



Scottish Cancer Patient Experience Survey 2015/16



Contents

Contents	2
Foreword	5
Executive Summary	6
Introduction	6
High overall rating.....	6
Importance of care plan	6
Clinical nurse specialist	6
Staff	7
Diagnosis	7
Information provided to patients on treatment.....	7
Non-clinical information provision	8
Care coordination and administration.....	8
Communication and support for side effects of treatment.....	8
Patients' worries and fears	8
Home care and support	9
Impact of deprivation	9
Tumour type variations	9
Introduction.....	10
The Scottish Care Experience Programme	11
Aims of the Cancer Patient Experience Survey.....	11
Survey design.....	12
Sample.....	12
Questionnaire	12
Survey fieldwork and response.....	13
Age and gender of respondents	13
Tumour group of respondents	13
Data analysis and interpretation	14
Results for tumour type and for level of deprivation	14
Results for Regional Cancer Networks, NHS Boards, and Cancer Centres	14
Analysis of survey comments	14
Cancer Patient Experience Surveys in other parts of the UK.....	15
Seeing the GP	16
Wait before seeing a GP or other doctor for the first time	16
Route to first hospital visit.....	17

Patients referred to hospital by GP	17
Going to hospital following a screening appointment	18
Going to hospital directly	18
Patients' feelings regarding their wait before seeing hospital doctor	19
Diagnostic tests	21
Information about the test	21
Time waiting for diagnostic test to be done	23
Understanding the test results	24
Finding out what was wrong	25
Bringing a friend or family member	25
Sensitivity of cancer diagnosis	26
Understanding cancer diagnosis	27
Written information following diagnosis	28
Deciding the best treatment	30
Treatment options	30
Involvement in decisions about care and treatment	31
Side effects of treatments	31
Immediate side effects	31
Future side effects	32
Practical advice and support for dealing with side effects	34
Clinical Nurse Specialist	35
Ease of contacting Clinical Nurse Specialist	36
Questions for Clinical Nurse Specialist	37
Support for people with cancer	39
Information about support or self-help groups	39
Information on impact of cancer on day to day activities	40
Information on financial help and benefits	41
Operations	43
Information before the operation	43
Information after the operation	44
Hospital care as an inpatient	46
Hospital doctors	46
Confidence in hospital doctors	46
Family access to doctor	47
Hospital nurses	47
Confidence in hospital nurses	47

Enough nurses on duty	48
Hospital Doctors and Nurses	49
Doctors and nurses talking as if patient wasn't there	49
Doctors and nurses using patient's preferred name	50
Privacy when discussing care and treatment	51
Worries and fears	52
Pain control.....	53
Respect and dignity	53
Leaving hospital.....	54
Information about what do after leaving hospital	54
Who to contact after leaving hospital.....	55
Hospital care as day patient/outpatient.....	57
Worries or fears as outpatient/ day patient.....	57
Right documents available for outpatient appointment.....	58
Radiotherapy and Chemotherapy	60
Radiotherapy	60
Chemotherapy	62
Home Care and Support	64
Information to family and friends to help care for patient at home	64
Support from health and social services during treatment	65
Support from health and social services after treatment	66
Care from GP practice.....	68
GP receiving information about hospital treatment.....	68
Support from GP practice during cancer treatment	68
Overall NHS Care	70
Different practitioners working together	70
Cancer research	70
Administration of care	71
Waits when attending clinics and appointments.....	72
Care plan	73
Overall rating of care	75
Differences in experiences between most and least deprived areas	76
Annex A: Survey questionnaire	78
Annex B: Significance testing.....	90
Annex C: Guide to positive scoring.....	92

Foreword

The Scottish Government and Macmillan Cancer Support are pleased to report the results of the first Scottish Cancer Patient Experience Survey.

This survey, which was jointly funded by the Scottish Government and Macmillan Cancer Support, asked people with cancer to provide feedback on their experience of the care that they received during the different stages of their cancer journey.

Around five thousand people responded to the survey, providing valuable information on all aspects of their cancer care – from presentation and diagnosis to the care they received after treatment. Some people may have received help from their family or friends in completing the survey and we wish to thank everyone who took the time to provide such helpful feedback.

The survey responses indicated that the vast majority of people (94%) say they had a good experience overall, 84% had access to a cancer nurse specialist and 87% felt that they were always treated with dignity and respect. This provides helpful reassurance that health and social care services are delivering high quality care across Scotland.

However, we cannot be complacent. The results found areas where improvements could be made, particularly around helping people access support for their wider emotional, financial and practical needs.

The results of the survey will help us better understand what is important to people with cancer as we work together to implement the Scottish Cancer Strategy.

Executive Summary

Introduction

Around 5,000 patients took part in Scotland's first cancer patient experience survey. The survey covered the care journey that a cancer patient experiences, from thinking that something might be wrong with them to the support they received after their acute-care treatment.

High overall rating

Overall perceptions of care were very positive – when asked to provide an overall rating of their care on a scale from 0 (very poor) to 10 (very good), 94 per cent of patients rated their care as '7' or higher.

Importance of care plan

Survey results highlighted the importance of patients having a care plan; **across all 50 questions** where responses could be classed as either positive or negative, patients who had a care plan responded statistically more positively than those that did not, including:

- the overall rating of care (98% positive among those who had a care plan vs 92% positive among those who did not)
- receiving enough care and support from health or social services after treatment (73% positive vs 34% positive)
- receiving information about how to get financial help and benefits (75% positive vs 42% positive)

These results are particularly notable given that only 22 per cent of patients in the survey reported being given a care plan.

Clinical nurse specialist

The survey also highlighted the role that clinical nurse specialists can play in providing information and signposting services:

- 84 per cent of patients reported that they had been provided with a clinical nurse specialist – the large majority of these patients reported that they had asked their clinical nurse specialist important questions
- Of these cases, 90 per cent received answers they could understand 'all' or 'most of the time'

Staff

Results on patient interactions with staff included:

- 87 per cent of patients felt that they were always treated with dignity and respect
- 86 per cent had confidence and trust in all the doctors treating them and 77 per cent had confidence and trust in all the nurses treating them

Seventy-two per cent of patients felt that there were 'always' or 'nearly always' enough nurses on duty to care for them. This is a more positive result than that received for the equivalent question in the 2014 Scottish Inpatient Experience Survey (64%), which covers patients with a range of conditions.

Diagnosis

There were mixed responses regarding patients' experience of their diagnosis:

- The majority of patients, 86 per cent, reported that they were told that they had cancer sensitively
- 28 per cent of patients were not told that they could bring a family member or friend with them when they were told they had cancer
- A quarter of patients (25%) did not fully understand the explanation of what was wrong with them
- 1 in 3 patients (33%) were not given written information about the type of cancer they had. Patients with certain cancers were significantly less likely to have received written information about their type of cancer following diagnosis

Information provided to patients on treatment

Patients reported inconsistencies in the provision of information and advice at different time points during their clinical care. For example:

- Patients were more positive about receiving information before an operation (93%) than they were about receiving information afterwards about how it had gone (80%)
- Patients were more positive about receiving information before radiotherapy and chemotherapy treatment (81% and 77% positive respectively) than they were about receiving information during the treatment as to how it was progressing (54% and 62% positive respectively).

Non-clinical information provision

Patients were generally less positive when asked about the information they had received from hospital staff that did not relate to clinical care:

- One in five (21%) patients who wanted it received no information regarding self-help or support groups
- One in four (23%) patients who wanted it received no information regarding the impact of cancer on their day to day activities
- Most strikingly however, almost half of patients (49%) who wanted it received no information on financial help or benefits.

Care coordination and administration

Patients were generally positive about the coordination and administration of their care:

- 90 per cent of patients considered that the administration of their care was 'very good' or 'good'
- 89 per cent of patients responded that different people treating them worked well together 'always' or 'most of the time'
- However, 43 per cent of patients' family or friends were not given all the information needed to help them care for the patient at home

There were also particularly positive results around record-keeping and professional communication:

- 98 per cent of patients responded positively to the survey question regarding whether the doctor had the right documents for their outpatient appointments
- and 96 per cent responded positively to the question regarding whether their GP received information about their treatment and condition from hospitals

Communication and support for side effects of treatment

- More than 1 in 4 (29%) patients reported not having the side effects of their treatment fully and clearly explained to them prior to starting the treatment
- Moreover, almost half (47%) were not fully informed about side effects that could affect them in the future, potentially after their treatment finished
- Almost 1 in 10 were offered no practical advice or support for coping with side effects

Patients' worries and fears

The majority of patients experienced worries and fears during their outpatient / daycase care (81%) and during inpatient stays (73%). Although worries were more common amongst outpatients, they were also more likely to find someone to talk to about them (69% of outpatients found someone to talk to vs 50% of inpatients).

Home care and support

Not all patients needed care and support at home, however amongst those that did:

- Only 54 per cent reported getting enough care and support from health and social services during their treatment
- While only 45 per cent reported receiving enough care and support after treatment

Impact of deprivation

Results for fourteen questions showed a statistical difference between respondents residing in the most deprived areas and those in the least deprived areas. Patients from the least deprived areas were more positive in their responses to 10 of these 14 questions; for example, respondents in the least deprived areas reported more positive experiences in receiving explanations in a way they could understand (3 questions in total).

Tumour type variations

Results show variation across tumour types – out of the 50 questions where responses could be classed as positive or negative, 36 showed significant differences across patients with certain cancer types. Colorectal / lower gastrointestinal patients were the most likely to report positive experiences, while urological cancer patients were the least likely to report positive experiences of their care.

Introduction

The Scottish Cancer Patient Experience Survey is a postal survey conducted in partnership by the Scottish Government and Macmillan Cancer Support. This is the first time the survey has been run in Scotland.

The survey was sent to cancer patients aged 16 or over that had an inpatient stay or hospital visit as a day case between January and September 2014 as well as a cancer diagnosis between July 2013 and March 2014.

The survey questionnaire is based on the questionnaire used for equivalent English Cancer Patient Experience Survey and covers:

- Referral to hospital by GP
- Diagnosis
- Decisions about treatment
- Role of the Clinical Nurse Specialist
- Support for people with cancer
- Hospital doctors and ward nurses
- Hospital care and treatment (including inpatient stays, day case or outpatient visits, and operations)
- Radiotherapy and Chemotherapy
- Home care and support
- Care from general practice
- Overall NHS care

The survey was carried out with the assistance of Information Services Division (ISD), part of NHS National Services Scotland, whose role included advising on survey methodology, sampling patients, producing national and local analysis and producing local level reports.

The administration of the survey fieldwork was undertaken by an approved survey contractor Quality Health Ltd.

This report presents the national findings from the survey. Detailed findings for individual Cancer Networks, NHS Boards, and Cancer Centres are available at:

www.gov.scot/cancersurvey

The Scottish Care Experience Programme

The Scottish Cancer Patient Experience Survey forms part of the Scottish Care Experience Survey Programme.

The Care Experience Surveys aim to provide local and national information on the quality of health and care services from the perspective of those using them. They allow local health and care providers to compare with other areas of Scotland and to track progress in improving the experiences of people.

The other regular national care experience surveys are:

[Inpatient Experience Survey](#)
[Health and Care Experience Survey](#)
[Maternity Care Experience Survey](#)

A one-off [Radiotherapy Survey](#) was also completed in 2014.

The survey programme supports the three quality ambitions of the 'Healthcare Quality Strategy for NHSScotland' (or Quality Strategy)¹ - Safe, Effective, Person-centred by providing a basis for the measurement of quality as experienced by service users across Scotland. In particular the surveys support the person-centred quality ambition which is focused on:

- Putting people at the centre of care,
- Ensuring that care that is responsive to individual personal preferences, needs and values,
- Assuring that individual values guide all care decisions.

Aims of the Cancer Patient Experience Survey

The survey's aims are to:

- Provide comparative feedback to Regional Cancer Networks, Cancer Centres and NHS Boards that will be used to highlight areas of best practice, and to indicate where improvement work might need to be considered.
- Explore if there are differences in experience of treatment between groups of cancer patients (for example different cancer types and level of deprivation).
- Allow assessment of change in cancer care experience over time.

With respondent consent and the necessary approvals, results from the survey can in future be linked to data from other health and social care datasets by NHS

¹ <http://www.gov.scot/Topics/Health/Policy/Quality-Strategy>

Scotland statisticians. This would provide further insight into patients' experience of their care and treatments and link these to outcomes.

Survey design

Sample

The sampling for the survey was carried out by ISD.

Direct sampling from the Scottish Cancer Registry (SMR6²) is not permitted for a postal survey of this sort. Therefore, the primary sampling frame was a national dataset containing records of acute hospital activity (SMR01³). This was used to identify adults (aged 16 years and over) with an inpatient or day case record with any mention of cancer during the period between 1st January 2014 and 30th September 2014.

In order to confirm the diagnosis of cancer and to minimise the risk of sending surveys to patients who did not have cancer, validation was completed using the Scottish Cancer Registry. The sample identified from the hospital records was checked to identify patients who had a Cancer Registry diagnosis date between 1st July 2013 and 31st March 2014 and who were alive at 31st July 2015. Patients sampled from SMR01 but not present in SMR6 were excluded from the sample.

The survey was sent to all patients successfully identified through the process above.

ISD also co-ordinated regular death checking against National Health Service Central Register (NHSCR) and English NHS Health & Social Care Information Centre (NHS HSCIC) records to reduce the risk of sending survey packs to deceased patients.

Questionnaire

The questionnaire (contained in Annex A) was developed and reviewed by a steering group comprising representatives from NHS Boards, ISD, the third sector, cancer patients and the Scottish Government.

The survey questionnaire is based on the most recent version of the questionnaire used in the equivalent English survey. The English questionnaire was revised for their survey this year and was very kindly shared with the steering group whilst under development.

Questions were added to the Scottish questionnaire to confirm the hospital in which the respondents' care took place. Additionally, freetext comment boxes were

² <http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=104>

³ <http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=2>

introduced throughout the questionnaire relating to specific sections of questions. This is in contrast to the typical approach of asking for general comments at the end of the questionnaire.

Survey fieldwork and response

Fieldwork was undertaken by Quality Health Ltd, an approved survey contractor on behalf of the Scottish Government and Macmillan Cancer Support between 7th October 2015 and 22nd January 2016.

In total, 7,949 valid survey packs were sent to patients and 4,835 were returned, giving an overall response rate of 61%.

Age and gender of respondents

Survey respondents were asked to provide demographic information. Of the patients that answered these questions:

- 43 per cent were male and 57 per cent were female
- 2 per cent were aged 16-34, 17 per cent were aged 35-54, 60 per cent were aged 55-74 and 22 per cent were aged 75 or over.

Tumour group of respondents

The number of survey responses from each tumour group is as below.

Table 1: Number of survey responses from each tumour group

Tumour group	Number of respondents
Brain / central nervous system	39
Breast	1187
Colorectal / lower gastrointestinal	721
Gynaecological	359
Haematological	379
Head and neck	264
Lung	292
Prostate	592
Sarcoma	34
Skin	129
Upper gastrointestinal	189
Urological	308
Other	13
Tumour group unknown	329
Total	4,835

Data analysis and interpretation

The survey data were collected by the contractor Quality Health Ltd. A pseudonymised dataset containing the survey responses was then securely transferred to ISD who carried out the analysis at a national and local level and produced reports at Cancer Network, NHS Board and Cancer Centre level.

When interpreting the results in this report please note that:

- Results in this publication and in the local reports have not been weighted.
- Unless stated, percentages in this report are calculated excluding any patients from the denominator who did not answer the question or answered “not relevant”, “don’t know”, or similar.
- Differences between tumour groups and the national average are only highlighted and discussed if they are statistically significant (see Annex B for details of significance testing used).
- Where there are fewer than 20 responses to a particular question from a tumour group, that tumour group has not been presented in the relevant chart
- Where analysis has been done to compare the percentage of patients responding positively, the guide in Annex C has been used to class responses as positive and negative for each question.

Results for tumour type and for level of deprivation

This report contains discussion of results for different tumour groups and differing levels of deprivation. Spreadsheets with these results breakdowns are available at:

www.gov.scot/cancersurvey

Results for Regional Cancer Networks, NHS Boards, and Cancer Centres

Reports have been produced for individual regional cancer networks, NHS Boards and Cancer Centres. These are also available at:

www.gov.scot/cancersurvey

Analysis of survey comments

In July this year, analysis of the freetext survey comments will be published at:

www.gov.scot/cancersurvey

Cancer Patient Experience Surveys in other parts of the UK

Cancer Patient Experience Surveys have previously been carried out in England, Northern Ireland, and Wales. Further information is available below:

England: <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

Northern Ireland: <https://www.quality-health.co.uk/surveys/northern-ireland-cancer-patient-experience-survey>

Wales: <https://www.quality-health.co.uk/surveys/welsh-cancer-patient-experience-survey>

Seeing the GP

The first questions in the survey seek to understand patients' experiences leading up to their first hospital visit for their cancer, which marks a key milestone in their cancer care.

Early diagnosis is a critical issue in Scotland, and is widely recognised as significant in improving people's chances of surviving cancer.

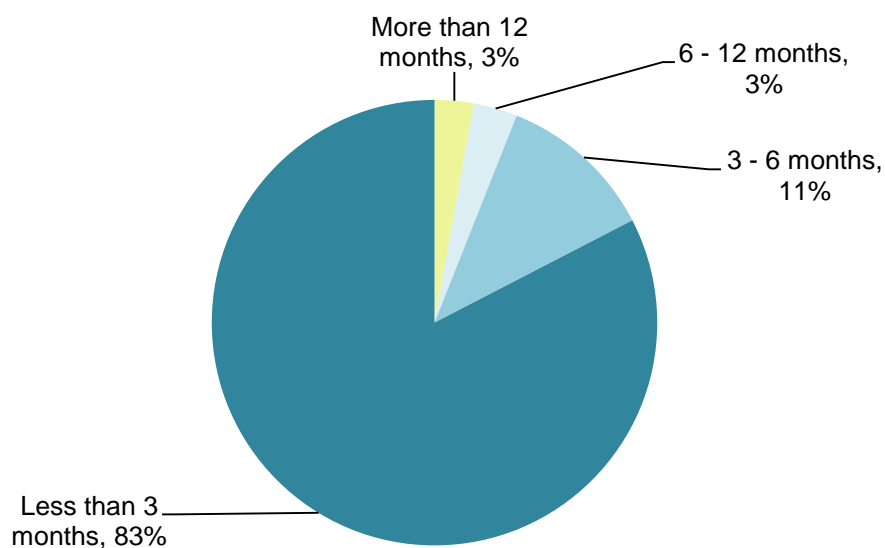
The impact of screening initiatives among certain cancers are reflected in the results, with breast cancer patients being the most likely to go to hospital following a screening appointment; conversely, those patients with brain/central nervous system and lung cancer – which can be more difficult to diagnose - are more likely to have gone directly to hospital without seeing their GP.

Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

Wait before seeing a GP or other doctor for the first time

Once patients first felt that something might be wrong, most cancer patients (83%) reported waiting less than three months before going to see their GP or another doctor about the problem. Six per cent of patients waited at least six months before seeing a doctor (Figure 1).

Figure 1: How long patient waited once first thinking something might be wrong before seeing a doctor



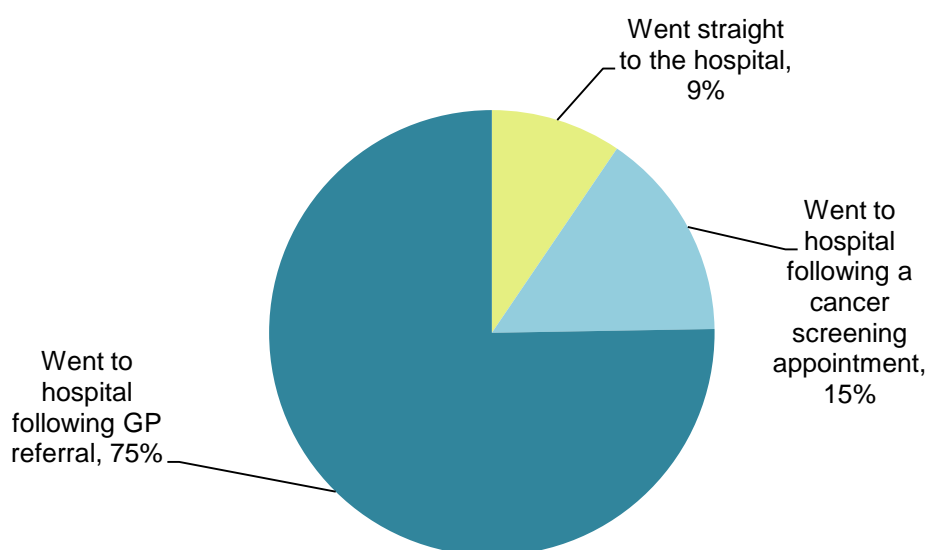
Amongst different tumour groups, those with breast tumours were the most likely to see a doctor within 3 months (89%). This was the only tumour group with a score statistically above the all-cancer average. Head and neck (76%), and prostate (77%) tumours were statistically below the all-cancer average.

Route to first hospital visit

Patients referred to hospital by GP

The majority of patients (75%) were referred on to hospital for their cancer by their GP (Figure 2).

Figure 2: Patient's route to first hospital visit



Of these patients, the majority (78%) reported seeing their GP only once or twice before being told that they needed to go to hospital. However, around one in five saw their GP 3 or more times before being referred to hospital (Table 2).

Table 2: Number of visits to GP before hospital

Before you were told you needed to go to hospital about cancer, how many times did you see your GP about the health problem caused by cancer?	n	%
I saw my GP once	1,921	57%
I saw my GP twice	708	21%
I saw my GP 3 or 4 times	463	14%
I saw my GP 5 or more times	293	9%
Total	3,385	100%

Patients from certain tumour groups tended to take longer to reach hospital once they had approached their GP. Patients in colorectal / lower gastrointestinal (71%), haematological (66%), lung (70%) and upper gastrointestinal (70%) tumour groups were all statistically less likely to be referred to hospital within two GP visits than the all-cancer average.

In contrast, patients with breast tumours (95%) and skin tumours (85%) were statistically above average. This may reflect relative difficulties in identifying some types of cancer.

Going to hospital following a screening appointment

Fifteen per cent of patients attended hospital following a screening appointment. The highest rates for this were observed amongst patients with breast (33%) and colorectal (23%) tumours.

Going to hospital directly

Nine per cent of patients went directly to hospital. This was most common amongst patients with brain / central nervous system tumours (37%).

Patients' feelings regarding their wait before seeing hospital doctor

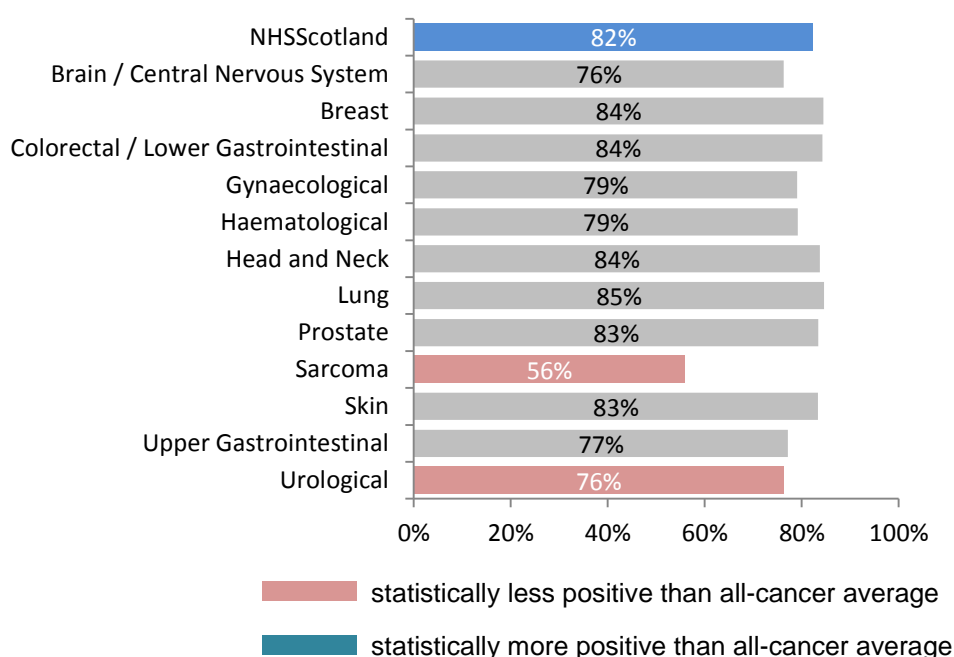
The majority of patients (82%) felt that they were seen by a hospital doctor as soon as they thought it was necessary (Table 3).

Table 3: Length of time before first appointment with hospital doctor

How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	n	%
I was seen as soon as I thought was necessary	3,856	82%
I should have been seen a bit sooner	549	12%
I should have been seen a lot sooner	280	6%
Total	4,685	100%

Patients from different tumour groups felt differently about the length of wait to see a hospital doctor. Results for patients with sarcoma and urological tumours were statistically below the all-cancer average (Figure 3).

Figure 3: % seen by hospital doctor as soon as they thought necessary, by tumour group



Differences in patients' views about the wait before seeing a hospital doctor can partly be explained by the route that they took to hospital. Those that went to hospital following a screening appointment were most likely to be positive (95%) and unsurprisingly those who attended hospital after five or more visits to their GP practice were least likely to be positive (46%) (Table 4).

Table 4: % seen by hospital doctor as soon as they thought was necessary, by route to hospital

Route to first hospital appointment	% seen 'as soon as necessary'
Patient went to hospital following a cancer screening appointment	95%
Patient went straight to the hospital	89%
Patient saw GP once	86%
Patient saw GP twice	80%
Patient saw GP three or four times	64%
Patient saw GP 5 or more times	46%

Diagnostic tests

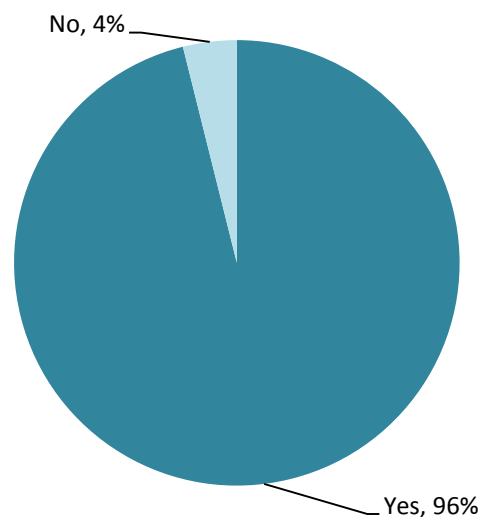
In this section we ask patients who have undergone a diagnostic test such as an endoscopy, biopsy, mammogram or scan their views on the process.

This can involve taking in a large amount of information – often both complicated and with a personal impact – and can be an unsettling time for patients.

Therefore it's important we find out whether patients had enough written information about their tests, whether the results of the tests were explained clearly, and how they felt about the length of time they had to wait to have the tests.

The vast majority of respondents (96%) reported having some form of diagnostic test for their cancer (Figure 4).

Figure 4: Has patient had diagnostic test



Information about the test

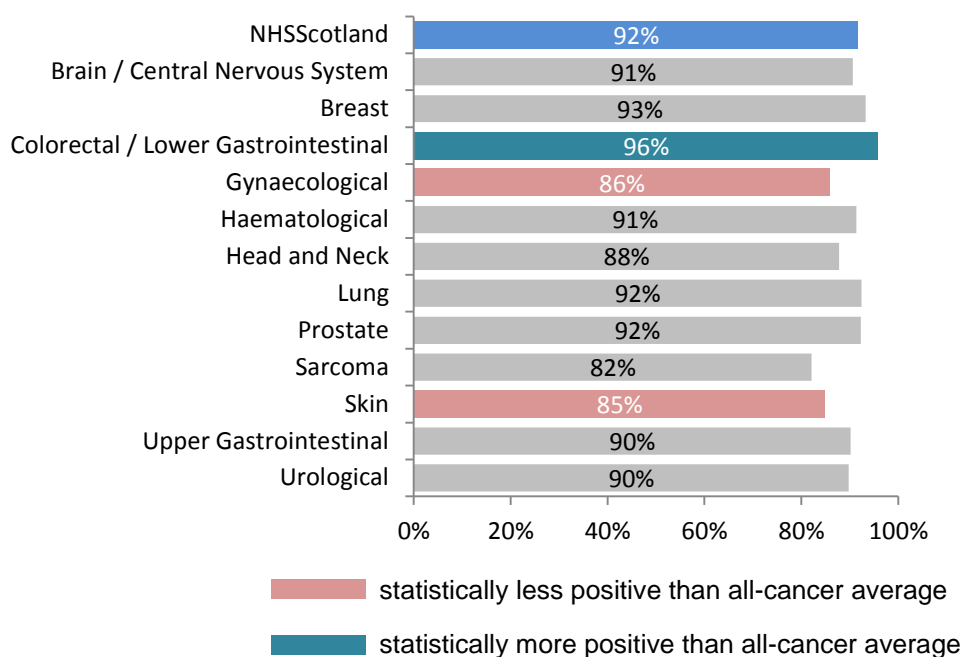
Of the patients that did have a diagnostic test, the large majority (92%) had the information they needed beforehand. Amongst those that did not have the information they needed, there was more or less an equal desire for more verbal and more written information (Table 5).

Table 5: Information before diagnostic test

Beforehand, did you have all the information you needed about your test?	n	%
Yes	3,941	92%
No, I would have liked more written information	145	3%
No, I would have liked more verbal information	158	4%
No, I would have liked BOTH more written information and more verbal information	50	1%
Total	4,294	100%

Patients from different tumour groups responded differently regarding having enough information about their diagnostic tests. Patients with colorectal / lower gastrointestinal tumours were statistically more likely to respond positively (96%), whereas patients with gynaecological (86%) and skin tumours (85%) were statistically less positive (Figure 5).

Figure 5: % given written information before test, by tumour group



Time waiting for diagnostic test to be done

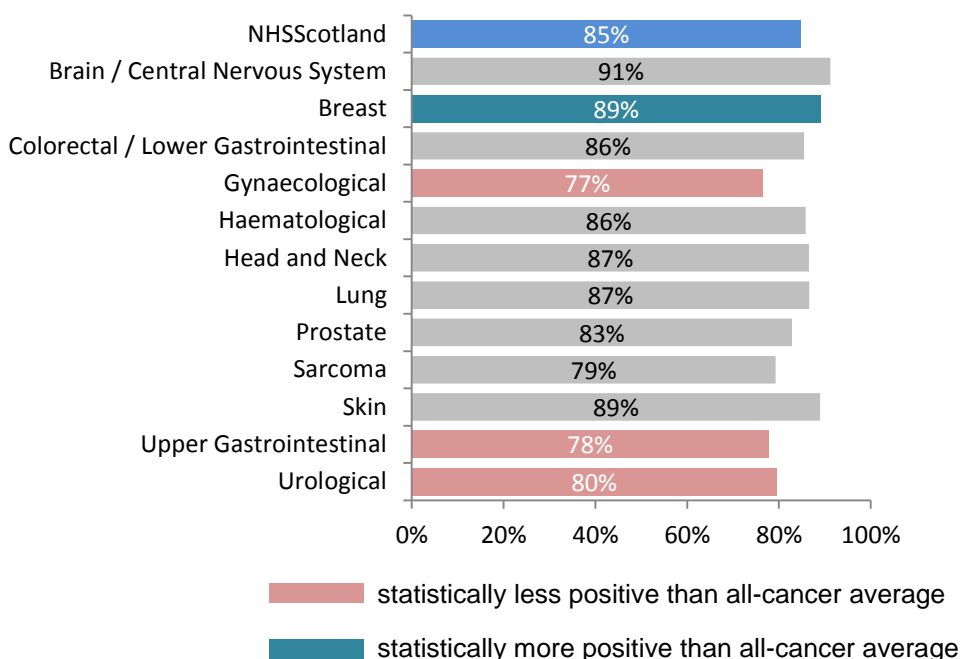
The majority of patients (85%) felt that the length of time waiting for their diagnostic test to be done was 'about right' (Table 6).

Table 6: Length of time waiting for diagnostic test to be done

Overall, how did you feel about the length of time you had to wait for your test to be done?	n	%
It was about right	3,812	85%
It was a little too long	493	11%
It was much too long	188	4%
Total	4,493	100%

There was some variation in how patients from different tumour groups responded to the question. Breast cancer patients were statistically more likely than the all-tumour average to respond that their wait was 'about right' (89%). Upper gastrointestinal (78%), gynaecological (77%) and urological (80%) tumour groups were all statistically below the average (Figure 6).

Figure 6: % positive about test wait, by tumour group



Understanding the test results

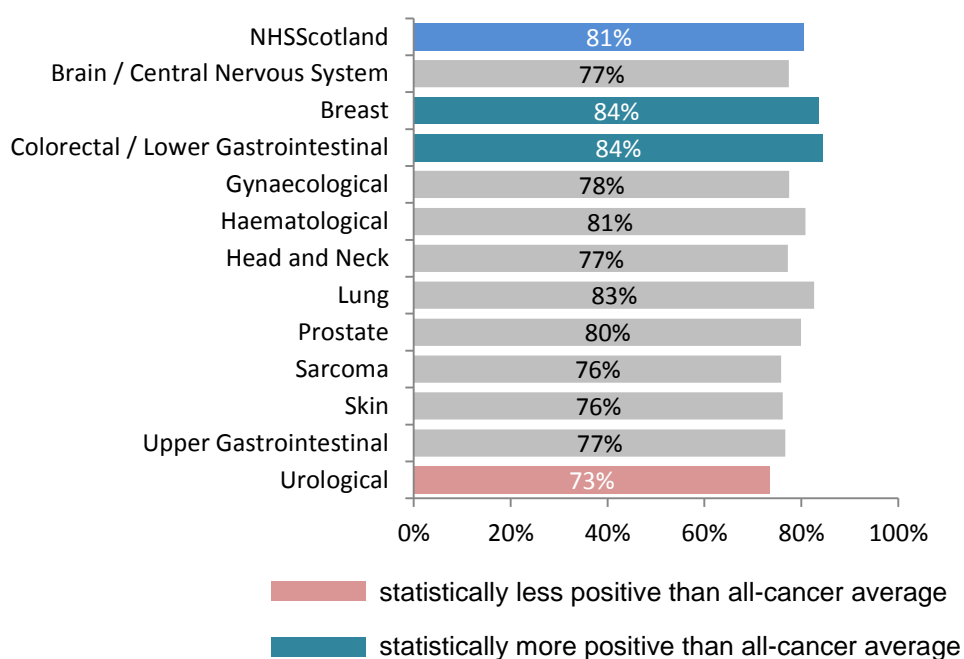
Most patients (81%) felt that the tests were explained to them in a way they could understand 'completely'. Around one in six (18%) only understood their test results 'to some extent'. A very small percentage either received no explanation or did not understand the explanation given (Table 7).

Table 7: Explanation of test results

Were the results of the test explained in a way you could understand?	n	%
Yes, completely	3,637	81%
Yes, to some extent	805	18%
No, I did not understand the explanation	36	1%
I did not have an explanation but would have liked one	40	1%
Total	4,518	100%

Patients with breast and colorectal / lower gastrointestinal tumours were statistically more positive about the way that their results had been explained than the all-cancer average (both saw 84% of patients responding 'yes, completely'). Urological tumour patients were less positive (73% responding 'yes, completely') (Figure 7).

Figure 7: % receiving understandable explanation of test results, by tumour group



Finding out what was wrong

Finding out you have cancer can be a daunting experience.

In this set of questions we seek to understand how patients felt about the way their diagnosis was communicated to them: if they felt it was done in a sensitive way, if they were told they could bring a family member with them, if they understood the explanation, and if they were given clear written information.

Bringing a friend or family member

Twelve per cent of patients were either told that they had cancer by telephone or letter, or did not feel it was necessary to bring a family member with them to their diagnosis.

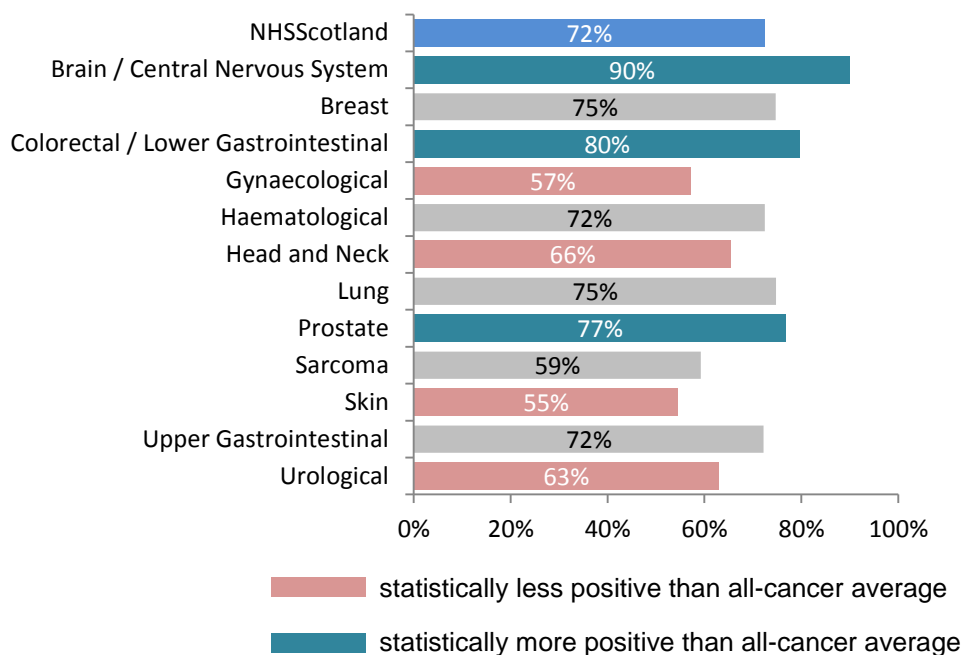
Of the patients who would have liked to bring a family member to their diagnosis, over a quarter (28%) were not told that they could bring someone with them to the appointment where they were told that they had cancer (Table 8).

Table 8: Bringing a family member or friend to cancer diagnosis

When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	n	%
Yes	2,819	72%
No	1,076	28%
Total	3,895	100%

There was variation amongst those in different tumour groups. Patients with brain / central nervous system (90%), colorectal / lower gastrointestinal (80%), and prostate tumours (77%) were all statistically more likely to have been told they could bring a family member or friend than the all-cancer average. Patients with gynaecological (57%), head and neck (66%) urological (63%) and skin tumours (55%) were less likely to have been told this (Figure 8).

Figure 8: % told they could bring family member/friend to diagnosis, by tumour group



Sensitivity of cancer diagnosis

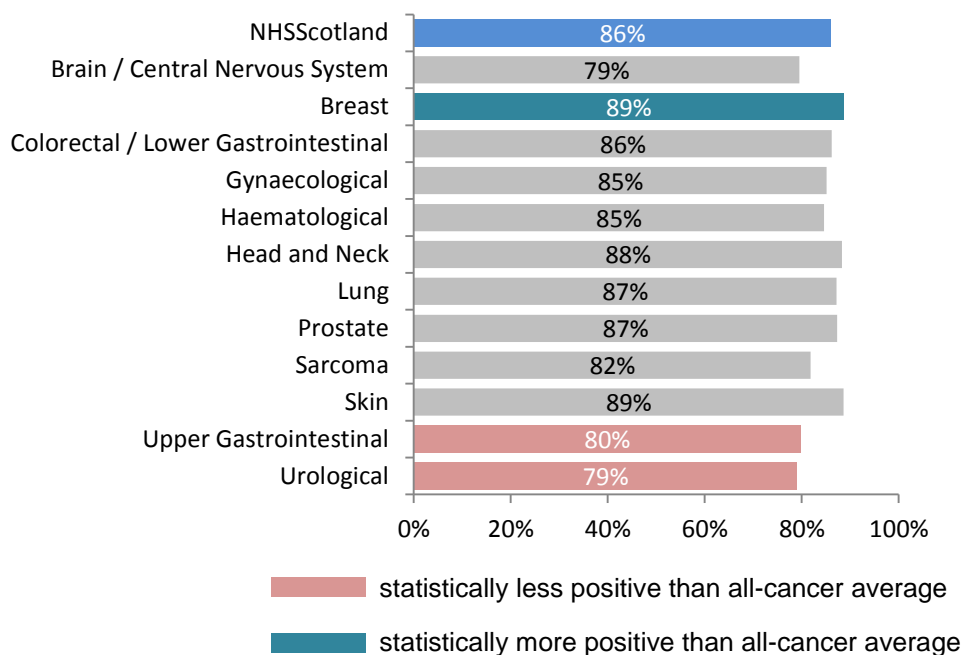
The majority of cancer patients (86%) reported being told they had cancer in a sensitive way. One in twenty felt that it should have been done ‘a lot more’ sensitively (Table 9).

Table 9: Sensitivity of cancer diagnosis

How do you feel about the way you were told you had cancer?	n	%
It was done sensitively	4,021	86%
It should have been done a bit more sensitively	425	9%
It should have been done a lot more sensitively	229	5%
Total	4,675	100%

Patients with breast tumours (89%) were the only group to respond statistically more positively than the all-cancer average. Upper gastrointestinal (80%) and urological (79%) were both statistically below average on this question (Figure 9).

Figure 9: % told they had cancer sensitively, by tumour group



Understanding cancer diagnosis

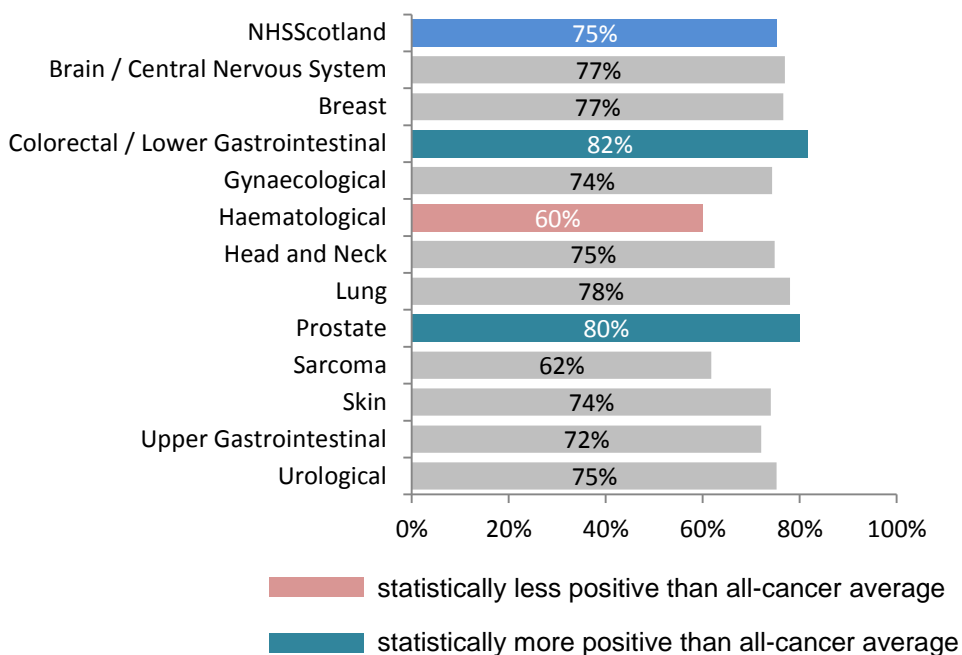
A quarter of patients (25%) did not fully understand the explanation of what was wrong with them. Most of these respondents understood ‘some of it’ (Table 10).

Table 10: Explanation of what was wrong with the patient

Did you understand the explanation of what was wrong with you?	n	%
Yes, I completely understood it	3,603	75%
Yes, I understood some of it	1,084	23%
No, I did not understand it	93	2%
Total	4,780	100%

Patients with colorectal / lower gastrointestinal (82%) and prostate (80%) tumours were statistically more likely to have ‘completely’ understood the explanation of what was wrong with them than the average. Haematological patients were less likely to have understood ‘completely’ (60%) (Figure 10).

Figure 10: % understanding explanation of what was wrong, by tumour group



Written information following diagnosis

In a third of cases no written information about the type of cancer they had was given to the patient when they received their cancer diagnosis (Table 11).

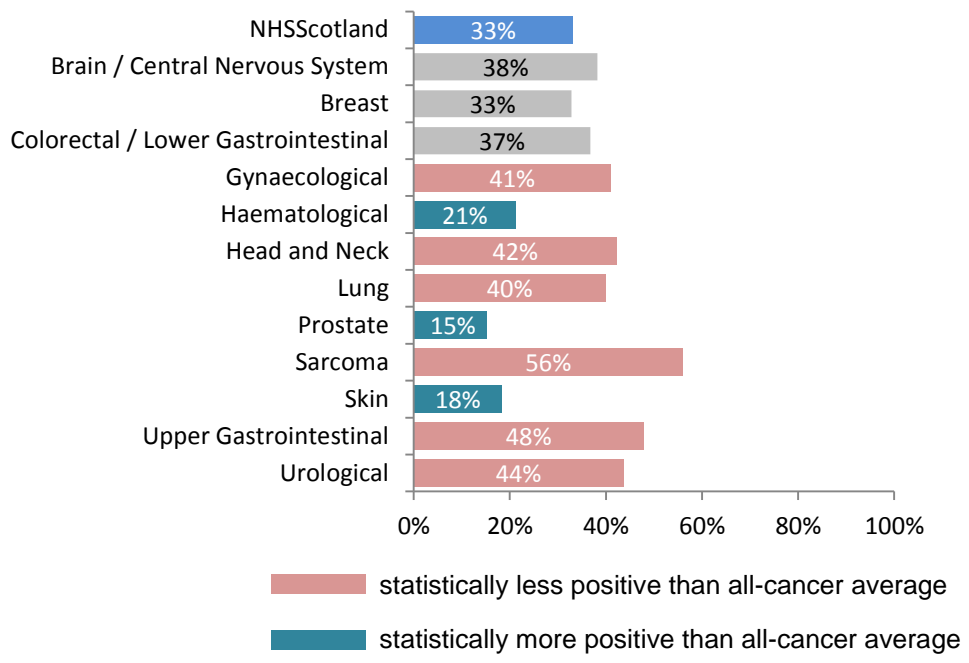
Table 11: Written information about type of cancer

When you were told you had cancer, were you given written information about the type of cancer you had?	n	%
Yes, and it was easy to understand	2,310	60%
Yes, but it was difficult to understand	247	6%
No, I was not given written information about the type of cancer I had	1,263	33%
Total	3,820	100%

Of the patients that did receive written information, 90 per cent found it easy to understand

There was significant variation in the percentage of patients receiving written information following diagnosis. Tumour groups that were statistically less likely to receive this information included patients with upper gastrointestinal (48% received no written information) and urological (44% received no written information) (Figure 11).

Figure 11: % receiving no written information about their type of cancer, by tumour group



Deciding the best treatment

It's important that patients feel fully informed to be able to make the decision about which treatment, if any, they want to undergo.

As more people are living with cancer than ever before⁴, understanding side effects of treatment which may affect them in the future as well as immediately becomes increasingly important.

In this section we seek to understand both the relational aspects of treatment decisions - whether the patients felt involved enough in the decisions about their care – and the processes that support this: whether the treatment options were explained, whether possible side effects (both immediate and future) were communicated, and whether practical advice and support in dealing with the side effects of treatment were offered.

Treatment options

Patients were asked whether their treatment options were explained to them. Thirteen per cent of respondents indicated that there was only one type of treatment suitable for them.

Of the patients with more than one treatment option available, the majority (86%) had their treatment options explained to them 'completely' (Table 12).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not significant.

Table 12: Explanation of treatment options

Before your cancer treatment started, were your treatment options explained to you?	n	%
Yes, completely	3,457	86%
Yes, to some extent	483	12%
No	82	2%
Total	4,022	100%

⁴ http://www.isdscotland.org/Health-Topics/Cancer/Publications/2016-05-17/Cancer_in_Scotland_summary_m.pdf

Involvement in decisions about care and treatment

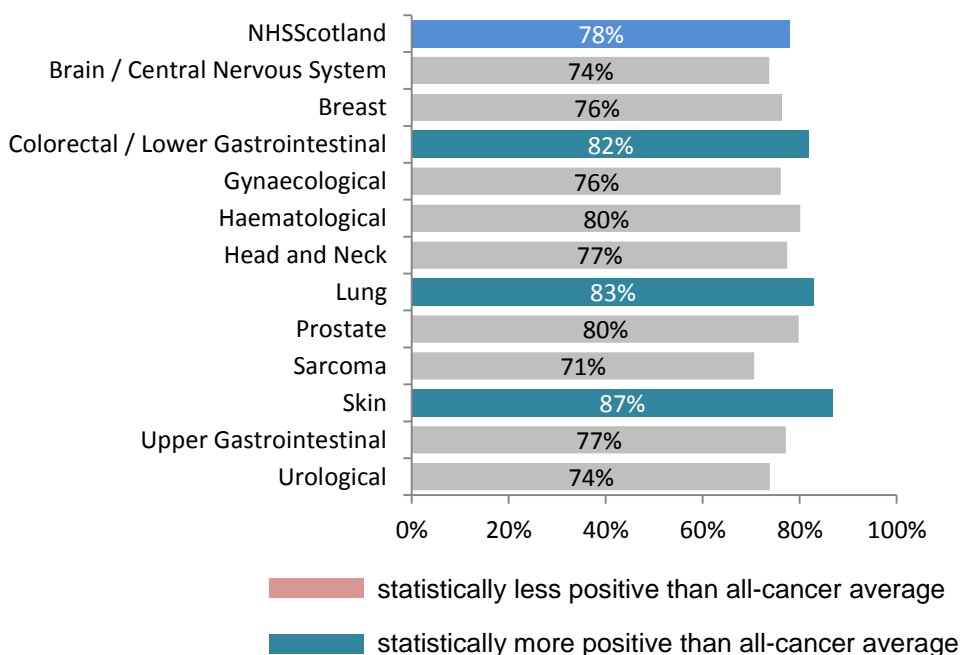
Patients were also asked whether they were involved as much as they wanted to be in decisions about their care and treatment. Over three quarters of patients (78%) were ‘definitely’ involved as much as they wanted to be (Table 13).

Table 13: Involvement in decisions about care and treatment

Were you involved as much as you wanted to be in decisions about your care and treatment?	n	%
Yes, definitely	3,554	78%
Yes, to some extent	820	18%
No, but I would like to have been more involved	183	4%
Total	4,557	100%

Patients with colorectal / lower gastrointestinal (82%), lung (83%), and skin (87%) tumours were all statistically more positive than the all-cancer average regarding involvement in decisions (Figure 12).

Figure 12: % involved in decisions about care and treatment, by tumour group



Side effects of treatments

Immediate side effects

Patients were asked whether the possible side effects of treatment were explained in a way they could understand.

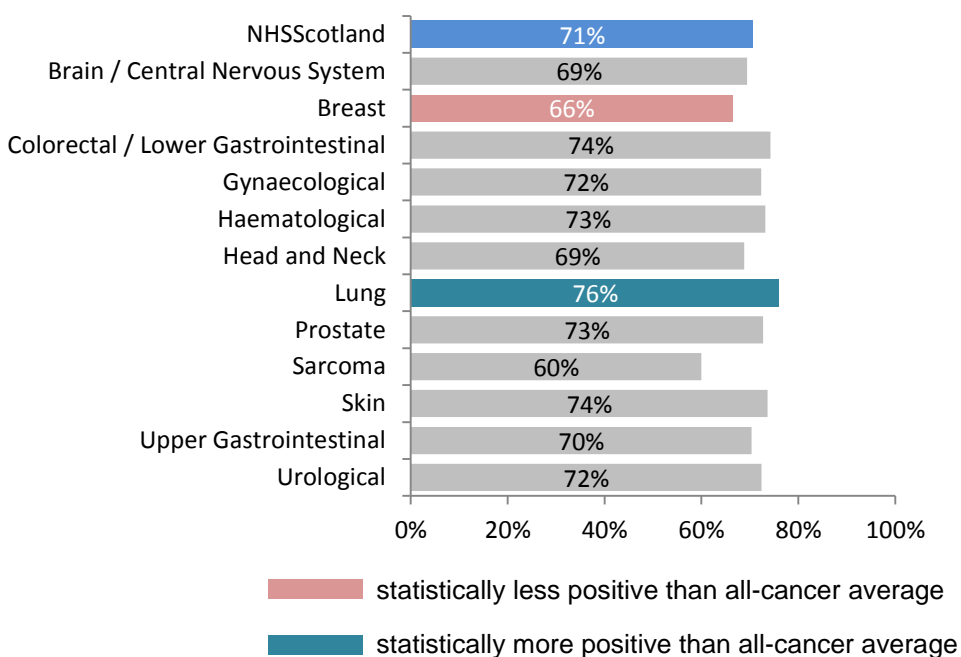
Five per cent of patients responded that they did not need an explanation. Of those that did need an explanation, the majority (71%) reported side effects ‘definitely’ being explained in a way that they could understand (Table 14).

Table 14: Explanation of side effects of treatment

Were the possible side effects of treatment(s) explained in a way you could understand?	n	%
Yes, definitely	3,103	71%
Yes, to some extent	1,056	24%
No, side effects were not explained	230	5%
Total	4,389	100%

Responses to this question varied by tumour group, with breast tumour patients being statistically below the all-cancer average (66%) and lung tumour patients being above average (76%) (Figure 13).

Figure 13: % receiving understandable explanation of side effects, by tumour group



Future side effects

Patients were also asked whether they were told about side effects of treatment that could affect them in the future rather than straight away. Seven per cent responded that they did not need an explanation.

Of those that did require explanation, only fifty-three per cent reported that they were ‘definitely’ told about future side effects (Table 15). This is notably less

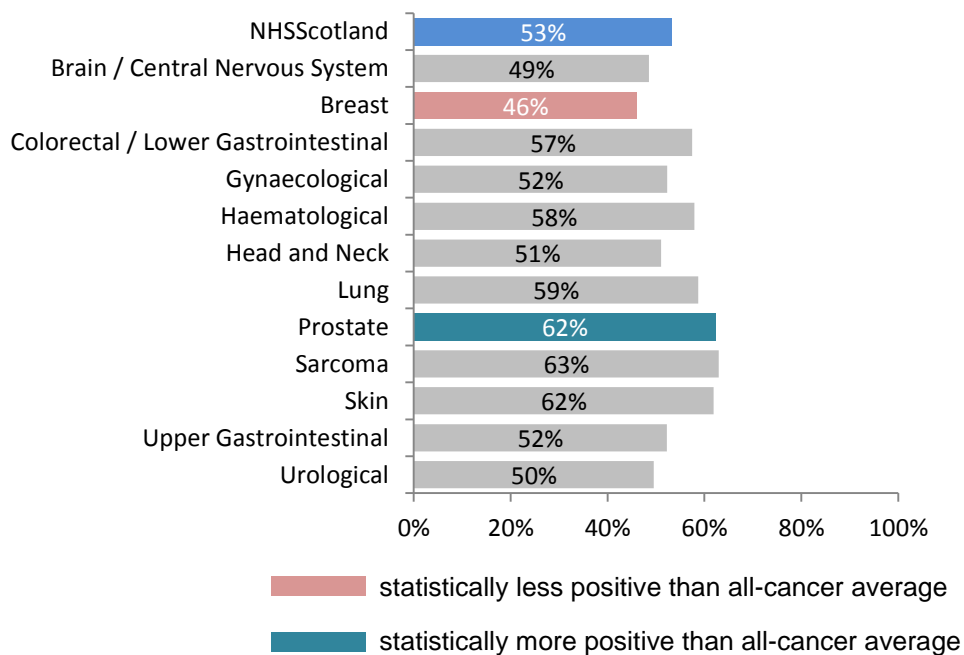
positive than the question relating to more immediate side-effects being explained (53% and 71% respectively responding positively). One in five patients (19%) did not receive any explanation of future side effects at all.

Table 15: Future side effects of treatment

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?	n	%
Yes, definitely	2,178	53%
Yes, to some extent	1,115	27%
No, future side effects were not explained	786	19%
Total	4,079	100%

As with the previous question regarding more immediate side effects, patients with breast tumours (46%) were less likely to be positive than the all cancer average. Patients in the prostate tumour group (62%) were statistically more likely to be positive than the all-cancer average (Figure 14).

Figure 14: % told about future side effects, by tumour group



Practical advice and support for dealing with side effects

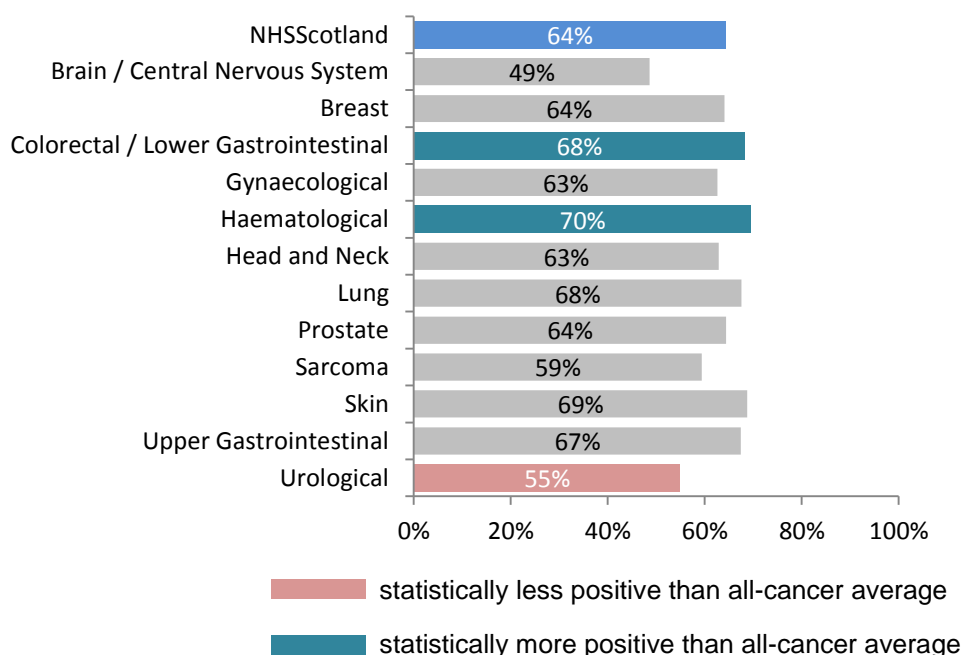
Patients were asked whether they were offered any practical advice and support in dealing with side effects of their treatment. Almost one in ten (9%) patients were not offered any practical advice or support (Table 16).

Table 16: Practical advice and support for dealing with side effects

Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	n	%
Yes, definitely	2,814	64%
Yes, to some extent	1,151	26%
No, I was not offered any practical advice or support	407	9%
Total	4,372	100%

Patients with haematological tumours (70%) were most likely to have received practical advice and support for side effects, whilst urological tumour patients (55%) were the only group statistically below the all-cancer average (Figure 15).

Figure 15: % receiving practical advice and support for side effects, by tumour group



Clinical Nurse Specialist

Questions in this section ask patients if they were given the name of a Clinical Nurse Specialist (CNS) to support them through their treatment, and if so, their views on both the ease of contacting their CNS and how frequently they got clear answers from them on important questions.

It has been previously demonstrated across other Cancer Patient Experience Surveys that access to a CNS can have a significant positive influence on patients' experiences⁵.

The majority of patients (84%) had been given the name of a CNS who would support them through their treatment (Table 17).

Table 17: Provision of Clinical Nurse Specialist

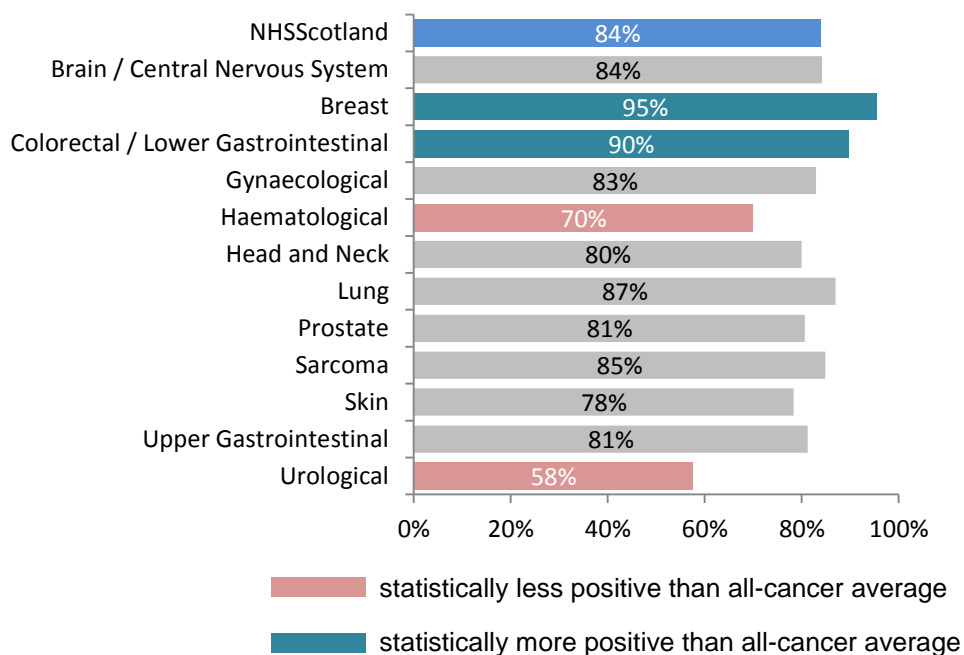
Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	n	%
Yes	3,800	84%
No	725	16%
Total	4,525	100%

Patients with breast (95%) and colorectal / lower gastrointestinal tumours (90%) were statistically more likely than the all-cancer average to have been given the name of a CNS. Patients with urological tumours (58%) and haematological (70%) were less likely (Figure 16).

⁵ English National Cancer Patient Experience Survey, National Report 2014, September 2014. Northern Ireland Cancer Patient Experience Survey, 2015 All Trusts Report, October 2015. Wales Cancer Patient Experience Survey, National Report, January 2014

Analysis demonstrated that CNS provision was the most important driver of high scores given by patients. Patients who had a CNS were more likely to report positive experiences of their care across the majority of survey questions in England, Wales and Northern Ireland CPES.

Figure 16: % given the name of Clinical Nurse Specialist, by tumour group



Ease of contacting Clinical Nurse Specialist

Ninety per cent of patients found it 'very' or 'quite easy' to contact their CNS, with only four per cent finding it 'quite' or 'very' difficult (Table 18).

Differences between tumour groups in how easy they found it to contact their CNS were not significant overall.

Table 18: Ease of contacting Clinical Nurse Specialist

How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	n	%
Very easy	2,143	64%
Quite easy	887	26%
Neither easy nor difficult	186	6%
Quite difficult	105	3%
Very difficult	36	1%
Total	3,357	100%

Questions for Clinical Nurse Specialist

Fifteen per cent of patients reported that they had not asked any questions of their CNS, meaning that the large majority (85%) of patients did approach their CNS with questions.

Of those that did have questions for their CNS, 90% responded that they got answers that they could understand 'all or most of the time'. Only two per cent 'rarely or never' got answers they could understand (Table 19).

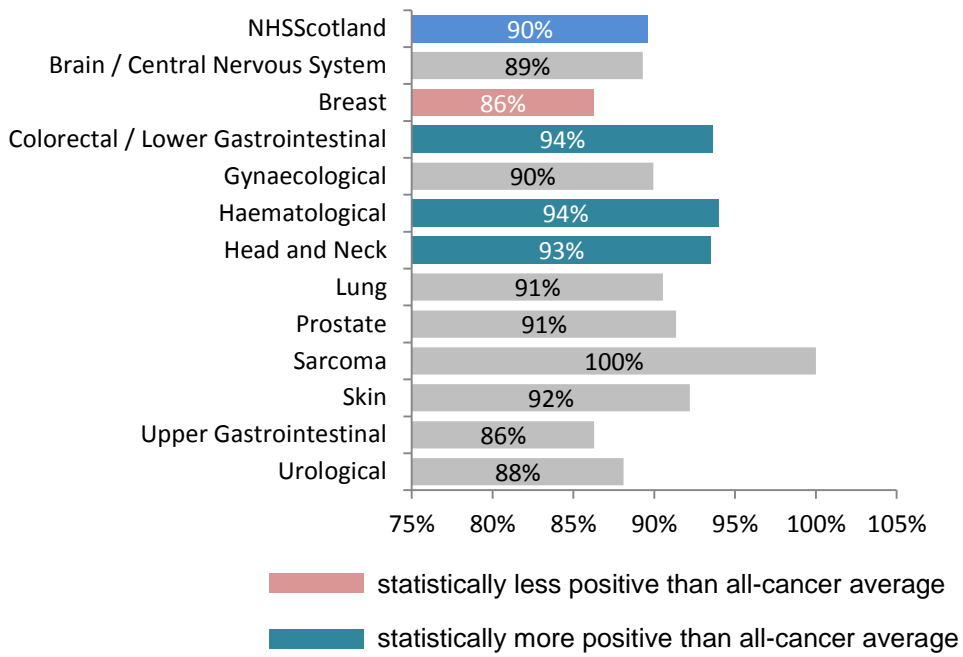
Table 19: Questions for Clinical Nurse Specialist

When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	n	%
All or most of the time	2,839	90%
Some of the time	268	8%
Rarely or never	61	2%
Total	3,168	100%

There were differences in how positively patients from different tumour groups responded to this question. Breast tumour patients (86%) were statistically less likely to respond that they got answers they could understand to their important questions.

In contrast, patients with colorectal / lower gastrointestinal, (94%), haematological (94%), and head and neck tumours (93%) were all more likely than the all-cancer average to have responded positively (Figure 17).

Figure 17: % receiving answers from Clinical Nurse Specialist they could understand, by tumour group



Support for people with cancer

Cancer and its treatments can affect every aspect of life, bringing problems from debt to depression. These problems can last beyond the end of treatment.

Support is often available but people may not always be told how to access it. Ensuring that patients are given clear, understandable and high quality information is therefore of clear importance.

Questions in the survey explore the information provided by hospital staff about support or self-help groups for cancer patients, the impact cancer can have on daily life, and how to get financial help or benefits.

Information about support or self-help groups

Patients were asked whether hospital staff had provided them with information about support or self-help groups. Around a quarter of patients (23%) responded that this was not necessary.

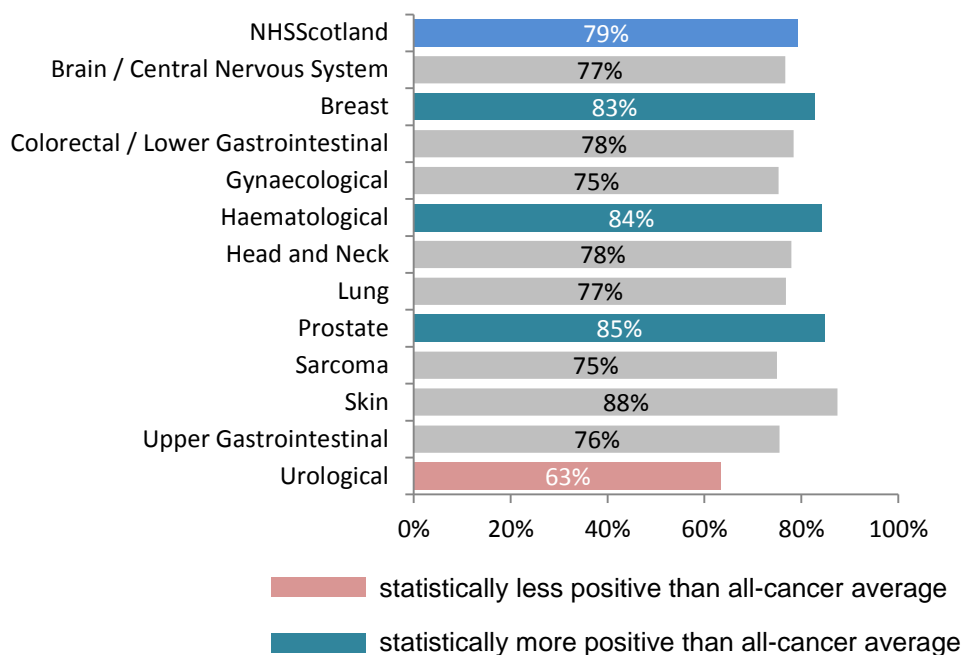
Of those that would have liked this information from hospital staff, one in five (21%) did not receive it (Table 20).

Table 20: Information about support or self-help groups

Did hospital staff give you information about support or self-help groups for people with cancer?	n	%
Yes	2,733	79%
No, but I would have liked information	716	21%
Total	3,449	100%

Amongst tumour groups that were significantly different from the all-cancer average, patients with urological tumours (63%) reported a below-average rate of receiving information about support or self-help groups. Patients with prostate (85%), haematological (84%), and breast tumours (83%) reported a rate that was statistically above average (Figure 18).

Figure 18: % given information about self-help or support groups, by tumour group



Information on impact of cancer on day to day activities

Patients were also asked whether hospital staff provided information or a discussion on the impact that cancer would have on their day to day activities. One third of patients (33%) responded that it was not necessary/relevant.

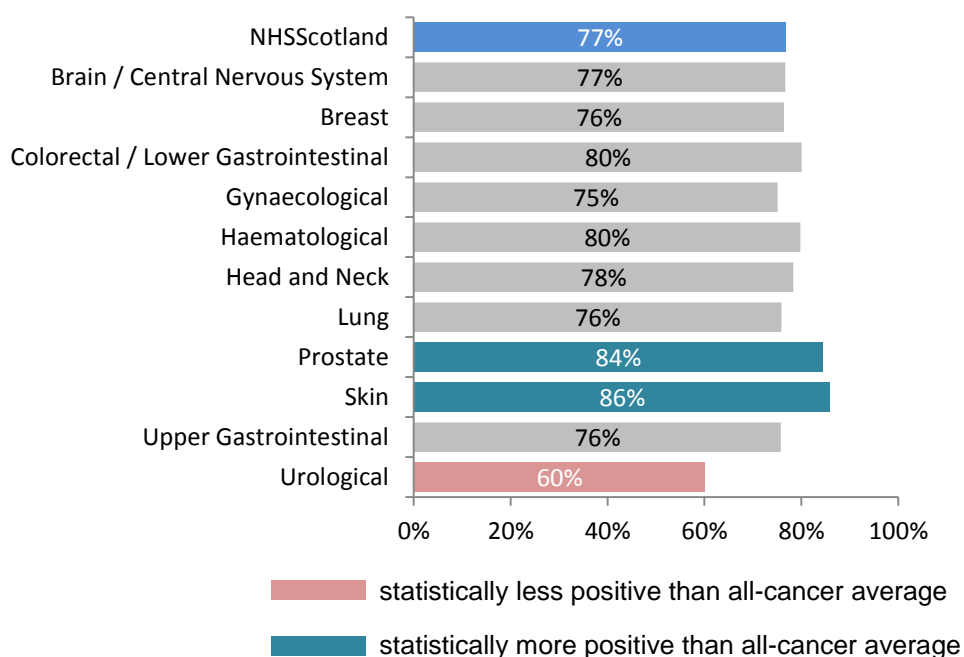
Of those that would have liked a discussion or information about the impact from hospital staff, around a quarter (23%) did not receive any (Table 21).

Table 21: Information on impact of cancer on day to day activities

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)?	n	%
Yes	2,343	77%
No, but I would have liked a discussion or information	707	23%
Total	3,050	100%

Patients with urological tumours (60%) were statistically less likely than the all-cancer average to report receiving information about the impact cancer could have on their day to day activities. Patients with skin (86%) and prostate tumours (84%) were statistically more likely to report this (Figure 19).

Figure 19: % given information on impact of cancer on day to day activities, by tumour group



Information on financial help and benefits

Patients were asked whether hospital staff had given them information about how to get financial help or benefits to which they might be entitled. Around half of patients (48%) responded that this was not necessary.

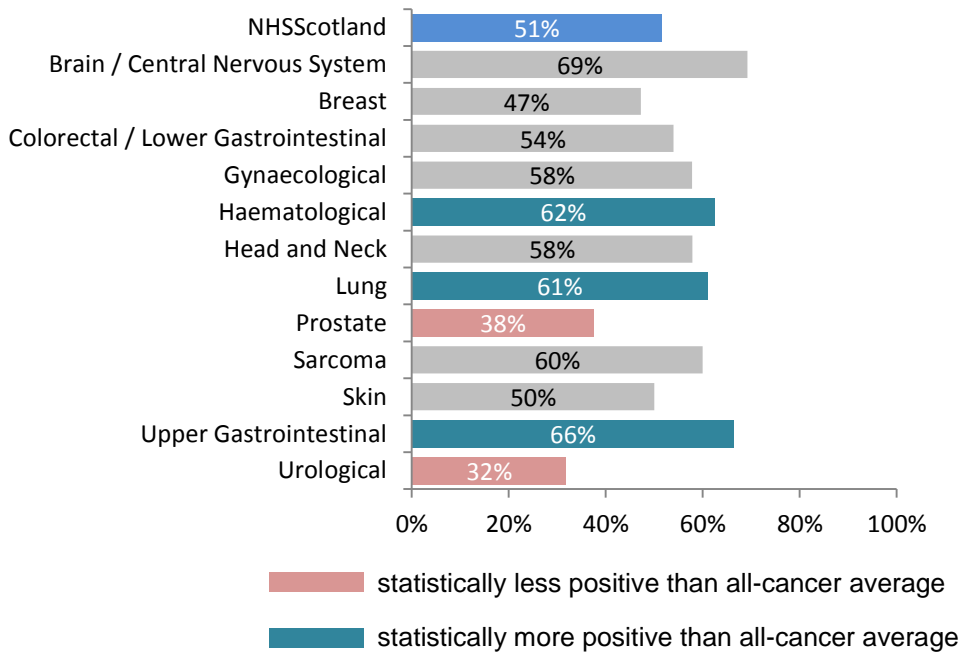
Of the patients that would have liked information on financial help and benefits from hospital staff, only half (51%) received this (Table 22).

Table 22: Information on financial help and benefits

Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	n	%
Yes	1,212	51%
No, but I would have liked information	1,142	49%
Total	2,354	100%

Again, patients with urological tumours were statistically below the all-cancer average for this question, with only 32 per cent of patients reporting that they received information about financial help and benefits. Patients with lung (61%) and upper gastrointestinal (66%) tumours were both statistically above the average (Figure 20).

Figure 20: % given information on financial help and benefits, by tumour group



Operations

In order to prepare themselves for what to expect when having an operation for their cancer and what the results mean, patients need to be given clear explanations and information about their procedure.

Among the 77 per cent who had had an operation, such as a removal of a tumour or lump, we sought to understand cancer patients' views on whether they had sufficient information before their operation, and afterwards whether the outcome was clearly explained to them.

Over three-quarters of respondents (77%) had had an operation for their cancer (Table 23).

Table 23: Operations for cancer

Have you had an operation (such as removal of a tumour or lump) for your cancer?	n	%
Yes	3,713	77%
No	1,079	23%
Total	4,792	100%

Information before the operation

The large majority of patients had all the information they needed before their operation (93%). Amongst those that did not have the information they needed, there was a similar desire for more verbal and more written information (Table 24).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Table 24: Information before operation

Beforehand, did you have all the information you needed about your operation?	n	%
Yes	3,281	93%
No, I would have liked more written information	128	4%
No, I would have liked more verbal information	91	3%
Options 2 and 3 (No, I would have liked more written information and more verbal information)	41	1%
Total	3,541	100%

Information after the operation

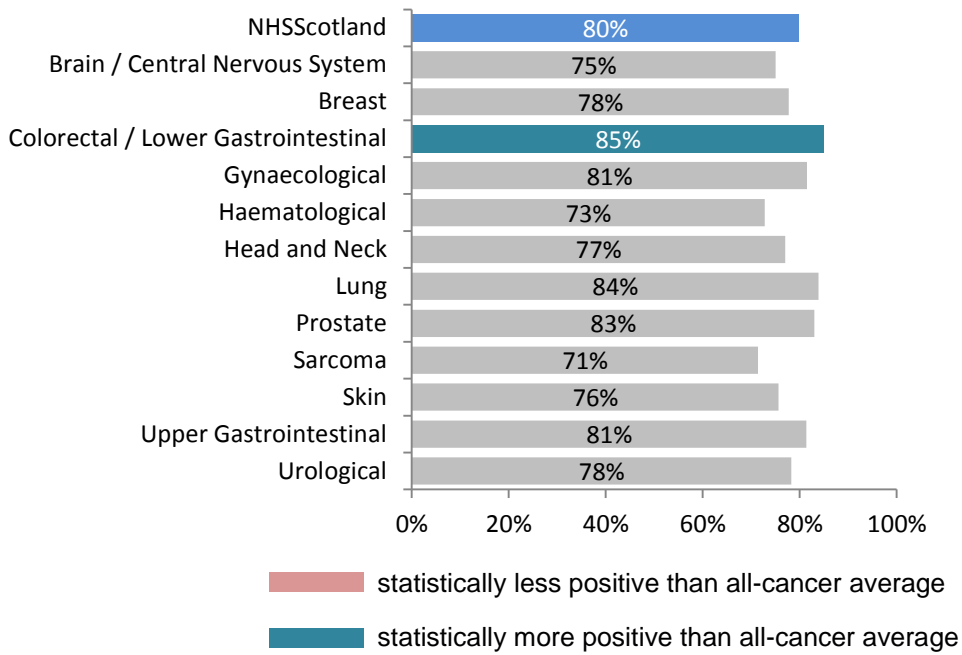
After the operation, most patients (80%) received an explanation of how the operation had gone in a way they could understand (Table 25). However, this was less common than receiving sufficient information *before* the operation (80% vs 93%).

Table 25: Information after the operation

After the operation, did a member of staff explain how it had gone in a way you could understand?	n	%
Yes, completely	2,901	80%
Yes, to some extent	624	17%
No, but I would have liked an explanation	110	3%
Total	3,635	100%

The only tumour type statistically different from the all-cancer average was colorectal / lower gastrointestinal which was above average (85%) Figure 21).

Figure 21: % receiving explanation of how operation had gone, by tumour group



Hospital care as an inpatient

Care as an inpatient means going into hospital for diagnosis or treatment that requires an operation or overnight stay, with 83 per cent of survey respondents being in inpatient at some point in their cancer journey.

In order to understand how cancer patients experienced their stay, the survey asked about their interactions with health professionals (primarily doctors and nurses).

It is important for patients to have confidence and trust in the people looking after them. Such confidence relates to the availability and capacity of staff, the clarity and availability of information and support, and the quality of inpatient care.

How doctors and nurses interact with patients - having enough privacy when discussing their cancer, and being asked what their preferred name was - can help patients to feel they are viewed as more than their cancer diagnosis.

The importance of the quality of care extends beyond the immediate inpatient stay. This is why this section asks cancer patients if they felt they received enough information about their condition prior to discharge, and if they clearly understood who they could contact for support and advice upon discharge.

Hospital doctors

Confidence in hospital doctors

The majority of patients (86%) had confidence and trust in all of the doctors treating them, with 14 per cent having confidence and trust in only 'some of them' (Table 26).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Table 26: Confidence and trust in hospital doctors

Did you have confidence and trust in the doctors treating you?	n	%
Yes, in all of them	3,378	86%
Yes, in some of them	536	14%
No, in none of them	18	0%
Total	3,932	100%

Family access to doctor

Three quarters of patients (75%) reported that their family or someone else were 'definitely' able to talk to a doctor if they wanted to (Table 27).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Table 27: Family access to hospital doctor

If your family or someone else close to you wanted to talk to a doctor, were they able to?	n	%
Yes, definitely	2,394	75%
Yes, to some extent	648	20%
No	131	4%
Total	3,173	100%

Hospital nurses

Confidence in hospital nurses

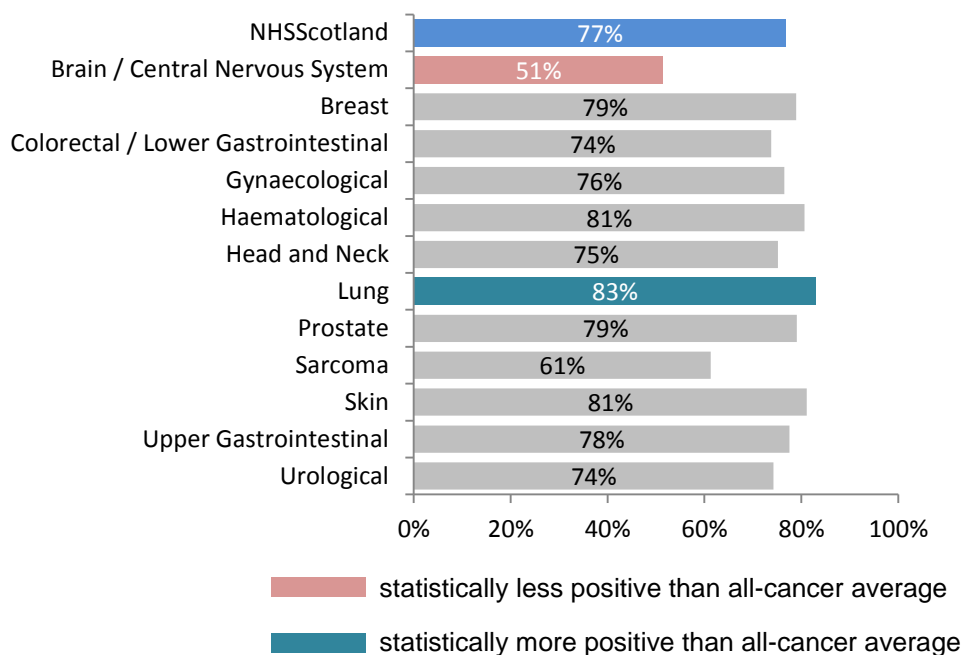
Compared with the equivalent question for doctors, a lower proportion of patients reported that they had confidence and trust in the nurses treating them (77% vs 86%) (Table 28).

Table 28: Confidence and trust in ward nurses

Did you have confidence and trust in the ward nurses treating you?	n	%
Yes, in all of them	3,031	77%
Yes, in some of them	881	22%
No, in none of them	35	1%
Total	3,947	100%

Amongst different tumour groups, only two were statistically different from the all-cancer average. Patients with lung tumours (83%) were more likely to have confidence and trust in all the nurses treating them, whereas patients with brain / central nervous system tumours (51%) were less likely (Figure 22).

Figure 22: % with confidence and trust in all ward nurses, by tumour group



Enough nurses on duty

Seventy-two per cent of patients reported that there were ‘always or nearly always’ enough nurses on duty to treat them (Table 29). These are more positive results than when the same question was asked in the most recent Scottish inpatient survey⁶ (72% vs 64%). The inpatient survey includes inpatients with a range of conditions.

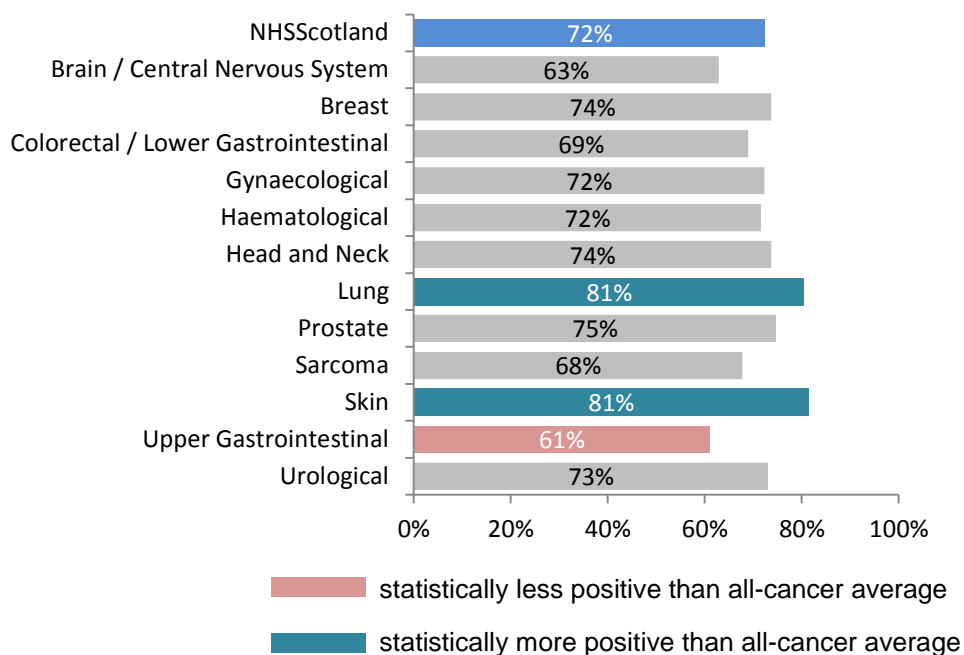
Table 29: Enough nurses on duty

In your opinion, were there enough nurses on duty to care for you in hospital?	n	%
There were always or nearly always enough on duty	2,814	72%
There were sometimes enough on duty	866	22%
There were rarely or never enough on duty	203	5%
Total	3,883	100%

Patients with lung and skin tumours (both 81%) were statistically more likely than the all-cancer average to report there always or nearly always being enough nurses on duty. Patients with upper gastrointestinal tumours (61%) were statistically less likely to report this (Figure 23).

⁶ <http://www.gov.scot/Publications/2014/08/4194/302864#chart11>

Figure 23: % reporting always or nearly always enough nurses on duty, by tumour group



Hospital Doctors and Nurses

Doctors and nurses talking as if patient wasn't there

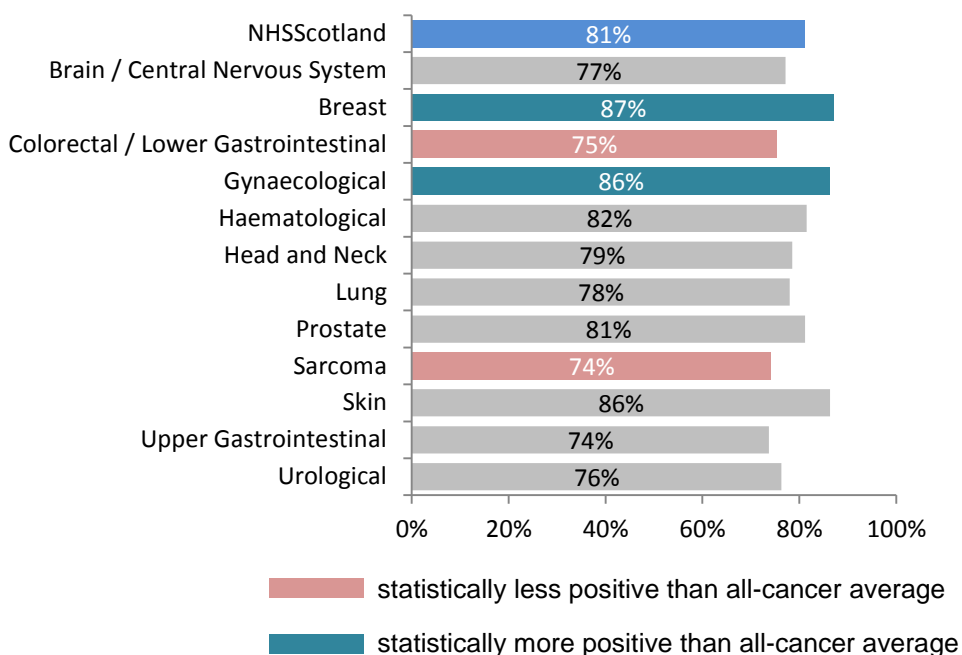
Around one in five patients reported groups of doctors and nurses talking about them as if they weren't there (Table 30). Although, this was more likely to have happened only 'sometimes' (15%) rather than 'often' (4%).

Table 30: Doctors and nurses talking as if patient wasn't there

Did groups of doctors and nurses talk in front of you as if you weren't there?	n	%
Yes, often	160	4%
Yes, sometimes	579	15%
No	3,179	81%
Total	3,918	100%

There were some differences in how patients from different tumour groups responded to this question. Breast (87%) and gynaecological tumour (86%) patients were both statistically above average in reporting that doctors and nurses did not talk in front of them as if they were not there (Figure 24).

Figure 24: % reporting doctors and nurses did not talk as if they were not there, by tumour group



Doctors and nurses using patient’s preferred name

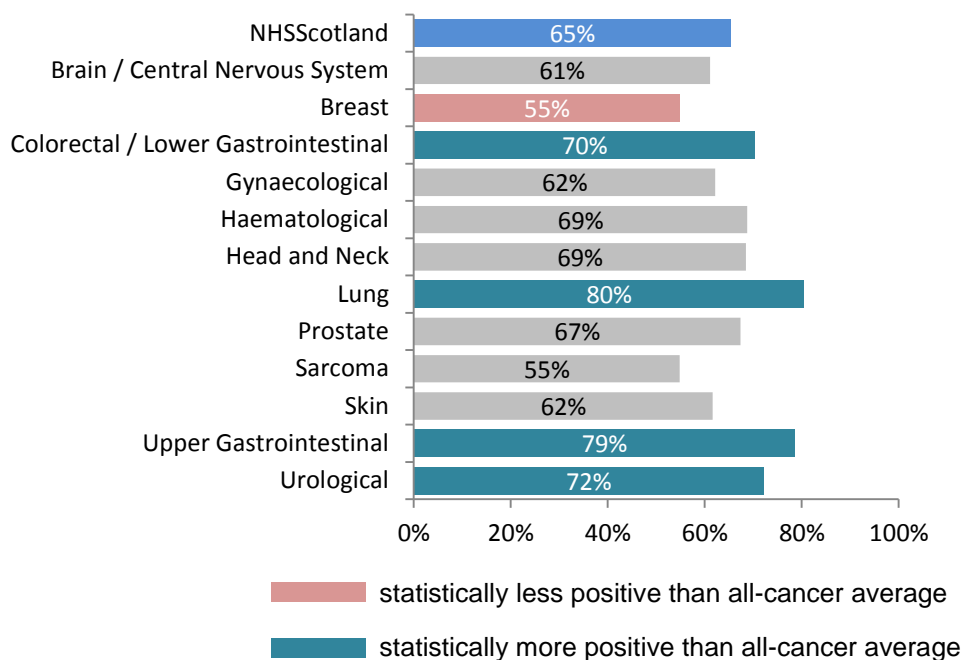
Over a third of patients (35%) reported that not all doctors and nurses asked what name they wanted to be called by, with 15 per cent reporting that ‘none’ of them did (Table 31).

Table 31: Doctors and nurses using patients preferred name

While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	n	%
Yes, all of them did	2,539	65%
Only some of them did	765	20%
None of them did	581	15%
Total	3,885	100%

There were a number of statistically significant differences between tumour groups and the all-cancer average. These included patients with breast tumours (55%) being less likely than average to report being asked what name they preferred to be called and lung tumour patients (80%) being above average (Figure 25).

Figure 25: % asked what name they preferred to be called by, by tumour group



Privacy when discussing care and treatment

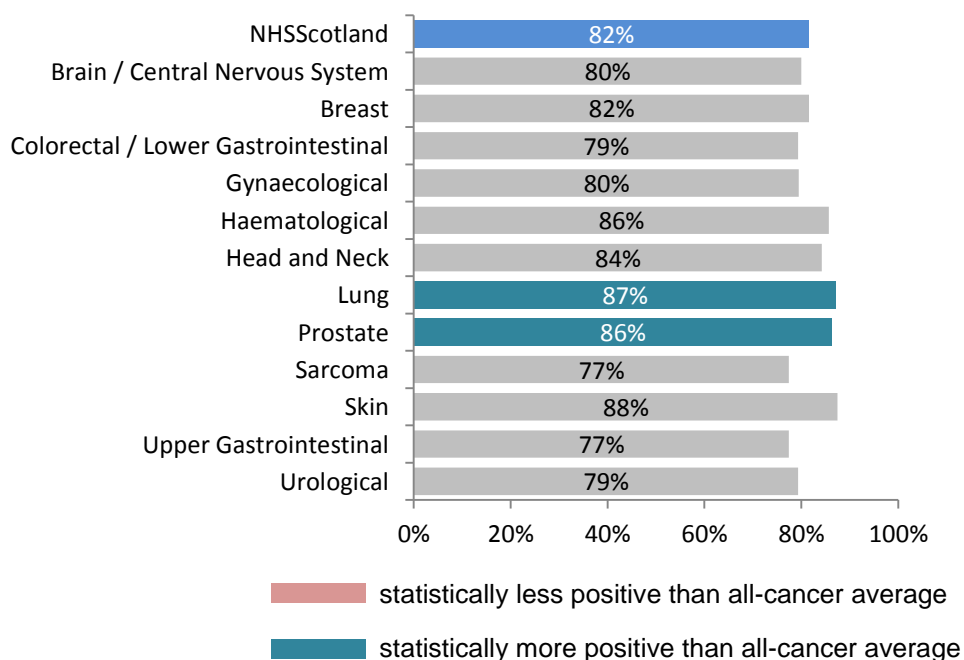
Eighteen per cent of patients reported that they were not always given enough privacy when discussing their condition or treatment (Table 32).

Table 32: Privacy when discussing care and treatment

Were you given enough privacy when discussing your condition or treatment?	n	%
Yes, always	3,198	82%
Yes, sometimes	559	14%
No	165	4%
Total	3,922	100%

Patients from two tumour groups were statistically different from the all-cancer average in how they responded to this question. Both lung (87%) and prostate tumour (86%) patients were more likely to respond that they were 'always' given enough privacy when discussing their condition and treatment (Figure 26).

Figure 26: % given enough privacy when discussing condition or treatment, by tumour group



Worries and fears

Patients were asked whether they found someone on hospital staff to talk about their worries and fears with. Twenty-seven per cent of patients reported that they had no worries or fears.

Of those that did have worries and fears, 18 per cent were unable to find someone to talk to about them. This is a higher percentage than the equivalent question for day case patients / outpatients, where only nine per cent responded that they were unable to find someone (Table 33).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Table 33: Worries and fears as inpatient

During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	n	%
Yes, definitely	1,424	50%
Yes, to some extent	907	32%
No	519	18%
Total	2,850	100%

Pain control

Eighty-seven per cent of patients believed that hospital staff ‘definitely’ did everything they could to help control their pain (Table 34).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Table 34: Pain control

Do you think the hospital staff did everything they could to help control your pain?	n	%
Yes, definitely	3,075	87%
Yes, to some extent	370	10%
No	95	3%
Total	3,540	100%

Respect and dignity

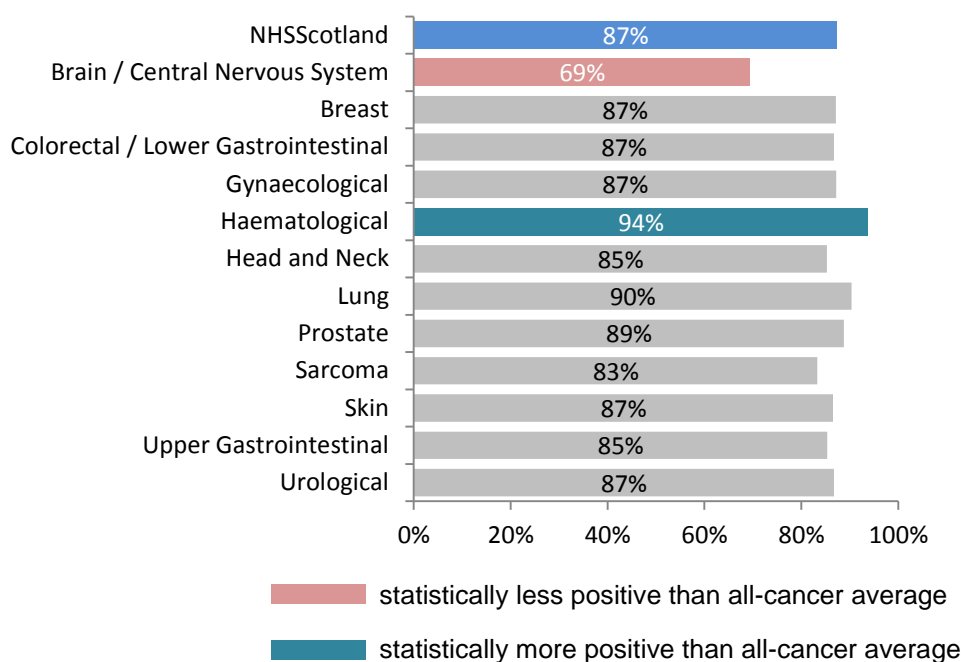
Eighty seven per cent of patients also felt that they were ‘always’ treated with respect and dignity (Table 35).

Table 35: Patients treated with respect and dignity

Overall, did you feel you were treated with respect and dignity while you were in hospital?	n	%
Yes, always	3,448	87%
Yes, sometimes	449	11%
No	47	1%
Total	3,944	100%

Patients with brain / central nervous system tumours (69%) were statistically less likely to report that they were treated with respect and dignity than the all-cancer average. Haematological tumour patients (94%) were statistically above the average (Figure 27).

Figure 27: % treated with respect and dignity, by tumour group



Leaving hospital

Information about what do after leaving hospital

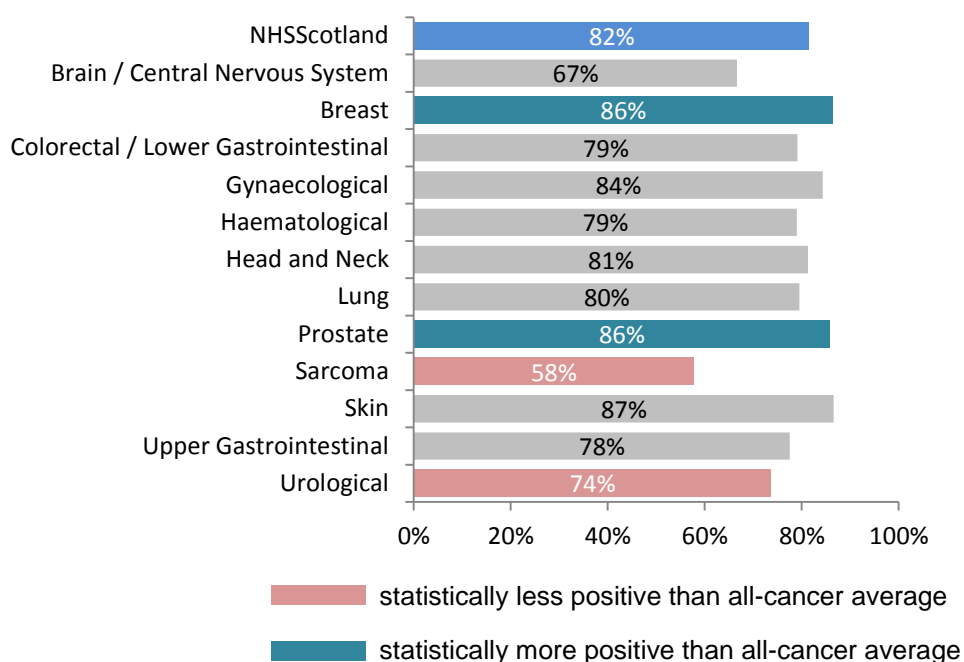
Around one in six patients (18%) were not given clear written information about what they should or should not do after leaving hospital (Table 36).

Table 36: Information about what to do after leaving hospital

Were you given clear written information about what you should or should not do after leaving hospital	n	%
Yes	2,944	82%
No	664	18%
Total	3,608	100%

Patients with breast and prostate tumours (both 86%) were statistically more likely than the all-cancer average to report that they were given clear written information about what they should or should not do after leaving hospital. Sarcoma (58%) and urological tumour patients (74%) were both statistically below average (Figure 28).

Figure 28: % given written information about what to do after leaving hospital, by tumour group



Who to contact after leaving hospital

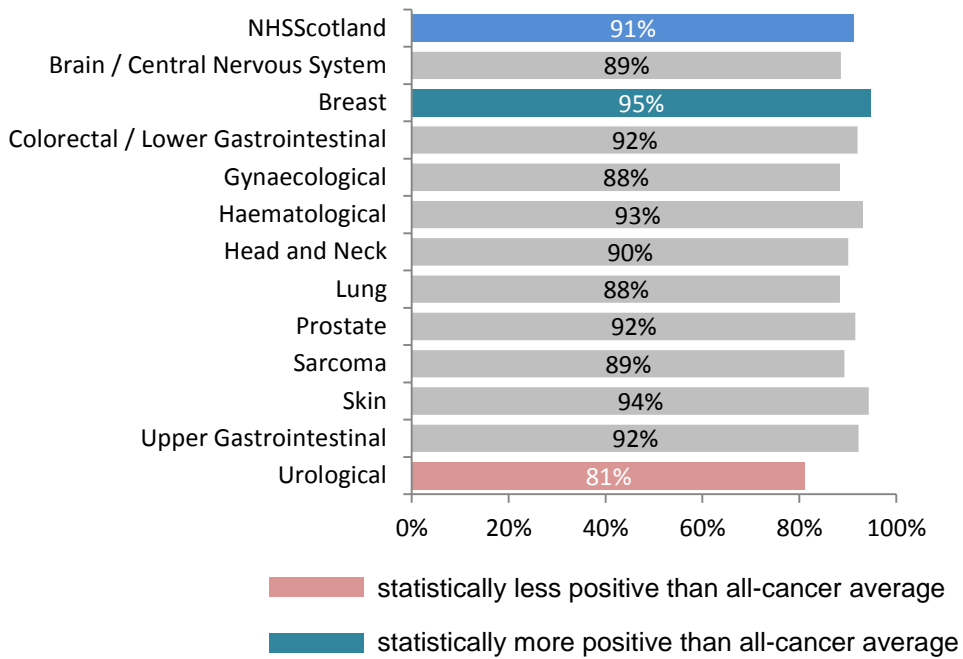
Patients were also asked whether hospital staff had told them who to contact if they were worried about their condition or treatment after they had left hospital. Around one in ten (9%) patients were not told who to contact if they were worried about their condition or treatment after they left hospital (Table 37).

Table 37: Who to contact after leaving hospital

Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	n	%
Yes	3,401	91%
No	327	9%
Total	3,728	100%

Only two tumour groups were statistically different from the all-cancer average. Breast tumour patients (95%) were more likely to report being told who to contact if they were worried about their condition and urological tumour patients (81%) were less likely to report being told this (Figure 29).

Figure 29: % told who to contact after leaving hospital, by tumour group



Hospital care as day patient/outpatient

When patients go to hospital for shorter periods of time – such as for specialist clinics, treatment, or follow-ups – it is equally important for them to experience continuity of care, feel supported and informed, and be able to access someone to speak to about any worries and fears.

Questions in this section seek to gauge people's experiences of these aspects of care.

One of the areas explored is whether patients received coordinated and consistent administration. One key to good care is health professionals having the correct records and documents, not only for medical accuracy but also to instill confidence and trust in the care being received and to avoid patients having to repeat details of their care to date.

The majority of patients (84%) had been treated as an outpatient or day case for cancer care (Table 38).

Table 38: Treatment as outpatient or day case

Have you been treated as an outpatient or day case for cancer care?	n	%
Yes	4,018	84%
No	742	16%
Total	4,760	100%

Worries or fears as outpatient/ day patient

Patients were asked whether they were able to find someone on the hospital staff to talk to about their worries and fears. Nineteen per cent of patients reported that they did not have worries or fears, indicating that around four in five patients do experience worries or fears during outpatient or day case episodes (a higher rate than for inpatient stays).

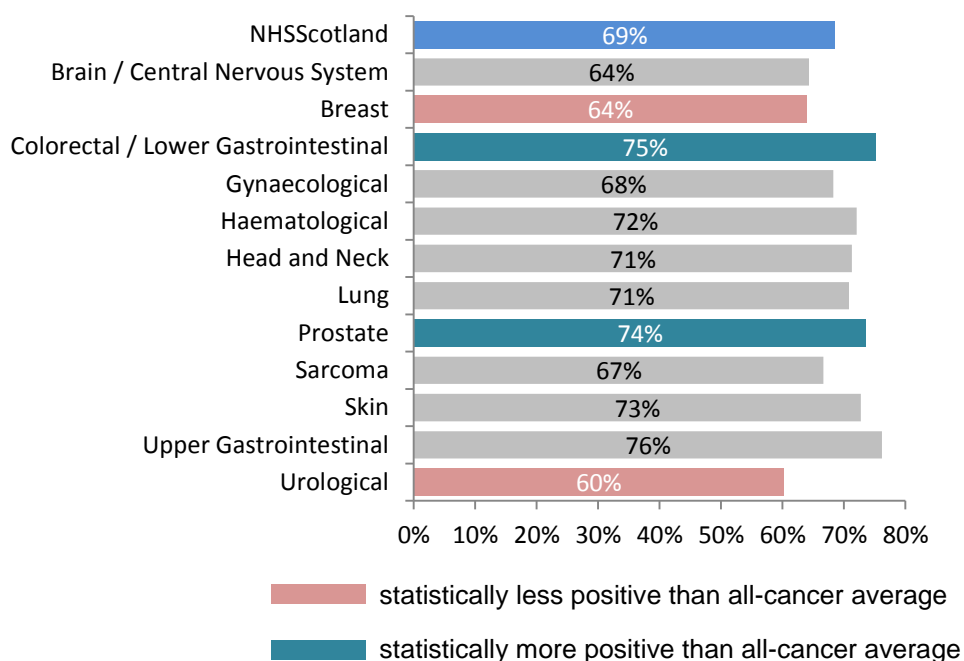
Of the patients that did experience worries/fears, around one in ten (9%) were not able to find someone to talk to (Table 39). This is a more positive result than the similar question asked for inpatient cancer treatment, where double the proportion of patients (18%) were unable to find someone to speak to about their worries or fears.

Table 39: Worries and fears as outpatient / day case

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?	n	%
Yes, definitely	2,173	69%
Yes, to some extent	701	22%
No	294	9%
Total	3,168	100%

Patients with breast (64%) and urological tumours (60%) were both statistically below the all-cancer average in reporting being able to find someone to speak to about their worries and fears. Patients with colorectal / lower gastrointestinal (75%) and prostate tumours (74%) were both statistically above average (Figure 30).

Figure 30: % finding staff member to talk to about worries or fears, by tumour group



Right documents available for outpatient appointment

In the overwhelming majority of cases (98%), patients reported that cancer doctors had the right paperwork for their outpatient appointment (Table 40).

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Table 40: Right documents available for outpatient appointment

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?	n	%
Yes	3,707	98%
No	95	2%
Total	3,802	100%

Radiotherapy and Chemotherapy

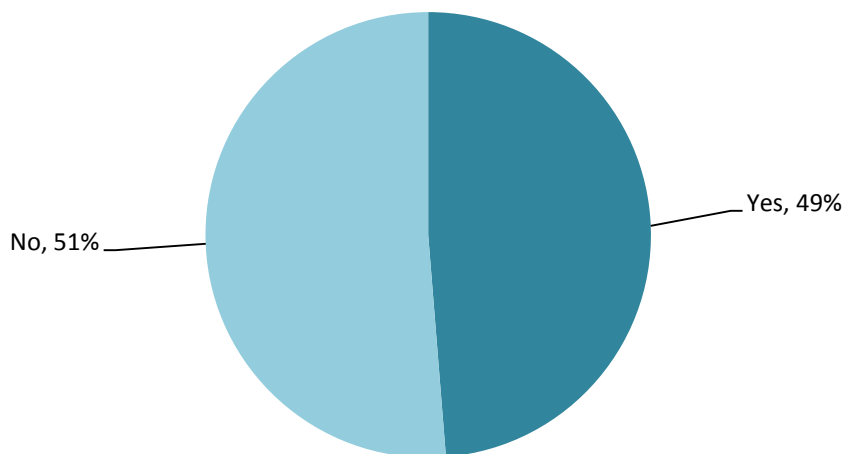
Going through chemotherapy and radiotherapy can be a very difficult experience. To help them prepare, patients, families and carers should be offered all the information they need, in a format they can understand. They should also be kept informed of how the treatment is progressing if they want this.

Clarity of communication is crucial given the many different types of chemotherapy drugs and types of radiotherapy, the rate at which new drugs and techniques emerge, and the many possible side effects that patients can experience, both during the actual course of treatment and in the future.

Radiotherapy

Around half of survey respondents (49%) had received radiotherapy treatment (Figure 31).

Figure 31: Has patient received radiotherapy treatment?



The patients that had received radiotherapy were asked:

- whether they had all the information they needed beforehand about their radiotherapy treatment; and
- whether once they had started their treatment, they were given enough information about whether their radiotherapy was working in a way they could understand.

Patients were noticeably more positive about having all of the information they required beforehand (81% responding 'yes, completely') than they were about getting enough information on whether the treatment was working (only 54% responding 'yes, completely') (Table 41).

Table 41: Information about radiotherapy treatment

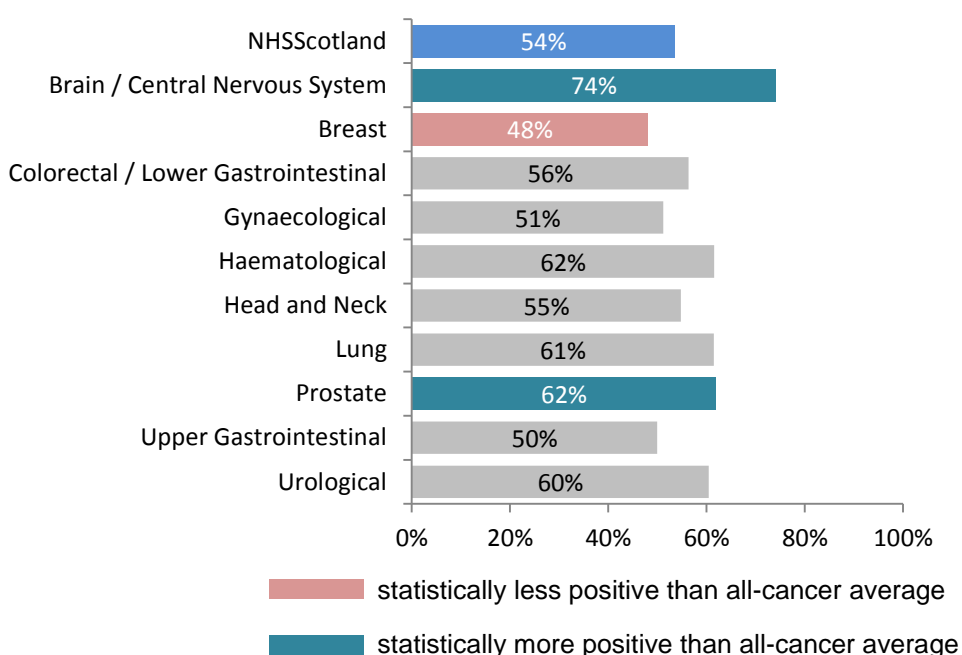
Beforehand, did you have all of the information you needed about your radiotherapy treatment?	n	%
Yes, completely	1,829	81%
Yes, to some extent	354	16%
No	65	3%
Total	2,248	100%

Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	n	%
Yes, completely	1,083	54%
Yes, to some extent	554	27%
No	383	19%
Total	2,020	100%

Whilst there was no influence from tumour group on the question regarding having information beforehand, responses did vary on the question regarding information on whether the radiotherapy treatment was working once it had started.

Breast tumour patients were statistically less positive (48%) than the all-cancer average. Patients with brain / central nervous system (74%) and prostate tumours (62%) were more positive than the all-cancer average (Figure 32).

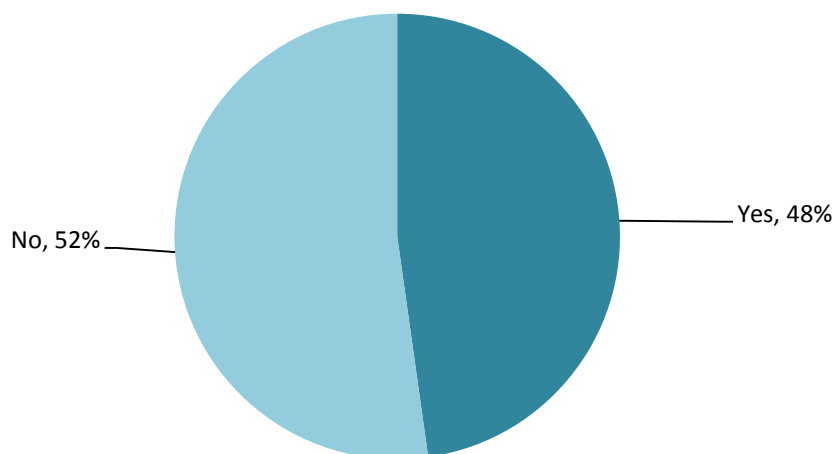
Figure 32: % receiving enough information about whether radiotherapy was working, by tumour group



Chemotherapy

As with radiotherapy, around half of survey respondents (48%) had received chemotherapy treatment (Figure 33).

Figure 33: Has patient had chemotherapy treatment?



The patients that had received chemotherapy were also asked:

- whether they had all the information they needed beforehand about their chemotherapy treatment; and
- whether once they had started their treatment, they were given enough information about whether their chemotherapy was working in a way they could understand.

Results showed a similar pattern to the radiotherapy questions. Patients were more positive about receiving the required information before their chemotherapy treatment (77% 'yes, completely') than they were about receiving information on whether the treatment working once it had started (62% 'yes, completely') (Table 42).

Table 42: Information about chemotherapy treatment

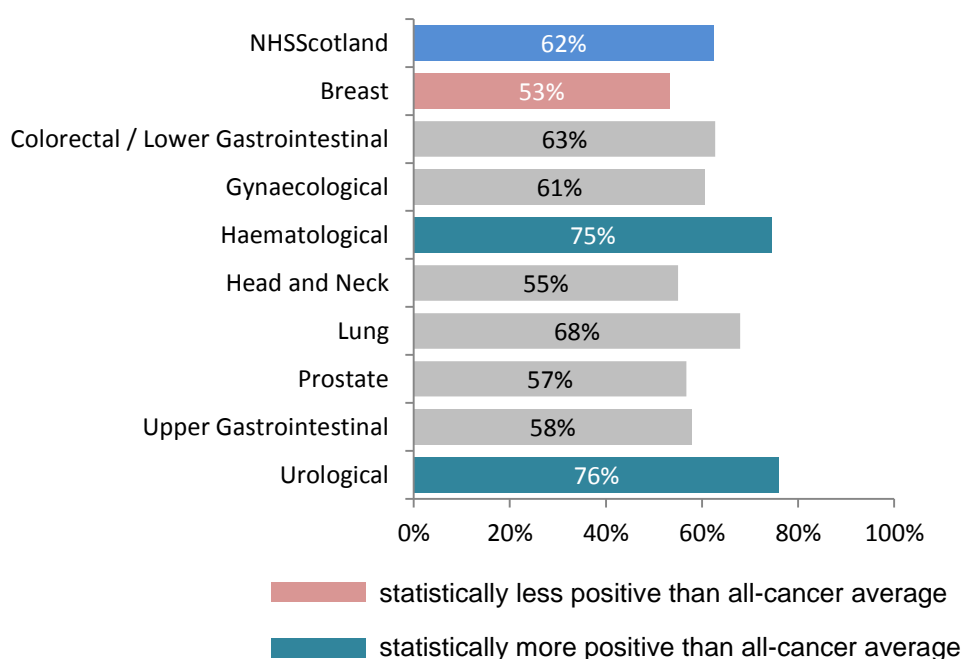
Beforehand, did you have all of the information you needed about your chemotherapy treatment?	n	%
Yes, completely	1,695	77%
Yes, to some extent	441	20%
No	68	3%
Total	2,204	100%

Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	n	%
Yes, completely	1,266	62%
Yes, to some extent	565	28%
No	197	10%
Total	2,028	100%

There was no effect of tumour group on the question regarding information beforehand. However, responses did vary on the question regarding information on whether the chemotherapy treatment was working once it had started.

Patients with breast tumours (53%) were statistically below the all-cancer average in reporting that they had received this information in a way they could understand. Patients with urological (76%) and haematological tumours (75%) were statistically above average (Figure 34).

Figure 34: % receiving enough information about whether radiotherapy was working



Home Care and Support

Both during and after treatment most patients will require help and support at home from family and friends. For others to help with cancer patients' care, adequate information is needed.

Similarly, many patients will need to access health and social care services (such as district nurses, home helps, and physiotherapists) both during and after treatment. Feeling adequately supported and cared for by these services is vital for both a positive care experience while in hospital and for the transition out of the hospital care setting.

Information to family and friends to help care for patient at home

Patients were asked whether doctors or nurses gave their family or someone close to them all the information they needed to help care for the patient at home.

Sixteen per cent of patients responded that either there were no family or friends involved, or their family or friends did not need information.

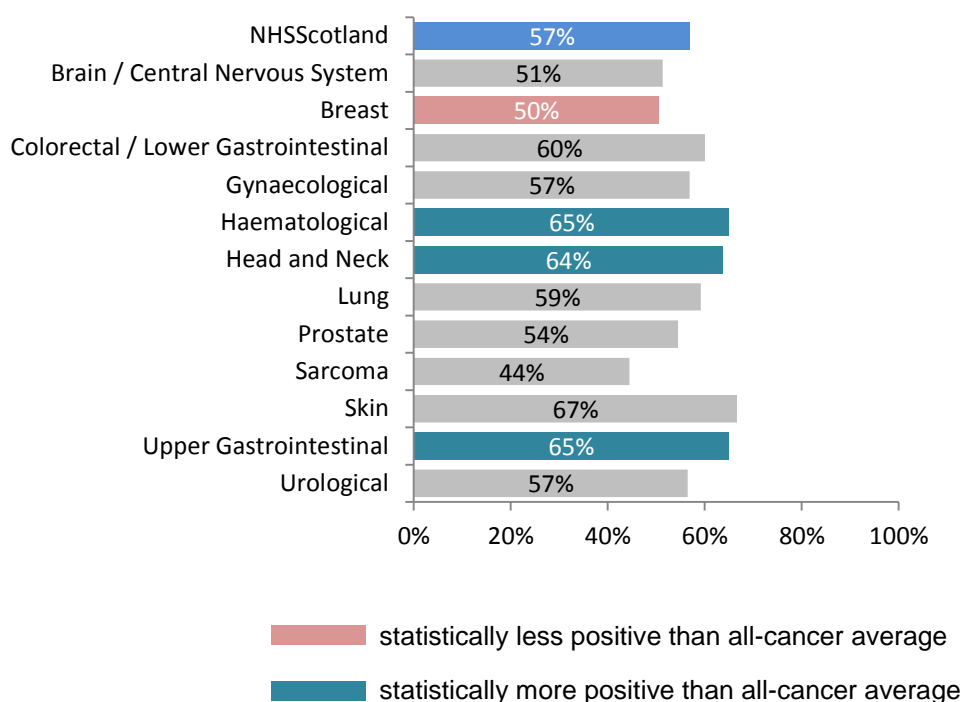
Of the patients that did want their family or friends to have information to help care for them, one in five (20%) reported that doctors or nurses did not provide this. A further 23 per cent of patients responded that this information was only received 'to some extent' (Table 43).

Table 43: Information to family and friends to help care for patient at home

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?	n	%
Yes, definitely	2,196	57%
Yes, to some extent	876	23%
No	783	20%
Total	3,855	100%

Patients with breast tumours (50%) were statistically below the all-cancer average in reporting that doctors had given someone close to them the information they needed to care for the patient at home. Patients with haematological and upper gastrointestinal tumours (both 65%) were statistically above average (Figure 35).

Figure 35: % reporting information provided to family and friends to help care for patient at home, by tumour group



Support from health and social services during treatment

Patients were asked whether they were given enough support from health or social services during their cancer treatment. Forty-two per cent of patients responded that they did not need such support.

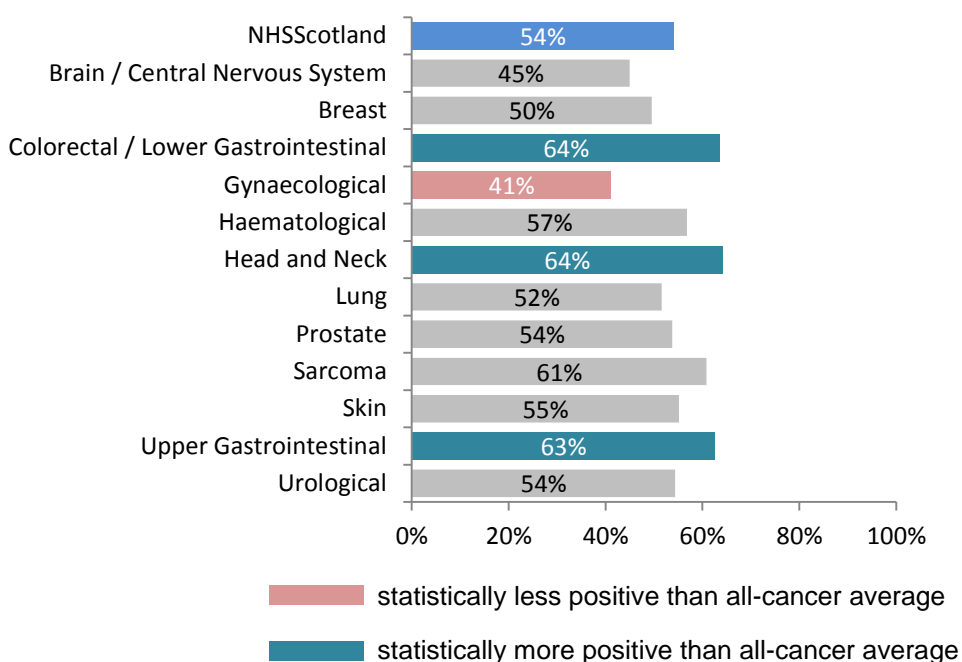
Of those patients that did need it, a quarter (25%) reported that they did not receive enough support during their treatment. A further 21 per cent of patients only responded that they received enough support 'to some extent' (Table 44).

Table 44: Support from health and social services during treatment

During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	n	%
Yes, definitely	1,430	54%
Yes, to some extent	555	21%
No	660	25%
Total	2,645	100%

The only tumour group statistically below the all-cancer average for this question was patients with gynaecological tumours (41%) (Figure 36).

Figure 36: % receiving enough support from health or social services during treatment, by tumour group



Support from health and social services after treatment

Patients were also asked whether they were given enough support from health or social services *after* their cancer treatment.

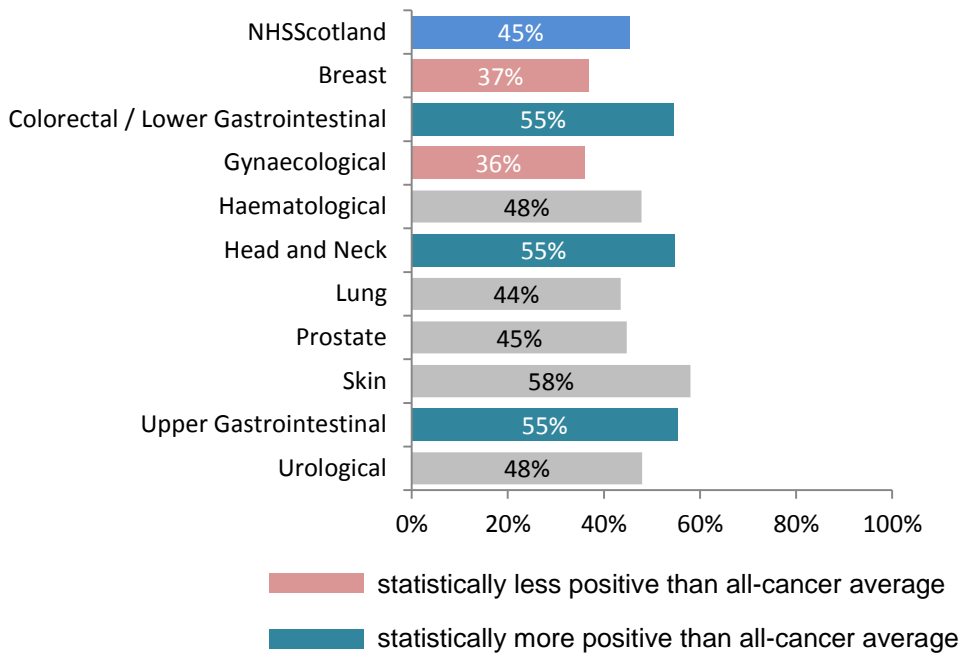
Over half of patients (54%) responded either that they did not need support, or they were still receiving treatment.

Of those that did need it, around a third of patients (32%) reported that they did not receive enough care and support after their treatment. A further 23 per cent of patients only responded that they received enough support ‘to some extent’ (Table 45). These results are less positive than those for the question regarding care and support *during* treatment.

Table 45: Support from health and social services after treatment

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)?	n	%
Yes, definitely	953	45%
Yes, to some extent	476	23%
No	672	32%
Total	2,101	100%

Figure 37: % receiving enough care and support from health or social services after treatment, by tumour group



Patients with colorectal / lower gastrointestinal, head and neck, and upper gastrointestinal tumours were all statistically above the all cancer average for receiving enough care and support from health or social services (all had 55% responding 'yes definitely') (Figure 37)

Care from GP practice

During treatment a cancer patient will often continue to need the support and care of their local general practitioner and nurses. When treatment finishes and a cancer patient's care returns to being primarily delivered by their local general practice surgery, there are several significant factors, such as the availability of comprehensive records and sufficient support, which facilitate the shift in focus from treating the disease to overall health and wellbeing.

GPs and the wider multi-disciplinary teams need sufficient information about a cancer patient's condition and treatment, as well as their ongoing support needs, in order to deliver coordinated care that smoothly transitions from a secondary care setting back to primary and community care settings.

GP receiving information about hospital treatment

The large majority of patients (96%) reported that, as far as they knew, their GP was given enough information about their condition and treatment at hospital (Table 46).

Table 46: GP receiving information about hospital treatment

As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	n	%
Yes	3,749	96%
No	173	4%
Total	3,922	100%

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Support from GP practice during cancer treatment

Patients were asked whether the GPs and nurses had done everything they could to support them while they were having cancer treatment. Seventy per cent of patients felt that GPs and practice nurses had 'definitely' done all they could. Most of the remainder felt that this had been the case 'to some extent' (22%) (Table 47).

Table 47: Support from GP practice during treatment

Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	n	%
Yes, definitely	2,535	70%
Yes, to some extent	779	22%
No, they could have done more	304	8%
Total	3,618	100%

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Overall NHS Care

The survey asks about the coordination of the patients' care across all health professionals, the administration of records and appointments, and the wait times at various clinical appointments. These all contribute to how patients experience the quality of their care.

It is also important for patients to know that should they want to participate in cancer research, they have the opportunity to do so.

Finally, a care plan is a document that sets out the patients' needs and goals for caring for their cancer. It is an agreement or plan between the patient and their health professional to help meet those goals.

Different practitioners working together

Eighty-nine per cent of patients considered that the different people treating them had worked well together to give them the best possible care 'always' or 'most of the time' (Table 48).

Table 48: Different practitioners working well together

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?	n	%
Yes, always	2,867	63%
Yes, most of the time	1,190	26%
Yes, some of the time	373	8%
No, never	111	2%
Total	4,541	100%

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Cancer research

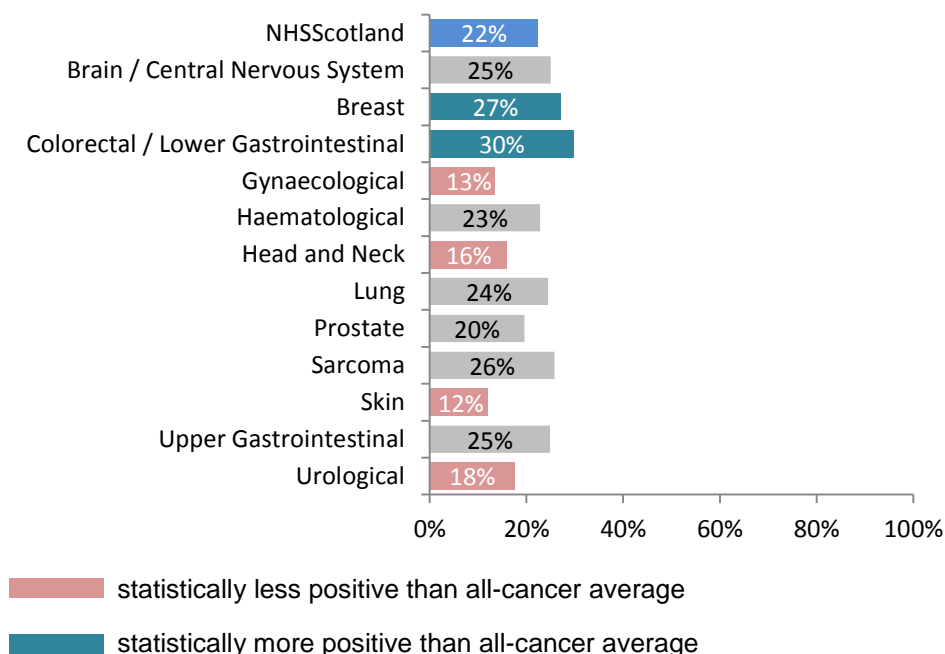
Patients were asked whether anyone had discussed taking part in cancer research with them. Only 22 per cent of patients reported that they had discussed this. However, of the patients who had not been involved in a discussion regarding research, only a minority would have liked to have been (Table 49).

Table 49: Discussion about taking part in cancer research

Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	n	%
Yes	1,007	22%
No	3,280	73%
No, but I would have liked them to	198	4%
Total	4,485	100%

Patients with colorectal / lower gastrointestinal (30%) and breast (27%) tumours were statistically more likely to have had a discussion regarding taking part in research than the all-cancer average. Tumour groups that were statistically below average included skin (12%) and gynaecological (13%) (Figure 38).

Figure 38: % receiving discussion about taking part in cancer research, by tumour group



Administration of care

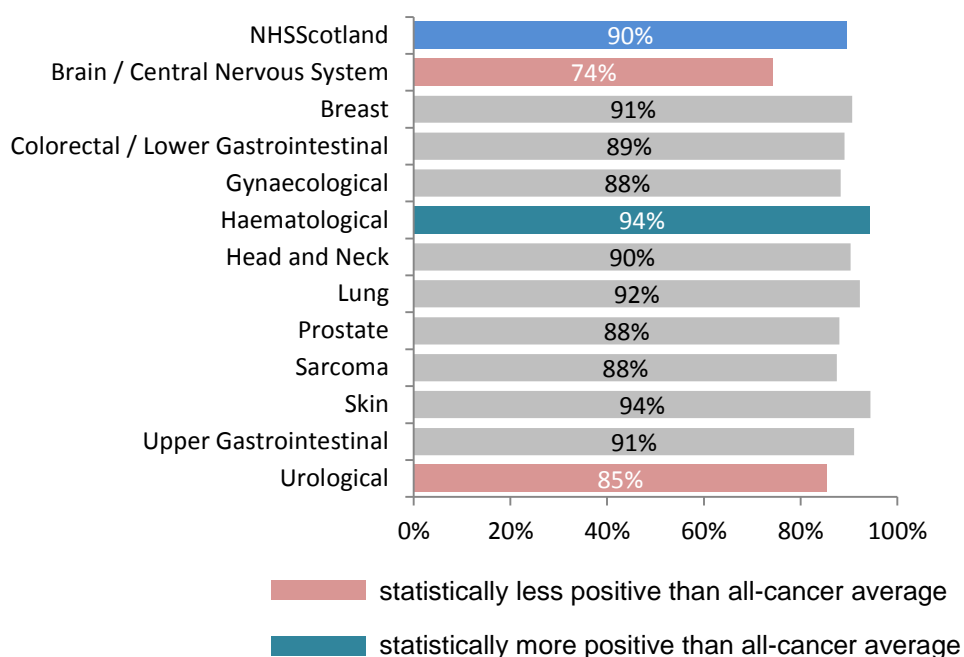
Patients were generally positive about the administration of their care. Ninety per cent rated the administration as either 'very good' or 'good'. Three per cent of patients described it as 'quite bad' or 'very bad' (Table 50).

Table 50: Administration of care

Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?	n	%
Very good	2,832	60%
Good	1,368	29%
Neither good nor bad	328	7%
Quite bad	111	2%
Very bad	51	1%
Total	4,690	100%

Statistical differences from the all-cancer average included haematological tumour patients, who were above average with 94 per cent responding ‘very good’ or ‘good’ (Figure 39).

Figure 39: % rating administration of care as ‘very good’ or ‘good’, by tumour type



Waits when attending clinics and appointments

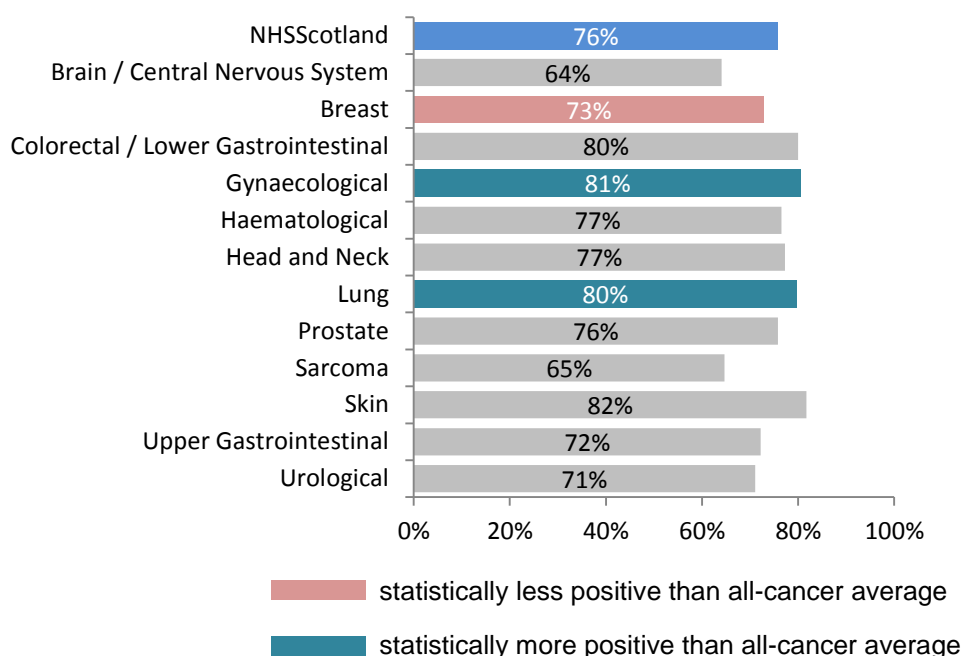
Overall, around a quarter of patients described the length of time they had to wait when attending clinics and appointments as either ‘much too long’ (6%) or ‘a little too long’ (19%) (Table 51).

Table 51: Waits at clinics and appointments

Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	n	%
Much too long	258	6%
A little too long	866	19%
About right	3,521	76%
Total	4,645	100%

Patients with breast tumours (73%) were statistically less likely than the all-cancer average to describe their waits for clinics and appointments as ‘about right’ (73%). Patients with colorectal / lower gastrointestinal (80%) and gynaecological tumours (81%) were both statistically more likely than average (Figure 40).

Figure 40: % reporting waits at clinics and appointments as ‘about right’, by tumour group



Care plan

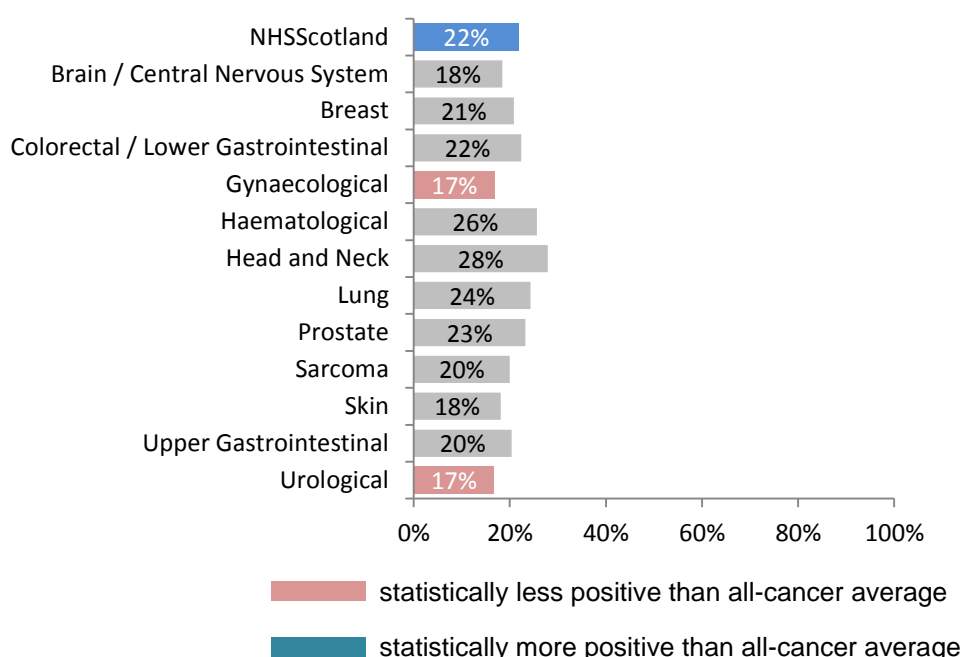
Patients were asked whether they had been given a care plan. Only twenty-two per cent of patients confirmed that they had been given a care plan. The other patients responded that they either did not have one (66%) or did not know what a care plan was (12%), which is strongly suggestive that they did not have one (Table 52).

Table 52: Care plan

Have you been given a care plan?	n	%
Yes	913	22%
No	2,759	66%
I do not know / understand what a care plan is	496	12%
Total	4,168	100%

The only tumour groups which were statistically different from the all-cancer average were gynaecological and urological tumours, which were both below average at 17 per cent (Table 41).

Figure 41: % given care plan, by tumour group



Fifty of the questions in the survey had response options that could be categorised as either positive or negative (Annex C). For each of these questions, the percentage of patients with a care plan responding positively was compared to the percentage of patients responding positively who did not have a care plan, or did not know what one was.

For every single question, patients who had a care plan responded statistically more positively. This included the overall rating of care (98% positive response amongst those with a care plan vs 92% positive response amongst those without a care plan) and large differences for questions such as receiving enough care and support from health or social services after treatment (73% vs 34%) and receiving information about how to get financial help and benefits (75% vs 42%).

Overall rating of care

At the conclusion of the survey, patients were asked to provide an overall rating of the cancer care they had received. The scale ranged from 0 ('very poor') to 10 ('very good'). Responses were highly positive with 94 per cent of patients selecting a rating between seven and ten. One per cent of patients gave a negative rating (0-3) (Table 53, Figure 42).

Figure 42: Breakdown of overall rating of care

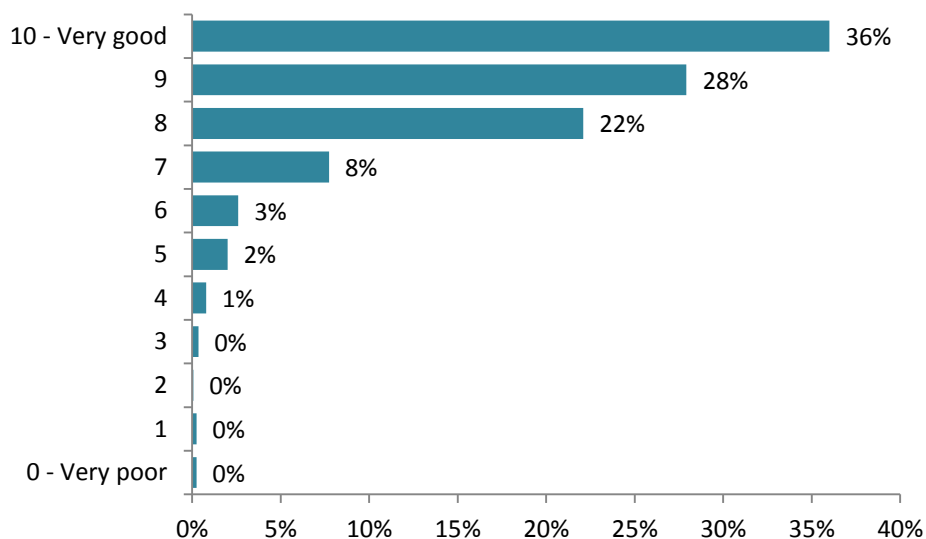


Table 53: Overall rating of care

Overall, how would you rate your care (scale from 0 to 10)?	n	%
Positive (7-10)	4,320	94%
Neutral (4-6)	248	5%
Negative (0-3)	41	1%
Total	4,609	100%

There was some variation in responses from different tumour groups. However, statistical tests concluded that these differences as a whole were not statistically significant.

Differences in experiences between most and least deprived areas

The social causes of health inequalities are often deep rooted and complex, with socio-economic position being based on multiple factors, including educational level, employment status, housing situation, and skills training.

Residing in a deprived area is associated with unfavourable health outcomes of residents across the full clinical course of cancer, from the stage at diagnosis through to survival⁷. This can be linked to a range of possible reasons, such as: variations in cancer incidence and prevalence across the deprivation categories in Scotland; literacy or language challenges to information comprehension; or differences in uptake of treatments.

Analysis was conducted to investigate whether patients' responses varied depending on how deprived the area they lived in was. The Scottish Index of Multiple Deprivation (SIMD)⁸ was used as the measure of deprivation, with survey respondents assigned to one of five SIMD quintiles (SIMD 1 being the most deprived and SIMD 5 the least deprived).

Fifty questions in the survey had response options that could be categorised as either positive or negative (annex ref). For each of these questions, the percentage responding positively in the most-deprived SIMD quintile and in the least deprived SIMD quintile were compared to see if they were different to a statistically significant degree.

Fourteen of the fifty were significantly different. In the majority of cases (10/14), patients from the least deprived areas were more positive (Table 54).

One particular topic on which those in the least deprived areas reported more positive experiences related to patients receiving explanations in a way that they could understand. Three of the ten questions where patients from the least deprived areas were significantly more positive related to this (Table 54).

Questions where patients from the most deprived areas responded more positively included whether hospital staff had provided information about how to get financial help and benefits (57% vs 50%), and whether the patient had been provided a care plan (26% vs 19%).

⁷ https://www.isdscotland.org/Health-Topics/Cancer/Publications/2015-11-17/dim_cancer_all_types.xls

⁸ <http://www.gov.scot/Topics/Statistics/SIMD>

Table 54: Significant differences in % positive response between most and least deprived SIMD quintiles

Section / Question	SIMD quintile				
	1=most deprived	2	3	4	5=least deprived
Seeing the GP					
How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	85%	84%	81%	81%	81%
Diagnostic tests					
Beforehand, did you have all the information you needed about your test?	88%	91%	93%	93%	93%
Were the results of the test explained in a way you could understand?	78%	80%	81%	81%	83%
Finding out what was wrong					
Did you understand the explanation of what was wrong with you?	72%	74%	74%	78%	79%
Support for people with cancer					
Did hospital staff give you information about support or self-help groups for people with cancer?	77%	79%	79%	81%	82%
Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	57%	54%	52%	45%	50%
Operations					
After the operation, did a member of staff explain how it had gone in a way you could understand?	76%	79%	80%	82%	81%
Hospital care as an inpatient					
Did groups of doctors and nurses talk in front of you as if you weren't there?	74%	83%	80%	82%	85%
While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	69%	66%	68%	68%	58%
Home care and support					
During your cancer treatment, were you given enough care and support from health or social services?	52%	57%	55%	51%	59%
Care from GP practice					
As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	93%	96%	95%	97%	97%
Overall NHS care					
Have you been given a care plan?	26%	22%	23%	21%	19%
Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	21%	22%	21%	24%	25%
Overall, how would you rate your care?	92%	93%	94%	95%	95%

 Denotes most positive out of the 1st or 5th quintile

Annex A: Survey questionnaire



Cancer Patient Experience Survey

This survey is about your experiences of cancer care received in Scotland.

The responses you give will help improve cancer services and support.
All of the answers you provide will be entirely confidential.

Please read the enclosed letter for more information about this survey.



If you would prefer, you may also complete this survey online:

Go to www.quality-health.co.uk/scc15

Or scan the QR Code with your tablet / smartphone →



To do this you will need to enter the User name and Password which can be found on the letter which came with this survey.

Instructions

The questions should be answered by the person named on the letter which came with the survey. A friend or carer can help you complete the survey but the answers should be yours not theirs.

The survey takes around 20 minutes to complete. Please answer all questions, unless the instructions ask you to skip a question. For each question, please place a tick in the box next to the answer that most closely matches your own experience. For example, if your answer is yes, write in a tick as below:

Yes

No

Don't worry if you make a mistake. Simply cross it out and tick the correct answer.



Helpline
0800 783 1775
Monday – Friday
9am – 5pm

Please return in the envelope provided or to:

Quality Health
FREEPOST RSKS-ZERR-UAGY
Unit 1, Holmewood Business Park
Chesterfield Road
Holmewood
Chesterfield
S42 5US

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. Have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?

- 1 Yes → **Go to Q5**
- 2 No → **Go to Q9**

Thinking about the LAST time you had a diagnostic test for your cancer....

5. Beforehand, did you have all the information you needed about your test? (Tick **ALL** that apply)
 - 1 Yes
 - 2 No, I would have liked more **written** information
 - 3 No, I would have liked more **verbal** information
 - 4 I did not need / want any information
 - 5 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

8. Did the test take place at the hospital named on the letter that came with this survey?

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

FINDING OUT WHAT WAS WRONG WITH YOU

9. 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 It was not necessary
- 4 I was told by phone or letter
- 5 Don't know / can't remember

10. 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

11. 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

12. 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

If there is anything else you would like to tell us about the lead-up to your cancer diagnosis, or the way you found out you had cancer, please do so here.

DECIDING THE BEST TREATMENT FOR YOU

13. 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

14. 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

15. 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

16. 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

17. Were you involved as much as you wanted to be in decisions about your care and treatment?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would like to have been more involved
- 4 Don't know / can't remember

If there is anything else you would like to tell us about the way decisions were made about your treatment please do so here.

CLINICAL NURSE SPECIALIST

A Clinical Nurse Specialist is a specialist cancer nurse who helps you get the right care and gives you help and advice on coping with cancer.

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

- 1 Yes → Go to Q19
- 2 No → Go to Q21
- 3 Don't know / can't remember → Go to Q21

19. 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 did not try to contact my Clinical Nurse Specialist

20. 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

21. 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

22. 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

23. 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

If there is anything else you would like to tell us about the support you received (including from a clinical nurse specialist) please do so here.

OPERATIONS

24. Have you had an operation (such as removal of a tumour or lump) for your cancer?

- 1 Yes → Go to Q25
 2 No → Go to Q28

Thinking about the LAST time you went into hospital for an operation for your cancer ...

25. Beforehand, did you have all the information you needed about your operation? (**Tick ALL that apply**)

- 1 Yes
 2 No, I would have liked more **written** information
 3 No, I would have liked more **verbal** information
 4 I did not need / want information
 5 Don't know / can't remember

26. After the operation, did a member of staff explain how it had gone in a way you could understand?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, but I would have liked an explanation
- 4 I did not need an explanation

27. Did the operation take place at the hospital named on the letter that came with this survey?

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

HOSPITAL CARE AS AN INPATIENT

28. Have you had an operation or stayed overnight **for cancer care**?

- 1 Yes → Go to Q29
- 2 No → Go to Q42

Thinking about the LAST time you had an operation or stayed overnight for cancer care...

29. Did groups of **doctors and nurses** talk in front of you as if you weren't there?

- 1 Yes, often
- 2 Yes, sometimes
- 3 No

30. 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

31. 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

32. 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

33. 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

34. While you were in hospital did the **doctors and nurses** ask you what name you prefer to be called by?

- 1 Yes, all of them did
- 2 Only some of them did
- 3 None of them did

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

- 1 Yes, always
- 2 Yes, sometimes
- 3 No

36. 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

37. 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

38. Overall, did you feel you were treated with respect and dignity while you were in hospital?

- 1 Yes, always
 2 Yes, sometimes
 3 No

39. 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

40. 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

41. Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?

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

If there is anything else you would like to tell us about the care you received when you had an operation or stayed overnight in hospital, please do so here.

HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT

42. Have you been treated as an outpatient or day case **for cancer care**?

- 1 Yes → **Go to Q43**
 2 No → **Go to Q46**

Thinking about the LAST time you attended hospital as a day patient or outpatient for cancer care ...

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 didn't have an appointment with a cancer doctor
- 4 Don't know / can't remember

45. The last time you attended hospital as a day case or outpatient, was this at the hospital named on the letter that came with this survey?

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

If there is anything else you would like to tell us about the day patient/outpatient care you received please do so here.

RADIOTHERAPY AND CHEMOTHERAPY

46. Have you had radiotherapy treatment?

- 1 Yes → **Go to Q47**
- 2 No → **Go to Q50**

47. 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

48. 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

49. Did your radiotherapy treatment take place at the hospital named on the letter that came with this survey?

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

50. Have you had chemotherapy treatment?

- 1 Yes → **Go to Q51**
- 2 No → **Go to Q54**

51. 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

52. 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

53. Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?

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

If there is anything else you would like to tell us about your chemotherapy / radiotherapy treatment please do so here.

HOME CARE AND SUPPORT

54. 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

55. **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

56. 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

57. 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

58. 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

59. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?

1 Yes, always

2 Yes, most of the time

3 Yes, some of the time

4 No, never

5 Don't know / can't remember

60. 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

61. 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

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

1 Much too long

2 A little too long

3 About right

4 Don't know / can't remember

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

1 Yes

2 No

3 No, but I would have liked them to

4 Don't know / can't remember

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

Very poor

Very good

0 1 2 3 4 5 6 7 8 9 10

If there is anything else you would like to say about your experiences of cancer care please do so here.

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 named on the covering letter

65. 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

66. 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 Q68**
- 2 No → **Go to Q67**
- 3 Don't know → **Go to Q68**
- 4 Does not apply to my type of cancer → **Go to Q68**

67. 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.

68. What was your age on your last birthday?

69. Are you male or female?

- 1 Male
- 2 Female

70. Which of the following best describes your sexual orientation? (**Tick one box only**)

- 1 Heterosexual / straight
- 2 Bisexual
- 3 Gay or Lesbian
- 4 Other

71. What is your ethnic group?

*(Tick **ONE** box which **best describes** your ethnic group)*

- 1 White
- 2 Mixed or multiple ethnic groups
- 3 Asian, Asian Scottish or Asian British
- 4 African, Caribbean or Black
- 5 Other ethnic group

72. What is your **main** employment status?
(If on maternity or sick leave answer in relation to your usual employment status)

- 1 Work full time
- 2 Work part time
- 3 In full time education or training
- 4 Retired
- 5 Unemployed / looking for work
- 6 Don't work due to illness or disability
- 7 Other

73. Do you have any of the following?
*Please tick **ALL** that apply*

- 1 Deafness or severe hearing impairment
- 2 Blindness or severe vision impairment
- 3 A physical disability
- 4 A learning disability
- 5 A mental health condition
- 6 Chronic pain lasting at least 3 months
- 7 Another long-term condition
- 8 None of the above

74. Could NHS Scotland, the Scottish Government, or Macmillan Cancer Support send you a survey in the future to ask about cancer and cancer care?

- 1 Yes, and I understand that this does **NOT** mean that I would have to take part in the survey
- 2 No, I would prefer you not to contact me again

We would like your permission to add your survey responses to other information held about your health and care by NHS Scotland (e.g. about the kind of treatment you have had for your cancer or whether or not you have any other health conditions). Your information will be used only for research and it will not be possible to identify you individually.

If you give your permission to add your survey results to other health and care information held about you, it will not be shared with the people who look after you and will in no way affect your current or future treatment or care.

75. Do you give your permission for NHS Scotland Statisticians to add your survey results to other information about your health and care for the purpose of this cancer patient experience survey?

- 1 Yes
- 2 No

76. Do you give your permission for NHS Scotland Statisticians to add your survey results to other information about your health and care for the purposes of other future research?

The future research would be conducted by NHS Scotland, the Scottish Government, Macmillan Cancer Support, or an organisation working on their behalf.

- 1 Yes
- 2 No

Annex B: Significance testing

a. Comparison of results between most and least deprived SIMD quintiles

For each question where responses could be classed as positive or negative (see Annex C) significance testing was conducted to see if the percentage of those living in the least deprived SIMD quintile was significantly different from those living in the most deprived quintile.

The test statistic can be calculated as follows:

$$Z_{cal} = \frac{P_2 - P_1}{error}$$

To illustrate this, let the:

- percentage positive score for the most and least deprived SIMD quintiles be denoted by p_1 and p_2 respectively.
- number of valid responses from most and least deprived SIMD quintiles be denoted by n_1 and n_2 respectively.

The standard error can be calculated as:

$$error = \sqrt{\left[\frac{p_1 * (1 - p_1)}{n_1} \right] + \left[\frac{p_2 * (1 - p_2)}{n_2} \right]}$$

For a result in the most deprived quintile to not be statistically significantly different from the least deprived quintile, then

$$-Z_{\alpha/2} < Z_{cal} < Z_{\alpha/2}$$

For the purpose of this testing, α was 0.05

b. Tumour group scores

For each question where responses could be classed as positive or negative (see Annex C) a Pearson chi-square test was used to detect any statistically significant differences in the distribution of positive responses between tumour groups ($\alpha = 0.05$). This excluded patients where the tumour group was unknown, or their tumour type was included in the 'other' category.

Where statistically significant differences were found, significance testing was conducted to see if each tumour group was significantly different from the national

(or 'all-cancer') average. As per the SIMD analysis, the test statistic can be calculated as follows:

$$Z_{cal} = \frac{p_2 - p_1}{error}$$

To illustrate this, let the:

- percentage positive score for all respondents and the tumour group in question be denoted by p_1 and p_2 respectively.
- number of valid responses from all respondents and the tumour group in question be denoted by n_1 and n_2 respectively.

The standard error can be calculated as:

$$error = \sqrt{\left[\frac{p_1 * (1 - p_1)}{n_1} \right] + \left[\frac{p_2 * (1 - p_2)}{n_2} \right]}$$

A result for a particular tumour group was not statistically significantly different from the national (all-cancer) figure where

$$-Z_{\alpha/2} < Z_{cal} < Z_{\alpha/2}$$

For the purpose of this testing, α was 0.05

Annex C: Guide to positive scoring

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	I was seen as soon as I thought was necessary	I should have been seen a bit sooner	I should have been seen a lot sooner
5	Beforehand, did you have all the information you needed about your test?	Yes		No, I would have liked more written information No, I would have liked more verbal information
6	Overall, how did you feel about the length of time you had to wait for your test to be done?	It was about right	It was a little too long	It was much too long
7	Were the results of the test explained in a way you could understand?	Yes, completely	Yes, to some extent	No, I did not understand the explanation I did not have an explanation but would have liked one
9	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Yes		No
10	How do you feel about the way you were told you had cancer?	It was done sensitively	It should have been done a bit more sensitively	It should have been done a lot more sensitively
11	Did you understand the explanation of what was wrong with you?	Yes, I completely understood it	Yes, I understood some of it	No, I did not understand it

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
12	When you were told you had cancer, were you given written information about the type of cancer you had?	Yes, and it was easy to understand	-	Yes, but it was difficult to understand No, I was not given written information about the type of cancer I had
13	Before your cancer treatment started, were your treatment options explained to you?	Yes, completely	Yes, to some extent	No
14	Were the possible side effects of treatment(s) explained in a way you could understand?	Yes, definitely	Yes, to some extent	No, side effects were not explained
15	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	Yes, definitely	Yes, to some extent	No, I was not offered any practical advice or support
16	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?	Yes, definitely	Yes, to some extent	No, future side effects were not explained
17	Were you involved as much as you wanted to be in decisions about your care and treatment?	Yes, definitely	Yes, to some extent	No, but I would like to have been more involved
18	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	Yes	-	No

Question number	Original Question Text	Positive	Neither positive nor negative	Negative
19	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	Very easy Quite easy	Neither easy nor difficult	Quite difficult Very difficult
20	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	All or most of the time	Some of the time	Rarely or never
21	Did hospital staff give you information about support or self-help groups for people with cancer?	Yes		No, but I would have liked information
22	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)?	Yes		No, but I would have liked a discussion or information
23	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	Yes		No, but I would have liked information
25	Beforehand, did you have all the information you needed about your operation?	Yes		No, I would have liked more written information No, I would have liked more verbal information

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
26	After the operation, did a member of staff explain how it had gone in a way you could understand?	Yes, completely	Yes, to some extent	No, but I would have liked an explanation
29	Did groups of doctors and nurses talk in front of you as if you weren't there?	No	Yes, sometimes	Yes, often
30	Did you have confidence and trust in the doctors treating you?	Yes, in all of them	Yes, in some of them	No, in none of them
31	If your family or someone else close to you wanted to talk to a doctor, were they able to?	Yes, definitely	Yes, to some extent	No
32	Did you have confidence and trust in the ward nurses treating you?	Yes, in all of them	Yes, in some of them	No, in none of them
33	In your opinion, were there enough nurses on duty to care for you in hospital?	There were always or nearly always enough on duty	There were sometimes enough on duty	There were rarely or never enough on duty
34	While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	Yes, all of them did	Only some of them did	None of them did
35	Were you given enough privacy when discussing your condition or treatment?	Yes, always	Yes, sometimes	No

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
36	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	Yes, definitely	Yes, to some extent	No
37	Do you think the hospital staff did everything they could to help control your pain?	Yes, definitely	Yes, to some extent	No
38	Overall, did you feel you were treated with respect and dignity while you were in hospital?	Yes, always	Yes, sometimes	No
39	Were you given clear written information about what you should or should not do after leaving hospital?	Yes	-	No
40	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Yes	-	No
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?	Yes, definitely	Yes, to some extent	No

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
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?	Yes	-	No
47	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	Yes, completely	Yes, to some extent	No
48	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	Yes, completely	Yes, to some extent	No
51	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	Yes, completely	Yes, to some extent	No
52	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	Yes, completely	Yes, to some extent	No

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
54	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?	Yes, definitely	Yes, to some extent	No
55	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	Yes, definitely	Yes, to some extent	No
56	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)?	Yes, definitely	Yes, to some extent	No
57	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Yes	-	No
58	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	Yes, definitely	Yes, to some extent	No, they could have done more

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
59	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?	Yes, always Yes, most of the time	Yes, some of the time	No, never
60	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.	Yes	-	No I do not know / understand what a care plan is
61	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/tests results, etc)?	Very good Good	Neither good nor bad	Quite bad Very bad
62	Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	About right	A little too long	Much too long

Question number	Original Question Text	Positive %	Neither positive nor negative %	Negative %
63	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Yes	-	No No, but I would have liked them to
64	Overall, how would you rate your care (rating from 1 to 10)?	7,8,9,10	4,5,6	0,1,2,3

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