

Cancer Patient Experience Survey 2015

Results for NHS Lothian



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 by NHS Lothian.

Survey questionnaires were sent out in October 2015 to 1,590 patients who were diagnosed with cancer between 1st July 2013 and 31st March 2014 and who received cancer treatment and care within NHS Lothian 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

1,006 NHS Lothian patients (63%) returned feedback on their experiences. Of those patients willing to provide information about themselves:

- 44% were male and 56% were female.
- 0% were aged 16 - 25; 2% were aged 26 - 35; 9% were aged 36 - 50; 35% were aged 51 - 65; 34% were aged 66 - 75 and 20% were aged 76 and over.
- 52% 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 NHS Lothian 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 took place outside of NHS Lothian. Please also note that results for questions 1 - 3 (seeing your GP), 55 - 56 and 58 (home care and support) are based on responses from patients who were resident within NHS Lothian at the time of their cancer diagnosis / treatment. This differs from the other results in this report, which are based on responses from patients who received their hospital treatment in this NHS Board.

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 NHS Lothian

The tables / charts in this chapter show how patients treated within this NHS Board responded to questions about their cancer care. Results for this NHS Board 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 NHS Board 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 NHS Board. 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 NHS Board who responded positively to the question.

Difference from NHS Scotland - the difference between this NHS Board's percent positive result and the equivalent result for NHS Scotland (for example, -2 means that the result for this NHS Board 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 NHS Board and NHS Scotland as a whole.

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

Median rating - the "average" rating that respondents gave their overall care within this NHS Board. 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.

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

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

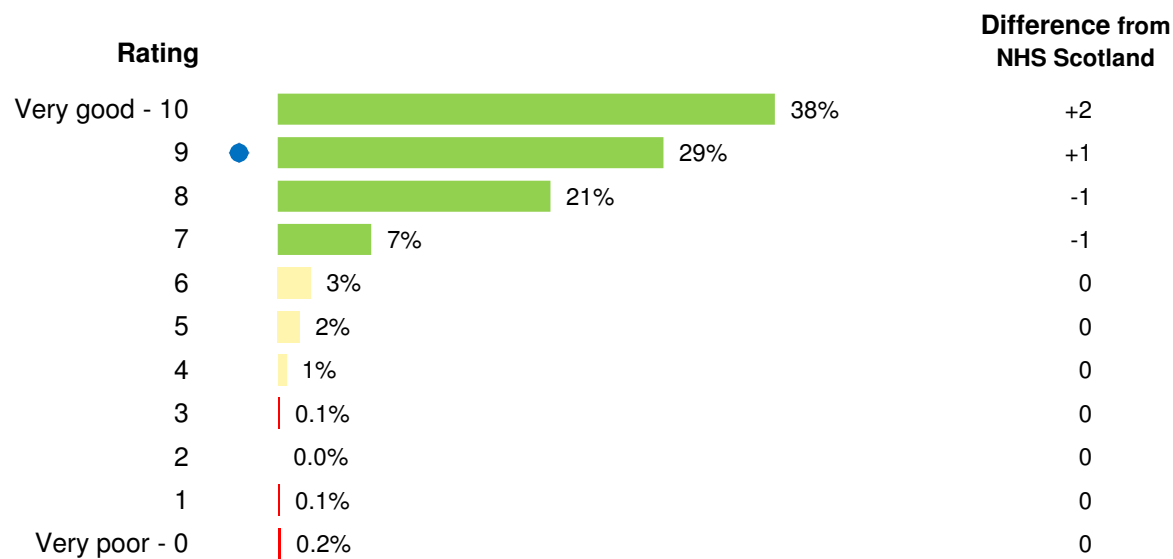
- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

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?	957	95	5		95	+1

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



Difference from NHS Scotland Median (●): 0.0

1.2 Seeing your GP

Note: Questions 1 - 3 relate to GP or community-based care. As such, results for these questions are based on responses from patients who were **resident within this NHS Board** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

1.		(%) NHS Board	(%) NHS Scotland
	None – I went straight to hospital	9	9
	None – I went to hospital following a cancer screening appointment	18	15
	I saw my GP once	43	43
	I saw my GP twice	16	16
	I saw my GP 3 or 4 times	8	10
	I saw my GP 5 or more times	6	7

(Number of responses within this NHS Board = 671).

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
2.	690	84	11	5	84	+2

3.		(%) NHS Board	(%) NHS Scotland
	Less than 3 months	82	83
	3 - 6 months	12	11
	6 - 12 months	3	3
	More than 12 months	2	3

(Number of responses within this NHS Board = 644).

1.3 Diagnostic tests

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

(Number of responses within this NHS Board = 1,000).

¹ Of the respondents who had a diagnostic test(s), 58% indicated that the test(s) took place at a hospital within this NHS Board. The results for questions 5 - 7 below only include responses from those patients who said that their test(s) took place within this NHS Board.

	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?	521	93	7	93	+1	
6. Overall, how did you feel about the length of time you had to wait for your test to be done?	552	86	12	86	+1	
7. Were the results of the test explained in a way you could understand?	555	85	14	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?	808	75		25	75	+3
10. How do you feel about the way you were told you had cancer?	969	86	10	4	86	0
11. Did you understand the explanation of what was wrong with you?	1,002	78	20		78	+3 ^s
12. When you were told you had cancer, were you given written information about the type of cancer you had?	782	62		38	62	+2

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?	836	88	11	88	+2	
14. Were the possible side effects of treatment(s) explained in a way you could understand?	910	72	24	4	72	+1
15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	909	65	26	9	65	+1
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?	839	55	29	16	55	+2
17. Were you involved as much as you wanted to be in decisions about your care and treatment?	964	82	15		82	+4 ^s

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	942	82		18	82	-2
19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	688	91	5	5	91	+1
20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	634	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?	700	83		17	83	+4 ^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)?	634	81		19	81	+4 ^S
23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	415	48		52	48	-3

1.8 Operations

24. Have you had an operation (such as removal of a tumour or lump) for your cancer?	(%) NHS Board	(%) NHS Scotland
Yes ¹	81	77
No	19	23

(Number of responses within this NHS Board = 996).

¹ Of the respondents who had an operation, 79% indicated that the operation took place at a hospital within this NHS Board. The results for questions 25 - 26 below only include responses from those patients who said that their operation took place within this NHS Board.

	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?	613	94	6	94	+1	
26. After the operation, did a member of staff explain how it had gone in a way you could understand?	623	80	17	80	0	

1.9 Hospital care as an inpatient

28. Have you had an operation or stayed overnight for cancer care?	(%) NHS Board	(%) NHS Scotland
Yes ¹	84	83
No	16	17

(Number of responses within this NHS Board = 998).

¹ Of the respondents who had an operation / stayed overnight, 83% indicated that the operation / stay took place at a hospital within this NHS Board. The results for questions 29 - 40 below only include responses from those patients who said that their operation / stay took place within this NHS Board.

	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?	694	81	15	4	81	0
30. Did you have confidence and trust in the doctors treating you?	698	87	13		87	+1
31. If your family or someone else close to you wanted to talk to a doctor, were they able to?	543	79	17	4	79	+4
32. Did you have confidence and trust in the ward nurses treating you?	695	80	20		80	+3
33. In your opinion, were there enough nurses on duty to care for you in hospital?	684	76	21	3	76	+4 ^s
34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	683	69	19	12	69	+4
35. Were you given enough privacy when discussing your condition or treatment?	694	84	13	3	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?	463	51	33	16	51	+1
37. Do you think the hospital staff did everything they could to help control your pain?	611	90	8		90	+3 ^s
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?	697	90	9		90	+3 ^s
39. Were you given clear written information about what you should or should not do after leaving hospital?	644	86	14		86	+4 ^s
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	664	94	6		94	+3 ^s

1.10 Hospital care as a day patient / outpatient

42. Have you been treated as an outpatient or day case for cancer care?	(%) NHS Board	(%) NHS Scotland
Yes ¹	81	84
No	19	16

(Number of responses within this NHS Board = 992).

¹ Of the respondents who had been treated as an outpatient or day case, 73% indicated that the treatment / care took place at a hospital within this NHS Board. The results for questions 43 - 44 below only include responses from those patients who said that their treatment / care took place within this NHS Board.

	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?	455	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?	571	98			98	0

1.11 Radiotherapy

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

(Number of responses within this NHS Board = 982).

¹ Of the respondents who had radiotherapy treatment, 78% indicated that the treatment took place at a hospital within this NHS Board. The results for questions 47 - 48 below only include responses from those patients who said that their radiotherapy took place within this NHS Board.

	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?	370	84	13	84	+3	
48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	325	56	26	18	56	+2

1.12 Chemotherapy

50. Have you had chemotherapy treatment?	(%) NHS Board	(%) NHS Scotland
Yes ¹	45	48
No	55	52

(Number of responses within this NHS Board = 985).

¹ Of the respondents who had chemotherapy treatment, 77% indicated that the treatment took place at a hospital within this NHS Board. The results for questions 51 - 52 below only include responses from those patients who said that their chemotherapy took place within this NHS Board.

	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?	337	78	19		78	+1
52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	299	66	24	10	66	+4

1.13 Home care and support

Note: Questions 55, 56 and 58 relate to GP or community-based care. As such, results for these questions are based on responses from patients who were **resident within this NHS Board** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**.

	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?	794	59	23	18	59	+2
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)?	345	57	24	19	57	+3
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)?	283	51	23	26	51	+6

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?	830	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?	534	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?	943	90	8		90	+1
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.	868	22	78		22	0
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)?	979	91	7		91	+1
62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	977	78	18	4	78	+2
63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	935	32	68		32	+10 ^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?	571	98			98	0
57.	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	830	96		4	96	0
64.	Overall, how would you rate your care?	957	95		5	95	+1
40.	Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	664	94		6	94	+3 ^s
25.	Beforehand, did you have all the information you needed about your operation?	613	94		6	94	+1

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.	868	22		78	22	0
63.	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	935	32		68	32	+10 ^s
23.	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	415	48		52	48	-3
12.	When you were told you had cancer, were you given written information about the type of cancer you had?	782	62		38	62	+2
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)?	283	51	23	26	51	+6

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 NHS Board Results across Scotland

The tables / charts in this chapter show this NHS Board's percent positive results in relation to the range of percent positive results across all NHS Boards in Scotland. The percent positive results for NHS Scotland are also shown.

Notes on Interpretation

■ Range of percent positive results across all NHS Boards in Scotland - ranges from lowest NHS Board result to highest NHS Board result.

■ This NHS Board's percent positive result.

| NHS Scotland percent positive result.

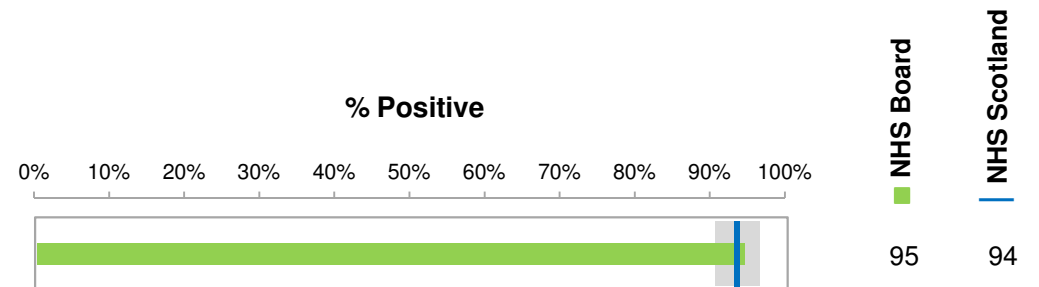
S Indicates a statistically significant difference in the percent positive result between this NHS Board and NHS Scotland as a whole.

NT Indicates that a significance test was not carried out because fewer than five respondents within this NHS Board selected a positive response or because fewer than five respondents within this NHS Board 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

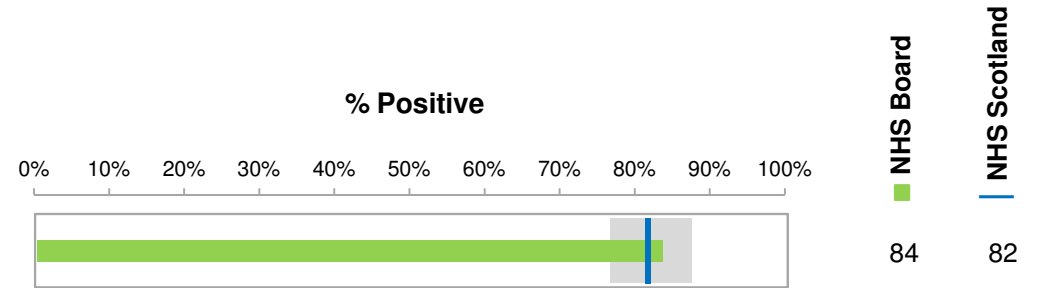
64. Overall, how would you rate your care?



2.2 Seeing your GP

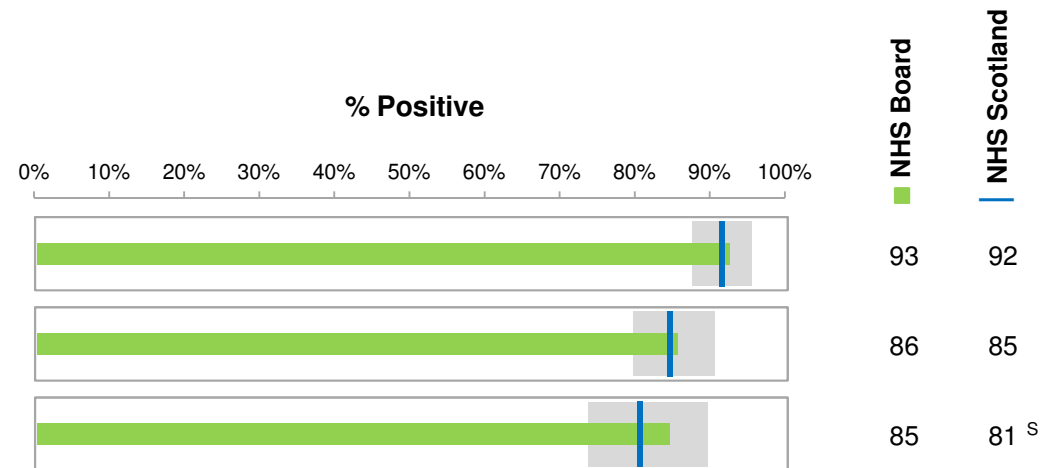
Note: Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this NHS Board** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

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

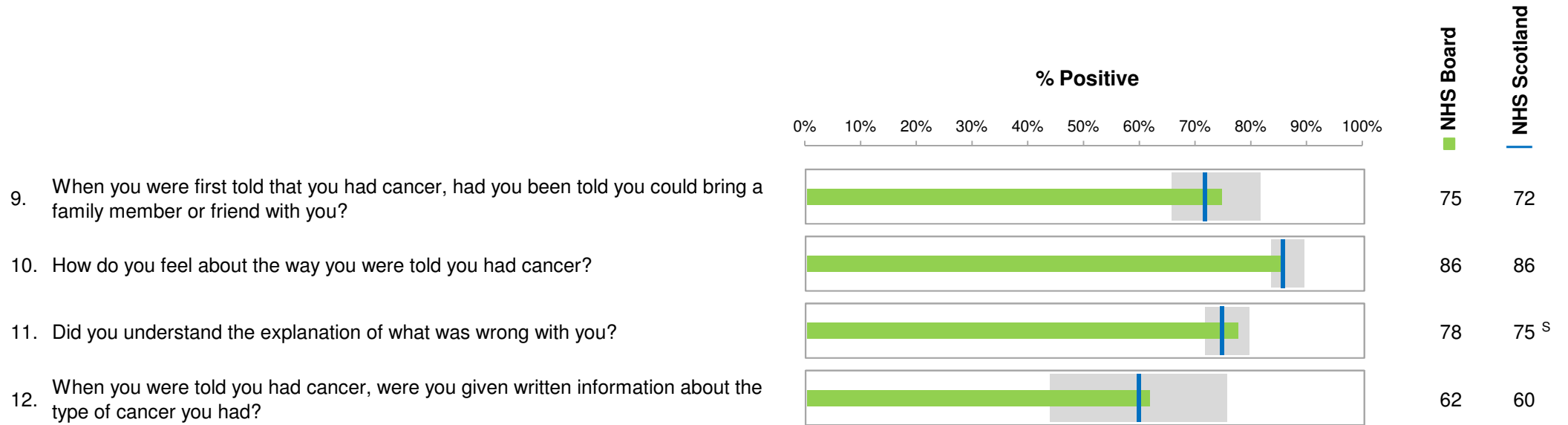


2.3 Diagnostic tests

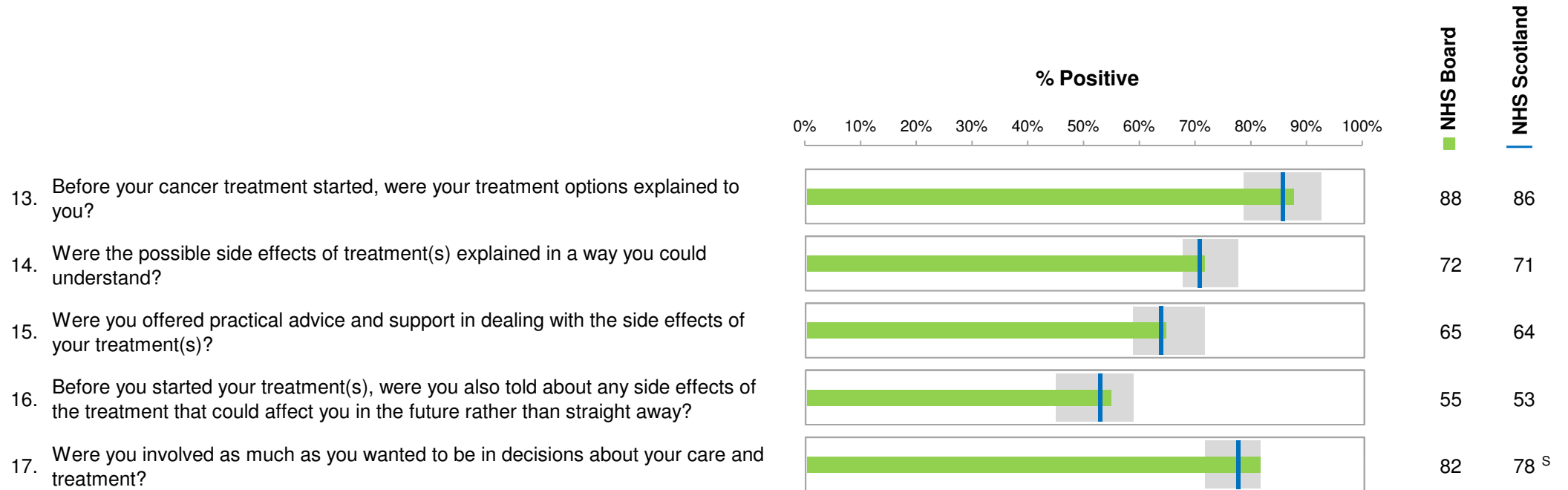
5. Beforehand, did you have all the information you needed about your test?
6. Overall, how did you feel about the length of time you had to wait for your test to be done?
7. Were the results of the test explained in a way you could understand?



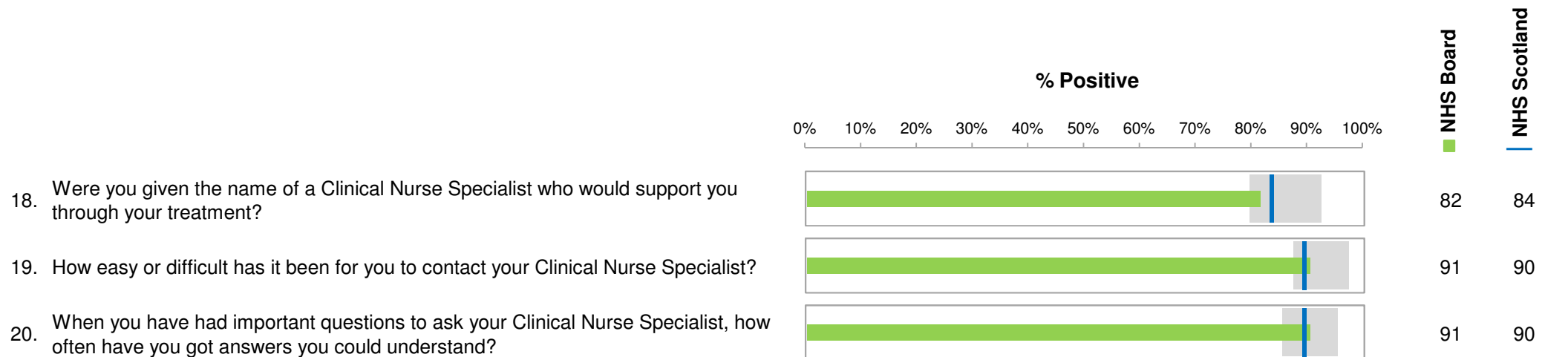
2.4 Finding out what was wrong with you



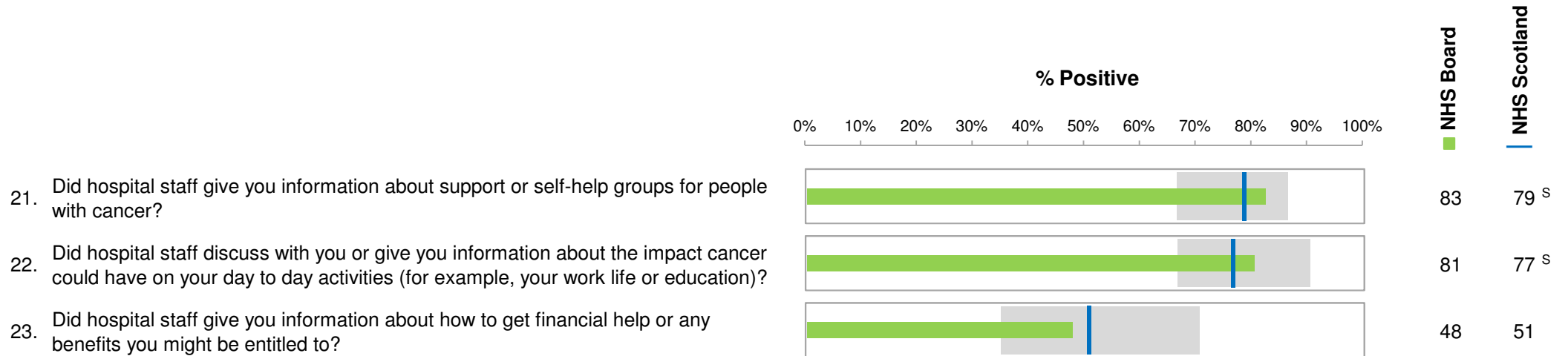
2.5 Deciding the best treatment for you



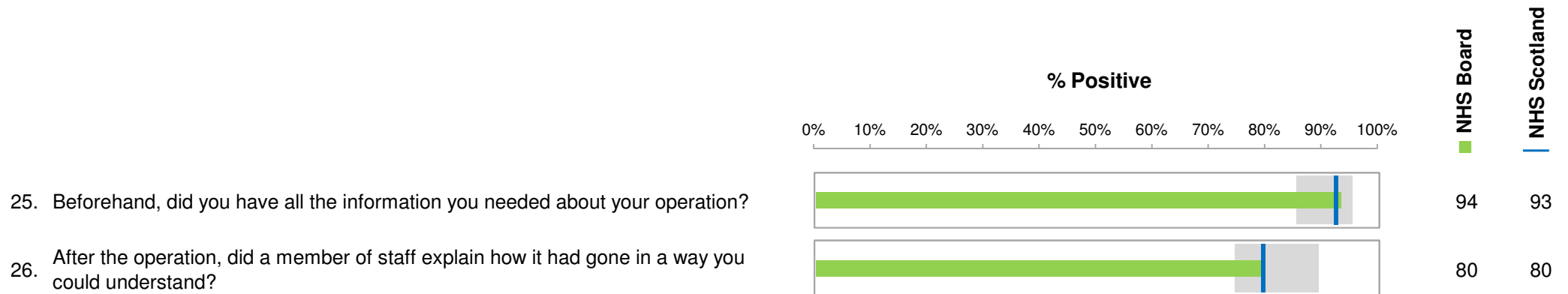
2.6 Clinical Nurse Specialist



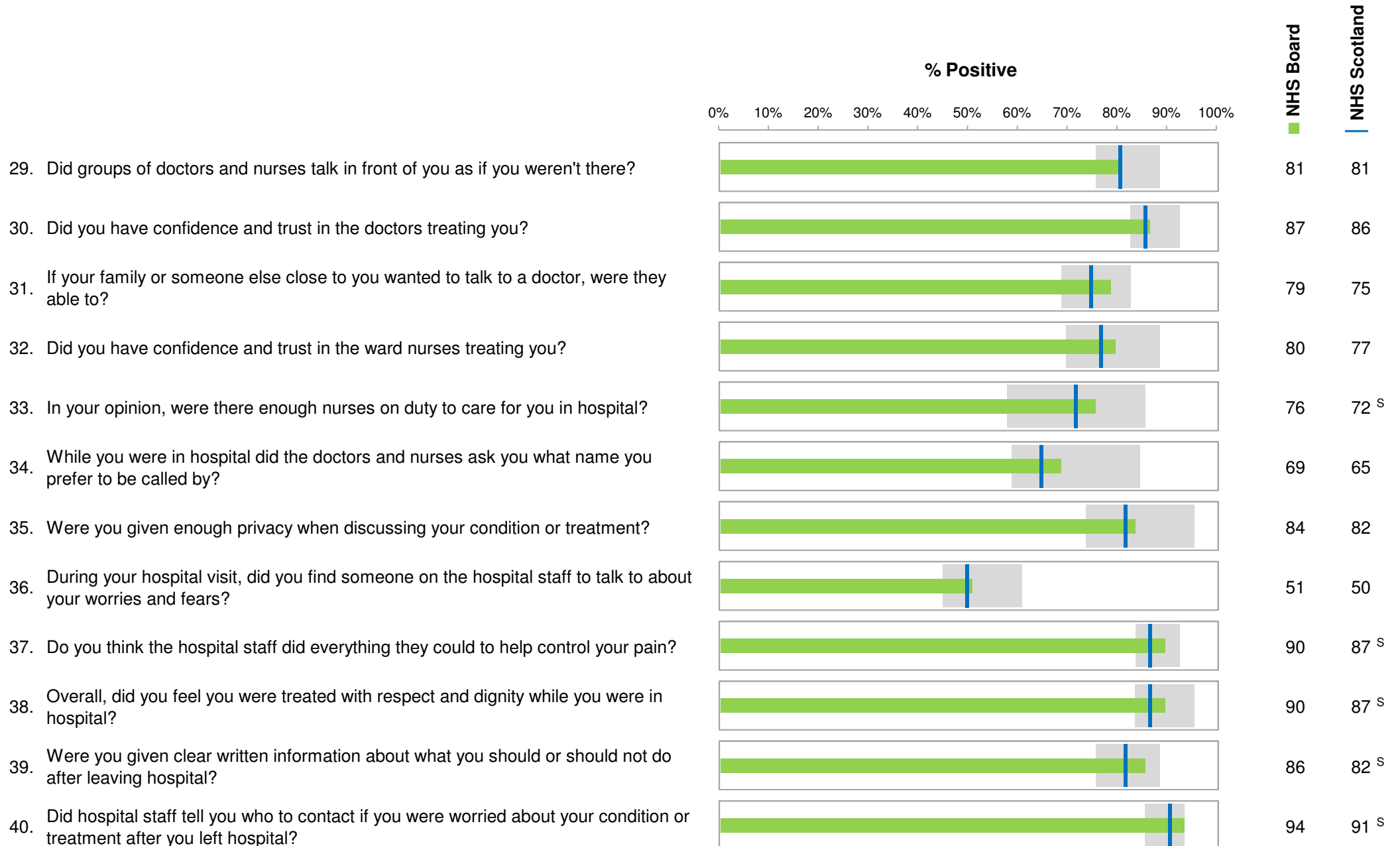
2.7 Support for people with cancer



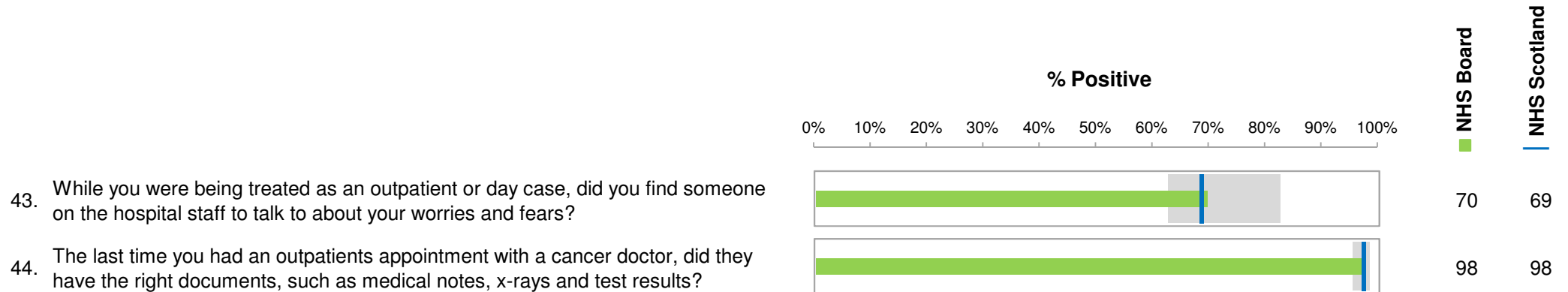
2.8 Operations



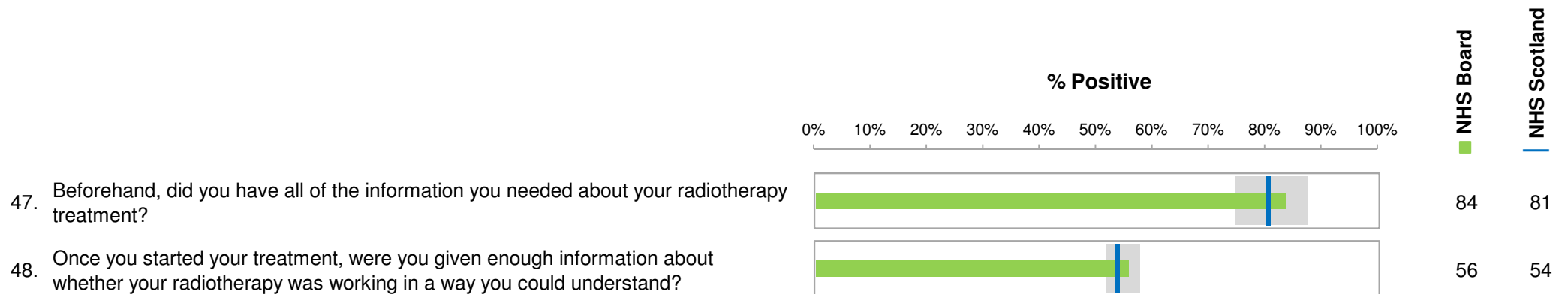
2.9 Hospital care as an inpatient



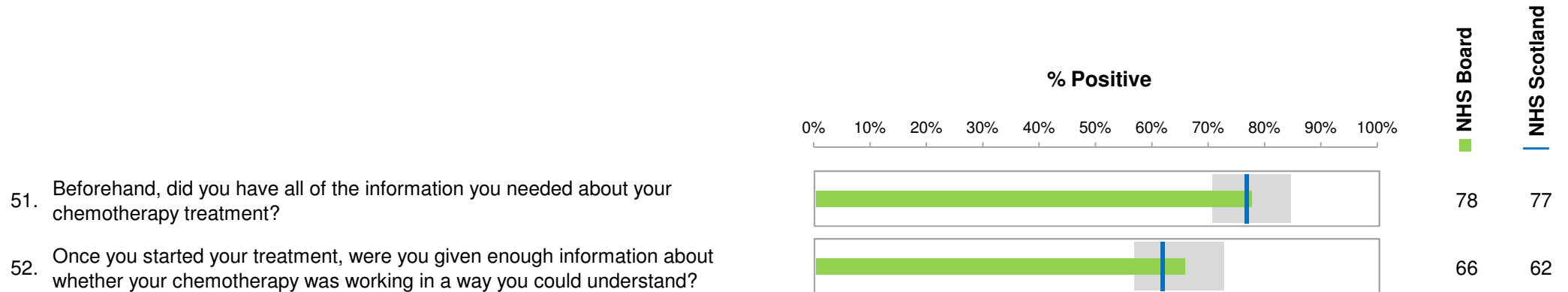
2.10 Hospital care as a day patient / outpatient



2.11 Radiotherapy

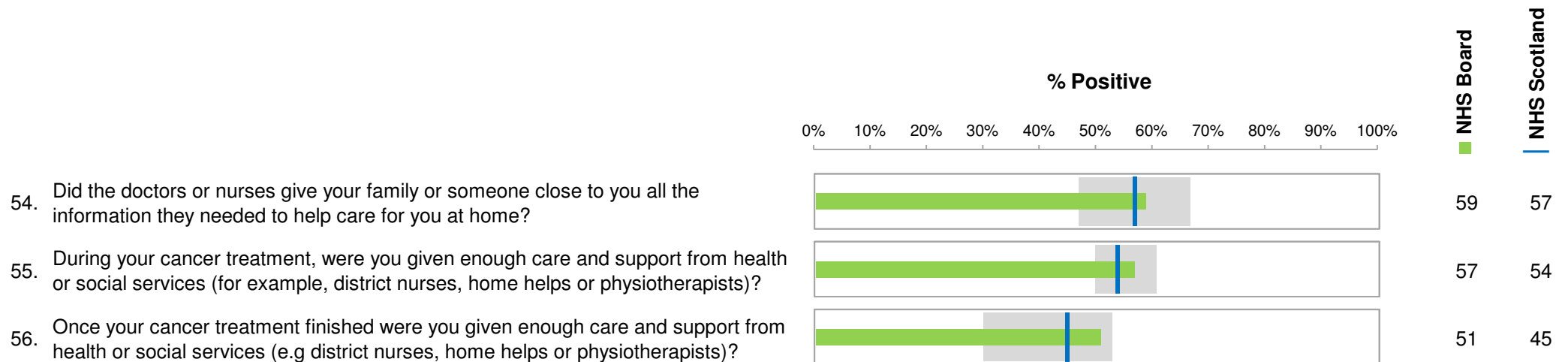


2.12 Chemotherapy



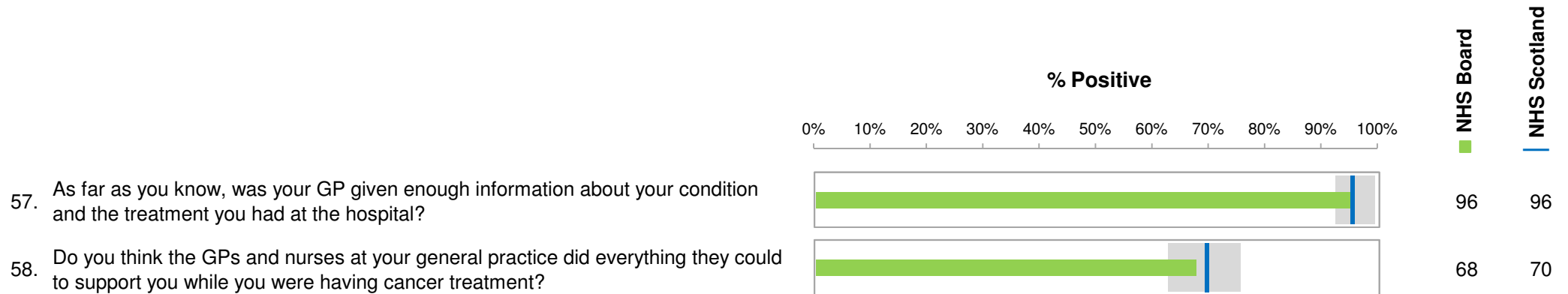
2.13 Home care and support

Note: Questions 55 and 56 relate to community-based care. As such, results for these questions are based on responses from patients who were **resident within this NHS Board** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**.

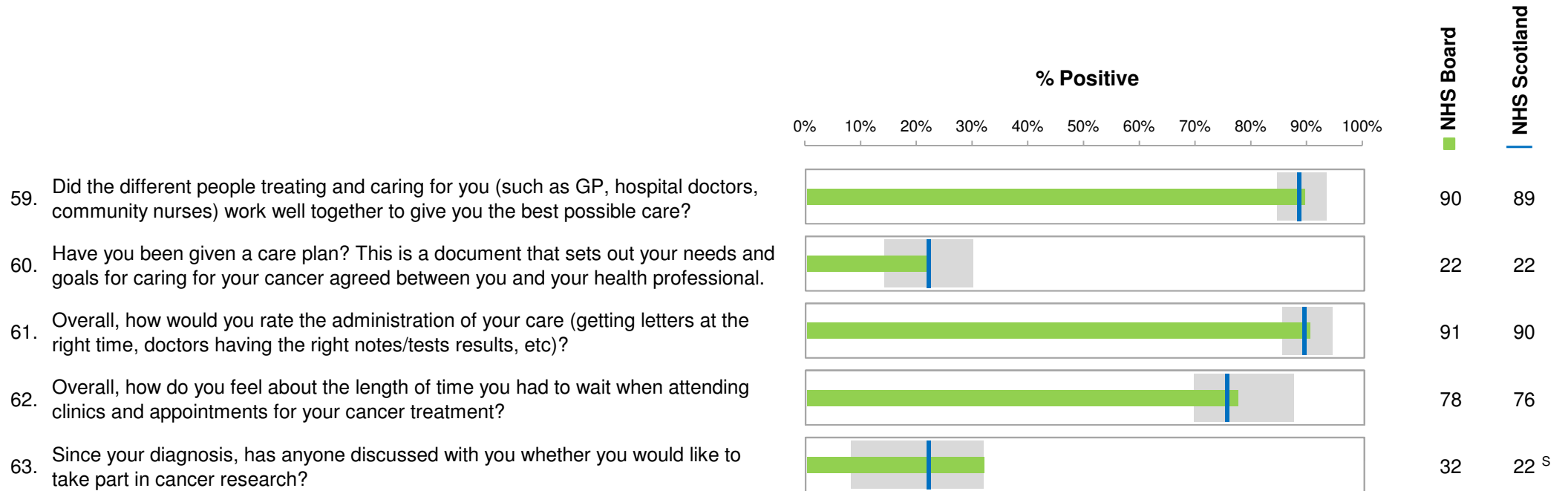


2.14 Care from your General Practice

Note: Question 58 relates to GP care. As such, results for this question are based on responses from patients who were **resident within this NHS Board** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**.



2.15 Your overall NHS Care



Chapter 3. Results by Tumour Group for NHS Lothian

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	
	NHS Board	NHS Scotland
Breast	26	25
Colorectal / Lower Gastrointestinal	13	15
Lung	6	6
Prostate	11	12
Brain / Central Nervous System	2	1
Gynaecological	7	7
Haematological	7	8
Head & Neck	6	5
Sarcoma	1	1
Skin	2	3
Upper Gastrointestinal	5	4
Urological	7	6
Other	0	0
Tumour group unknown	5	7

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

Notes on Interpretation

NHS Board - the percent positive result for this NHS Board; the total percentage of patients treated within this NHS Board 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	NHS Board	NHS Scotland
Breast	95	94
Colorectal / Lower Gastrointestinal	95	94
Lung	90	94
Prostate	96	94
Brain / Central Nervous System	--	89
Gynaecological	97	95
Haematological	97	97
Head & Neck	97	93
Sarcoma	--	90
Skin	96	97
Upper Gastrointestinal	87	91
Urological	97	93
Other	--	--
Tumour group unknown	94	89
All Tumour Groups	95	94

3.2 Seeing your GP

Note: Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this NHS Board** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

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	NHS Board	NHS Scotland
Breast	93	84
Colorectal / Lower Gastrointestinal	86	84
Lung	85	85
Prostate	86	83
Brain / Central Nervous System	--	76
Gynaecological	74	79
Haematological	78	79
Head & Neck	77	84
Sarcoma	--	56
Skin	73	83
Upper Gastrointestinal	68	77
Urological	80	76
Other	--	--
Tumour group unknown	--	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	94	93	93	89	88	84
Colorectal / Lower Gastrointestinal	99	96	83	86	82	84
Lung	93	92	90	87	83	83
Prostate	92	92	79	83	78	80
Brain / Central Nervous System	--	91	--	91	--	77
Gynaecological	93	86	74	77	84	78
Haematological	93	91	91	86	91	81
Head & Neck	92	88	89	87	89	77
Sarcoma	--	82	--	79	--	76
Skin	--	85	--	89	--	76
Upper Gastrointestinal	77	90	79	78	88	77
Urological	87	90	85	80	85	73
Other	--	--	--	--	--	--
Tumour group unknown	96	91	81	84	77	76
All Tumour Groups	93	92	86	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
	Breast	83	75	87	89	80	77	60
Colorectal / Lower Gastrointestinal	76	80	88	86	90	82	70	59
Lung	73	75	83	87	83	78	58	54
Prostate	82	77	84	87	76	80	79	78
Brain / Central Nervous System	--	90	--	79	--	77	--	47
Gynaecological	47	57	85	85	78	74	59	54
Haematological	76	72	89	85	68	60	72	70
Head & Neck	64	66	83	88	80	75	49	51
Sarcoma	--	59	--	82	--	62	--	36
Skin	--	55	84	89	76	74	81	74
Upper Gastrointestinal	72	72	84	80	63	72	40	45
Urological	63	63	87	79	77	75	43	51
Other	--	--	--	--	--	--	--	--
Tumour group unknown	84	73	84	85	72	70	59	53
All Tumour Groups	75	72	86	86	78	75	62	60

3.5 Deciding the best treatment for you

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?

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	86	85	70	66	70	64	55	46
Colorectal / Lower Gastrointestinal	85	89	77	74	71	68	57	57
Lung	90	87	70	76	59	68	46	59
Prostate	90	86	70	73	59	64	59	62
Brain / Central Nervous System	--	87	--	69	--	49	--	49
Gynaecological	86	85	73	72	61	63	55	52
Haematological	93	89	75	73	79	70	61	58
Head & Neck	88	89	59	69	56	63	49	51
Sarcoma	--	78	--	60	--	59	--	63
Skin	86	86	--	74	59	69	--	62
Upper Gastrointestinal	93	87	76	70	68	67	50	52
Urological	93	82	82	72	56	55	60	50
Other	--	--	--	--	--	--	--	--
Tumour group unknown	85	84	74	67	61	58	44	49
All Tumour Groups	88	86	72	71	65	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	NHS Board	NHS Scotland
Breast	82	76
Colorectal / Lower Gastrointestinal	88	82
Lung	83	83
Prostate	84	80
Brain / Central Nervous System	--	74
Gynaecological	79	76
Haematological	87	80
Head & Neck	75	77
Sarcoma	--	71
Skin	87	87
Upper Gastrointestinal	80	77
Urological	83	74
Other	--	--
Tumour group unknown	73	70
All Tumour Groups	82	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	95	95	88	88	87	86
Colorectal / Lower Gastrointestinal	91	90	90	92	94	94
Lung	87	87	89	90	88	91
Prostate	84	81	90	90	90	91
Brain / Central Nervous System	--	84	--	82	--	89
Gynaecological	83	83	91	88	98	90
Haematological	65	70	98	94	97	94
Head & Neck	77	80	90	93	97	93
Sarcoma	--	85	--	96	--	100
Skin	87	78	--	94	--	92
Upper Gastrointestinal	59	81	85	90	88	86
Urological	47	58	95	91	90	88
Other	--	--	--	--	--	--
Tumour group unknown	80	78	94	90	93	84
All Tumour Groups	82	84	91	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	89	83	85	76	53	47
Colorectal / Lower Gastrointestinal	84	78	86	80	51	54
Lung	68	77	75	76	53	61
Prostate	90	85	84	84	34	38
Brain / Central Nervous System	--	77	--	77	--	69
Gynaecological	85	75	75	75	48	58
Haematological	85	84	82	80	59	62
Head & Neck	68	78	92	78	43	58
Sarcoma	--	75	--	--	--	60
Skin	--	88	--	86	--	50
Upper Gastrointestinal	73	76	76	76	50	66
Urological	71	63	65	60	36	32
Other	--	--	--	--	--	--
Tumour group unknown	74	72	64	67	35	45
All Tumour Groups	83	79	81	77	48	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	95	93	76	78
Colorectal / Lower Gastrointestinal	90	95	88	85
Lung	93	92	67	84
Prostate	96	94	77	83
Brain / Central Nervous System	--	90	--	75
Gynaecological	100	93	86	81
Haematological	--	89	--	73
Head & Neck	91	91	74	77
Sarcoma	--	93	--	71
Skin	--	90	--	76
Upper Gastrointestinal	95	93	82	81
Urological	96	90	93	78
Other	--	--	--	--
Tumour group unknown	86	90	82	76
All Tumour Groups	94	93	80	80

3.9 Hospital care as an inpatient

Tumour Group	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?	
	% Positive		% Positive		% Positive		% Positive	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	87	87	84	86	84	74	83	79
Colorectal / Lower Gastrointestinal	70	75	87	85	71	75	73	74
Lung	74	78	77	85	79	79	79	83
Prostate	84	81	88	86	77	75	86	79
Brain / Central Nervous System	--	77	--	83	--	57	--	51
Gynaecological	83	86	86	87	77	74	74	76
Haematological	81	82	88	88	85	83	76	81
Head & Neck	83	79	90	89	85	77	80	75
Sarcoma	--	74	--	90	--	73	--	61
Skin	--	86	--	92	--	76	--	81
Upper Gastrointestinal	80	74	91	87	82	80	85	78
Urological	74	76	88	84	79	72	76	74
Other	--	--	--	--	--	--	--	--
Tumour group unknown	86	78	86	83	73	73	90	71
All Tumour Groups	81	81	87	86	79	75	80	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	80	74	59	55	85	82	56	49
Colorectal / Lower Gastrointestinal	66	69	71	70	73	79	49	52
Lung	82	81	82	80	82	87	46	55
Prostate	82	75	72	67	92	86	57	51
Brain / Central Nervous System	--	63	--	61	--	80	--	40
Gynaecological	74	72	68	62	81	80	35	43
Haematological	74	72	67	69	90	86	45	57
Head & Neck	79	74	68	69	92	84	68	53
Sarcoma	--	68	--	55	--	77	--	39
Skin	--	81	--	62	--	88	--	58
Upper Gastrointestinal	57	61	89	79	77	77	55	52
Urological	76	73	76	72	81	79	44	45
Other	--	--	--	--	--	--	--	--
Tumour group unknown	79	72	66	62	83	75	48	43
All Tumour Groups	76	72	69	65	84	82	51	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	92	88	91	87	92	86	99	95
Colorectal / Lower Gastrointestinal	95	88	88	87	83	79	96	92
Lung	89	87	92	90	71	80	89	88
Prostate	91	88	89	89	92	86	95	92
Brain / Central Nervous System	--	74	--	69	--	67	--	89
Gynaecological	92	86	98	87	85	84	89	88
Haematological	88	89	95	94	78	79	95	93
Head & Neck	85	85	88	85	91	81	100	90
Sarcoma	--	85	--	83	--	58	--	89
Skin	--	81	--	87	--	87	--	94
Upper Gastrointestinal	86	88	89	85	84	78	89	92
Urological	86	83	88	87	79	74	85	81
Other	--	--	--	--	--	--	--	--
Tumour group unknown	92	86	93	87	93	78	93	89
All Tumour Groups	90	87	90	87	86	82	94	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	66	64	99	97
Colorectal / Lower Gastrointestinal	77	75	100	96
Lung	76	71	97	97
Prostate	66	74	100	99
Brain / Central Nervous System	--	64	--	94
Gynaecological	69	68	95	98
Haematological	70	72	98	98
Head & Neck	--	71	100	99
Sarcoma	--	67	--	96
Skin	--	73	--	97
Upper Gastrointestinal	--	76	--	99
Urological	73	60	98	96
Other	--	--	--	--
Tumour group unknown	67	58	97	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	86	81	52	48
Colorectal / Lower Gastrointestinal	83	80	57	56
Lung	--	85	--	61
Prostate	79	85	69	62
Brain / Central Nervous System	--	88	--	74
Gynaecological	88	82	55	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	84	81	56	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	73	75	63	53
Colorectal / Lower Gastrointestinal	76	77	70	63
Lung	81	82	--	68
Prostate	--	71	--	57
Brain / Central Nervous System	--	82	--	--
Gynaecological	79	72	59	61
Haematological	88	82	77	75
Head & Neck	--	71	--	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	80	--	58
Urological	--	80	--	76
Other	--	--	--	--
Tumour group unknown	--	73	--	64
All Tumour Groups	78	77	66	62

3.13 Home care and support

Note: Questions 55 and 56 relate to community-based care. As such, results for these questions are based on responses from patients who were **resident within this NHS Board** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**.

Tumour Group	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)?	
	% Positive		% Positive		% Positive	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	57	50	44	50	37	37
Colorectal / Lower Gastrointestinal	59	60	71	64	62	55
Lung	54	59	67	52	--	44
Prostate	49	54	46	54	46	45
Brain / Central Nervous System	--	51	--	45	--	--
Gynaecological	55	57	--	41	--	36
Haematological	66	65	63	57	44	48
Head & Neck	69	64	69	64	68	55
Sarcoma	--	44	--	61	--	--
Skin	--	67	--	55	--	58
Upper Gastrointestinal	65	65	--	63	--	55
Urological	59	57	69	54	54	48
Other	--	--	--	--	--	--
Tumour group unknown	68	53	--	42	--	33
All Tumour Groups	59	57	57	54	51	45

3.14 Care from your General Practice

Note: Question 58 relates to GP care. As such, results for this question are based on responses from patients who were **resident within this NHS Board** at the time of their treatment. This differs from most other results in this report, which are based on responses from patients who **received their hospital treatment in this NHS Board**.

Tumour Group	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?	
	% Positive		% Positive	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	97	96	66	70
Colorectal / Lower Gastrointestinal	96	97	69	72
Lung	93	93	84	71
Prostate	98	97	64	72
Brain / Central Nervous System	--	89	--	73
Gynaecological	89	95	46	64
Haematological	94	96	66	66
Head & Neck	100	94	67	69
Sarcoma	--	96	--	71
Skin	--	95	--	74
Upper Gastrointestinal	95	97	--	74
Urological	99	95	75	72
Other	--	--	--	--
Tumour group unknown	95	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	
	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland	NHS Board	NHS Scotland
Breast	91	90	20	21	92	91	76	73
Colorectal / Lower Gastrointestinal	89	90	26	22	92	89	80	80
Lung	87	89	21	24	92	92	84	80
Prostate	86	89	24	23	91	88	70	76
Brain / Central Nervous System	--	79	--	18	--	74	--	64
Gynaecological	87	88	10	17	88	88	79	81
Haematological	96	91	29	26	95	94	84	77
Head & Neck	90	90	26	28	93	90	82	77
Sarcoma	--	90	--	20	--	88	--	65
Skin	83	90	20	18	96	94	88	82
Upper Gastrointestinal	85	90	15	20	88	91	81	72
Urological	92	87	17	17	85	85	73	71
Other	--	--	--	--	--	--	--	--
Tumour group unknown	91	87	24	24	86	85	84	72
All Tumour Groups	90	89	22	22	91	90	78	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	NHS Board	NHS Scotland
Breast	39	27
Colorectal / Lower Gastrointestinal	50	30
Lung	29	24
Prostate	34	20
Brain / Central Nervous System	--	25
Gynaecological	28	13
Haematological	15	23
Head & Neck	12	16
Sarcoma	--	26
Skin	17	12
Upper Gastrointestinal	28	25
Urological	26	18
Other	--	--
Tumour group unknown	25	14
All Tumour Groups	32	22

Chapter 4. Condition / Demographic Questions for NHS Lothian

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

Notes on Interpretation

(%) **NHS Board** - Percentage of respondents treated within this NHS Board who selected a 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

	(%) NHS Board	(%) NHS Scotland
65. How long is it since you were first treated for this cancer?		
Less than 1 year	5	6
1 to 5 years	93	93
More than 5 years	1	1

(Number of responses within this NHS Board = 968).

	(%) NHS Board	(%) 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	14	14
No ¹	84	85
Does not apply to my type of cancer	2	1

(Number of responses within this NHS Board = 938).

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

4.1 Your condition (cont.)

67. Which of the following applies?	(%) NHS Board	(%) NHS Scotland
My cancer has been taken out / treated without any sign of further problem	79	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	15	14

(Number of responses within this NHS Board = 743).

4.2 About you

68. What was your age on your last birthday?	(%) NHS Board	(%) NHS Scotland
16 - 25	0	0
26 - 35	2	2
36 - 50	9	10
51 - 65	35	34
66 - 75	34	35
76+	20	19

(Number of responses within this NHS Board = 968).

69. Are you male or female?	(%) NHS Board	(%) NHS Scotland
Male	44	43
Female	56	57

(Number of responses within this NHS Board = 981).

4.2 About you (cont.)

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

(Number of responses within this NHS Board = 961).

71. What is your ethnic group?	(%) NHS Board	(%) 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 within this NHS Board = 981).

72. What is your main employment status?	(%) NHS Board	(%) NHS Scotland
Work full time	17	17
Work part time	11	10
In full time education or training	0	0
Retired	63	62
Unemployed / looking for work	1	1
Don't work due to illness or disability	6	8
Other	2	2

(Number of responses within this NHS Board = 981).

4.2 About you (cont.)

73. Do you have any of the following? ¹	(%) NHS Board	(%) NHS Scotland
Deafness or severe hearing impairment	15	15
Blindness or severe vision impairment	2	3
A physical disability	15	13
A learning disability	1	1
A mental health condition	3	4
Chronic pain lasting at least 3 months	14	14
Another long - term condition	25	25
None of the above	52	51

(Number of responses within this NHS Board = 918).

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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Data source may be made available on request, subject to consideration of legal and ethical factors. For further information please contact:
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