
- 5 Don't know / can't remember

The impact of having cancer does not always end when treatment finishes. There can sometimes be long-term side effects that are present during treatment or arise sometime after treatment ends.

47 Before you started your treatment(s), did hospital staff explain the possible long-term side effects, including the impact on your day-to-day activities, in a way you could understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I didn't need an explanation
- 5 Don't know / can't remember

48 Were you able to discuss options for managing the impact of those long-term side effects on your day-to-day activities?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked to
- 4 No, I didn't need to
- 5 Don't know / can't remember

Support while at home

49 Did the team looking after you give your family, or someone close to you, the information they needed to help care for you at home?

- 1 Yes, they were given all the information they needed
- 2 Yes, they were given some of the information they needed
- 3 No
- 4 Not applicable
- 5 Don't know / can't remember

50 During your cancer treatment, could you get enough care and support at home from community or voluntary services?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I didn't need care and support from community or voluntary services
- 5 Don't know / can't remember

Care from your GP practice

51 Did you get the right amount of support from staff at your GP practice while you were having cancer treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 My GP practice wasn't involved
- 5 Don't know / can't remember

52 Have you had a review of your cancer care by a member of staff at your GP practice?

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

Living with and beyond cancer

53 Once your cancer treatment had finished, could you get emotional support at home from community or voluntary services (for example, district nurses, paid carers, mental health support or physiotherapists)?

- 1 My treatment hasn't finished
- 2 Yes, definitely
- 3 Yes, to some extent
- 4 No
- 5 I didn't need care and support from community or voluntary services
- 6 Don't know / can't remember

54 Thinking about the time between your final treatment and your first follow up appointment, did the team looking after you provide you with information and support that was right for you?

- 1 My treatment hasn't finished
- 2 Yes, I was given enough information and support
- 3 I was given enough information but not enough support
- 4 I was given enough support but not enough information
- 5 No
- 6 Don't know / can't remember

55 Were you given information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if you had concerns?

- 1 Yes, I was given enough information
- 2 Yes, I was given some information but I would have liked more
- 3 No, and I think I should have been given information
- 4 No, because this information would not be relevant to me
- 5 Don't know / can't remember

Your overall NHS care

This includes care received from GP practice staff, hospital staff and community staff.

56 Did the whole team looking after you work well together to give you the best possible care?

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

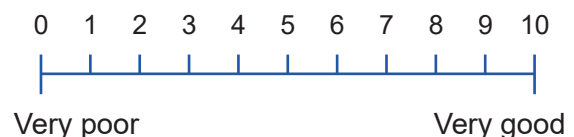
57 Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/ tests results, etc)?

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

58 Since your diagnosis, has anyone discussed with you whether there are any cancer research opportunities that you could take part in (for example: clinical trials, tissue donation, additional scans, sharing data)?

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

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



Your condition

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 Question 63
- 2 No Go to Question 62
- 3 Don't know Go to Question 63
- 4 Does not apply to my type of cancer Go to Question 63

62 Which of the following applies to you?

- 1 My cancer was 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 in the same place or surrounding area
- 3 My cancer was taken out/treated without any sign of further problem, but has since spread to other parts of my body
- 4 None of the above options apply to my type of cancer
- 5 Would prefer not to say
- 6 Don't know / can't remember

About you

The following questions will help us to understand how experiences vary between different groups of people. We will keep your answers completely confidential.

63 What year were you born?
Please write in e.g

1	9	7	4
---	---	---	---

--	--	--	--

64 Which of the following best describes you?

- 1 Female
 - 2 Male
 - 3 Non-binary
 - 4 Prefer to self-describe
-
- 5 Prefer not to say

65 Is your gender identity the same as the sex you were registered at birth?

- 1 Yes
- 2 No
- 3 Prefer not to say

66 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

67 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 Learning disability
- 9 Autism or autism spectrum condition
- 10 Mental health condition
- 11 Neurological condition, such as epilepsy
- 12 Other long-term condition
- 13 I don't have any of these conditions

Go to Question 69

68 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

69 Can NHS England contact you in the future to tell you about other surveys or research about your healthcare experiences?

- 1 Yes, and I understand that this does NOT mean that I would have to take part in any future surveys or research
- 2 No, I would prefer not to be contacted again

70 Is English your first language?

- 1 Yes
- 2 No

71 What is your ethnic group? (Cross ONE only)

a. WHITE

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

b. MIXED / MULTIPLE ETHNIC GROUPS

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

c. ASIAN OR ASIAN BRITISH

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

d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

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

e. OTHER ETHNIC GROUP

- 18 Arab
- 19 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 boxes below will be looked at in full by the NHS Trust, Cancer Alliance, 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.

Please tell us in the box below what you found to be positive about your experience of cancer care.

NOT FOR USE WITHOUT PERMISSION

Please tell us in the box below how your experience of cancer care could have been better.

NOT FOR USE WITHOUT PERMISSION

THANK YOU VERY MUCH FOR YOUR HELP