

National Cancer Patient Experience Survey 2021

National report (Quantitative)

1 Introduction and methodology

2 Understanding the results

3 Headline findings

4 About the respondents

5 Overall experience

6 Support from your GP practice

7 Diagnostic tests

8 Finding out that you had cancer

9 Support from a main contact person

10 Deciding on the best treatment

11 Care planning

12 Support from hospital staff

13 Hospital care

14 Your treatment

15 Immediate and long term side effects

16 Support while at home

17 Care from your GP practice

18 Living with and beyond cancer



This report sets out the national headline findings. Detailed national, alliance, system-level and trust-level results are available at www.ncpes.co.uk



An interactive reporting tool allowing you to explore the survey data by sub-group (e.g. by tumour group, ethnicity, age and more) is available at www.ncpes.co.uk/interactive-results

1

Introduction and methodology

Introduction

The National Cancer Patient Experience Survey 2021 is the eleventh iteration of the survey first undertaken in 2010. It has been designed to monitor national progress on experience of cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting cancer patients.

The questionnaire was reviewed in 2021 to reflect changes to cancer services and commitments to cancer care as detailed in the NHS Long Term Plan which is available at www.longtermplan.nhs.uk/online-version/.

The survey was overseen by a National Cancer Patient Experience Advisory Group. This group advises on the principles and objectives of the survey programme and supports questionnaire development.

The survey was commissioned and managed by NHS England. The survey provider, Picker, is responsible for technical design, implementation and analysis of the survey.

The 2021 survey involved 134 NHS trusts. Out of 107,412 people, 59,352 people responded to the survey, yielding a response rate of 55%.

Eligibility

The sample for the survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from a NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June 2021.

Fieldwork

The fieldwork for the survey was undertaken between October 2021 and February 2022.

Survey methods

The survey used a mixed mode methodology. Questionnaires were sent by post, with two reminders where necessary, but also included an option to complete the questionnaire online.

A Freephone helpline and email were available for respondents to opt out, ask questions about the survey, enable them to complete their questionnaire over the phone and provide access to a translation and interpreting facility for those whose first language was not English.

2

Understanding the results

Note on question comparability

The questionnaire was redeveloped for the 2021 National Cancer Patient Experience Survey. Due to the significant changes made to the questionnaire, no trend data or year on year comparisons are presented in this year's results. Comparisons to previous years' results should not be made.

Scoring methodology

Sixty-one questions from the questionnaire are scored, as these questions relate directly to patient experience. For all but one question (Q59), scores are presented as the percentage of positive responses out of all scored responses.

For Q59, respondents rated their overall care on a scale of 0 to 10, of which the average was calculated for this question's presented score.

For each scored question, each response option has been identified as either a positive, negative, or neutral response. Scores were calculated using the total number of positive responses as the numerator and the total number of positive and negative responses as the denominator. Neutral scores (e.g., 'Don't know / can't remember') were excluded from this calculation.

Sub-group comparisons

Sub-group comparisons allow us to explore differences in how people experience cancer care. Some of the groups may be quite small and so caution should be taken when looking at results. See '[About the Respondents](#)' for information on the number of responses for sub-groups. For detailed sub-group analysis at a national level, please see the national Excel tables available at www.ncpes.co.uk.

Suppression rules

To protect the identity of respondents, suppression rules have been applied to scores.

Where the total number of responses to a question is <11, data for the question are suppressed, indicated by an asterisk (*).

Where the base size for any groups for sub-group comparisons (e.g., a specific diagnostic/cancer group) is <11, data for that sub-group AND the next smallest sub-group are suppressed.

For further detail on additional suppression rules used at alliance, ICS, and trust level, please see the Technical Document available at www.ncpes.co.uk.

COVID-19 pandemic

It is important to note that the survey sampling period took place during an unprecedented year for the health and social care sector, with the continuation of the outbreak of the global COVID-19 pandemic. This had an impact on the NHS and may have influenced people's care perceptions and experiences, and therefore how they answered the survey. For example, at various points throughout 2021 the COVID-19 pandemic meant that there were restrictions in place in terms of services available, visiting rules, access to facilities, hygiene protocols and many more aspects of care.

It is important when interpreting the results in this report to consider findings alongside these wider circumstances, particularly as most restrictions were set in place by the government and were therefore the standard way of operating during these times.

Technical document

For more information on the methodology, please see the Technical Document available at www.ncpes.co.uk.

3

Headline findings



Overall experience

8.92

Respondents' average rating of care scored from very poor to very good (scale from 0 to 10).



Support from your GP practice

64.1%

of respondents who had contacted their GP practice said that the referral for diagnosis was explained in a way they could completely understand.



Diagnostic tests

94.4%

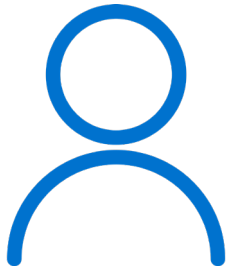
always had enough privacy when receiving diagnostic test results.



Finding out that you had cancer

71.4%

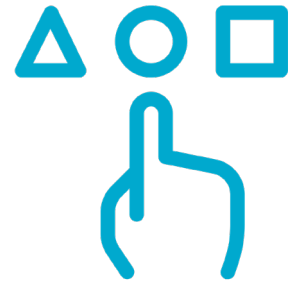
said that when they were first told that they had cancer, they had been given the option of having a family member, carer or friend with them.



Support from a main contact person

91.9%

said they had a main contact person within the team looking after them who would support them through treatment.



Deciding on the best treatment

79.2%

said they were definitely involved as much as they wanted to be in decisions about treatment options.



Care planning

71.7%

said that before their treatment started, they had a discussion with a member of the team looking after them about their needs or concerns.



Support from hospital staff

89.6%

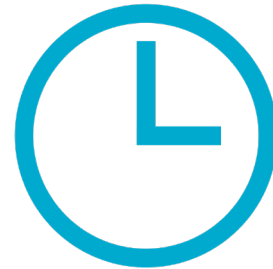
of respondents said hospital staff gave them information that was relevant to them about support or self-help groups, events or resources for people with cancer.



Hospital care

80.9%

of respondents who had an overnight stay said they had confidence and trust in all of the team looking after them.



Your treatment

79.1%

said they felt the length of waiting time at the clinic or day unit used for cancer treatment was about right.



Immediate and long-term side effects

59.5%

said the possible long-term side effects, including the impact on their day-to-day activities, were definitely explained in a way they could understand.



Support while at home

55.4%

said their family or someone else close to them were given all the information necessary to help care for them at home.



Care from your GP practice

43.7%

of respondents who said their GP practice was involved in their care while they were having treatment said they got the right amount of support from staff at their practice.



Living with and beyond cancer

62.5%

said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns.

4 About the respondents

Overall response rate

The 2021 survey involved 134 NHS trusts. Out of 107,412 people, 59,352 people responded to the survey, yielding a response rate of 55%.

The response rate (55%) has slightly declined in comparison to previous iterations of the survey (61% in 2019, 64% in 2018, 63% in 2017, 66% in 2016, 66% in 2015).

Respondents by survey mode

Response mode	Number of respondents	Proportion of respondents
Paper	48,667	82.0%
Online	10,589	17.8%
Phone	91	0.2%
Translation service	5	0.0%
Total	59,352	100.0%

Number of responses by gender¹

	No. of responses	% of responses
Female	30,642	51.6%
Male	25,742	43.4%
Non-binary	17	0.0%
Prefer to self-describe	18	0.0%
Prefer not to say	56	0.1%
Not given	2,877	4.8%
Total	59,352	100.0%

Number of responses by 'Is your gender identity the same as the sex you were registered at birth?'²

	No. of responses	% of responses
Same sex registered at birth	56,142	94.6%
Different sex registered at birth	100	0.2%
Prefer not to say	111	0.2%
Not given	2,999	5.1%
Total	59,352	100.0%

¹ Self reported in Q64 of the survey.

² Self reported in Q65 of the survey.

Number of responses by ethnic background¹

Ethnicity	No. of responses	% of responses
White	52,158	87.9%
Asian	1,531	2.6%
Black	914	1.5%
Mixed	474	0.8%
Other ²	198	0.3%
Not given	4,077	6.9%
Total	59,352	100.0%

Number of responses by tumour group³

Tumour group	No. of responses	% of responses
Breast	13,533	22.8%
Haematological	8,501	14.3%
Colorectal / LGT	7,649	12.9%
Prostate	5,590	9.4%
Urological	4,470	7.5%
Lung	3,630	6.1%
Gynaecological	2,789	4.7%
Upper gastro	2,504	4.2%
Skin	1,961	3.3%
Head and Neck	1,633	2.8%
Sarcoma	548	0.9%
Brain / CNS	245	0.4%
Other	6,299	10.6%
Total	59,352	100.0%

¹ Ethnic background is self reported in Q71 of the survey.

² 'Other' includes Arab and any other ethnic group not listed in Q71.

³ Details of how tumour groups were formed can be found in the Technical Document, available on the survey website: www.ncpes.co.uk

Number of responses by age

Age'	No. of responses	% of responses
16-24	200	0.3%
25-34	566	1.0%
35-44	1,800	3.0%
45-54	5,457	9.2%
55-64	12,927	21.8%
65-74	20,612	34.7%
75-84	15,053	25.4%
85+	2,737	4.6%
Total	59,352	100.0%

Number of responses by IMD¹ quintile (deprivation)

Quintile	No. of responses	% of responses
1 (most deprived)	7,192	12.1%
2	10,194	17.2%
3	12,785	21.5%
4	14,025	23.6%
5 (least deprived)	14,791	24.9%
Outside England	365	0.6%
Total	59,352	100.0%

¹ Indices of Multiple Deprivation (IMD) classifies geographic areas into five quintiles based on relative disadvantage.

Number of responses for long-term condition status¹

Long-term condition	No. of responses	% of responses
Yes	36,081	60.8%
No	18,837	31.7%
Not given	4,434	7.5%
Total	59,352	100.0%

Number of responses for mental health condition status²

Mental health condition	No. of responses	% of responses
No	52,333	88.2%
Yes	2,585	4.4%
Not given	4,434	7.5%
Total	59,352	100.0%

¹ Self-reported in Q67 of the survey.

² Self-reported in Q67 of the survey.

Number of responses by long-term condition¹

Long-term condition	No. of responses	% of responses
Joint problem, such as arthritis	17,344	31.6%
Breathing problem, such as asthma	10,429	19.0%
Deafness or hearing loss	8,434	15.4%
Diabetes	6,858	12.5%
Heart problem, such as angina	5,789	10.5%
Neurological condition	3,304	6.0%
Mental health condition	2,585	4.7%
Blindness or partial sight	1,601	2.9%
Dementia or Alzheimer's disease	350	0.6%
Learning disability	309	0.6%
Other long-term condition	7,144	13.0%
I don't have any of these conditions	18,837	34.3%

¹ Self-reported in Q67 of the survey. Q67 is a multi-choice question and so percentages across response options will add up to more than 100%.

5

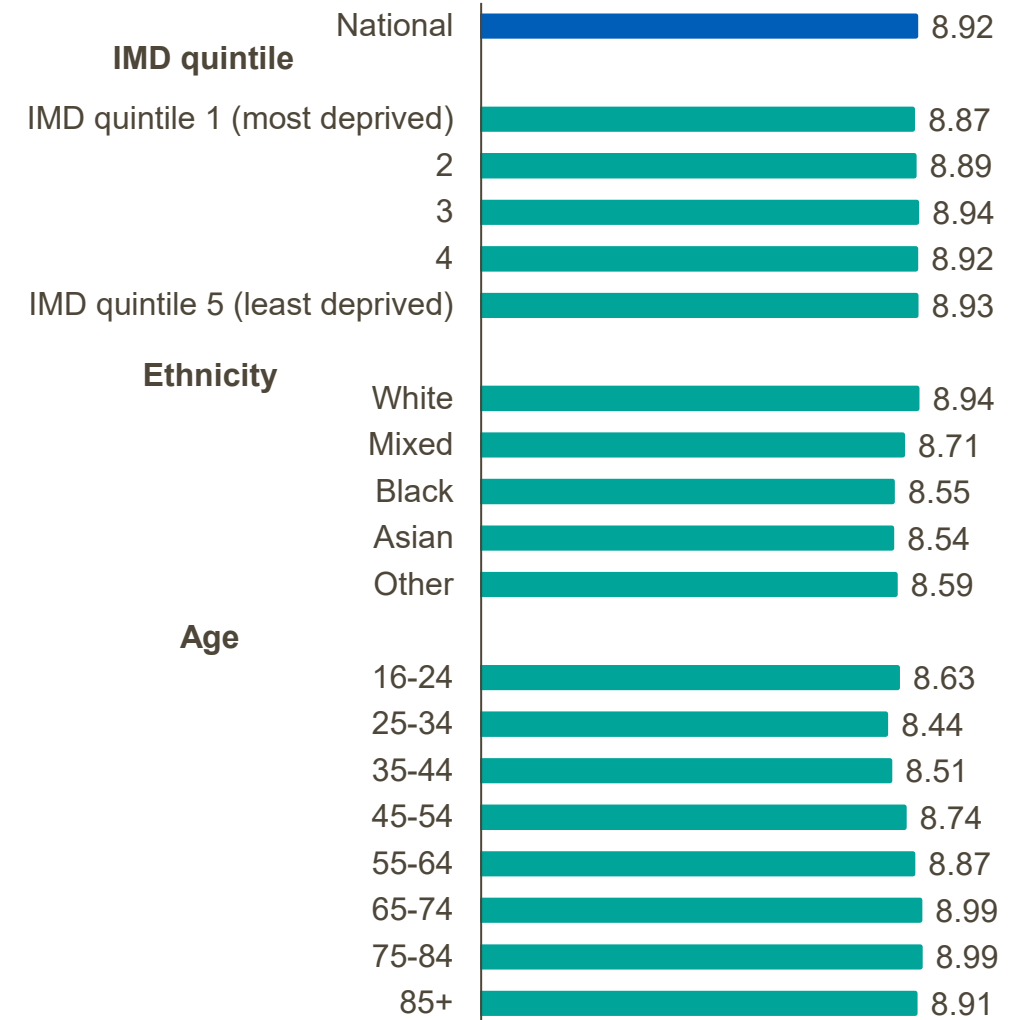
Overall experience

Most respondents (90.8%) felt the whole care team worked well together to provide the best possible care for them (Q56).

When asked how they would rate the administration of their care (getting letters at the right time, doctors having the right notes/ tests results, etc), 88.2% of respondents said the administration of their care was 'very good' or 'good' (Q57).

Respondents were asked to rate their overall care on a scale of 0 (very poor) to 10 (very good). The average rating of care given by respondents was 8.92 (Q59).

Average rating of care scored from very poor to very good (Q59). National base = 56,506.



IMD quintile

Respondents in the **least deprived** group gave a higher average rating of care than respondents in the **most deprived** group (Q59).

Ethnicity

Respondents from **white** ethnic backgrounds gave a higher average rating of care than respondents from **mixed**, **Asian**, and **black** ethnic backgrounds (Q59).

Age

Older respondents (45+) gave higher average ratings of care than **younger** respondents (16-44 age groups) (Q59).

6

Support from your GP practice

The first section in the questionnaire asked respondents about the support they received from their GP practice before they knew they had cancer.

Respondents were asked how many times they spoke to a healthcare professional at their GP practice about health problems caused by cancer before they were diagnosed (Q2). 77.0% of those who had contacted their GP practice said they only spoke to a healthcare professional once or twice before their cancer diagnosis.

64.1% of respondents who had contacted their GP practice said that the referral for diagnosis was explained in a way they could completely understand (Q3).

Long-term condition

Respondents with a [learning disability](#) were the least likely to say that their referral for diagnosis was explained in a way they could completely understand (Q3).

Ethnicity

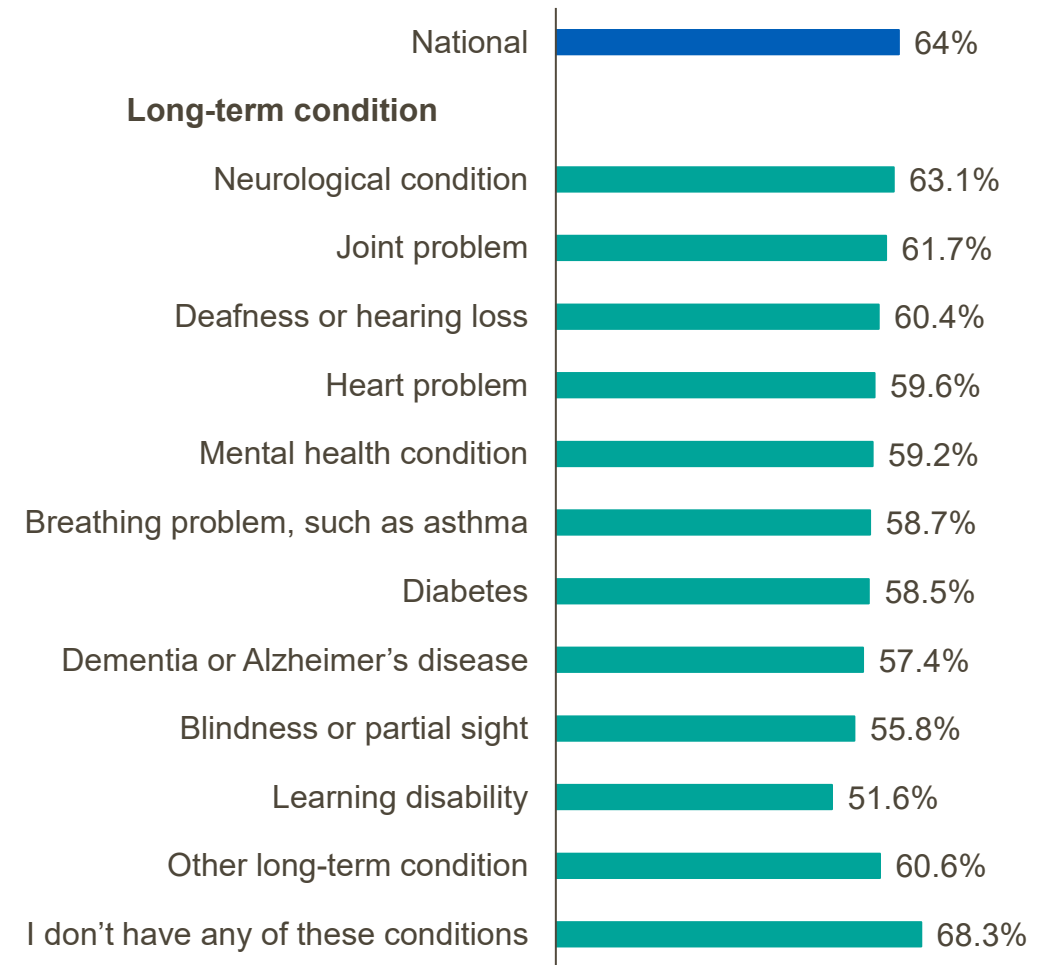
Respondents in the [white](#) ethnic group were more likely to say that their referral for diagnosis was explained in a way they could completely understand (64.8%).

Respondents in the [Asian](#) ethnic group were the least likely to say they understood the referral for diagnosis (54.8%) (Q3).

Age

Respondents in the [16-24](#) age group were the least likely to say that their referral for diagnosis was explained in a way they could completely understand (50.0%) (Q3).

% who said referral for diagnosis was explained in a way the patient could completely understand (Q3). National base = 38,947.



7

Diagnostic tests

Of those respondents (86.4%) who had tests that helped to diagnose their cancer, 92.6% said they received all the information needed in advance (Q5). And 83.9% said that healthcare staff they saw appeared to completely have all the information they needed about them (Q6).

When asked how they felt about the length of the time they had to wait for their test results, 81.9% felt the length of time was about right (Q7).

78.8% of respondents who received a test said that the results were explained to them in a way they could completely understand (Q8).

Respondents were asked whether enough privacy was always given when receiving diagnostic test results. 94.4% said this was always the case (Q9).

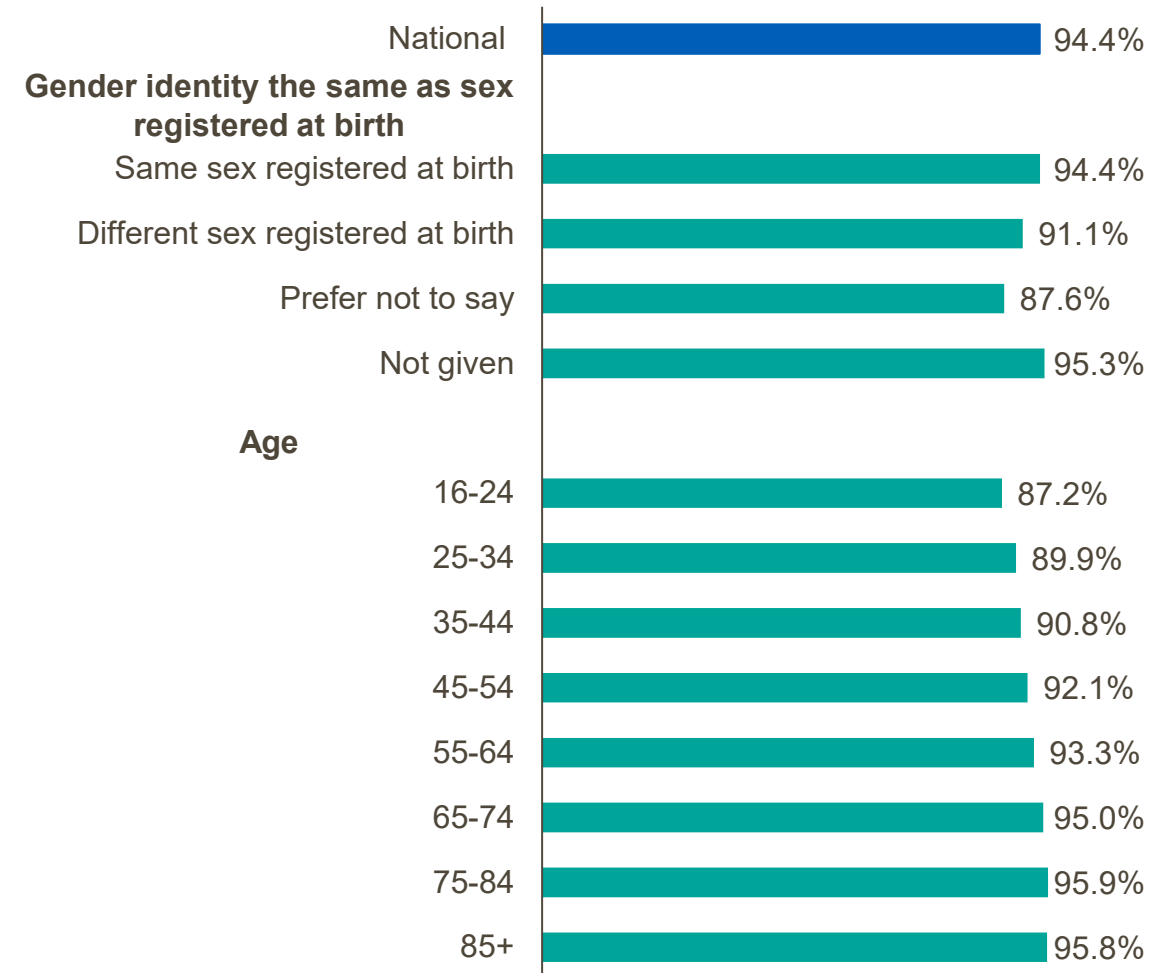
Gender identity the same as sex registered at birth

Respondents who [preferred not to say](#) if their gender identity is different from their sex registered at birth were the least likely to say that they were always given enough privacy when receiving diagnostic test results (Q9).

Age

Respondents in the [75-84](#) age group were the most likely to say enough privacy was given. Respondents in the [16-24](#) age group were the least likely to say that they were always given enough privacy when receiving diagnostic test results (Q9).

% who said enough privacy was always given when receiving diagnostic test results (Q9).
National base = 49,738.



8

Finding out that you had cancer

82.4% of all respondents reported that they were told by a specialist or consultant at hospital that they had cancer (Q11). The majority (87.6% of all respondents) reported that they were first told about their cancer more than six months prior to completing the questionnaire (Q10), with 9.3% being told more than five years ago.

Just under three quarters of all respondents (71.4%) said that when they were first told that they had cancer they had been given the option of having a family member, carer or friend with them (Q12).

When asked how they felt about the way they were told they had cancer, 73.5% said they were told sensitively (Q13). Overall, 84.2% said that they were definitely told about their diagnosis in a place that was appropriate for them (Q15).

76.5% said their cancer diagnosis was explained in a way they could completely understand (Q14). With 82.9% saying they were told they could go back later for more information about their diagnosis after they had had time to reflect on what it meant (Q16).

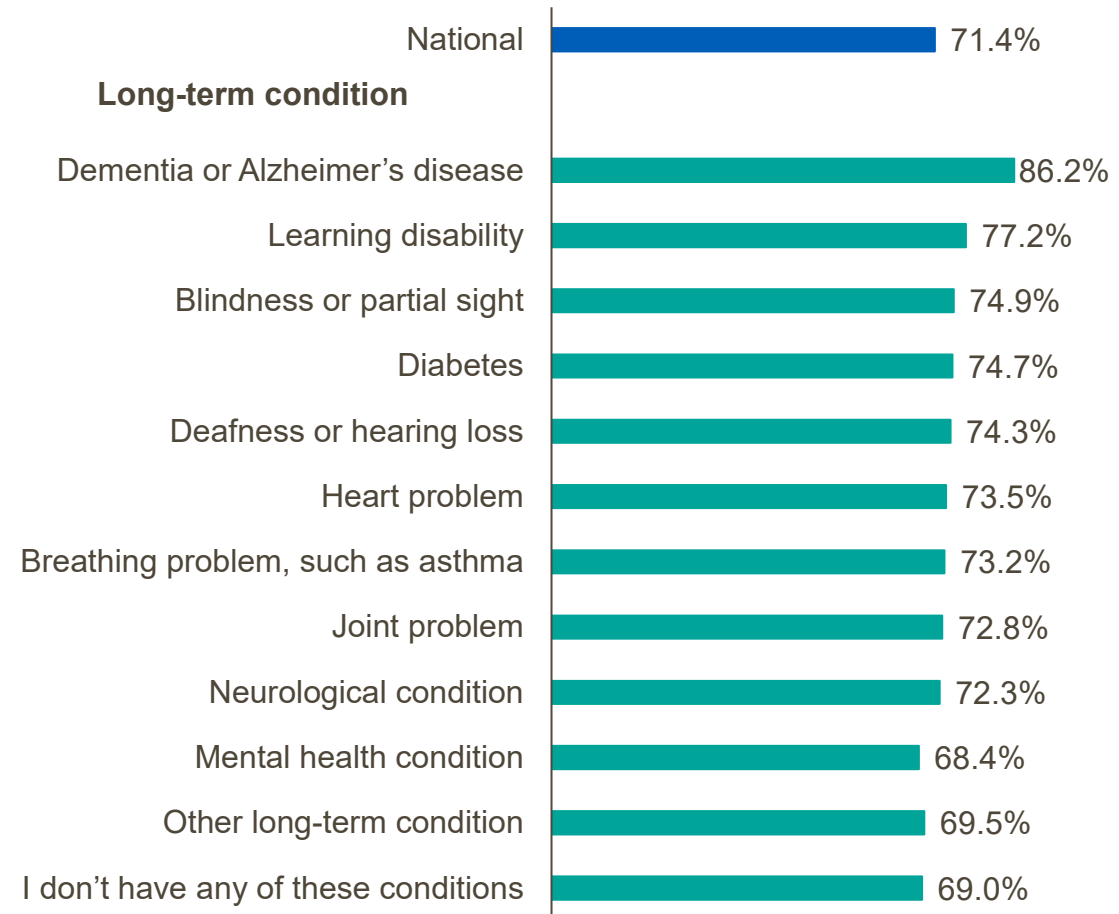
Long-term condition

Respondents with **dementia or Alzheimer's disease** were the most likely to say that they had been given the option of having a family member, carer or friend with them. Respondents with a **mental health condition** were the least likely to say they had been given the option (Q12).

Age

Respondents in the **16-24** age group were the most likely to say that they had been given the option of having a family member, carer or friend with them. The **35-44** age group were the least likely to say this was the case (Q12).

% who said that when they were first told that they had cancer they had been given the option of having a family member, carer or friend with them (Q12).
National base = 54,192.



9

Support from a main contact person

If we remove the people who didn't know or couldn't remember, nine out of ten respondents (91.9%) said they had a main contact person within the team looking after them who would support them through treatment, with 84.0%¹ saying that this person was a specialist nurse (Q17).

Of these respondents, 85.0% said it was 'very' or 'quite easy' to contact their main contact person (Q18). And 95.8% said that they found the advice from their main contact person to be 'very' or 'quite helpful' (Q19).

Age

Respondents in the **16-24** age group were the most likely to say it was 'very' or 'quite easy' to contact their main contact person. Respondents in the **25-34** age group were the least likely to say this was the case (Q18).

Ethnicity

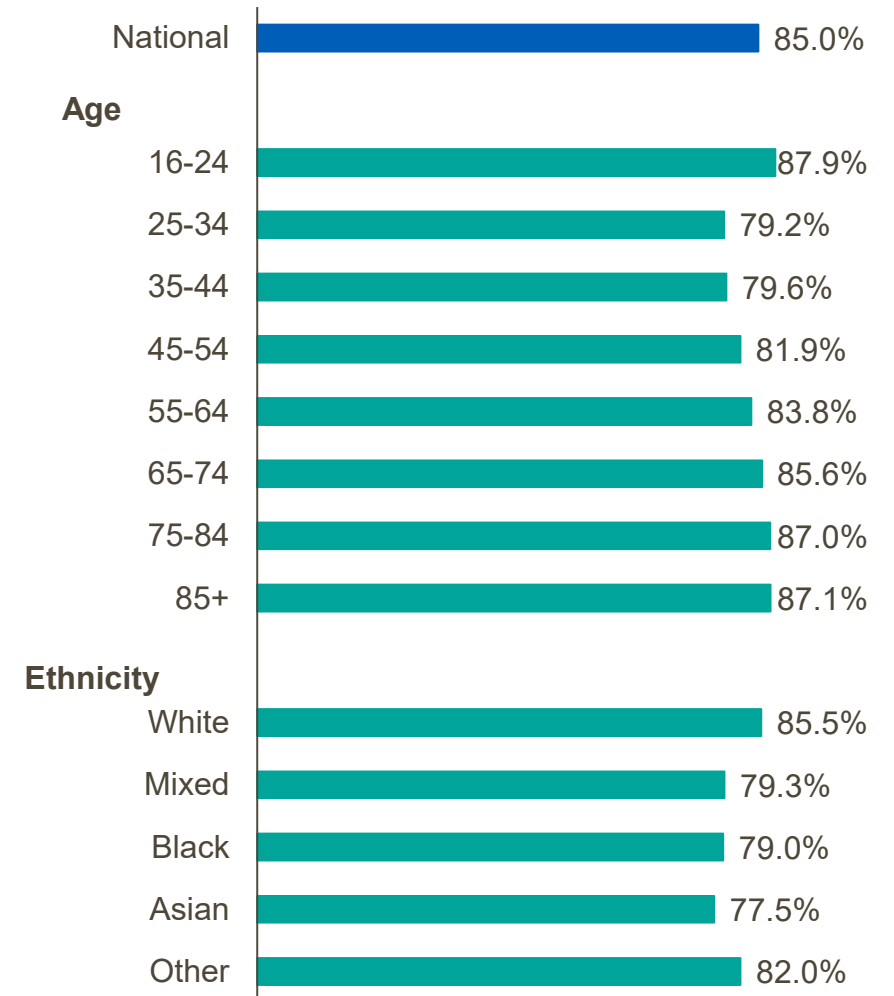
Respondents from **white** ethnic backgrounds were the most likely to say it was 'very' or 'quite easy' to contact their main contact person. Respondents from **Asian** ethnic backgrounds were the least likely to say it was 'very' or 'quite easy' to contact their main contact person (Q18).

Tumour group

Respondents in the **head and neck** tumour group were the most likely to say it was 'very' or 'quite easy' to contact their main contact person (88.3%) (Q18).

Respondents in the **prostate** tumour group were the least likely to say this was the case (81.6%) (Q18).

% who said it was 'very' or 'quite easy' to contact their main contact person (Q18). National base = 47,829.



¹ This percentage does not match that shown in the national Excel data tables, as the more detailed results also show the percentage who didn't know or couldn't remember, and are therefore calculated using a slightly larger denominator.

10

Deciding on the best treatment

82.2% of respondents said their treatment options were completely explained to them in a way they could understand before their cancer treatment started (Q20).

When respondents were asked if they were involved as much as they wanted to be in decisions about treatment options, 79.2% said 'yes definitely' (Q21). And three quarters of respondents (74.7%) said that their family and/or carers were able to be involved in decisions about their treatment options (Q22).

Just over a half of all respondents (52.4%) said that they could get further advice or a second opinion before making decisions about their treatment options (Q23).

Tumour group

Respondents in the [skin](#) tumour group were the most likely to say they were definitely involved as much as they wanted to be in decisions about their treatment. Respondents in the [brain / CNS](#) tumour group were the least likely to say this was the case (Q21).

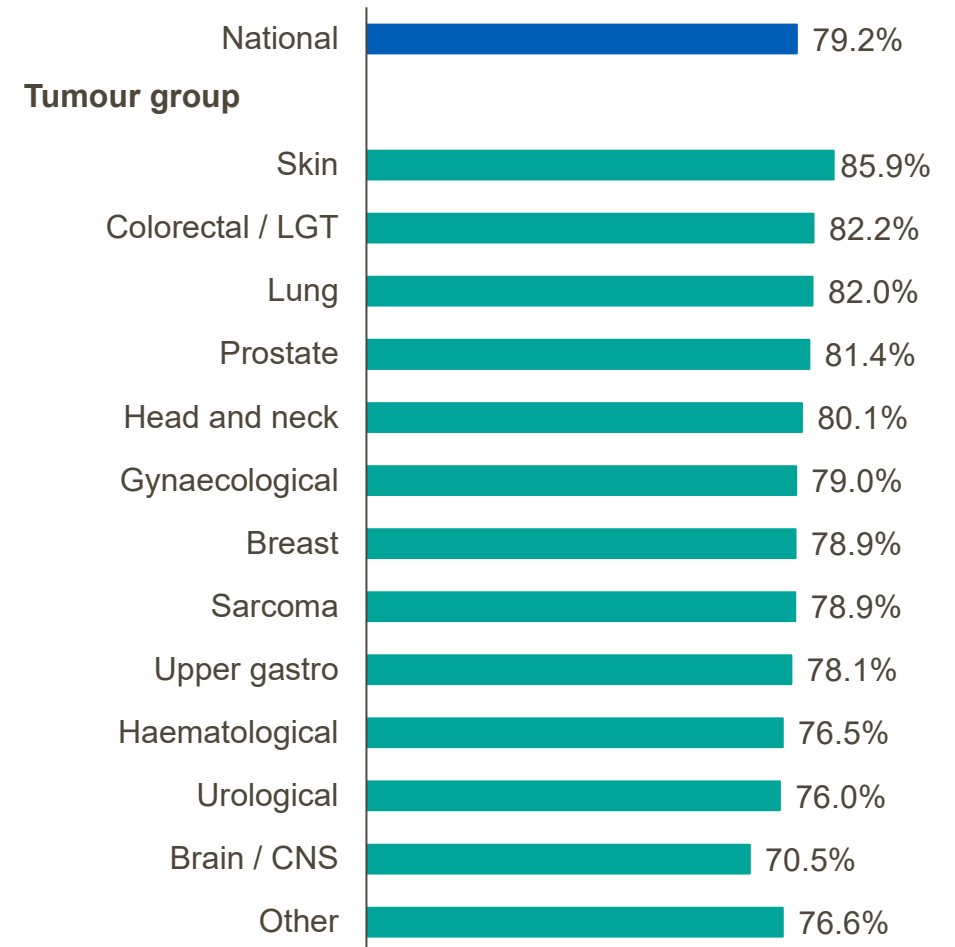
Age

Respondents in the [75-84](#) age group were the most likely to say they were involved as much as they wanted to be in decisions about their treatment (81.4%). Respondents in the [35-44](#) age group were the least likely to say this was the case (68.3%) (Q21).

Ethnicity

Respondents from [white](#) ethnic backgrounds were the most likely to say they were involved as much as they wanted to be in decisions about their treatment (79.7%). Respondents from [black](#) ethnic backgrounds were the least likely to say this was the case (70.9%) (Q21).

% who said they were definitely involved as much as they wanted to be in decisions about their treatment (Q21).
National base = 57,857.



11

Care planning

Respondents were asked questions about how they were supported during their cancer care.

71.7% said that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24).

Of those who had a discussion about needs and concerns, 93.1% said that their care team had helped them to create a care plan to address these (Q25).

And 98.7% said a member of the team looking after them reviewed the plan with them to make sure it continued to reflect their needs or concerns (Q26).

Age

Respondents in the [35-44](#) age group were the least likely to say that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24).

Gender

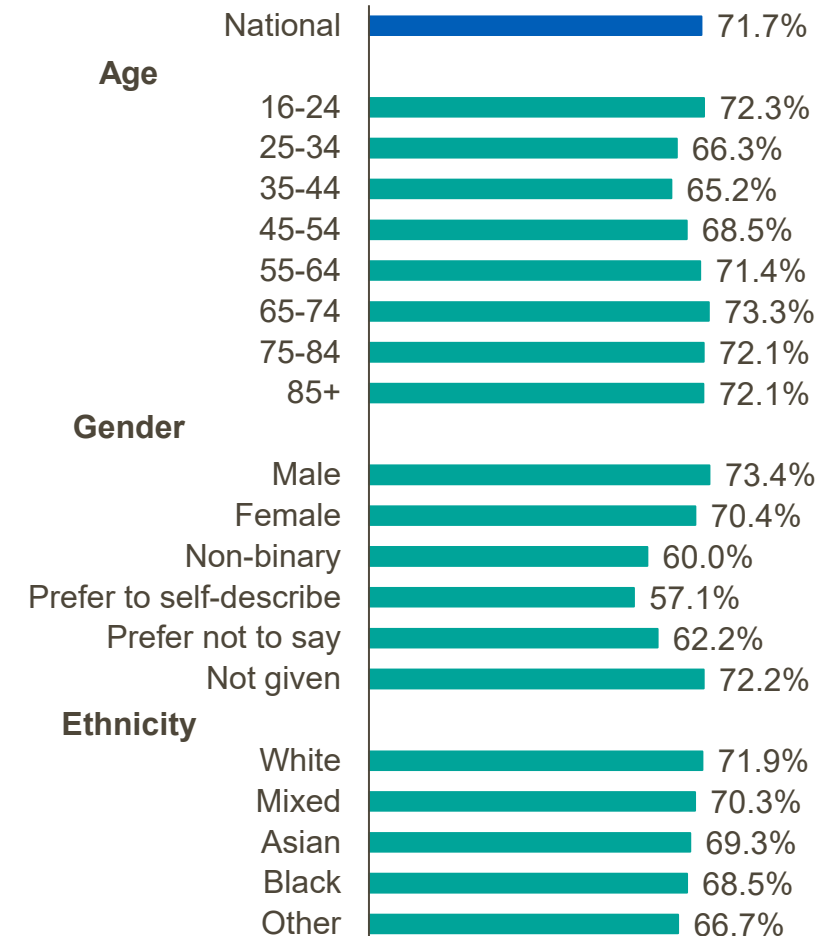
[Males](#) were the most likely to say that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24).

Ethnicity

Respondents in the [other*](#) ethnic group were the least likely to say that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24).

*Respondents from an Arab ethnic background or any other ethnic group not listed as a response in Q71.

% who said that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24). National base = 52,509.



12

Support from hospital staff

89.6% of respondents said hospital staff gave them information that was relevant to them about support or self help groups, events or resources for people with cancer (Q27).

When asked whether they got the right amount of support with their overall health and wellbeing from hospital staff, three quarters of respondents (75.7%) said this was definitely the case (Q28).

And when asked whether or not hospital staff gave them information about how to get financial help or any benefits they might be entitled to, 69.4% of respondents who needed this information said 'yes' (Q29).

Age

Respondents in the in the **75-84** age group were the most likely to say they definitely got the right level of support for their overall health and wellbeing from hospital staff. Respondents in the **35-44** age group were the least likely to say this was the case (Q28).

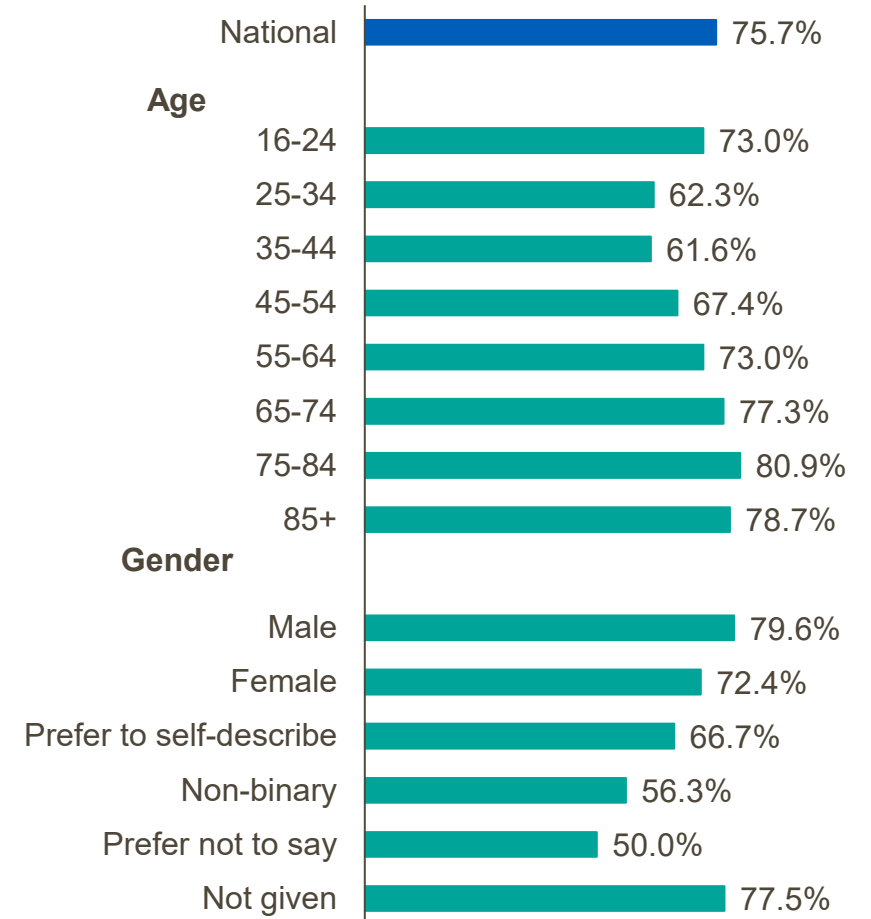
Gender

Males were the most likely to say they definitely got the right level of support for their overall health and wellbeing from hospital staff. Respondents who **preferred not to say** were the least likely (Q28).

Long-term condition

Respondents **without a long-term condition** were the most likely to say they definitely got the right level of support for their overall health and wellbeing from hospital staff (77.5%). Respondents with a **mental health condition** were the least likely to say this was the case (62.8%) (Q28).

% who said they definitely got the right level of support for their overall health and wellbeing from hospital staff (Q28). National base = 58,018.



13

Hospital care

Of those who had stayed overnight for cancer care in the 12 months prior to receiving the questionnaire (n= 26,865), 80.9% said they had confidence and trust in all of the team looking after them (Q31).

Six out of ten (60.6%) respondents who had stayed overnight said family or someone else close to them were definitely able to talk to someone on the team looking after them if they wanted to (Q32).

70.3% of respondents said they always felt involved in decisions about their own care and treatment whilst in hospital (Q33).

76.2% said they could always get help from hospital staff when they needed it (Q34).

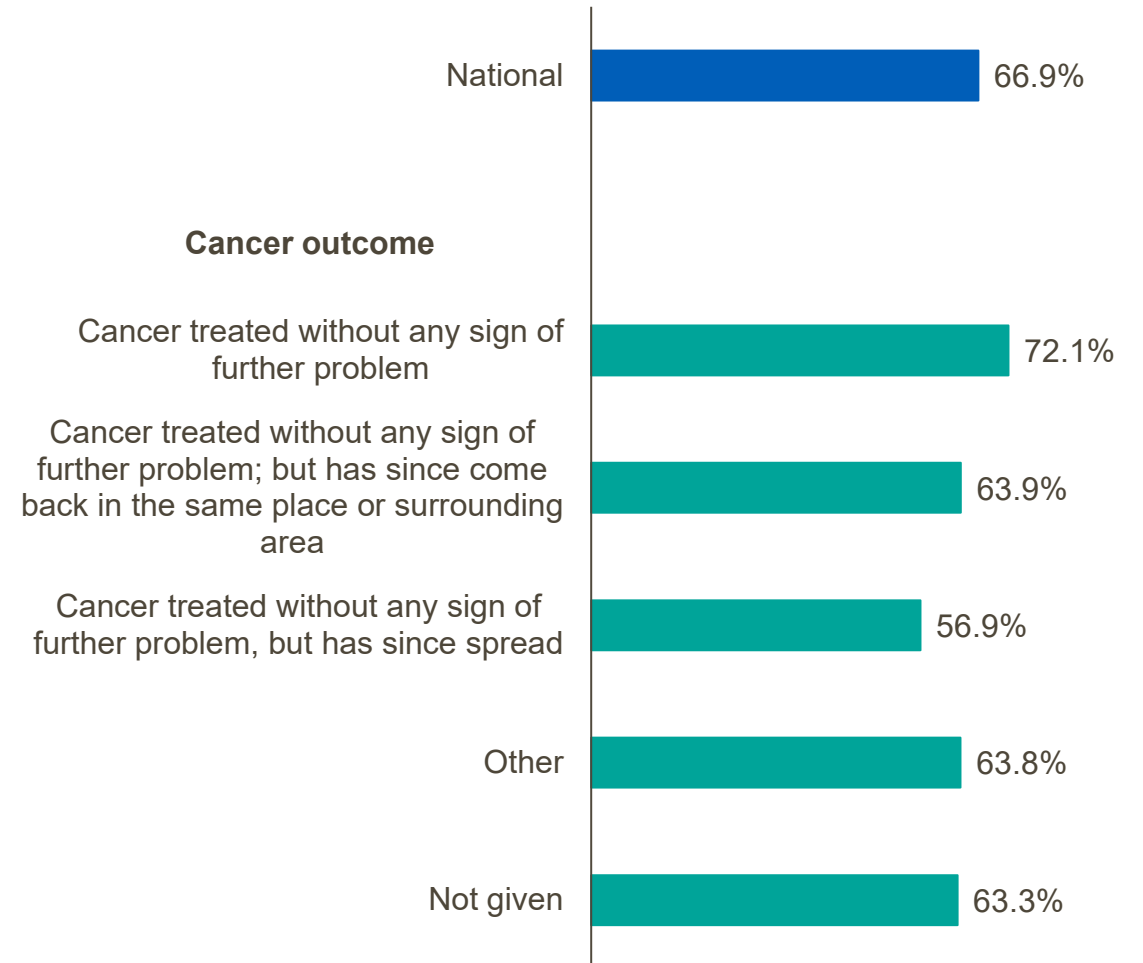
During their hospital stay, 66.9% of respondents said they could always talk to the hospital staff about their worries and fears if they needed to (Q35).

Cancer outcome

Respondents [whose cancer was treated without any sign of further problem](#) were more likely to say they could always talk to the hospital staff about their worries and fears if they needed to (Q35).

Respondents [whose cancer was treated without any sign of further problem, but has since spread](#) were the least likely to say they could always talk to the hospital staff about their worries and fears if they needed to (Q35).

% who said they could always talk to the hospital staff about their worries and fears if they needed to (Q35). National base = 25,566.



When asked 'Did the hospital staff do everything you wanted to help control your pain?', 85.9% of respondents said this was definitely the case (Q36).

89.2% of respondents felt that they were always treated with respect and dignity while they were in the hospital (Q37).

When asked whether they were given clear written information about what they should or should not do after leaving hospital, 88.5% of respondents felt they were and that this information was easy to understand (Q38).

Respondents were also asked to think about outpatient or day case appointments. Those that had been treated as an outpatient or day case were asked if they were able to talk to hospital staff about their worries or fears if they needed to. 78.3% said 'yes this was always the case' (Q39).

Ethnicity

The **other*** ethnic group were the most likely to say they were always treated with respect and dignity while they were in the hospital.

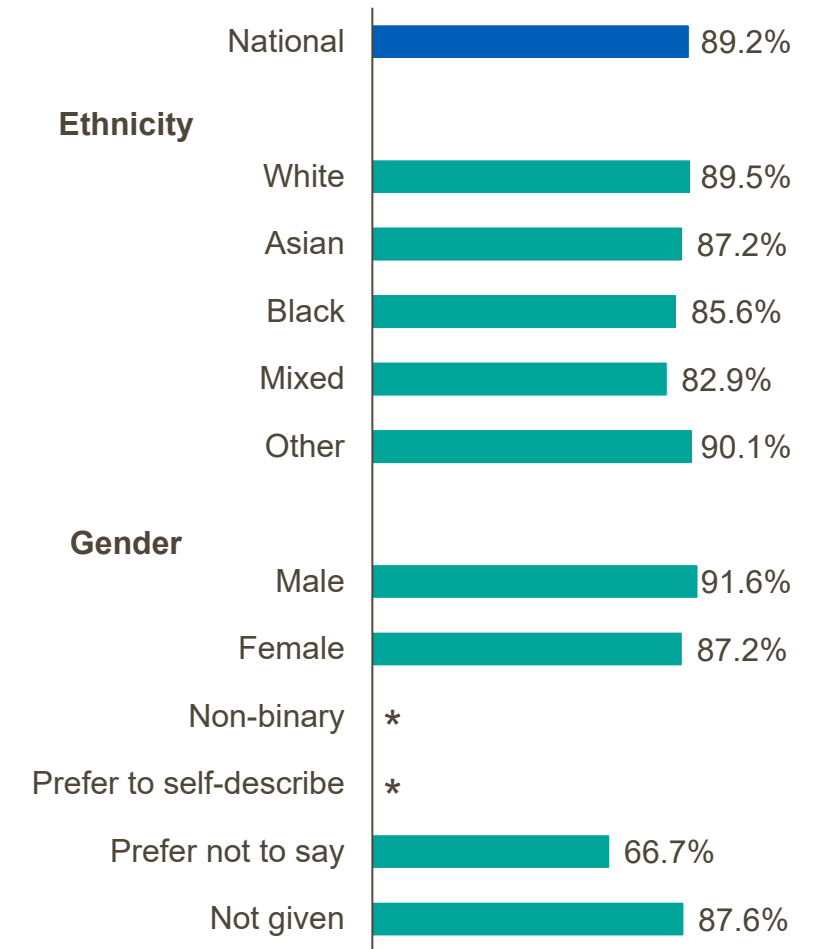
Respondents from a **mixed** ethnic background were the least likely to say this was the case (Q37).

Gender

Males were the most likely to say they were always treated with respect and dignity while they were in the hospital. Respondents who **preferred not to say** were the least likely (Q37).

*Respondents from an Arab ethnic background or any other ethnic group not listed as a response in Q71.

% who said they felt that they were always treated with respect and dignity while they were in the hospital (Q37). National base = 26,631.



* Score suppressed due to a low base size

14

Your treatment

Less than half of all respondents (44.1%) said cancer research opportunities were discussed with them (Q58).

79.1% of respondents felt the length of waiting time at the clinic or day unit for cancer treatment was about right (Q43).

Tumour group

Respondents in the [prostate](#) tumour group were the most likely to say the length of waiting time at the clinic or day unit used for cancer treatment was about right (Q43).

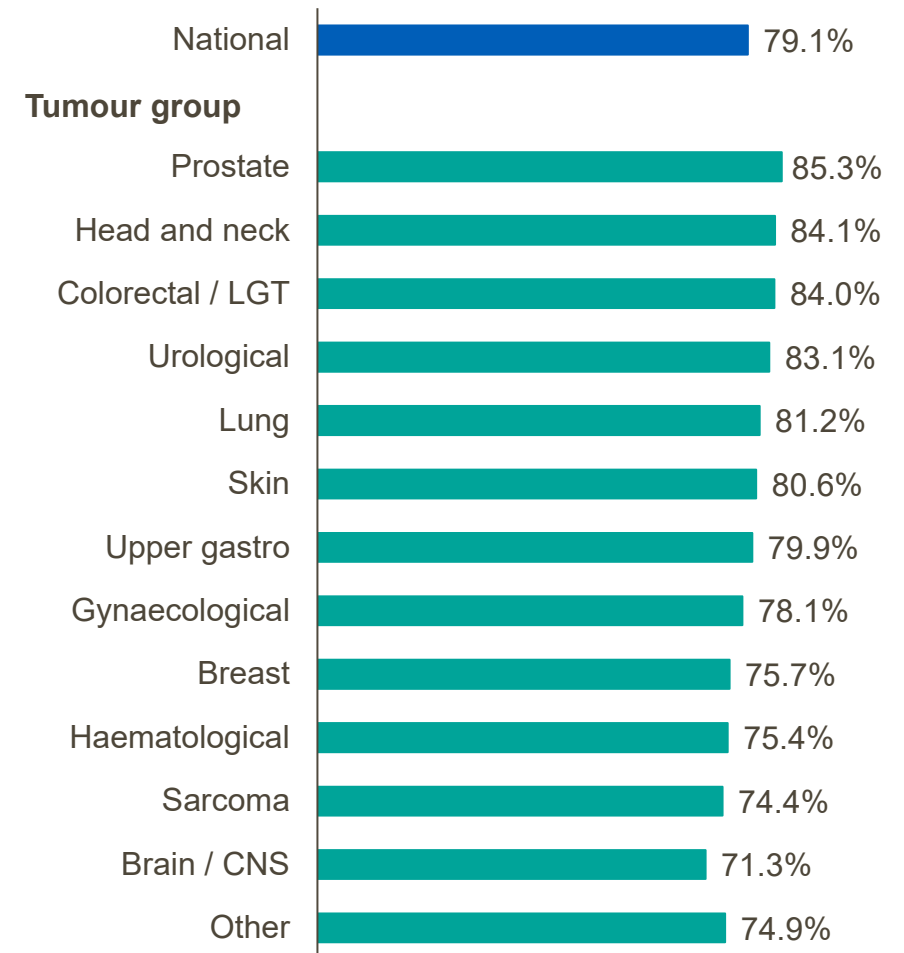
Respondents in the [brain / CNS](#) tumour group were the least likely to say this was the case (Q43).

Age

Respondents in the [85+](#) age group were the most likely to say the length of waiting time at the clinic or day unit used for cancer treatment was about right (81.8%) (Q43).

Respondents in the [16-24](#) age group were the least likely to say this was the case (57.3%) (Q43).

% who said they felt the length of waiting time at the clinic or day unit used for cancer treatment was about right (Q43). National base = 57,067.



Before treatment

Of those who had **surgery** (n = 33,208), 89.4% said that before their treatment had started they had the information they needed in a way they could understand (Q41_1).

Of those who had **chemotherapy** (n = 29,585), 85.0% said that before their treatment had started they had the information they needed in a way they could understand (Q41_2).

Of those who had **radiotherapy** (n = 18,253), 87.7% said that before their treatment had started they had the information they needed in a way they could understand (Q41_3).

Of those who had **hormone therapy** (n = 10,232), 78.4% said that before their treatment had started they had the information they needed in a way they could understand (Q41_4).

Of those who had **immunotherapy** (n = 7,802), 82.7% said that before their treatment had started they had the information they needed in a way they could understand (Q41_5).

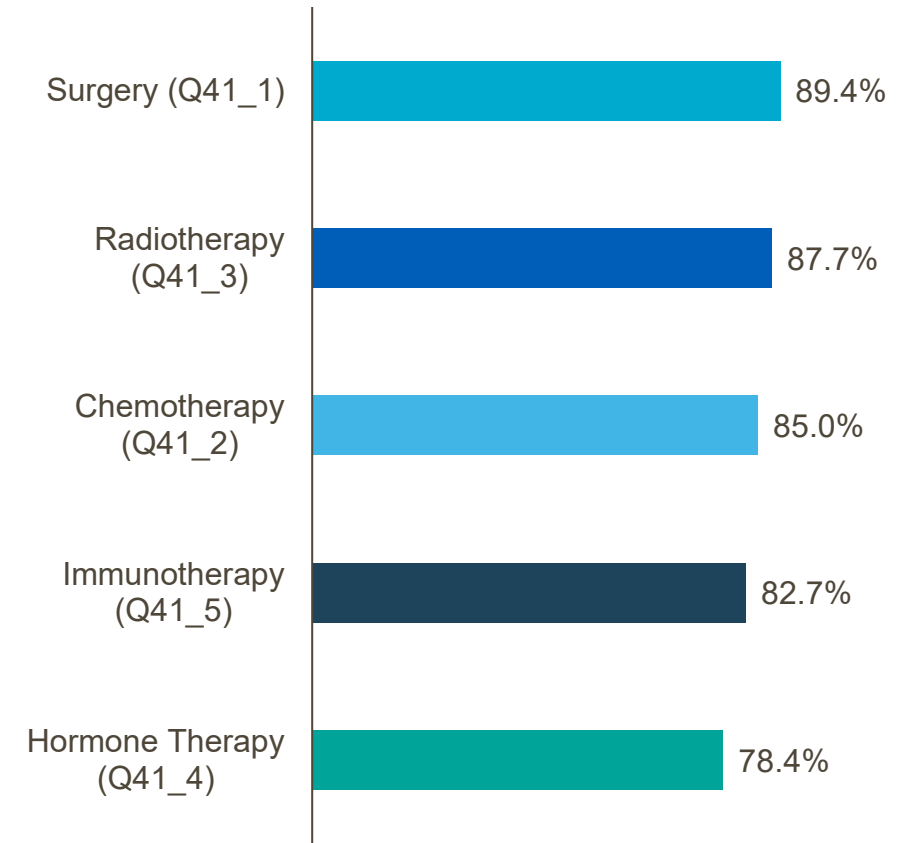
Hormone therapy

Gender

Males were the most likely to say that before their hormone therapy had started they had all the information they needed in a way they could understand (82.8%).

Females were the least likely to say this was the case (76.3%) (Q41_4).

% who said that before their treatment had started they had all the information they needed in a way they could understand



During treatment

Of those who had **surgery** (n = 33,208), 84.7% said that once their treatment had started they were given enough information about their progress in a way they could understand (Q42_1).

Of those who had **chemotherapy** (n = 29,585), 78.6% said that once their treatment had started they were given enough information about their progress in a way they could understand (Q42_2).

Of those who had **radiotherapy** (n = 18,253), 79.6% said that once their treatment had started they were given enough information about their progress in a way they could understand (Q42_3).

Of those who had **hormone therapy** (n = 10,232), 72.0% said that once their treatment had started they were given enough information about progress in a way they could understand (Q42_4).

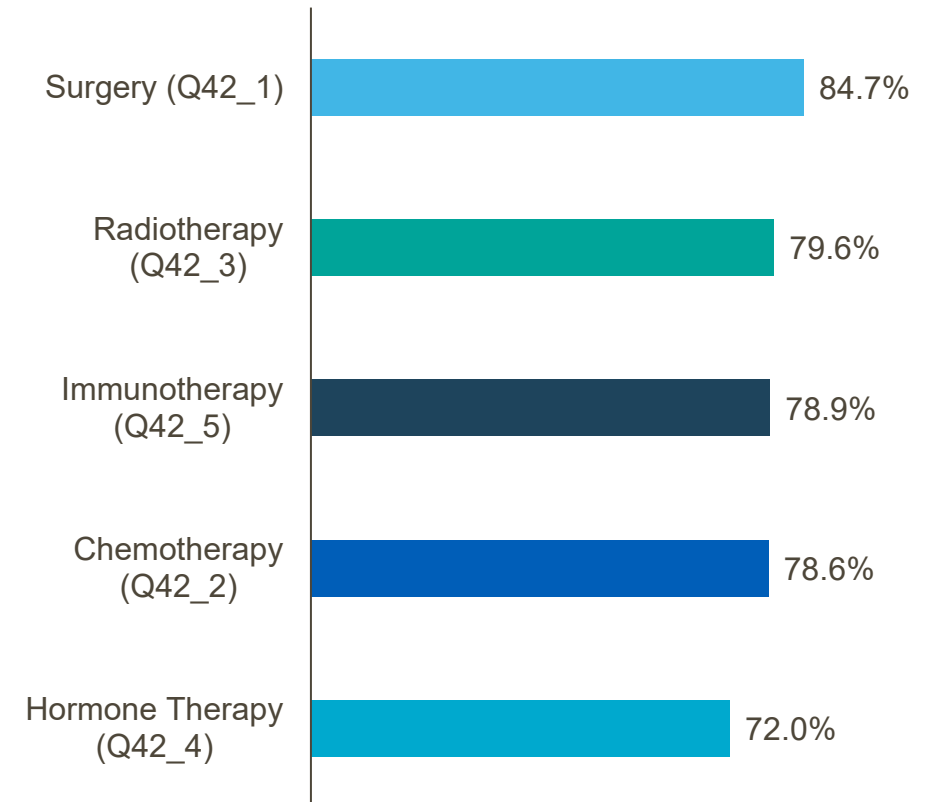
Of those who had **immunotherapy** (n = 7,802), 78.9% said that once their treatment had started they were given enough information about progress in a way they could understand (Q42_5).

Surgery

Spread of cancer

Respondents who said their **cancer had not spread to other organs or parts of their body** at time of diagnosis were more likely than respondents whose **cancer had spread** to say that they were given enough information about their progress in a way they could understand (86.1% and 83.0% respectively) (Q42_1).

% who said that during their treatment they had been given enough information about their progress in a way they could understand



15

Immediate and long term side effects

Overall, 74.3% of respondents said that before they started their treatment(s), the possible side effects of the treatment(s) were definitely explained in a way they could understand (Q44).

When asked if they were offered practical advice and support in dealing with the immediate side effects of their treatment(s), 69.9% said they 'always were' (Q45).

85.8% said they were given information that they could access about support in dealing with immediate side effects from treatment (Q46).

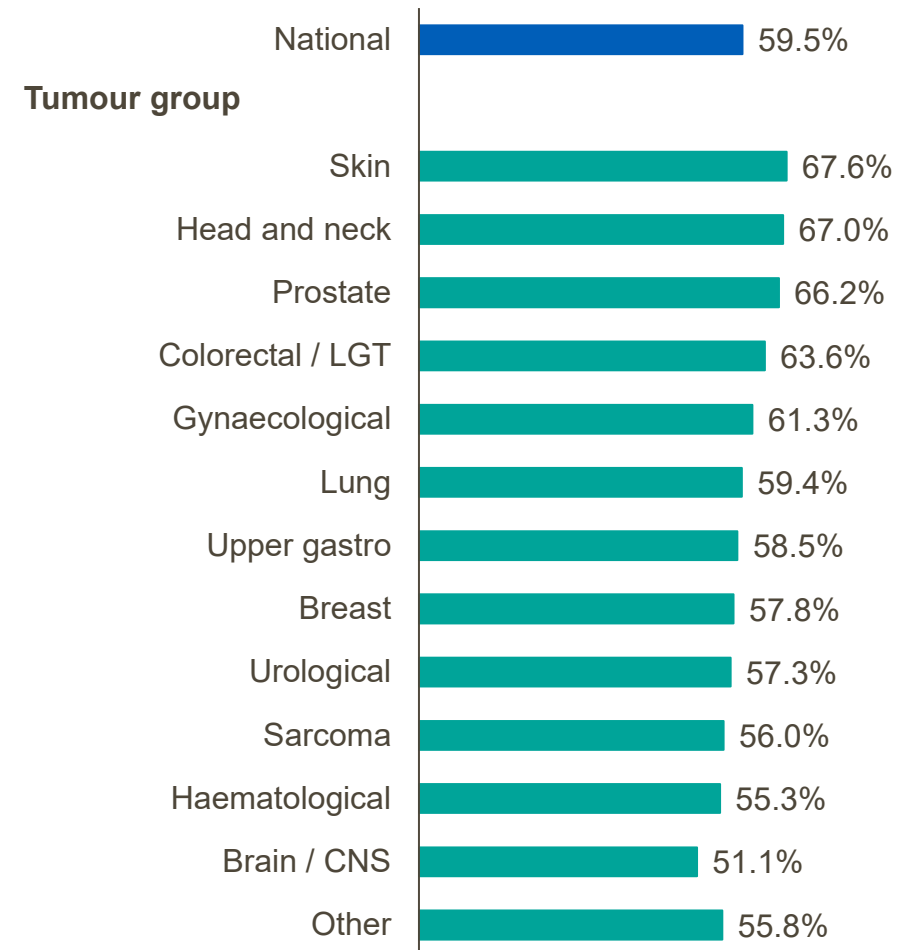
59.5% said the possible long-term side effects, including the impact on their day-to-day activities, were definitely explained in a way they could understand (Q47). 53.6% said they were definitely able to discuss options for managing the impact of any long-term side effects (Q48).

Tumour group

Respondents in the [skin](#) tumour group were the most likely to say possible long-term side effects were definitely explained in a way they could understand in advance of their treatment (Q47).

Respondents in the [brain / CNS](#) tumour group were the least likely to say long-term side effects were definitely explained in a way they could understand in advance of their treatment (Q47).

**% who said possible long-term side effects were definitely explained in a way they could understand in advance of their treatment (Q47).
National base = 52,135.**



16

Support while at home

Respondents were asked two questions about the support they were given while at home.

55.4% said their family or someone else close to them were given all the information they needed to help care for them at home (Q49).

When asked if during their cancer treatment they could get enough care and support at home from community or voluntary services, 51.5% of respondents said 'yes definitely' (Q50).

Long-term condition

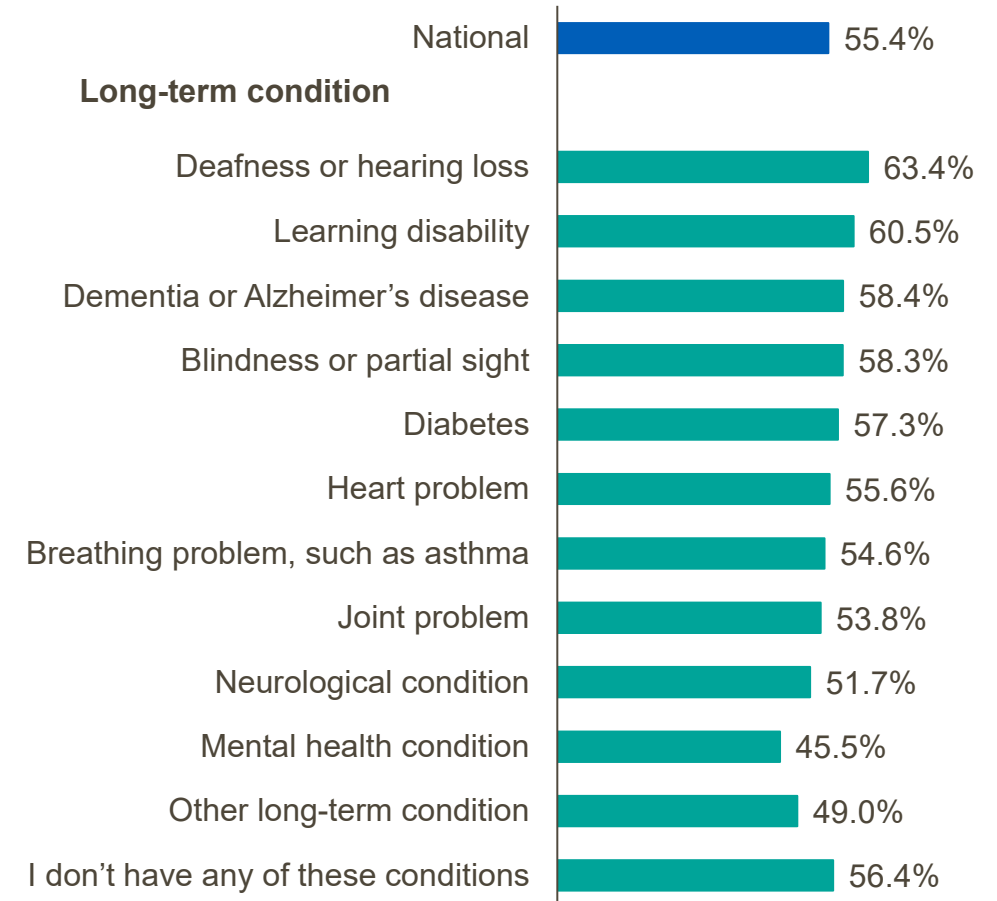
Respondents with a [mental health condition](#) were the least likely to say their family or someone else close to them were given all the information they needed from the team looking after them to help care for them at home (Q49).

Tumour group

Respondents in the [head and neck](#) tumour group were the most likely to say their family or someone else close to them were given all the information they needed from the team looking after them to help care for them at home (65.9%).

Respondents in the [breast](#) tumour group were the least likely to say their family or someone else close to them were given all the information they needed from the team looking after them to help care for them at home (48.2%) (Q49).

% who said their family or someone else close to them were given all the information they needed from the team looking after them to help care for them at home (Q49). National base = 37,985.



17

Care from your GP practice

Respondents were asked if they got the right amount of support from staff at their GP practice while they were having cancer treatment. Of those that said their GP practice was involved in their cancer treatment, 43.7% said this was definitely the case (Q51).

18.0% of all respondents said they had a review of their cancer care by a member of staff at their GP practice (Q52).

IMD quintile

Respondents in the **least deprived** group were the most likely to say they got the right amount of support from staff at their GP practice while they were having cancer treatment.

Respondents in the **most deprived** group were the least likely to say that they got the right amount of support (Q51).

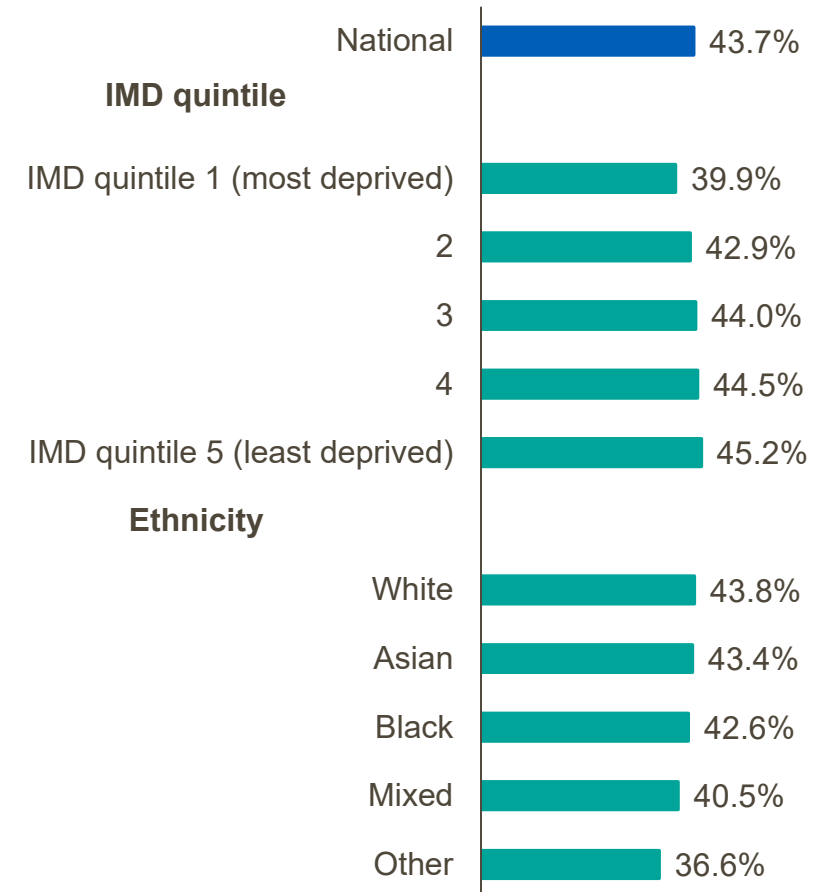
Ethnicity

Respondents from **white** ethnic backgrounds were the most likely to say that they got the right amount of support from staff at their GP practice while they were having cancer treatment.

The **other*** ethnic group were the least likely to say this was the case (Q51).

*Respondents from an Arab ethnic background or any other ethnic group not listed as a response in Q71.

**% who said they definitely received the right amount of support from their GP practice during treatment (Q51).
National base = 32,287.**



18

Living with and beyond cancer

Respondents were asked whether once their cancer treatment had finished, they could get emotional support at home from community or voluntary services. 31.8% of respondents that needed care and support said this was definitely the case (Q53).

Respondents were also asked if during the time between their final treatment and their first follow-up appointment, they were provided information and support that was right for them. 78.1% said this was the case (Q54).

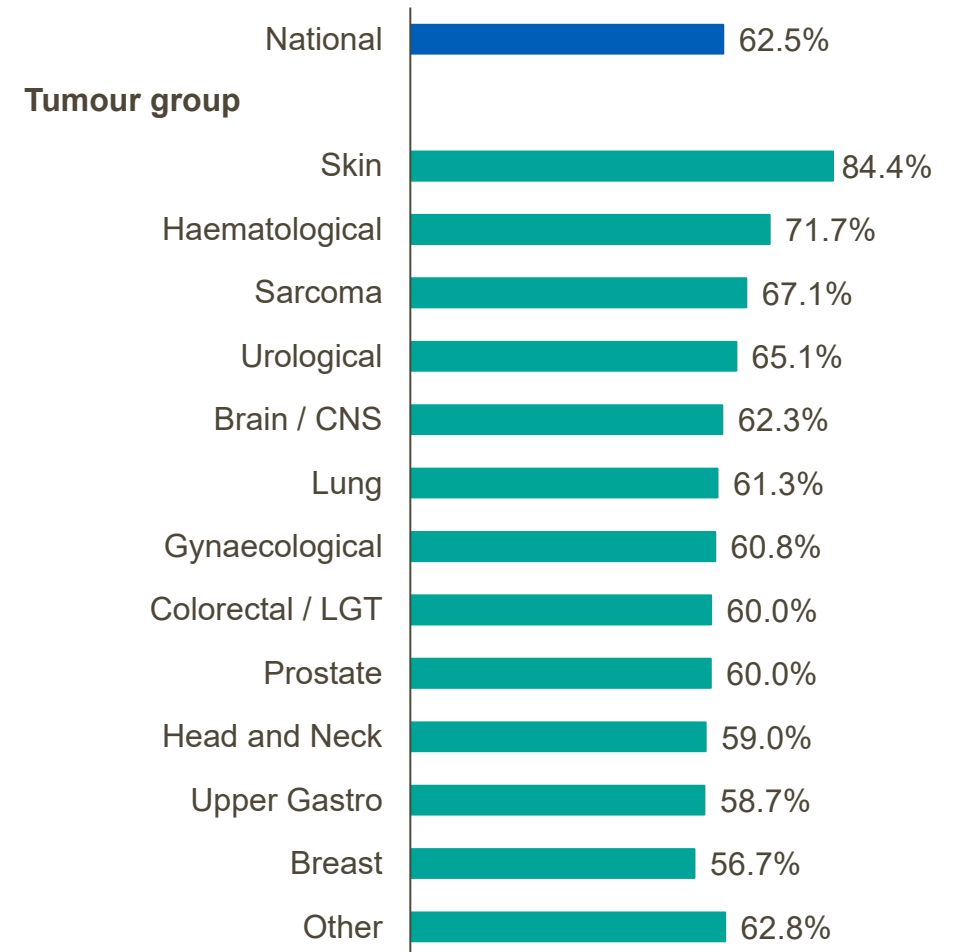
62.5% said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns (Q55).

Tumour group

Respondents in the [skin](#) tumour group were the most likely to say they were given enough information about the possibility and signs of cancer coming back or spreading (Q55).

Respondents in the [breast](#) tumour group were the least likely to say they were given enough information about the possibility and signs of cancer coming back or spreading (Q55).

% who said they were given enough information about the possibility and signs of cancer coming back or spreading (Q55). National base = 46,066.



Further information

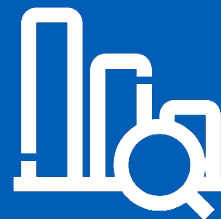
This research was carried out in accordance with the international standard for organisations conducting social research (accreditation to ISO20252:2012; certificate number GB08/74322). The 2021 survey data has been produced and published in line with the Code of Practice for Official Statistics.

For more information on the methodology and for all other outputs at national, trust, ICS and cancer alliance level, please see the PDF reports, Excel tables and dashboards at www.ncpes.co.uk.

For frequently asked questions (FAQs) about the survey, go to www.ncpes.co.uk/faq/.



This report sets out the national headline findings. Detailed national, alliance, system-level and trust-level results are available at www.ncpes.co.uk



An interactive reporting tool allowing you to explore the survey data by sub-group (e.g. by tumour group, ethnicity, age and more) is available at www.ncpes.co.uk/interactive-results