

# Cancer Patient Experience Survey 2015

## Results for NHS Tayside



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 Tayside.

Survey questionnaires were sent out in October 2015 to 577 patients who were diagnosed with cancer between 1st July 2013 and 31st March 2014 and who received cancer treatment and care within NHS Tayside 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](http://www.gov.scot/cancersurvey)

380 NHS Tayside patients (66%) returned feedback on their experiences. Of those patients willing to provide information about themselves:

- 47% were male and 53% were female.
- 1% were aged 16 - 25; 2% were aged 26 - 35; 10% were aged 36 - 50; 32% were aged 51 - 65; 36% were aged 66 - 75 and 21% were aged 76 and over.
- 49% 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 Tayside 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 Tayside. 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 Tayside 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](http://www.gov.scot/cancersurvey)

# Chapter 1. Overall Results for NHS Tayside

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.

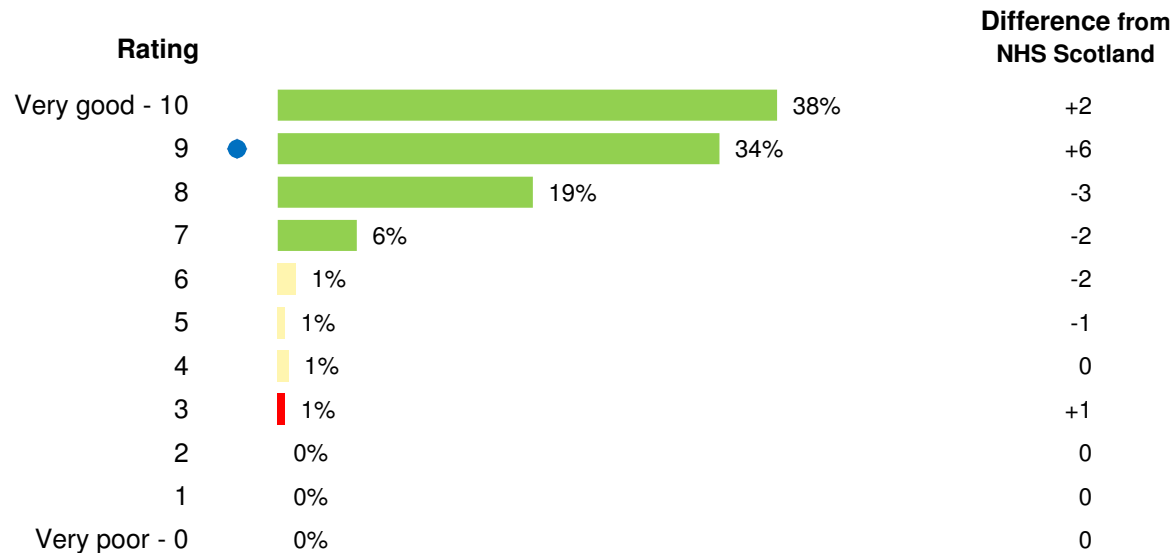
**- -** Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

# 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?	367	97			97	+3 <sup>S</sup>

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
	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?		
	None – I went straight to hospital	10	9
	None – I went to hospital following a cancer screening appointment	15	15
	I saw my GP once	42	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	8	7

(Number of responses within this NHS Board = 322).

	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?	334	84	10	5	84	+2

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	2	3
	More than 12 months	3	3

(Number of responses within this NHS Board = 309).

## 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 <sup>1</sup>	96	96
No	4	4

(Number of responses within this NHS Board = 379).

<sup>1</sup> Of the respondents who had a diagnostic test(s), 77% 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?	259	94	6	94	+2	
6. Overall, how did you feel about the length of time you had to wait for your test to be done?	274	88	10	88	+3	
7. Were the results of the test explained in a way you could understand?	272	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?	293	73		27	73	+1
10. How do you feel about the way you were told you had cancer?	369	87	8	5	87	+1
11. Did you understand the explanation of what was wrong with you?	376	77	20		77	+2
12. When you were told you had cancer, were you given written information about the type of cancer you had?	311	68		32	68	+8 <sup>s</sup>



## 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?	310	88	9	3	88	+2
14. Were the possible side effects of treatment(s) explained in a way you could understand?	346	72	21	6	72	+1
15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	342	70	21	8	70	+6 <sup>s</sup>
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?	320	55	27	18	55	+2
17. Were you involved as much as you wanted to be in decisions about your care and treatment?	356	78	19	3	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? <sup>1</sup>	356	86		14	86	+2
19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	270	92	5	3	92	+2
20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	254	93		7	93	+3 <sup>s</sup>

<sup>1</sup> 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?	269	86		14	86	+7 <sup>s</sup>
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)?	237	85		15	85	+8 <sup>s</sup>
23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	160	56		44	56	+5

## 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 <sup>1</sup>	81	77
No	19	23

(Number of responses within this NHS Board = 379).

<sup>1</sup> Of the respondents who had an operation, 86% 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?	250	96	4	96	+3 <sup>s</sup>	
26. After the operation, did a member of staff explain how it had gone in a way you could understand?	260	82	16	82	+2	

## 1.9 Hospital care as an inpatient

28. Have you had an operation or stayed overnight for cancer care?	(%) NHS Board	(%) NHS Scotland
Yes <sup>1</sup>	85	83
No	15	17

(Number of responses within this NHS Board = 377).

<sup>1</sup> Of the respondents who had an operation / stayed overnight, 90% 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?	283	81	15	4	81	0
30. Did you have confidence and trust in the doctors treating you?	281	87	13		87	+1
31. If your family or someone else close to you wanted to talk to a doctor, were they able to?	234	78	20		78	+3
32. Did you have confidence and trust in the ward nurses treating you?	285	82	17		82	+5 <sup>s</sup>
33. In your opinion, were there enough nurses on duty to care for you in hospital?	283	77	20	3	77	+5
34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	284	71	21	7	71	+6 <sup>s</sup>
35. Were you given enough privacy when discussing your condition or treatment?	285	82	15		82	0

## 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?	206	61	29	10	61	+11 <sup>s</sup>
37. Do you think the hospital staff did everything they could to help control your pain?	254	87	12		87	0
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?	286	90	9		90	+3
39. Were you given clear written information about what you should or should not do after leaving hospital?	266	86	14		86	+4 <sup>s</sup>
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	272	93	7		93	+2

## 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 <sup>1</sup>	81	84
No	19	16

(Number of responses within this NHS Board = 374).

<sup>1</sup> Of the respondents who had been treated as an outpatient or day case, 84% 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?	204	78	18	4	78	+9 <sup>S</sup>
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?	243	98			98	0 <sup>NT</sup>

## 1.11 Radiotherapy

46. Have you had radiotherapy treatment?	(%) NHS Board	(%) NHS Scotland
Yes <sup>1</sup>	43	49
No	57	51

(Number of responses within this NHS Board = 371).

<sup>1</sup> Of the respondents who had radiotherapy treatment, 85% 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?	134	88	12	88	+7 <sup>s</sup>	
48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	123	58	25	17	+4	

## 1.12 Chemotherapy

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

(Number of responses within this NHS Board = 368).

<sup>1</sup> Of the respondents who had chemotherapy treatment, 84% 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?	137	81	17	81	+4	
52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	129	58	33	9	-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?	298	61	20	19	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)?	170	55	20	25	55	+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)?	138	49	21	30	49	+4

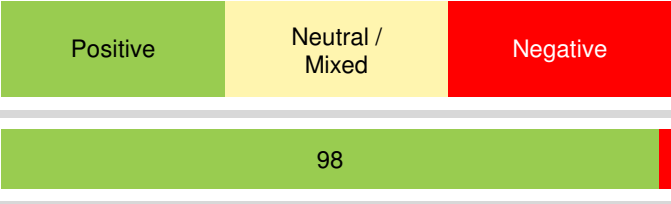




## 1.14 Care from your General Practice

	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?	304	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?	255	75	18	7	75	+5

## 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?	351	93	5		93	+4 <sup>s</sup>
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.	330	28	72		28	+6 <sup>s</sup>
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)?	370	94	4		94	+4 <sup>s</sup>
62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	363	87	10		87	+11 <sup>s</sup>
63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	345	29	71		29	+7 <sup>s</sup>

## 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?	243				98	0 <sup>NT</sup>
64.	Overall, how would you rate your care?	367				97	+3 <sup>S</sup>
57.	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	304				96	0
25.	Beforehand, did you have all the information you needed about your operation?	250				96	+3 <sup>S</sup>
5.	Beforehand, did you have all the information you needed about your test?	259				94	+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		
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.	330	28		72	28	+6 <sup>s</sup>
63.	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	345	29		71	29	+7 <sup>s</sup>
23.	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	160	56		44	56	+5
12.	When you were told you had cancer, were you given written information about the type of cancer you had?	311	68		32	68	+8 <sup>s</sup>
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)?	138	49	21	30	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.

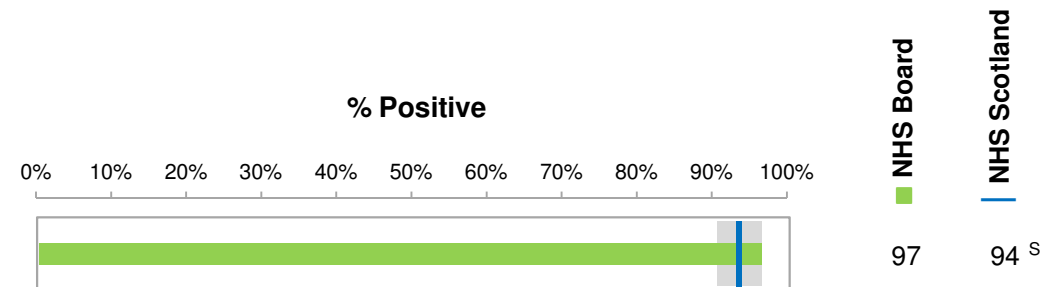
<sup>S</sup> Indicates a statistically significant difference in the percent positive result between this NHS Board and NHS Scotland as a whole.

<sup>NT</sup> 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

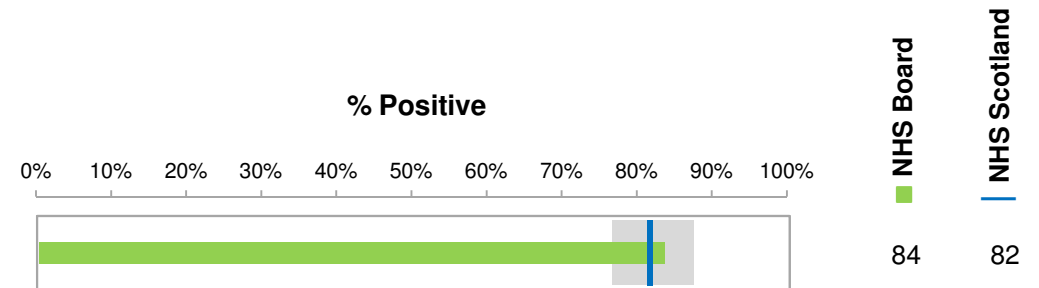
64. Overall, how would you rate your care?



## 2.2 Seeing your GP

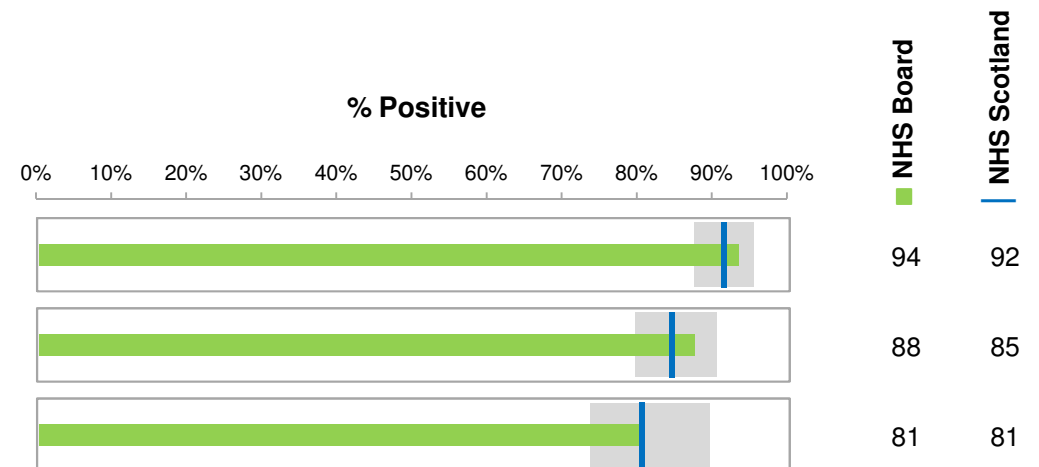
**Note:** Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this NHS Board** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received 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?

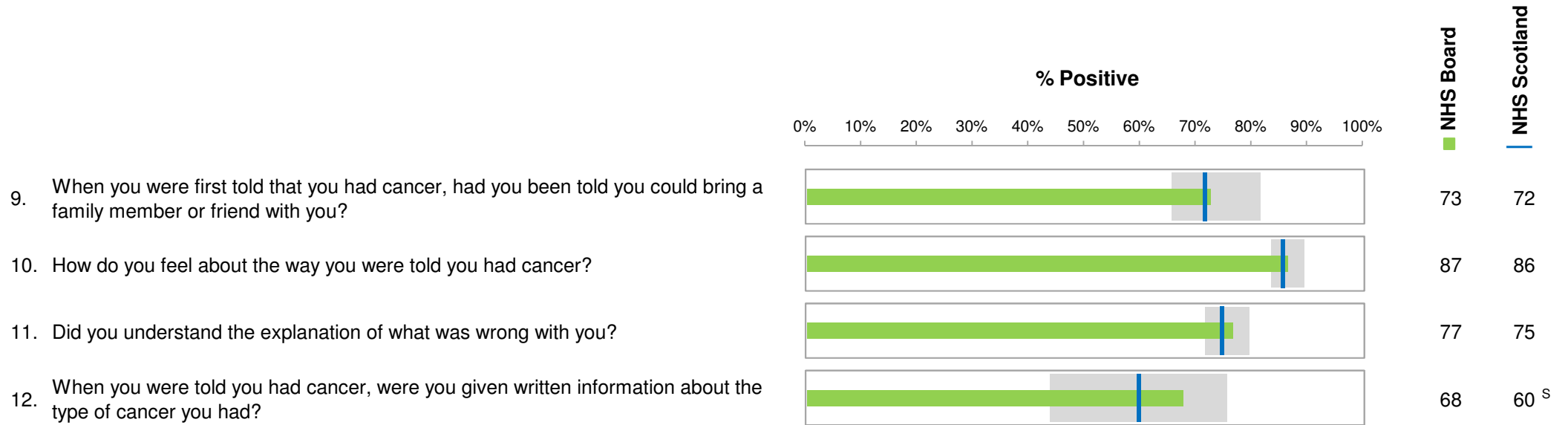


## 2.3 Diagnostic tests

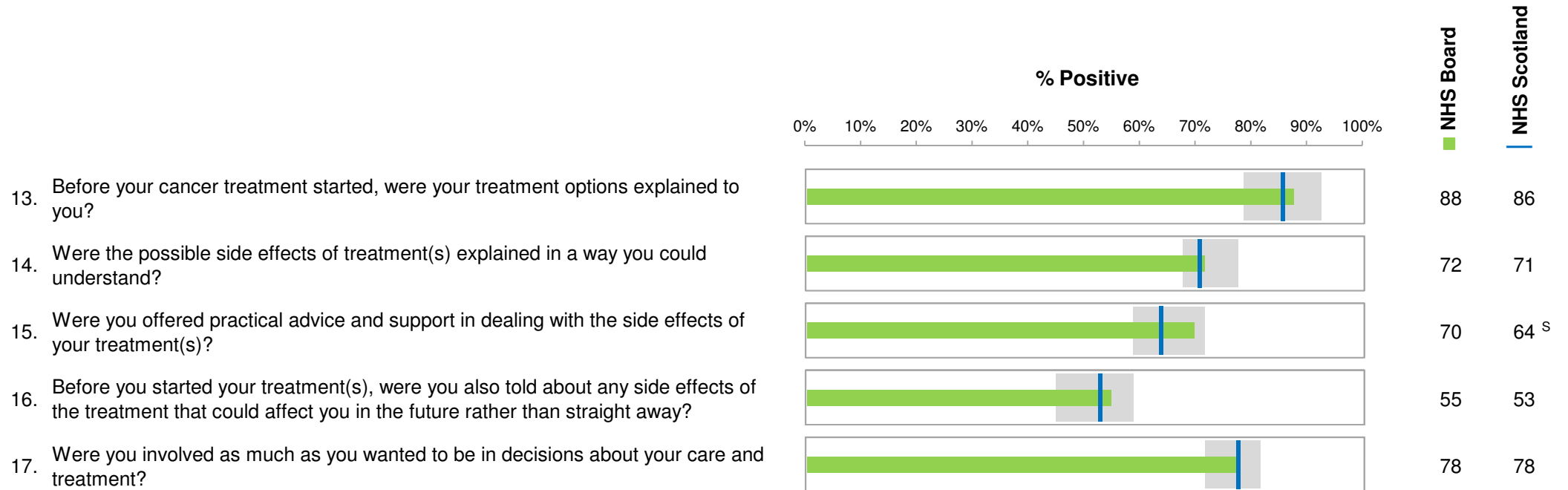
5. Beforehand, did you have all the information you needed about your test?
6. Overall, how did you feel about the length of time you had to wait for your test to be done?
7. Were the results of the test explained in a way you could understand?



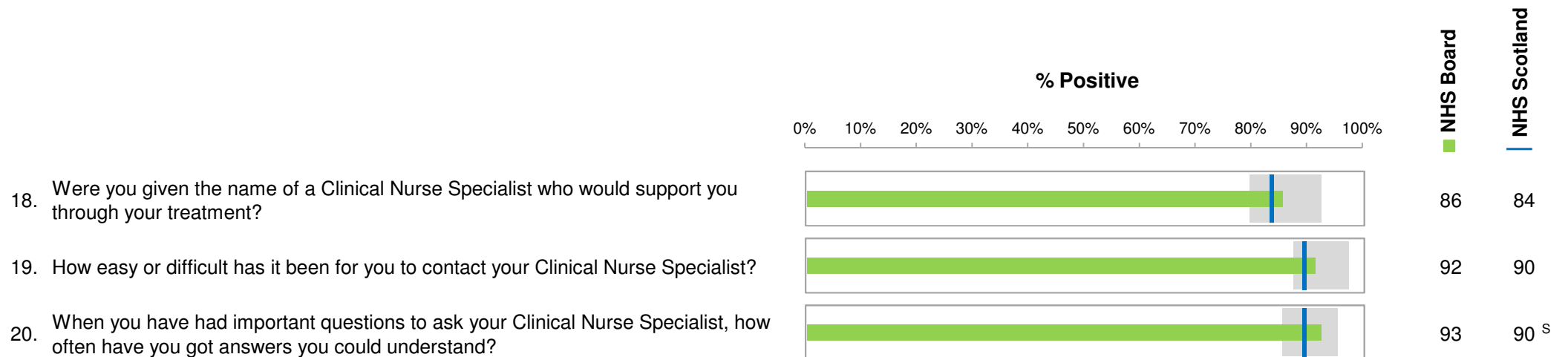
## 2.4 Finding out what was wrong with you



## 2.5 Deciding the best treatment for you

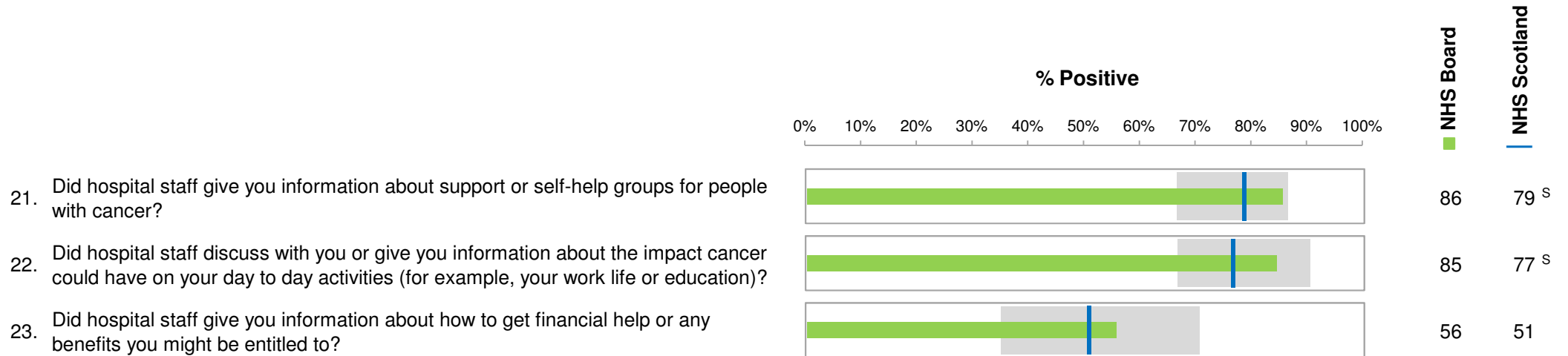


## 2.6 Clinical Nurse Specialist

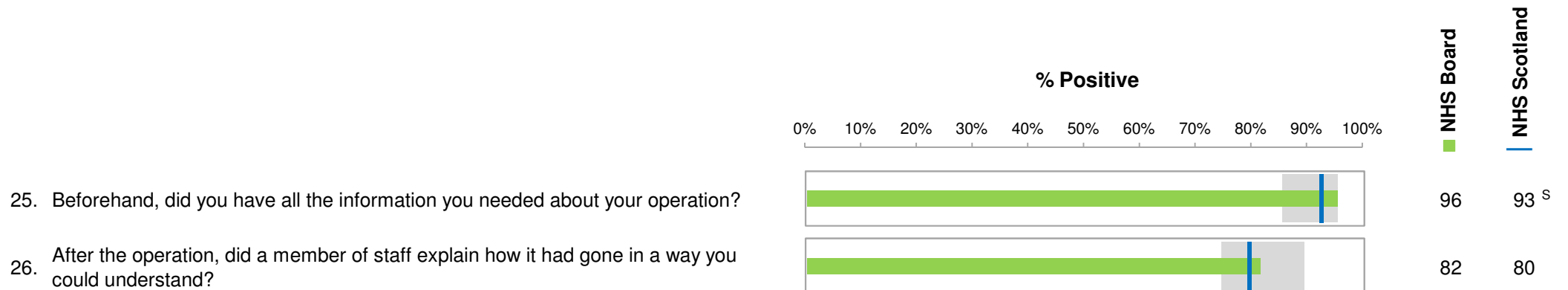




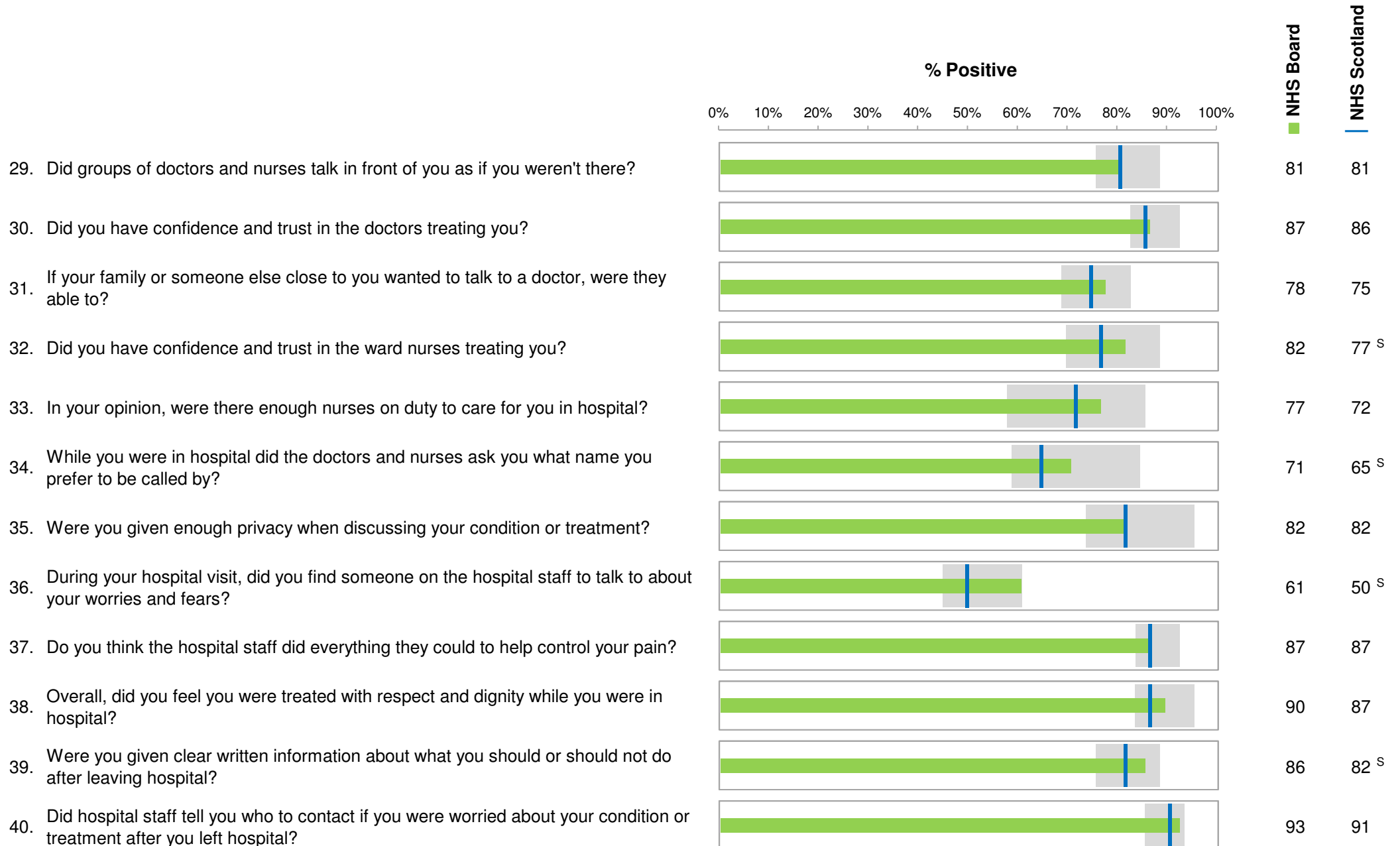
## 2.7 Support for people with cancer



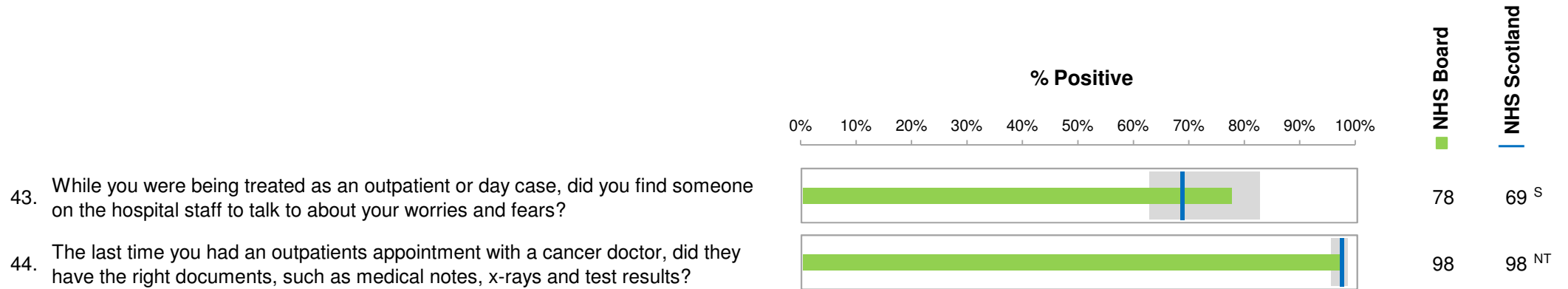
## 2.8 Operations



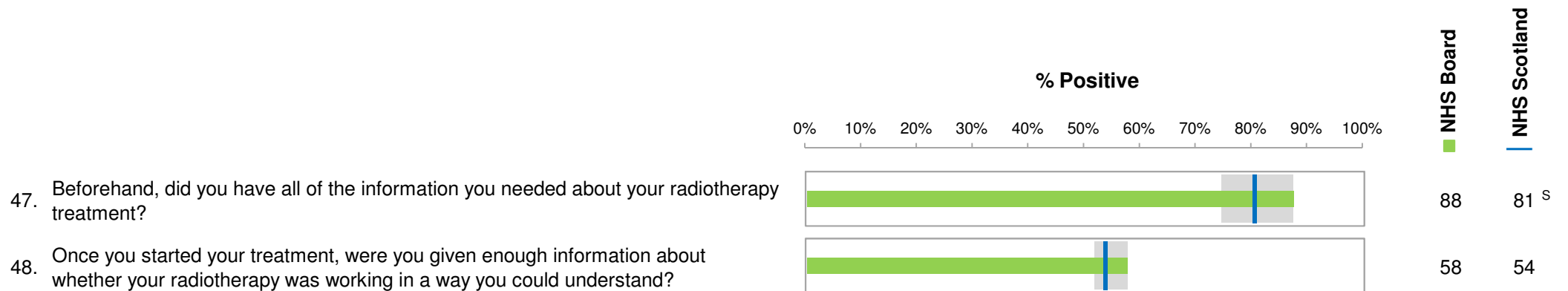
## 2.9 Hospital care as an inpatient



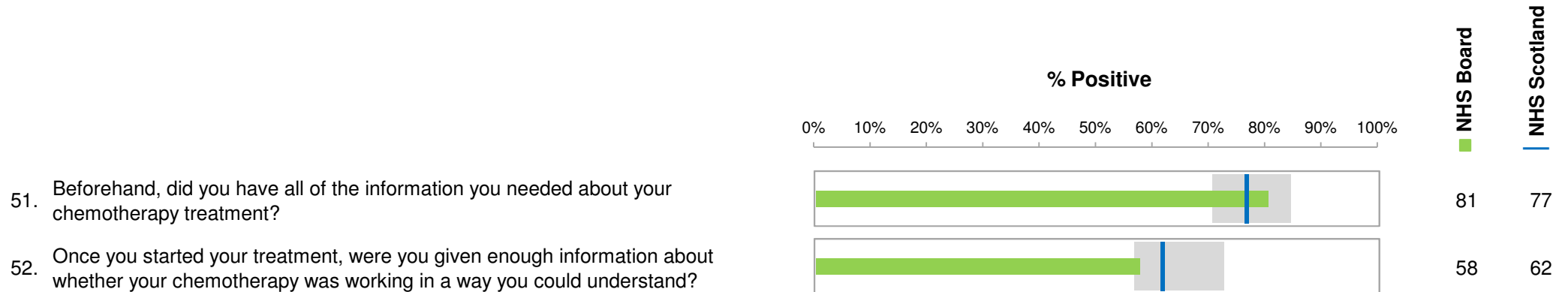
## 2.10 Hospital care as a day patient / outpatient



## 2.11 Radiotherapy

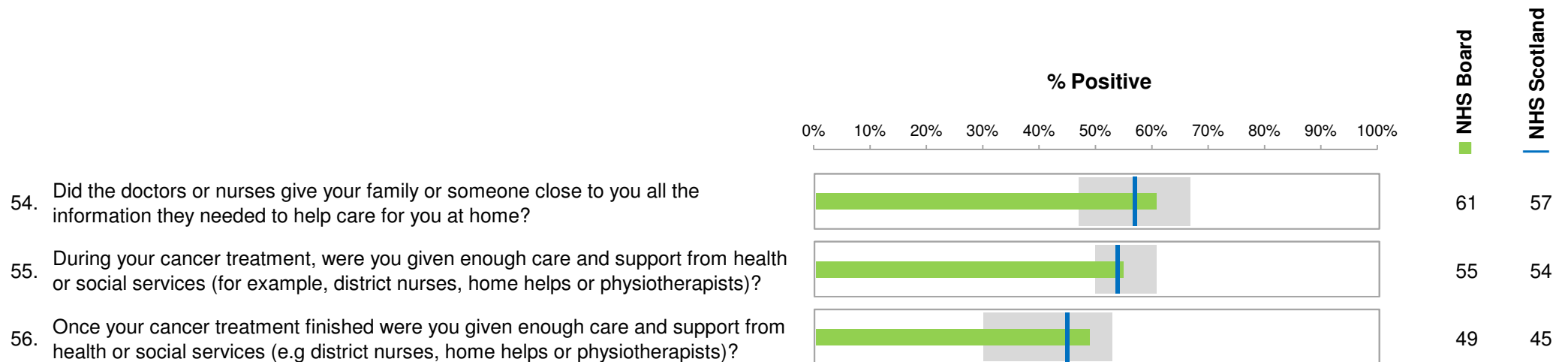


## 2.12 Chemotherapy



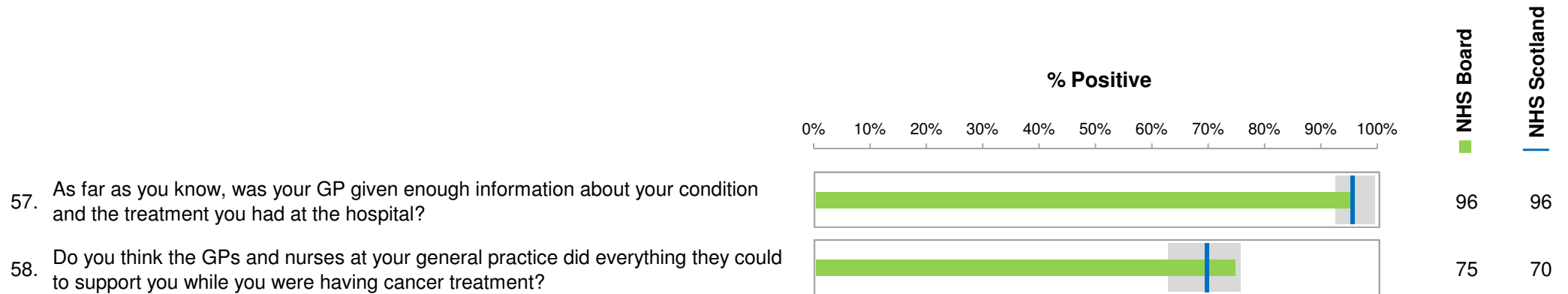
## 2.13 Home care and support

**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**.

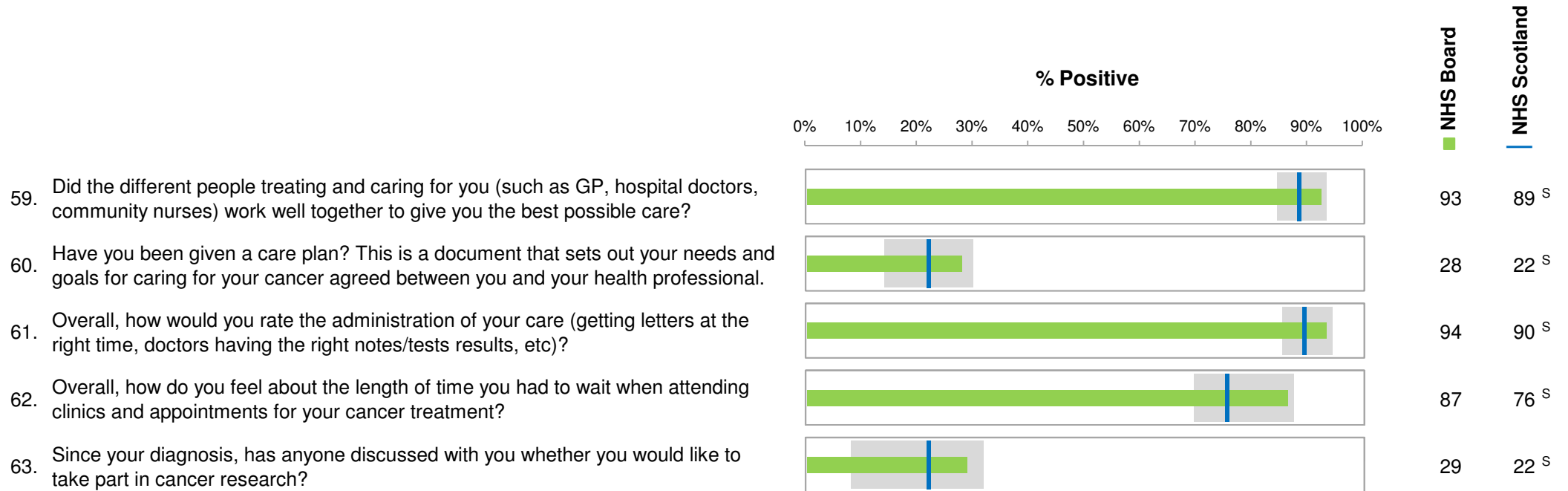


## 2.14 Care from your General Practice

**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 Tayside

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	24	25
Colorectal / Lower Gastrointestinal	21	15
Lung	4	6
Prostate	11	12
Brain / Central Nervous System	0	1
Gynaecological	7	7
Haematological	7	8
Head & Neck	7	5
Sarcoma	1	1
Skin	3	3
Upper Gastrointestinal	3	4
Urological	8	6
Other	0	0
Tumour group unknown	4	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	100	94
Colorectal / Lower Gastrointestinal	95	94
Lung	--	94
Prostate	98	94
Brain / Central Nervous System	--	89
Gynaecological	92	95
Haematological	96	97
Head & Neck	100	93
Sarcoma	--	90
Skin	--	97
Upper Gastrointestinal	--	91
Urological	90	93
Other	--	--
Tumour group unknown	--	89
<b>All Tumour Groups</b>	<b>97</b>	<b>94</b>



## 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**

<b>Tumour Group</b>	<b>NHS Board</b>	<b>NHS Scotland</b>
Breast	87	84
Colorectal / Lower Gastrointestinal	80	84
Lung	86	85
Prostate	95	83
Brain / Central Nervous System	--	76
Gynaecological	88	79
Haematological	79	79
Head & Neck	95	84
Sarcoma	--	56
Skin	--	83
Upper Gastrointestinal	--	77
Urological	70	76
Other	--	--
Tumour group unknown	--	85
<b>All Tumour Groups</b>	<b>84</b>	<b>82</b>

## 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	97	93	92	89	81	84
Colorectal / Lower Gastrointestinal	94	96	87	86	86	84
Lung	--	92	--	87	--	83
Prostate	92	92	74	83	81	80
Brain / Central Nervous System	--	91	--	91	--	77
Gynaecological	--	86	--	77	--	78
Haematological	95	91	95	86	81	81
Head & Neck	100	88	86	87	86	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
<b>All Tumour Groups</b>	<b>94</b>	<b>92</b>	<b>88</b>	<b>85</b>	<b>81</b>	<b>81</b>

## 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	76	75	93	89	82	77	82
Colorectal / Lower Gastrointestinal	77	80	86	86	78	82	57	59
Lung	--	75	--	87	--	78	--	54
Prostate	67	77	81	87	70	80	76	78
Brain / Central Nervous System	--	90	--	79	--	77	--	47
Gynaecological	--	57	88	85	73	74	59	54
Haematological	--	72	79	85	56	60	70	70
Head & Neck	--	66	100	88	80	75	--	51
Sarcoma	--	59	--	82	--	62	--	36
Skin	--	55	--	89	--	74	--	74
Upper Gastrointestinal	--	72	--	80	--	72	--	45
Urological	64	63	80	79	83	75	64	51
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	73	--	85	--	70	--	53
<b>All Tumour Groups</b>	<b>73</b>	<b>72</b>	<b>87</b>	<b>86</b>	<b>77</b>	<b>75</b>	<b>68</b>	<b>60</b>

## 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	87	85	70	66	71	64	54	46
Colorectal / Lower Gastrointestinal	87	89	72	74	69	68	52	57
Lung	--	87	--	76	--	68	--	59
Prostate	85	86	72	73	76	64	71	62
Brain / Central Nervous System	--	87	--	69	--	49	--	49
Gynaecological	--	85	70	72	63	63	45	52
Haematological	91	89	75	73	87	70	52	58
Head & Neck	--	89	79	69	77	63	50	51
Sarcoma	--	78	--	60	--	59	--	63
Skin	--	86	--	74	--	69	--	62
Upper Gastrointestinal	--	87	--	70	--	67	--	52
Urological	87	82	71	72	54	55	52	50
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	84	--	67	--	58	--	49
<b>All Tumour Groups</b>	<b>88</b>	<b>86</b>	<b>72</b>	<b>71</b>	<b>70</b>	<b>64</b>	<b>55</b>	<b>53</b>

## 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	78	76
Colorectal / Lower Gastrointestinal	82	82
Lung	--	83
Prostate	71	80
Brain / Central Nervous System	--	74
Gynaecological	73	76
Haematological	86	80
Head & Neck	87	77
Sarcoma	--	71
Skin	--	87
Upper Gastrointestinal	--	77
Urological	72	74
Other	--	--
Tumour group unknown	--	70
<b>All Tumour Groups</b>	<b>78</b>	<b>78</b>

## 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	93	88	97	86
Colorectal / Lower Gastrointestinal	84	90	84	92	92	94
Lung	--	87	--	90	--	91
Prostate	88	81	94	90	97	91
Brain / Central Nervous System	--	84	--	82	--	89
Gynaecological	96	83	--	88	--	90
Haematological	74	70	--	94	--	94
Head & Neck	74	80	--	93	--	93
Sarcoma	--	85	--	96	--	100
Skin	--	78	--	94	--	92
Upper Gastrointestinal	--	81	--	90	--	86
Urological	56	58	--	91	--	88
Other	--	--	--	--	--	--
Tumour group unknown	--	78	--	90	--	84
<b>All Tumour Groups</b>	<b>86</b>	<b>84</b>	<b>92</b>	<b>90</b>	<b>93</b>	<b>90</b>

## 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	93	83	91	76	62	47
Colorectal / Lower Gastrointestinal	70	78	83	80	53	54
Lung	--	77	--	76	--	61
Prostate	91	85	92	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
<b>All Tumour Groups</b>	<b>86</b>	<b>79</b>	<b>85</b>	<b>77</b>	<b>56</b>	<b>51</b>

## 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	99	93	81	78
Colorectal / Lower Gastrointestinal	96	95	84	85
Lung	--	92	--	84
Prostate	96	94	84	83
Brain / Central Nervous System	--	90	--	75
Gynaecological	90	93	81	81
Haematological	--	89	--	73
Head & Neck	--	91	--	77
Sarcoma	--	93	--	71
Skin	--	90	--	76
Upper Gastrointestinal	--	93	--	81
Urological	91	90	78	78
Other	--	--	--	--
Tumour group unknown	--	90	--	76
<b>All Tumour Groups</b>	<b>96</b>	<b>93</b>	<b>82</b>	<b>80</b>



## 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	89	87	87	86	77	74	88	79
Colorectal / Lower Gastrointestinal	75	75	79	85	79	75	83	74
Lung	--	78	--	85	--	79	--	83
Prostate	85	81	88	86	67	75	74	79
Brain / Central Nervous System	--	77	--	83	--	57	--	51
Gynaecological	86	86	86	87	--	74	68	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	71	76	100	84	--	72	95	74
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	78	--	83	--	73	--	71
<b>All Tumour Groups</b>	<b>81</b>	<b>81</b>	<b>87</b>	<b>86</b>	<b>78</b>	<b>75</b>	<b>82</b>	<b>77</b>

## 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	81	74	68	55	83	82	63	49
Colorectal / Lower Gastrointestinal	71	69	72	70	85	79	59	52
Lung	--	81	--	80	--	87	--	55
Prostate	73	75	63	67	81	86	60	51
Brain / Central Nervous System	--	63	--	61	--	80	--	40
Gynaecological	81	72	62	62	73	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	76	73	86	72	95	79	--	45
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	72	--	62	--	75	--	43
<b>All Tumour Groups</b>	<b>77</b>	<b>72</b>	<b>71</b>	<b>65</b>	<b>82</b>	<b>82</b>	<b>61</b>	<b>50</b>

## 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	96	88	94	87	96	86	97	95
Colorectal / Lower Gastrointestinal	84	88	88	87	73	79	89	92
Lung	--	87	--	90	--	80	--	88
Prostate	76	88	81	89	84	86	96	92
Brain / Central Nervous System	--	74	--	69	--	67	--	89
Gynaecological	75	86	86	87	95	84	95	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	95	87	80	74	--	81
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	86	--	87	--	78	--	89
<b>All Tumour Groups</b>	<b>87</b>	<b>87</b>	<b>90</b>	<b>87</b>	<b>86</b>	<b>82</b>	<b>93</b>	<b>91</b>

## 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	83	64	100	97
Colorectal / Lower Gastrointestinal	79	75	95	96
Lung	--	71	--	97
Prostate	92	74	100	99
Brain / Central Nervous System	--	64	--	94
Gynaecological	--	68	--	98
Haematological	--	72	--	98
Head & Neck	--	71	--	99
Sarcoma	--	67	--	96
Skin	--	73	--	97
Upper Gastrointestinal	--	76	--	99
Urological	--	60	--	96
Other	--	--	--	--
Tumour group unknown	--	58	--	98
<b>All Tumour Groups</b>	<b>78</b>	<b>69</b>	<b>98</b>	<b>98</b>

## 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	92	81	62	48
Colorectal / Lower Gastrointestinal	--	80	--	56
Lung	--	85	--	61
Prostate	--	85	--	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
<b>All Tumour Groups</b>	<b>88</b>	<b>81</b>	<b>58</b>	<b>54</b>

## 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	92	75	62	53
Colorectal / Lower Gastrointestinal	75	77	57	63
Lung	--	82	--	68
Prostate	--	71	--	57
Brain / Central Nervous System	--	82	--	--
Gynaecological	--	72	--	61
Haematological	--	82	--	75
Head & Neck	--	71	--	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	80	--	58
Urological	--	80	--	76
Other	--	--	--	--
Tumour group unknown	--	73	--	64
<b>All Tumour Groups</b>	<b>81</b>	<b>77</b>	<b>58</b>	<b>62</b>

## 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	58	50	62	50	55	37
Colorectal / Lower Gastrointestinal	59	60	55	64	53	55
Lung	--	59	--	52	--	44
Prostate	68	54	58	54	--	45
Brain / Central Nervous System	--	51	--	45	--	--
Gynaecological	60	57	--	41	--	36
Haematological	--	65	--	57	--	48
Head & Neck	48	64	--	64	--	55
Sarcoma	--	44	--	61	--	--
Skin	--	67	--	55	--	58
Upper Gastrointestinal	--	65	--	63	--	55
Urological	61	57	--	54	--	48
Other	--	--	--	--	--	--
Tumour group unknown	--	53	--	42	--	33
<b>All Tumour Groups</b>	<b>61</b>	<b>57</b>	<b>55</b>	<b>54</b>	<b>49</b>	<b>45</b>

## 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	79	70
Colorectal / Lower Gastrointestinal	96	97	78	72
Lung	--	93	--	71
Prostate	97	97	76	72
Brain / Central Nervous System	--	89	--	73
Gynaecological	100	95	--	64
Haematological	95	96	70	66
Head & Neck	--	94	--	69
Sarcoma	--	96	--	71
Skin	--	95	--	74
Upper Gastrointestinal	--	97	--	74
Urological	92	95	75	72
Other	--	--	--	--
Tumour group unknown	--	92	--	67
<b>All Tumour Groups</b>	<b>96</b>	<b>96</b>	<b>75</b>	<b>70</b>



## 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	93	90	38	21	96	91	96	73
Colorectal / Lower Gastrointestinal	96	90	15	22	91	89	84	80
Lung	--	89	--	24	--	92	--	80
Prostate	97	89	37	23	93	88	77	76
Brain / Central Nervous System	--	79	--	18	--	74	--	64
Gynaecological	92	88	18	17	92	88	84	81
Haematological	92	91	32	26	92	94	80	77
Head & Neck	95	90	24	28	96	90	91	77
Sarcoma	--	90	--	20	--	88	--	65
Skin	--	90	--	18	--	94	--	82
Upper Gastrointestinal	--	90	--	20	--	91	--	72
Urological	90	87	16	17	90	85	93	71
Other	--	--	--	--	--	--	--	--
Tumour group unknown	--	87	--	24	--	85	--	72
<b>All Tumour Groups</b>	<b>93</b>	<b>89</b>	<b>28</b>	<b>22</b>	<b>94</b>	<b>90</b>	<b>87</b>	<b>76</b>

## 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	40	30
Lung	--	24
Prostate	15	20
Brain / Central Nervous System	--	25
Gynaecological	10	13
Haematological	25	23
Head & Neck	33	16
Sarcoma	--	26
Skin	--	12
Upper Gastrointestinal	--	25
Urological	18	18
Other	--	--
Tumour group unknown	--	14
<b>All Tumour Groups</b>	<b>29</b>	<b>22</b>

## Chapter 4. Condition / Demographic Questions for NHS Tayside

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

65. How long is it since you were first treated for this cancer?	(%) NHS Board	(%) NHS Scotland
Less than 1 year	5	6
1 to 5 years	95	93
More than 5 years	1	1

(Number of responses within this NHS Board = 371).

66. Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?	(%) NHS Board	(%) NHS Scotland
Yes	12	14
No <sup>1</sup>	87	85
Does not apply to my type of cancer	1	1

(Number of responses within this NHS Board = 350).

<sup>1</sup> 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	7	5
None of the above options apply to my type of cancer	10	14

(Number of responses within this NHS Board = 290).

## 4.2 About you

68. What was your age on your last birthday?	(%) NHS Board	(%) NHS Scotland
16 - 25	1	0
26 - 35	2	2
36 - 50	10	10
51 - 65	32	34
66 - 75	36	35
76+	21	19

(Number of responses within this NHS Board = 368).

69. Are you male or female?	(%) NHS Board	(%) NHS Scotland
Male	47	43
Female	53	57

(Number of responses within this NHS Board = 375).

## 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	0	0
Other	1	0

(Number of responses within this NHS Board = 368).

71. What is your ethnic group?	(%) NHS Board	(%) NHS Scotland
White	99	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 = 373).

72. What is your main employment status?	(%) NHS Board	(%) NHS Scotland
Work full time	17	17
Work part time	9	10
In full time education or training	1	0
Retired	65	62
Unemployed / looking for work	1	1
Don't work due to illness or disability	6	8
Other	1	2

(Number of responses within this NHS Board = 378).

## 4.2 About you (cont.)

73. Do you have any of the following? <sup>1</sup>	(%) NHS Board	(%) NHS Scotland
Deafness or severe hearing impairment	18	15
Blindness or severe vision impairment	2	3
A physical disability	9	13
A learning disability	0	1
A mental health condition	5	4
Chronic pain lasting at least 3 months	16	14
Another long - term condition	27	25
None of the above	49	51

(Number of responses within this NHS Board = 362).

<sup>1</sup> 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

# An Official Statistics Publication for Scotland

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The technical report is available at: [www.gov.scot/cancersurvey](http://www.gov.scot/cancersurvey)

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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