

Cancer Patient Experience Survey 2015

Results for NHS Highland



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 Highland.

Survey questionnaires were sent out in October 2015 to 427 patients who were diagnosed with cancer between 1st July 2013 and 31st March 2014 and who received cancer treatment and care within NHS Highland 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

284 NHS Highland patients (67%) returned feedback on their experiences. Of those patients willing to provide information about themselves:

- 43% were male and 57% were female.
- 0% were aged 16 - 25; 0% were aged 26 - 35; 9% were aged 36 - 50; 35% were aged 51 - 65; 37% were aged 66 - 75 and 18% were aged 76 and over.
- 56% 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 Highland 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 Highland. 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 Highland 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 Highland

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.

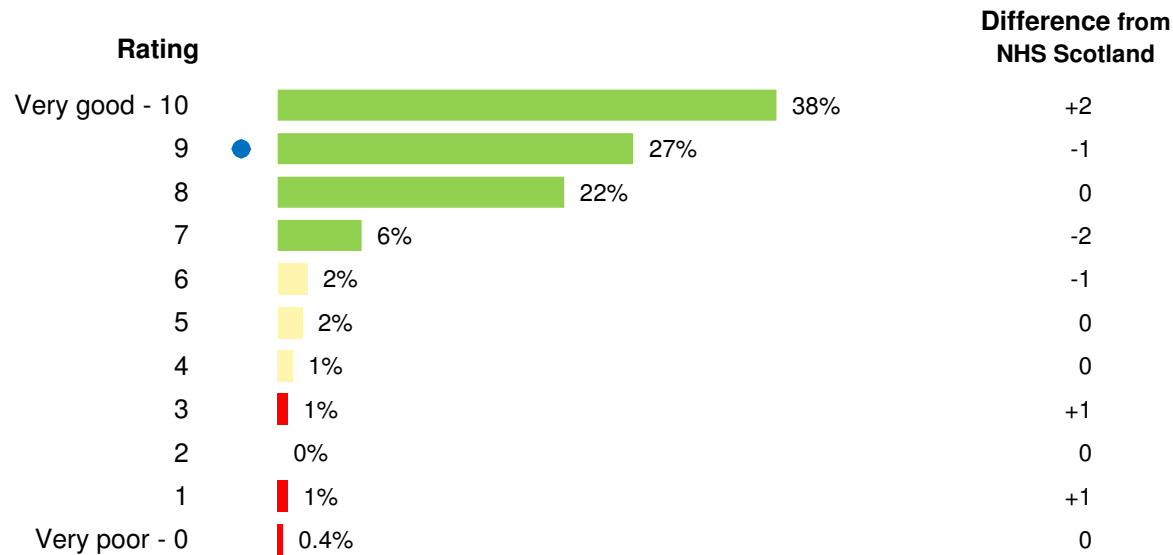
- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

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?	267	93	5		93	-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	16	15
	I saw my GP once	42	43
	I saw my GP twice	16	16
	I saw my GP 3 or 4 times	13	10
	I saw my GP 5 or more times	4	7

(Number of responses within this NHS Board = 308).

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland	
		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?	327	83	12	5	83	+1

3.		(%) NHS Board	(%) 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	83	83
	3 - 6 months	11	11
	6 - 12 months	3	3
	More than 12 months	3	3

(Number of responses within this NHS Board = 308).

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	98	96
No	2	4

(Number of responses within this NHS Board = 281).

¹ Of the respondents who had a diagnostic test(s), 83% 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?	219	92	8	92	0	
6. Overall, how did you feel about the length of time you had to wait for your test to be done?	222	86	12	86	+1	
7. Were the results of the test explained in a way you could understand?	228	81	18	81	0	

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?	222	73		27	73	+1
10. How do you feel about the way you were told you had cancer?	270	89	9		89	+3
11. Did you understand the explanation of what was wrong with you?	278	77	20		77	+2
12. When you were told you had cancer, were you given written information about the type of cancer you had?	213	60		40	60	0

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?	243	88	10	88	+2	
14. Were the possible side effects of treatment(s) explained in a way you could understand?	262	71	25	4	71	0
15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	262	67	26	8	67	+3
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?	249	53	29	18	53	0
17. Were you involved as much as you wanted to be in decisions about your care and treatment?	267	78	18	4	78	0

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	264	80		20	80	-4
19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	190	88	7	5	88	-2
20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	185	92	8		92	+2

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?	209	82		18	82	+3
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)?	167	80		20	80	+3
23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	114	47		53	47	-4

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	76	77
No	24	23

(Number of responses within this NHS Board = 279).

¹ Of the respondents who had an operation, 85% 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?	172	96	4	96	+3 ^s	
26. After the operation, did a member of staff explain how it had gone in a way you could understand?	178	85	13	85	+5	

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	81	83
No	19	17

(Number of responses within this NHS Board = 281).

¹ Of the respondents who had an operation / stayed overnight, 84% 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?	188	84	13	4	84	+3
30. Did you have confidence and trust in the doctors treating you?	191	86	14		86	0
31. If your family or someone else close to you wanted to talk to a doctor, were they able to?	147	76	18	6	76	+1
32. Did you have confidence and trust in the ward nurses treating you?	191	83	16		83	+6 ^s
33. In your opinion, were there enough nurses on duty to care for you in hospital?	191	76	18	6	76	+4
34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	189	77	14	8	77	+12 ^s
35. Were you given enough privacy when discussing your condition or treatment?	190	84	14		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?	136	52	34	14	52	+2
37. Do you think the hospital staff did everything they could to help control your pain?	169	92	7		92	+5 ^s
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?	190	91	8		91	+4
39. Were you given clear written information about what you should or should not do after leaving hospital?	172	76		24	76	-6
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	179	92		8	92	+1

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	87	84
No	13	16

(Number of responses within this NHS Board = 275).

¹ Of the respondents who had been treated as an outpatient or day case, 87% 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?	154	73	18	8	73	+4
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?	198	98			98	0 ^{NT}

1.11 Radiotherapy

46. Have you had radiotherapy treatment?	(%) NHS Board	(%) NHS Scotland
Yes ¹	50	49
No	50	51

(Number of responses within this NHS Board = 272).

¹ Of the respondents who had radiotherapy treatment, 80% 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?	110	75	21	4	75	-6
48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	101	54	27	19	54	0

1.12 Chemotherapy

50. Have you had chemotherapy treatment?	(%) NHS Board	(%) NHS Scotland
Yes ¹	49	48
No	51	52

(Number of responses within this NHS Board = 276).

¹ Of the respondents who had chemotherapy treatment, 88% 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?	118	71	23	6	71	-6
52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	113	57	27	16	57	-5

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?	214	61	21	18	61	+4
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)?	180	53	20	27	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)?	134	49	16	34	49	+4

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?	233	97		3	97	+1
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?	268	73	17	10	73	+3

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?	265	90	7	3	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.	245	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)?	273	88	7	4	88	-2
62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	271	70	23	7	70	-6 ^s
63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	262	21	79		21	-1

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?	198	98			98	0 ^{NT}
57.	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	233	97	3		97	+1
25.	Beforehand, did you have all the information you needed about your operation?	172	96	4		96	+3 ^S
64.	Overall, how would you rate your care?	267	93	5		93	-1
20.	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	185	92	8		92	+2

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		
63.	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	262	21		79	21	-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.	245	23		77	23	+1
23.	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	114	47		53	47	-4
12.	When you were told you had cancer, were you given written information about the type of cancer you had?	213	60		40	60	0
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)?	134	49	16	34	49	+4

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.

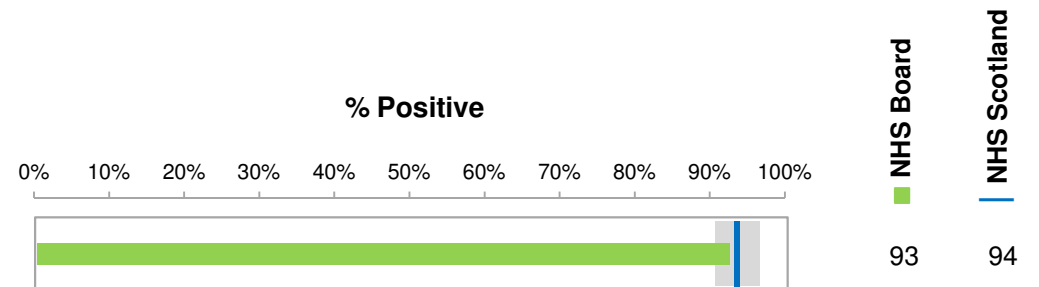
S Indicates a statistically significant difference in the percent positive result between this NHS Board and NHS Scotland as a whole.

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).

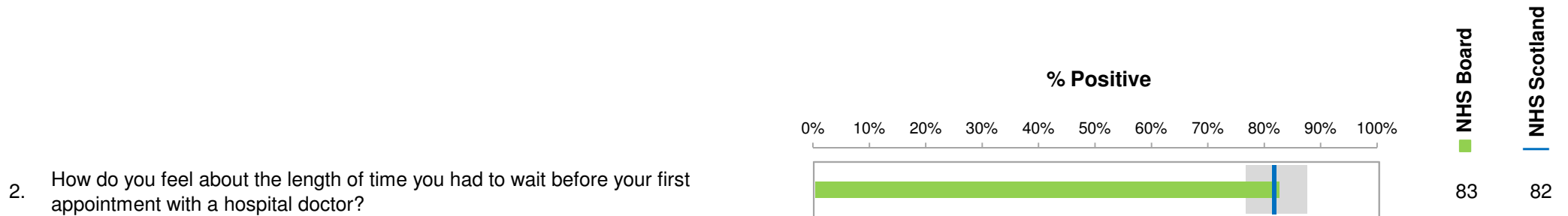
2.1 Overall Care

64. Overall, how would you rate your care?

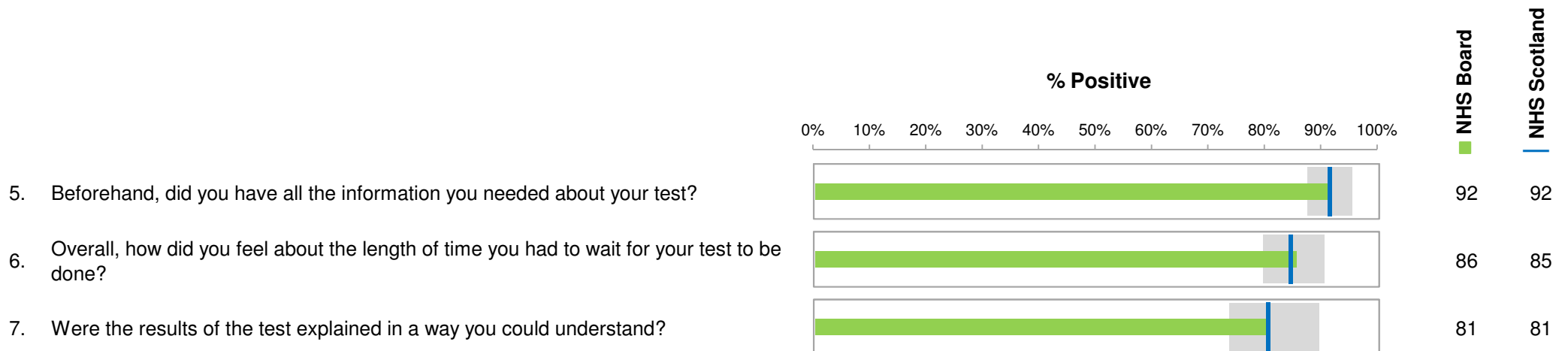


2.2 Seeing your GP

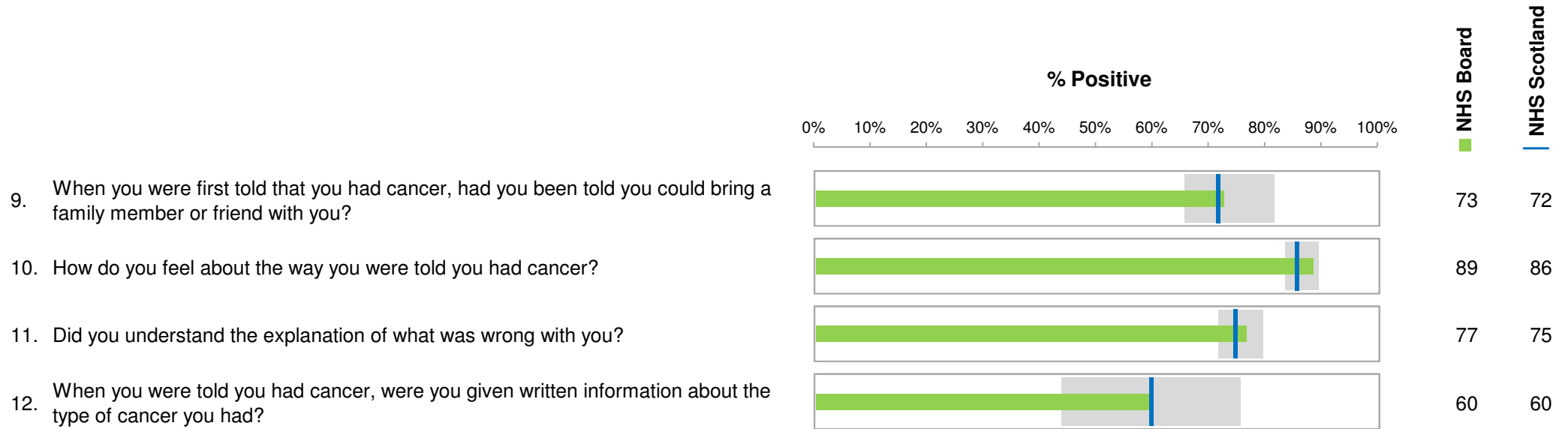
Note: Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this NHS Board** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received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



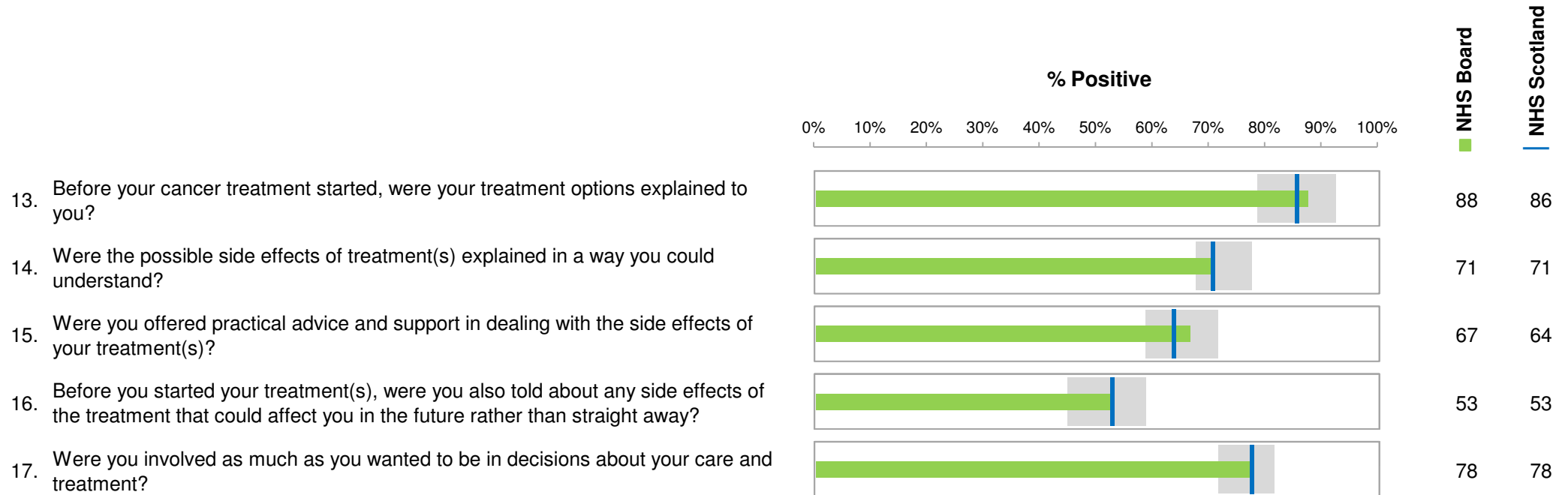
2.3 Diagnostic tests



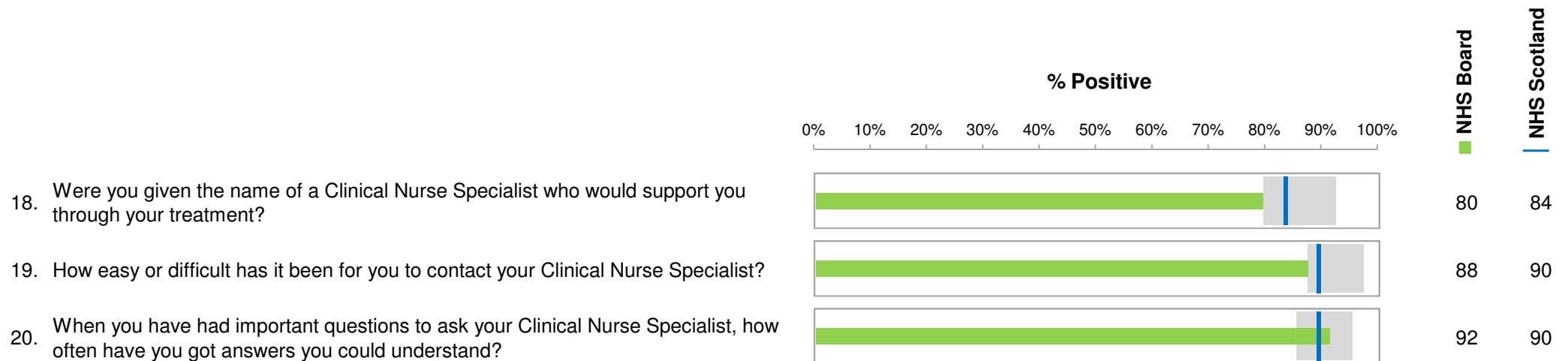
2.4 Finding out what was wrong with you



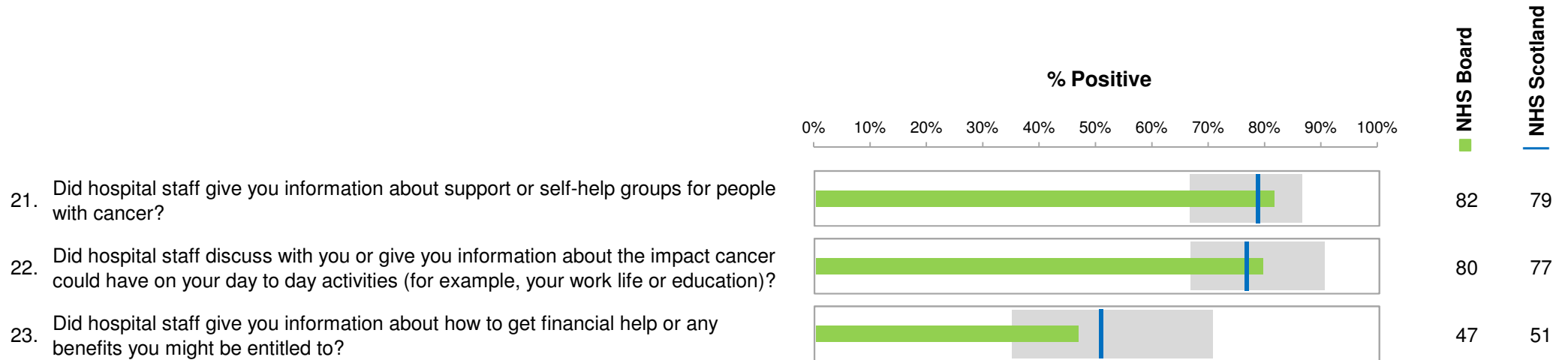
2.5 Deciding the best treatment for you



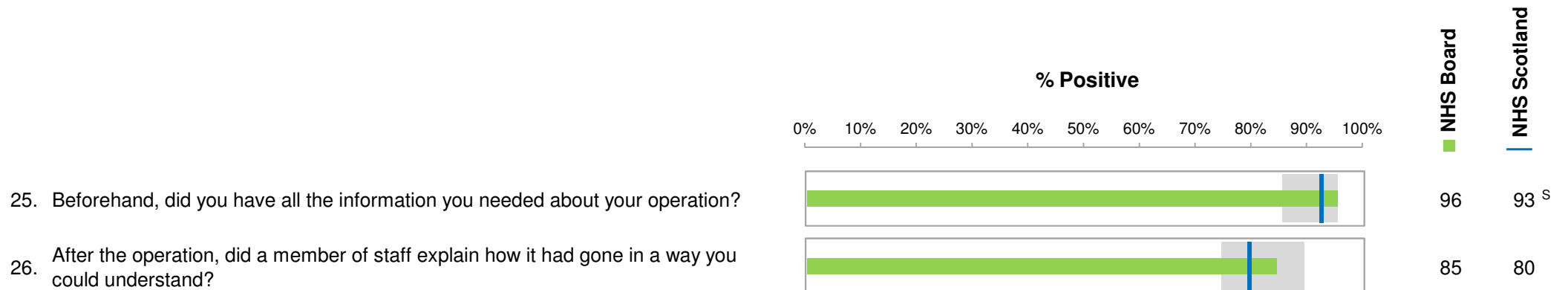
2.6 Clinical Nurse Specialist



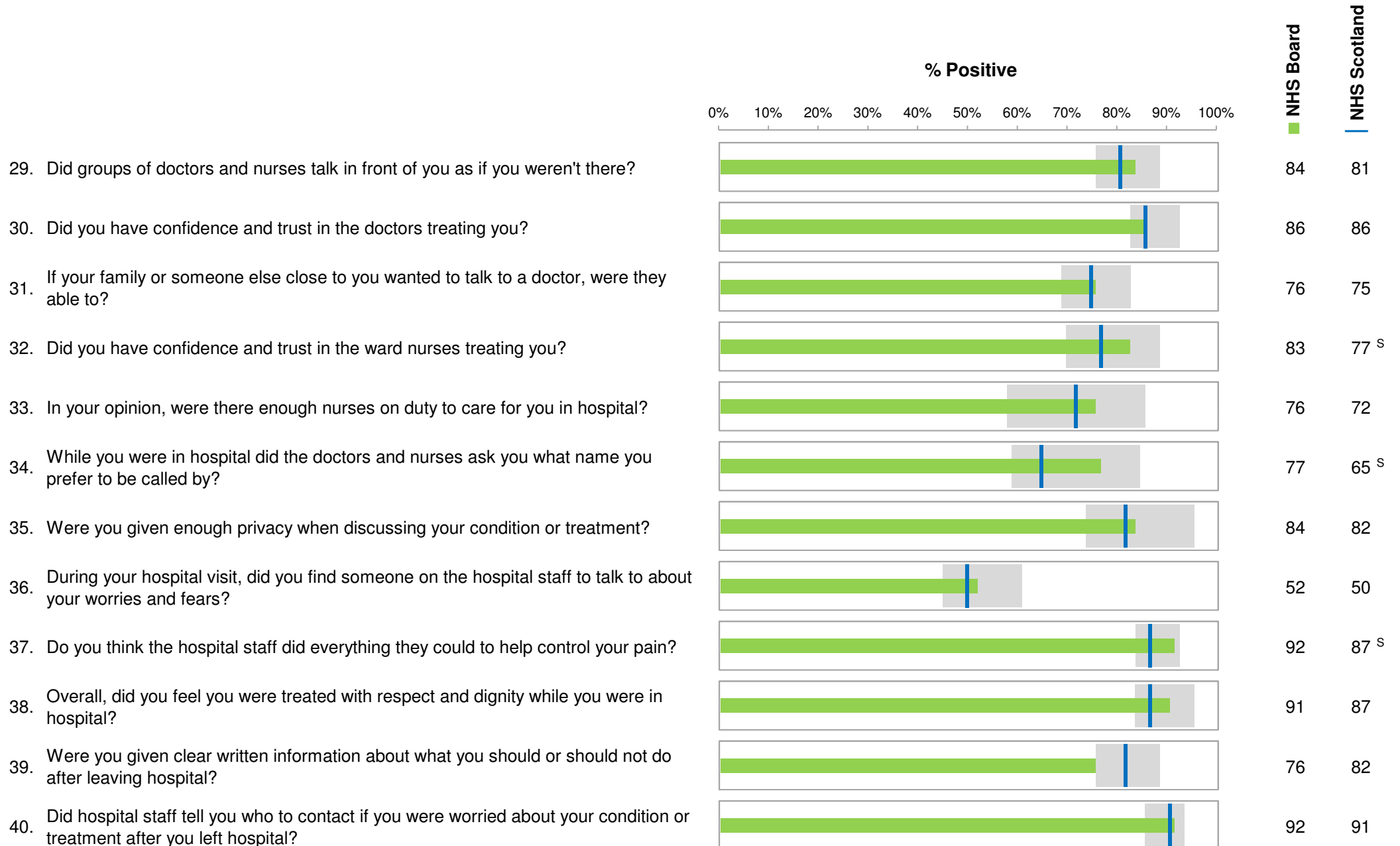
2.7 Support for people with cancer



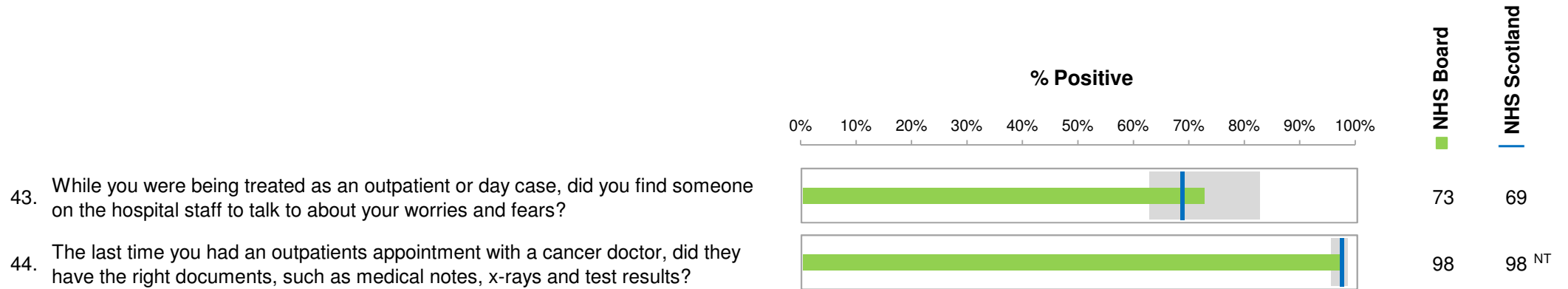
2.8 Operations



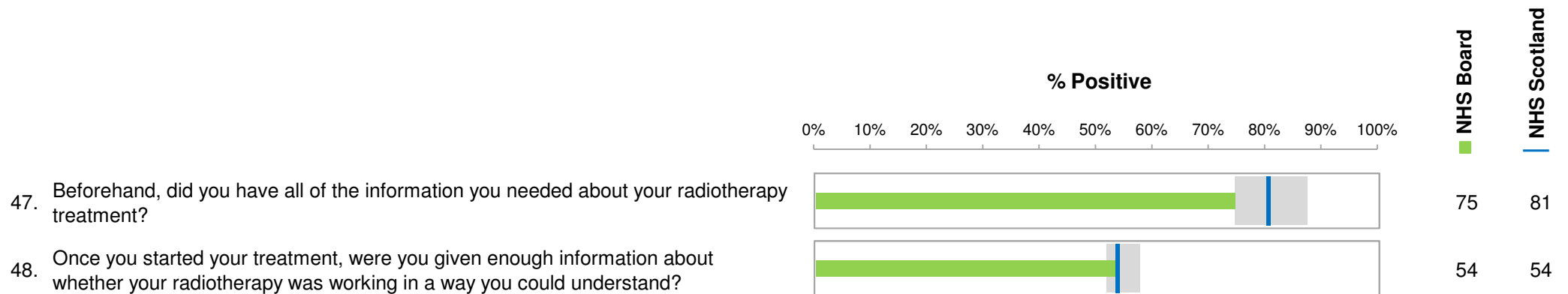
2.9 Hospital care as an inpatient



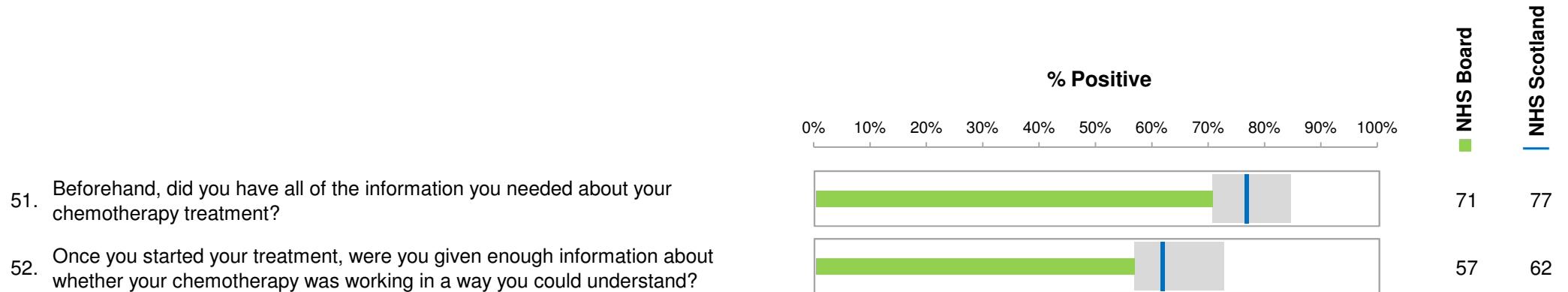
2.10 Hospital care as a day patient / outpatient



2.11 Radiotherapy

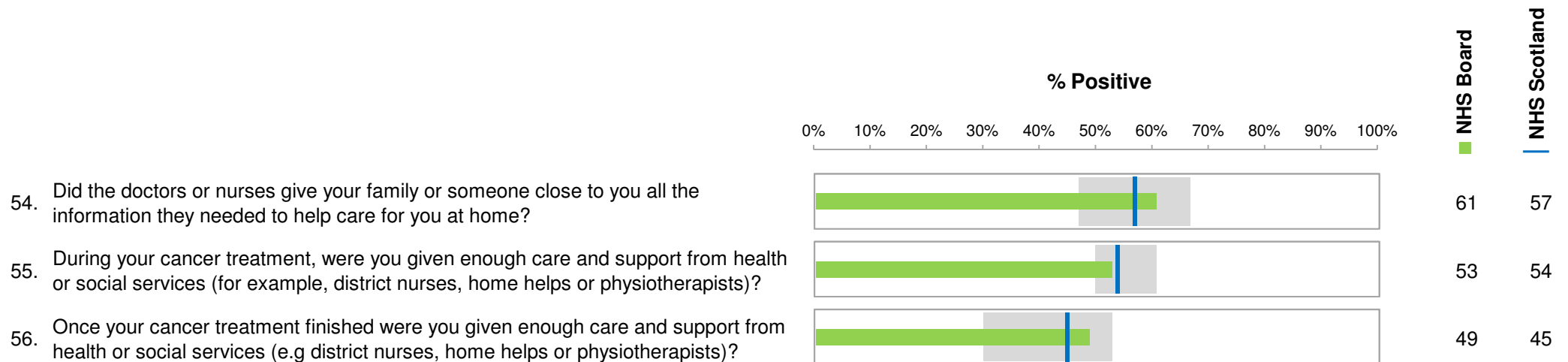


2.12 Chemotherapy



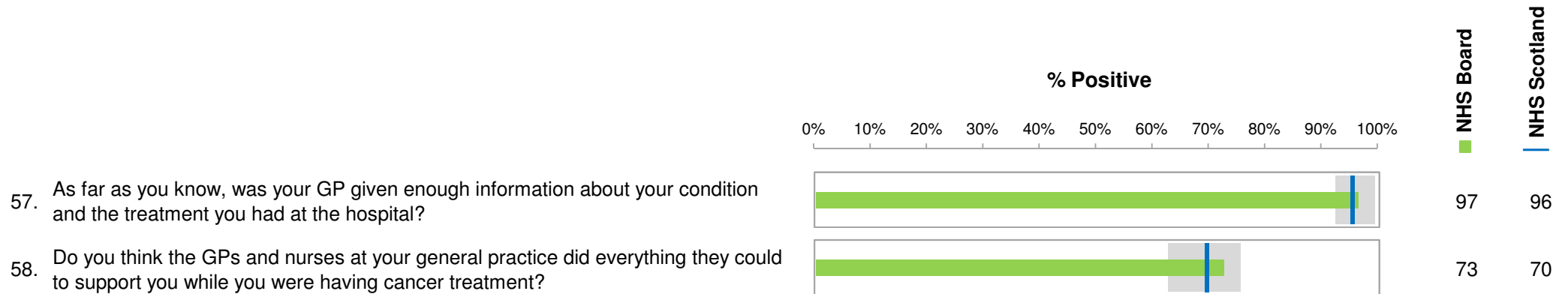
2.13 Home care and support

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**.

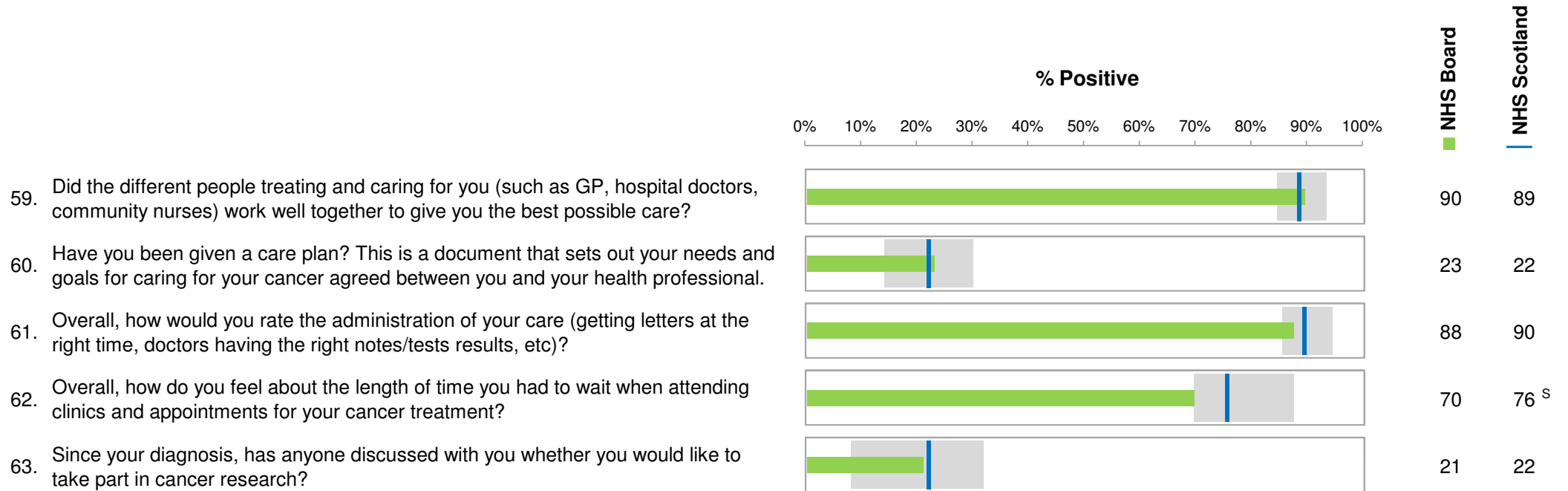


2.14 Care from your General Practice

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 Highland

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	29	25
Colorectal / Lower Gastrointestinal	15	15
Lung	2	6
Prostate	19	12
Brain / Central Nervous System	0	1
Gynaecological	5	7
Haematological	9	8
Head & Neck	5	5
Sarcoma	1	1
Skin	1	3
Upper Gastrointestinal	4	4
Urological	3	6
Other	0	0
Tumour group unknown	8	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	92	94
Colorectal / Lower Gastrointestinal	93	94
Lung	--	94
Prostate	96	94
Brain / Central Nervous System	--	89
Gynaecological	--	95
Haematological	96	97
Head & Neck	--	93
Sarcoma	--	90
Skin	--	97
Upper Gastrointestinal	--	91
Urological	--	93
Other	--	--
Tumour group unknown	--	89
All Tumour Groups	93	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	78	84
Colorectal / Lower Gastrointestinal	78	84
Lung	--	85
Prostate	88	83
Brain / Central Nervous System	--	76
Gynaecological	92	79
Haematological	77	79
Head & Neck	--	84
Sarcoma	--	56
Skin	--	83
Upper Gastrointestinal	--	77
Urological	--	76
Other	--	--
Tumour group unknown	--	85
All Tumour Groups	83	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	86	89	88	84
Colorectal / Lower Gastrointestinal	94	96	84	86	83	84
Lung	--	92	--	87	--	83
Prostate	100	92	90	83	82	80
Brain / Central Nervous System	--	91	--	91	--	77
Gynaecological	--	86	--	77	--	78
Haematological	--	91	--	86	--	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	92	92	86	85	81	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	70	75	94	89	79	77	53	61
Colorectal / Lower Gastrointestinal	84	80	85	86	81	82	63	59
Lung	--	75	--	87	--	78	--	54
Prostate	87	77	91	87	81	80	82	78
Brain / Central Nervous System	--	90	--	79	--	77	--	47
Gynaecological	--	57	--	85	--	74	--	54
Haematological	57	72	77	85	65	60	67	70
Head & Neck	--	66	--	88	--	75	--	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	--	73	95	85	76	70	--	53
All Tumour Groups	73	72	89	86	77	75	60	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	67	66	66	64	41	46
Colorectal / Lower Gastrointestinal	97	89	78	74	78	68	58	57
Lung	--	87	--	76	--	68	--	59
Prostate	88	86	75	73	69	64	66	62
Brain / Central Nervous System	--	87	--	69	--	49	--	49
Gynaecological	--	85	--	72	--	63	--	52
Haematological	91	89	65	73	58	70	48	58
Head & Neck	--	89	--	69	--	63	--	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	--	84	75	67	--	58	--	49
All Tumour Groups	88	86	71	71	67	64	53	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	75	76
Colorectal / Lower Gastrointestinal	83	82
Lung	--	83
Prostate	82	80
Brain / Central Nervous System	--	74
Gynaecological	--	76
Haematological	67	80
Head & Neck	--	77
Sarcoma	--	71
Skin	--	87
Upper Gastrointestinal	--	77
Urological	--	74
Other	--	--
Tumour group unknown	--	70
All Tumour Groups	78	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	91	95	83	88	85	86
Colorectal / Lower Gastrointestinal	93	90	91	92	97	94
Lung	--	87	--	90	--	91
Prostate	74	81	85	90	91	91
Brain / Central Nervous System	--	84	--	82	--	89
Gynaecological	--	83	--	88	--	90
Haematological	58	70	--	94	--	94
Head & Neck	--	80	--	93	--	93
Sarcoma	--	85	--	96	--	100
Skin	--	78	--	94	--	92
Upper Gastrointestinal	--	81	--	90	--	86
Urological	--	58	--	91	--	88
Other	--	--	--	--	--	--
Tumour group unknown	--	78	--	90	--	84
All Tumour Groups	80	84	88	90	92	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	90	83	78	76	36	47
Colorectal / Lower Gastrointestinal	86	78	88	80	60	54
Lung	--	77	--	76	--	61
Prostate	80	85	83	84	--	38
Brain / Central Nervous System	--	77	--	77	--	69
Gynaecological	--	75	--	75	--	58
Haematological	--	84	--	80	--	62
Head & Neck	--	78	--	78	--	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	82	79	80	77	47	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	98	93	83	78
Colorectal / Lower Gastrointestinal	94	95	77	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	96	93	85	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	95	87	88	86	78	74	81	79
Colorectal / Lower Gastrointestinal	74	75	89	85	76	75	83	74
Lung	--	78	--	85	--	79	--	83
Prostate	82	81	83	86	--	75	78	79
Brain / Central Nervous System	--	77	--	83	--	57	--	51
Gynaecological	--	86	--	87	--	74	--	76
Haematological	--	82	--	88	--	83	--	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	84	81	86	86	76	75	83	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	78	74	68	55	83	82	48	49
Colorectal / Lower Gastrointestinal	80	69	89	70	89	79	68	52
Lung	--	81	--	80	--	87	--	55
Prostate	57	75	78	67	86	86	--	51
Brain / Central Nervous System	--	63	--	61	--	80	--	40
Gynaecological	--	72	--	62	--	80	--	43
Haematological	--	72	--	69	--	86	--	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	76	72	77	65	84	82	52	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	88	87	87	86	95	95
Colorectal / Lower Gastrointestinal	91	88	89	87	75	79	91	92
Lung	--	87	--	90	--	80	--	88
Prostate	85	88	96	89	--	86	--	92
Brain / Central Nervous System	--	74	--	69	--	67	--	89
Gynaecological	--	86	--	87	--	84	--	88
Haematological	--	89	--	94	--	79	--	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	92	87	91	87	76	82	92	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	67	64	98	97
Colorectal / Lower Gastrointestinal	77	75	100	96
Lung	--	71	--	97
Prostate	90	74	100	99
Brain / Central Nervous System	--	64	--	94
Gynaecological	--	68	--	98
Haematological	--	72	96	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	73	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	68	81	49	48
Colorectal / Lower Gastrointestinal	--	80	--	56
Lung	--	85	--	61
Prostate	83	85	58	62
Brain / Central Nervous System	--	88	--	74
Gynaecological	--	82	--	51
Haematological	--	77	--	62
Head & Neck	--	76	--	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	79	--	50
Urological	--	77	--	60
Other	--	--	--	--
Tumour group unknown	--	83	--	56
All Tumour Groups	75	81	54	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	68	75	47	53
Colorectal / Lower Gastrointestinal	61	77	57	63
Lung	--	82	--	68
Prostate	--	71	--	57
Brain / Central Nervous System	--	82	--	--
Gynaecological	--	72	--	61
Haematological	83	82	68	75
Head & Neck	--	71	--	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	80	--	58
Urological	--	80	--	76
Other	--	--	--	--
Tumour group unknown	--	73	--	64
All Tumour Groups	71	77	57	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	47	50	50	50	42	37
Colorectal / Lower Gastrointestinal	66	60	59	64	59	55
Lung	--	59	--	52	--	44
Prostate	67	54	38	54	25	45
Brain / Central Nervous System	--	51	--	45	--	--
Gynaecological	--	57	--	41	--	36
Haematological	--	65	--	57	--	48
Head & Neck	--	64	--	64	--	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	61	57	53	54	49	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	98	96	66	70
Colorectal / Lower Gastrointestinal	97	97	71	72
Lung	--	93	--	71
Prostate	98	97	78	72
Brain / Central Nervous System	--	89	--	73
Gynaecological	--	95	68	64
Haematological	95	96	54	66
Head & Neck	--	94	--	69
Sarcoma	--	96	--	71
Skin	--	95	--	74
Upper Gastrointestinal	--	97	--	74
Urological	--	95	--	72
Other	--	--	--	--
Tumour group unknown	--	92	--	67
All Tumour Groups	97	96	73	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	88	90	26	21	90	91	70	73
Colorectal / Lower Gastrointestinal	93	90	18	22	84	89	67	80
Lung	--	89	--	24	--	92	--	80
Prostate	90	89	27	23	90	88	78	76
Brain / Central Nervous System	--	79	--	18	--	74	--	64
Gynaecological	--	88	--	17	--	88	--	81
Haematological	80	91	23	26	92	94	52	77
Head & Neck	--	90	--	28	--	90	--	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	--	87	--	24	--	85	--	72
All Tumour Groups	90	89	23	22	88	90	70	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	14	27
Colorectal / Lower Gastrointestinal	38	30
Lung	--	24
Prostate	18	20
Brain / Central Nervous System	--	25
Gynaecological	--	13
Haematological	32	23
Head & Neck	--	16
Sarcoma	--	26
Skin	--	12
Upper Gastrointestinal	--	25
Urological	--	18
Other	--	--
Tumour group unknown	--	14
All Tumour Groups	21	22

Chapter 4. Condition / Demographic Questions for NHS Highland

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	7	6
1 to 5 years	93	93
More than 5 years	1	1

(Number of responses within this NHS Board = 274).

	(%) 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	13	14
No ¹	87	85
Does not apply to my type of cancer	0	1

(Number of responses within this NHS Board = 257).

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	83	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	5	5
None of the above options apply to my type of cancer	12	14

(Number of responses within this NHS Board = 207).

4.2 About you

68. What was your age on your last birthday?	(%) NHS Board	(%) NHS Scotland
16 - 25	0	0
26 - 35	0	2
36 - 50	9	10
51 - 65	35	34
66 - 75	37	35
76+	18	19

(Number of responses within this NHS Board = 274).

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

(Number of responses within this NHS Board = 276).

4.2 About you (cont.)

70. Which of the following best describes your sexual orientation?	(%) NHS Board	(%) NHS Scotland
Heterosexual / Straight	98	99
Bisexual	0	0
Gay or Lesbian	0	0
Other	1	0

(Number of responses within this NHS Board = 260).

71. What is your ethnic group?	(%) NHS Board	(%) NHS Scotland
White	100	99
Mixed or multiple ethnic groups	0	0
Asian, Asian Scottish or Asian British	0	1
African, Caribbean or Black	0	0
Other ethnic group	0	0

(Number of responses within this NHS Board = 271).

72. What is your main employment status?	(%) NHS Board	(%) NHS Scotland
Work full time	18	17
Work part time	15	10
In full time education or training	0	0
Retired	60	62
Unemployed / looking for work	2	1
Don't work due to illness or disability	4	8
Other	1	2

(Number of responses within this NHS Board = 276).

4.2 About you (cont.)

73. Do you have any of the following? ¹	(%) NHS Board	(%) NHS Scotland
Deafness or severe hearing impairment	16	15
Blindness or severe vision impairment	1	3
A physical disability	8	13
A learning disability	1	1
A mental health condition	4	4
Chronic pain lasting at least 3 months	10	14
Another long - term condition	22	25
None of the above	56	51

(Number of responses within this NHS Board = 263).

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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