

# Northern Ireland Cancer Patient Experience Survey 2018

## All Trusts Report



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## 1. Foreword

We are delighted to launch the results of the second NI Cancer Patient Experience Survey (CPES). This survey asked people diagnosed with cancer and who were treated as an inpatient or a day-case between May and October 2017, about their experience of the treatment and care they received. We acknowledge the time that many patients and their families have taken to complete the survey and thank them for their valuable feedback.

We also wish to acknowledge Macmillan Cancer Support's generosity in part-funding CPES, alongside the Health and Social Care Board and the Public Health Agency, enabling us to undertake this important work and deliver a statistical analysis against the results of the 2017 Cancer Patient Experience Survey in England.

The key findings of the survey will help the Board, Agency and Trusts plan and structure future services. The survey respondents rated their care overall as 8.97 out of 10 and this provides explicit reassurance of the high-quality services provided across Northern Ireland.

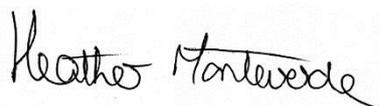
However, we must not be complacent. The survey responses indicate several areas where there is room for improvement, including patients feeling they have someone to talk to about their worries and fears when they are in hospital, being provided with appropriate information regarding side effects of treatment and access to clinical trials and research. These have been identified as priorities for service development.

The Cancer Patient Experience Survey 2018 provides important information and feedback to all of those working within the health and social care sector. It enables us to understand the impact of patient care initiatives and gain insight into the improvements required in patient care. The importance of CPES as an opportunity to benchmark our service against other areas of the UK, and as a vehicle to drive service improvement, cannot be underestimated and underlines its importance and relevance as an approach, now and in the future.

We extend our gratitude to all who helped administer the survey and collect responses and most importantly, to every individual who took the time to respond. We greatly appreciate your time, commitment and honest feedback which will help us to improve the standard of cancer care provided in Northern Ireland.



Ms Valerie Watts



Ms Heather Monteverde

## 2. Executive summary

Within the Health and Social Care sector the provision of high-quality cancer care is a priority. Among all providers, there is a clear focus on the provision of patient-centred services and on improving the patient experience of care. The Northern Ireland Cancer Patient Experience Survey (NI CPES) 2018 follows on from the successful delivery of the survey in Northern Ireland in 2015, and similar surveys in England, Scotland and Wales. The NI CPES 2018 gave patients the opportunity to give detailed confidential feedback on their experience of care across the five Health and Social Care Trusts in Northern Ireland, allowing comparison with the experience of cancer care in the England CPES 2017, enabling local monitoring of progress on cancer care, and providing evidence that can be used to drive quality improvements.

As with the 2015 survey, the NI CPES 2018 shows that the experience of cancer patients in Northern Ireland is generally very positive. There are encouraging improvements in a number of areas; however, there are also several areas where further work is needed to continue to improve patients' experience of cancer care in Northern Ireland. To this end, the survey provides rich data which will help to shape the future direction of cancer services in Northern Ireland.

This report provides a regional perspective on the results of the survey. Alongside this, a local report has been produced [for each Trust](#), comparing individual Trusts' results to other Trusts and to the regional scores for Northern Ireland. Detailed survey data – including response data broken down by Trust, cancer type and different demographic and clinical variables – are also available in the [NI CPES 2018 data tables](#).

## Headline Findings

The average score for overall rating of care was 8.97 (out of a maximum of 10), significantly higher than the most recent CPES carried out in England in 2017 (8.80)<sup>1</sup>.

Scores across many other survey questions also compared favourably to those for England in 2017. Of the 28 questions with significant differences between scores:

- NI 2018 scores were significantly higher than England 2017 scores on 20 questions;
- NI 2018 scores were significantly lower than England 2017 scores on 8 questions.

Comparing scores over time within NI also shows a generally positive picture, though these scores are not statistically comparable<sup>2</sup>. Of the 36 questions which were asked in both the NI CPES 2015 and the NI CPES 2018:

- On 21 questions, scores had improved between 2015 and 2018;
- On 15 questions, scores had declined between 2015 and 2018.

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<sup>1</sup> Comparison of this score to the previous NI CPES is not possible due to differences in how the question was asked.

<sup>2</sup> Due to changes in the survey questionnaire since NI CPES 2015, it has not been possible to test the statistical significance of changes in scores over time.

## Areas with Strong Performance

### ***Clinical Nurse Specialist (CNS) Provision***

The most increased score since NI 2015 was regarding CNS provision. The percentage of respondents stating that they had been given the name of a CNS who would support them through their treatment increased from 72% in 2015 to 82% in 2018. However, this remains significantly lower than England 2017 (91%).

It is important to note that respondents with access to a CNS had significantly higher scores than those without on 47 of the 48 comparable questions.

### ***Being offered a needs assessment and care plan***

The proportion of patients being offered a needs assessment and care plan increased from 21% in NI 2015 to 28% in NI 2018, which is encouraging.

As with CNS provision, respondents who were offered a needs assessment and care plan reported significantly higher scores than those who were not on 46 of the 50 comparable questions.

### ***Provision of written information***

A higher proportion of patients received written information about the type of cancer they had in 2018 compared to 2015 (from 64% to 69%), but this is significantly lower than England 2017 (73%).

### ***Being asked preferred name***

The proportion of patients being asked by doctors and nurses what name they preferred to be called by had increased from 59% in NI 2015 to 69% in NI 2018. The England 2017 score was also 69%.

### ***Enough nurses being on duty***

The proportion of patients who thought there were enough nurses on duty to care for them increased from 60% in NI 2015 to 67% in NI 2018. The England 2017 score was 66%.

### ***Other aspects of inpatient experience***

On several other questions, many relating to inpatient care, scores were significantly higher than England 2017 and higher than NI 2015:

- Patients being given information about how to get financial help or benefits: 66% in NI 2015, 58% in England 2017 and 68% in NI 2018;
- Patients having confidence and trust in the ward nurses treating them: 78% in NI 2015, 76% in England 2017 and 81% in NI 2018;
- Patients' families or someone close to them being able to talk to a doctor if they wanted to: 69% in NI 2015, 73% in England 2017 and 76% in NI 2018.

## Areas for Improvement

While findings indicate a positive overall picture of cancer patient experience in Northern Ireland, there are some clear areas where there is scope for improvement.

### ***Finding someone in hospital to talk to about worries and fears***

Despite increasing CNS provision and strong performance across other aspects of inpatient care, there was a reduction in scores between 2015 and 2018 in people finding someone on the hospital staff to talk to about their worries and fears during their hospital visit(s) (from 70% to 53%). However, the NI 2018 score is the same as England 2017.

### ***Side effects***

The proportion of patients who felt that potential side effects had been adequately explained to them was lower than England 2017 and had decreased within NI since 2015:

- Patients having possible side effects of treatment explained to them in an understandable way: 78% in NI 2015, 73% in England 2017 and 72% in NI 2018;
- Patient being told about possible future side effects of treatment (late effects): 58% in NI 2015, 56% in England 2017 and 54% in NI 2018.

### ***Cancer research / clinical trials***

Fewer patients reported being asked about taking part in cancer research / clinical trials in 2018 (15%) than in 2015 (18%). This is a concern and, notably, the equivalent – though not directly comparable – score in the England CPES 2017 was also markedly higher at 31%.

### ***Primary care***

There was a considerable drop in the proportion of patients who felt that primary care staff did everything that they could to support them while they were having their cancer treatment: 77% in NI 2015, 60% in England 2017 and 71% in NI 2018.

## The Way Forward

Within cancer services there is ongoing work taking place looking at the delivery of non-surgical oncology treatments, in line with the regional transformation agenda and there has been significant patient engagement throughout this project. The NI CPES 2018 results will also contribute to influencing how these services can be delivered more effectively with continued patient centred care.

The NI 2015 survey highlighted the importance of the CNS role within patient experience.

Since 2014 we have seen an additional 60 CNS recruited across NI, largely supported by the CNS workforce expansion plan, supported by the Health and Social Care Board and Macmillan Cancer Support.

The expansion plan is ongoing with further CNS recruitment planned through to 2021.

There is recognition that there needs to be increased engagement between primary care and secondary care to enhance care for patients with cancer. The NI Cancer Network in conjunction with Macmillan Cancer Support have appointed a Primary Care Director in December 2018 to progress work in this area.

Furthermore, as a result of the NI CPES 2018 survey, there will be an overarching regional action plan and local Trust action plans to address:

- Finding someone in hospital to talk to about worries and fears;
- The provision of information on side effects and late effects;
- Increasing the numbers of patients being offered to take part in clinical trials.

## 3. Methodology

### 3.1. Fieldwork

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.

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 1<sup>st</sup> May and 31<sup>st</sup> 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.

## 3.2. Response rates

The response rate to the NI CPES 2018 (57% or almost 3,500 people), while lower than the rate for the NI CPES in 2015 (62%), compares favourably with the response rate for other NHS surveys and is similar to the rate achieved in the 2017 CPES in England (63%).

It is also encouraging that a high proportion of respondents (72% or almost 2,300 people) have again indicated that they would be willing to be contacted about participating in further surveys designed to understand their experiences of cancer services.

## 3.3. Analysis

### 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 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.

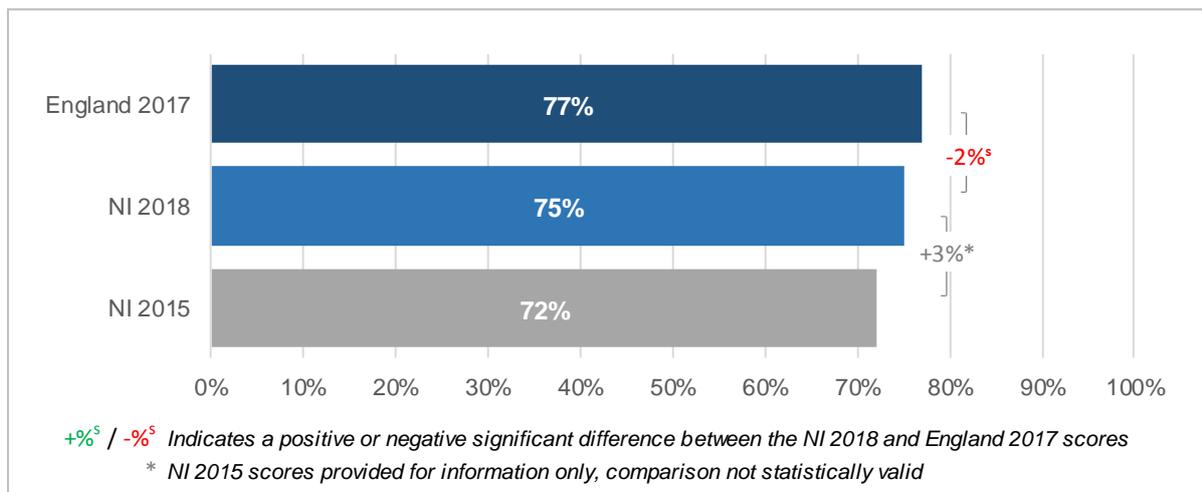
Only questions that have been designated a score have been included in this report. Questions which aim only to clarify the respondent's treatment pathway or to direct them through the questionnaire (for example, question 5 “Did the test(s) take place at the hospital named on the letter that came with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

### Significance tests

Significance tests have been used to establish whether there are statistically significant differences between responses from different groups of respondents on a particular question.

In this report, we have tested the significance of differences between scores on the NI CPES 2018 and the England CPES 2017. Among respondents to the NI CPES 2018, significance has also been tested for between different groups of patients based on demographic factors (gender, age, ethnicity, deprivation and employment status) and clinical factors (cancer type, cancer status, co-morbidities, access to Clinical Nurse Specialists and access to needs assessment/care plan) – see Chapter 6.

### 3.4. Sample Chart



In the chart above the top line represent the score for the England 2017 survey, the middle line is the score for the Northern Ireland 2018 survey and the bottom line is the score for the Northern Ireland 2015 survey. The score for each survey is shown on the relevant bar, and where there is no comparable question there will be a placeholder graphic stating this:

No comparable England data

No comparable 2015 data

To the right of each bar is an indicator of the difference in scores between the relevant surveys, where applicable.

When comparing the England 2017 survey to the Northern Ireland 2018 survey:

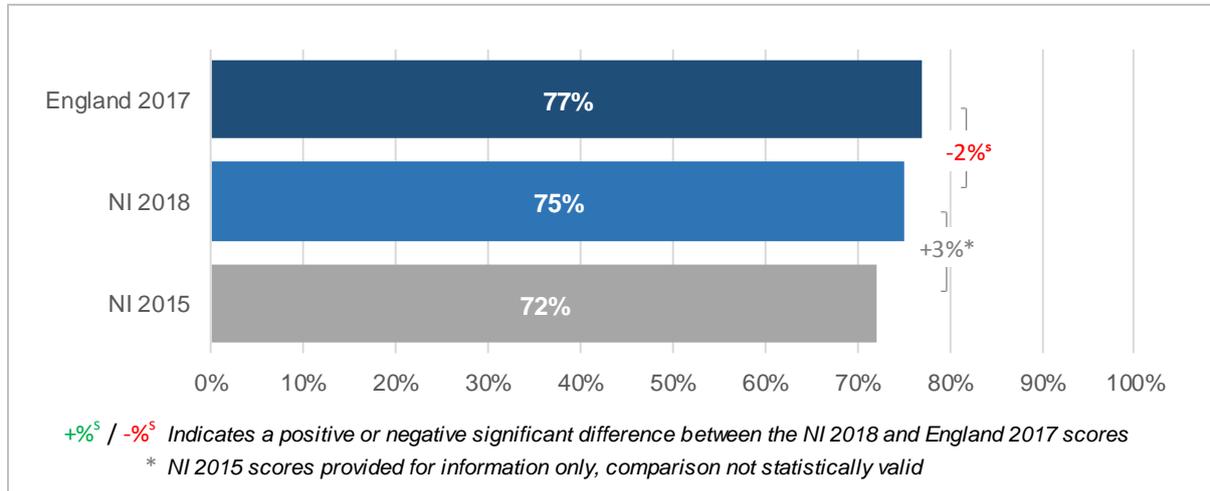
- if this indicator is coloured green, it means that the Northern Ireland 2018 score is significantly more positive than the England 2017 score.
- if this indicator is coloured red (as per the example above) it means that the Northern Ireland 2018 score is significantly more negative than the England 2017 score.
- if this indicator is coloured grey, it means that the Northern Ireland 2018 score is neither significantly more positive nor negative than the England 2017 score.

**Please note that Northern Ireland 2015 scores are not comparable to Northern Ireland 2018 scores, due to changes in the sampling timeframe and questionnaire design. Northern Ireland 2015 scores are therefore shown for information purposes only.**

## 4. Survey results

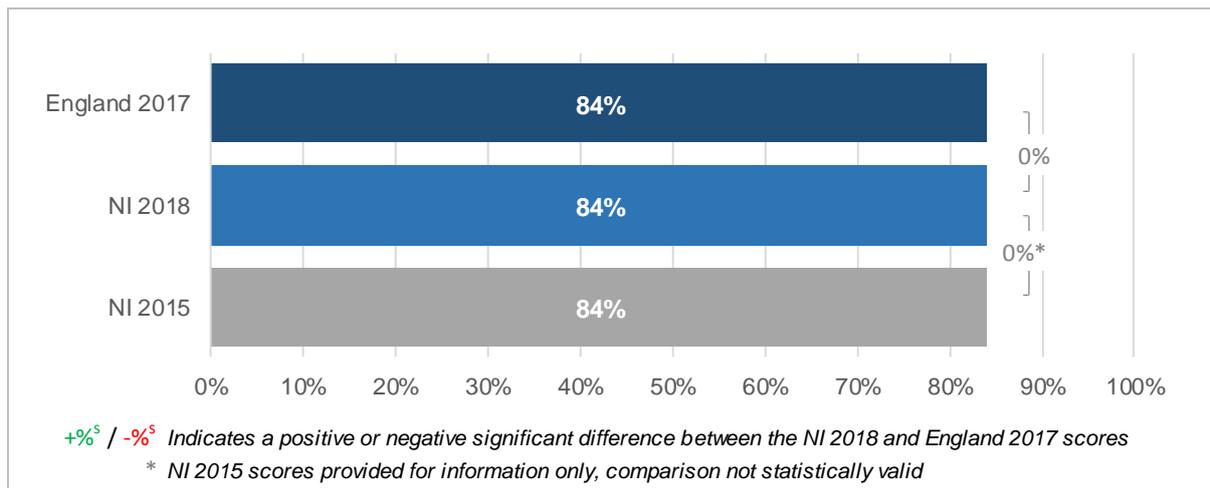
### 4.1. Before Your Diagnosis

#### Q1. Patient saw GP once or twice before being told they had to go to the hospital



75% of patients saw their GP either once or twice before being told they needed to go to the hospital about their cancer. This is significantly lower than the England 2017 score of 77%. However, it is an improvement of 3% on the Northern Ireland 2015 score of 72%.

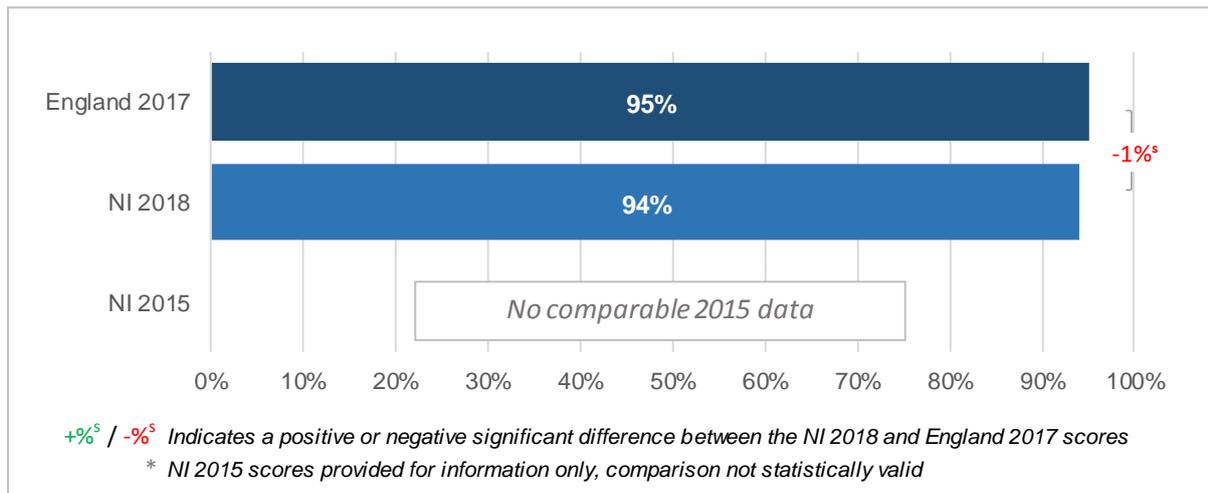
#### Q2. Patient thought they were seen as soon as necessary for their first appointment



84% of patients felt they were seen for their first appointment with a hospital doctor as soon as they thought necessary. This is the same as the England 2017 score of 84%. It is also the same as the Northern Ireland 2015 score of 84%.

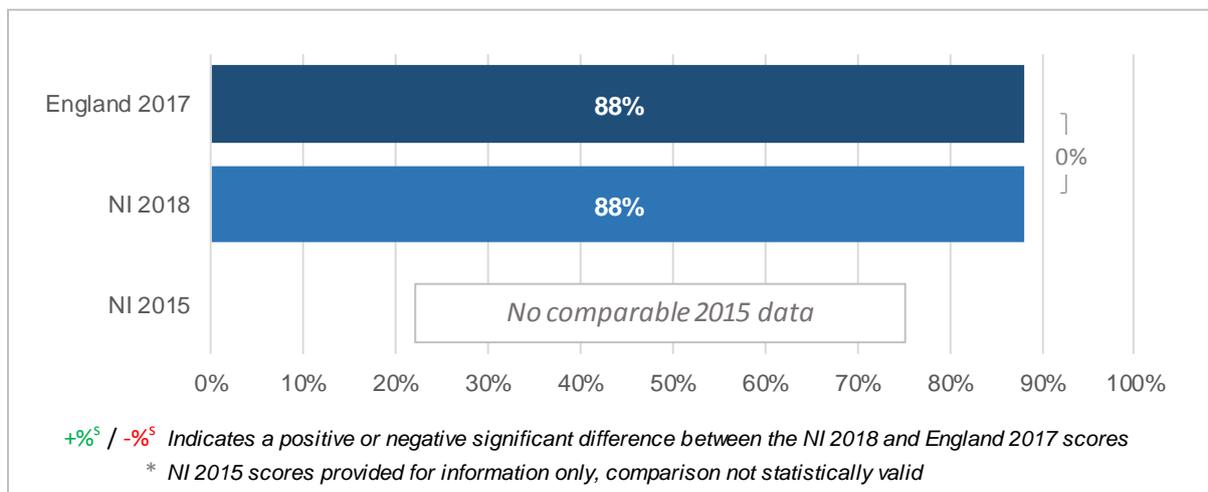
## 4.2. Diagnostic Tests

### Q6. Patient had all the information needed about their test beforehand



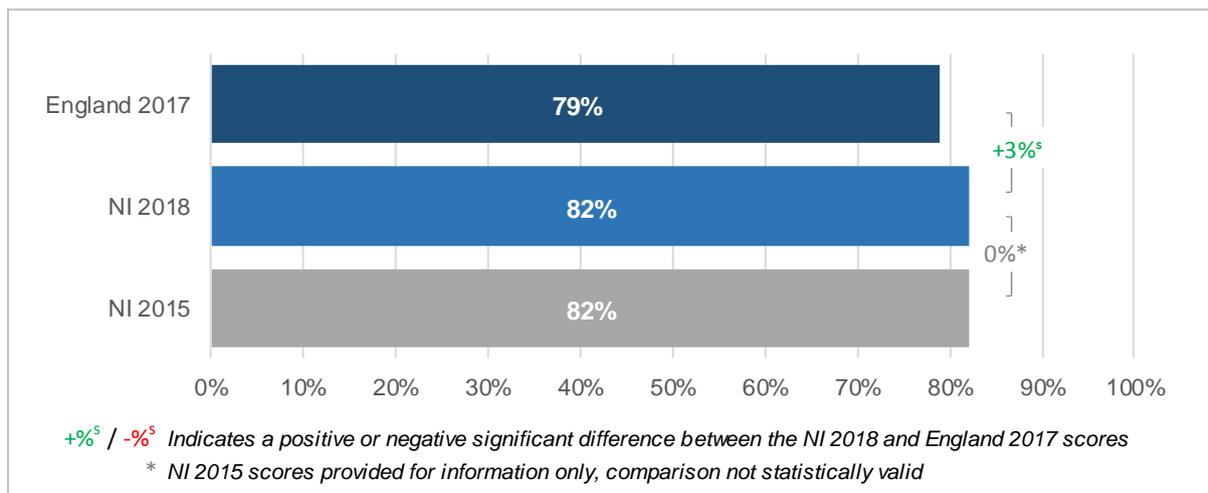
94% of patients had all the information they needed about their test before it took place. This is significantly lower than the England 2017 score of 95%. This was not a question asked on the Northern Ireland 2015 survey.

### Q7. Patient thought length of time for test to be done was about right



88% of patients thought the length of time they had to wait for their test to be done was about right. This is the same as the England 2017 score of 88%. This was not a question asked on the Northern Ireland 2015 survey.

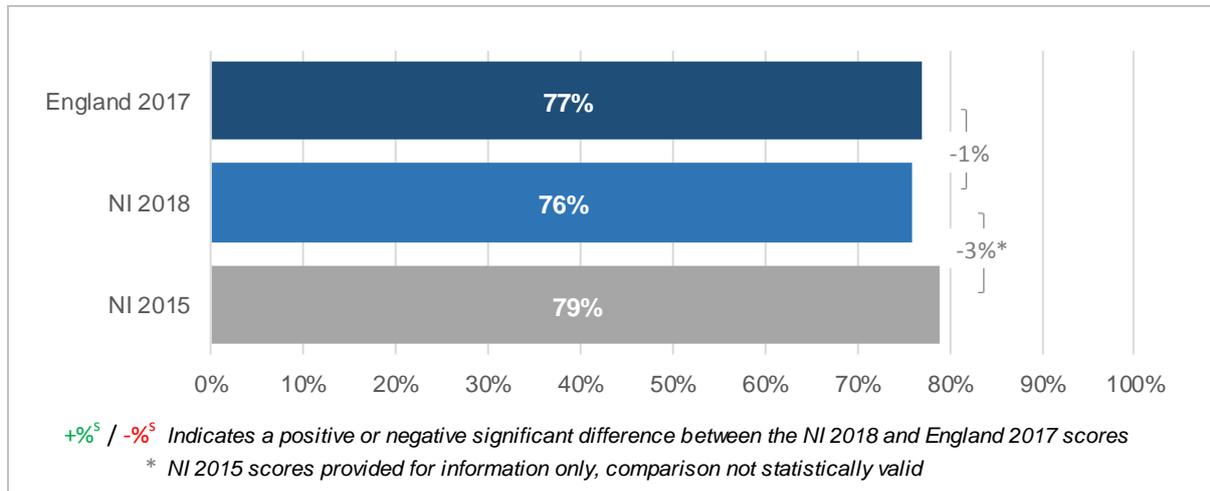
### Q8. Results of test were explained in a way the patient completely understood



82% of patients thought the results of their tests were explained in a way they could completely understand. This is significantly higher than the England 2017 score of 79%. It is the same as the Northern Ireland 2015 score of 82%.

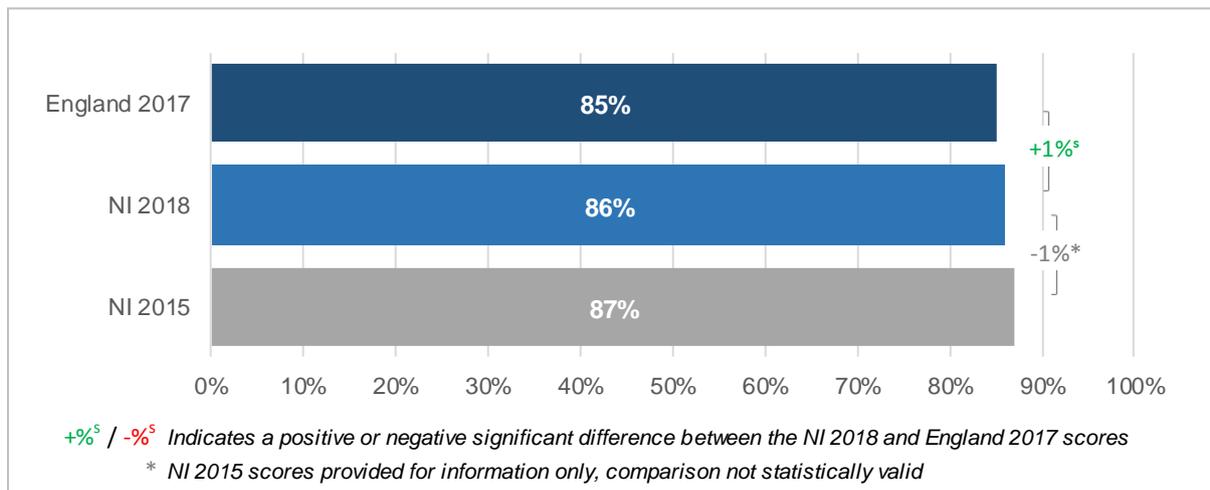
## 4.4. Finding Out What Was Wrong with You

### Q9. Patient had been told they could bring a family member or friend when they were first told about cancer



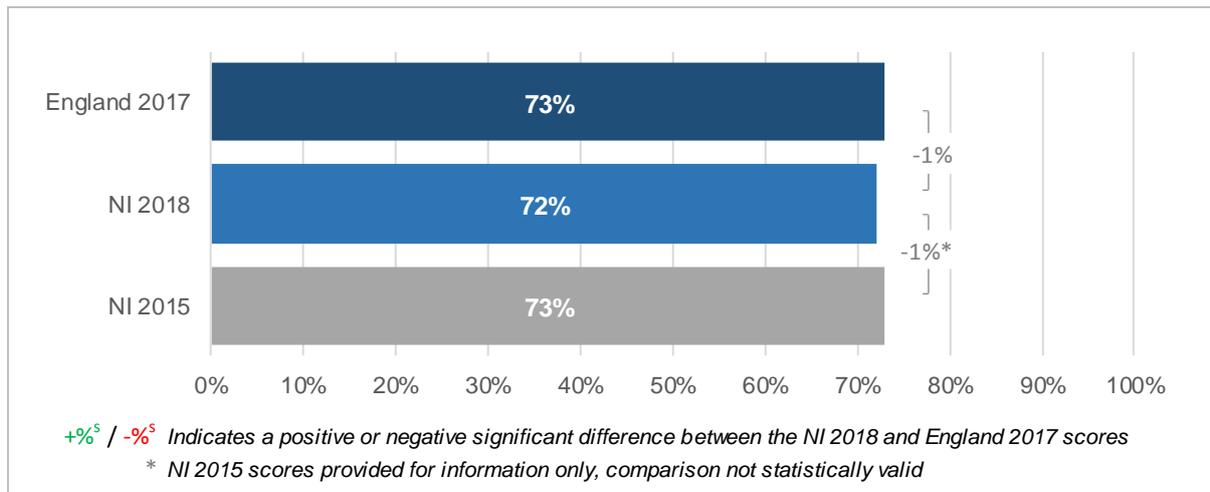
76% of patients were told they could bring a family member or friend with them when they were first told they had cancer. This is lower than the England 2017 score of 77%. Additionally, it is a decrease of 3% on the Northern Ireland 2015 score of 79%.

### Q10. Patient thought they were told they had cancer in a sensitive manner



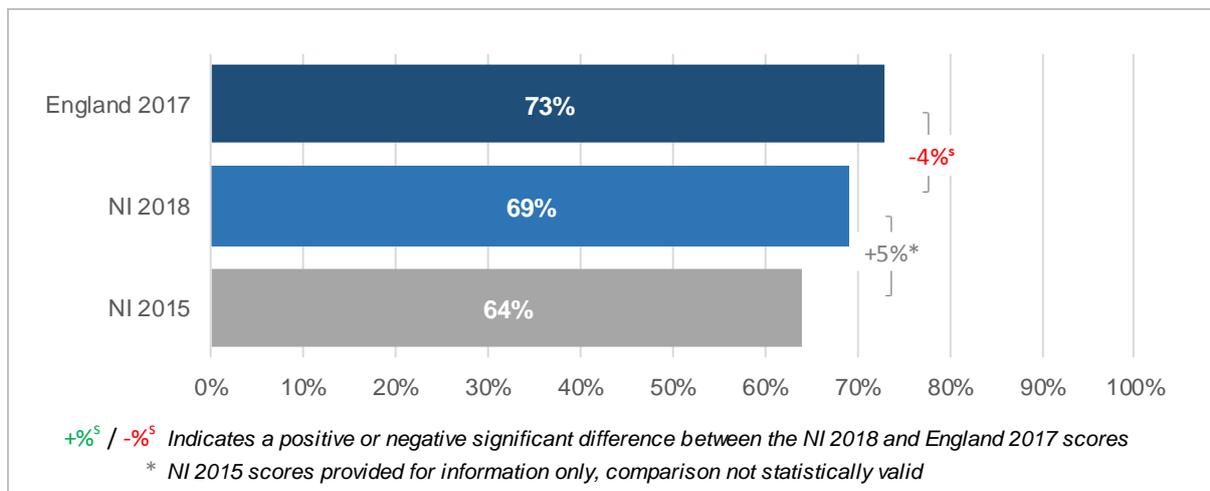
86% of patients thought that they had been told they had cancer in a sensitive manner. This is significantly higher than the England 2017 score of 85%. However, it is a decline of 1% on the Northern Ireland 2015 score of 87%.

**Q11. Patient completely understood the explanation of what was wrong with them**



72% of patients completely understood the explanation of what was wrong with them. This is lower than the England 2017 score of 73%. Additionally, it is a decrease of 1% on the Northern Ireland 2015 score of 73%.

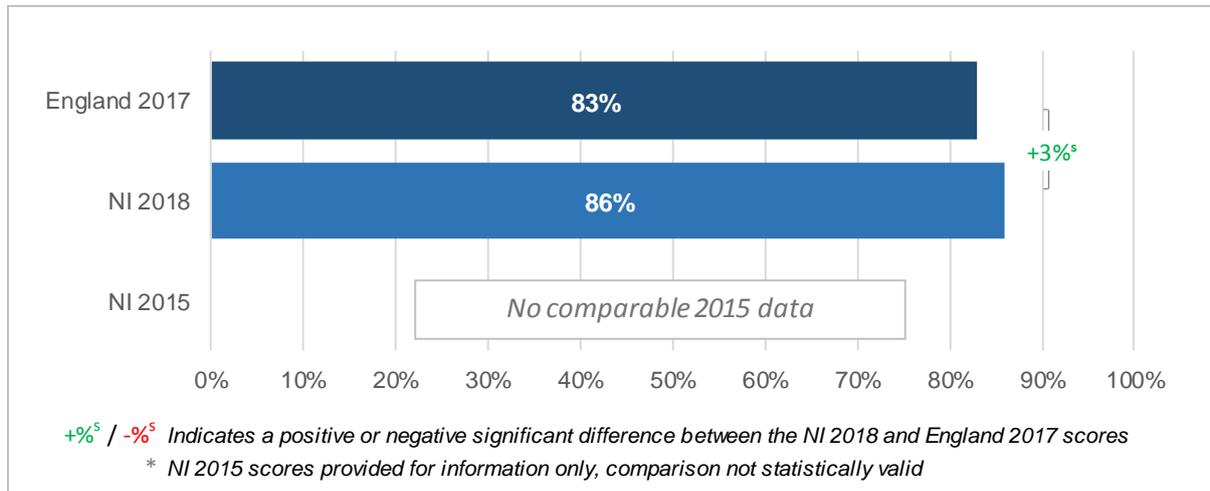
**Q12. Patient was given easy to understand written information about the type of cancer they had when they were first told they had cancer**



69% of patients were given written information about the type of cancer they had and found it easy to understand. This is significantly lower than the England 2017 score of 73%. However, it is an improvement of 5% on the Northern Ireland 2015 score of 64%.

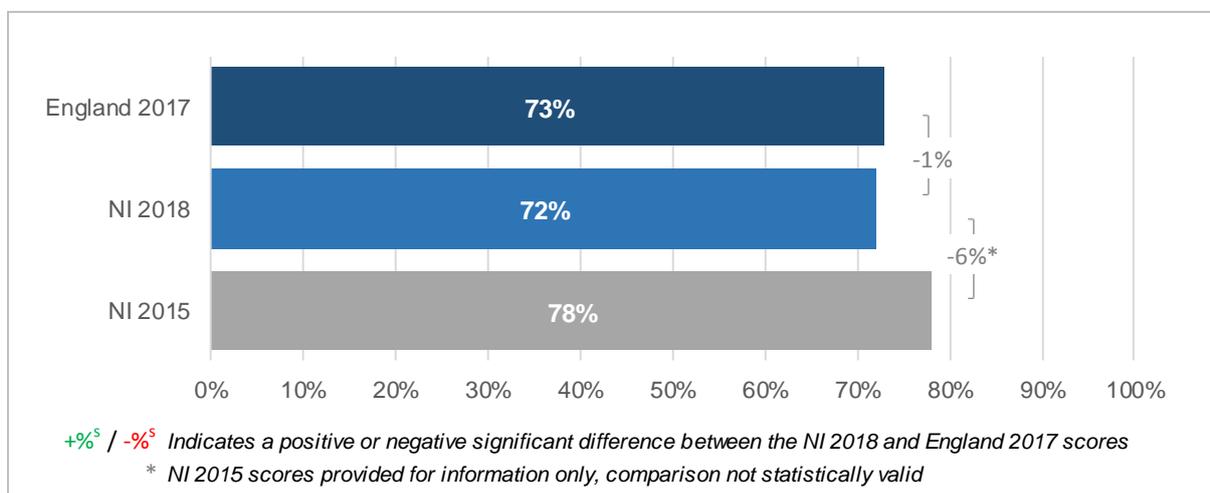
## 4.6. Deciding the Best Treatment for You

### Q13. Treatment options were completely explained to patient before treatment started



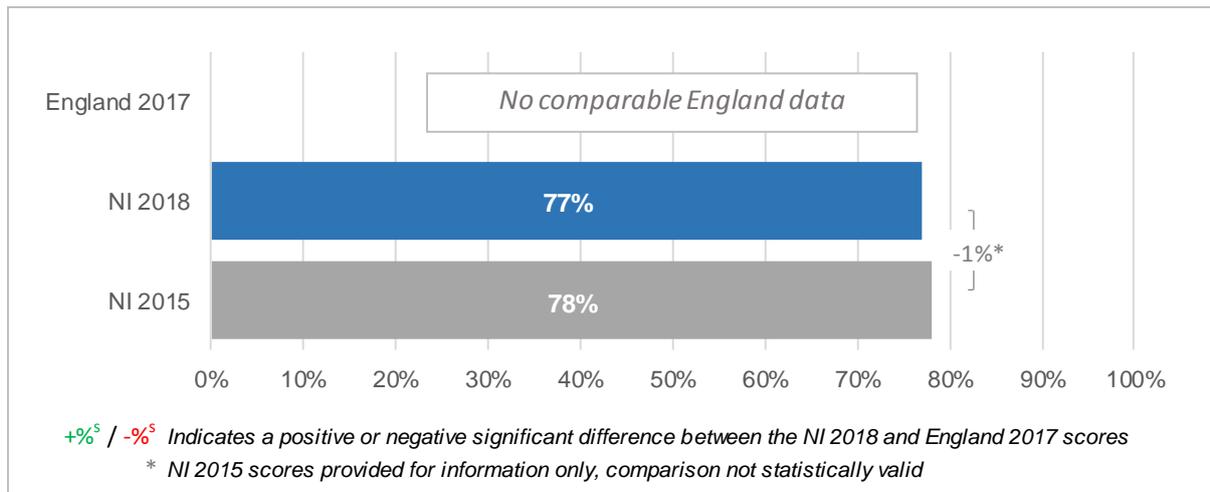
86% of patients felt the options for treatment were completely explained to them, before treatment started. This is significantly higher than the England 2017 score of 83%. This was not a question asked on the Northern Ireland 2015 survey.

### Q14. Side effects of treatment were definitely explained in a way the patient could understand



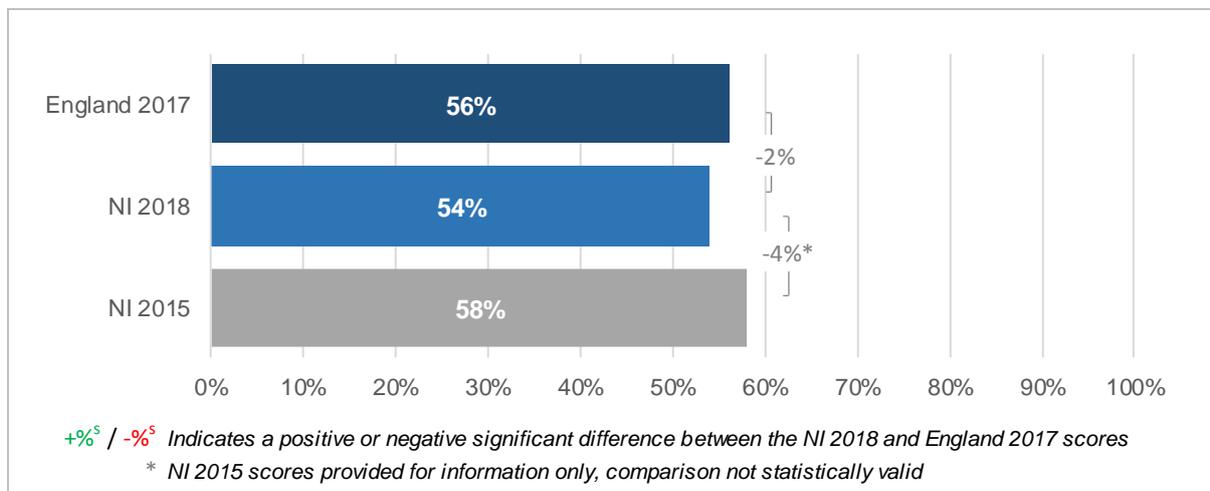
72% of patients definitely felt the possible side effects of treatment(s) were explained in a way they could understand. This is lower than the England 2017 score of 73%. Additionally, it is a decrease of 6% on the Northern Ireland 2015 score of 78%.

**Q15. Patient was given easy to understand written information regarding side effects**



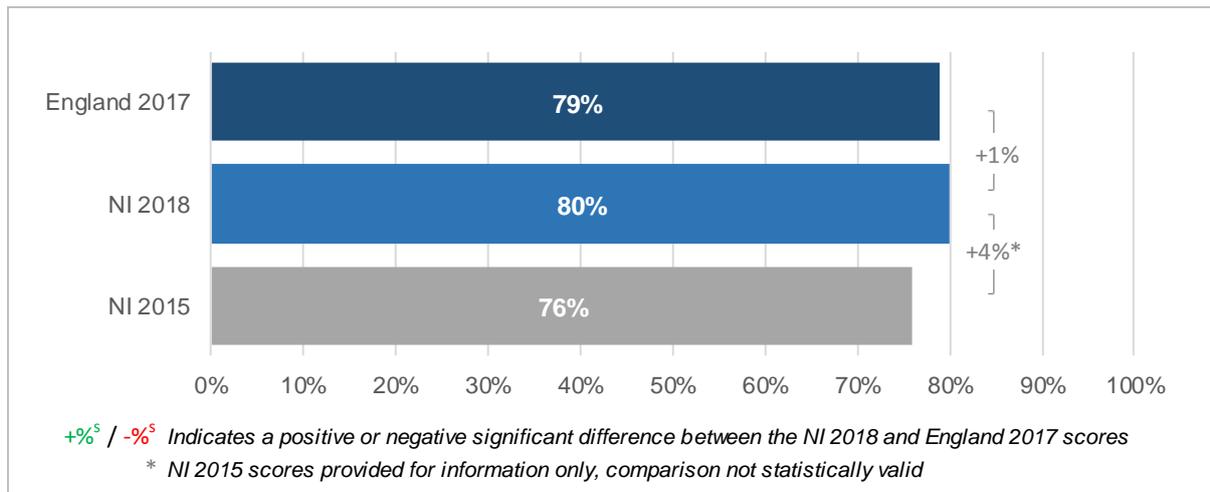
77% of patients were given written information about the side effects of treatment(s) before treatment started and found it easy to understand. This was not a question asked on the England 2017 survey. However, it is a decline of 1% on the Northern Ireland 2015 score of 78%.

**Q16. Patient was definitely told about future side effects before treatment**



54% of patients were definitely told before treatment about any side effects of treatment(s) that could affect them in the future. This is lower than the England 2017 score of 56%. Additionally, it is a decrease of 4% on the Northern Ireland 2015 score of 58%.

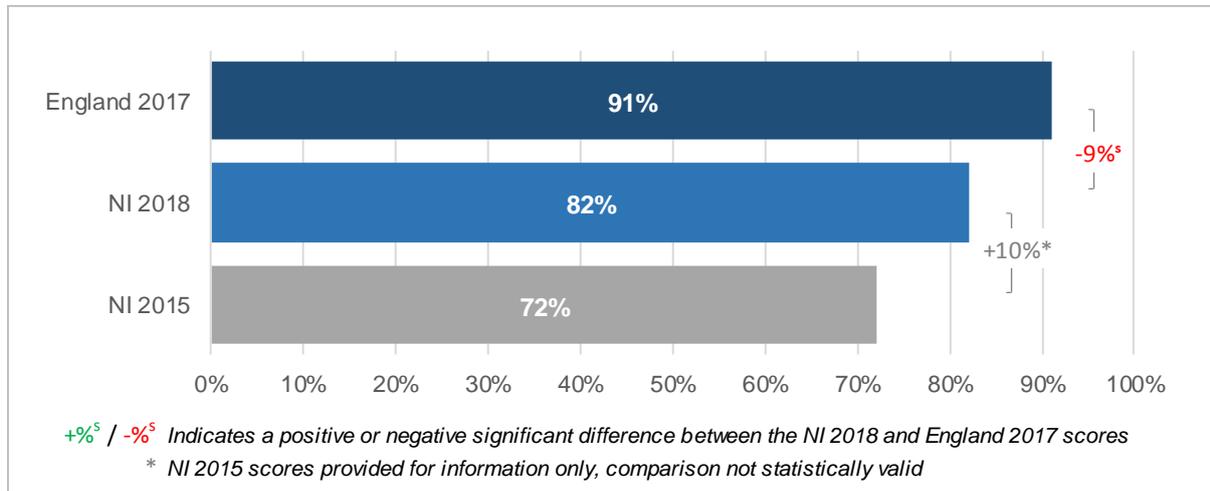
### Q17. Patient was definitely involved as much as they wanted to be in decisions about their care



80% of patients felt they were definitely involved as much as they wanted to be in decisions about their care and treatment. This is higher than the England 2017 score of 79%. Additionally, it is an improvement of 4% on the Northern Ireland 2015 score of 76%.

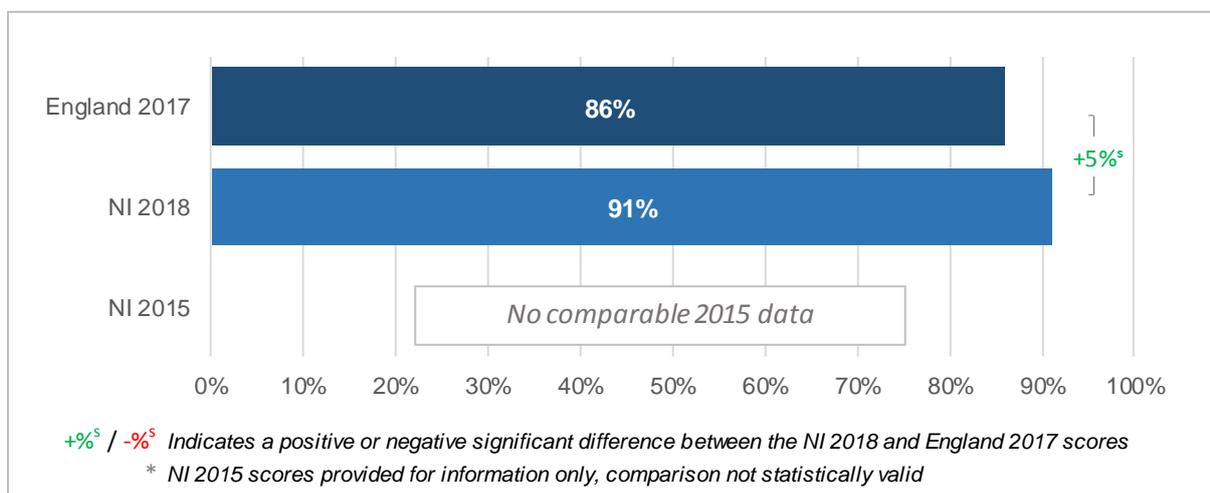
## 4.7. Clinical Nurse Specialist

### Q18. Patient was given the name of a Clinical Nurse Specialist who would support them through treatment



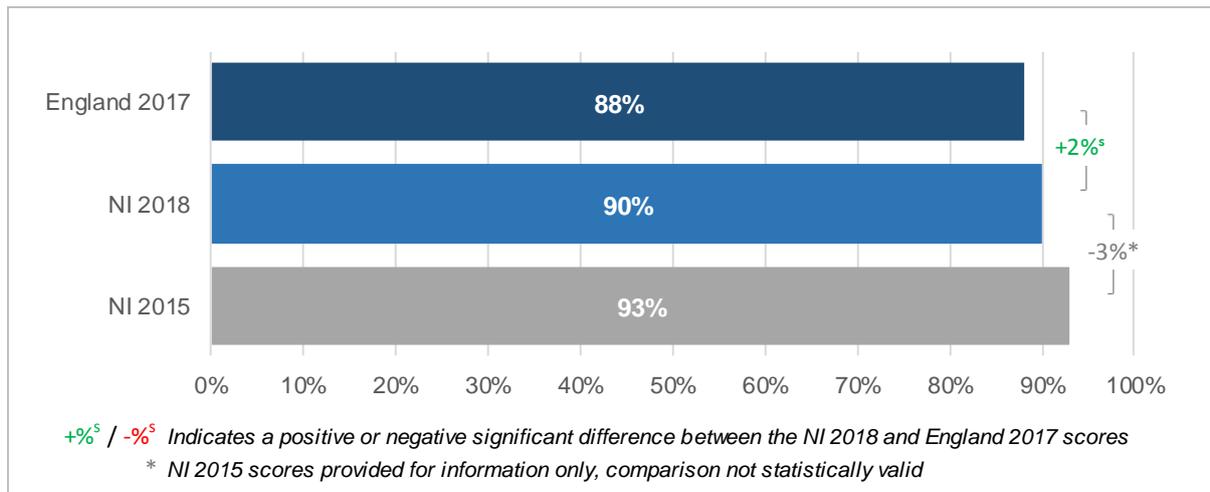
82% of patients were given the name of a Clinical Nurse Specialist. This is significantly lower than the England 2017 score of 91%. However, it is an improvement of 10% on the Northern Ireland 2015 score of 72%.

### Q19. Patient found it very easy or quite easy to contact their Clinical Nurse Specialist



91% of patients found it either 'Quite easy' or 'Very easy' to contact their Clinical Nurse Specialist when required. This is significantly higher than the England 2017 score of 86%. This was not a question asked on the Northern Ireland 2015 survey.

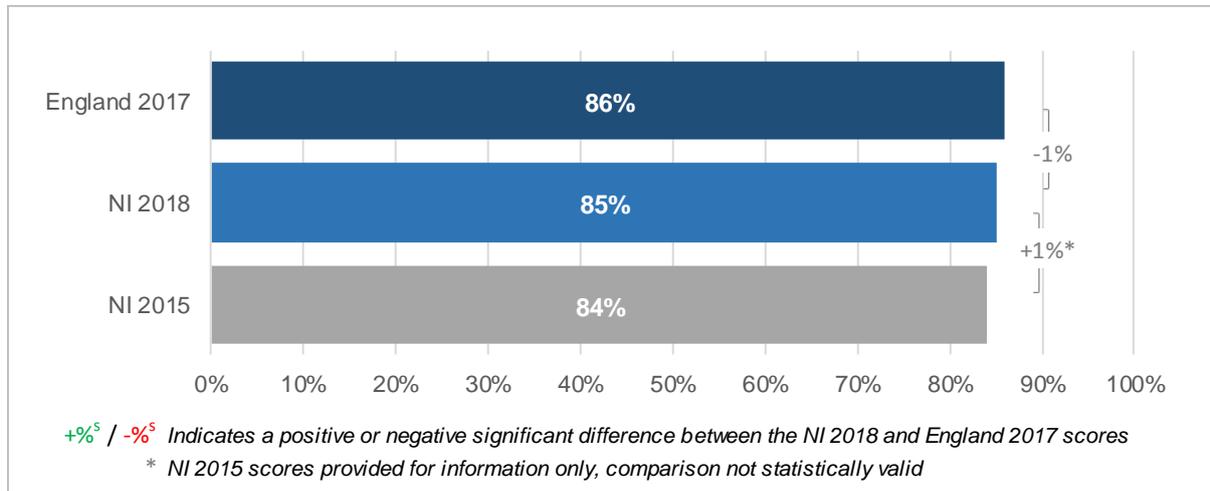
**Q20. Patient was able to get answers they could understand from their Clinical Nurse Specialist all or most of the time**



90% of patients felt they got answers they could understand all or most of the time, when they had an important question for their Clinical Nurse Specialist. This is significantly higher than the England 2017 score of 88%. However, it is a decline of 3% on the Northern Ireland 2015 score of 93%.

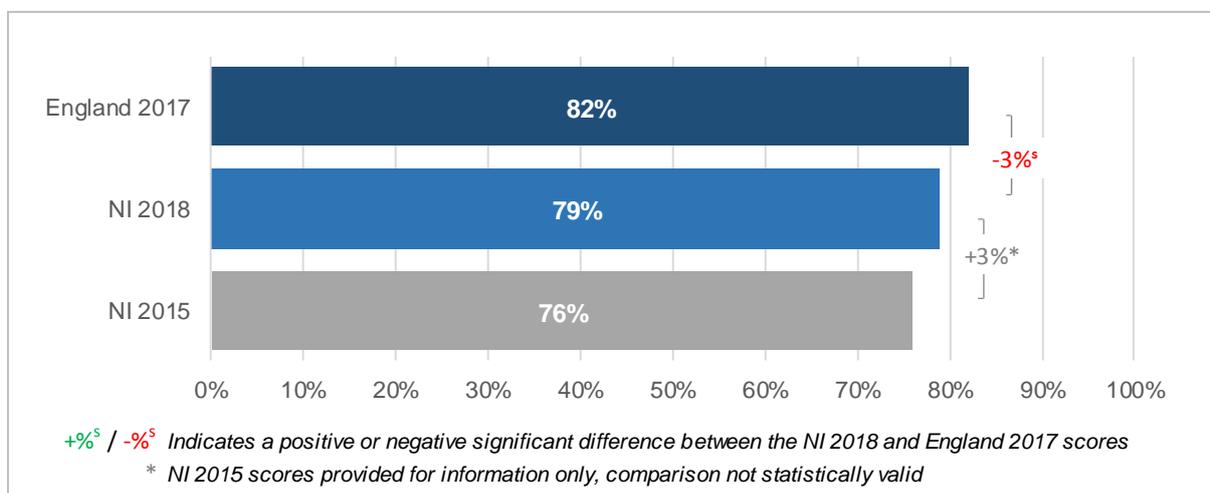
## 4.8. Support for People with Cancer

### Q21. Patient was given information by hospital staff about support or self-help groups



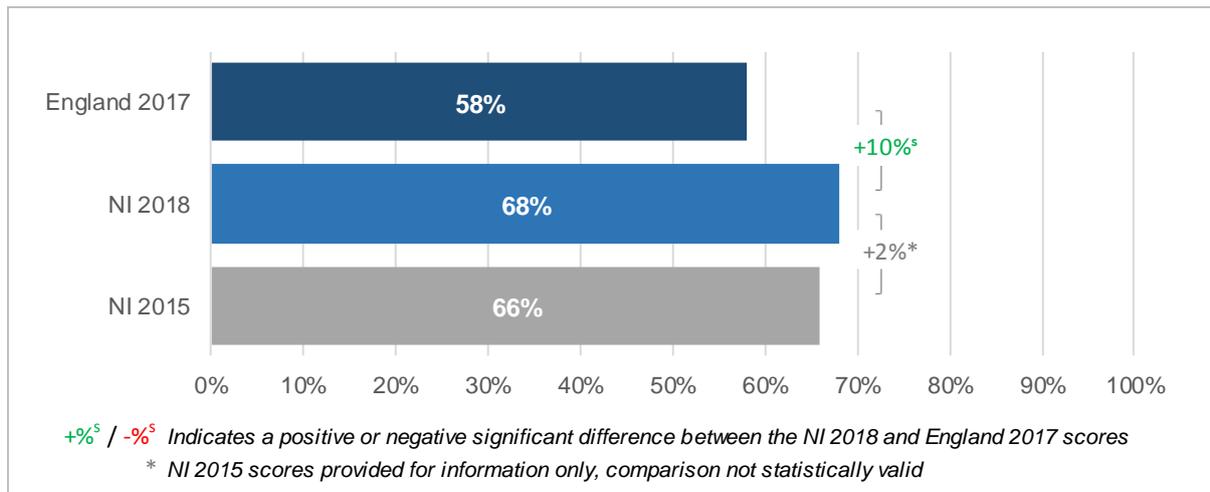
85% of patients were given information about support or self-help groups for people with cancer by hospital staff. This is lower than the England 2017 score of 86%. However, it is an improvement of 1% on the Northern Ireland 2015 score of 84%.

### Q22. Staff discussed / gave patient information about the impact cancer could have on their work-life or education



79% of patients either discussed with hospital staff or were given information about the impact cancer could have on their work-life or education. This is significantly lower than the England 2017 score of 82%. However, it is an improvement of 3% on the Northern Ireland 2015 score of 76%.

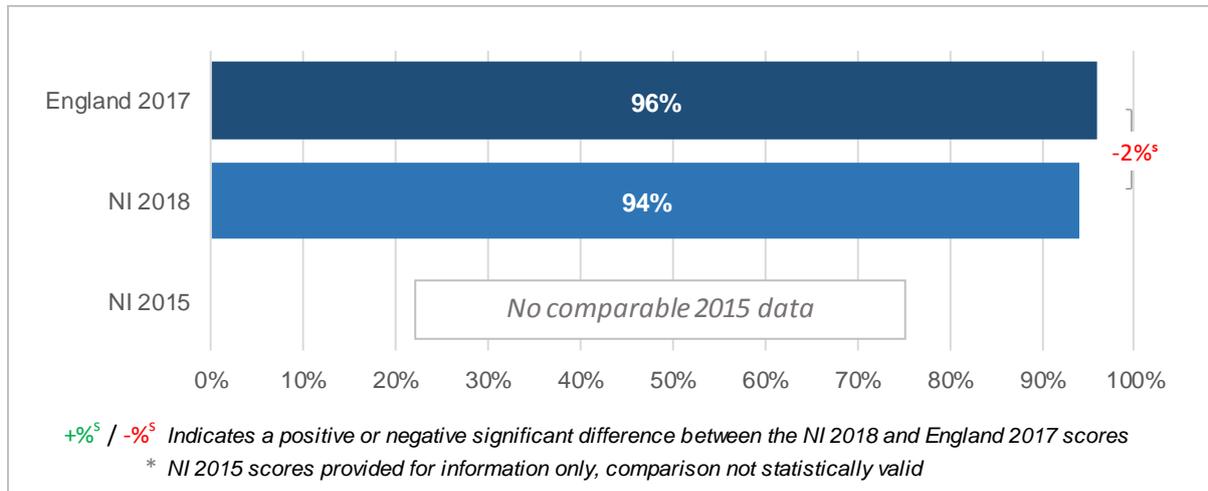
### Q23. Hospital staff gave patient information about financial help and benefits available



68% of patients were given information by hospital staff about how to get financial help or benefits they may be entitled to. This is significantly higher than the England 2017 score of 58%. Additionally, it is an improvement of 2% on the Northern Ireland 2015 score of 66%.

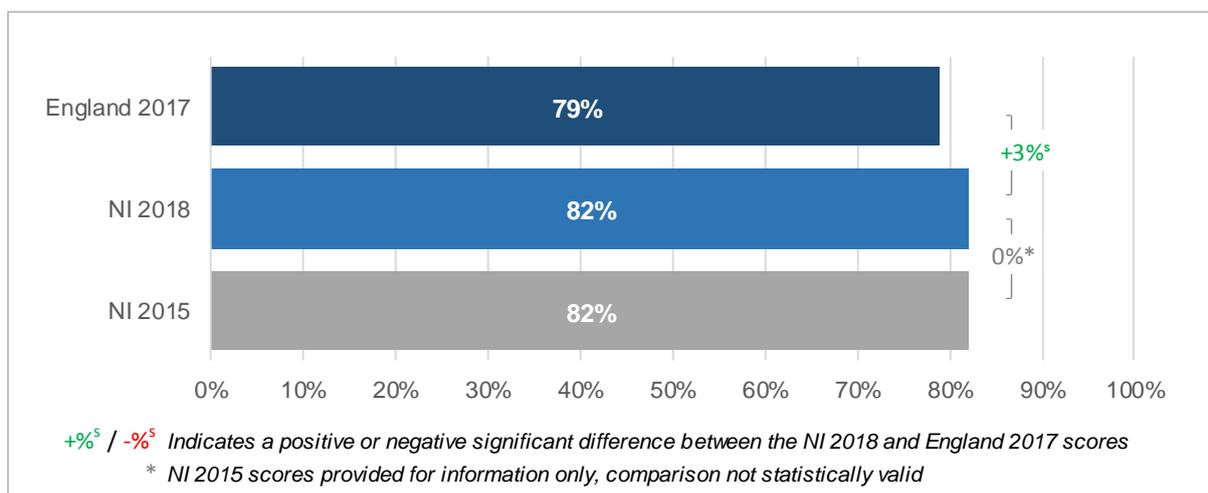
## 4.9. Operations

### Q26. Patient had all the information they needed about their operation beforehand



94% of patients were given all the information required about their operation, before their operation. This is significantly lower than the England 2017 score of 96%. This was not a question asked on the Northern Ireland 2015 survey.

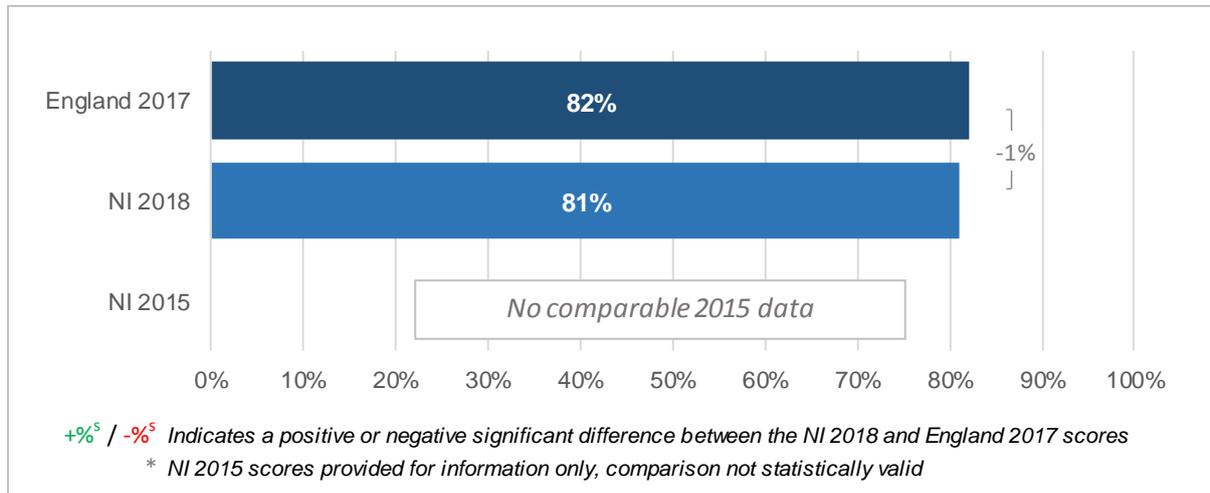
### Q27. A member of staff completely explained outcome of the operation to the patient in a way they could understand



82% of patients completely understood the explanation given by a member of staff about how their operation had gone. This is significantly higher than the England 2017 score of 79%. It is the same as the Northern Ireland 2015 score of 82%.

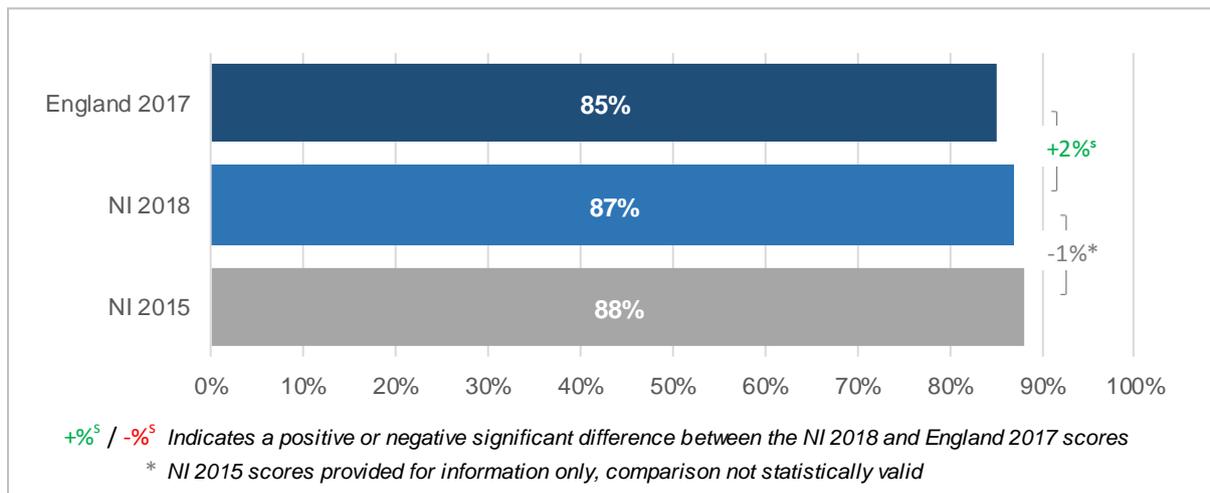
## 4.10. Hospital Care as An Inpatient

### Q30. Patient thought no doctors or nurses talked in front of them as if they weren't there



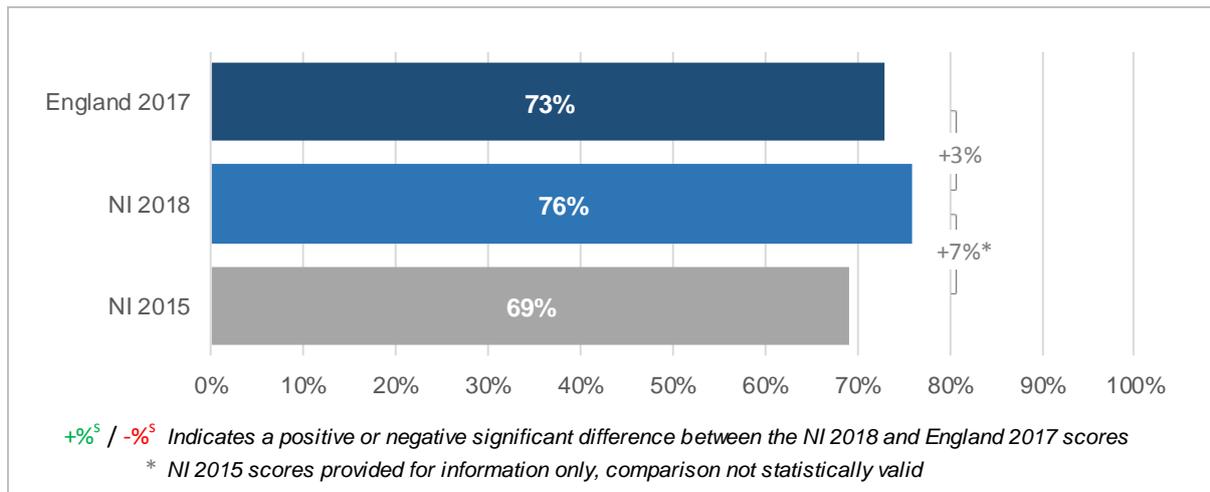
81% of patients said that no groups of doctors or nurses ever talked in front of them as if they weren't there. This is lower than the England 2017 score of 82%. This was not a question asked on the Northern Ireland 2015 survey.

### Q31. Patient had confidence and trust in all of the doctors treating them



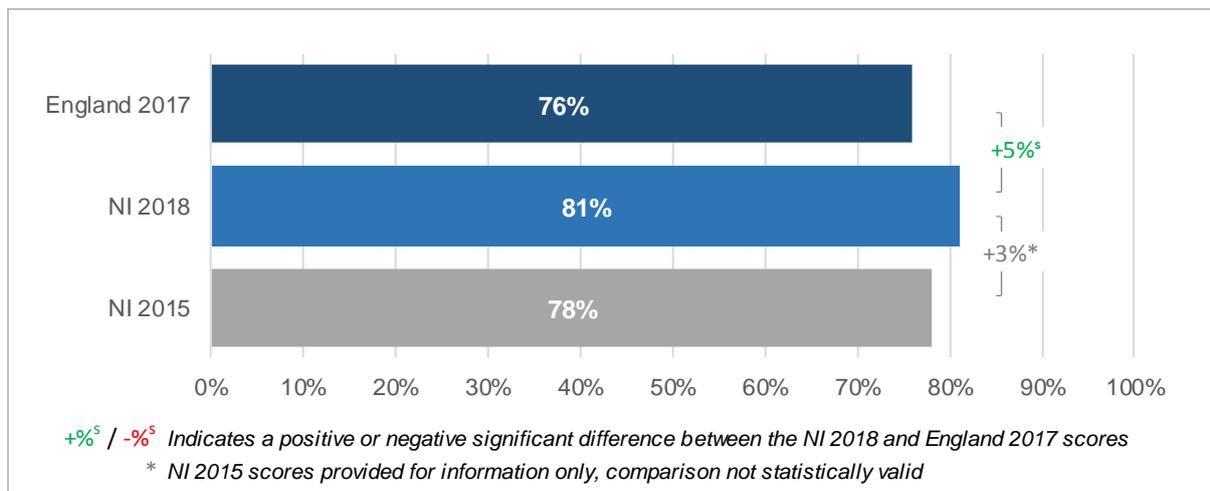
87% of patients had confidence and trust in all the doctors who treated them. This is significantly higher than the England 2017 score of 85%. However, it is a decline of 1% on the Northern Ireland 2015 score of 88%.

**Q32. Family or friends of the patient were definitely able to talk to a doctor if they wanted to**



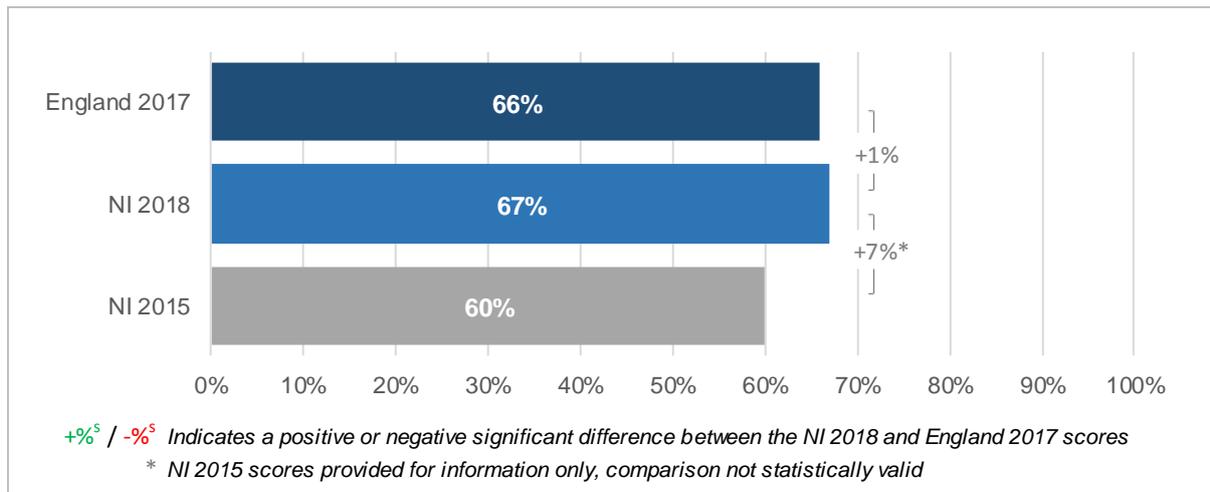
76% of patients said that if their family or someone else close to themselves wanted to talk to a doctor, they were definitely able to. This is higher than the England 2017 score of 73%. Additionally, it is an improvement of 7% on the Northern Ireland 2015 score of 69%.

**Q33. Patient had confidence and trust in all of the nurses treating them**



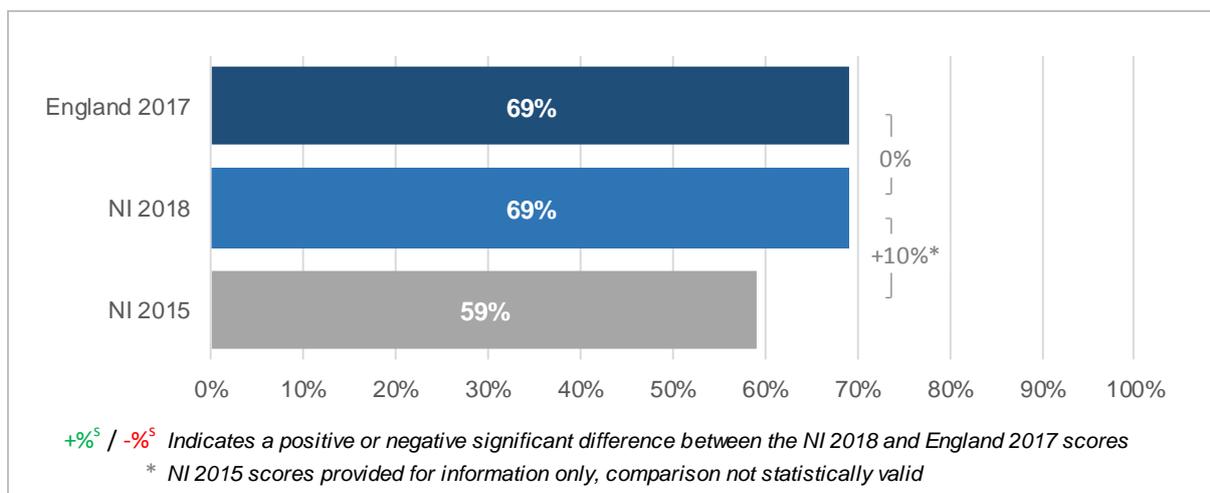
81% of patients had confidence and trust in all of the ward nurses who treated them. This is significantly higher than the England 2017 score of 76%. Additionally, it is an improvement of 3% on the Northern Ireland 2015 score of 78%.

**Q34. Patient thought there were always or nearly always enough nurses on duty to care for them in hospital**



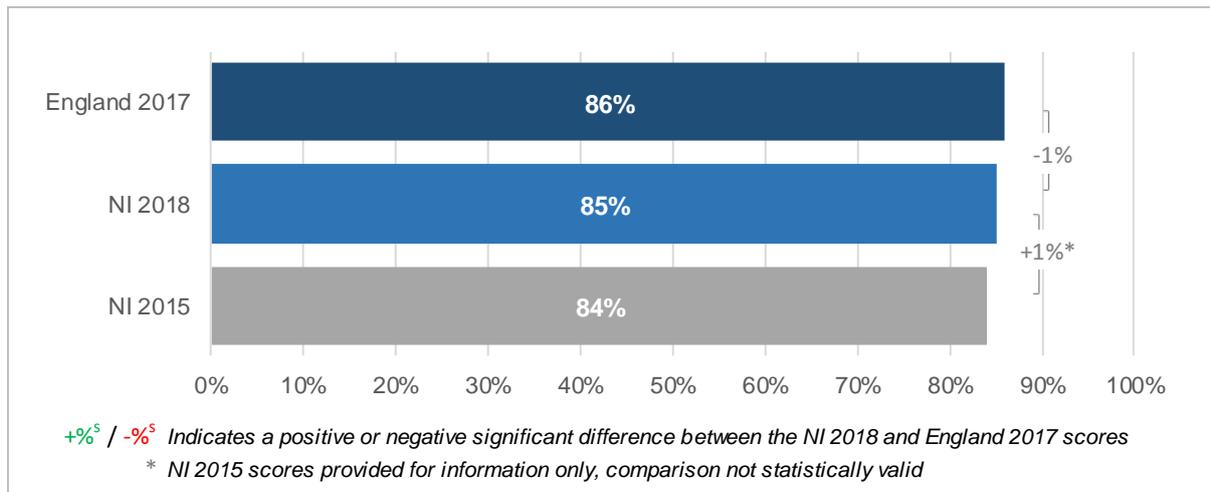
67% of patients thought that there were always or nearly always enough nurses on duty to care for them in hospital. This is higher than the England 2017 score of 66%. Additionally, it is an improvement of 7% on the Northern Ireland 2015 score of 60%.

**Q35. Patient was asked which name they prefer to be called by all doctors and nurses**



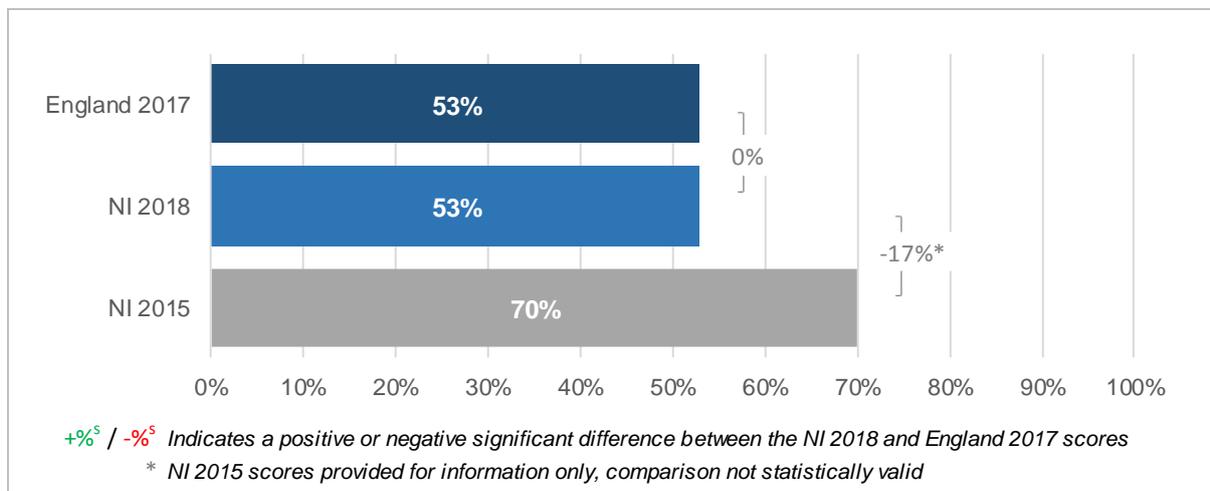
69% of patients said all of the doctors and nurses they saw asked which name they prefer to be called by. This is the same as the England 2017 score of 69%. It is an improvement of 10% on the Northern Ireland 2015 score of 59%.

**Q36. Patient was always given enough privacy when discussing their condition or treatment**



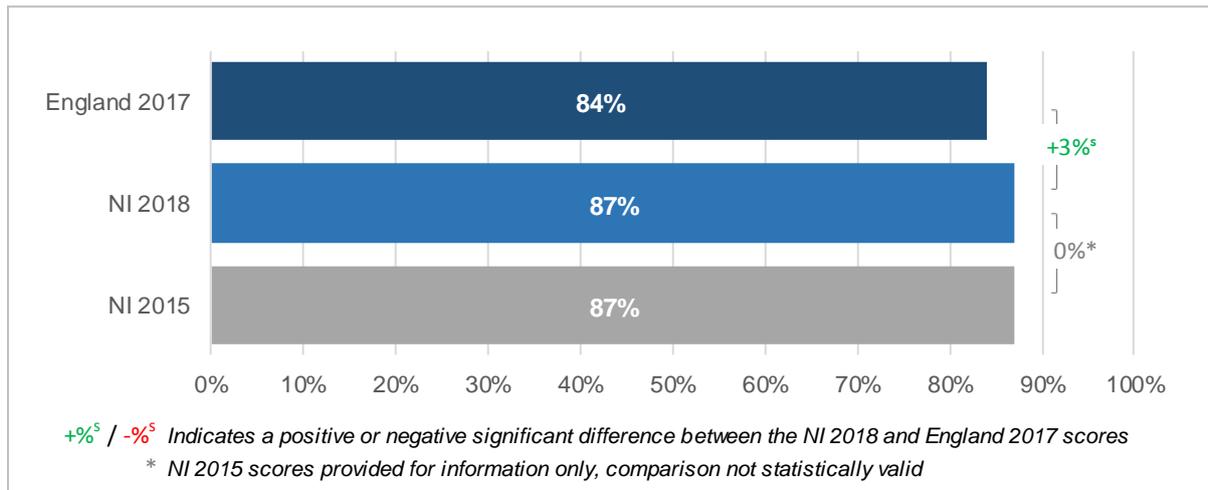
85% of patients were always given enough privacy when discussing their condition or treatment. This is lower than the England 2017 score of 86%. However, it is an improvement of 1% on the Northern Ireland 2015 score of 84%.

**Q37. As an inpatient, patient was definitely able to find a member of hospital staff to talk to about their worries and fears**



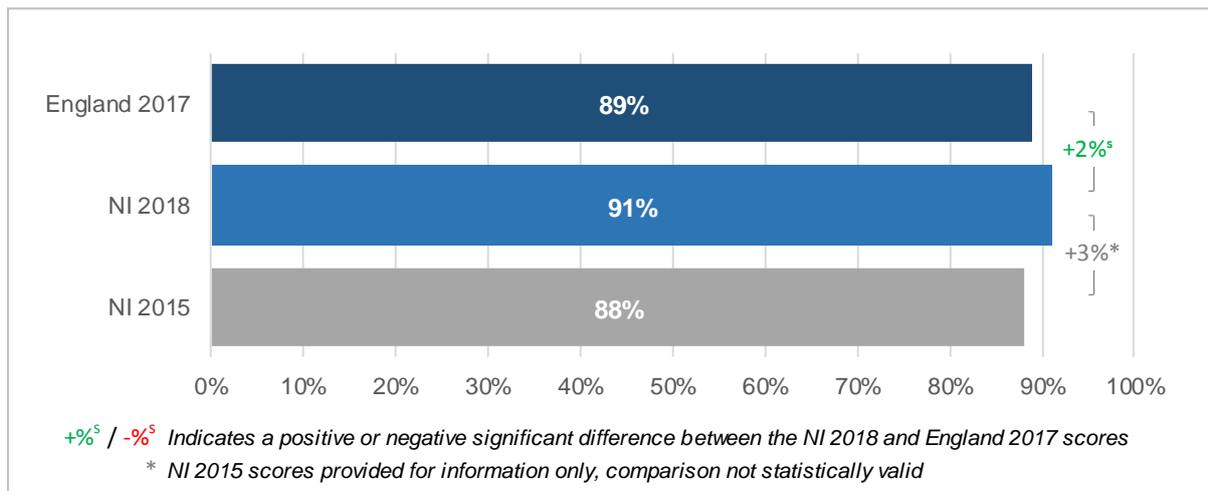
53% of patients definitely found someone on the hospital staff to talk to about their worries and fears during their hospital visit as an inpatient. This is the same as the England 2017 score of 53%. However, it is a decrease of 17% on the Northern Ireland 2015 score of 70%.

### Q38. Patient thought staff definitely did all they could to help control their pain



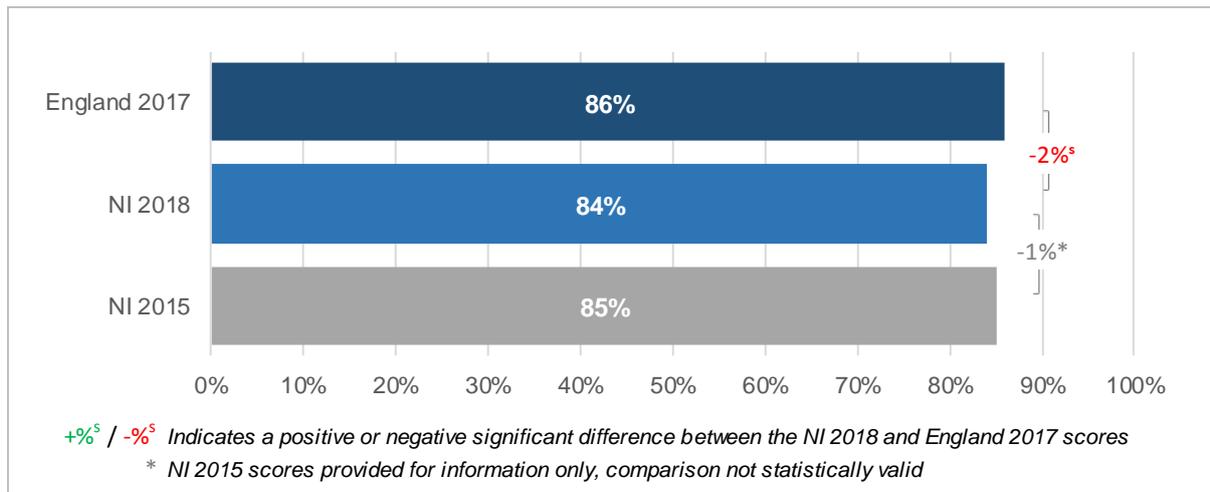
87% of patients definitely thought that hospital staff did everything they could to help control their pain. This is significantly higher than the England 2017 score of 84%. It is the same as the Northern Ireland 2015 score of 87%.

### Q39. Patient thought they were always treated with respect and dignity while in hospital



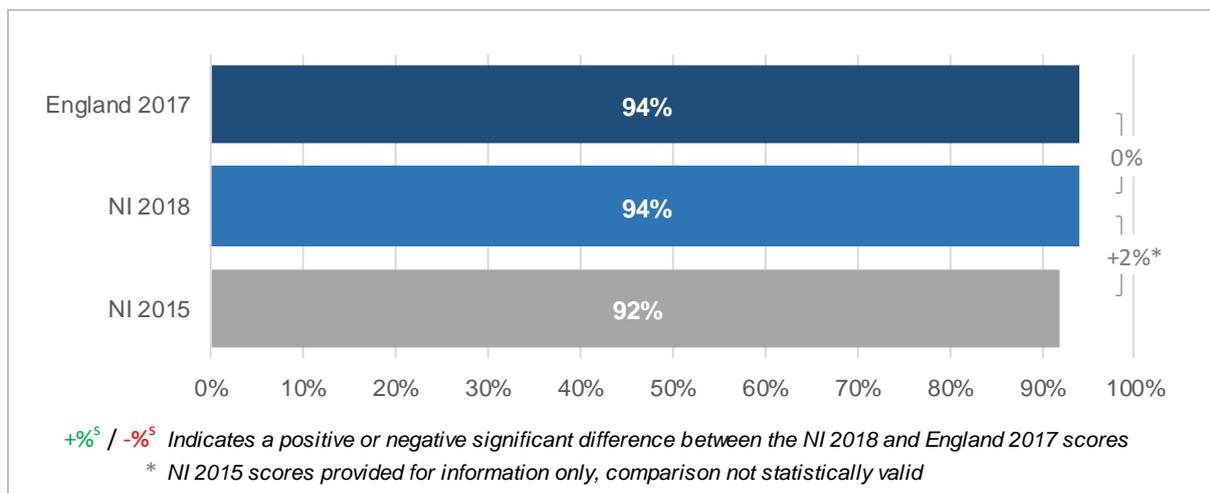
91% of patients felt like they were always treated with respect and dignity whilst in hospital. This is significantly higher than the England 2017 score of 89%. Additionally, it is an improvement of 3% on the Northern Ireland 2015 score of 88%.

**Q40. Patient was given clear written information about what they should or should not do after leaving hospital**



84% of patients were given clear written information about what they should or should not do after leaving hospital. This is significantly lower than the England 2017 score of 86%. Additionally, it is a decrease of 1% on the Northern Ireland 2015 score of 85%.

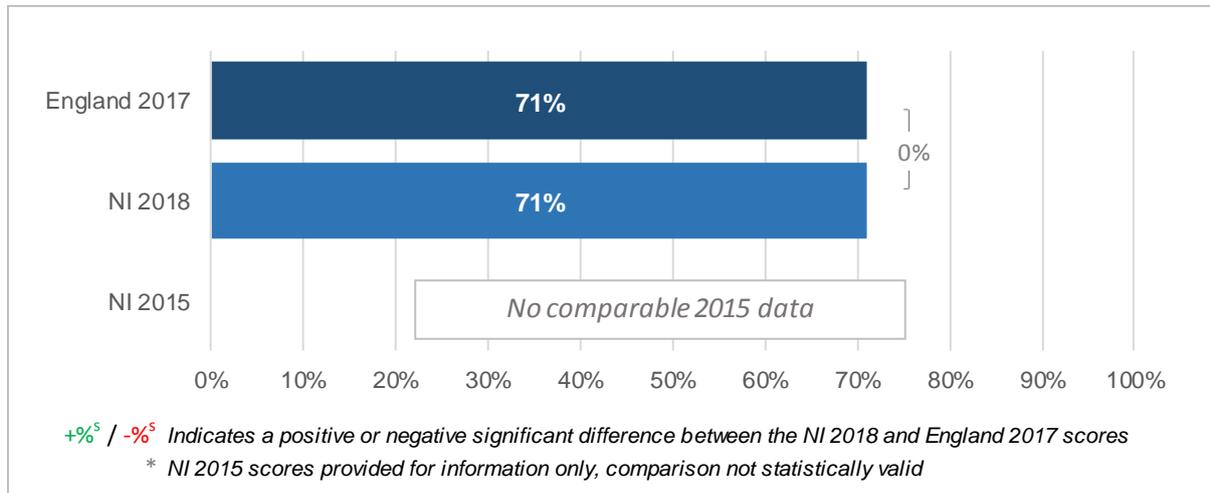
**Q41. Patient was told who to contact if they were worried about their condition or treatment after leaving hospital**



94% of patients were told by hospital staff who to contact if they were worried about their condition or treatment after leaving hospital. This is the same as the England 2017 score of 94%. Additionally, it is an improvement of 2% on the Northern Ireland 2015 score of 92%.

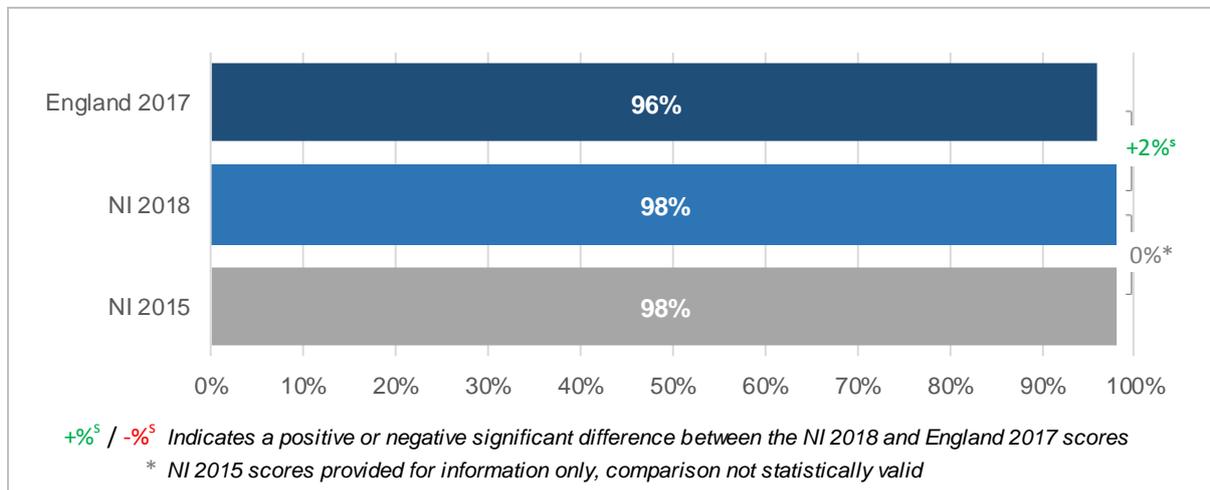
## 4.11. Hospital Care as A Day Patient / Outpatient

### Q44. As an outpatient, patient was able to find a member of hospital staff to talk to about their worries and fears



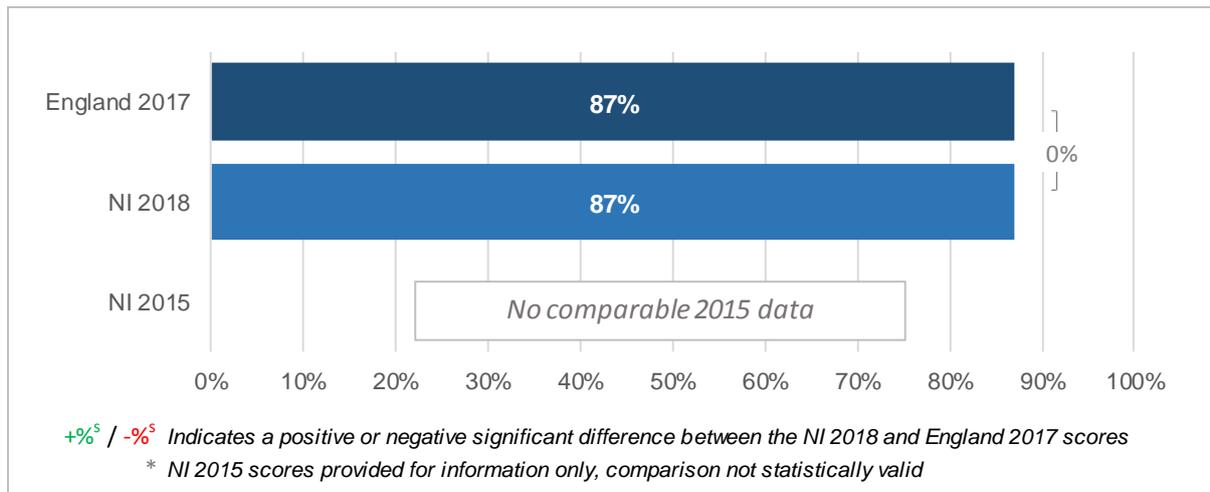
71% of patients were definitely able to find someone on the hospital staff to talk to about their worries and fears, whilst being treated as an outpatient or day case. This is the same as the England 2017 score of 71%. This was not a question asked on the Northern Ireland 2015 survey.

### Q45. Cancer doctor had the right documents during patient's last outpatient appointment



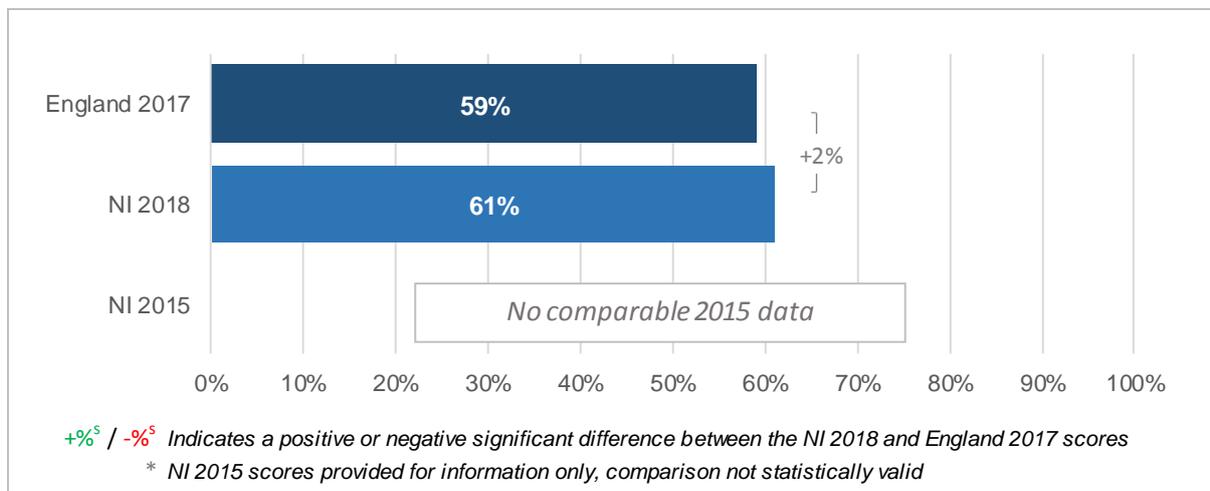
98% of patients said that the last time they had an outpatients appointment with a cancer doctor, the doctor had all the right documents. This is significantly higher than the England 2017 score of 96%. It is the same as the Northern Ireland 2015 score of 98%.

**Q47. Patient had all the information they needed about their radiotherapy beforehand**



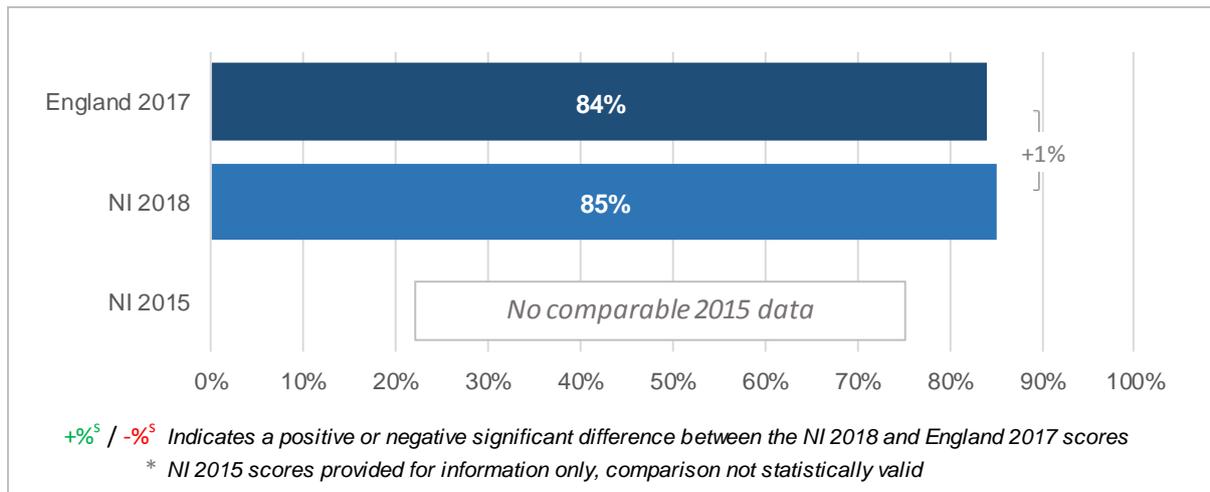
87% of patients were given all the information they needed about their radiotherapy treatment before the treatment started. This is the same as the England 2017 score of 87%. This was not a question asked on the Northern Ireland 2015 survey.

**Q48. Patient was given enough information about whether their radiotherapy was working, in a way they could completely understand**



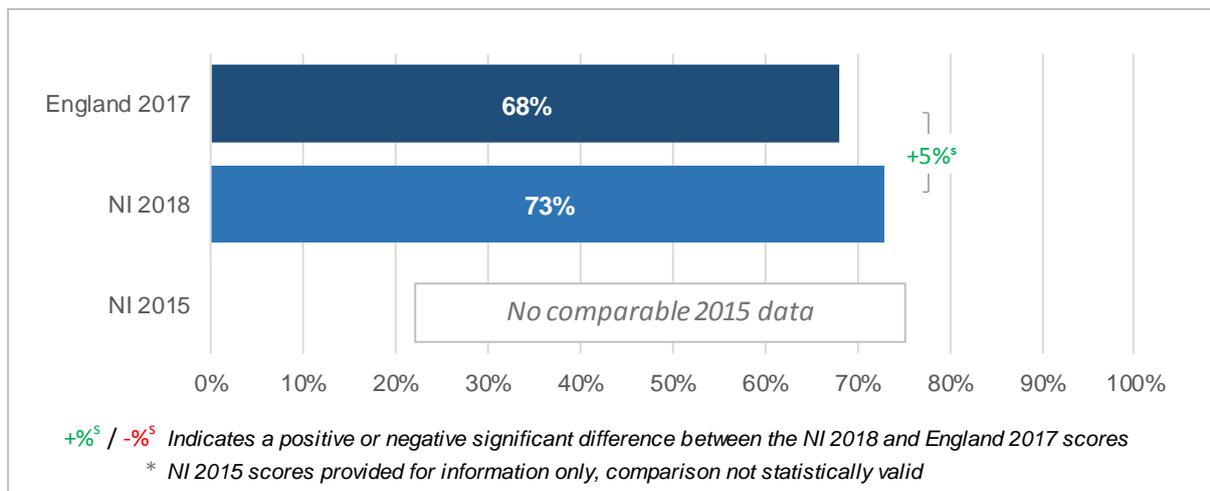
61% of patients felt they were given enough information about whether or not their radiotherapy was working, in a way they understood. This is higher than the England 2017 score of 59%. This was not a question asked on the Northern Ireland 2015 survey.

### Q50. Patient had all the information they needed about their chemotherapy beforehand



85% of patients were given all the information they needed about their chemotherapy treatment before the treatment started. This is higher than the England 2017 score of 84%. This was not a question asked on the Northern Ireland 2015 survey.

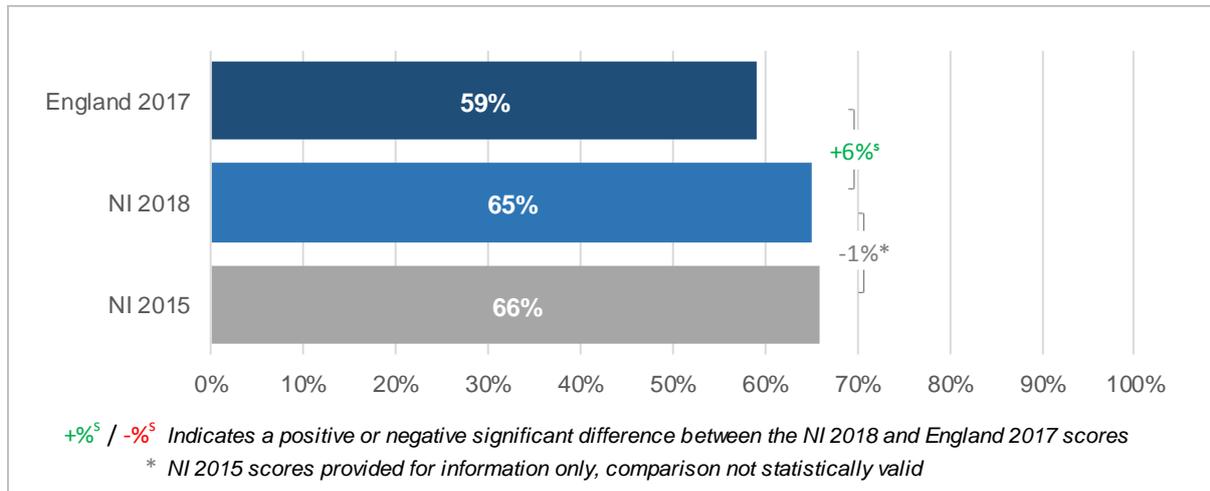
### Q51. Patient was given enough information about whether their chemotherapy was working, in a way they could completely understand



73% of patients felt they were completely given enough information about whether or not their chemotherapy was working in a way they understood. This is significantly higher than the England 2017 score of 68%. This was not a question asked on the Northern Ireland 2015 survey.

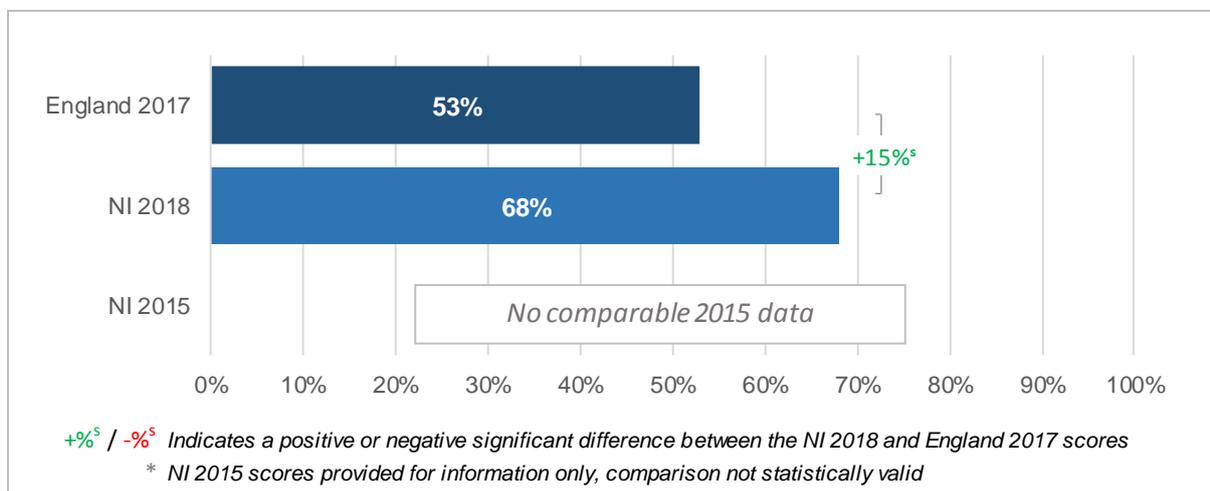
## 4.12. Home Care and Support

### Q52. Doctors or nurses definitely gave the patient's family or friends all the information they needed to help care for them at home



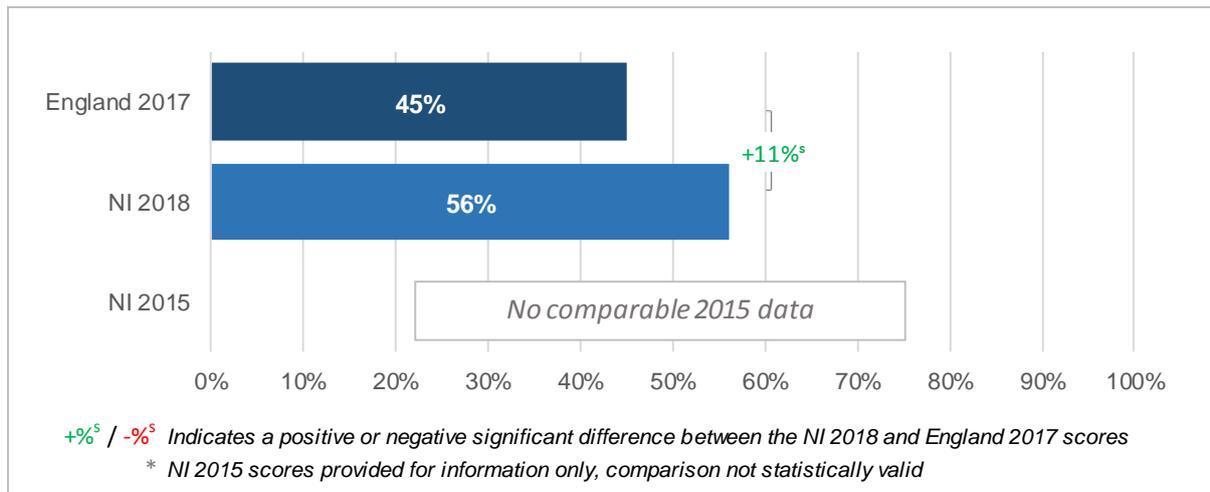
65% of patients said the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home. This is significantly higher than the England 2017 score of 59%. However, it is a decline of 1% on the Northern Ireland 2015 score of 66%.

### Q53. Patient was definitely given enough care and support by health or social services during treatment



68% of patients definitely felt they were given enough care and support from health or social services during their cancer treatment. This is significantly higher than the England 2017 score of 53%. This was not a question asked on the Northern Ireland 2015 survey.

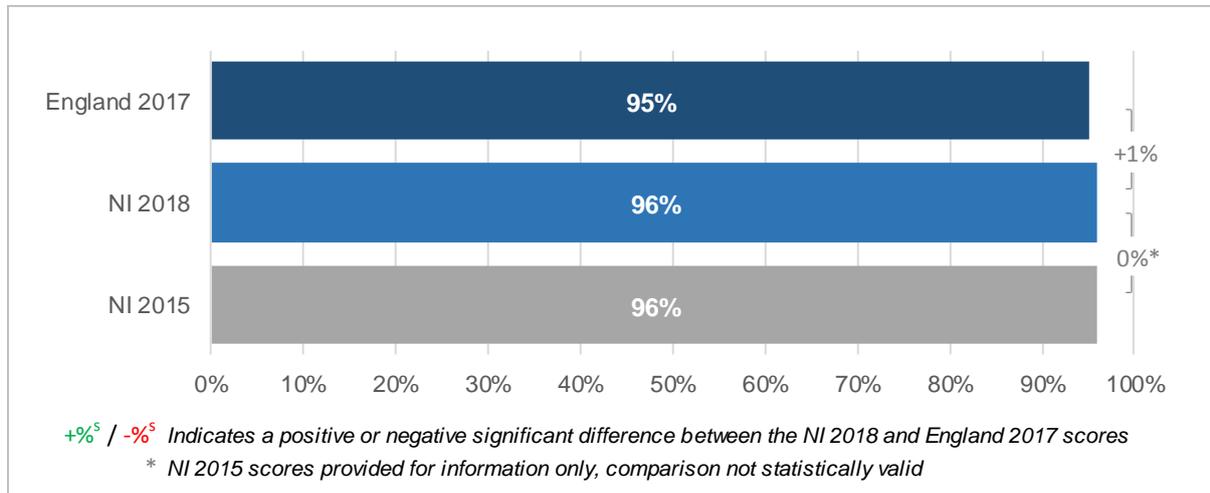
### Q54. Patient was definitely given enough care and support by health or social services after treatment



56% of patients definitely felt they were given enough care and support from health or social services once their cancer treatment finished. This is significantly higher than the England 2017 score of 45%. This was not a question asked on the Northern Ireland 2015 survey.

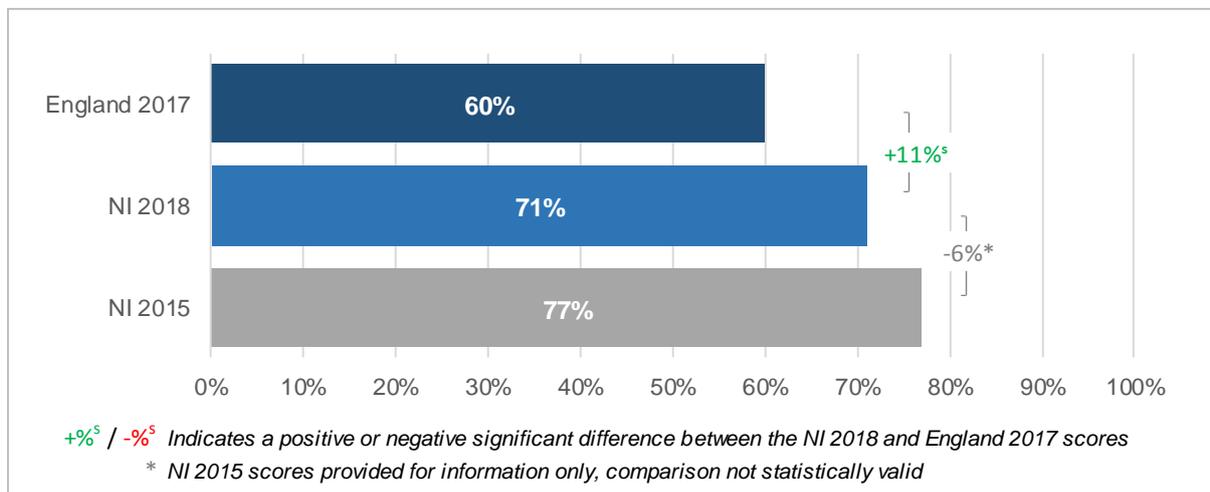
## 4.13. Care from Your General Practice

### Q55. Patient thought their GP was given enough information about their condition and treatment



96% of patients said that their GP was given enough information about their condition and the treatment they had at the hospital. This is higher than the England 2017 score of 95%. It is the same as the Northern Ireland 2015 score of 96%.

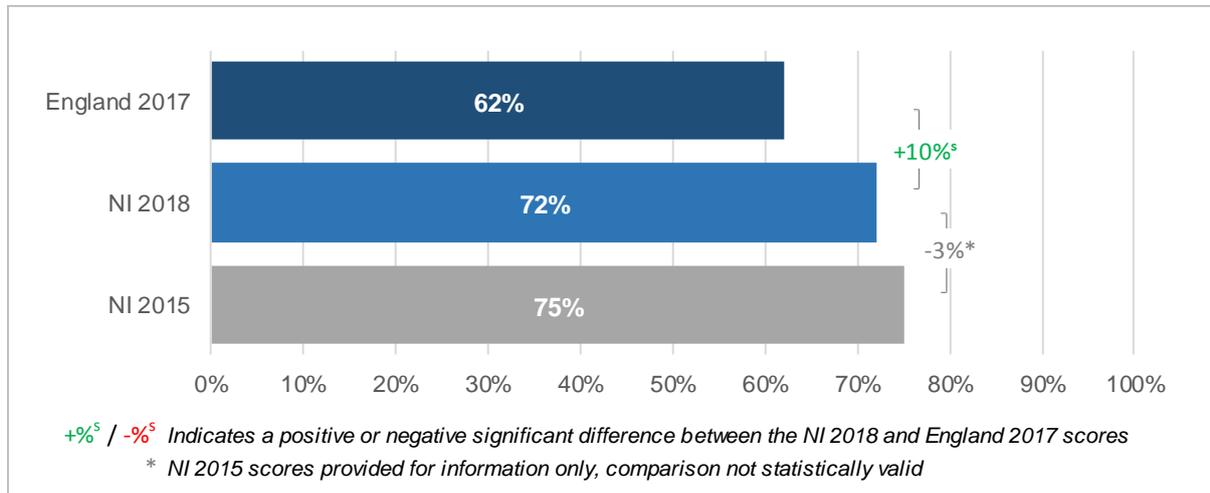
### Q56. Patient thought GP staff definitely did everything they could to support them during treatment



71% of patients definitely felt that the GPs and nurses at their general practice definitely did everything they could to support them during their cancer treatment. This is significantly higher than the England 2017 score of 60%. However, it is a decline of 6% on the Northern Ireland 2015 score of 77%.

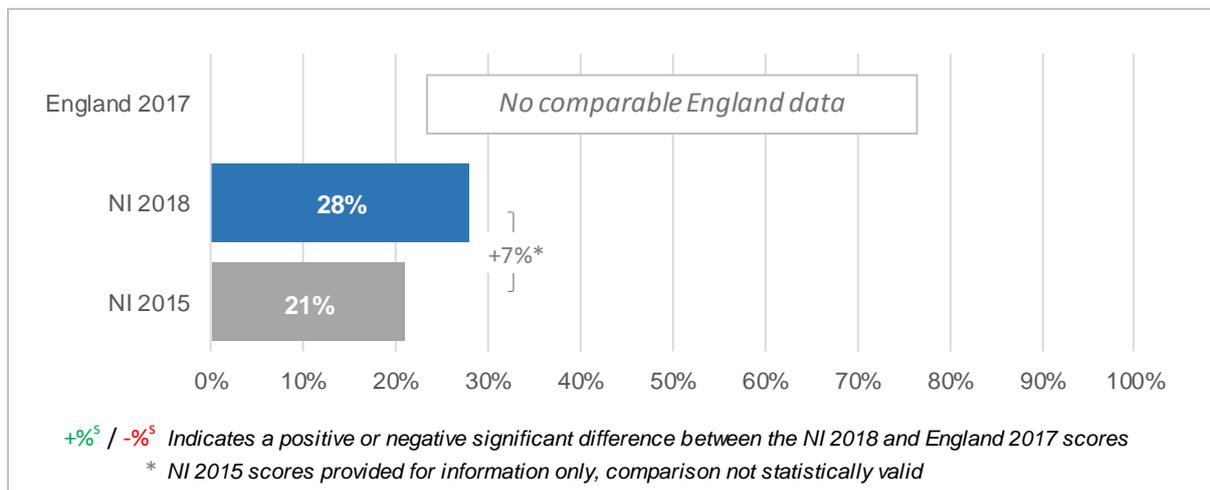
## 4.14. Your Overall Care

### Q57. Patient thought all the different people treating and caring for them always worked well together



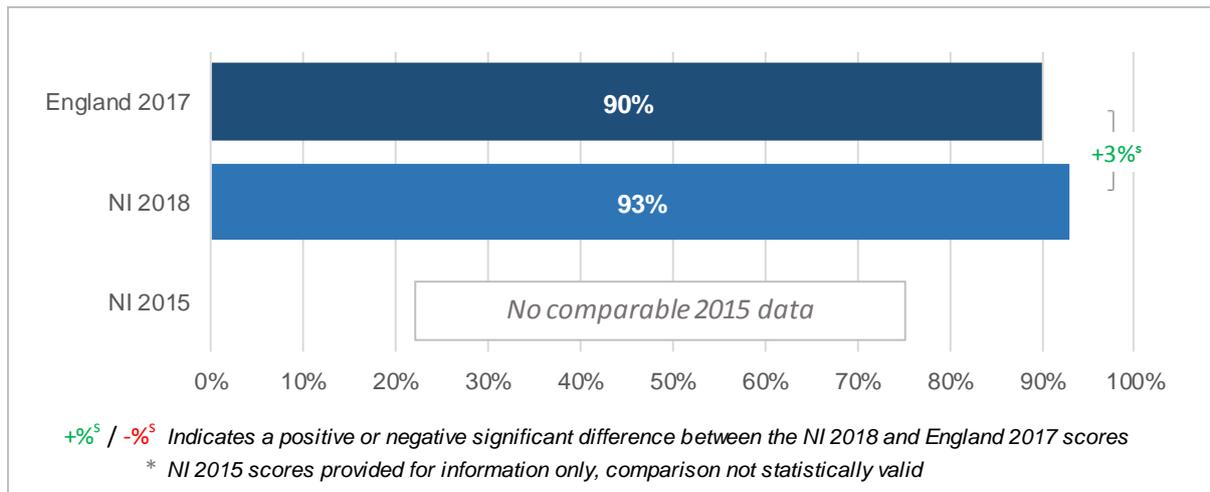
72% of patients always felt that the different people treating and caring for them worked well together to provide the best possible care. This is significantly higher than the England 2017 score of 62%. However, it is a decline of 3% on the Northern Ireland 2015 score of 75%.

### Q58. Patient was offered a needs assessment and care plan



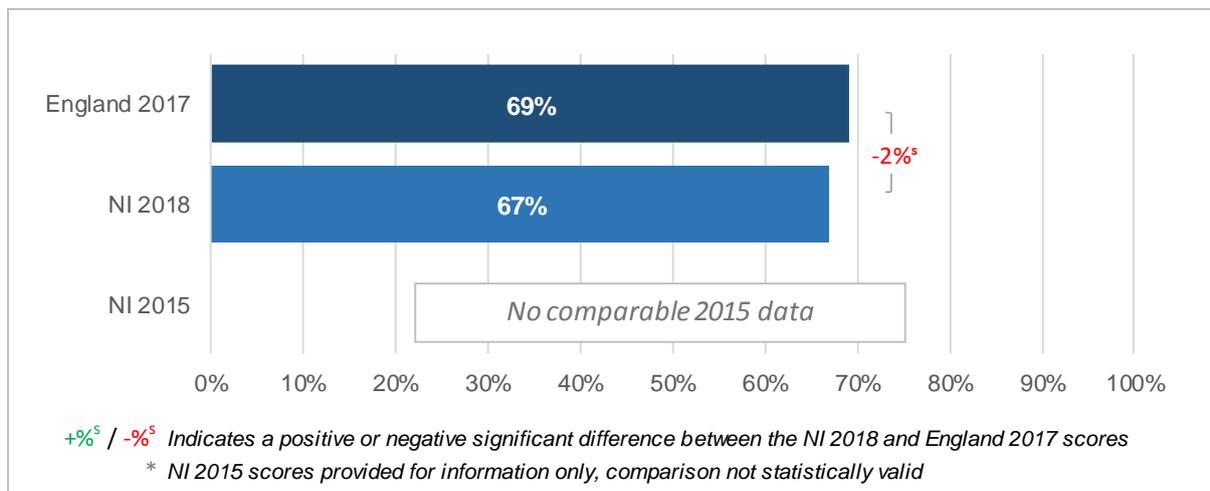
28% of patients have been offered a needs assessment and care plan. This was not a question asked on the England 2017 survey. However, it is an improvement of 7% on the Northern Ireland 2015 score of 21%.

**Q59. Patient thought the administration of their care was either good or very good**



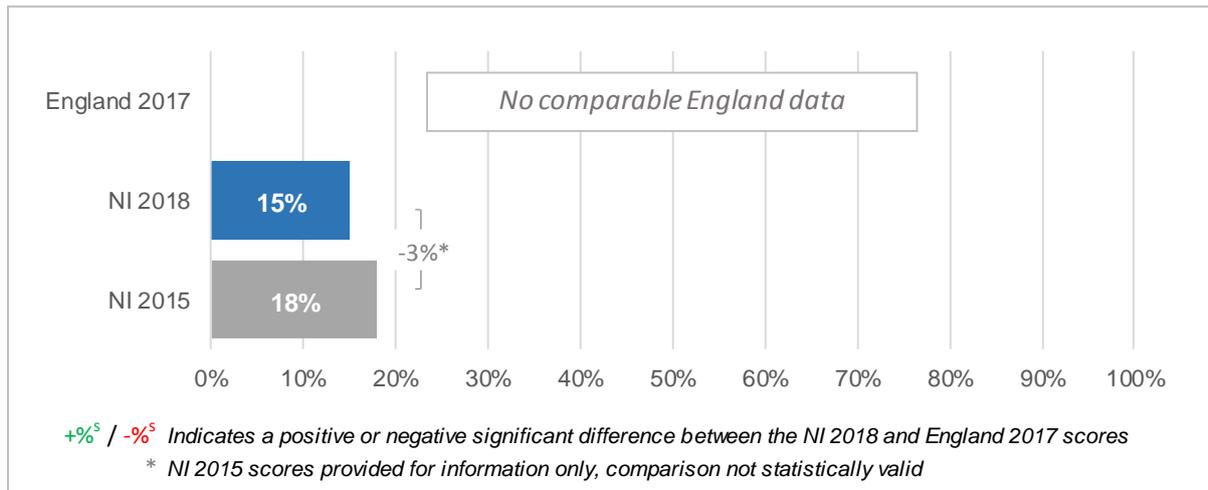
93% of patients rated the administration of their overall care as either 'Good' or 'Very good'. This is significantly higher than the England 2017 score of 90%. This was not a question asked on the Northern Ireland 2015 survey.

**Q60. Patient thought the wait time when attending clinics for treatment was about right**



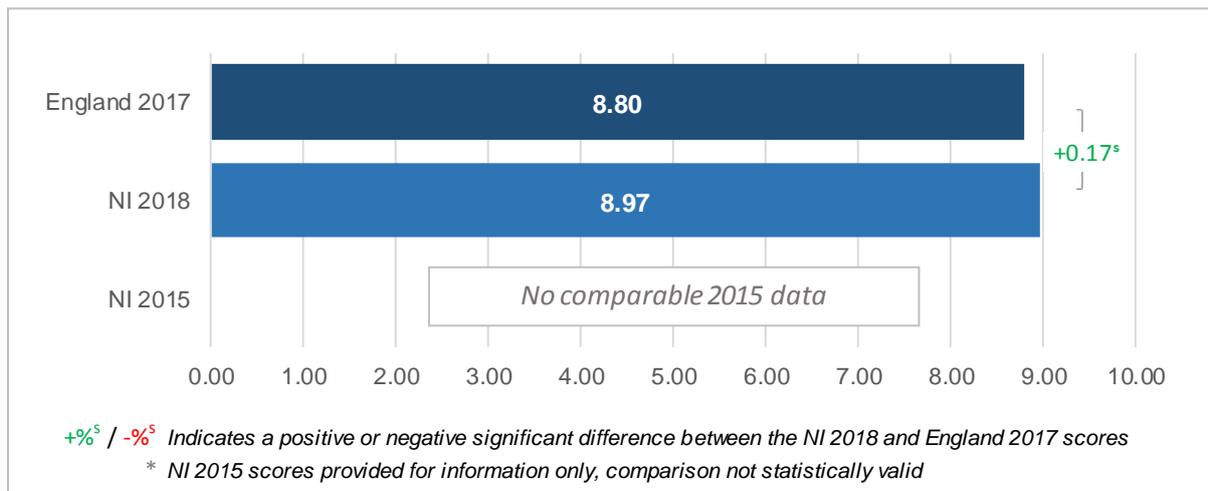
67% of patients felt the length of time they had to wait whilst attending clinics and appointments for their cancer treatment was about right. This is significantly lower than the England 2017 score of 69%. This was not a question asked on the Northern Ireland 2015 survey.

## Q61. Patient was asked whether they would like to take part in cancer research



15% of patients had, since diagnosis, had someone discuss with them whether they would like to participate in cancer research. This was not a question asked on the England 2017 survey. However, it is a decline of 3% on the Northern Ireland 2015 score of 18%.

## Q62. Overall rating patient gave for care received



Patients for Northern Ireland 2018 gave an average overall rating of 8.97 for their care, on a scale of 0 (Very Poor) to 10 (Very Good). This is significantly higher than the England 2017 score of 8.80. This was not a question asked on the Northern Ireland 2015 survey.

## 5. Variation in scores across Trusts

In this section, we highlight the survey questions with the greatest variation between the highest lowest scores by Trust. For any questions where the difference between the scores for the highest and lowest scoring Trusts was 10% or more, the table below shows the highest score, the lowest score and the difference between these scores.

		<i>Highest</i>	<i>Lowest</i>	<i>Difference</i>
Q23	Hospital staff gave patient information about financial help and benefits available	81.7%	62.5%	19.2%
Q60	Patient thought the wait time when attending clinics for treatment was about right	74.6%	56.8%	17.9%
Q36	Patient was always given enough privacy when discussing their condition or treatment	95.6%	80.1%	15.5%
Q61	Patient was asked whether they would like to take part in cancer research	21.5%	8.6%	12.9%
Q50	Patient had all the information they needed about their chemotherapy beforehand	91.8%	79.2%	12.6%
Q54	Patient was definitely given enough care and support by health or social services after treatment	64.4%	52.1%	12.3%
Q53	Patient was definitely given enough care and support by health or social services during treatment	75.3%	63.5%	11.8%
Q30	Patient thought no doctors or nurses talked in front of them as if they weren't there	86.5%	74.9%	11.6%
Q38	Patient thought staff definitely did all they could to help control their pain	89.8%	79.1%	10.7%
Q51	Patient was given enough information about whether their chemotherapy working, in a way they could completely understand	79.1%	68.8%	10.4%
Q37	As an inpatient, patient was definitely able to find a member of hospital staff to talk to about their worries and fears	61.3%	51.1%	10.2%
Q33	Patient had confidence and trust in all of the nurses treating them	86.8%	76.7%	10.1%
Q58	Have you been offered a needs assessment and care plan?	33.6%	23.6%	10.0%

## 6. Comparison between different groups of cancer patients

### 6.1. Demographics

For this section, we have tested for differences in patient experience between different cohorts of patients, by dividing respondents into groups based on gender, age, cancer type, etc. and then testing for significant differences between the scores for different groups across all questions. This allows us to highlight any statistically significant inequalities in cancer patient experience in Northern Ireland based on patients' demographic characteristics or clinical factors

For more detail on the methods used, see Appendix 1. For more detailed results from the analysis presented here, please view the NI CPES 2018 data tables at this link:

<https://www.quality-health.co.uk/surveys/northern-ireland-cancer-patient-experience-survey-2018>

There are significant differences between **genders** on 19 questions (men higher on 14 questions, women on 5).

There are significant differences between **ethnic groups** on only 5 questions.

There are significant differences between **age groups** on 35 questions.

On most questions, there is at least one **cancer type** that has significantly higher or lower scores than the others.

There are significant differences between **deprivation quintiles** 1 and 5 on only 6 questions. On all of these, respondents from the most deprived quintile report a more positive score than those from the least deprived.

### 6.2. Impact of a CNS

There is a statistically significant association between being given the name of a CNS (question 18) and positive scores elsewhere in the survey.

Those who answer 'Yes' to question 18 have statistically higher scores on 47 of the other 48 questions.

### 6.3. Impact of a care plan

There is a statistically significant association between being offered a needs assessment and care plan (question 58) and positive scores elsewhere in the survey.

Those who answer 'Yes' to question 58 have significantly higher scores on 46 of the other 50 questions.

## **6.4. Cancer status**

There are some differences in responses between those whose cancer remained after treatment and those whose cancer had been successfully treated or removed.

Those whose cancer remained score significantly lower on 18 questions; and significantly higher on none.

## **6.5. Comorbidities**

There are some differences in responses between those with comorbidities and those without.

Those with comorbidities score significantly lower on 26 questions; and significantly higher on only two.

## **6.6. Unemployment**

There are some differences in responses between who were employed at the time of diagnosis and those who weren't.

Those who were unemployed score significantly lower on 19 questions; and significantly higher on only three.

## APPENDIX 1

### How to interpret the results

The significance level was set at  $p < 0.05$  for all comparisons. The combined Northern Ireland 2018 score was compared, where applicable, to the England 2017 survey score with the significance noted. There is no comparability between the 2018 & 2015 Northern Ireland surveys due to changes in the sampling timeframe and questionnaire design and so the difference in score is only shown for information purposes and is in no way statistically significant.

### Methodology

In order to establish whether differences between groups of respondents on a particular question are statistically significant, two standard tests of significance have been used:

- A test of proportion (Stata's `prtest`) to test whether there is a significant difference between the scores of two groups (e.g. gender)
- A chi-squared test, to test whether there are significant differences in scores across multiple patient sub-groups (e.g. across ethnic groups, or across age bands).

Both tests examine, for any particular question, differences in the proportion of 'positive' responses across the various sub-groups, e.g. age bands. If there were no differences, the proportion of 'positive' responses would be constant across all sub-groups (and equal to the overall proportion).

### Question 62 (overall rating of care)

For question 62, an average score is calculated (rather than a "percentage positive"). Significance Testing for this question takes two forms:

1. For the gender breakdown, a t-test compares the average scores for males and females. Similarly, for deprivation, a t-test compares the average scores for the 1st and 5th deprivation quintiles
2. For cancer type, age band and ethnic group, t-tests compare each sub-group to the national score.

Stata 14 was used for the statistical analysis. The immediate form of the pr-test and t-test was used for the comparison between NI CPES 2018 and England CPES 2017.