

Cancer Patient Experience Survey 2015

Results for West of Scotland Cancer Network (WOSCAN)



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 within the West of Scotland Cancer Network (WOSCAN).

Survey questionnaires were sent out in October 2015 to 3,750 patients who were diagnosed with cancer between 1st July 2013 and 31st March 2014 and who received cancer treatment and care within WOSCAN 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

2,153 WOSCAN patients (57%) returned feedback on their experiences. Of those patients willing to provide information about themselves:

- 42% were male and 58% were female.
- 1% were aged 16 - 25; 2% were aged 26 - 35; 11% were aged 36 - 50; 34% were aged 51 - 65; 35% were aged 66 - 75 and 18% were aged 76 and over.
- 51% 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 WOSCAN 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 WOSCAN. 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 the WOSCAN area 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 within this regional cancer network.

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 WOSCAN

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

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

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

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

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

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

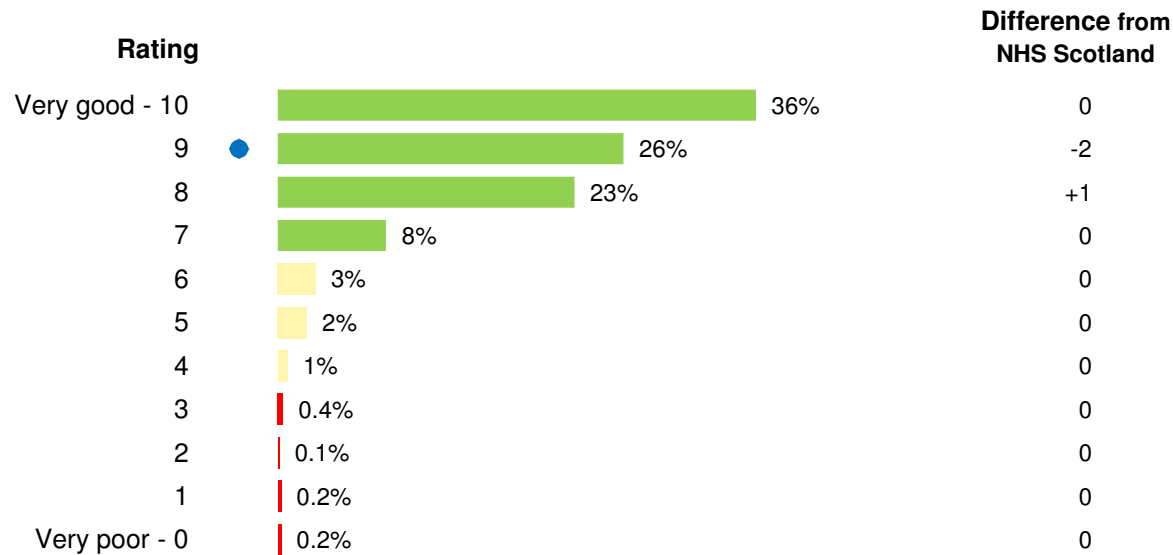
- - Indicates that a result has been suppressed due to the low number of valid responses to the question (fewer than 20).

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?	2,056	93	6		93	-1

A full breakdown showing the percentage of respondents who selected each rating within this network is shown below along with the difference from the NHS Scotland result. The median rating given by respondents treated within this network 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 network area** 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 within this network**. Responses from patients who were diagnosed at non-NHS Scotland facilities have been excluded.

1.		(%) Network	(%) NHS Scotland
	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	43	43
	I saw my GP twice	15	16
	I saw my GP 3 or 4 times	10	10
	I saw my GP 5 or more times	7	7

(Number of responses within this network = 1,862).

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
2.	1,938	82	11	6	82	0

3.		(%) Network	(%) NHS Scotland
	Less than 3 months	83	83
	3 - 6 months	11	11
	6 - 12 months	4	3
	More than 12 months	3	3

(Number of responses within this network = 1,824).

1.3 Diagnostic tests

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

(Number of responses within this network = 2,137).

¹ Of the respondents who had a diagnostic test(s), 60% indicated that the test(s) took place at a hospital within this network. The results for questions 5 - 7 below only include responses from those patients who said that their test(s) took place within this network.

	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?	1,153	94	6	94	+2 ^s	
6. Overall, how did you feel about the length of time you had to wait for your test to be done?	1,209	86	10	4	86	+1
7. Were the results of the test explained in a way you could understand?	1,208	81	17		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?	1,774	72		28	72	0
10. How do you feel about the way you were told you had cancer?	2,083	85	9	5	85	-1
11. Did you understand the explanation of what was wrong with you?	2,124	73	24		73	-2
12. When you were told you had cancer, were you given written information about the type of cancer you had?	1,697	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?	1,798	86	12	2	86	0
14. Were the possible side effects of treatment(s) explained in a way you could understand?	1,957	70	24	6	70	-1
15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	1,961	63	27	10	63	-1
16. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	1,832	52	27	21	52	-1
17. Were you involved as much as you wanted to be in decisions about your care and treatment?	2,031	76	19	4	76	-2

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	2,031	86		14	86	+2
19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	1,535	90	6	4	90	0
20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	1,463	88	9		88	-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?	1,573	77		23	77	-2 ^S
22. Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	1,399	73		27	73	-4 ^S
23. Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	1,228	56		44	56	+5 ^S

1.8 Operations

24. Have you had an operation (such as removal of a tumour or lump) for your cancer?	(%) Network	(%) NHS Scotland
Yes ¹	76	77
No	24	23

(Number of responses within this network = 2,135).

¹ Of the respondents who had an operation, 68% indicated that the operation took place at a hospital within this network. The results for questions 25 - 26 below only include responses from those patients who said that their operation took place within this network.

	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?	1,060	92	8	92	-1	
26. After the operation, did a member of staff explain how it had gone in a way you could understand?	1,091	81	16	3	81	+1

1.9 Hospital care as an inpatient

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

(Number of responses within this network = 2,131).

¹ Of the respondents who had an operation / stayed overnight, 71% indicated that the operation / stay took place at a hospital within this network. The results for questions 29 - 40 below only include responses from those patients who said that their operation / stay took place within this network.

	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?	1,247	83	13	4	83	+2
30. Did you have confidence and trust in the doctors treating you?	1,252	87	12		87	+1
31. If your family or someone else close to you wanted to talk to a doctor, were they able to?	1,029	76	20	4	76	+1
32. Did you have confidence and trust in the ward nurses treating you?	1,254	76	23		76	-1
33. In your opinion, were there enough nurses on duty to care for you in hospital?	1,227	73	22	5	73	+1
34. While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	1,234	62	19	19	62	-3
35. Were you given enough privacy when discussing your condition or treatment?	1,246	82	13	5	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?	932	50	31	19	50	0
37. Do you think the hospital staff did everything they could to help control your pain?	1,099	86	11	3	86	-1
38. Overall, did you feel you were treated with respect and dignity while you were in hospital?	1,250	87	12		87	0
39. Were you given clear written information about what you should or should not do after leaving hospital?	1,152	80		20	80	-2
40. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	1,187	91		9	91	0

1.10 Hospital care as a day patient / outpatient

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

(Number of responses within this network = 2,122).

¹ Of the respondents who had been treated as an outpatient or day case, 68% indicated that the treatment / care took place at a hospital within this network. The results for questions 43 - 44 below only include responses from those patients who said that their treatment / care took place within this network.

	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?	1,003	70	22	9	70	+1
44. The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	1,208	97			97	-1

1.11 Radiotherapy

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

(Number of responses within this network = 2,079).

¹ Of the respondents who had radiotherapy treatment, 39% indicated that the treatment took place at a hospital within this network. The results for questions 47 - 48 below only include responses from those patients who said that their radiotherapy took place within this network.

	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?	407	80	16	4	80	-1
48. Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	365	52	28	20	52	-2

1.12 Chemotherapy

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

(Number of responses within this network = 2,082).

¹ Of the respondents who had chemotherapy treatment, 73% indicated that the treatment took place at a hospital within this network. The results for questions 51 - 52 below only include responses from those patients who said that their chemotherapy took place within this network.

	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?	763	78	20	2	78	+1
52. Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	710	63	27	9	63	+1

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 network area** 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 within this network**.

	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?	1,747	56	22	22	56	-1
55. During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	1,188	55	19	26	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)?	955	45	23	32	45	0

1.14 Care from your General Practice

	Number of responses	Response (%)			% Positive	Difference from NHS Scotland
		Positive	Neutral / Mixed	Negative		
57. As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	1,733	95		5	95	-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?	1,502	70	23	8	70	0

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?	2,031	89	9		89	0
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.	1,876	21	79		21	-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)?	2,086	89	7	4	89	-1
62. Overall, how do you feel about the length of time you had to wait when attending clinics and appointments for your cancer treatment?	2,068	73	20	6	73	-3 ^s
63. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	1,996	19	81		19	-3 ^s

1.16 Questions with highest percent positive response

		Number of responses	Response (%)			% Positive	Difference from NHS Scotland
			Positive	Neutral / Mixed	Negative		
44.	The last time you had an outpatients appointment with a cancer doctor, did they have the right documents, such as medical notes, x-rays and test results?	1,208	97			97	-1
57.	As far as you know, was your GP given enough information about your condition and the treatment you had at the hospital?	1,733	95	5		95	-1
5.	Beforehand, did you have all the information you needed about your test?	1,153	94	6		94	+2 ^s
64.	Overall, how would you rate your care?	2,056	93	6		93	-1
25.	Beforehand, did you have all the information you needed about your operation?	1,060	92	8		92	-1

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

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

1.17 Questions with highest percent negative response

		Number of responses	Response (%)			% Positive	Difference from NHS Scotland
			Positive	Neutral / Mixed	Negative		
63.	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	1,996	19		81	19	-3 ^s
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.	1,876	21		79	21	-1
23.	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	1,228	56		44	56	+5 ^s
12.	When you were told you had cancer, were you given written information about the type of cancer you had?	1,697	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)?	955	45	23	32	45	0

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

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

Chapter 2. Variation in Regional Cancer Network Results across Scotland

The tables / charts in this chapter show this network's percent positive results in relation to the range of percent positive results across all three of the regional cancer networks in Scotland. The percent positive results for NHS Scotland are also shown.

Notes on Interpretation

■ Range of percent positive results across all regional cancer networks in Scotland - ranges from the lowest network result to the highest network result.

■ This network's percent positive result.

■ NHS Scotland percent positive result (includes results from patients treated at all hospitals in Scotland, not just those within a regional cancer network).

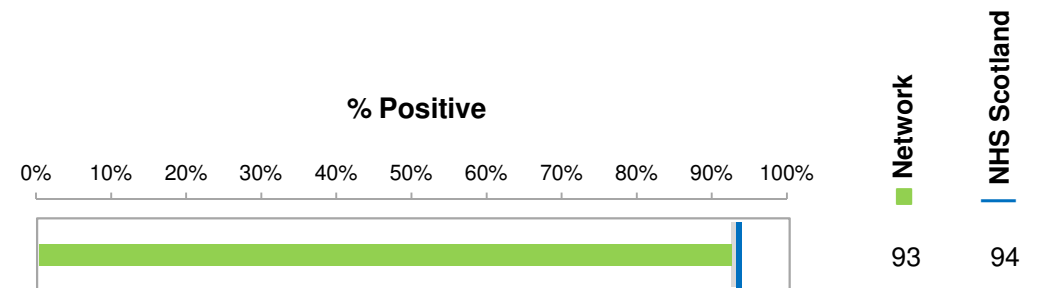
S Indicates a statistically significant difference in the percent positive result between this network and NHS Scotland as a whole.

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

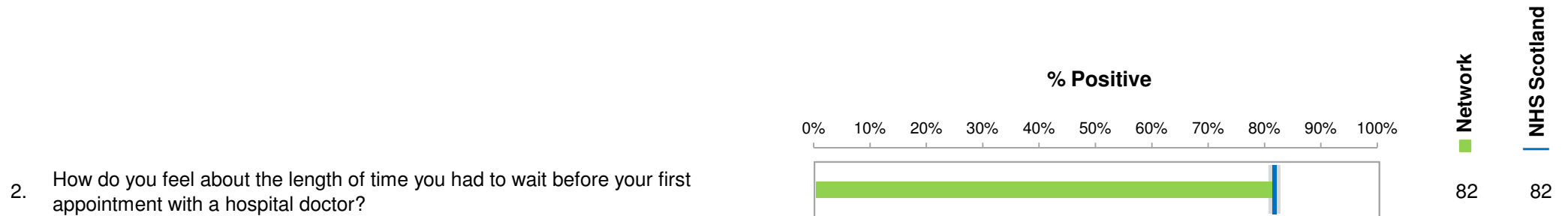
2.1 Overall Care

64. Overall, how would you rate your care?

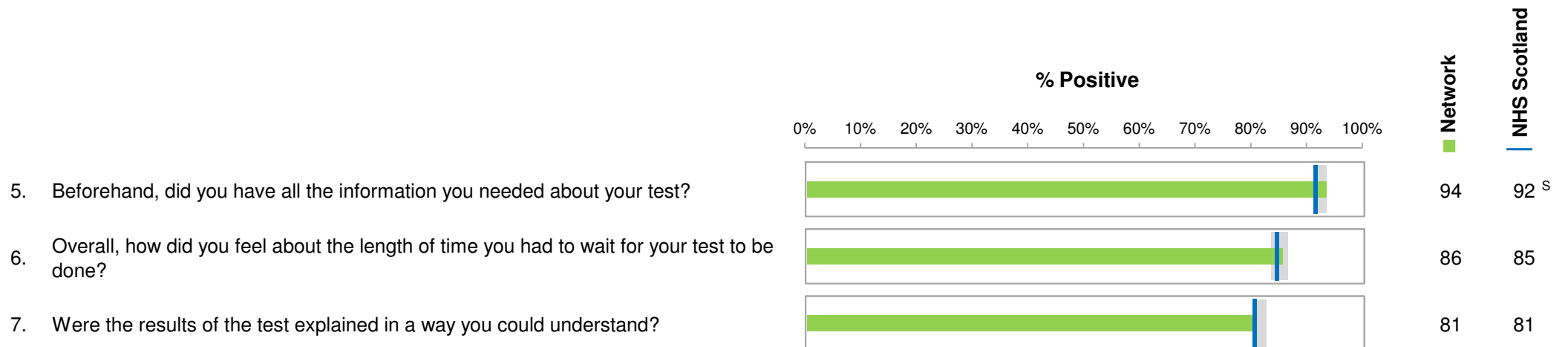


2.2 Seeing your GP

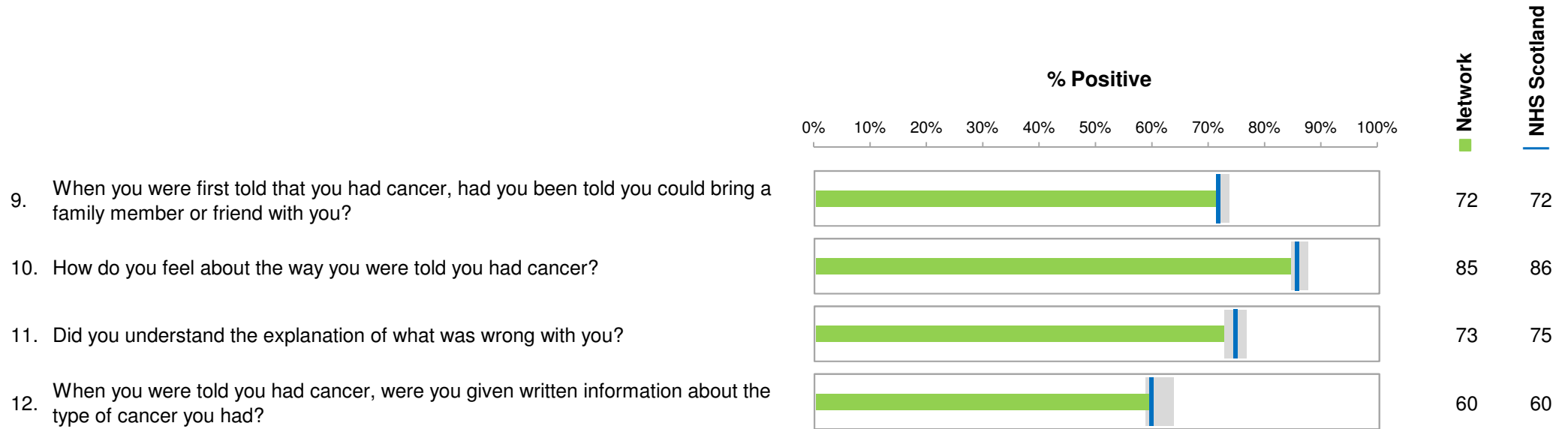
Note: Question 2 relates to GP care. As such, the results for this question are based on responses from patients who were **resident within this network area** at the time of their cancer diagnosis. This differs from most other results in this report, which are based on responses from patients who **received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



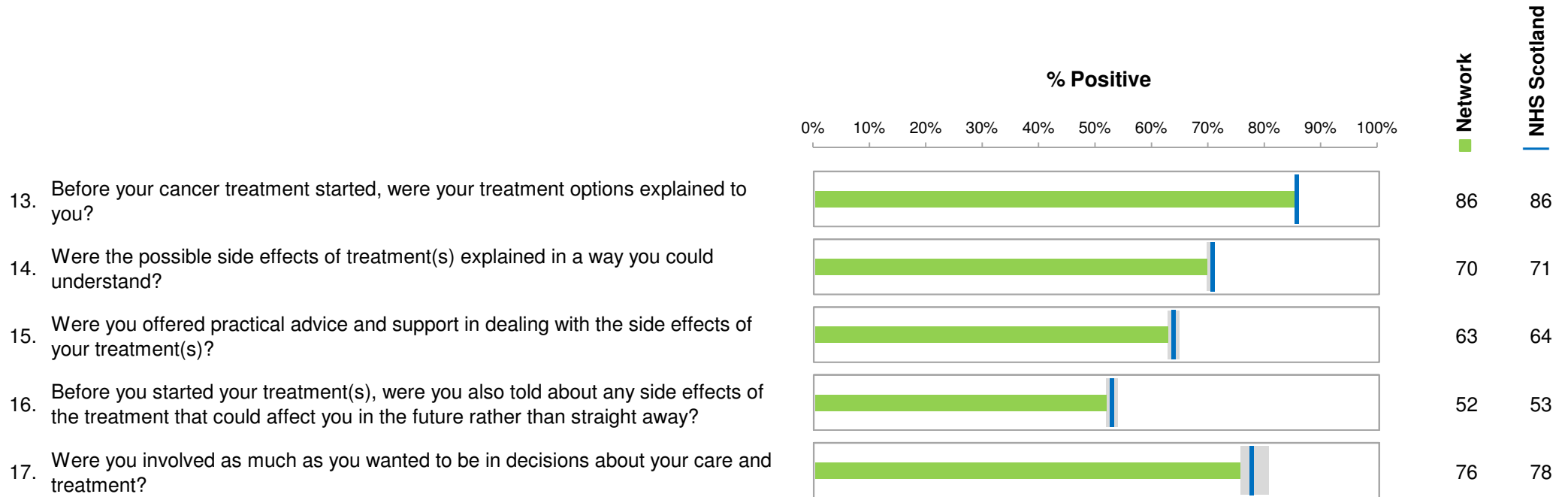
2.3 Diagnostic tests



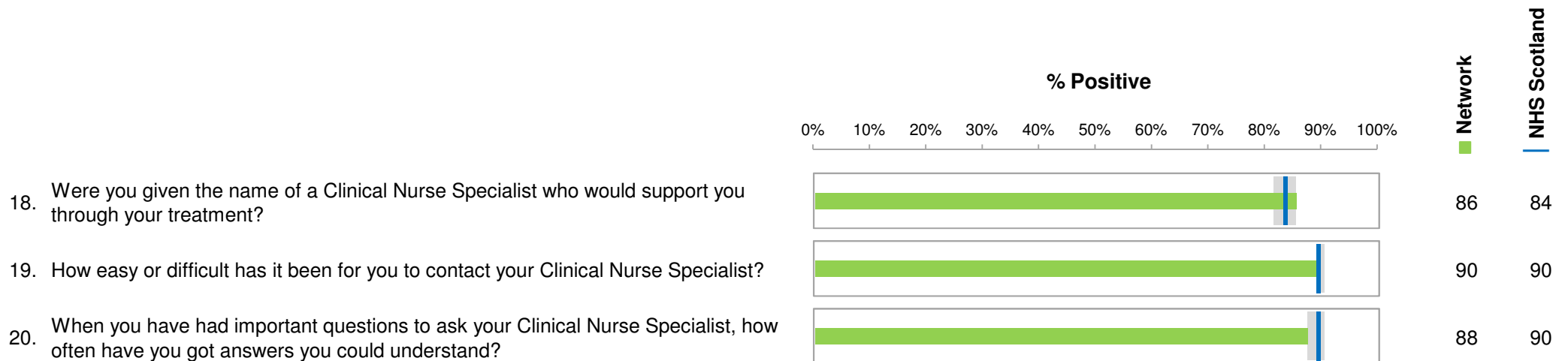
2.4 Finding out what was wrong with you



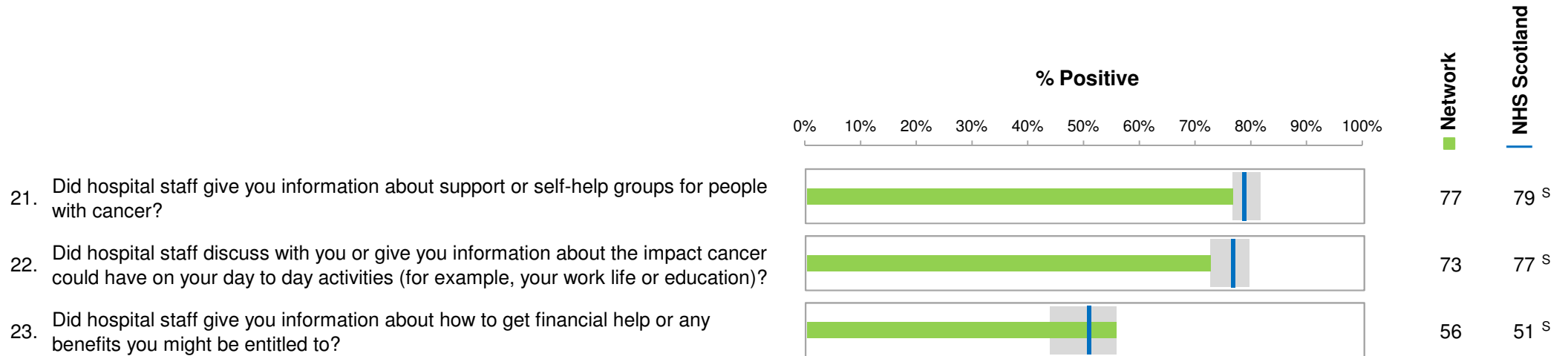
2.5 Deciding the best treatment for you



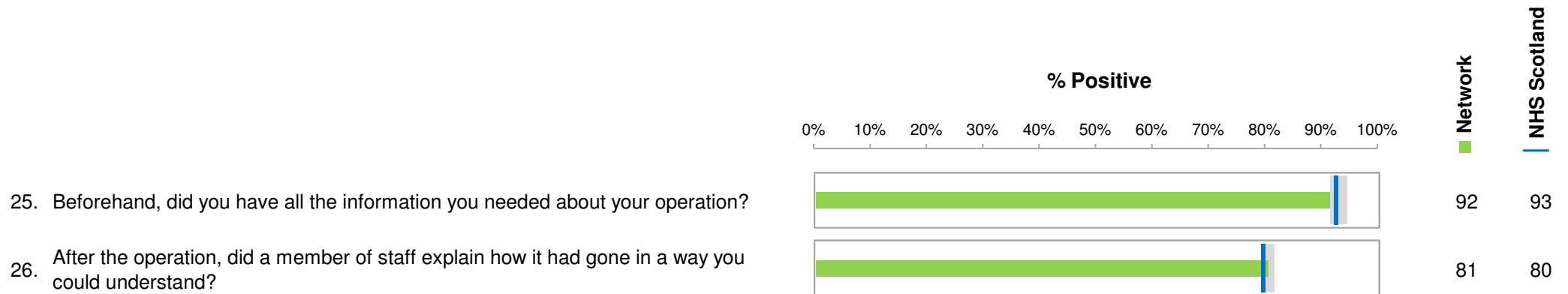
2.6 Clinical Nurse Specialist



2.7 Support for people with cancer



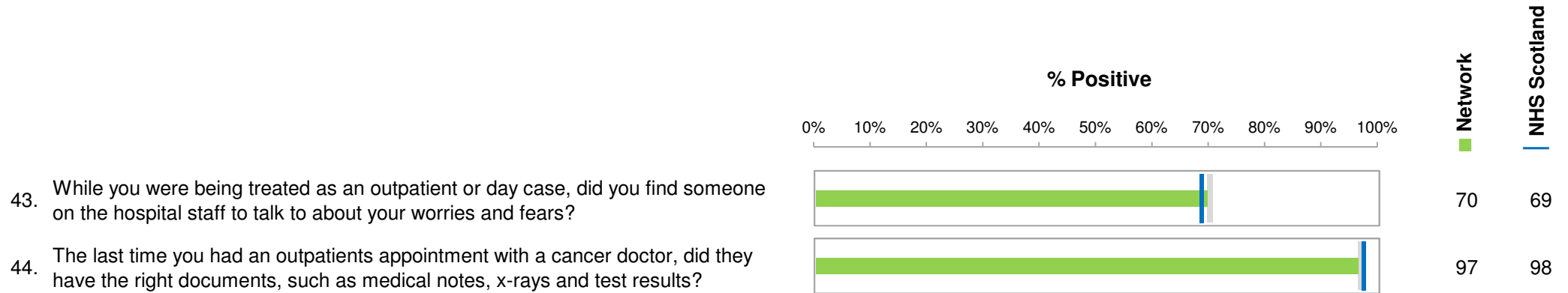
2.8 Operations



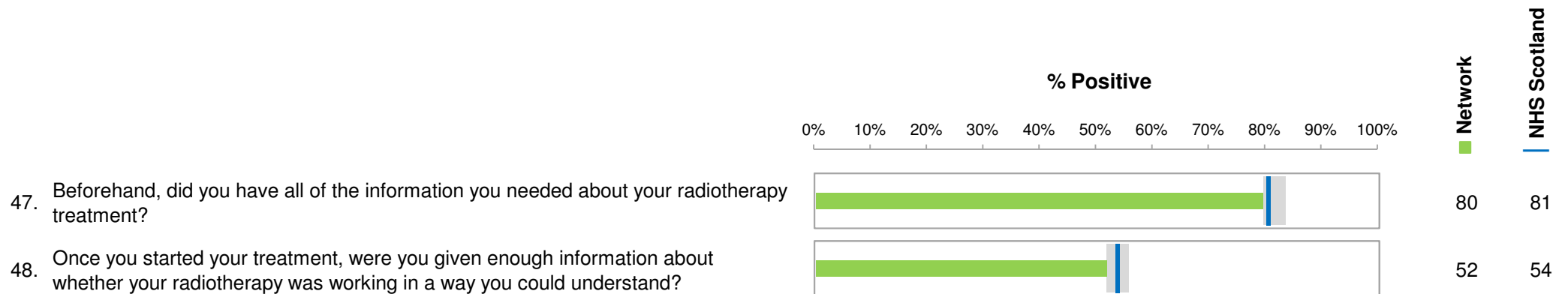
2.9 Hospital care as an inpatient



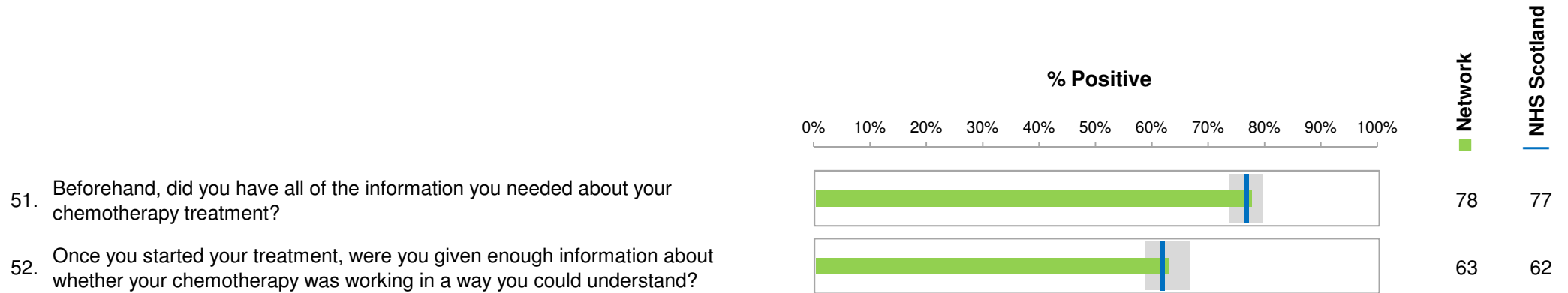
2.10 Hospital care as a day patient / outpatient



2.11 Radiotherapy

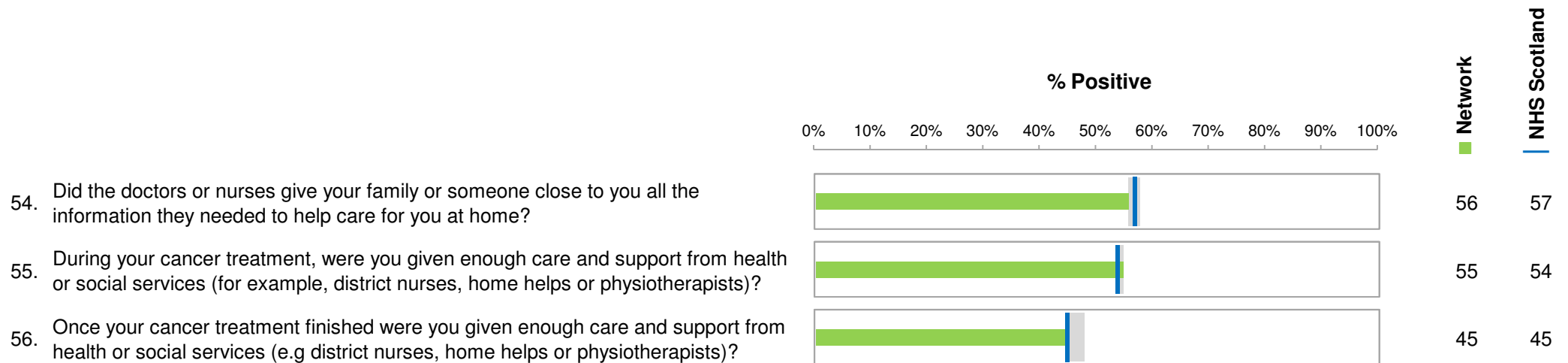


2.12 Chemotherapy



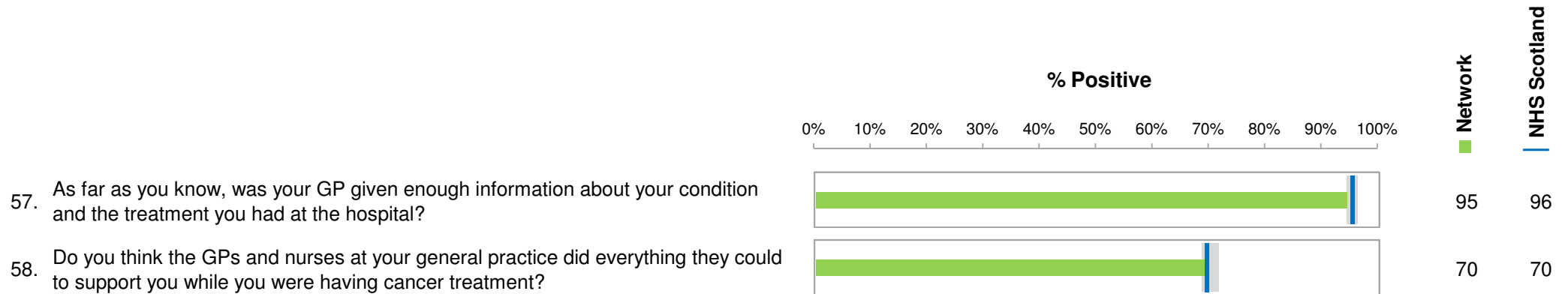
2.13 Home care and support

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 network area** 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 within this network**.

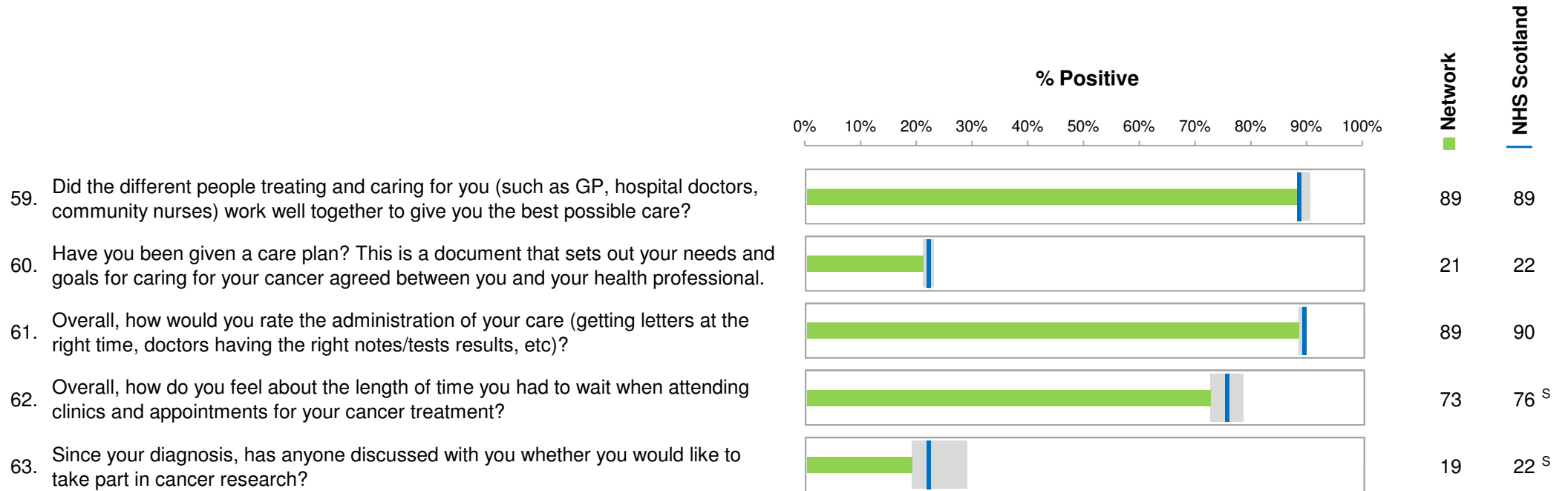


2.14 Care from your General Practice

Note: Question 58 relates to GP care. As such, results for this question are based on responses from patients who were **resident within this network area** 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 within this network**.



2.15 Your overall NHS Care



Chapter 3. Results by Tumour Group for WOSCAN

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	
	Network	NHS Scotland
Breast	25	25
Colorectal / Lower Gastrointestinal	14	15
Lung	4	6
Prostate	11	12
Brain / Central Nervous System	1	1
Gynaecological	8	7
Haematological	8	8
Head & Neck	6	5
Sarcoma	1	1
Skin	3	3
Upper Gastrointestinal	4	4
Urological	7	6
Other	0	0
Tumour group unknown	8	7

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

Notes on Interpretation

Network - the percent positive result for this network; the total percentage of patients treated within this network 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	Network	NHS Scotland
Breast	94	94
Colorectal / Lower Gastrointestinal	94	94
Lung	94	94
Prostate	93	94
Brain / Central Nervous System	--	89
Gynaecological	94	95
Haematological	96	97
Head & Neck	92	93
Sarcoma	--	90
Skin	98	97
Upper Gastrointestinal	92	91
Urological	92	93
Other	--	--
Tumour group unknown	87	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 network area** 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 within this network**. 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	Network	NHS Scotland
Breast	82	84
Colorectal / Lower Gastrointestinal	87	84
Lung	82	85
Prostate	82	83
Brain / Central Nervous System	--	76
Gynaecological	79	79
Haematological	81	79
Head & Neck	86	84
Sarcoma	--	56
Skin	84	83
Upper Gastrointestinal	83	77
Urological	77	76
Other	--	--
Tumour group unknown	--	85
All Tumour Groups	82	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	93	93	86	89	81	84
Colorectal / Lower Gastrointestinal	96	96	89	86	90	84
Lung	100	92	85	87	86	83
Prostate	93	92	86	83	80	80
Brain / Central Nervous System	--	91	--	91	--	77
Gynaecological	93	86	85	77	77	78
Haematological	94	91	90	86	84	81
Head & Neck	89	88	87	87	77	77
Sarcoma	--	82	--	79	--	76
Skin	89	85	85	89	78	76
Upper Gastrointestinal	97	90	79	78	80	77
Urological	92	90	79	80	73	73
Other	--	--	--	--	--	--
Tumour group unknown	95	91	87	84	79	76
All Tumour Groups	94	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
	Breast	72	75	89	89	72	77	60
Colorectal / Lower Gastrointestinal	82	80	85	86	81	82	57	59
Lung	83	75	91	87	75	78	63	54
Prostate	78	77	86	87	80	80	77	78
Brain / Central Nervous System	--	90	--	79	--	77	--	47
Gynaecological	59	57	83	85	72	74	53	54
Haematological	72	72	83	85	59	60	70	70
Head & Neck	65	66	89	88	70	75	51	51
Sarcoma	--	59	--	82	--	62	--	36
Skin	58	55	90	89	73	74	76	74
Upper Gastrointestinal	77	72	79	80	78	72	49	45
Urological	59	63	77	79	79	75	57	51
Other	--	--	--	--	--	--	--	--
Tumour group unknown	67	73	84	85	68	70	51	53
All Tumour Groups	72	72	85	86	73	75	60	60

3.5 Deciding the best treatment for you

Tumour Group	13. Before your cancer treatment started, were your treatment options explained to you?		14. Were the possible side effects of treatment(s) explained in a way you could understand?		15. Were you offered practical advice and support in dealing with the side effects of your treatment(s)?		16. Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	
	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	84	85	63	66	59	64	41	46
Colorectal / Lower Gastrointestinal	90	89	73	74	69	68	60	57
Lung	90	87	84	76	74	68	68	59
Prostate	84	86	73	73	61	64	62	62
Brain / Central Nervous System	--	87	--	69	--	49	--	49
Gynaecological	85	85	72	72	65	63	50	52
Haematological	87	89	76	73	69	70	59	58
Head & Neck	90	89	70	69	66	63	52	51
Sarcoma	--	78	--	60	--	59	--	63
Skin	78	86	77	74	72	69	57	62
Upper Gastrointestinal	83	87	69	70	67	67	51	52
Urological	80	82	75	72	58	55	52	50
Other	--	--	--	--	--	--	--	--
Tumour group unknown	84	84	61	67	59	58	46	49
All Tumour Groups	86	86	70	71	63	64	52	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	Network	NHS Scotland
Breast	74	76
Colorectal / Lower Gastrointestinal	82	82
Lung	88	83
Prostate	79	80
Brain / Central Nervous System	--	74
Gynaecological	74	76
Haematological	79	80
Head & Neck	78	77
Sarcoma	--	71
Skin	83	87
Upper Gastrointestinal	76	77
Urological	73	74
Other	--	--
Tumour group unknown	68	70
All Tumour Groups	76	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	95	95	87	88	84	86
Colorectal / Lower Gastrointestinal	89	90	95	92	95	94
Lung	90	87	92	90	90	91
Prostate	81	81	87	90	89	91
Brain / Central Nervous System	--	84	--	82	--	89
Gynaecological	85	83	86	88	87	90
Haematological	76	70	95	94	91	94
Head & Neck	86	80	92	93	93	93
Sarcoma	--	85	--	96	--	100
Skin	90	78	92	94	89	92
Upper Gastrointestinal	90	81	91	90	86	86
Urological	62	58	86	91	87	88
Other	--	--	--	--	--	--
Tumour group unknown	78	78	92	90	81	84
All Tumour Groups	86	84	90	90	88	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	78	83	70	76	49	47
Colorectal / Lower Gastrointestinal	79	78	78	80	60	54
Lung	86	77	80	76	68	61
Prostate	80	85	81	84	39	38
Brain / Central Nervous System	--	77	--	77	--	69
Gynaecological	71	75	73	75	68	58
Haematological	84	84	78	80	66	62
Head & Neck	80	78	76	78	65	58
Sarcoma	--	75	--	--	--	60
Skin	84	88	87	86	54	50
Upper Gastrointestinal	79	76	78	76	73	66
Urological	57	63	59	60	31	32
Other	--	--	--	--	--	--
Tumour group unknown	68	72	66	67	50	45
All Tumour Groups	77	79	73	77	56	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	
	Network	NHS Scotland	Network	NHS Scotland
Breast	91	93	78	78
Colorectal / Lower Gastrointestinal	94	95	86	85
Lung	--	92	--	84
Prostate	97	94	92	83
Brain / Central Nervous System	--	90	--	75
Gynaecological	92	93	77	81
Haematological	86	89	83	73
Head & Neck	92	91	76	77
Sarcoma	--	93	--	71
Skin	91	90	72	76
Upper Gastrointestinal	100	93	88	81
Urological	91	90	81	78
Other	--	--	--	--
Tumour group unknown	89	90	81	76
All Tumour Groups	92	93	81	80

3.9 Hospital care as an inpatient

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

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

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

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

Tumour Group	% Positive		% Positive		% Positive		% Positive	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	87	87	86	86	74	74	77	79
Colorectal / Lower Gastrointestinal	83	75	90	85	82	75	73	74
Lung	72	78	79	85	70	79	83	83
Prostate	86	81	89	86	73	75	73	79
Brain / Central Nervous System	--	77	--	83	--	57	--	51
Gynaecological	86	86	86	87	69	74	74	76
Haematological	80	82	90	88	84	83	86	81
Head & Neck	78	79	92	89	79	77	76	75
Sarcoma	--	74	--	90	--	73	--	61
Skin	89	86	89	92	71	76	92	81
Upper Gastrointestinal	79	74	90	87	83	80	82	78
Urological	80	76	85	84	72	72	73	74
Other	--	--	--	--	--	--	--	--
Tumour group unknown	76	78	86	83	73	73	70	71
All Tumour Groups	83	81	87	86	76	75	76	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	73	74	50	55	81	82	45	49
Colorectal / Lower Gastrointestinal	74	69	70	70	83	79	55	52
Lung	69	81	79	80	83	87	43	55
Prostate	73	75	62	67	91	86	45	51
Brain / Central Nervous System	--	63	--	61	--	80	--	40
Gynaecological	73	72	64	62	78	80	49	43
Haematological	71	72	67	69	83	86	63	57
Head & Neck	71	74	72	69	86	84	54	53
Sarcoma	--	68	--	55	--	77	--	39
Skin	85	81	74	62	91	88	64	58
Upper Gastrointestinal	68	61	66	79	76	77	48	52
Urological	76	73	70	72	81	79	45	45
Other	--	--	--	--	--	--	--	--
Tumour group unknown	70	72	62	62	77	75	47	43
All Tumour Groups	73	72	62	65	82	82	50	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	85	88	85	87	84	86	95	95
Colorectal / Lower Gastrointestinal	89	88	88	87	77	79	94	92
Lung	78	87	90	90	81	80	86	88
Prostate	84	88	88	89	83	86	91	92
Brain / Central Nervous System	--	74	--	69	--	67	--	89
Gynaecological	83	86	84	87	80	84	91	88
Haematological	90	89	94	94	88	79	92	93
Head & Neck	88	85	87	85	81	81	90	90
Sarcoma	--	85	--	83	--	58	--	89
Skin	87	81	83	87	94	87	94	94
Upper Gastrointestinal	88	88	87	85	76	78	95	92
Urological	83	83	87	87	67	74	75	81
Other	--	--	--	--	--	--	--	--
Tumour group unknown	88	86	89	87	75	78	85	89
All Tumour Groups	86	87	87	87	80	82	91	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	
	Network	NHS Scotland	Network	NHS Scotland
Breast	60	64	97	97
Colorectal / Lower Gastrointestinal	77	75	96	96
Lung	73	71	97	97
Prostate	76	74	99	99
Brain / Central Nervous System	--	64	--	94
Gynaecological	74	68	100	98
Haematological	76	72	99	98
Head & Neck	75	71	99	99
Sarcoma	--	67	--	96
Skin	76	73	97	97
Upper Gastrointestinal	86	76	98	99
Urological	60	60	94	96
Other	--	--	--	--
Tumour group unknown	60	58	98	98
All Tumour Groups	70	69	97	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	
	Network	NHS Scotland	Network	NHS Scotland
Breast	77	81	40	48
Colorectal / Lower Gastrointestinal	71	80	44	56
Lung	80	85	--	61
Prostate	86	85	69	62
Brain / Central Nervous System	--	88	--	74
Gynaecological	80	82	51	51
Haematological	--	77	--	62
Head & Neck	82	76	63	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	--	79	--	50
Urological	--	77	--	60
Other	--	--	--	--
Tumour group unknown	--	83	--	56
All Tumour Groups	80	81	52	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	
	Network	NHS Scotland	Network	NHS Scotland
Breast	75	75	52	53
Colorectal / Lower Gastrointestinal	80	77	63	63
Lung	87	82	81	68
Prostate	--	71	--	57
Brain / Central Nervous System	--	82	--	--
Gynaecological	72	72	61	61
Haematological	76	82	75	75
Head & Neck	76	71	53	55
Sarcoma	--	--	--	--
Skin	--	--	--	--
Upper Gastrointestinal	83	80	57	58
Urological	91	80	82	76
Other	--	--	--	--
Tumour group unknown	79	73	74	64
All Tumour Groups	78	77	63	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 network area** 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 within this network**.

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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	50	50	52	50	35	37
Colorectal / Lower Gastrointestinal	61	60	65	64	54	55
Lung	57	59	50	52	44	44
Prostate	51	54	56	54	48	45
Brain / Central Nervous System	--	51	--	45	--	--
Gynaecological	60	57	35	41	32	36
Haematological	64	65	60	57	50	48
Head & Neck	66	64	64	64	54	55
Sarcoma	--	44	--	61	--	--
Skin	69	67	61	55	69	58
Upper Gastrointestinal	66	65	63	63	57	55
Urological	57	57	51	54	39	48
Other	--	--	--	--	--	--
Tumour group unknown	50	53	--	42	--	33
All Tumour Groups	56	57	55	54	45	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 network area** 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 within this network**.

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	
	Network	NHS Scotland	Network	NHS Scotland
Breast	95	96	69	70
Colorectal / Lower Gastrointestinal	96	97	68	72
Lung	92	93	67	71
Prostate	96	97	73	72
Brain / Central Nervous System	--	89	--	73
Gynaecological	95	95	65	64
Haematological	97	96	69	66
Head & Neck	95	94	73	69
Sarcoma	--	96	--	71
Skin	93	95	79	74
Upper Gastrointestinal	96	97	76	74
Urological	93	95	71	72
Other	--	--	--	--
Tumour group unknown	92	92	--	67
All Tumour Groups	95	96	70	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	
	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland	Network	NHS Scotland
Breast	88	90	19	21	91	91	68	73
Colorectal / Lower Gastrointestinal	90	90	24	22	89	89	82	80
Lung	90	89	21	24	93	92	79	80
Prostate	87	89	20	23	84	88	77	76
Brain / Central Nervous System	--	79	--	18	--	74	--	64
Gynaecological	86	88	20	17	90	88	79	81
Haematological	92	91	26	26	95	94	77	77
Head & Neck	91	90	28	28	90	90	73	77
Sarcoma	--	90	--	20	--	88	--	65
Skin	92	90	16	18	94	94	78	82
Upper Gastrointestinal	93	90	25	20	92	91	66	72
Urological	86	87	19	17	87	85	64	71
Other	--	--	--	--	--	--	--	--
Tumour group unknown	89	87	24	24	82	85	69	72
All Tumour Groups	89	89	21	22	89	90	73	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	Network	NHS Scotland
Breast	22	27
Colorectal / Lower Gastrointestinal	23	30
Lung	24	24
Prostate	17	20
Brain / Central Nervous System	--	25
Gynaecological	12	13
Haematological	23	23
Head & Neck	17	16
Sarcoma	--	26
Skin	8	12
Upper Gastrointestinal	23	25
Urological	18	18
Other	--	--
Tumour group unknown	10	14
All Tumour Groups	19	22

Chapter 4. Condition / Demographic Questions for WOSCAN

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

Notes on Interpretation

(%) **Network** - Percentage of respondents treated within this network 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

	(%) Network	(%) 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	92	93
More than 5 years	2	1

(Number of responses within this network = 2,070).

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

(Number of responses within this network = 1,980).

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

4.1 Your condition (cont.)

67. Which of the following applies?	(%) Network	(%) NHS Scotland
My cancer has been taken out / treated without any sign of further problem	81	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	14	14

(Number of responses within this network = 1,543).

4.2 About you

68. What was your age on your last birthday?	(%) Network	(%) NHS Scotland
16 - 25	1	0
26 - 35	2	2
36 - 50	11	10
51 - 65	34	34
66 - 75	35	35
76+	18	19

(Number of responses within this network = 2,058).

69. Are you male or female?	(%) Network	(%) NHS Scotland
Male	42	43
Female	58	57

(Number of responses within this network = 2,087).

4.2 About you (cont.)

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

(Number of responses within this network = 2,041).

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

(Number of responses within this network = 2,088).

72. What is your main employment status?	(%) Network	(%) NHS Scotland
Work full time	16	17
Work part time	9	10
In full time education or training	0	0
Retired	61	62
Unemployed / looking for work	1	1
Don't work due to illness or disability	10	8
Other	2	2

(Number of responses within this network = 2,106).

4.2 About you (cont.)

73. Do you have any of the following? ¹	(%) Network	(%) NHS Scotland
Deafness or severe hearing impairment	14	15
Blindness or severe vision impairment	3	3
A physical disability	14	13
A learning disability	1	1
A mental health condition	4	4
Chronic pain lasting at least 3 months	15	14
Another long - term condition	24	25
None of the above	51	51

(Number of responses within this network = 1,986).

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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How to access background or source data

The technical report is available at: 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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