

Cancer Patient Experience Survey 2015

Results for Edinburgh Cancer Centre



June 2016, Official Statistics

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Introduction

This report gives a summary of the results of the NHS Scotland Cancer Patient Experience Survey 2015 for patients who were treated at Edinburgh Cancer Centre.

Survey questionnaires were sent out in October 2015 to 826 patients who were diagnosed with cancer between 1st July 2013 and 31st March 2014 and who received cancer treatment and care at Edinburgh Cancer Centre between 1st January 2014 and 30th September 2014.

The survey asked questions about people's experiences of diagnosis, treatment, support, operations, in / outpatient care and home care / support. You can find a full copy of the survey at:

www.gov.scot/cancersurvey

558 Edinburgh Cancer Centre patients (68%) returned feedback on their experiences. Of those patients willing to provide information about themselves:

- 32% were male and 68% were female.
- 0% were aged 16 - 25; 2% were aged 26 - 35; 12% were aged 36 - 50; 38% were aged 51 - 65; 32% were aged 66 - 75 and 16% were aged 76 and over.
- 53% did not have any limiting illness or disability.

The survey was commissioned by the Scottish Government as part of the Scottish Care Experience Survey Programme, which aims to use the public's experiences of health and care services to improve those services. The survey was jointly funded by Macmillan Cancer Support and the Scottish Government and was managed by the Scottish Government in partnership with Macmillan Cancer Support and ISD Scotland (part of NHS National Services Scotland). The survey fieldwork was carried out by Quality Health Ltd.

The results of the survey will be used by Edinburgh Cancer Centre and the Scottish Government to improve the quality of cancer care in Scotland by focusing on the areas that patients tell us are important to them and where they consider improvements could be made.

Please note that many of the patients who responded to the survey will have had contact with a variety of treatment centres / hospitals during their cancer journey, therefore some of their experiences may relate to treatment or care that did not take place at Edinburgh Cancer Centre. For example, questions 1 - 3, 55 - 56 and 58 relate to GP and / or community-based care.

National results for this survey and further details of the methods used to generate this report are available at:

www.gov.scot/cancersurvey

Chapter 1. Overall Results for Edinburgh Cancer Centre

The tables / charts in this chapter show how patients treated at this hospital responded to questions about their cancer care. Results for this hospital are shown alongside the results for NHS Scotland as a whole.

Two types of table / chart are shown in this chapter:

- (a) The first type of table / chart shows how positively or negatively patients responded to questions. For each question, the percentages of positive, neutral / mixed and negative responses are shown. Please see Appendix A for a full breakdown of how patients' responses were grouped into the positive, neutral / mixed or negative categories.
- (b) The second type of table / chart reports the percentage of respondents who selected a particular response in relation to a question. These types of questions are designed to gather background information about respondents (for example, how often a patient visited his / her GP prior to attending hospital for cancer care).

Notes on Interpretation

Number of responses - the number of patients treated within this hospital who provided a valid response to the question. Note that respondents who indicated that a question was not relevant, or who did not know the answer, are not included in these results. Where a result to a question does not appear within this section it has been suppressed due to the low number of valid responses (fewer than 20).

Response (%) - the percentage of positive, neutral / mixed and negative responses received for the question from patients treated within this hospital. For example, when asked how he / she felt about the length of time he / she had to wait for an appointment, the percentage positive refers to patients who felt they were seen as soon as necessary. Where patients said they should have been seen a lot sooner these responses have been counted as negative. Where patients said they should have been seen a bit sooner their responses have been counted as neutral / mixed. The coloured bars illustrate the percentage positive as green and the percentage negative as red. Where answers were neither positive nor negative (neutral / mixed) the percentage is shown in yellow. Note that results have been rounded to the nearest whole percentage and this occasionally results in the sum of positive, neutral and negative percentages not adding up to exactly 100%.

% Positive - the percent positive result; the total percentage of patients treated within this hospital who responded positively to the question.

Difference from NHS Scotland - the difference between this hospital's percent positive result and the equivalent result for NHS Scotland (for example, -2 means that the result for this hospital is two percentage points lower than for NHS Scotland as a whole).

S Indicates a statistically significant difference in the percent positive result between this hospital and NHS Scotland as a whole.

NT Indicates that a significance test was not carried out because fewer than five respondents within this hospital selected a positive response or because fewer than five respondents within this hospital selected a negative / neutral response.

Median rating - the "average" rating that respondents gave their overall care within this hospital. Patients were asked to rate their care on a scale between 0 (Very poor) and 10 (Very good). To calculate the median, ratings from all respondents are listed in numerical order; the median rating is the middle value within that list, with half the ratings placed equal to or above the median and half placed equal to or below the median. The higher the median, the more positive the "average" rating.

(%) Hospital - Percentage of respondents treated within this hospital who selected this particular response option.

(%) NHS Scotland - Percentage of respondents treated within NHS Scotland who selected this particular response option.

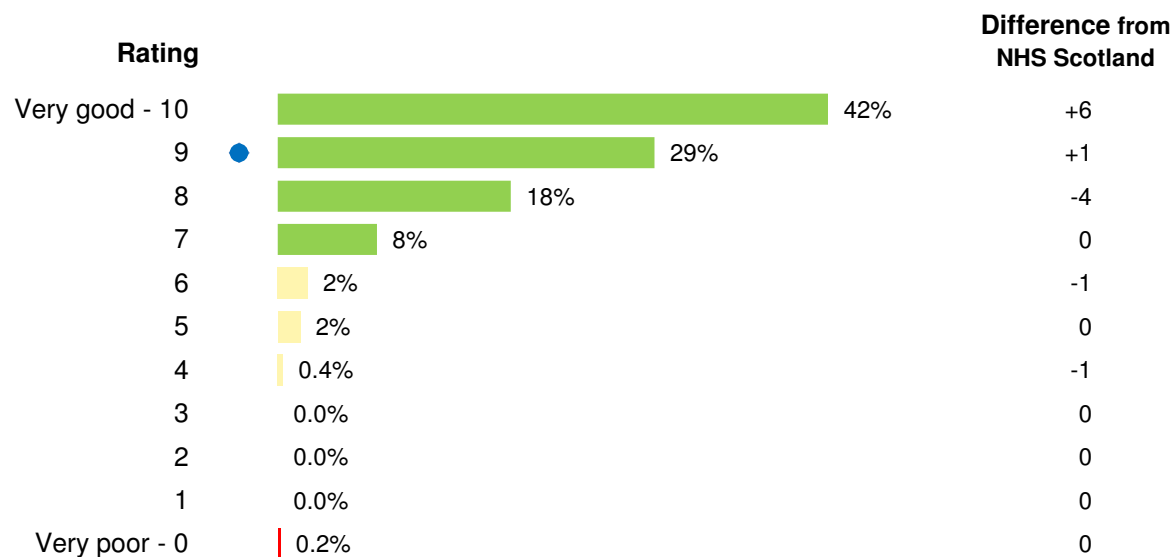
- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

1.1 Overall Care

Patients were asked to rate their overall care on a scale between 0 (Very poor) and 10 (Very good). Ratings of 7 - 10 have been categorised as positive; ratings of 4 - 6 have been categorised as neutral / mixed; ratings of 0 - 3 have been categorised as negative.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
64. Overall, how would you rate your care?	532	95	4	95	+1	

A full breakdown showing the percentage of respondents who selected each rating at this hospital is shown below along with the difference from the NHS Scotland result. The median rating given by respondents treated at this hospital is denoted by the blue dot (●).



Difference from NHS Scotland Median (●): 0.0

1.2 Seeing your GP

1.		(%) Hospital	(%) NHS Scotland
	None – I went straight to hospital	9	9
	None – I went to hospital following a cancer screening appointment	22	15
	I saw my GP once	41	43
	I saw my GP twice	13	16
	I saw my GP 3 or 4 times	9	10
	I saw my GP 5 or more times	6	7

(Number of responses from this hospital = 526).

		Response (%)			% Positive	Difference from NHS Scotland	
	Number of responses	Positive	Neutral / Mixed	Negative			
2.	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	538	84	11	5	84	+2

3.		(%) Hospital	(%) NHS Scotland
	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?		
	Less than 3 months	85	83
	3 - 6 months	10	11
	6 - 12 months	3	3
	More than 12 months	2	3

(Number of responses from this hospital = 509).

1.3 Diagnostic tests

4. Have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?	(%) Hospital	(%) NHS Scotland
Yes ¹	97	96
No	3	4

(Number of responses from this hospital = 556).

¹ Of the respondents who had a diagnostic test(s), 59% indicated that the test(s) took place at this hospital. The results for questions 5 - 7 below only include responses from those patients who said that their test(s) took place at this hospital.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
5. Beforehand, did you have all the information you needed about your test?	297	95	5	95	+3 ^s	
6. Overall, how did you feel about the length of time you had to wait for your test to be done?	313	89	8	89	+4 ^s	
7. Were the results of the test explained in a way you could understand?	315	85	15	85	+4 ^s	

1.4 Finding out what was wrong with you

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
9. When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	459	76		24	76	+4
10. How do you feel about the way you were told you had cancer?	538	87	9	4	87	+1
11. Did you understand the explanation of what was wrong with you?	555	78	20		78	+3
12. When you were told you had cancer, were you given written information about the type of cancer you had?	442	64		36	64	+4

1.5 Deciding the best treatment for you

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
13. Before your cancer treatment started, were your treatment options explained to you?	477	87	11	4	87	+1
14. Were the possible side effects of treatment(s) explained in a way you could understand?	525	70	27	4	70	-1
15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	527	68	25	7	68	+4
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?	499	55	29	16	55	+2
17. Were you involved as much as you wanted to be in decisions about your care and treatment?	549	81	16	3	81	+3

1.6 Clinical Nurse Specialist

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
18. Were you given the name of a Clinical Nurse Specialist who would support you through your treatment? ¹	530	89	11	89	+5 ^S	
19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	424	90	5	90	0	
20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	399	91	8	91	+1	

¹ The results for questions 19 - 20 only include responses from patients who said that they were given the name of a Clinical Nurse Specialist.

1.7 Support for people with cancer

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
21. Did hospital staff give you information about support or self-help groups for people with cancer?	424	86	14	86	+7 ^S	
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)?	390	83	17	83	+6 ^S	
23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	240	54	46	54	+3	

1.8 Operations

24. Have you had an operation (such as removal of a tumour or lump) for your cancer?	(%) Hospital	(%) NHS Scotland
Yes ¹	77	77
No	23	23

(Number of responses from this hospital = 549).

¹ Of the respondents who had an operation, 75% indicated that the operation took place at this hospital. The results for questions 25 - 26 below only include responses from those patients who said that their operation took place at this hospital.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
25. Beforehand, did you have all the information you needed about your operation?	303	93	7	93	0	
26. After the operation, did a member of staff explain how it had gone in a way you could understand?	309	77	19	3	77	-3

1.9 Hospital care as an inpatient

28. Have you had an operation or stayed overnight for cancer care?	(%) Hospital	(%) NHS Scotland
Yes ¹	83	83
No	17	17

(Number of responses from this hospital = 555).

¹ Of the respondents who had an operation / stayed overnight, 81% indicated that the operation / stay took place at this hospital. The results for questions 29 - 40 below only include responses from those patients who said that their operation / stay took place at this hospital.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
29. Did groups of doctors and nurses talk in front of you as if you weren't there?	365	86	12	86	+5 ^S	
30. Did you have confidence and trust in the doctors treating you?	369	85	15	85	-1	
31. If your family or someone else close to you wanted to talk to a doctor, were they able to?	277	82	15	82	+7 ^S	
32. Did you have confidence and trust in the ward nurses treating you?	367	81	19	81	+4	
33. In your opinion, were there enough nurses on duty to care for you in hospital?	360	78	19	78	+6 ^S	
34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	358	66	22	13	66	+1
35. Were you given enough privacy when discussing your condition or treatment?	368	84	13	84	+2	

1.9 Hospital care as an inpatient (cont.)

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
36. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	262	53	33	14	53	+3
37. Do you think the hospital staff did everything they could to help control your pain?	313	90	8		90	+3 ^s
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?	369	91	9		91	+4 ^s
39. Were you given clear written information about what you should or should not do after leaving hospital?	338	90	10		90	+8 ^s
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	355	97			97	+6 ^s

1.10 Hospital care as a day patient / outpatient

42. Have you been treated as an outpatient or day case for cancer care?	(%) Hospital	(%) NHS Scotland
Yes ¹	86	84
No	14	16

(Number of responses from this hospital = 550).

¹ Of the respondents who had been treated as an outpatient or day case, 81% indicated that the treatment / care took place at this hospital. The results for questions 43 - 44 below only include responses from those patients who said that their treatment / care took place at this hospital.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
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?	310	70	23	7	70	+1
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?	372	98			98	0

1.11 Radiotherapy

46. Have you had radiotherapy treatment?	(%) Hospital	(%) NHS Scotland
Yes ¹	66	49
No	34	51

(Number of responses from this hospital = 546).

¹ Of the respondents who had radiotherapy treatment, 93% indicated that the treatment took place at this hospital. The results for questions 47 - 48 below only include responses from those patients who said that their radiotherapy took place at this hospital.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?	328	85	12	85	+4	
48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	284	57	26	57	+3	

1.12 Chemotherapy

50. Have you had chemotherapy treatment?	(%) Hospital	(%) NHS Scotland
Yes ¹	60	48
No	40	52

(Number of responses from this hospital = 552).

¹ Of the respondents who had chemotherapy treatment, 86% indicated that the treatment took place at this hospital. The results for questions 51 - 52 below only include responses from those patients who said that their chemotherapy took place at this hospital.

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
51. Beforehand, did you have all of the information you needed about your chemotherapy treatment?	282	79	18		79	+2
52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	251	65	24	10	65	+3

1.13 Home care and support

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	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?	437	60	23	17	60	+3
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)?	253	53	20	26	53	-1
56. Once your cancer treatment finished were you given enough care and support from health or social services (e.g district nurses, home helps or physiotherapists)?	204	45	23	32	45	0

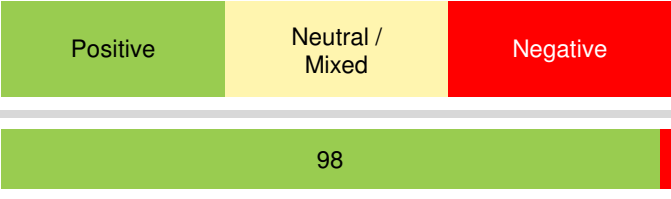




1.14 Care from your General Practice

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
57. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	470	96		4	96	0
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?	424	68	23	9	68	-2

1.15 Your overall NHS Care

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
59. Did the different people treating and caring for you (such as GP, hospital doctors, community nurses) work well together to give you the best possible care?	525	91	6	3	91	+2
60. Have you been given a care plan? This is a document that sets out your needs and goals for caring for your cancer agreed between you and your health professional.	484	23	77		23	+1
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)?	547	93	5		93	+3 ^s
62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	545	80	16	3	80	+4 ^s
63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	523	37	63		37	+15 ^s

1.16 Questions with highest percent positive response

		Number of responses	Response (%)			% Positive	Difference from NHS Scotland
			Positive	Neutral / Mixed	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?	372				98	0
40.	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	355				97	+6 ^s
57.	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	470				96	0
64.	Overall, how would you rate your care?	532				95	+1
5.	Beforehand, did you have all the information you needed about your test?	297				95	+3 ^s

Note 1: Where a question number has been shaded blue, this denotes that the question was also amongst those with the highest percent positive response for NHS Scotland as a whole.

Note 2: Some questions in the survey did not have a neutral / mixed response option, therefore respondents only had the opportunity to select either positive or negative response options. Questions that only had positive / negative response options are more likely to be included in the table above than questions that had positive / neutral / negative options. Please see Appendix A for a full breakdown of how responses were grouped into the positive, neutral / mixed and negative categories.

1.17 Questions with highest percent negative response

		Number of responses	Response (%)			% Positive	Difference from NHS Scotland
			Positive	Neutral / Mixed	Negative		
60.	Have you been given a care plan? This is a document that sets out your needs and goals for caring for your cancer agreed between you and your health professional.	484	23		77	23	+1
63.	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	523	37		63	37	+15 ^s
23.	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	240	54		46	54	+3
12.	When you were told you had cancer, were you given written information about the type of cancer you had?	442	64		36	64	+4
56.	Once your cancer treatment finished were you given enough care and support from health or social services (e.g district nurses, home helps or physiotherapists)?	204	45	23	32	45	0

Note 1: Where a question number has been shaded blue, this denotes that the question was also amongst those with the highest percent negative response for NHS Scotland as a whole.

Note 2: Some questions in the survey did not have a neutral / mixed response option, therefore respondents only had the opportunity to select either positive or negative response options. Questions that only had positive / negative response options are more likely to be included in the table above than questions that had positive / neutral / negative options. Please see Appendix A for a full breakdown of how responses were grouped into the positive, neutral / mixed and negative categories.

Chapter 2. Variation in Results across the Main Cancer Treatment Centres in Scotland

The tables / charts in this chapter show this hospital's percent positive results in relation to the range of percent positive results across the five main cancer treatment centres in Scotland. The percent positive results for NHS Scotland are also shown.

Notes on Interpretation

■ Range of percent positive results across the five main cancer treatment centres in Scotland - ranges from lowest centre's result to highest centre's result.

■ This hospital's percent positive result.

■ NHS Scotland percent positive result (includes results from patients treated at all hospitals in Scotland).

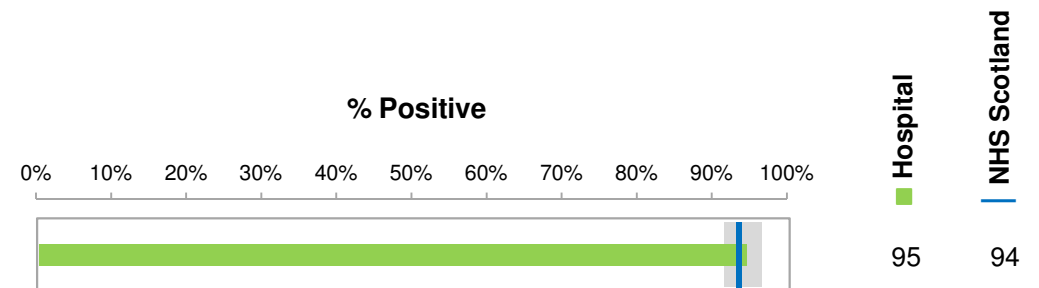
S Indicates a statistically significant difference in the percent positive result between this hospital and NHS Scotland as a whole.

NT Indicates that a significance test was not carried out because fewer than five respondents at this hospital selected a positive response or because fewer than five respondents at this hospital selected a negative / neutral response.

Where a result to a question does not appear within this section it has been suppressed due to the low number of valid responses (fewer than 20).

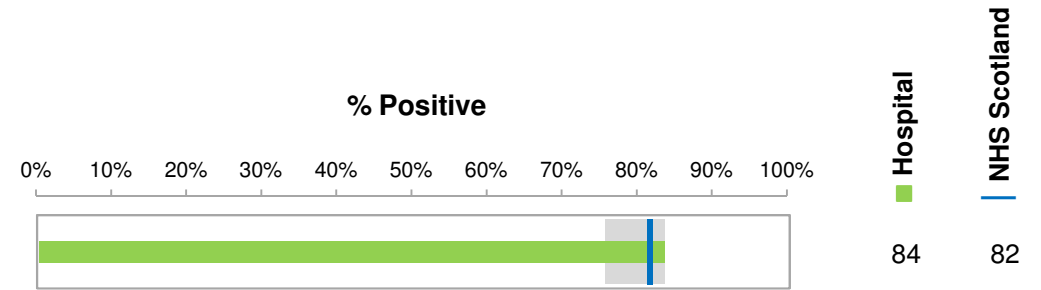
2.1 Overall Care

64. Overall, how would you rate your care?



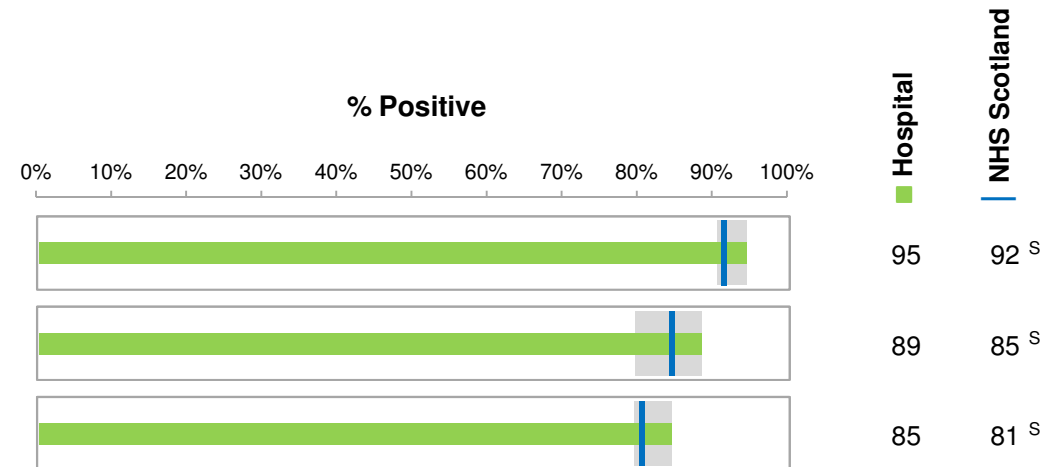
2.2 Seeing your GP

2. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?

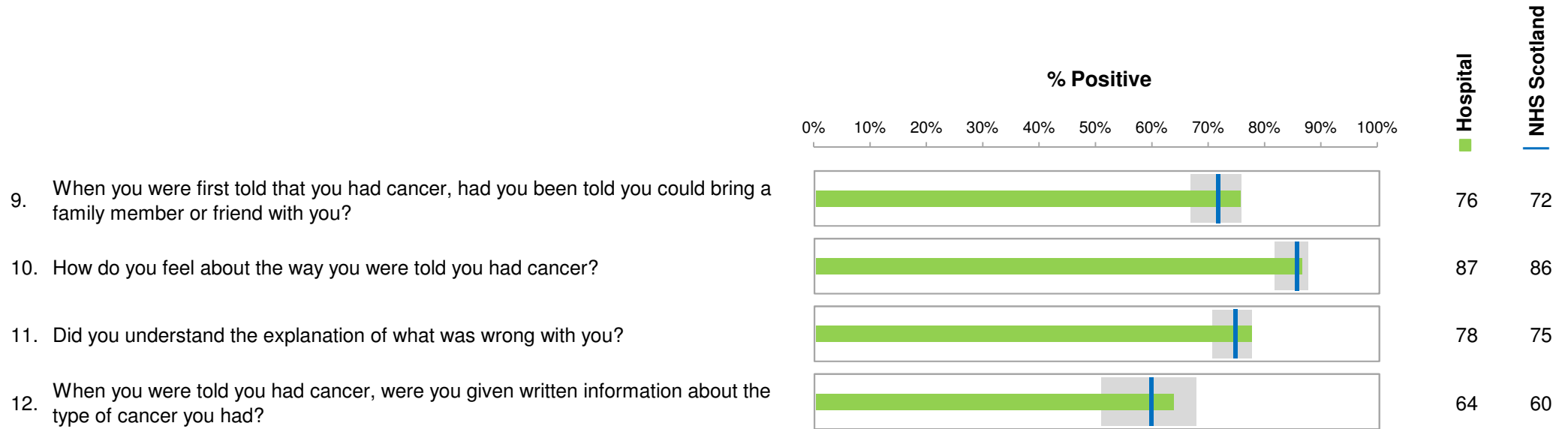


2.3 Diagnostic tests

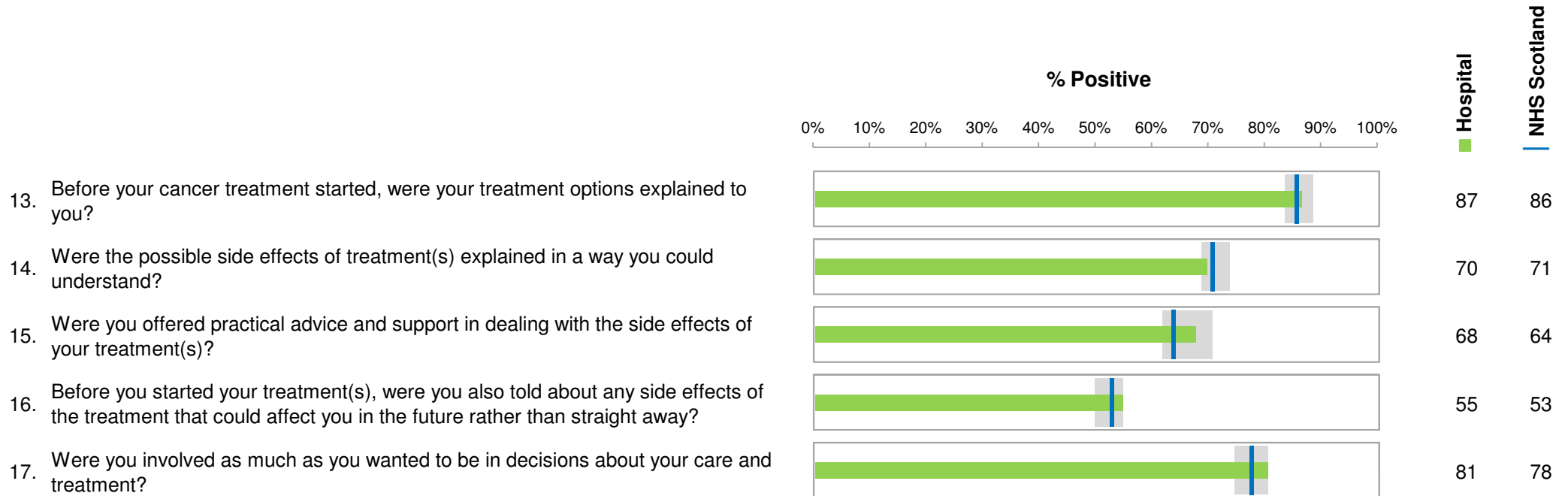
5. Beforehand, did you have all the information you needed about your test?
6. Overall, how did you feel about the length of time you had to wait for your test to be done?
7. Were the results of the test explained in a way you could understand?



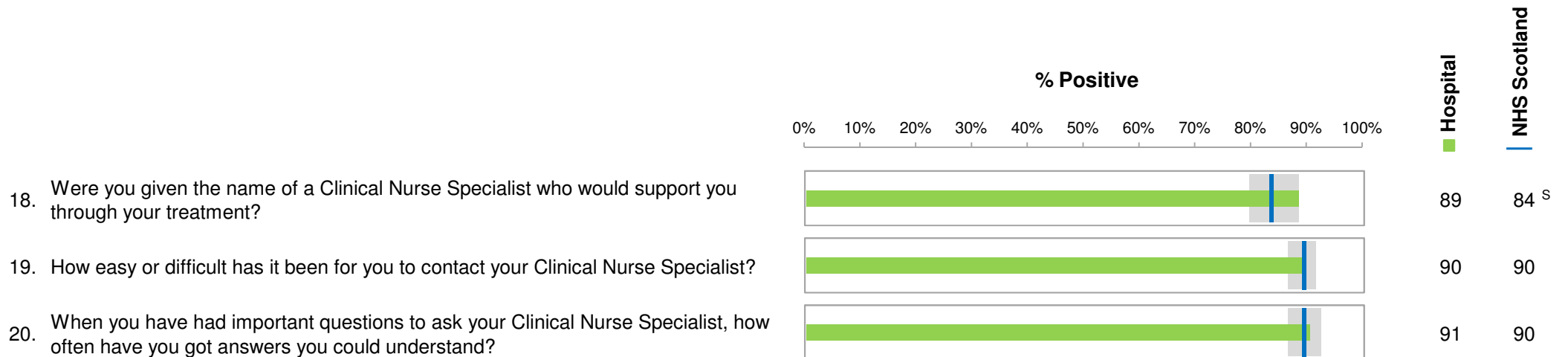
2.4 Finding out what was wrong with you



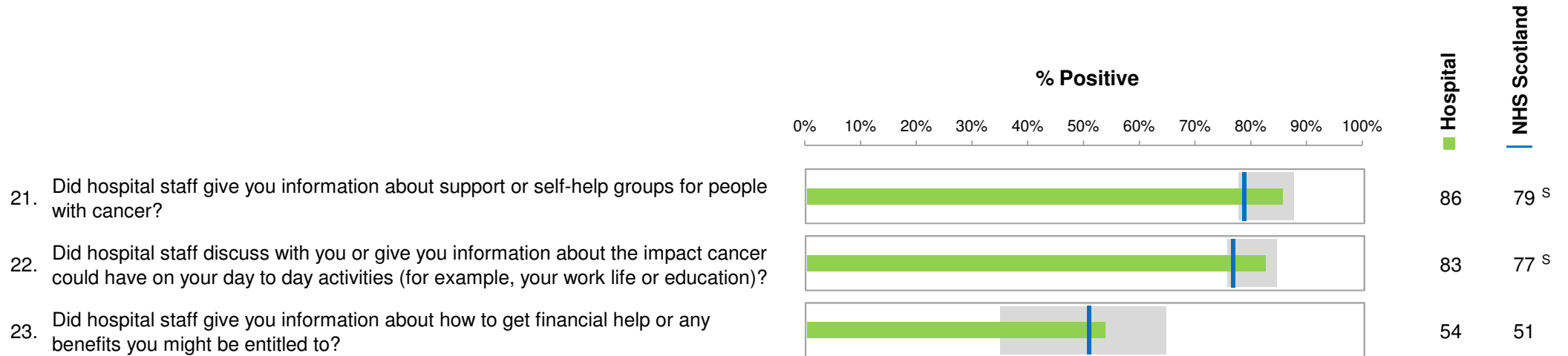
2.5 Deciding the best treatment for you



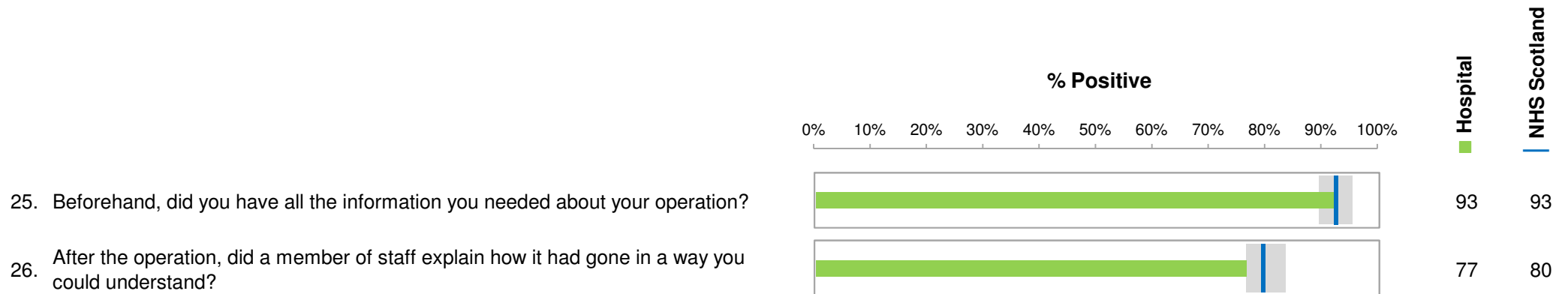
2.6 Clinical Nurse Specialist



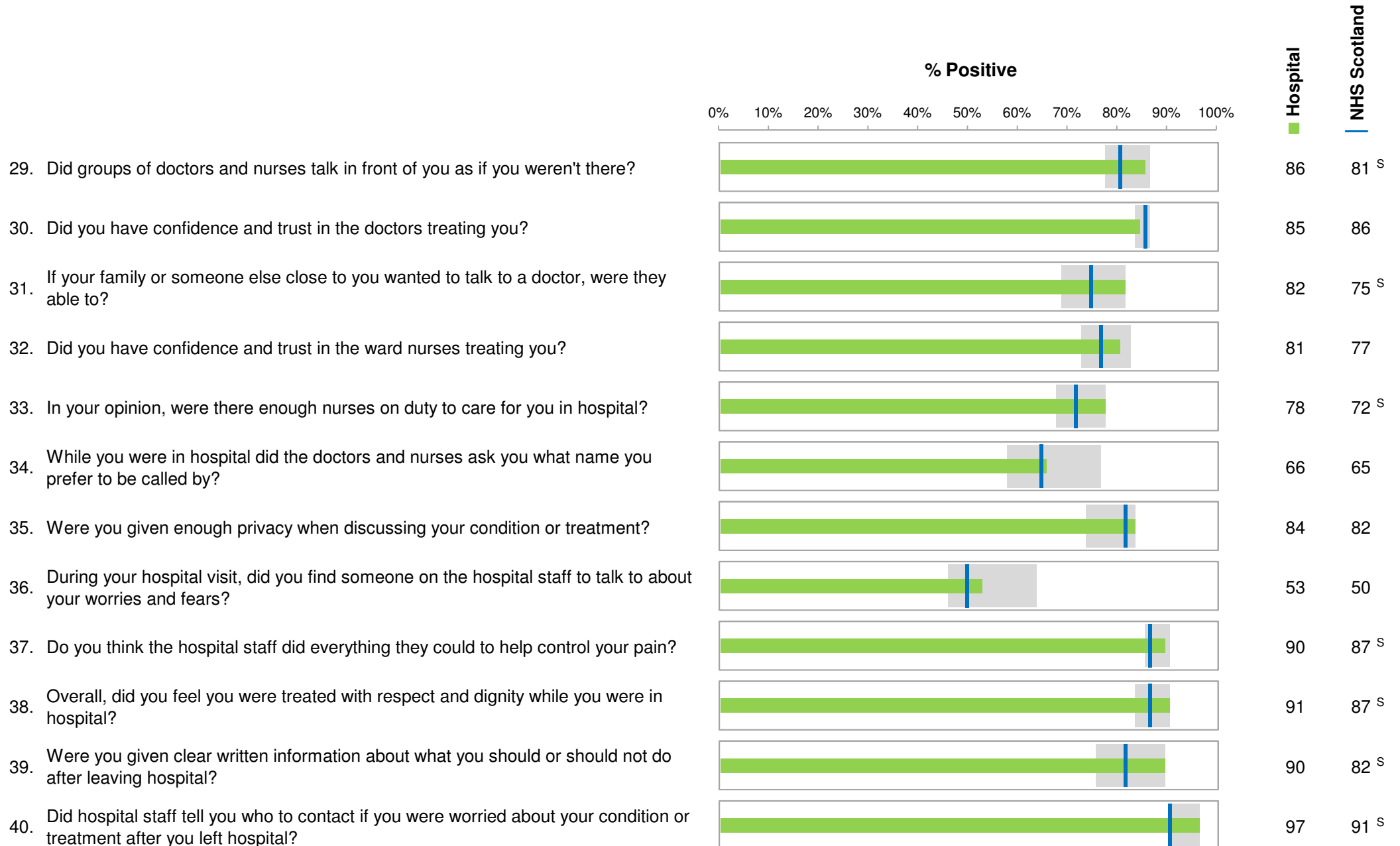
2.7 Support for people with cancer



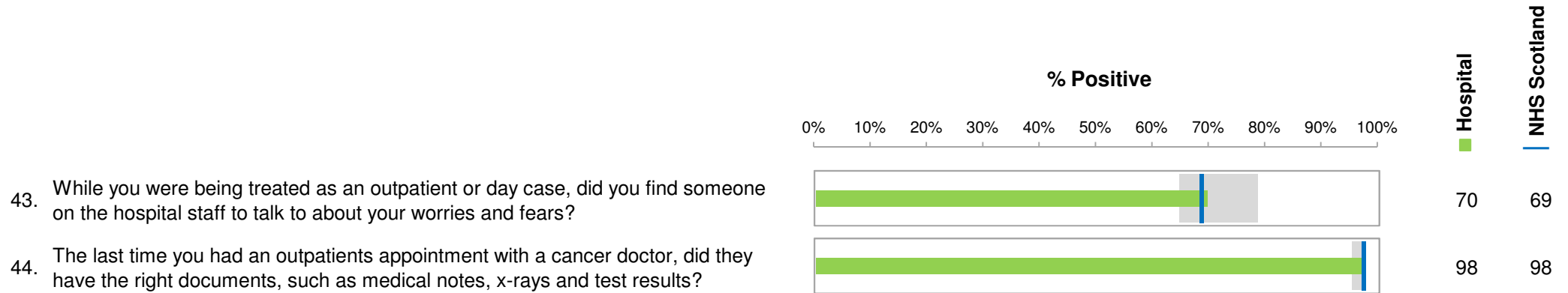
2.8 Operations



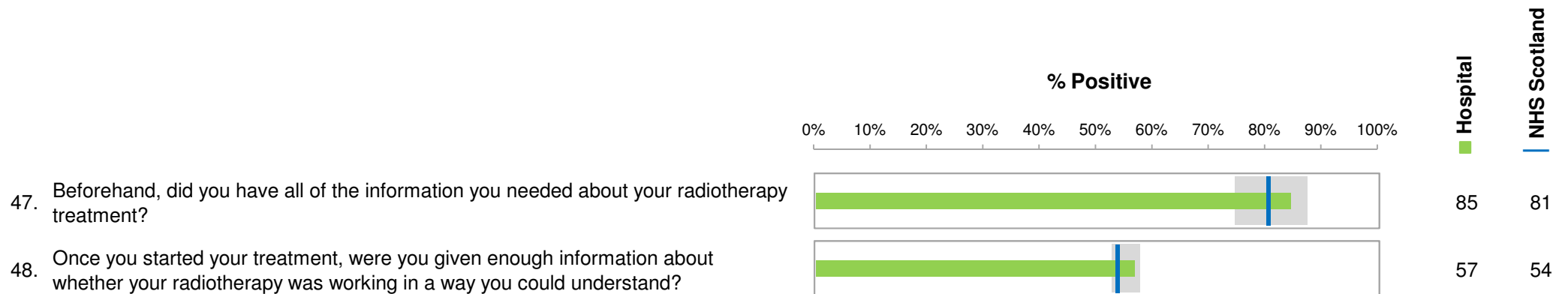
2.9 Hospital care as an inpatient



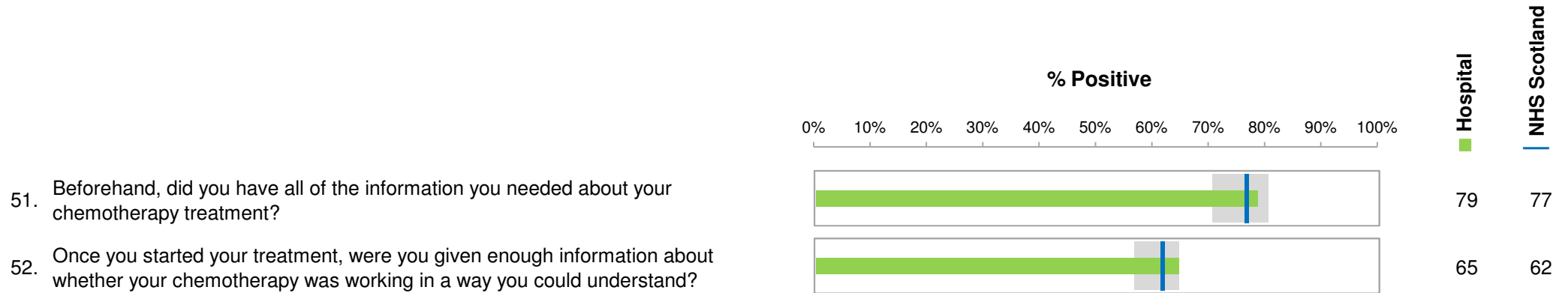
2.10 Hospital care as a day patient / outpatient



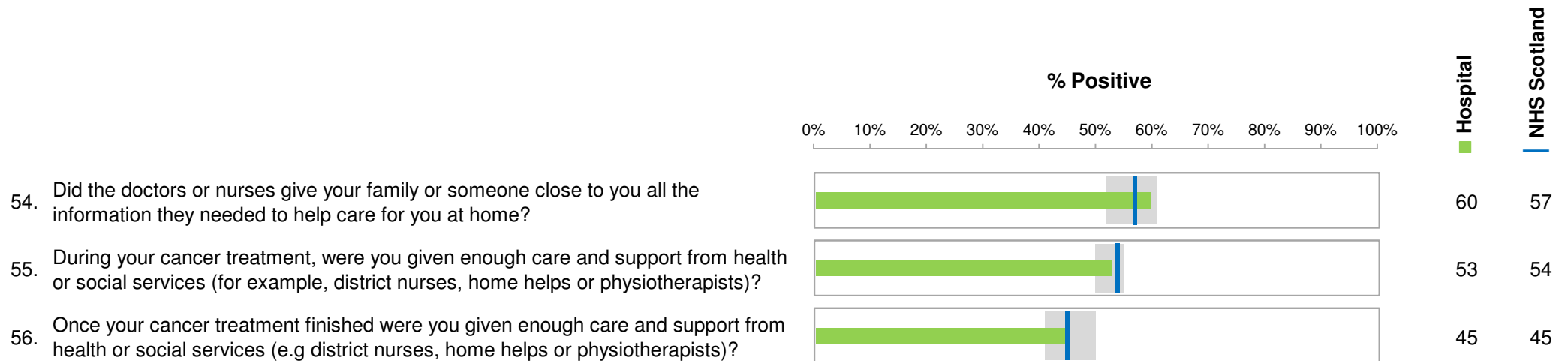
2.11 Radiotherapy



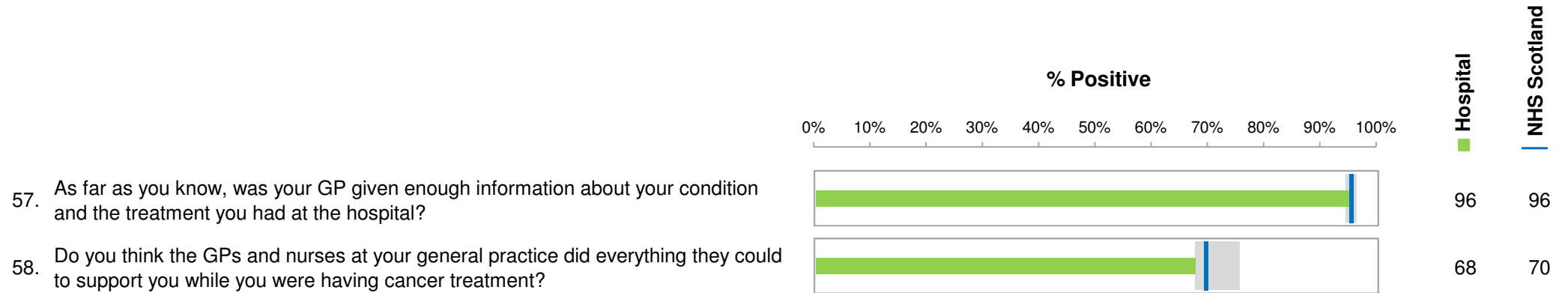
2.12 Chemotherapy



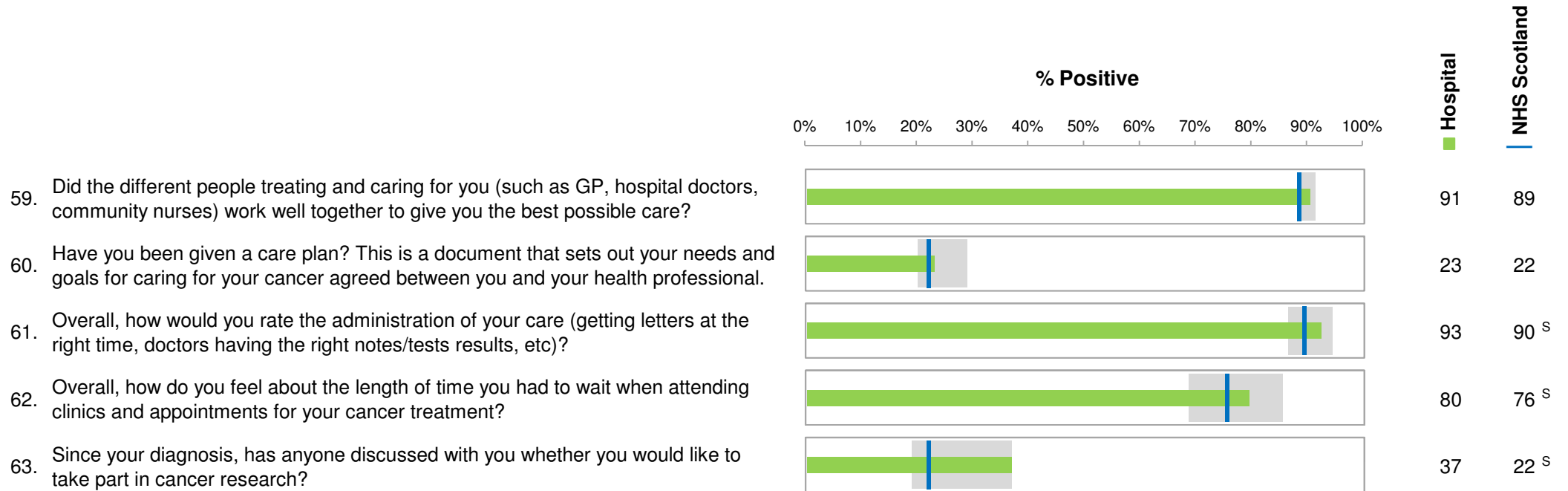
2.13 Home care and support



2.14 Care from your General Practice



2.15 Your overall NHS Care



Chapter 3. Results by Tumour Group for Edinburgh Cancer Centre

Survey respondents were allocated to one of 13 tumour groups, based on the type of cancer they were treated for. Where a respondent did not give permission for his / her survey results to be linked to information about his / her cancer type, he / she has been allocated to the "Tumour group unknown" group.

Tumour Group	% of Respondents	
	Hospital	NHS Scotland
Breast	40	25
Colorectal / Lower Gastrointestinal	8	15
Lung	5	6
Prostate	7	12
Brain / Central Nervous System	2	1
Gynaecological	7	7
Haematological	11	8
Head & Neck	5	5
Sarcoma	1	1
Skin	3	3
Upper Gastrointestinal	2	4
Urological	3	6
Other	1	0
Tumour group unknown	4	7

The tables in this chapter show this hospital's percent positive results by tumour group. The percent positive results for NHS Scotland are also shown.

Notes on Interpretation

Hospital - the percent positive result for this hospital; the total percentage of patients treated at this hospital who responded positively to the question.

NHS Scotland - the percent positive result for NHS Scotland; the total percentage of patients treated within NHS Scotland who responded positively to the question.

- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

3.1 Overall Care

64. Overall, how would you rate your care?

% Positive

Tumour Group	Hospital	NHS Scotland
Breast	95	94
Colorectal / Lower Gastrointestinal	98	94
Lung	92	94
Prostate	95	94
Brain / Central Nervous System	--	89
Gynaecological	97	95
Haematological	97	97
Head & Neck	97	93
Sarcoma	--	90
Skin	--	97
Upper Gastrointestinal	--	91
Urological	--	93
Other	--	--
Tumour group unknown	--	89
All Tumour Groups	95	94

3.2 Seeing your GP

2. How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?

% Positive

Tumour Group	Hospital	NHS Scotland
Breast	92	84
Colorectal / Lower Gastrointestinal	86	84
Lung	93	85
Prostate	84	83
Brain / Central Nervous System	--	76
Gynaecological	73	79
Haematological	79	79
Head & Neck	72	84
Sarcoma	--	56
Skin	--	83
Upper Gastrointestinal	--	77
Urological	--	76
Other	--	--
Tumour group unknown	77	85
All Tumour Groups	84	82

3.3 Diagnostic tests

Tumour Group	5. Beforehand, did you have all the information you needed about your test?		6. Overall, how did you feel about the length of time you had to wait for your test to be done?		7. Were the results of the test explained in a way you could understand?	
	% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	93	93	93	89	88	84
Colorectal / Lower Gastrointestinal	100	96	81	86	75	84
Lung	--	92	--	87	--	83
Prostate	--	92	--	83	--	80
Brain / Central Nervous System	--	91	--	91	--	77
Gynaecological	--	86	--	77	--	78
Haematological	95	91	90	86	90	81
Head & Neck	--	88	--	87	--	77
Sarcoma	--	82	--	79	--	76
Skin	--	85	--	89	--	76
Upper Gastrointestinal	--	90	--	78	--	77
Urological	--	90	--	80	--	73
Other	--	--	--	--	--	--
Tumour group unknown	--	91	--	84	--	76
All Tumour Groups	95	92	89	85	85	81

3.4 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?

10. How do you feel about the way you were told you had cancer?

11. Did you understand the explanation of what was wrong with you?

12. When you were told you had cancer, were you given written information about the type of cancer you had?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
	Breast	82	75	87	89	82	77	60
Colorectal / Lower Gastrointestinal	70	80	85	86	87	82	72	59
Lung	75	75	81	87	82	78	56	54
Prostate	82	77	85	87	85	80	80	78
Brain / Central Nervous System	--	90	--	79	--	77	--	47
Gynaecological	37	57	79	85	71	74	60	54
Haematological	76	72	92	85	69	60	71	70
Head & Neck	65	66	83	88	73	75	52	51
Sarcoma	--	59	--	82	--	62	--	36
Skin	--	55	--	89	--	74	--	74
Upper Gastrointestinal	--	72	--	80	--	72	--	45
Urological	--	63	--	79	--	75	--	51
Other	--	--	--	--	--	--	--	--
Tumour group unknown	90	73	90	85	61	70	--	53
All Tumour Groups	76	72	87	86	78	75	64	60

3.5 Deciding the best treatment for you

Tumour Group	13. Before your cancer treatment started, were your treatment options explained to you?		14. Were the possible side effects of treatment(s) explained in a way you could understand?		15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?		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?	
	% Positive		% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	85	85	69	66	69	64	55	46
Colorectal / Lower Gastrointestinal	86	89	73	74	67	68	51	57
Lung	95	87	68	76	71	68	52	59
Prostate	87	86	72	73	56	64	63	62
Brain / Central Nervous System	--	87	--	69	--	49	--	49
Gynaecological	83	85	73	72	63	63	53	52
Haematological	94	89	76	73	82	70	63	58
Head & Neck	88	89	52	69	53	63	53	51
Sarcoma	--	78	--	60	--	59	--	63
Skin	--	86	--	74	--	69	--	62
Upper Gastrointestinal	--	87	--	70	--	67	--	52
Urological	--	82	--	72	--	55	--	50
Other	--	--	--	--	--	--	--	--
Tumour group unknown	80	84	75	67	52	58	45	49
All Tumour Groups	87	86	70	71	68	64	55	53

3.5 Deciding the best treatment for you (cont.)

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

% Positive

Tumour Group	% Positive	
	Hospital	NHS Scotland
Breast	81	76
Colorectal / Lower Gastrointestinal	83	82
Lung	86	83
Prostate	90	80
Brain / Central Nervous System	--	74
Gynaecological	76	76
Haematological	87	80
Head & Neck	72	77
Sarcoma	--	71
Skin	--	87
Upper Gastrointestinal	--	77
Urological	--	74
Other	--	--
Tumour group unknown	68	70
All Tumour Groups	81	78

3.6 Clinical Nurse Specialist

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

19. How easy or difficult has it been for you to contact your 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?

Tumour Group	% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	94	95	88	88	88	86
Colorectal / Lower Gastrointestinal	95	90	92	92	93	94
Lung	100	87	85	90	87	91
Prostate	92	81	94	90	87	91
Brain / Central Nervous System	--	84	--	82	--	89
Gynaecological	90	83	91	88	97	90
Haematological	67	70	97	94	97	94
Head & Neck	82	80	91	93	95	93
Sarcoma	--	85	--	96	--	100
Skin	--	78	--	94	--	92
Upper Gastrointestinal	--	81	--	90	--	86
Urological	--	58	--	91	--	88
Other	--	--	--	--	--	--
Tumour group unknown	76	78	--	90	--	84
All Tumour Groups	89	84	90	90	91	90

3.7 Support for people with cancer

21. Did hospital staff give you information about support or self-help groups for people with cancer?

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)?

23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?

Tumour Group	% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	88	83	85	76	52	47
Colorectal / Lower Gastrointestinal	89	78	84	80	--	54
Lung	77	77	--	76	--	61
Prostate	96	85	89	84	--	38
Brain / Central Nervous System	--	77	--	77	--	69
Gynaecological	82	75	73	75	48	58
Haematological	83	84	80	80	55	62
Head & Neck	75	78	91	78	55	58
Sarcoma	--	75	--	--	--	60
Skin	--	88	--	86	--	50
Upper Gastrointestinal	--	76	--	76	--	66
Urological	--	63	--	60	--	32
Other	--	--	--	--	--	--
Tumour group unknown	--	72	--	67	--	45
All Tumour Groups	86	79	83	77	54	51

3.8 Operations

25. Beforehand, did you have all the information you needed about your operation?

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

Tumour Group	% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	96	93	75	78
Colorectal / Lower Gastrointestinal	86	95	81	85
Lung	--	92	--	84
Prostate	--	94	--	83
Brain / Central Nervous System	--	90	--	75
Gynaecological	--	93	--	81
Haematological	--	89	--	73
Head & Neck	--	91	--	77
Sarcoma	--	93	--	71
Skin	--	90	--	76
Upper Gastrointestinal	--	93	--	81
Urological	--	90	--	78
Other	--	--	--	--
Tumour group unknown	--	90	--	76
All Tumour Groups	93	93	77	80

3.9 Hospital care as an inpatient

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

30. Did you have confidence and trust in the doctors treating you?

31. If your family or someone else close to you wanted to talk to a doctor, were they able to?

32. Did you have confidence and trust in the ward nurses treating you?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	90	87	85	86	84	74	83	79
Colorectal / Lower Gastrointestinal	68	75	80	85	74	75	68	74
Lung	--	78	--	85	--	79	--	83
Prostate	100	81	94	86	78	75	90	79
Brain / Central Nervous System	--	77	--	83	--	57	--	51
Gynaecological	--	86	--	87	--	74	--	76
Haematological	83	82	88	88	86	83	77	81
Head & Neck	--	79	--	89	--	77	--	75
Sarcoma	--	74	--	90	--	73	--	61
Skin	--	86	--	92	--	76	--	81
Upper Gastrointestinal	--	74	--	87	--	80	--	78
Urological	--	76	--	84	--	72	--	74
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	78	--	83	--	73	--	71
All Tumour Groups	86	81	85	86	82	75	81	77

3.9 Hospital care as an inpatient (cont.)

Tumour Group	33. In your opinion, were there enough nurses on duty to care for you in hospital?		34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?		35. Were you given enough privacy when discussing your condition or treatment?		36. During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	
	% Positive		% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	82	74	61	55	84	82	55	49
Colorectal / Lower Gastrointestinal	63	69	60	70	61	79	50	52
Lung	--	81	--	80	--	87	--	55
Prostate	94	75	75	67	100	86	--	51
Brain / Central Nervous System	--	63	--	61	--	80	--	40
Gynaecological	--	72	--	62	--	80	--	43
Haematological	74	72	67	69	92	86	45	57
Head & Neck	--	74	--	69	--	84	--	53
Sarcoma	--	68	--	55	--	77	--	39
Skin	--	81	--	62	--	88	--	58
Upper Gastrointestinal	--	61	--	79	--	77	--	52
Urological	--	73	--	72	--	79	--	45
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	72	--	62	--	75	--	43
All Tumour Groups	78	72	66	65	84	82	53	50

3.9 Hospital care as an inpatient (cont.)

37. Do you think the hospital staff did everything they could to help control your pain?

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

39. Were you given clear written information about what you should or should not do after leaving hospital?

40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	93	88	91	87	91	86	99	95
Colorectal / Lower Gastrointestinal	93	88	83	87	83	79	97	92
Lung	--	87	--	90	--	80	--	88
Prostate	90	88	97	89	100	86	100	92
Brain / Central Nervous System	--	74	--	69	--	67	--	89
Gynaecological	--	86	--	87	--	84	--	88
Haematological	88	89	95	94	76	79	95	93
Head & Neck	--	85	--	85	--	81	--	90
Sarcoma	--	85	--	83	--	58	--	89
Skin	--	81	--	87	--	87	--	94
Upper Gastrointestinal	--	88	--	85	--	78	--	92
Urological	--	83	--	87	--	74	--	81
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	86	--	87	--	78	--	89
All Tumour Groups	90	87	91	87	90	82	97	91

3.10 Hospital care as a day patient / outpatient

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?

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?

Tumour Group	% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	65	64	99	97
Colorectal / Lower Gastrointestinal	79	75	100	96
Lung	--	71	--	97
Prostate	--	74	--	99
Brain / Central Nervous System	--	64	--	94
Gynaecological	70	68	94	98
Haematological	70	72	100	98
Head & Neck	--	71	--	99
Sarcoma	--	67	--	96
Skin	--	73	--	97
Upper Gastrointestinal	--	76	--	99
Urological	--	60	--	96
Other	--	--	--	--
Tumour group unknown	--	58	--	98
All Tumour Groups	70	69	98	98

3.11 Radiotherapy

47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?

48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?

Tumour Group	% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	86	81	52	48
Colorectal / Lower Gastrointestinal	--	80	--	56
Lung	--	85	--	61
Prostate	--	85	--	62
Brain / Central Nervous System	--	88	--	74
Gynaecological	87	82	--	51
Haematological	90	77	--	62
Head & Neck	64	76	41	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	79	--	50
Urological	--	77	--	60
Other	--	--	--	--
Tumour group unknown	--	83	--	56
All Tumour Groups	85	81	57	54

3.12 Chemotherapy

51. Beforehand, did you have all of the information you needed about your chemotherapy treatment?

52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?

Tumour Group	% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	75	75	61	53
Colorectal / Lower Gastrointestinal	75	77	65	63
Lung	81	82	--	68
Prostate	--	71	--	57
Brain / Central Nervous System	--	82	--	--
Gynaecological	78	72	61	61
Haematological	89	82	78	75
Head & Neck	--	71	--	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	80	--	58
Urological	--	80	--	76
Other	--	--	--	--
Tumour group unknown	--	73	--	64
All Tumour Groups	79	77	65	62

3.13 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?

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)?

56. Once your cancer treatment finished were you given enough care and support from health or social services (e.g district nurses, home helps or physiotherapists)?

Tumour Group	% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
	Breast	57	50	45	50	35
Colorectal / Lower Gastrointestinal	60	60	63	64	48	55
Lung	60	59	--	52	--	44
Prostate	46	54	--	54	--	45
Brain / Central Nervous System	--	51	--	45	--	--
Gynaecological	47	57	--	41	--	36
Haematological	62	65	63	57	42	48
Head & Neck	71	64	77	64	67	55
Sarcoma	--	44	--	61	--	--
Skin	--	67	--	55	--	58
Upper Gastrointestinal	--	65	--	63	--	55
Urological	--	57	--	54	--	48
Other	--	--	--	--	--	--
Tumour group unknown	--	53	--	42	--	33
All Tumour Groups	60	57	53	54	45	45

3.14 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?

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?

Tumour Group	% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	97	96	65	70
Colorectal / Lower Gastrointestinal	95	97	63	72
Lung	96	93	88	71
Prostate	100	97	74	72
Brain / Central Nervous System	--	89	--	73
Gynaecological	90	95	54	64
Haematological	95	96	63	66
Head & Neck	100	94	65	69
Sarcoma	--	96	--	71
Skin	--	95	--	74
Upper Gastrointestinal	--	97	--	74
Urological	--	95	--	72
Other	--	--	--	--
Tumour group unknown	--	92	--	67
All Tumour Groups	96	96	68	70

3.15 Your overall NHS care

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

60. Have you been given a care plan? This is a document that sets out your needs and goals for caring for your cancer agreed between you and your health professional.

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)?

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

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland	Hospital	NHS Scotland
Breast	92	90	19	21	93	91	75	73
Colorectal / Lower Gastrointestinal	91	90	37	22	96	89	80	80
Lung	89	89	36	24	96	92	89	80
Prostate	93	89	23	23	95	88	85	76
Brain / Central Nervous System	--	79	--	18	--	74	--	64
Gynaecological	86	88	6	17	95	88	79	81
Haematological	95	91	30	26	94	94	82	77
Head & Neck	86	90	33	28	93	90	80	77
Sarcoma	--	90	--	20	--	88	--	65
Skin	--	90	--	18	--	94	--	82
Upper Gastrointestinal	--	90	--	20	--	91	--	72
Urological	--	87	--	17	--	85	--	71
Other	--	--	--	--	--	--	--	--
Tumour group unknown	86	87	--	24	87	85	87	72
All Tumour Groups	91	89	23	22	93	90	80	76

3.15 Your overall NHS care (cont.)

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

% Positive

Tumour Group	Hospital	NHS Scotland
Breast	44	27
Colorectal / Lower Gastrointestinal	64	30
Lung	36	24
Prostate	34	20
Brain / Central Nervous System	--	25
Gynaecological	37	13
Haematological	16	23
Head & Neck	14	16
Sarcoma	--	26
Skin	--	12
Upper Gastrointestinal	--	25
Urological	--	18
Other	--	--
Tumour group unknown	23	14
All Tumour Groups	37	22

Chapter 4. Condition / Demographic Questions for Edinburgh Cancer Centre

The tables in this chapter show results for condition related / demographic questions. These tables show the percentage of patients treated at this hospital who selected each response option when answering these questions. Equivalent results for NHS Scotland are also shown.

Notes on Interpretation

(%) **Hospital** - Percentage of respondents treated within this hospital who selected this particular response option.

(%) **NHS Scotland** - Percentage of respondents treated within NHS Scotland who selected a particular response option.

- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

4.1 Your condition

	(%) Hospital	(%) NHS Scotland
65. How long is it since you were first treated for this cancer?		
Less than 1 year	4	6
1 to 5 years	95	93
More than 5 years	1	1
(Number of responses from this hospital = 541).		

	(%) Hospital	(%) NHS Scotland
66. Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?		
Yes	15	14
No ¹	82	85
Does not apply to my type of cancer	3	1
(Number of responses from this hospital = 531).		

¹ Respondents who answered "No" were asked to respond to Q67 overleaf.

4.1 Your condition (cont.)

67. Which of the following applies?	(%) Hospital	(%) NHS Scotland
My cancer has been taken out / treated without any sign of further problem	78	81
My cancer was taken out / treated without any sign of further problem, but has since come back / spread to other parts of my body	6	5
None of the above options apply to my type of cancer	16	14

(Number of responses from this hospital = 402).

4.2 About you

68. What was your age on your last birthday?	(%) Hospital	(%) NHS Scotland
16 - 25	0	0
26 - 35	2	2
36 - 50	12	10
51 - 65	38	34
66 - 75	32	35
76+	16	19

(Number of responses from this hospital = 542).

69. Are you male or female?	(%) Hospital	(%) NHS Scotland
Male	32	43
Female	68	57

(Number of responses from this hospital = 548).

4.2 About you (cont.)

70. Which of the following best describes your sexual orientation?	(%) Hospital	(%) NHS Scotland
Heterosexual / Straight	99	99
Bisexual	0	0
Gay or Lesbian	1	0
Other	0	0

(Number of responses from this hospital = 535).

71. What is your ethnic group?	(%) Hospital	(%) NHS Scotland
White	98	99
Mixed or multiple ethnic groups	0	0
Asian, Asian Scottish or Asian British	1	1
African, Caribbean or Black	0	0
Other ethnic group	0	0

(Number of responses from this hospital = 547).

72. What is your main employment status?	(%) Hospital	(%) NHS Scotland
Work full time	19	17
Work part time	14	10
In full time education or training	0	0
Retired	57	62
Unemployed / looking for work	1	1
Don't work due to illness or disability	7	8
Other	2	2

(Number of responses from this hospital = 540).

4.2 About you (cont.)

73. Do you have any of the following? ¹	(%) Hospital	(%) NHS Scotland
Deafness or severe hearing impairment	13	15
Blindness or severe vision impairment	2	3
A physical disability	12	13
A learning disability	1	1
A mental health condition	4	4
Chronic pain lasting at least 3 months	14	14
Another long - term condition	26	25
None of the above	53	51

(Number of responses from this hospital = 507).

¹ Respondents were asked to "tick all that apply", therefore results may not add up to 100%.

Appendix A: Mapping of Response Options to Positive, Neutral and Negative Categories

The table below lists the questions that were asked as part of the NHS Scotland Cancer Patient Experience Survey 2015. Where question responses have been coded into positive, neutral / mixed or negative categories, the table indicates which responses have been allocated to each category.

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
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?	Information	N/A	N/A	N/A
2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	Pos / Neu / Neg	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?	Information	N/A	N/A	N/A
4	Have you had diagnostic test(s) for cancer such as an endoscopy, biopsy, mammogram, or scan?	Information	N/A	N/A	N/A
5	Beforehand, did you have all the information you needed about your test? (Tick ALL that apply)	Pos / Neu / Neg	1: Yes		2: No, I would have liked more written information 3: No, I would have liked more verbal information 4: Combination of responses 2 & 3
6	Overall, how did you feel about the length of time you had to wait for your test to be done?	Pos / Neu / Neg	1: It was about right	2: It was a little too long	3: It was much too long
7	Were the results of the test explained in a way you could understand?	Pos / Neu / Neg	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
8	Did the test take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
9	When you were first told that you had cancer, had you been told you could bring a family member or friend with you?	Pos / Neu / Neg	1: Yes		2: No
10	How do you feel about the way you were told you had cancer?	Pos / Neu / Neg	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?	Pos / Neu / Neg	1: Yes, I completely understood it	2: Yes, I understood some of it	3: No, I did not understand it

Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
12	When you were told you had cancer, were you given written information about the type of cancer you had?	Pos / Neu / Neg	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
13	Before your cancer treatment started, were your treatment options explained to you?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
14	Were the possible side effects of treatment(s) explained in a way you could understand?	Pos / Neu / Neg	1; Yes, definitely	2: Yes, to some extent	3: No, side effects were not explained
15	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: 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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: 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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: 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?	Pos / Neu / Neg	1: Yes		2: No
19	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	Pos / Neu / Neg	1: Very easy 2: Quite easy	3: Neither easy nor difficult	4: Quite difficult 5: Very difficult
20	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	Pos / Neu / Neg	1: All or most of the time	2: Some of the time	3: Rarely or never
21	Did hospital staff give you information about support or self-help groups for people with cancer?	Pos / Neu / Neg	1: Yes		2: 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)?	Pos / Neu / Neg	1: Yes		2: 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?	Pos / Neu / Neg	1: Yes		2: No, but I would have liked information
24	Have you had an operation (such as removal of a tumour or lump) for your cancer?	Information	N/A	N/A	N/A

Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
25	Beforehand, did you have all the information you needed about your operation? (Tick ALL that apply)	Pos / Neu / Neg	1: Yes		2: No, I would have liked more written information 3: No, I would have liked more verbal information 4: Combination of responses 2 & 3
26	After the operation, did a member of staff explain how it had gone in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No, but I would have liked an explanation
27	Did the operation take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
28	Have you had an operation or stayed overnight for cancer care?	Information	N/A	N/A	N/A
29	Did groups of doctors and nurses talk in front of you as if you weren't there?	Pos / Neu / Neg	3: No	2: Yes, sometimes	1: Yes, often
30	Did you have confidence and trust in the doctors treating you?	Pos / Neu / Neg	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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
32	Did you have confidence and trust in the ward nurses treating you?	Pos / Neu / Neg	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?	Pos / Neu / Neg	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?	Pos / Neu / Neg	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?	Pos / Neu / Neg	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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
37	Do you think the hospital staff did everything they could to help control your pain?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
38	Overall, did you feel you were treated with respect and dignity while you were in hospital?	Pos / Neu / Neg	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?	Pos / Neu / Neg	1: Yes		2: No

Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
40	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Pos / Neu / Neg	1: Yes		2: No
41	Did your overnight stay or operation take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
42	Have you been treated as an outpatient or day case for cancer care?	Information	N/A	N/A	N/A
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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
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?	Pos / Neu / Neg	1: Yes		2: No
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?	Information	N/A	N/A	N/A
46	Have you had radiotherapy treatment?	Information	N/A	N/A	N/A
47	Beforehand, did you have all of the information you needed about your radiotherapy treatment?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
48	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
49	Did your radiotherapy treatment take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A
50	Have you had chemotherapy treatment?	Information	N/A	N/A	N/A
51	Beforehand, did you have all of the information you needed about your chemotherapy treatment?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
52	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	Pos / Neu / Neg	1: Yes, completely	2: Yes, to some extent	3: No
53	Did your chemotherapy treatment take place at the hospital named on the letter that came with this survey?	Information	N/A	N/A	N/A

Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: 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)?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: 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)?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No
57	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	Pos / Neu / Neg	1: Yes		2: 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?	Pos / Neu / Neg	1: Yes, definitely	2: Yes, to some extent	3: No, they could have done more
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?	Pos / Neu / Neg	1: Yes, always 2: Yes, most of the time	3: Yes, some of the time	4: 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.	Pos / Neu / Neg	1: Yes		2: No 3: 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)?	Pos / Neu / Neg	1: Very good 2: Good	3: Neither good nor bad	4: Quite bad 5: 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?	Pos / Neu / Neg	3: About right	2: A little too long	1: Much too long
63	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	Pos / Neu / Neg	1: Yes		2: No 3: No, but I would have liked them to
64	Overall, how would you rate your care?	Pos / Neu / Neg	7,8,9,10	4,5,6	0,1,2,3
65	How long is it since you were first treated for this cancer?	Information	N/A	N/A	N/A

Appendix A (cont.)

Question No.	Question	Question Type	Positive Responses	Neutral and Mixed Responses	Negative Responses
66	Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?	Information	N/A	N/A	N/A
67	Which of the following applies? (Current cancer status)	Information	N/A	N/A	N/A
68	What was your age on your last birthday?	Information	N/A	N/A	N/A
69	Are you male or female?	Information	N/A	N/A	N/A
70	Which of the following best describes your sexual orientation? (Tick ONE box only)	Information	N/A	N/A	N/A
71	What is your ethnic group? (Tick ONE box which best describes your ethnic group)	Information	N/A	N/A	N/A
72	What is your main employment status? (If on maternity or sick leave answer in relation to your usual employment status)	Information	N/A	N/A	N/A
73	Do you have any of the following? Please tick ALL that apply (Disability / Impairment / Condition)	Information	N/A	N/A	N/A

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Correspondence and enquiries

For enquiries about this publication please contact:

Andrew Paterson
Health Analytical Services
Scottish Government
St Andrews House
Edinburgh
EH1 3DG
0131 244 3201
andrew.paterson@gov.scot

For general enquiries, suggestions and complaints about Scottish Government statistics please contact:

Office of the Chief Statistician
Scottish Government
St Andrews House
Edinburgh
EH1 3DG
0131 244 0442
statistics.enquiries@scotland.gsi.gov.uk

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andrew.paterson@gov.scot

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