





# **Northern Ireland Cancer Patient Experience Survey 2018**

# South Eastern Health & Social Care Trust

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The Northern Ireland Cancer Patient Experience Survey is undertaken by Quality Health on behalf of the Northern Ireland Health and Social Care Board and Public Health Agency and Macmillan Cancer Support



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#### Introduction

The Northern Ireland Cancer Patient Experience Survey (NI CPES) 2018 follows on from the successful delivery of the surveys in England, Scotland, Wales and Northern Ireland, (7 iterations in England, 2 in Scotland, 2 in Wales and 1 in Northern Ireland).

The survey has been designed to monitor progress on cancer care; to provide information that can be used to drive local quality improvements; to assist Multi-Disciplinary Teams, Commissioners, and Trusts in improving services for patients; and to inform the work of the charities supporting cancer patients.

#### **Participating Trusts**

The survey was carried out across all five Health and Social Care Trusts providing cancer services, accounting for every Trust that provides adult cancer care in Northern Ireland.

#### Patients selected to take part

The inclusion criteria were that patients had to:

- Be 16 or over:
- Have a confirmed primary diagnosis of cancer, with an International Classification of Disease (ICD10) code of C00-C99 or D05;
- Have been discharged from a hospital within the Trust (inpatient or day case) between 1st May and 31st October 2017.

Patients were excluded if they:

- Had a primary diagnosis of ICD10 code C44 or C84;
- Were deceased at the time of posting surveys:
- Received their treatment privately;
- Were current inpatients at the time of posting surveys;
- Only attended as an outpatient during the sample period;
- Did not have a valid Northern Ireland postal address.

The survey population included all those with rarer cancers as well as patients in the "Big 4" cancer groups – i.e. breast, prostate, lung, and colorectal/lower GI.

Patients eligible for the survey were identified from the Trusts' Patient Administration Systems. Trust samples and patient lists were then checked rigorously for duplicates to ensure that patients did not receive multiple copies of the questionnaire.

Deceased checks on Trust samples were carried out on at least three occasions during the fieldwork, to ensure that the numbers of deceased patients receiving survey packs or reminder letters was reduced to an absolute minimum. This process was undertaken by the Business Services Organisation.

#### Survey method

Survey packs (including cover letter, questionnaire, and information sheet) were sent by post in June 2018, with two reminder letters sent during July 2018 to those who had yet to respond. Survey packs included an option to complete online, and details of a free telephone line which patients could call to ask questions, complete the questionnaire verbally, or to access an interpreting service. Survey packs were prepared by Quality Health, couriered to Trust staff and posted to patients.

#### Response rate

A total of 6,256 patients who had received treatment for cancer between May 2017 and October 2017 were included in the sample for the Cancer Patient Experience Survey. These patients were allocated to 13 different cancer groups.

1,043 eligible patients from the South Eastern Trust were sent a survey, and 598 questionnaires were returned completed. This represents a response rate of 58% once deceased patients and questionnaires returned undelivered had been accounted for. The response rate for Northern Ireland as a whole was 57% (3,478 respondents) and for South Eastern Trust in 2015 the response rate was 78%.

#### **Percentage scores**

The findings from the survey have been summarised as the percentage of patients who reported a positive experience in response to each question. For example, the percentage scores represent the proportion of patients who were given information about support or self-help groups for people with cancer by staff or the proportion of patients who said that groups of doctors and nurses did NOT talk in front of them as if they were not there. Neutral responses, such as "Don't know / can't remember" and "I did not need an explanation" have not been included in the denominator when computing scores.

The higher the score the better the Trust's performance. Some scores relate only to one care setting (e.g. acute) but others represent performance across a pathway involving primary and community care in addition to acute care.

Scoring for question 62 - in which patients were asked to give an 'overall rating' of their cancer care - is based on an average score out of 10, rather than a 'percentage positive'.

Most of the questions in the NI CPES 2018 are in the same format as and have similar wording to the 2017 CPES for England, and the scoring system for them is identical, thus enabling robust comparisons to be made.

Only questions that have been designated a score have been included in this report. Questions which aim only to clarify the respondent's treatment pathway or to direct them through the questionnaire (for example, question 5 "Did the test(s) take place at the hospital named on the letter that came with this questionnaire?") are not included in the report.

#### Low numbers of respondents

Some Trusts have relatively small numbers of patients with certain cancer types, so the number of respondents to the survey may be lower within these groups despite the high response rate. Responses from patients with rarer cancers have been analysed in the normal way, but the results for these cancer types may need to be treated with caution.

In almost all Trusts, there were cancer types where the number of respondents was less than 20; this is particularly true of rarer cancers. Where the number of respondents with a particular cancer type was less than 20, we have supressed this data. This is further explained in the introduction to the cancer type tables in this report.

#### **Benchmark charts**

Percentage scores are displayed on benchmark bar charts in the following section.

#### For each question:

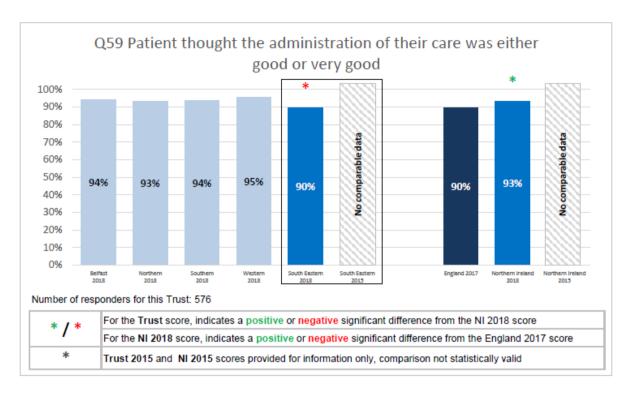
- the left of the chart shows the 2018 score for each Trust in Northern Ireland. Where applicable, the 2015 NI CPES score for the South Eastern Trust is presented alongside these 2018 bars.
- the right of the chart shows the score for the England 2017 CPES, for the Northern Ireland 2018 CPES as a whole, and for the Northern Ireland 2015 CPES survey (where applicable).

Where possible, significance tests have been used to establish whether there are statistically significant differences on each question between:

- the South Eastern Trust's score for 2018 and the Northern Ireland 2018 score:
- the Northern Ireland 2018 score and the England 2017 score.

Where the variation between scores has been found to be statistically significant, the relevant bar has been marked with an asterisk, which is coloured green where the score displayed in the bar is more positive and red where the score displayed in the bar is more negative than the comparator score.

Please note that the Northern Ireland scores for 2015 are not statistically comparable to Northern Ireland 2018 scores due to changes in the sampling timeframe and questionnaire design.



In the chart above, the South Eastern Trust has a statistically significantly lower score (90%) than Northern Ireland 2018 (93%), while Northern Ireland 2018 has a statistically significantly higher score than England 2017 (90%).

Following these charts is further information which show the scores for each question for each of the 13 cancer types at this Trust, with a comparative score for that cancer type across all Trusts in Northern Ireland.

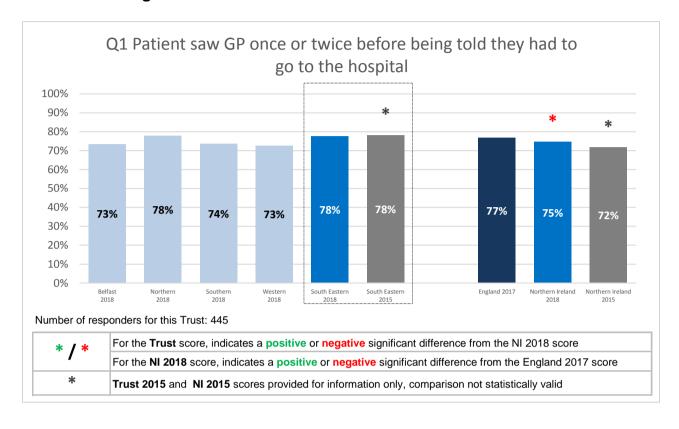
\* Further information on the England survey can be found at: www.ncpes.co.uk

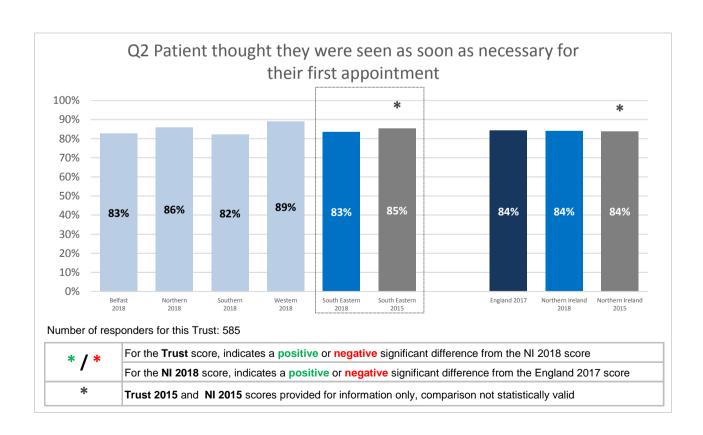
#### **Further information**

Full details of the survey and analysis methods are in the All Trusts Report of the Northern Ireland Cancer Patient Experience Survey 2018, which is available at: <a href="https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey-2018/northern-ireland-cancer-patient-experience-survey-reports-2018">www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey-reports-2018</a>

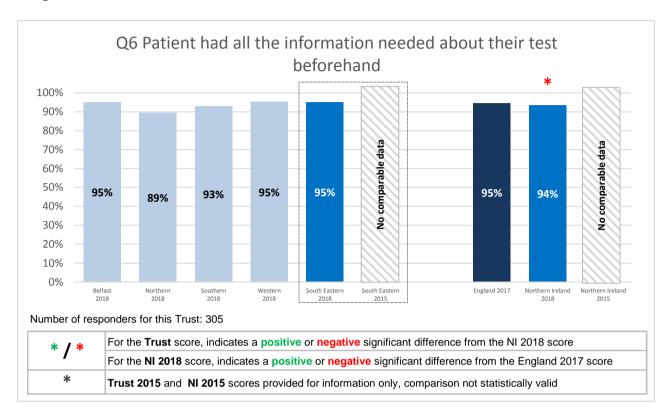
Copies of the questionnaire and covering letters can also be viewed at: <a href="https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey-2018/northern-ireland-cancer-patient-experience-survey-material-2018">www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey-material-2018</a>

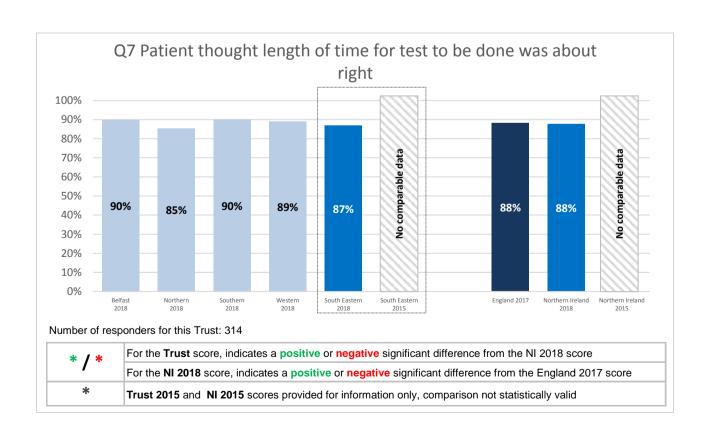
#### **Before Your Diagnosis**



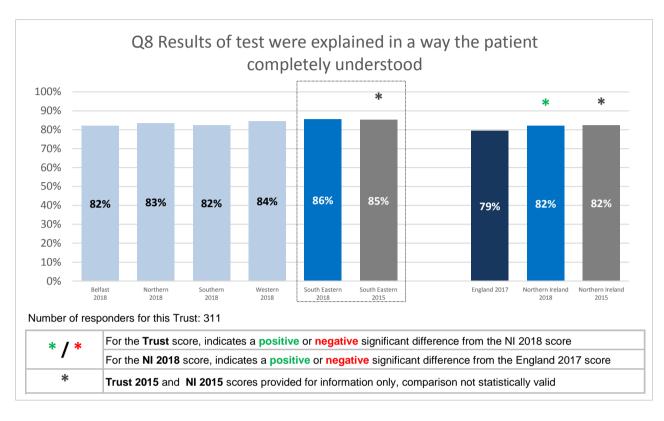


#### **Diagnostic Tests**

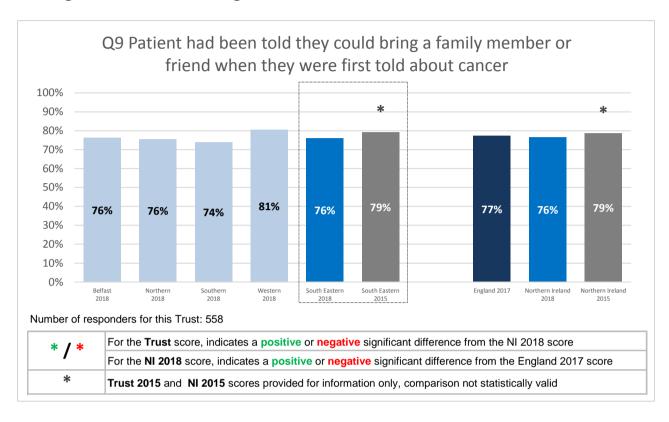


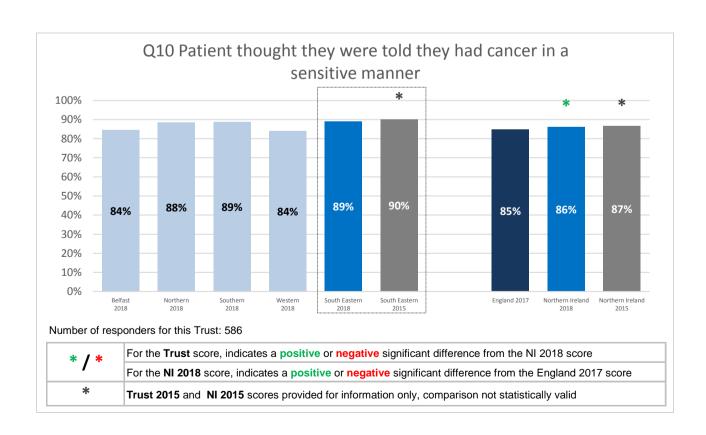


#### **Diagnostic Tests (continued)**

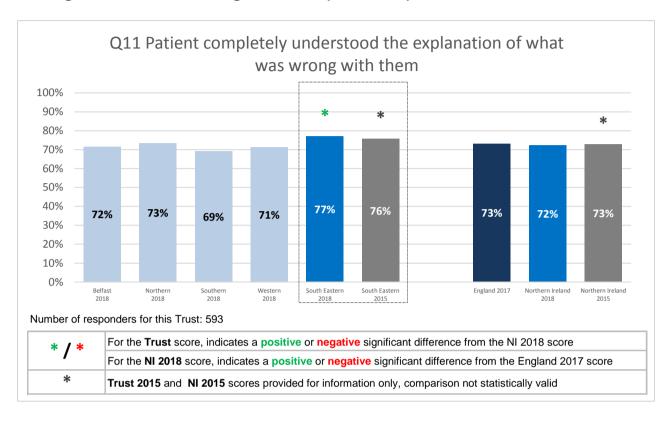


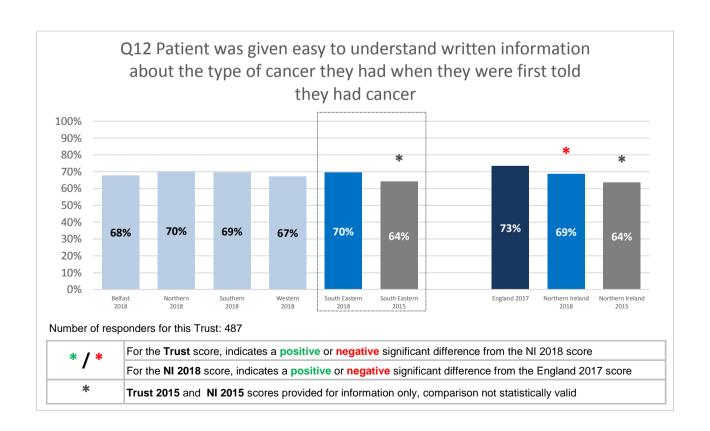
#### **Finding Out What Was Wrong With You**



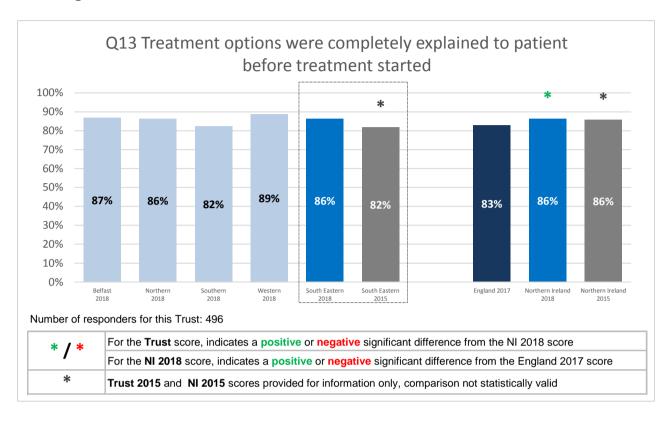


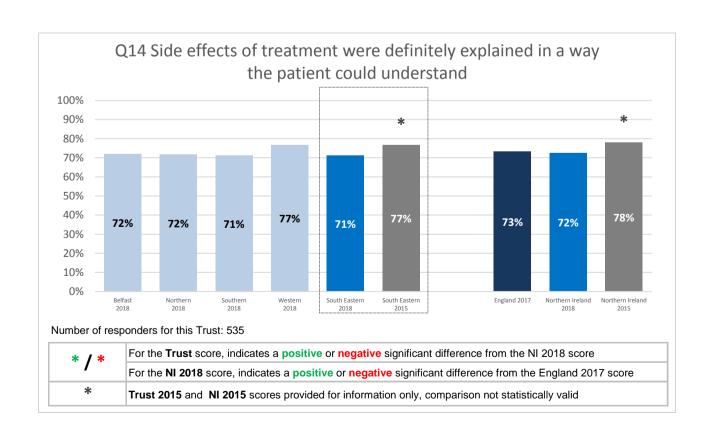
#### Finding Out What Was Wrong With You (continued)



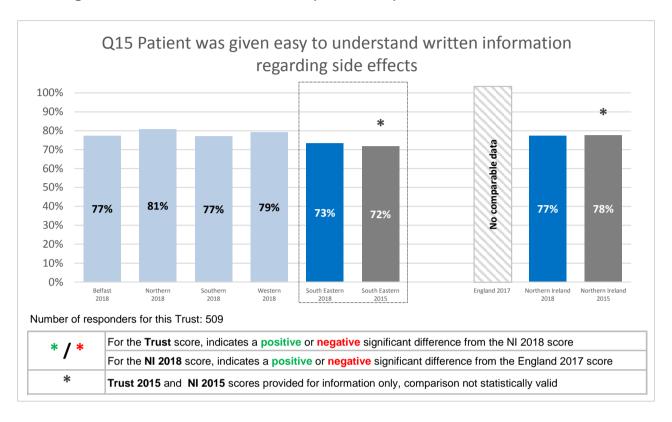


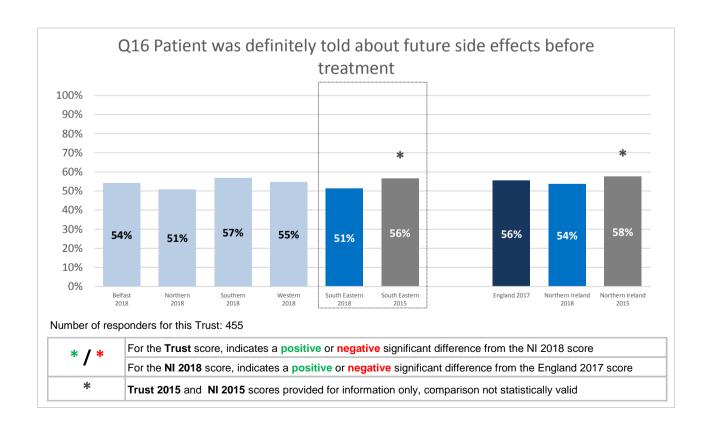
#### **Deciding The Best Treatment For You**



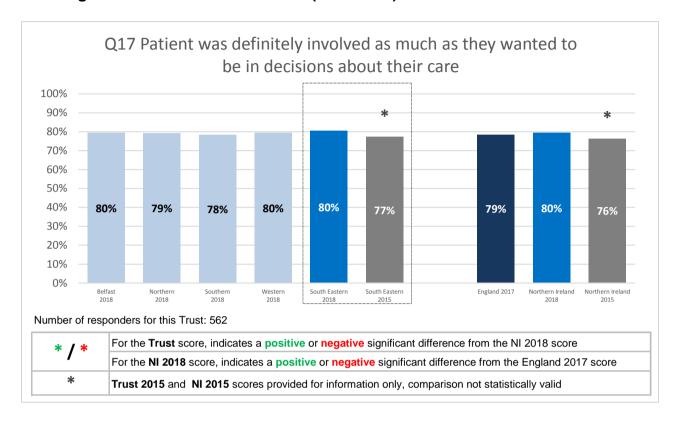


#### **Deciding The Best Treatment For You (continued)**

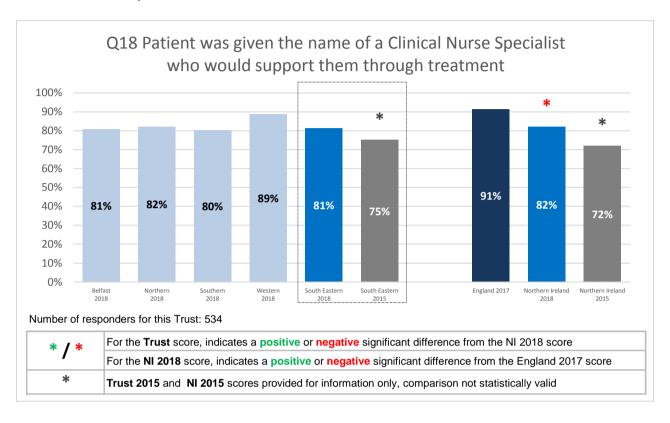


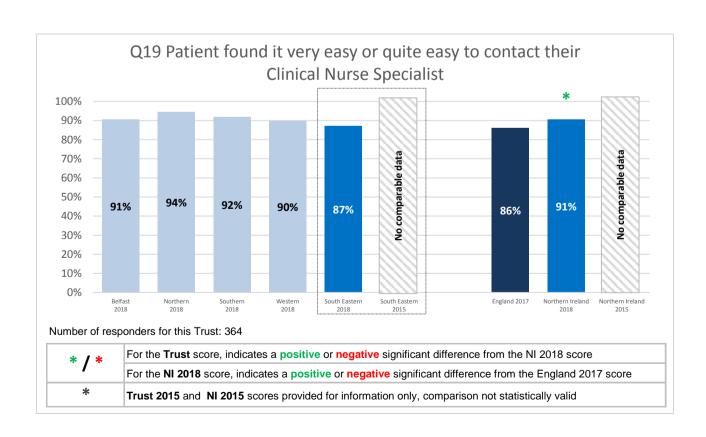


#### **Deciding The Best Treatment For You (continued)**

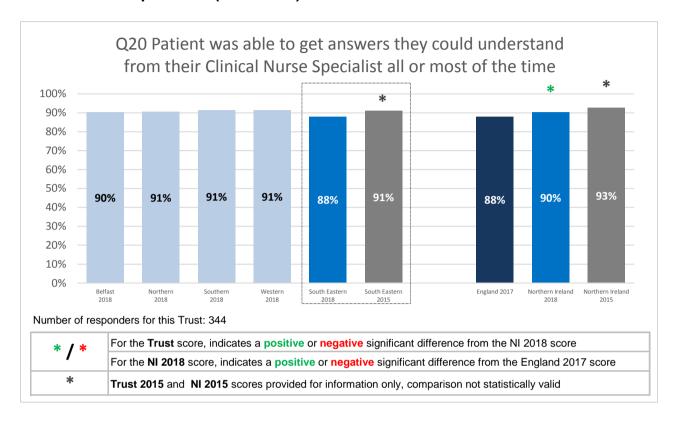


#### **Clinical Nurse Specialist**

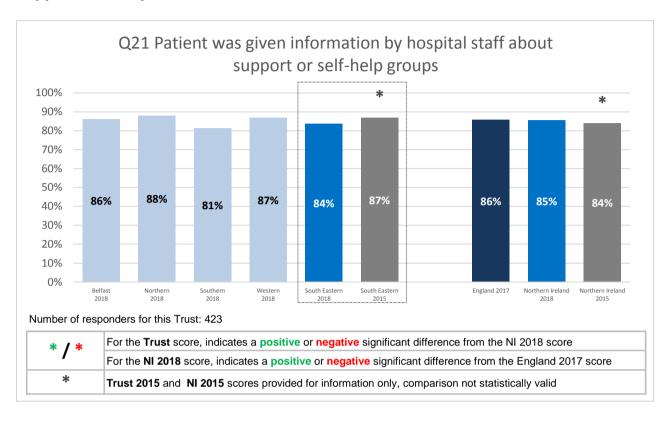


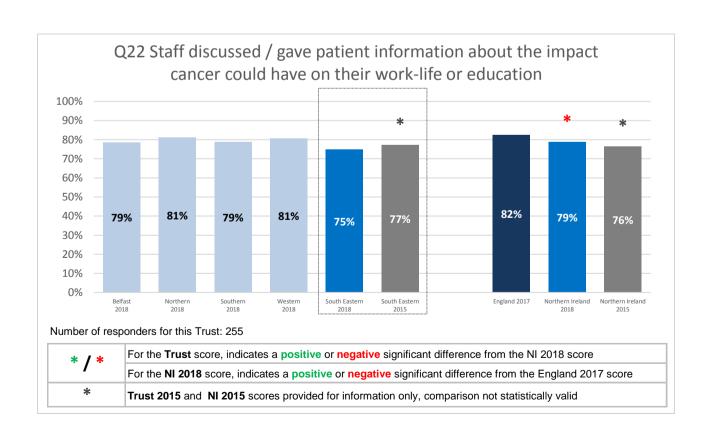


#### **Clinical Nurse Specialist (continued)**

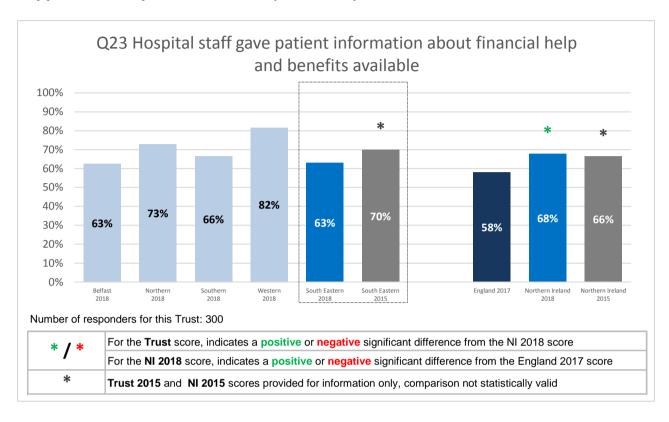


#### **Support For People With Cancer**

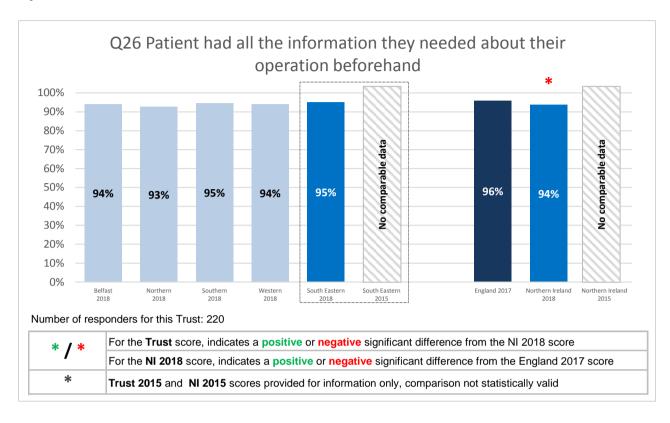


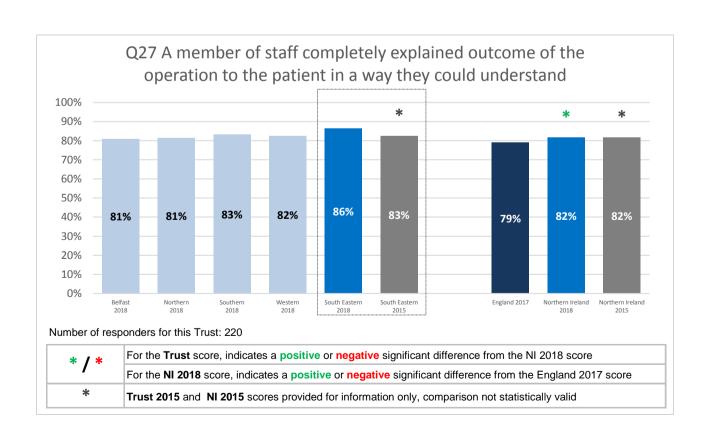


#### **Support For People With Cancer (continued)**

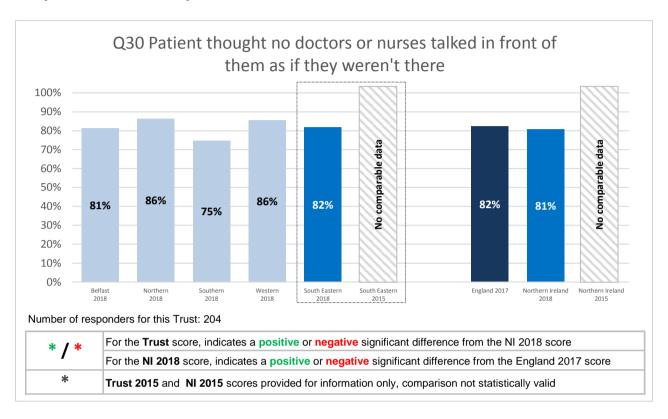


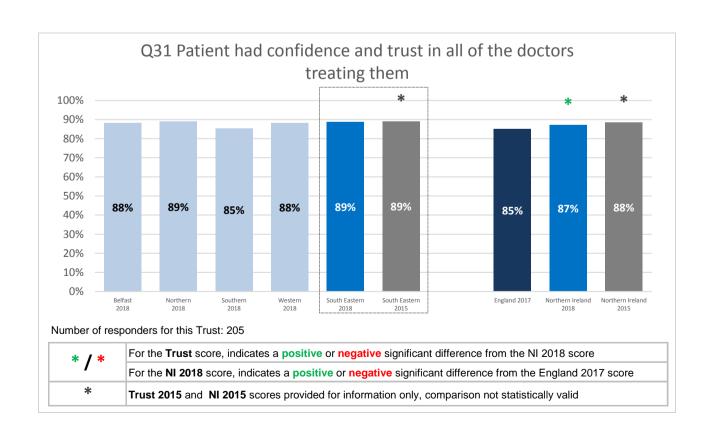
#### **Operations**

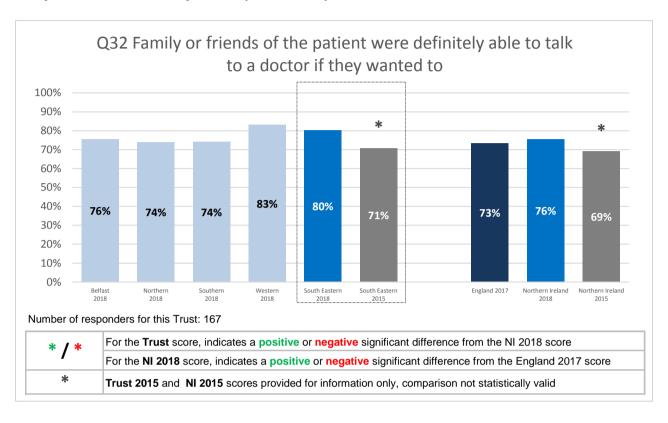


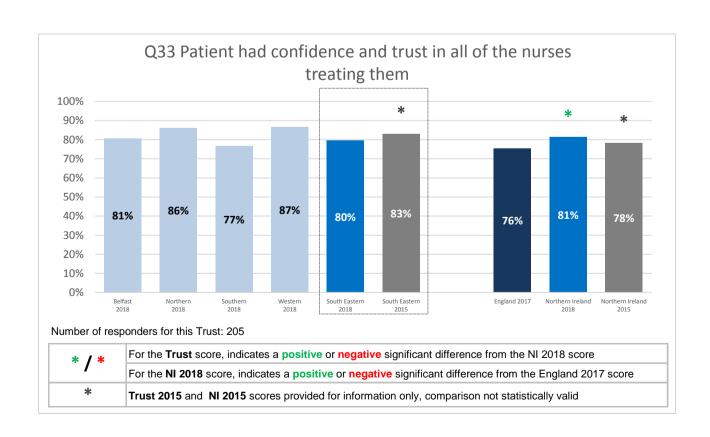


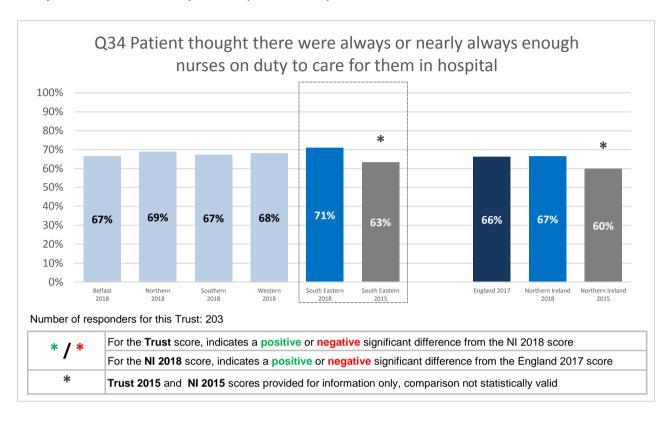
#### **Hospital Care As An Inpatient**

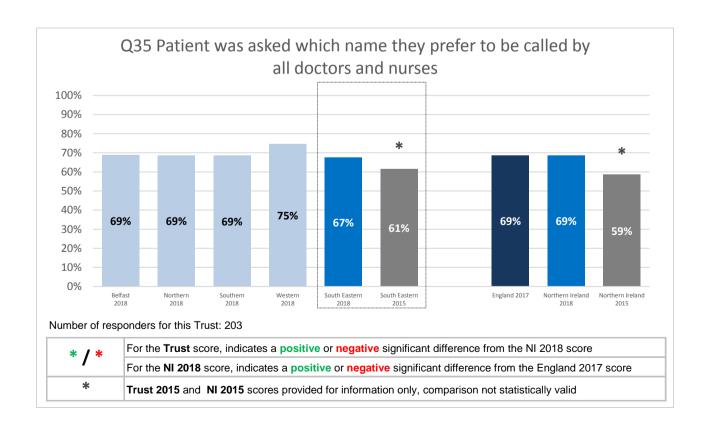


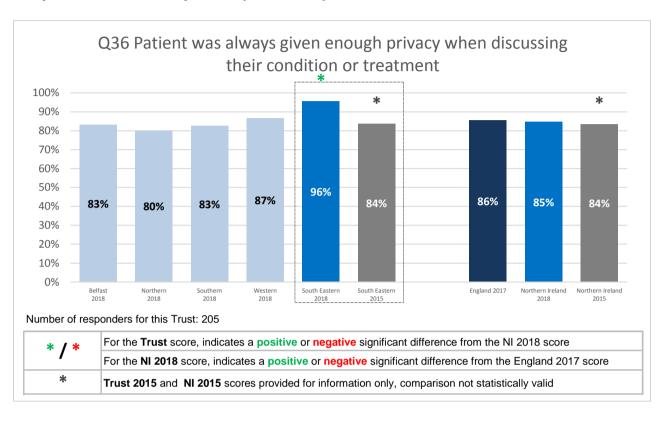


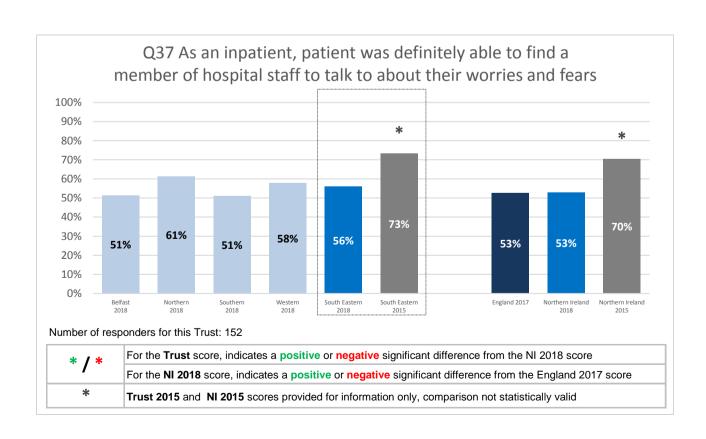


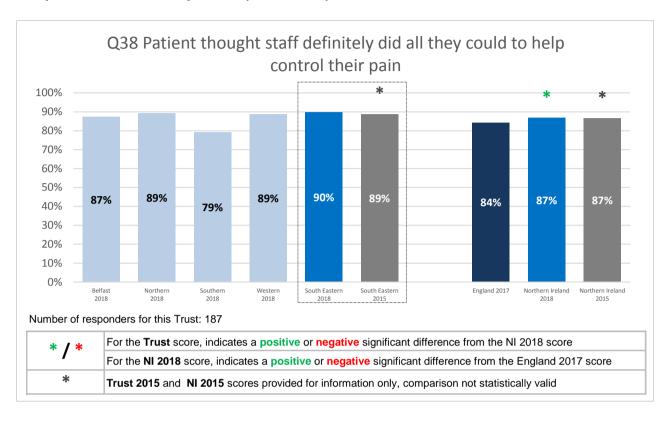


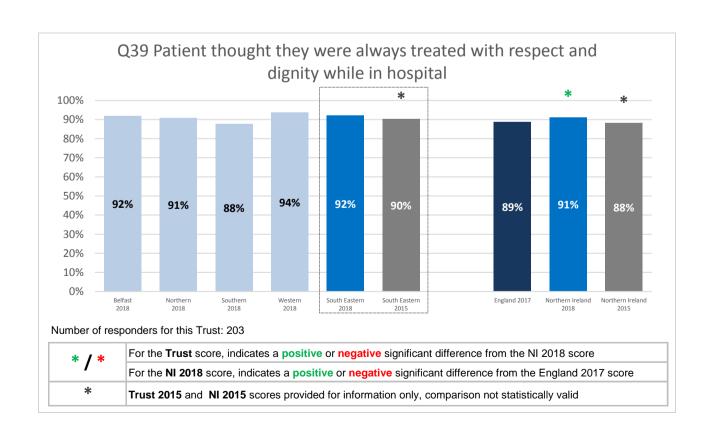


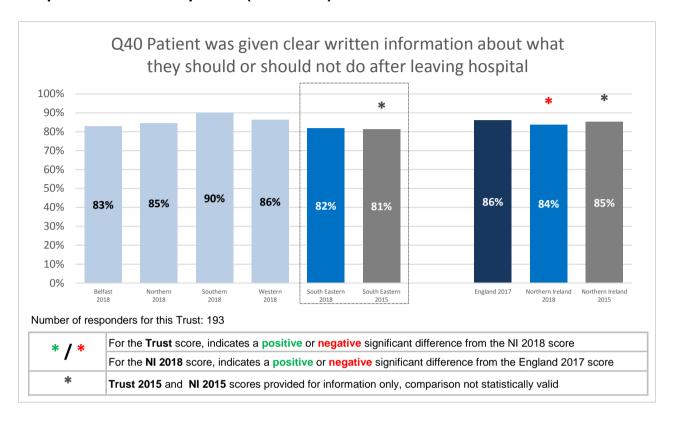


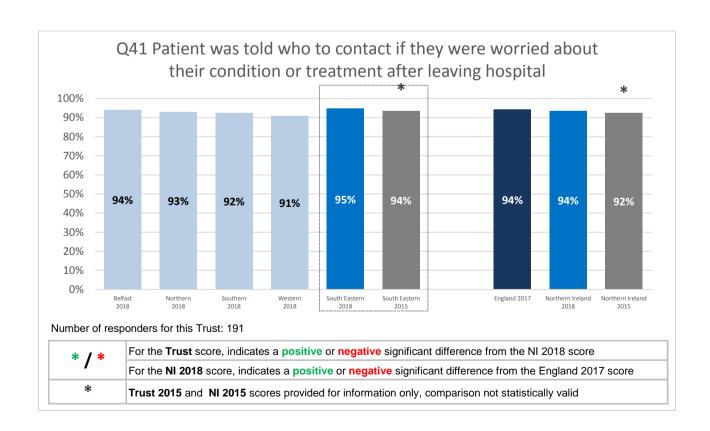




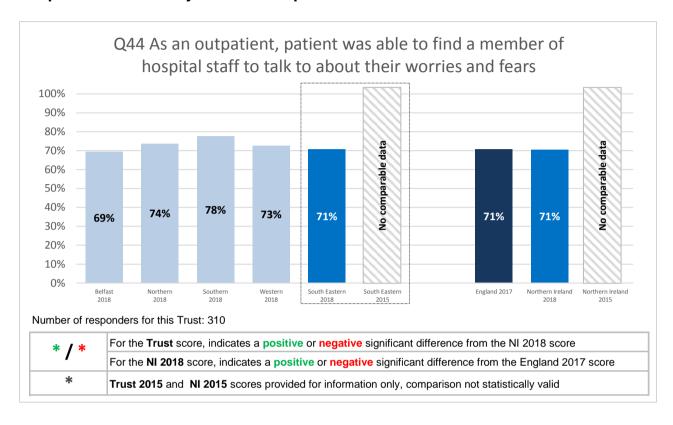


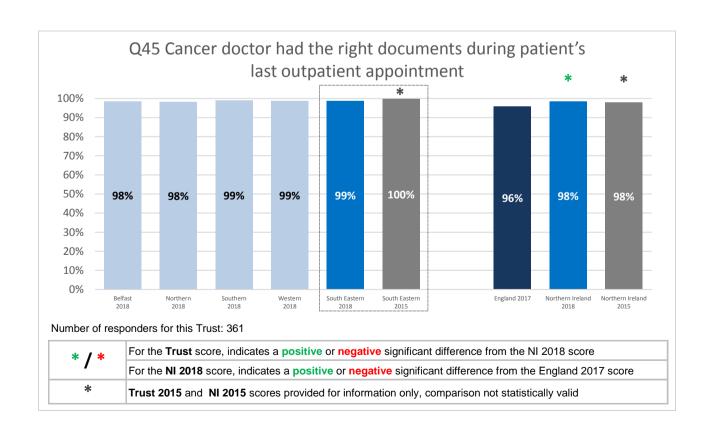






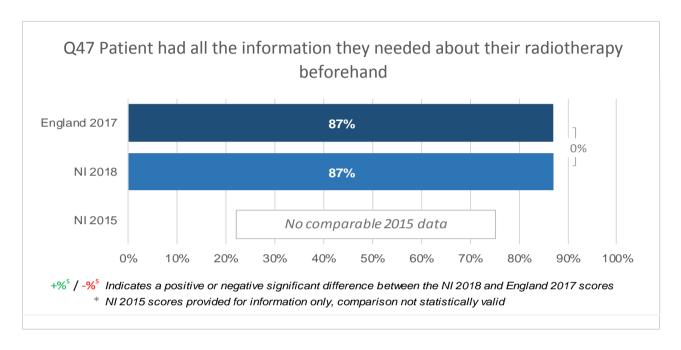
#### **Hospital Care As A Day Patient / Outpatient**

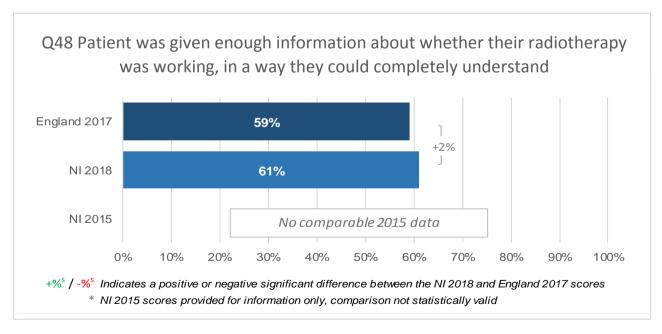




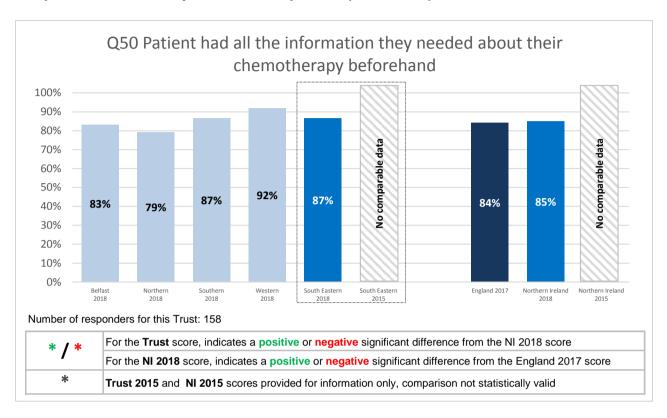
#### **Hospital Care As A Day Patient / Outpatient (continued)**

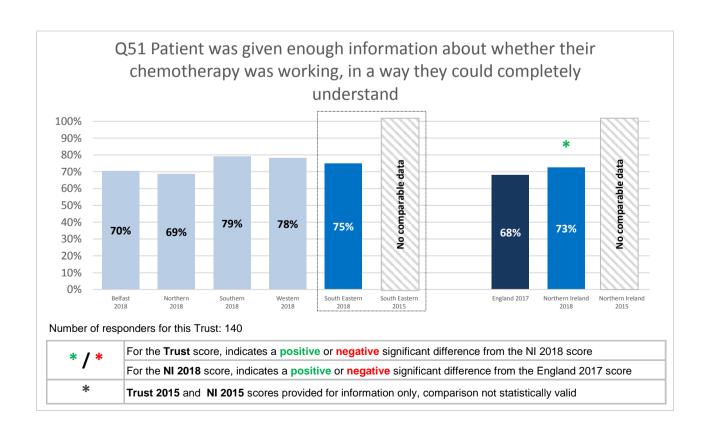
Northern Ireland's two radiotherapy centres are located in the Belfast Trust and the Western Trust. The following two charts present combined regional data on all responses across Northern Ireland.



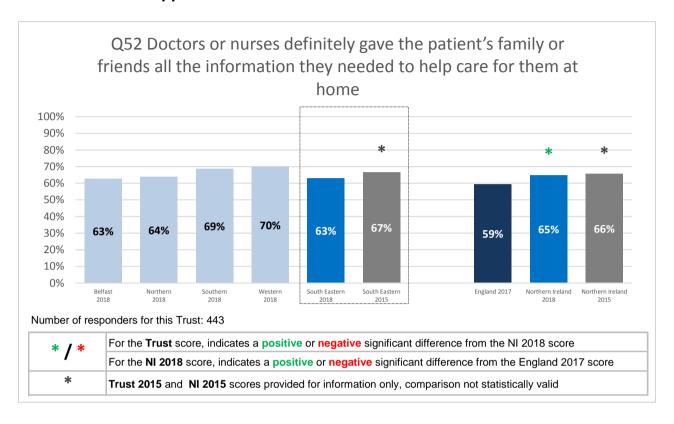


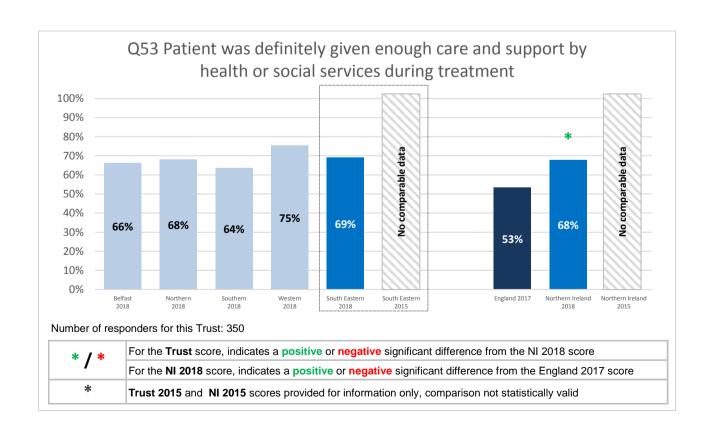
#### **Hospital Care As A Day Patient / Outpatient (continued)**



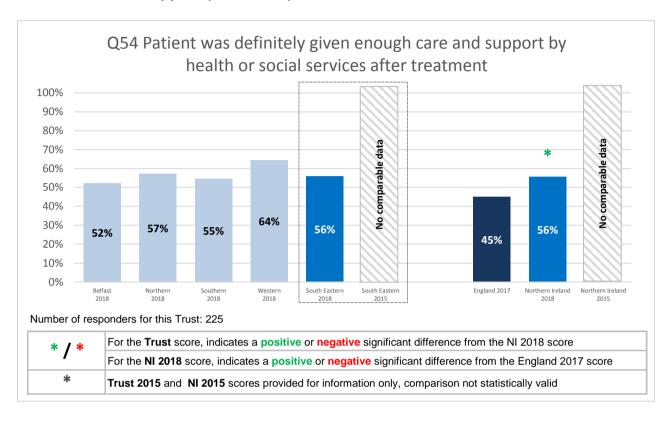


#### **Home Care And Support**

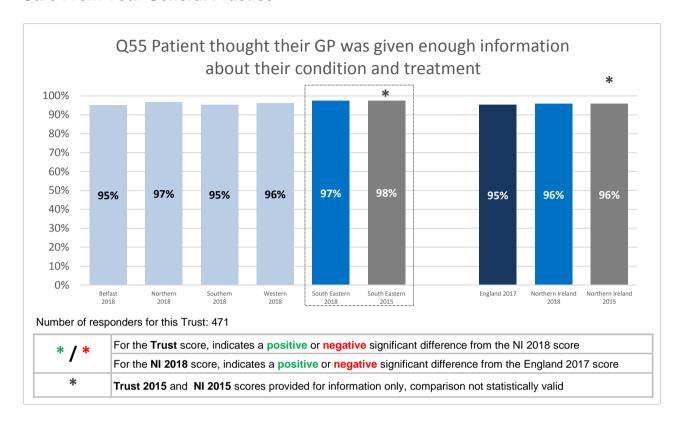


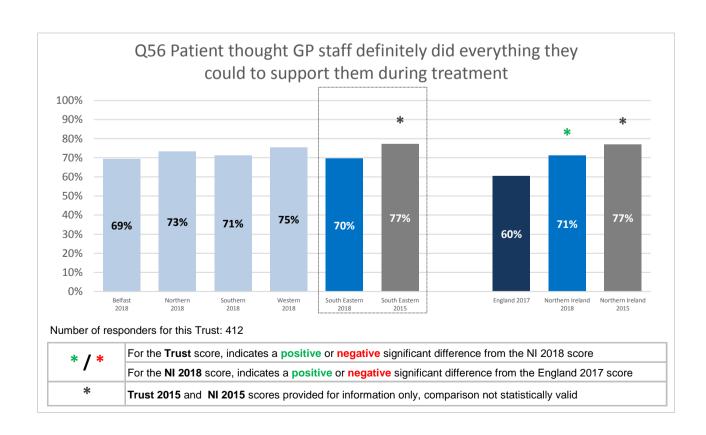


#### **Home Care And Support (continued)**

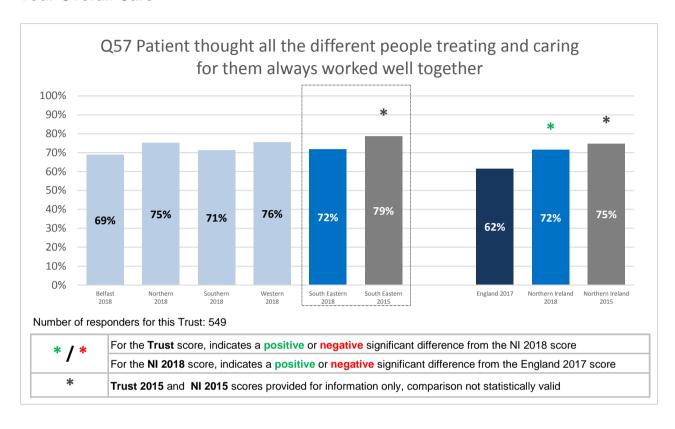


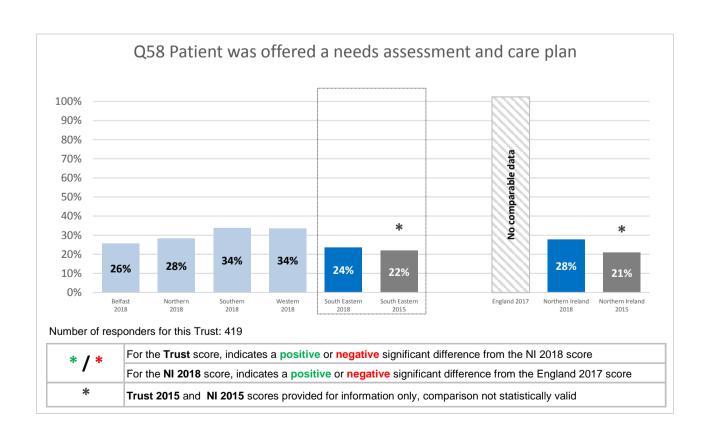
#### **Care From Your General Practice**



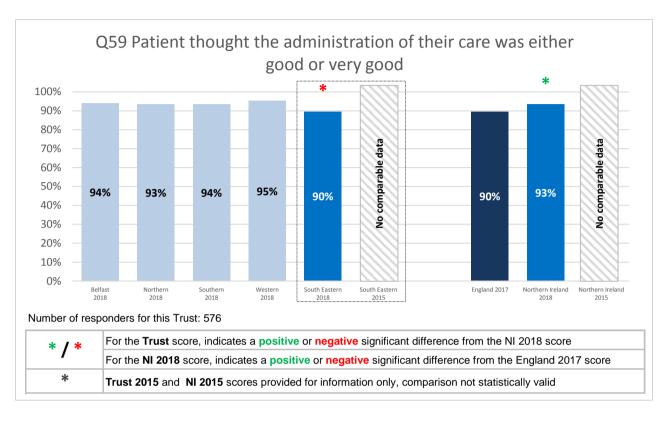


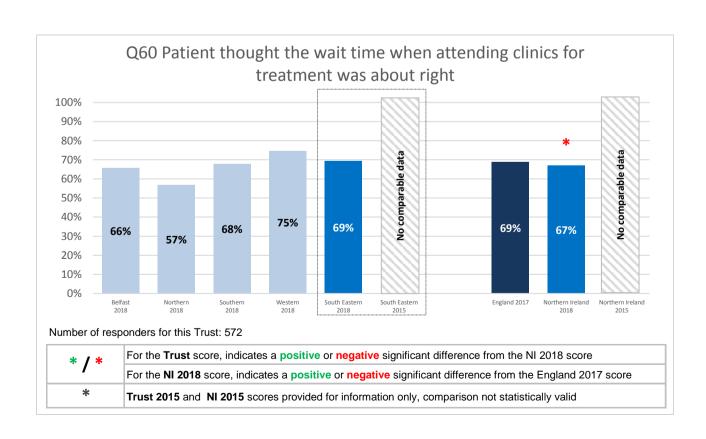
#### **Your Overall Care**



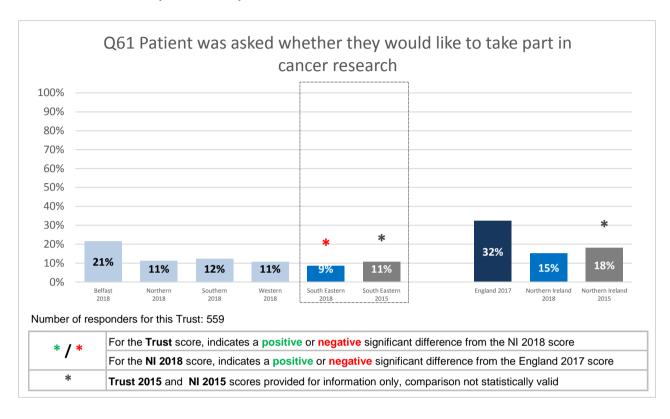


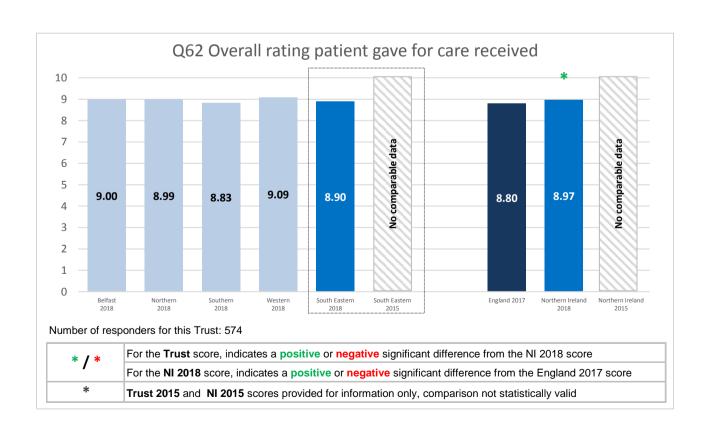
#### Your Overall Care (continued)





#### **Your Overall Care (continued)**





#### **Response Rates**

	Sample Size	Excluded	Adjusted Sample	Not Returned	Blank / Refused	Completed	Response Rate
Northern Ireland	6256	126	6130	2383	242	3478	56.7%
South Eastern	1043	15	1028	367	56	598	58.2%

#### Respondents by cancer type

Cancer Type	Number of respondents*		
Brain / CNS	0		
Breast	121		
Colorectal / Lower Gastro	97		
Gynaecological	16		
Haematological	77		
Head and Neck	17		
Lung	26		
Prostate	68		
Sarcoma	8		
Skin	32		
Upper Gastro	5		
Urological (exc. Prostate)	59		
Other Cancers	72		

<sup>\*</sup> These figures may not match the numerator for all questions in the 'Comparisons by cancer type' section of this report because not all questions were answered by all responders.

### Age and sex

The Trust provided the age information as part of the Sample data. This information has been amalgamated into 6 age bands. The age and gender distribution of respondents for the South Eastern Trust was as follows:

	16-25	26-35	36-50	51-65	66-75	76+	Total
Men	0	2	13	74	110	83	282
Women	1	8	45	105	90	67	316
Total	1	10	58	179	200	150	598

# **Comparisons by cancer type for this Trust**

The following tables show the Trust (in 2015 & 2018) and the all Northern Ireland percentage scores for each question broken down by cancer type. Where a cell in the table has an asterisk (\*) this indicates that the number of patients in that group was below 20 and too small to display. Where a cell in the table has a dash (-) this indicates that there is no comparability for this question. Where a cell in the table has an 'na' this indicates there was no response for that question within the cancer type.

### **BEFORE YOUR DIAGNOSIS**

	twice be	ient saw Gl efore being d to go to t	told told	Q2. Patient thought they were seen as soon as necessary for their first appointment			
		Q1		Q2			
Cancer type	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	
Brain / CNS	na	na	*	*	na	78%	
Breast	93%	100%	97%	86%	93%	90%	
Colorectal / Lower Gastro	68%	72%	72%	85%	84%	81%	
Gynaecological	*	*	81%	*	*	83%	
Haematological	73%	60%	63%	86%	82%	85%	
Head and Neck	*	*	76%	91%	*	81%	
Lung	*	60%	63%	92%	75%	85%	
Prostate	75%	70%	71%	80%	84%	84%	
Sarcoma	*	*	*	*	*	*	
Skin	92%	87%	88%	88%	81%	74%	
Upper Gastro	*	*	72%	*	*	81%	
Urological (exc. Prostate)	70%	80%	78%	86%	77%	85%	
Other Cancers	90%	73%	67%	73%	77%	80%	
All Cancers	78% 78% 75%			85%	83%	84%	

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

### Northern Ireland Cancer Patient Experience Survey 2018 South Eastern Health and Social Care

## **Diagnostic Tests**

	Q6. Patient had all the information needed about their test beforehand			of time	ient though for test to out right	•	Q8. Results of test were explained in a way the patient completely understood		
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	-	na	*	-	na	90%	*	na	73%
Breast	ı	97%	92%	ı	90%	91%	85%	88%	84%
Colorectal / Lower Gastro	ı	98%	93%	ı	93%	87%	85%	93%	84%
Gynaecological	-	*	95%	-	*	82%	*	*	83%
Haematological	-	97%	95%	-	89%	91%	85%	83%	82%
Head and Neck	ı	*	94%	ı	*	87%	*	*	83%
Lung	-	*	89%	-	*	88%	83%	*	85%
Prostate	-	94%	97%	-	77%	83%	84%	86%	84%
Sarcoma	1	*	*	ı	*	*	*	*	*
Skin	-	*	95%	-	*	78%	*	*	71%
Upper Gastro	-	*	95%	-	*	88%	*	*	76%
Urological (exc. Prostate)	-	90%	92%	-	84%	89%	82%	77%	79%
Other Cancers	-	95%	96%	-	85%	85%	*	85%	82%
All Cancers	-	95%	94%	-	87%	88%	85%	86%	82%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Finding Out What Was Wrong With You**

	Q9. Patient had been told they could bring a family member or friend when they were first told about cancer			were to	tient thoug Id they had sitive man	d cancer	Q11. Patient completely understood the explanation of what was wrong with them		
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	na	na	82%	*	na	86%	*	na	75%
Breast	89%	82%	84%	89%	92%	91%	82%	78%	76%
Colorectal / Lower Gastro	76%	80%	79%	87%	91%	86%	83%	81%	77%
Gynaecological	*	*	71%	*	*	87%	*	*	74%
Haematological	79%	82%	74%	94%	90%	88%	58%	58%	59%
Head and Neck	75%	*	66%	100%	*	83%	77%	*	69%
Lung	82%	68%	82%	79%	65%	83%	71%	65%	76%
Prostate	87%	83%	79%	94%	88%	86%	80%	82%	79%
Sarcoma	*	*	*	*	*	*	*	*	*
Skin	*	68%	61%	96%	94%	85%	76%	90%	85%
Upper Gastro	*	*	73%	*	*	83%	*	*	72%
Urological (exc. Prostate)	60%	62%	75%	86%	91%	85%	79%	84%	77%
Other Cancers	64%	67%	72%	88%	88%	82%	74%	77%	68%
All Cancers	79%	76%	76%	90%	89%	86%	76%	77%	72%

	Q12. Patient was given easy to understand written information about the type of cancer they had when they were first told they had cancer					
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.			
Brain / CNS	*	na	64%			
Breast	67%	71%	78%			
Colorectal / Lower Gastro	68%	73%	59%			
Gynaecological	*	*	80%			
Haematological	75%	75%	74%			
Head and Neck	*	*	62%			
Lung	*	50%	63%			
Prostate	67%	79%	74%			
Sarcoma	*	*	*			
Skin	55%	73%	62%			
Upper Gastro	*	*	64%			
Urological (exc. Prostate)	40%	55%	61%			
Other Cancers	*	56%	58%			
All Cancers	64% 70% 69					

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Deciding The Best Treatment For You**

	Q13. Treatment options were completely explained to patient before treatment started			treatme explaine	le effects o ent were de ed in a way could unde	efinitely the	Q15. Patient was given easy to understand written information regarding side effects			
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	
Brain / CNS	ı	na	93%	*	na	66%	*	na	70%	
Breast	-	90%	87%	77%	71%	68%	80%	77%	81%	
Colorectal / Lower Gastro	ı	85%	87%	80%	72%	74%	72%	73%	74%	
Gynaecological	-	*	91%	*	*	80%	*	*	81%	
Haematological	-	85%	84%	80%	71%	71%	74%	76%	77%	
Head and Neck	ı	*	87%	75%	*	70%	*	*	68%	
Lung	-	71%	85%	76%	56%	75%	*	71%	76%	
Prostate	ı	88%	90%	78%	69%	78%	71%	77%	81%	
Sarcoma	-	*	*	*	*	*	*	*	*	
Skin	-	90%	85%	*	*	70%	*	70%	74%	
Upper Gastro	-	*	87%	*	*	76%	*	*	80%	
Urological (exc. Prostate)	-	82%	86%	75%	59%	70%	58%	59%	71%	
Other Cancers	-	87%	84%	71%	82%	74%	65%	77%	80%	
All Cancers	-	86%	86%	77%	71%	72%	72%	73%	77%	

	told abo	tient was o out future s before trea	ide	Q17. Patient was definit involved as much as the wanted to be in decision about their care			
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	
Brain / CNS	*	na	58%	*	na	76%	
Breast	55%	47%	54%	78%	79%	79%	
Colorectal / Lower Gastro	58%	44%	52%	79%	77%	78%	
Gynaecological	*	*	54%	*	*	84%	
Haematological	61%	51%	49%	81%	78%	80%	
Head and Neck	*	*	54%	70%	*	78%	
Lung	*	38%	55%	70%	73%	80%	
Prostate	60%	69%	68%	85%	81%	84%	
Sarcoma	*	*	*	*	*	*	
Skin	*	*	50%	81%	93%	80%	
Upper Gastro	*	*	51%	*	*	78%	
Urological (exc. Prostate)	43%	39%	51%	68%	76%	78%	
Other Cancers	*	63%	55%	64%	81%	78%	
All Cancers	56%	51%	54%	77%	80%	80%	

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

### Northern Ireland Cancer Patient Experience Survey 2018 South Eastern Health and Social Care

# **Clinical Nurse Specialist**

	Q18. Patient was given the name of a Clinical Nurse Specialist who would support them through treatment			easy or	tient found quite easy their Clinic st	to	Q20. Patient was able to get answers they could understand from their Clinical Nurse Specialist all or most of the time		
Cancer type	This Trust 2015 \$ 2018 N.I.			This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	*	na	79%	-	na	81%	*	na	81%
Breast	93%	94%	96%	ı	85%	88%	90%	88%	89%
Colorectal / Lower Gastro	71%	81%	76%	ı	89%	92%	95%	85%	89%
Gynaecological	*	*	95%	ı	*	91%	*	*	90%
Haematological	85%	90%	81%	ı	92%	95%	89%	87%	93%
Head and Neck	90%	*	82%	ı	*	88%	*	*	86%
Lung	*	100%	84%	ı	*	87%	*	*	89%
Prostate	67%	80%	83%	-	84%	91%	97%	91%	93%
Sarcoma	*	*	*	ı	*	*	*	*	*
Skin	50%	73%	74%	-	*	94%	*	*	84%
Upper Gastro	*	*	83%	-	*	94%	*	*	91%
Urological (exc. Prostate)	42%	54%	66%	-	83%	89%	*	95%	93%
Other Cancers	57%	69%	73%	-	86%	89%	*	90%	88%
All Cancers	75%	81%	82%	-	87%	91%	91%	88%	90%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Support For People With Cancer**

	Q21. Patient was given information by hospital staff about support or self-help groups			patient the imp	aff discusse informatio act cancer their worl	n about could	Q23. Hospital staff gave patient information about financial help and benefits available		
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	*	na	78%	na	na	*	*	na	*
Breast	92%	83%	91%	78%	74%	80%	69%	69%	77%
Colorectal / Lower Gastro	94%	85%	84%	73%	69%	72%	75%	60%	63%
Gynaecological	*	*	91%	*	*	84%	*	*	73%
Haematological	85%	91%	87%	85%	94%	86%	84%	88%	77%
Head and Neck	*	*	83%	*	*	69%	*	*	66%
Lung	90%	86%	84%	*	*	70%	*	70%	69%
Prostate	83%	90%	89%	76%	86%	89%	55%	35%	66%
Sarcoma	*	*	*	*	*	*	*	*	*
Skin	*	*	81%	*	*	61%	*	*	40%
Upper Gastro	*	*	86%	*	*	78%	*	*	68%
Urological (exc. Prostate)	65%	46%	69%	*	*	72%	*	*	44%
Other Cancers	*	80%	83%	*	75%	75%	*	53%	60%
All Cancers	87%	84%	85%	77%	75%	79%	70%	63%	68%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

### Northern Ireland Cancer Patient Experience Survey 2018 South Eastern Health and Social Care

## **Operations**

	informa	tient had a tion they r neir operat and	needed	complet outcom to the p	Q27. A member of staff completely explained outcome of the operation to the patient in a way they could understand			
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.		
Brain / CNS	-	na	95%	*	na	*		
Breast	-	97%	96%	80%	91%	83%		
Colorectal / Lower Gastro	-	93%	91%	81%	87%	82%		
Gynaecological	-	*	98%	*	*	81%		
Haematological	-	*	95%	*	*	80%		
Head and Neck	-	*	97%	90%	*	86%		
Lung	-	*	90%	*	*	76%		
Prostate	-	*	95%	*	*	81%		
Sarcoma	-	*	*	*	*	*		
Skin	-	*	86%	85%	*	83%		
Upper Gastro	-	*	95%	*	*	79%		
Urological (exc. Prostate)	-	93%	91%	76%	74%	80%		
Other Cancers	-	97%	94%	*	87%	81%		
All Cancers	-	95%	94%	83%	86%	82%		

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Hospital Care As An Inpatient**

	Q30. Patient thought no doctors or nurses talked in front of them as if they weren't there			confide	tient had nce and tru octors trea		Q32. Family or friends of the patient were definitely able to talk to a doctor if they wanted to		
Cancer type	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.
Brain / CNS	-	na	71%	*	na	95%	*	na	67%
Breast	-	87%	86%	88%	80%	85%	67%	74%	73%
Colorectal / Lower Gastro	-	76%	73%	92%	90%	88%	72%	78%	76%
Gynaecological	-	*	93%	*	*	89%	*	*	74%
Haematological	-	*	87%	88%	*	91%	83%	*	83%
Head and Neck	-	*	78%	*	*	82%	*	*	78%
Lung	-	*	65%	*	*	79%	*	*	75%
Prostate	-	*	83%	*	*	83%	*	*	79%
Sarcoma	-	*	*	*	*	*	*	*	*
Skin	-	*	*	*	*	*	*	*	*
Upper Gastro	-	*	63%	*	*	90%	*	*	83%
Urological (exc. Prostate)	-	83%	81%	88%	100%	92%	*	*	72%
Other Cancers	-	78%	83%	*	78%	80%	*	73%	71%
All Cancers	-	82%	81%	89%	89%	87%	71%	80%	76%

	Q33. Patient had confidence and trust in all of the nurses treating them			were al	tient thoug ways or ne enough nu care for the	arly rses on	Q35. Patient was asked which name they prefer to be called by all doctors and nurses		
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	*	na	86%	*	na	67%	*	na	70%
Breast	80%	70%	79%	55%	68%	66%	58%	51%	64%
Colorectal / Lower Gastro	77%	85%	83%	75%	73%	67%	58%	78%	72%
Gynaecological	*	*	82%	*	*	68%	*	*	68%
Haematological	91%	*	84%	59%	*	66%	83%	*	69%
Head and Neck	*	*	72%	*	*	60%	*	*	62%
Lung	*	*	84%	*	*	69%	*	*	69%
Prostate	*	*	89%	*	*	78%	*	*	80%
Sarcoma	*	*	*	*	*	*	*	*	*
Skin	*	*	*	*	*	*	*	*	*
Upper Gastro	*	*	86%	*	*	65%	*	*	72%
Urological (exc. Prostate)	88%	83%	85%	70%	74%	72%	76%	71%	74%
Other Cancers	*	78%	73%	*	61%	59%	*	65%	66%
All Cancers	83%	80%	81%	63%	71%	67%	61%	67%	69%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Hospital Care As An Inpatient (continued)**

	Q36. Patient was always given enough privacy when discussing their condition or treatment			patient to find a hospita	an inpatie was definit a member o I staff to ta heir worrie	ely able of lk to	Q38. Patient thought staff definitely did all they could to help control their pain			
Cancer type	This Trust 2015 \$ 2018 N.I.			This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	
Brain / CNS	*	na	*	*	na	*	*	na	85%	
Breast	83%	91%	82%	66%	51%	53%	92%	89%	89%	
Colorectal / Lower Gastro	79%	95%	85%	75%	56%	52%	90%	90%	89%	
Gynaecological	*	*	82%	*	*	54%	*	*	88%	
Haematological	100%	*	90%	86%	*	63%	92%	*	89%	
Head and Neck	*	*	79%	*	*	45%	*	*	89%	
Lung	*	*	85%	*	*	49%	*	*	83%	
Prostate	*	*	94%	*	*	76%	*	*	84%	
Sarcoma	*	*	*	*	*	*	*	*	*	
Skin	*	*	*	*	*	*	*	*	*	
Upper Gastro	*	*	86%	*	*	54%	*	*	97%	
Urological (exc. Prostate)	82%	100%	88%	77%	*	48%	85%	85%	75%	
Other Cancers	*	100%	81%	*	*	48%	*	*	84%	
All Cancers	84%	96%	85%	73%	56%	53%	89%	90%	87%	

	Q39. Patient thought they were always treated with respect and dignity while in hospital			clear wi about w	tient was g ritten infor rhat they s not do afte	mation hould or	Q41. Patient was told who to contact if they were worried about their condition or treatment after leaving hospital		
Cancer type	This Trust 2015 \$	This Trust 2015 \$ 2018 N.I.			This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	*	na	90%	*	na	*	*	na	95%
Breast	88%	88%	91%	84%	84%	91%	97%	96%	96%
Colorectal / Lower Gastro	91%	90%	92%	78%	80%	81%	92%	97%	93%
Gynaecological	*	*	90%	*	*	90%	*	*	95%
Haematological	100%	*	95%	85%	*	83%	100%	*	98%
Head and Neck	*	*	93%	*	*	82%	*	*	95%
Lung	*	*	93%	*	*	83%	*	*	89%
Prostate	*	*	94%	*	*	79%	*	*	92%
Sarcoma	*	*	*	*	*	*	*	*	*
Skin	*	*	*	*	*	*	*	*	*
Upper Gastro	*	*	91%	*	*	80%	*	*	97%
Urological (exc. Prostate)	94% 92% 89%			73%	63%	81%	87%	86%	85%
Other Cancers	*	96%	89%	*	86%	77%	*	*	93%
All Cancers	90%	92%	91%	81%	82%	84%	94%	95%	94%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

# **Hospital Care As A Day Patient / Outpatient**

	patient membe	an outpati was able to r of hospita about their	o find a al staff to	right do	ncer docto cuments d 's last outp ment	uring	informa	tient had a ntion they r heir radioth nand	eeded
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	ı	na	*	na	na	91%	-	na	*
Breast	ı	73%	70%	100%	97%	98%	-	92%	86%
Colorectal / Lower Gastro	ı	65%	64%	99%	100%	99%	-	*	81%
Gynaecological	ı	*	72%	*	*	99%	-	*	85%
Haematological	-	75%	78%	100%	97%	99%	-	*	89%
Head and Neck	1	*	68%	*	*	99%	-	*	79%
Lung	-	*	66%	100%	*	99%	-	*	85%
Prostate	-	79%	77%	100%	100%	98%	-	92%	94%
Sarcoma	1	*	*	*	*	*	-	*	*
Skin	-	*	62%	100%	*	96%	-	na	*
Upper Gastro	-	*	65%	*	*	98%	-	na	*
Urological (exc. Prostate)	-	54%	68%	100%	100%	100%	-	*	90%
Other Cancers	-	72%	71%	*	98%	98%	-	*	89%
All Cancers	-	71%	71%	100%	99%	98%	-	91%	87%

	enough whethe was wo	tient was g information r their radion rking, in a w ompletely and	on about otherapy	informa	tient had a tion they r neir chemo and	eeded	enough whethe chemot working	herapy wa g, in a way ompletely	on about
Cancer type	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.
Brain / CNS	-	na	*	ı	na	90%	-	na	*
Breast	-	50%	55%	ı	82%	82%	-	71%	62%
Colorectal / Lower Gastro	-	*	52%	-	94%	82%	-	79%	69%
Gynaecological	-	*	54%	-	na	91%	-	na	70%
Haematological	-	*	73%	-	83%	88%	-	77%	82%
Head and Neck	-	*	56%	ı	na	*	-	na	*
Lung	-	*	64%	ı	*	85%	-	*	79%
Prostate	-	71%	69%	ı	*	89%	-	*	74%
Sarcoma	-	*	*	1	*	*	-	*	*
Skin	-	na	*	-	na	*	-	na	*
Upper Gastro	-	na	*	-	*	85%	-	*	68%
Urological (exc. Prostate)	-	*	82%	-	*	78%	-	*	73%
Other Cancers	-	*	72%	-	95%	87%	-	*	73%
All Cancers	-	59%	61%	-	87%	85%	-	75%	73%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

### Northern Ireland Cancer Patient Experience Survey 2018 South Eastern Health and Social Care

# **Home Care And Support**

	definite family o informa	octors or no ly gave the or friends a tion they r e for them	e patient's Il the needed to	given er support	tient was c nough care by health during tre	and or social	given ei support	tient was o nough care by health after trea	and or social
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.
Brain / CNS	*	na	41%	-	na	*	-	na	*
Breast	63%	58%	61%	ı	67%	-	41%	50%	
Colorectal / Lower Gastro	62%	65%	65%	1	74%	-	54%	61%	
Gynaecological	*	*	66%	ı	*	-	*	58%	
Haematological	86%	81%	73%	-	73%	73%	-	75%	64%
Head and Neck	*	*	62%	ı	*	50%	-	*	39%
Lung	*	59%	69%	-	*	63%	-	*	54%
Prostate	*	68%	68%	-	61%	55%	-	*	56%
Sarcoma	*	*	*	-	*	*	-	*	*
Skin	*	*	52%	-	*	61%	-	*	*
Upper Gastro	*	*	66%	-	*	_	*	62%	
Urological (exc. Prostate)	63%	42%	62%	-	55%	58%	-	*	48%
Other Cancers	*	58%	59%	-	76%	73%	-	*	59%
All Cancers	67%	63%	65%	-	69%	68%	-	56%	56%

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Care From Your General Practice**

	GP was informa	tient thoug given enou tion about on and trea	igh their	staff de everyth	tient thoug finitely did ing they co them duri ent	uld to			
Cancer type	This Trust 2015 \$	This Trust 2018	This Trust 2015 \$	This Trust 2018	N.I.				
Brain / CNS	na	na	96%	na	na	62%			
Breast	97%	99%	97%	78%	67%	72%			
Colorectal / Lower Gastro	99%	96%	97%	80%	73%	70%			
Gynaecological	*	*	97%	*	*	70%			
Haematological	100%	98%	96%	82%	71%	73%			
Head and Neck	*	*	91%	*	*	68%			
Lung	90%	100%	96%	*	65%	72%			
Prostate	96%	96%	96%	78%	72%	77%			
Sarcoma	*	*	*	*	*	*			
Skin	100%	100%	98%	*	71%	70%			
Upper Gastro	*	*	98%	*	*	63%			
Urological (exc. Prostate)	98% 96% 94% 80% 56%								
Other Cancers	95% 95% 95% * 70% 7								
All Cancers	98%	95% 95% 95% 70% 7							

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid

## **Your Overall Care**

	differen	tient thou t people tr ng for the well toget	reating m always		tient was c ssessment		adminis	tient thoug tration of t ner good o	heir care		
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.		
Brain / CNS	*	na	55%	na	na	-	na	90%			
Breast	72%	67%	69%	26%	25%	-	94%	94%			
Colorectal / Lower Gastro	88%	70%	70%	17%	21%	-	84%	92%			
Gynaecological	*	*	71%	*	*	-	*	95%			
Haematological	87%	78%	77%	40%	37%	-	99%	98%			
Head and Neck	67%	*	63%	*	*	23%	-	*	95%		
Lung	73%	57%	70%	25%	*	24%	-	77%	88%		
Prostate	83%	79%	78%	19%	15%	22%	-	91%	95%		
Sarcoma	*	*	*	*	*	*	-	*	*		
Skin	96%	88%	80%	5%	29%	29%	-	91%	86%		
Upper Gastro	*	*	67%	*	*	-	*	93%			
Urological (exc. Prostate)	69%	66%	71%	9%	6%	-	80%	91%			
Other Cancers	83%	69%	69%	17%	29%	29%	-	88%	92%		
All Cancers	79%	72%	72%	22%	24%	28%	6 - 90% 939				

	wait tim	tient thoug ne when at or treatme ght	tending	whethe	tient was a r they wou rt in cancer	ld like to	-	verall rating r care recei	•
Cancer type	This Trust 2015 \$	This Trust 2018	N.I.	This Trust 2015 <sup>\$</sup>	This Trust 2018	N.I.	This Trust 2015 \$	This Trust 2018	N.I.
Brain / CNS	-	na	32%	*	na	4%	-	na	8.26
Breast	-	65%	65%	13%	13%	16%	1	8.83	9.05
Colorectal / Lower Gastro	-	73%	71%	14%	5%	10%	-	8.82	8.92
Gynaecological	-	*	65%	*	*	14%	-	*	9.04
Haematological	-	61%	60%	17%	18%	19%	-	9.29	9.17
Head and Neck	-	*	82%	14%	*	11%	ı	*	8.92
Lung	-	52%	64%	5%	12%	13%	-	8.25	8.84
Prostate	-	75%	80%	14%	11%	31%	-	9.12	9.14
Sarcoma	-	*	*	*	*	*	ı	*	*
Skin	-	80%	77%		3%	8%	-	9.09	8.85
Upper Gastro	-	*	62%					*	8.80
Urological (exc. Prostate)	-	82%	77%					8.55	8.80
Other Cancers	-	64%	56%	4%	8%	13%	-	8.68	8.78
All Cancers	-	69%	67%	11%	9%	15%	-	8.90	8.97

<sup>\$</sup> Trust 2015 cancer type scores provided for information only, comparison not statistically valid



# **2018 Northern Ireland CPES**

Northern Ireland Cancer Patient Experience Survey
Detailed Results Tables - all Trusts combined

**Produced by Quality Health** 

#### **BEFORE YOUR DIAGNOSIS**

1. Before you were told you needed to go to hospital about cancer, how many times did you see your	Belf	ast	North	nern	South	nern	South E	astern	West	ern	NI C	PES
GP (family doctor) about the health problem caused by cancer?	#	%	#	%	#	%	#	%	#	%	#	%
None - I went straight to hospital	158	11%	36	9%	41	9%	47	8%	33	7%	315	10%
None - I went to hospital following a cancer screening appointment	134	10%	69	17%	55	12%	47	8%	57	12%	362	11%
* I saw my GP once	534	54%	177	63%	163	51%	257	58%	197	53%	1,328	55%
* I saw my GP twice	192	19%	40	14%	71	22%	89	20%	74	20%	466	19%
* I saw my GP 3 or 4 times	161	16%	43	15%	53	17%	66	15%	67	18%	390	16%
* I saw my GP 5 or more times	103	10%	19	7%	31	10%	33	7%	35	9%	221	9%
Don't know / can't remember	31	2%	7	2%	21	5%	12	2%	9	2%	80	2%
Other	68	5%	11	3%	13	3%	24	4%	22	4%	138	4%
Missing	74		22		25		23		34		178	

2. How do you feel about the length of time you had to wait before your first appointment with a	Belfast		North	nern	South	iern	South Eastern		Western		NI C	PES
hospital doctor?	#	%	#	%	#	%	#	%	#	%	#	%
I was seen as soon as I thought was necessary	1,166	83%	356	86%	379	82%	488	83%	461	89%	2,850	84%
I should have been seen a bit sooner	128	9%	41	10%	48	10%	51	9%	36	7%	304	9%
I should have been seen a lot sooner	115	8%	17	4%	34	7%	46	8%	21	4%	233	7%
Missing	46		10		12		13		10		91	

3. How long was it from the time you first thought something might be wrong with you until you first	Belf	ast	Nort	nern	South	ern	South E	astern	West	ern	NI CI	PES
saw a GP or other doctor?	#	%	#	%	#	%	#	%	#	%	#	%
Less than 3 months	1,062	76%	331	82%	334	74%	448	78%	380	76%	2,555	77%
3-6 months	165	12%	33	8%	51	11%	68	12%	53	11%	370	11%
6-12 months	54	4%	13	3%	22	5%	16	3%	19	4%	124	4%
More than 12 months	44	3%	10	2%	20	4%	16	3%	16	3%	106	3%
Don't know / can't remember	71	5%	18	4%	25	6%	26	5%	35	7%	175	5%
Missing	59		19		21		24		25		148	

#### **DIAGNOSTIC TESTS**

4. In the last 12 months, have you had a diagnostic test(s) for cancer such as an endoscopy, biopsy,	Belfast		North	nern	South	nern	South E	astern	West	ern	NI CP	PES
mammogram, or scan?	#	%	#	%	#	%	#	%	#	%	#	%
Yes	1,195	86%	328	81%	371	82%	477	82%	426	84%	2,797	84%
No	201	14%	79	19%	83	18%	102	18%	82	16%	547	16%
Missing	59		17		19		19		20		134	

5. Did the test(s) take place at the hospital named on the letter that came with this questionnaire?	Belfast		Nort	hern	South	ern	South E	astern	West	ern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	875	74%	226	72%	283	79%	316	71%	328	80%	2,028	75%
No, at another NHS hospital in Northern Ireland	247	21%	77	25%	66	18%	101	23%	73	18%	564	21%
No, at a private hospital / centre in Northern Ireland	31	3%	1	0%	3	1%	15	3%	3	1%	53	2%
No, somewhere outside Northern Ireland	6	1%	0	0%	0	0%	1	0%	3	1%	10	0%
Don't know / can't remember	17	1%	10	3%	8	2%	14	3%	4	1%	53	2%
Missing	279		110		113		151		117		770	

6. Beforehand, did you have all the information you needed about your test?	Belf	ast	Nort	hern	Sout	nern	South E	South Eastern		Western		PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	811	95%	195	89%	251	93%	290	95%	301	95%	2,593	93%
* No, I would have liked more information	42	5%	23	11%	19	7%	15	5%	15	5%	188	7%
Don't know / can't remember	19	2%	6	3%	9	3%	9	3%	10	3%	75	3%
Missing	583		200		194		284		202		622	

7. Overall, how did you feel about the length of time you had to wait for your test to be done?	Belf	ast	Nort	hern	South	nern	South E	astern	West	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* It was about right	760	90%	187	85%	245	90%	273	87%	283	89%	2,442	87%
* It was a little too long	72	9%	25	11%	21	8%	30	10%	30	9%	267	10%
* It was much too long	15	2%	7	3%	6	2%	11	4%	5	2%	86	3%
Don't know / can't remember	7	1%	4	2%	4	1%	0	0%	5	2%	26	1%
Missing	601		201		197		284		205		657	

### **DIAGNOSTIC TESTS (continued)**

8. Were the results of the test explained in a way you could understand?	Belf	ast	Nort	hern	South	hern	South E	astern	West	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	707	82%	186	83%	230	82%	266	86%	271	84%	2,316	82%
* Yes, to some extent	136	16%	32	14%	44	16%	39	13%	46	14%	458	16%
* No, I did not understand the explanation	7	1%	4	2%	3	1%	3	1%	3	1%	29	1%
* I did not have an explanation but would have liked one	12	1%	1	0%	2	1%	3	1%	1	0%	28	1%
I did not need an explanation	7	1%	2	1%	1	0%	1	0%	1	0%	16	1%
Don't know / can't remember	0	0%	0	0%	0	0%	2	1%	2	1%	8	0%
Missing	586		199		193		284		204		623	

#### 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	Belt	ast	North	nern	South	hern	South E	astern	Wes	tern	NI C	PES
or friend with you?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	1,033	76%	299	76%	331	74%	424	76%	406	81%	2,493	76%
* No	297	22%	90	23%	110	25%	124	22%	90	18%	711	22%
* I was told I had cancer by phone or letter	24	2%	7	2%	6	1%	10	2%	8	2%	55	2%
Don't know / can't remember	74	5%	22	5%	14	3%	32	5%	16	3%	158	5%
Missing	27		6		12		8		8		61	

10. How do you feel about the way you were told you had cancer?	Belf	ast	Nortl	nern	South	nern	South E	astern	West	ern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
It was done sensitively	1,201	84%	367	88%	412	89%	522	89%	431	84%	2,933	86%
It should have been done a bit more sensitively	151	11%	37	9%	35	8%	47	8%	58	11%	328	10%
It should have been done a lot more sensitively	70	5%	11	3%	17	4%	17	3%	24	5%	139	4%
Missing	33		9		9		12		15		78	

11. Did you understand the explanation of what was wrong with you?	Belf	ast	Nort	hern	South	hern	South E	astern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, I completely understood it	1,031	72%	303	73%	319	69%	457	77%	371	71%	2,481	72%
* Yes, I understood some of it	363	25%	102	25%	123	27%	126	21%	142	27%	856	25%
* No, I did not understand it	45	3%	8	2%	19	4%	10	2%	8	2%	90	3%
Don't know / can't remember	6	0%	4	1%	5	1%	2	0%	2	0%	19	1%
Missing	10		7		7		3		5		32	

12. When you were told you had cancer, were you given written information about the type of cancer	Belt	ast	Nort	hern	Souti	hern	South E	astern	West	tern	NI CI	PES
you had?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, and it was easy to understand	838	68%	257	70%	291	69%	339	70%	313	67%	2,038	69%
* Yes, but it was difficult to understand	115	9%	36	10%	41	10%	29	6%	43	9%	264	9%
* No, I was not given written information about the type of cancer I had	281	23%	74	20%	87	21%	119	24%	109	23%	670	23%
I did not need / want written information	127	9%	33	8%	24	5%	54	9%	25	5%	263	8%
Don't know / can't remember	68	5%	16	4%	18	4%	42	7%	25	5%	169	5%
Missing	26		8		12		15		13		74	

#### **DECIDING THE BEST TREATMENT FOR YOU**

13. Before your cancer treatment started, were your treatment options explained to you?	Ве	fast	Nort	hern	Souti	hern	South E	astern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	1,126	87%	309	86%	343	82%	428	86%	397	89%	2,603	86%
* Yes, to some extent	155	12%	46	13%	69	17%	58	12%	41	9%	369	12%
* No	15	1%	3	1%	4	1%	10	2%	9	2%	41	1%
There was only one type of treatment that was suitable for me	114	8%	51	12%	40	9%	76	13%	57	11%	338	10%
Don't know / can't remember	9	1%	2	0%	4	1%	5	1%	3	1%	23	1%
Missing	36		13		13		21		21		104	

14. Were the possible side effects of treatment(s) explained in a way you could understand?	Bel	fast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	989	72%	281	72%	305	71%	381	71%	370	77%	2,326	72%
* Yes, to some extent	331	24%	93	24%	104	24%	122	23%	98	20%	748	23%
* No, side effects were not explained	53	4%	18	5%	20	5%	32	6%	14	3%	137	4%
I did not need an explanation	35	2%	16	4%	17	4%	38	7%	17	3%	123	4%
Don't know / can't remember	15	1%	4	1%	8	2%	6	1%	7	1%	40	1%
Missing	32		12		19		19		22		104	

15. Before you started your treatment, were you given written information about the side effects of	Belf	ast	Nort	hern	South	nern	South E	astern	West	tern	NI C	PES
treatment(s)?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, and it was easy to understand	1,005	77%	310	81%	320	77%	374	73%	356	79%	2,365	77%
* Yes, but it was difficult to understand	110	8%	30	8%	39	9%	32	6%	29	6%	240	8%
* No, I was not given written information about side effects	183	14%	43	11%	56	13%	103	20%	64	14%	449	15%
Don't know / can't remember	100	7%	22	5%	24	5%	53	9%	40	8%	239	7%
Missing	57		19		34		36		39		185	

### **DECIDING THE BEST TREATMENT FOR YOU (continued)**

16. Before you started your treatment(s), were you also told about any side effects of the treatment	Belf	ast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
that could affect you in the future rather than straight away e.g. late effects?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	690	54%	181	51%	225	57%	233	51%	239	55%	1,568	54%
* Yes, to some extent	355	28%	107	30%	102	26%	120	26%	138	32%	822	28%
* No, future side effects were not explained	228	18%	68	19%	69	17%	102	22%	59	14%	526	18%
I did not need an explanation	61	4%	21	5%	22	5%	59	11%	25	5%	188	6%
Don't know / can't remember	65	5%	26	6%	25	6%	42	8%	31	6%	189	6%
Missing	56		21		30		42		36		185	

17. Were you involved as much as you wanted to be in decisions about your care and treatment?	Belt	fast	Nort	hern	Souti	nern	South E	astern	Wes	tern	NI C	CPES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	1,104	80%	319	79%	349	78%	452	80%	385	80%	2,609	80%
* Yes, to some extent	241	17%	70	17%	83	19%	88	16%	85	18%	567	17%
* No, but I would like to have been more involved	43	3%	13	3%	13	3%	22	4%	14	3%	105	3%
Don't know / can't remember	16	1%	3	1%	5	1%	6	1%	8	2%	38	1%
Missing	51		19		23		30		36		159	

#### **CLINICAL NURSE SPECIALIST**

18. Were you given the name of a Clinical Nurse Specialist who would support you through your	Belf	ast	Norti	hern	South	hern	South E	astern	West	tern	NI C	PES
treatment?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	1,069	81%	324	82%	346	80%	435	81%	423	89%	2,597	82%
* No	256	19%	70	18%	85	20%	99	19%	54	11%	564	18%
Don't know / can't remember	89	6%	19	5%	23	5%	42	7%	22	4%	195	6%
Missing	41		11		19		22		29		122	

19. How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	Bel	fast	Nort	hern	Souti	hern	South E	Eastern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Very easy	561	60%	202	70%	191	63%	225	62%	244	63%	1,423	63%
* Quite easy	282	30%	71	25%	88	29%	92	25%	103	27%	636	28%
* Neither easy nor difficult	<i>57</i>	6%	10	3%	18	6%	29	8%	23	6%	137	6%
* Quite difficult	22	2%	4	1%	4	1%	12	3%	12	3%	54	2%
* Very difficult	9	1%	2	1%	3	1%	6	2%	4	1%	24	1%
I have not tried to contact my Clinical Nurse Specialist	147	14%	38	12%	45	13%	70	16%	40	9%	340	13%
Missing	377		97		124		164		102		864	

20. When you have had important questions to ask your Clinical Nurse Specialist, how often have you	Belf	ast	Norti	hern	Soutl	nern	South E	astern	Wes	tern	NI C	PES
got answers you could understand?	#	%	#	%	#	%	#	%	#	%	#	%
* All or most of the time	818	90%	250	91%	262	91%	303	88%	329	91%	1,962	90%
* Some of the time	77	9%	26	9%	22	8%	32	9%	22	6%	179	8%
* Rarely or never	10	1%	0	0%	3	1%	9	3%	9	3%	31	1%
I have not asked any questions	159	15%	50	15%	57	17%	87	20%	59	14%	412	16%
Missing	391		98		129		167		109		894	

#### SUPPORT FOR PEOPLE WITH CANCER

21. Did hospital staff give you information about support or self-help groups for people with cancer?	Belf	ast	Norti	hern	South	hern	South E	astern	West	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	975	86%	310	88%	280	81%	354	84%	352	87%	2,271	85%
* No, but I would have liked information	159	14%	42	12%	64	19%	69	16%	53	13%	387	15%
It was not necessary	225	16%	49	12%	85	19%	116	20%	85	17%	560	17%
Don't know / can't remember	66	5%	14	3%	30	7%	32	6%	20	4%	162	5%
Missing	30		9		14		27		18		98	

22. Did hospital staff discuss with you or give you information about the impact cancer could have on	Belf	ast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
your work-life or education?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	588	79%	176	81%	191	79%	191	75%	225	81%	1,371	79%
* No, but I would have liked a discussion or information	160	21%	41	19%	51	21%	64	25%	54	19%	370	21%
It was not necessary / relevant to me	595	42%	179	43%	187	41%	292	51%	211	41%	1,464	44%
Don't know / can't remember	67	5%	18	4%	26	6%	25	4%	20	4%	156	5%
Missing	45		10		18		26		18		117	

23. Did hospital staff give you information about how to get financial help or any benefits you might be	Belf	fast	Nort	hern	South	nern	South E	astern	West	tern	NI C	PES
entitled to?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	566	63%	193	73%	206	66%	189	63%	322	82%	1,476	68%
* No, but I would have liked information	339	37%	72	27%	104	34%	111	37%	72	18%	698	32%
It was not necessary	450	32%	137	33%	123	27%	262	46%	102	20%	1,074	32%
Don't know / can't remember	61	4%	16	4%	24	5%	12	2%	12	2%	125	4%
Missing	39		6		16		24		20		105	

#### **OPERATIONS**

24. During the last 12 months, have you had an operation (such as removal of a tumour or lump)?	Belf	ast	North	iern	South	iern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	650	46%	199	48%	235	51%	295	51%	220	43%	1,599	47%
No	767	54%	218	52%	225	49%	280	49%	288	57%	1,778	53%
Missing	38		7		13		23		20		101	

25. Did the operation take place at the hospital named on the letter that came with this questionnaire?	Belf	ast	Norti	nern	South	ern	South E	astern	West	ern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	516	81%	126	69%	188	82%	224	81%	170	79%	1,224	79%
No, at another NHS hospital in Northern Ireland	101	16%	52	28%	37	16%	41	15%	36	17%	267	17%
No, at a private hospital / centre in Northern Ireland	12	2%	1	1%	2	1%	5	2%	0	0%	20	1%
No, somewhere outside Northern Ireland	5	1%	0	0%	1	0%	4	1%	4	2%	14	1%
Don't know / can't remember	6	1%	4	2%	1	0%	4	1%	4	2%	19	1%
Missing	815		241		244		320		314		1,934	

26. Beforehand, did you have all the information you needed about your operation?	Belf	ast	Nortl	hern	South	nern	South E	astern	West	tern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	481	94%	115	93%	174	95%	209	95%	158	94%	1,514	94%
* No, I would have liked more information	30	6%	9	7%	10	5%	11	5%	10	6%	101	6%
Don't know / can't remember	1	0%	0	0%	2	1%	2	1%	0	0%	13	1%
Missing	943		300		287		376		360		1,850	

27. After the operation, did a member of staff explain how it had gone in a way you could understand?	Belf	fast	Nort	hern	South	hern	South E	Eastern	West	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	410	81%	101	81%	153	83%	190	86%	136	82%	1,316	81%
* Yes, to some extent	83	16%	18	15%	25	14%	26	12%	25	15%	254	16%
* No, but I would have liked an explanation	13	3%	5	4%	6	3%	4	2%	4	2%	46	3%
I did not need an explanation	4	1%	0	0%	2	1%	3	1%	2	1%	16	1%
Missing	945		300		287		375		361		1,846	

#### **HOSPITAL CARE AS AN INPATIENT**

28. During the last 12 months, have you had an operation or stayed overnight for cancer care?	Belf	ast	North	ern	South	ern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	789	55%	230	56%	248	54%	276	48%	271	53%	1,814	54%
No	636	45%	184	44%	214	46%	298	52%	238	47%	1,570	46%
Missing	30		10		11		24		19		94	

29. Did the overnight stay take place at the hospital named on the letter that came with this	Belf	ast	North	nern	South	ern	South E	astern	West	ern	NI C	PES
questionnaire?	#	%	#	%	#	%	#	%	#	%	#	%
Yes	623	84%	153	72%	180	80%	205	82%	204	80%	1,365	81%
No, at another NHS hospital in Northern Ireland	93	13%	55	26%	43	19%	36	14%	40	16%	267	16%
No, at a private hospital / centre in Northern Ireland	11	1%	0	0%	1	0%	0	0%	0	0%	12	1%
No, somewhere outside Northern Ireland	5	1%	0	0%	1	0%	4	2%	5	2%	15	1%
Don't know / can't remember	8	1%	4	2%	0	0%	5	2%	5	2%	22	1%
Missing	715		212		248		348		274		1,797	

30. Did groups of doctors and nurses talk in front of you as if you weren't there?	Belf	ast	North	nern	South	nern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes, often	26	4%	8	5%	10	6%	12	6%	8	4%	86	5%
Yes, sometimes	89	14%	12	8%	35	20%	25	12%	21	10%	266	14%
No	505	81%	128	86%	134	75%	167	82%	173	86%	1,495	81%
Missing	835		276		294		394		326		1,631	

31. Did you have confidence and trust in the doctors treating you?	Belf	ast	Nort	hern	South	nern	South E	astern	West	ern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes, in all of them	546	88%	136	89%	153	85%	182	89%	180	88%	1,613	87%
Yes, in some of them	71	11%	17	11%	26	15%	23	11%	22	11%	236	13%
No, in none of them	2	0%	0	0%	0	0%	0	0%	2	1%	6	0%
Missing	836		271		294		393		324		1,623	

### **HOSPITAL CARE AS AN INPATIENT (continued)**

32. If your family or someone else close to you wanted to talk to a doctor, were they able to?	Belf	ast	Nort	hern	South	nern	South E	astern	West	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	407	76%	94	74%	115	74%	134	80%	143	83%	1,214	76%
* Yes, to some extent	112	21%	28	22%	38	25%	27	16%	25	15%	322	20%
* No	19	4%	5	4%	2	1%	6	4%	4	2%	54	3%
No family or friends were involved	32	5%	3	2%	8	4%	16	8%	7	3%	86	5%
My family did not want to talk to a doctor	28	5%	14	9%	9	5%	16	8%	18	9%	111	6%
I did not want my family or friends to talk to a doctor	22	4%	8	5%	8	4%	5	2%	5	2%	69	4%
Missing	835		272		293		394		326		1,622	

33. Did you have confidence and trust in the ward nurses treating you?	Belf	ast	North	nern	South	iern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes, in all of them	502	81%	131	86%	138	77%	163	80%	177	87%	1,513	81%
Yes, in some of them	118	19%	20	13%	40	22%	39	19%	24	12%	333	18%
No, in none of them	2	0%	1	1%	2	1%	3	1%	3	1%	15	1%
Missing	833		272		293		393		324		1,617	

34. In your opinion, were there enough nurses on duty to care for you in hospital?	Belf	ast	North	nern	South	nern	South E	astern	West	ern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
There were always or nearly always enough on duty	410	67%	102	69%	120	67%	144	71%	136	68%	1,234	67%
There were sometimes enough on duty	164	27%	34	23%	41	23%	48	24%	48	24%	463	25%
There were rarely or never enough on duty	42	7%	12	8%	17	10%	11	5%	16	8%	140	8%
Missing	839		276		295		395		328		1,641	

35. While you were in hospital did the doctors and nurses ask you what name you prefer to be called	Belf	ast	North	nern	South	hern	South E	astern	West	ern	NI C	PES
by?	#	%	#	%	#	%	#	%	#	%	#	%
Yes, all of them did	421	69%	103	69%	122	69%	137	67%	152	75%	1,253	68%
Only some of them did	122	20%	25	17%	46	26%	42	21%	25	12%	365	20%
None of them did	68	11%	22	15%	10	6%	24	12%	27	13%	215	12%
Missing	844		274		295		395		324		1,645	

### **HOSPITAL CARE AS AN INPATIENT (continued)**

36. Were you given enough privacy when discussing your condition or treatment?	Belfa	ast	North	nern	South	ern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes, always	515	83%	121	80%	148	83%	196	96%	175	87%	1,569	85%
Yes, sometimes	86	14%	27	18%	22	12%	6	3%	25	12%	232	13%
No	19	3%	3	2%	9	5%	3	1%	2	1%	53	3%
Missing	835		273		294		393		326		1,624	

37. During your hospital visit, did you find someone on the hospital staff to talk to about your worries	Belf	ast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
and fears?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	245	51%	73	61%	67	51%	85	56%	92	58%	<i>758</i>	53%
* Yes, to some extent	178	37%	30	25%	47	36%	43	28%	44	28%	465	33%
* No	54	11%	16	13%	17	13%	24	16%	23	14%	202	14%
I had no worries or fears	137	22%	30	20%	48	27%	53	26%	44	22%	417	23%
Missing	841		275		294		393		325		1,636	

38. Do you think the hospital staff did everything they could to help control your pain?	Belt	fast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	501	87%	126	89%	129	79%	168	90%	167	89%	1,465	86%
* Yes, to some extent	<i>57</i>	10%	13	9%	27	17%	16	9%	18	10%	191	11%
* No	15	3%	2	1%	7	4%	3	2%	3	2%	44	3%
I did not have any pain	47	8%	12	8%	17	9%	18	9%	16	8%	155	8%
Missing	835		271		293		393		324		1,623	

39. Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Belf	ast	North	hern	South	nern	South E	astern	West	tern	NI CF	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes, always	569	92%	138	91%	158	88%	187	92%	191	94%	1,687	91%
Yes, sometimes	45	7%	10	7%	19	11%	11	5%	8	4%	133	7%
No	5	1%	4	3%	3	2%	5	2%	5	2%	31	2%
Missing	836		272		293		395		324		1,627	

### **HOSPITAL CARE AS AN INPATIENT (continued)**

40. Were you given clear written information about what you should or should not do after leaving	Belf	ast	Norti	hern	South	nern	South E	astern	West	tern	NI C	PES
hospital?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	479	83%	120	85%	153	90%	158	82%	164	86%	1,467	84%
* No	98	17%	22	15%	17	10%	35	18%	26	14%	279	16%
Don't know / can't remember	39	6%	8	5%	8	4%	10	5%	13	6%	98	5%
Missing	839		274		295		395		325		1,634	

41. Did hospital staff tell you who to contact if you were worried about your condition or treatment	Belf	ast	Nort	hern	South	hern	South E	astern	West	tern	NI C	PES
after you left hospital?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	567	94%	134	93%	159	92%	181	95%	177	91%	1,657	93%
* No	36	6%	10	7%	13	8%	10	5%	18	9%	118	7%
Don't know / can't remember	15	2%	7	5%	6	3%	11	5%	7	3%	69	4%
Missing	837		273		295		396		326		1,634	

#### **HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT**

42. During the last 12 months, have you been treated as an outpatient or day case for cancer care?	Belf	ast	North	ern	South	ern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	1,253	88%	351	85%	400	87%	497	86%	448	88%	2,949	87%
No	171	12%	64	15%	60	13%	79	14%	61	12%	435	13%
Missing	31		9		13		22		19		94	

43. Was this at the hospital named on the letter that came with this questionnaire?	Bel	fast	Nort	hern	South	iern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	1,086	89%	237	72%	299	79%	374	79%	370	86%	2,366	83%
No, at another NHS hospital in Northern Ireland	115	9%	81	25%	72	19%	79	17%	55	13%	402	14%
No, at a private hospital / centre in Northern Ireland	5	0%	1	0%	0	0%	1	0%	0	0%	7	0%
No, somewhere outside Northern Ireland	2	0%	0	0%	0	0%	1	0%	0	0%	3	0%
Don't know / can't remember	16	1%	9	3%	9	2%	18	4%	7	2%	59	2%
Missing	231		96		93		125		96		641	

44. While you were being treated as an outpatient or day case, did you find someone on the hospital	Belf	ast	Norti	nern	South	nern	South E	astern	Wes	tern	NI C	PES
staff to talk to about your worries and fears?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	626	69%	146	74%	195	78%	219	71%	226	73%	1,741	71%
* Yes, to some extent	206	23%	31	16%	40	16%	63	20%	58	19%	514	21%
* No	71	8%	21	11%	16	6%	28	9%	27	9%	210	9%
I did not have any worries or fears	170	16%	36	15%	46	15%	58	16%	54	15%	477	16%
Missing	382		190		176		230		163		536	

45. The last time you had an outpatients appointment with a cancer doctor, did they have the right	Belf	ast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
documents, such as medical notes, x-rays and test results?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	1,042	98%	226	98%	282	99%	356	99%	349	99%	2,831	98%
* No	16	2%	4	2%	3	1%	5	1%	5	1%	44	2%
I didn't have an appointment with a cancer doctor	10	1%	3	1%	9	3%	10	3%	10	3%	56	2%
Don't know / can't remember	17	2%	3	1%	4	1%	3	1%	4	1%	50	2%
Missing	370		188		175		224		160		497	

### **HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT (continued)**

46. During the last 12 months, have you had radiotherapy?	Belf	ast	North	iern	South	ern	South E	astern	West	ern	NI CI	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	337	31%	77	33%	73	25%	106	28%	137	37%	940	32%
No	741	69%	158	67%	220	75%	266	72%	231	63%	2,031	68%
Missing	377		189		180		226		160		507	

47. Beforehand, did you have all of the information you needed about your radiotherapy treatment?	Belf	fast	Nort	hern	Soutl	nern	South E	astern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	295	88%	69	88%	65	86%	96	91%	121	88%	823	87%
* Yes, to some extent	38	11%	9	12%	11	14%	9	8%	13	9%	111	12%
* No	2	1%	0	0%	0	0%	1	1%	3	2%	10	1%
I did not need any information	2	1%	0	0%	1	1%	0	0%	0	0%	6	1%
Missing	1,118		346		396		492		391		2,528	

48. Once you started your treatment, were you given enough information about whether your	Belf	ast	Nort	hern	South	nern	South E	Eastern	West	tern	NI C	PES
radiotherapy was working in a way you could understand?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	169	59%	37	54%	43	60%	58	59%	93	71%	510	61%
* Yes, to some extent	73	26%	14	21%	17	24%	27	28%	25	19%	205	24%
* No	43	15%	17	25%	12	17%	13	13%	13	10%	126	15%
It is too early to know if my radiotherapy is working	33	10%	7	9%	2	3%	4	4%	4	3%	66	7%
I did not need any information	16	5%	3	4%	3	4%	3	3%	2	1%	36	4%
Missing	1,121		346		396		493		391		2,535	

49. During the last 12 months, have you had chemotherapy?	Bel	fast	North	nern	South	nern	South E	astern	West	tern	NI CF	PES
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	548	52%	127	55%	140	49%	156	43%	159	44%	1,365	47%
No	503	48%	105	45%	144	51%	208	57%	199	56%	1,536	53%
Missing	404		192		189		234		170		577	

### **HOSPITAL CARE AS A DAY PATIENT / OUTPATIENT (continued)**

50. Beforehand, did you have all of the information you needed about your chemotherapy treatment?	Belf	ast	Nortl	hern	South	hern	South E	Eastern	Wes	tern	NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	458	83%	99	79%	124	87%	137	87%	146	92%	1,164	85%
* Yes, to some extent	87	16%	23	18%	19	13%	20	13%	12	8%	197	14%
* No	6	1%	3	2%	0	0%	1	1%	1	1%	16	1%
I did not need any information	3	1%	2	2%	0	0%	0	0%	1	1%	9	1%
Missing	901		297		330		440		368		2,092	

51. Once you started your treatment, were you given enough information about whether your	Belt	fast	Nort	hern	South	nern	South E	astern	West	tern	NI C	PES
chemotherapy was working in a way you could understand?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, completely	352	70%	77	69%	106	79%	105	75%	121	78%	909	72%
* Yes, to some extent	115	23%	25	22%	22	16%	23	16%	28	18%	272	22%
* No	33	7%	10	9%	6	4%	12	9%	6	4%	84	7%
It is too early to know if my chemotherapy is working	38	7%	13	10%	3	2%	12	8%	4	3%	89	6%
I did not need any information	12	2%	4	3%	3	2%	5	3%	1	1%	25	2%
Missing	905		295		333		441		368		2,099	

#### **HOME CARE AND SUPPORT**

52. Did the doctors or nurses give your family or someone close to you all the information they needed	Belf	ast	Nort	hern	South	hern	South E	astern	West	tern	NI C	PES
to help care for you at home?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	756	63%	218	64%	274	69%	279	63%	296	70%	1,823	65%
* Yes, to some extent	273	23%	<i>75</i>	22%	71	18%	85	19%	80	19%	584	21%
* No	176	15%	48	14%	54	14%	79	18%	47	11%	404	14%
No family or friends were involved	69	5%	27	7%	23	5%	53	10%	29	6%	201	6%
My family or friends did not want or need information	79	6%	30	7%	14	3%	41	7%	23	5%	187	6%
I did not want my family or friends to be involved	27	2%	8	2%	13	3%	20	4%	7	1%	75	2%
Missing	75		18		24		41		46		204	

53. During your cancer treatment, were you given enough care and support from health or social	Belf	ast	Nort	hern	South	nern	South E	astern	Wes	tern	NI C	PES
services (for example, district nurses, home helps or physiotherapists)?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	623	66%	189	68%	176	64%	242	69%	250	75%	1,480	68%
* Yes, to some extent	175	19%	55	20%	56	20%	52	15%	48	14%	386	18%
* No	144	15%	34	12%	45	16%	56	16%	34	10%	313	14%
I did not need help from health or social services	441	32%	128	32%	163	37%	206	37%	153	31%	1,091	33%
Don't know / can't remember	8	1%	0	0%	1	0%	4	1%	4	1%	17	1%
Missing	64		18		32		38		39		191	

54. Once your cancer treatment finished, were you given enough care and support from health or social	Belt	ast	Norti	hern	South	nern	South E	astern	West	tern	NI C	PES
services (for example, district nurses, home helps or physiotherapists)?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	333	52%	114	57%	114	55%	126	56%	159	64%	846	56%
* Yes, to some extent	140	22%	48	24%	44	21%	37	16%	38	15%	307	20%
* No	166	26%	37	19%	51	24%	62	28%	50	20%	366	24%
I did not need help from health or social services	453	33%	126	32%	163	38%	230	41%	146	31%	1,118	35%
I am still having treatment	264	19%	72	18%	60	14%	94	17%	81	17%	571	18%
Don't know / can't remember	3	0%	1	0%	0	0%	6	1%	3	1%	13	0%
Missing	96		26		41		43		51		257	

#### CARE FROM YOUR GENERAL PRACTICE

55. As far as you know, was your GP given enough information about your condition and the treatment	Belf	Belfast		rthern Sou		Southern		n Eastern Western		tern	NI CPES	
you had at the hospital?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	1,094	95%	327	97%	381	95%	459	97%	412	96%	2,673	96%
* No	55	5%	11	3%	18	5%	12	3%	17	4%	113	4%
Don't know / can't remember	270	19%	71	17%	57	13%	106	18%	91	18%	595	18%
Missing	36		15		17		21		8		97	

56. Do you think the GPs and nurses at your general practice did everything they could to support you	Belf	ast	Nort	hern	Southern		South Easter		stern Western		NI CPES	
while you were having cancer treatment?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, definitely	739	69%	247	73%	271	71%	287	70%	313	75%	1,857	71%
* Yes, to some extent	223	21%	68	20%	74	19%	93	23%	71	17%	529	20%
* No, they could have done more	102	10%	22	7%	35	9%	32	8%	31	7%	222	9%
My general practice was not involved	336	24%	75	18%	69	15%	155	27%	96	19%	731	22%
Missing	55		12		24		31		17		139	

#### YOUR OVERALL CARE

57. Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses,	Belt	ast	Nort	hern	Southern		South Eastern		ern Western		NI C	PES
specialist nurses, community nurses) work well together to give you the best possible care?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes, always	934	69%	299	75%	317	71%	394	72%	381	76%	2,325	72%
* Yes, most of the time	298	22%	69	17%	95	21%	107	19%	95	19%	664	20%
* Yes, some of the time	92	7%	25	6%	28	6%	40	7%	20	4%	205	6%
* No, never	31	2%	5	1%	5	1%	8	1%	8	2%	<i>57</i>	2%
Don't know / can't remember	52	4%	13	3%	14	3%	19	3%	13	3%	111	3%
Missing	48		13		14		30		11		116	

58. Have you been offered a needs assessment and care plan?	Belf	Belfast		Northern		nern	South Eastern		stern Western		NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	255	26%	84	28%	108	34%	99	24%	119	34%	665	28%
* No	743	74%	213	72%	213	66%	320	76%	235	66%	1,724	72%
I do not know / understand what a needs assessment or care plan is	259	19%	67	17%	86	20%	88	16%	90	18%	590	18%
Don't know / can't remember	103	8%	31	8%	32	7%	43	8%	45	9%	254	8%
Missing	95		29		34		48		39		245	

59. Overall, how would you rate the administration of your care (getting letters at the right time,	Belfast		Northern		Southern		South E	South Eastern		Western		PES
doctors having the right notes/tests results, etc.)?	#	%	#	%	#	%	#	%	#	%	#	%
* Very good	979	69%	279	68%	292	64%	388	67%	369	71%	2,307	68%
* Good	355	25%	103	25%	134	29%	128	22%	128	25%	848	25%
* Neither good nor bad	49	3%	19	5%	21	5%	43	7%	16	3%	148	4%
* Quite bad	23	2%	6	1%	7	2%	12	2%	6	1%	54	2%
* Very bad	11	1%	2	0%	1	0%	5	1%	2	0%	21	1%
Don't know / can't remember	6	0%	3	1%	1	0%	6	1%	2	0%	18	1%
Missing	32		12		17		16		5		82	

### **YOUR OVERALL CARE (continued)**

60. Overall, how do you feel about the length of time you had to wait when attending clinics and		elfast Northern		hern	Southern		South Eastern		Western		NI C	PES
appointments for your cancer treatment?	#	%	#	%	#	%	#	%	#	%	#	%
* It was much too long	133	9%	64	16%	45	10%	<i>57</i>	10%	32	6%	331	10%
* It was a little too long	352	25%	112	28%	101	22%	118	21%	98	19%	781	23%
* It was about right	930	66%	231	57%	308	68%	397	69%	382	75%	2,248	67%
Don't know / can't remember	6	0%	3	1%	4	1%	1	0%	3	1%	17	1%
Missing	34		14		15		25		13		101	

61. Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer	Belfast		Northern		South	Southern		astern	stern Western		NI CPES	
research for example, clinical trials?	#	%	#	%	#	%	#	%	#	%	#	%
* Yes	296	21%	44	11%	55	12%	48	9%	54	11%	497	15%
* No	1,082	79%	351	89%	389	88%	511	91%	447	89%	2,780	85%
Don't know / can't remember	43	3%	16	4%	16	3%	22	4%	16	3%	113	3%
Missing	34		13		13		17		11		88	

62. Overall, how would you rate your care?	Bel	elfast	Northern		South	nern	South Eastern		Western		NI C	PES
	#	%	#	%	#	%	#	%	#	%	#	%
* Very Poor 0	2	0%	0	0%	0	0%	1	0%	0	0%	3	0%
* 1	2	0%	0	0%	3	1%	1	0%	1	0%	7	0%
* 2	3	0%	1	0%	0	0%	1	0%	3	1%	8	0%
* 3	4	0%	0	0%	1	0%	2	0%	0	0%	7	0%
* 4	8	1%	2	0%	3	1%	4	1%	0	0%	17	1%
* 5	16	1%	8	2%	8	2%	12	2%	7	1%	51	2%
* 6	24	2%	9	2%	15	3%	19	3%	9	2%	76	2%
* 7	74	5%	21	5%	29	6%	30	5%	25	5%	179	5%
* 8	256	18%	70	17%	79	17%	91	16%	84	17%	580	17%
* 9	358	26%	119	29%	132	29%	158	28%	114	22%	881	26%
* Very Good 10	656	47%	183	44%	183	40%	255	44%	265	52%	1,542	46%
Ambiguous Response	13	1%	2	0%	4	1%	4	1%	5	1%	28	1%
Missing	39	)	9		16		20		15		99	

# Northern Ireland Cancer Patient Experience Survey 2018 South Eastern Health and Social Care



The Northern Ireland Cancer Patient Experience Survey was undertaken by Quality Health, which specialises in measuring patients' experiences of hospital, primary care and mental health services, using this information to improve the quality of health care and the responsiveness of health services to patients and service users' needs.

Quality Health is a specialist health and social care survey organisation, working for public, private and not-for-profit sectors, in the UK and overseas.

Quality Health works with all acute hospitals in England, all independent providers of hospital care, and all Health Boards/Trusts in Scotland, Wales and Northern Ireland.

Quality Health is an approved contractor for the Care Quality Commission's patient survey programmes, NHS England's National Staff Survey programme, and the national Patient Reported Outcome Measures (PROMs).

Further information on the Cancer Patient Experience Survey programmes and the 2018 survey can be obtained at: www.quality-health.co.uk