# **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 oceanly 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 informations.

The letter sent to you with this questionnaire includes how your information is used, or go to www. icpe:.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.

1

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 nought something might be wrong with you intil you first contacted your GP practice to alk about it?  Not applicable - I didn't contact my GP		
		Go to Question 4	
	Not applicable - The General that something could be		
	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	
	Don't know / can't rem	nember	
		Go to Question 2	
2	Before you were diagnosed	•	
	did you speak to a healthca at your GP practice about h caused by cancer?  1 Once 2 Twice 3 Three or four times 4 Five or more times 5 Don't know / can rem	are professional pealth problems	

## Diagnostic tests

that helped to d of the hospitals	onths have you had any tests iagnose your cancer at one named in the covering letter? been an endoscopy, biopsy,
Yes	
	Go to Question 5
2 No	Go to Question 10
	(),
	last time you had a ests for your cancer at one med in the covering letter
given all the info the test(s) you we they would be a waiting?	t for you test(s), were you arm tion you needed about were having, including where and how long you would be
¹ Ves	
No, I would	d have liked more information
No, but I d	idn't need any information
Don't knov	v / can't remember
healthcare staff	for your test(s) did the that you saw appear to have on that they needed about
Yes, comp	letely
<sup>2</sup> Yes, to sor	me extent
3 No	
4 Don't knov	v / can't remember
_	
	d you feel about the length of wait for your test results to be
¹ It was abo	ut right
<sup>2</sup> It was a litt	tle too long
₃ It was mud	ch too long
4 Don't knov	v / can't remember

CPES25 Questionnaire PROTECT

Thinking more generally about your diagnostic tests for cancer	When you were first told that you had cancer, had you been given the option of having a
8 Were the results of the tests explained in a	family member, carer or friend with you while being told?
way you could understand?  Yes, completely	Yes, I was told I could have someone with me
<sup>2</sup> Yes, to some extent	No, I was not given the option to have
No, I didn't understand the explanation	someone with me
I didn't have an explanation but would have liked one	No, I was specifically told I could not have someone with me
5 I didn't need an explanation	No, I was told by letter or email
I haven't had the results yet	<sup>5</sup> □ Don't know / can't remember
Don't know / can't remember	When you were told you hau cancer
9 Were you given enough privacy when	Were you told in a sansitive way?
receiving the results of your tests?	1 Yes, definitely
Yes, always	Yes, to some extent
<sup>2</sup> Yes, sometimes <sup>3</sup> No	Don't know / can't remember
<ul><li>No</li><li>Don't know / can't remember</li></ul>	Don't know / can't remember
Don't know / can't remember	14 Was it explained to you in a way that you
Finding out that you had cancer	could understand?
thang out mat journal canto.	Yes, completely
10 How long ago were you told that you nee	Yes, to some extent
cancer?	3 No
Less than 6 months ago	Don't know / can't remember
At least 6 months age but not more	
than 12 months ego	Were you told in a place that was appropriate for you?
At least 12 months ago but not more	Yes, definitely
than 2 years ago	<sup>2</sup> Yes, to some extent
At least 2 years ago but not more than 5 years ago	3 No
5 At least 5 years ago	Don't know / not applicable
Don't know / can't remember	
	Were you told that you could go back for more information after you had time to reflect on
11) Who told you that you had cancer?	what it meant?
A specialist doctor or consultant	¹ Yes
<sup>2</sup> A specialist cancer nurse	<sup>2</sup> No
Another member of the team that looked after you at the hospital	Don't know / can't remember
Someone at your GP practice	
5 Someone else	
Don't know / can't romamber	

Support from a main contact person	Were you involved as much as you wanted to be in decisions about your treatment
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	options?  1 Yes, definitely 2 Yes, to some extent 3 No 4 Don't know / can't remember  Were your family and/or carers able to be involved as much as you wanted them to be
Go to Question 18  3 No Go to Question 20  4 Don't know / can't remember Go to Question 20	in decisions about your treatment option;?  Yes, definitely  Yes, to some extent  No, and I wanted thom to be
How easy has it been to contact your main contact person?  Very easy  Quite easy  Neither easy nor difficult  Quite difficult  Very difficult  I haven't needed to contact this person	No, but I didn't want them to be  Not applicable  Don't know / can't remember  If you wanted further advice from a different healthcare professional before making decisions, were you able to get it?  Yes  No
Overall, how helpful was the advice you received from your main contact person:  Very helpful  Quite helpful  Neither helpful nor unberpjul	I didn't want this  I wasn't aware I could get this  Don't know / can't remember  Care planning
Quite unhelpful  Very unhelpful  I haven't needed to ask for advice	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.
Pefore 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	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
- Don't know / can tremember	Don't know / can't remember  Go to Question 27

Has a member of the team looking after you helped you in creating a plan to address those needs or concerns?	Were you offered information about how to get financial help or any benefits you might be entitled to?
<sup>1</sup> Yes Go to Question 26	¹ Yes
<sup>2</sup> No, and I wanted this	<sup>2</sup> No, but I would have liked information
Go to Question 27	<sup>₃</sup> No, I didn't need information
₃ No, but this was not needed	Don't know / can't remember
Go to Question 27	
Don't know / can't remember	Hospital care
Go to Question 27	Troopital out
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	Overnight for cancer care at one of the hospitals named in the covering letter?  Yes Go to Question 31  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
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 by people with cancer?	Did you have confidence and trust in the team looking after you?  Yes, in all of them  Yes, in some of them  No  Don't know / can't remember
No, but I would have liked information  No, I did not need information  Don't know / can't remember  Do you feel you got the right amount of support with your overall health and well being from hospital staff?  Yes, definitely  Yes, to some extent  No  Don't know / not applicable	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

Did you feel you were involved in decisions about your care and treatment while you were in hospital?  Yes, always  Yes, sometimes  No  Don't know / can't remember	Did hospital staff give you information about what you should or should not do after leaving hospital?  Yes, and it was easy to understand  Yes, but it was difficult to understand  No  Don't know / can't remember
Could you get help from staff on the ward when you needed it?  Yes, always	Thinking about outpatient or day case appointments
Yes, sometimes  No  I didn't need any help  Don't know / can't remember	If you were treated as an outpatient or day case, were you able to talk to hospital staff about your worries or tears if you needed to?  1 Yes, all vays 2 Yes, simetimes
During your hospital stay, could you talk with hospital staff about your worries and fears if you needed to?  Yes, always  Yes, sometimes	No  I didn't have an outpatient or day case appointment  Don't know / can't remember
No Don't know / can't remember	Your treatment
Did the hospital staff do every ning you wanted to help control you pain.  1 Yes, always 2 Yes, sometimes 3 No 4 I didn't have any pain 5 Don't know / can't remember	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
37 Very you treated with respect and dignity during your stay in the hospital?  Yes, always  Yes, sometimes  No  Don't know / can't remember	None of these Go to Question 43

	Yes, completely	Yes, to some extent	No	Don't know /
Surgery				4
Chemotherapy				
Radiotherapy				
Hormone Therapy				
Immunotherapy			3	
Once your treatment hereatment in a way thanged.		nd? Please answer to Yes, to some		ent you crossed i Don't know
Surgery		extent		can't rememb
Chemotherapy	1		3	4
Radiotherapy			3	4
Hormone Therapy	<u></u> □ 1		□ 3 □	4 
Immunotherapy	L_1		<u></u>	4
Overall, how do you fe of time you generally he arrived at the clinic or o creatments?  It was much too loo It was a little too It was about right Don't know / can'	and to wait when you day unit for your cand	suppo effects	you offered praction dealing with of your treatme fes, always fes, to some extended, but I needed to, I didn't need fon't know / can'	the immediate sid nt(s)? ent it
mediate and long	term side effec		•	ation about where

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 happital staff explain the pessible long term side.	During your cancer treatment, could you get enough care and support at home from community or voluntary services?  Yes, definitely Yes, to some extent
hospital staff explain the possible long-term side effects, including the impact on your day-to-day	³ No
activities, in a way you could understand?	I didn't need care and support from community or voluntary services
Yes, definitely	5 Don't know / can't remember
<sup>2</sup> Yes, to some extent	
³ No	Comp from the property of the
I didn't need an explanation	Care from your GP practice
5 Don't know / can't remember	
Were you able to discuss options for managing the impact of those long-term side effects on your day-to-day activities?	Since your cancer diagnosis, have you had the help or support you needed from your GP practice?  Yes, definitely
Yes, definitely	2 Yes to some extent
<sup>2</sup> Yes, to some extent	No and I needed help or support
No, but I would have liked to	I have not needed any help or support
No, I didn't need to	from my GP practice
5 Don't know / can't remember	Don't know / can't remember
5 Bon t know / can tremember	As part of your care, you might be offered a
Support while at home	cancer care review by your GP practice. This involves a conversation with someone from your GP practice about how your cancer
Did the team looking after you give your family, or someone close to you, the information they needed to help care for you at no ne?	diagnosis and treatment affected your health and well-being. It is also an opportunity for you to talk about any concerns you have and ask for any information, support or care you
Yes, they were given all he information they needed	need.
Yes, they were given some of the information they needed  No.	Since your cancer diagnosis, have you had a cancer care review with someone from your GP practice about any concerns you have or any information, support or care you need?
4 Not applicable	Yes
Don't know / can't remember	No, and I was diagnosed less than or around 12 months ago
	No, and I was diagnosed <b>more than</b> 12
	months ago  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)?  My treatment hasn't finished
	<sup>2</sup> Yes, definitely
	Yes, to some extent
	4 No
	5 I didn't need care and support from
	community or voluntary services
	<sup>6</sup> ☐ 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?
	My treatment hasn't finished
	<sup>2</sup> Yes, I was given enough information and support
	I was given enough information but not enough support
	I was given enough support but not enough information
	5 No
	Don't know / can't remember
55	Were you given in trination about the
	possibility of the cancer coming back or spreading, such as what to look out for and
	what to do it you had concerns?
	Yes I was given enough information
	Yes, I was given some information but I
-	would have liked more
	No, and I think I should have been given information
	No, because this information would not be relevant to me
	5 Don't know / can't remember
	Don't know / can tremember

### 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
	<sup>2</sup> No
	Don't know / can't remembel
57	Overall, how would you ato the
	administration of your care (getting letters at
	the right time, doctors having the right notes/
	tests results, etc)?
	Very good
	2 Goot
	Neither good nor poor
	Poor
_\	5 Very poor
	Don't know / can't remember
	Bent know, can transmise
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)?  Yes
	No, and I would have liked them to
	No, but I didn't want them to
	Don't know / can't remember
59	Overall, how would you rate your care?

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

0	1	2	3	4	5	6	7	8	9	10
$\vdash$										4
। Very										good

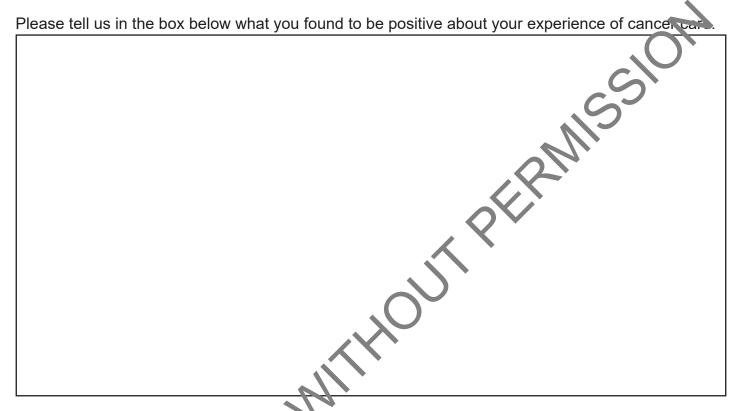
Your condition	About you		
How long is it since you were first treated for this cancer?  Less than 1 year	The following questions will help us to understand how experiences vary between different groups of people. We will keep your answers completely confidential.		
1 to 5 years	63 What year were you born?		
More than 5 years	Please write in e.g		
4 Don't know / can't remember	1 9 7 4		
61 Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?			
Yes Go to Question 63			
<sup>2</sup> No Go to Question 62	64 Which of the following best describes you?		
Don't know Go to Question 63	Female		
Does not apply to my type of cancer  Go to Question 63			
	Non-binary		
Which of the following applies to you?	Prefer to self-describe		
My cancer was taken out/treated without any sign of further problem			
My cancer was taken out/treated without any sign of further problem; but has since come back in the same piace or surrounding area	Frefer not to say  5 Prefer not to say  65 Is your gender identity the same as the sex		
My cancer was taken out/treated	65 Is your gender identity the same as the sex you were registered at birth?		
without any sign of furt ier problem, but	1 Yes		
has since spread to other parts of my body	2 No		
None of the cocke options apply to my type of cancer	□ Prefer not to say		
<sup>5</sup> Would prefer not to say	Which of the following options best describes		
Don't know / can't remember	how you think of yourself?		
	Heterosexual or Straight		
	<sup>2</sup> Gay or Lesbian		
H	₃ Bisexual		
•	4 Other		
	5 Prefer not to say		
	Don't know / not sure		
	Bont Miow / Hot suite		

Do you have any of the following? Select ALL conditions you have that have	What is your ethnic group? (Cross ONE only)
lasted or are expected to last for 12 months	a. WHITE
or more	English / Welsh / Scottish / Northern
Breathing problem, such as asthma	Irish / British
Blindness or partial sight	<sup>2</sup> Irish
Dementia or Alzheimer's disease	Gypsy or Irish Traveller
Deafness or hearing loss	4 Roma
<sup>5</sup> Diabetes	Any other White background (Please
6 Heart problem, such as angina	write in box)
Joint problem, such as arthritis	
<sup>ଃ</sup>	b. MIXED / MULTIPLE ETHNIC GROUPS
Autism or autism spectrum condition	<sup>6</sup> White and Bi⊾ck Caribbean
<sup>10</sup> Mental health condition	√ White an Ublack African
Neurological condition, such as epilepsy	8 White and Asian
Other long-term condition	Any other Mixed / multiple ethnic
<sup>13</sup> I don't have any of these conditions	background (Please write in box)
Go to Question 69	
	c. ASIAN OR ASIAN BRITISH
68 Do any of these reduce your ability to carry	10 Indian
out day-to-day activities?  Yes, a lot	<sup>11</sup> Pakistani
Yes, a little	<sup>12</sup> Bangladeshi
No, not at all	<sup>13</sup> Chinese
	<sup>14</sup> Any other Asian background (Please
69 Can NHS England contact you in the future	write in box)
to tell you about other surveys or research	
about your health arc experiences?	d. BLACK / AFRICAN / CARIBBEAN /
Yes, and i understand that this does  NOT near that I would have to take	BLACK BRITISH
part in any future surveys or research	15 African
<sup>2</sup> No I would prefer not to be contacted	<sup>16</sup> Caribbean
gain	Any other Black / African / Caribbean
	background (Please write in box)
70 Is English your first language?	
¹	e. OTHER ETHNIC GROUP
- 140	18 Arab
	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.

The comments you provide in the boxes below will be shared with and 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 be shared with these organisations. NHS England will remove any information that could identify you before it publishes findings based on any of your feedback.



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



THANK YOU VERY MUCH FOR YOUR HELP