

# Cancer Patient Experience Survey: Insight Report and League Table 2012–13

**INTELLIGENCE  
AND RESEARCH**

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# National results: areas of focus

Nationally, the 2012–13 National Cancer Patient Experience Survey (CPES) captures a picture of progress among hospital trusts, with marginal but consistent improvements across many areas. However, there are a number of areas where substantial progress is still needed. Some of the areas of concern nationally are shown below, along with examples of how Macmillan Cancer Support is helping to address these issues.

## Care planning:

- Before starting treatment almost half of patients (45%) were not fully informed about side effects that could affect them in the future
  - Almost four in five (78%) were not offered a written assessment and care plan
  - Around four in 10 (41%) were not given enough support from health and social services after leaving hospital
- Macmillan's report [Throwing light on the consequences of cancer and its treatment](#) sets out recommendations for how health professionals and service commissioners can improve the lives of those affected by the long-term consequences of cancer and its treatment.**

## Financial support:

- Although significant improvement has been made since the first survey in 2010, almost half of patients (46%) who would have liked information about how to get financial help or any benefits are still not receiving this.
- For more information about how a cancer diagnosis can impact on a person's finances and the importance of support and advice see Macmillan's report [Cancer's Hidden Price Tag](#).**

## Relational care:

- More than half of patients (58%) said that all doctors and nurses asked what name they preferred to be called by
- This is an example of one of the behaviours outlined in the [Macmillan Values Based Standard](#)<sup>®</sup> which is designed by patients, staff, carers and relatives, and demonstrates what can be done to change relationship dynamics between staff and patients. Macmillan's report [Improving care for people with cancer: Putting cancer patient experience at the heart of the new NHS](#) sets out our views on how to ensure people's experience of care, in particular the relational aspects, are given the same weight as their clinical outcomes and safety.**

# 10 most improved NHS trusts, 2011–12 to 2012–13

Trust, SHA, Number of scores showing statistically significant improvement/fall between 2011–12 to 2012–13

Top 10 most improved trusts - ranked by number of scores showing statistically significant improvement, then by number of scores showing statistically significant fall

Trust	Strategic health authority	Number of scores improving	Number of scores falling
University Hospital Southampton NHS Trust	South Central	18	1
Royal Cornwall Hospitals NHS Trust	South West	17	0
The Royal Wolverhampton NHS Trust	West Midlands	15	0
Nottingham University Hospitals NHS Trust	East Midlands	13	0
Oxford University Hospitals NHS Trust	South Central	12	0
Worcestershire Acute Hospitals NHS Trust	West Midlands	11	0
Royal Devon and Exeter NHS Foundation Trust	South West	10	0
East Kent Hospitals University NHS Foundation Trust	South East Coast	10	0
Basildon and Thurrock University Hospitals NHS Foundation Trust	East Of England	9	0
Derby Hospitals NHS Foundation Trust	East Midlands	8	0

Source: Analysis by Macmillan Cancer Support based on NHS England's National Cancer Patient Experience Survey 2012–13

\*Only scores showing a *statistically significant* improvement or fall are counted.

# 10 best and 10 poorest performing NHS trusts in England, 2012–13

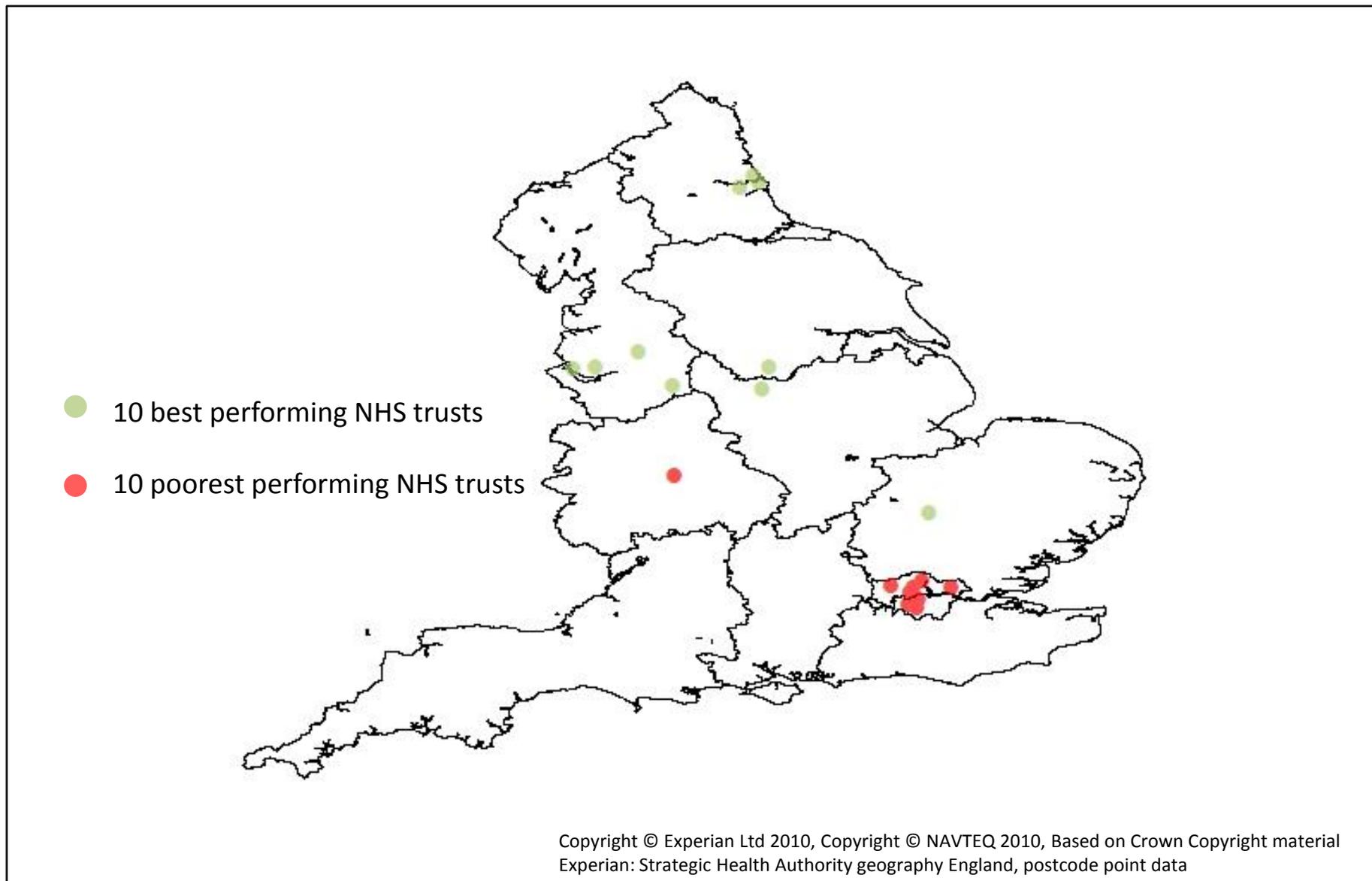
Rank, Trust, SHA, Number of responses, Number of questions falling into the top/bottom 20%, position in 2011–12

Top 10 best performing trusts - ranked by number of times in top 20%, then number of times in bottom 20%						
Rank	Trust	Strategic health authority	No. of responses	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%	Position in 2011–12 top ten
1	Gateshead Health NHS Foundation Trust	North East	361	1	44	5
2	East Cheshire NHS Trust	North West	131	2	43	-
3	South Tyneside NHS Foundation Trust	North East	110	2	41	2
4	The Rotherham NHS Foundation Trust	Yorkshire	63	4	41	-
5	Liverpool Women's NHS Foundation Trust	North West	74	6	39	-
6	Chesterfield Royal Hospital NHS Foundation Trust	East Midlands	174	3	38	6
7	St Helens and Knowsley Teaching Hospitals NHS Trust	North West	160	4	36	8
8	Bolton NHS Foundation Trust	North West	169	3	35	-
9	Papworth Hospital NHS Foundation Trust	Eastern	74	6	35	3
10	Northumbria Healthcare NHS Foundation Trust	North East	489	3	34	4
Bottom 10 poorest performing trusts - ranked by number of times in the bottom 20%, then number of times in top 20%						
Rank	Trust	Strategic health authority	No. of responses	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%	Position in 2011–12 bottom ten
1	Imperial College Healthcare NHS Trust	London	744	55	1	1
2	Barts Health NHS Trust	London	705	50	1	-
3	Croydon Health Services NHS Trust	London	44	43	4	-
4	Barking, Havering and Redbridge University Hospital NHS Trust	London	626	42	1	9
5	King's College Hospital NHS Foundation Trust	London	390	41	2	3
6	North Middlesex University Hospital NHS Trust	London	267	39	1	10
7	St George's Healthcare NHS Trust	London	474	39	1	-
8	Whittington Health	London	99	37	7	-
9	The North West London Hospitals NHS Trust	London	244	36	0	5
10	The Dudley Group NHS Foundation Trust	West Midlands	508	33	1	-

Source: Analysis by Macmillan Cancer Support based on NHS England's National Cancer Patient Experience Survey 2011–12 and 2012–13.

See Annex A for the top 10 and bottom 10 NHS trusts in 2011–12.

## 10 best and 10 poorest performing NHS trusts in England, 2012–13: Location by region



# The 'London effect'

As in previous years, cancer patients treated by London hospitals tend to report a less positive experience compared to hospitals elsewhere in England. This is not unique to cancer and is also reflected in other patient surveys. This year, new Macmillan research has revealed further detail on what could be causing the 'London effect', as explained below and on the following slides.

## **The poorer experience of patients treated by London hospitals is unlikely to be due to:**

- Patient case mix: although London hospitals tend to serve slightly younger patients, who are more likely to come from ethnic minorities and may have rarer cancer types, case mix only explains a relatively small part of poorer performance amongst London hospitals<sup>1</sup>
- High number of teaching hospitals (therefore more clinically complex cases): although many London hospitals are university hospitals and tertiary centres of speciality care, adjusting for teaching hospital status (in addition to case mix) has minimal impact on the differences between London and the rest of England

## **However, the poorer experience of patients treated by London hospitals may reflect:**

- Staffing levels, staff turnover and staff experience: these factors are likely to affect the amount of time spent with patients, and relationships between patients and staff
- Organisational complexity and priorities: the link between staff experience and patient experience (see slide 9) suggests that an organisational culture that prioritises one will also value the other

[1] Analysis by University of Cambridge, funded by Macmillan Cancer Support. "Exploring the influence of case-mix on hospital scores of cancer patient experience to better inform data interpretation and identify priorities for improvement actions" – presented at Cancer Outcomes Conference (National Cancer Intelligence Network). June 2013

# The role of case mix and case-mix adjustment

**Many clinicians and managers in hospitals that have performed worse than average may be asking the following question: “Are we providing poorer care, or is it that our patients are ‘different’?”**

The CPES reports NHS hospital trust performance without ‘adjusting’ for the types of patients a hospital treats. This may raise concerns about unfair comparisons and make it more difficult to engage staff in improvement efforts.

Some patient groups (e.g. younger patients, those from ethnic minorities and those with some rarer types of cancer) do tend to report worse experiences. So patient case mix may, for example, matter for hospitals that specialise in treatment of certain types of cancer, or serve patients who are more likely to be from ethnic minorities. However, *in practice*, case-mix adjustment makes little difference to unadjusted (crude) hospital ranks of cancer patient experience.

The great majority of hospitals that are performing poorly (e.g. in the bottom 20%) remain in the poorest performance category even after case-mix adjustment. On average hospitals that do improve their ‘rank’ after case-mix adjustment only do so by a small amount.

Source: Analysis by University of Cambridge, funded by Macmillan Cancer Support. “Exploring the influence of case-mix on hospital scores of cancer patient experience to better inform data interpretation and identify priorities for improvement actions” – presented at the Cancer Outcomes Conference (National Cancer Intelligence Network). June 2013. Note: This analysis is based on 2011–12 CPES data. For more details see the report:

<http://www.macmillan.org.uk/Aboutus/Ourresearchandevaluation/Researchandevaluation/Researchandevaluationreports.aspx>

# The links between patient and staff experience

**New analysis of the relationship between the CPES and the NHS Staff Survey results shows that at a trust level, positive patient experience is related to positive staff experience and vice versa. For example, where staff suffer high levels of discrimination, cancer patients are up to 18 times more likely to receive poor care.**

Specifically cancer patient experience was correlated to staff experiences of:

- Organisational culture (specifically experiences of discrimination, harassment or violence from colleagues)
- Management of the trust (specifically provision of equal opportunities, availability of hand-washing materials, training in health and safety)
- Staff engagement (specifically intention to leave)

The elements of patient experience linked to staff experience included:

- Information and explanations of tests and operations
- Involvement in decisions about treatment
- Communication with clinical nurse specialists (CNS), doctors and nurses

The underlying reason for these relationships is not immediately clear and is likely to be complex. It will almost certainly be affected by things that were not measured or possible to take into account in this research. More research is needed to fully understand the relationship and what, if any, initiatives to improve staff experience might also impact on cancer patient experience, or vice versa.

Notes: This analysis is based on the 2011–12 Cancer Patient Experience Survey and 2011 NHS Staff Survey.

Source: Macmillan Cancer Support. The relationship between cancer patient experience and staff survey results. 2013. For more details see the report:

<http://www.macmillan.org.uk/Aboutus/Ouresearchandevaluation/Researchandevaluation/Researchandevaluationreports.aspx>

# Key variations: tumour groups

Patients with more common cancers report better patient experience than those with rarer cancers.

Rank	Tumour group
1	Breast
2	Prostate
3	Skin
4	Bowel / lower gastrointestinal
5	Lung
6	Head and neck
7	Gynaecological
8	Haematological
9	Upper gastrointestinal
10	Sarcoma
11	Urological*
12	Brain and central nervous system (CNS)
13	Other

Overall, urological, brain and CNS, and 'other' cancer patients report the worst experiences. On some questions these groups score 20-30 percentage points lower than breast cancer patients, who report the best experience. Sarcoma patients' experiences ranked worst in the 2010 and 2011-12 surveys but have seen improvement in 2012-13

Further work exploring variation within multidisciplinary team specialties (i.e. the tumour groups presented here), looking at 36 different cancer types, will be published soon.

Analysis by the University of Cambridge, funded by Macmillan Cancer Support

\*Urological excludes prostate cancer, which was included as a separate tumour group in the survey.

Source: Analysis by Macmillan Cancer Support of NHS England's National Cancer Patient Experience Survey 2012-13.

## Key variations: age, ethnicity and gender

Younger patients tend to report more negative experiences across a number of different elements of patient experience. The exception to this is for information provision, where it is oldest patients (75-84 and 85+) who report the worst experiences.

Ethnic minorities consistently report less positive experiences. Chinese patients and patients from 'other' ethnic backgrounds report the worst experiences, followed by Asian<sup>1</sup> and Black patients. The only exception here is that all ethnic minority groups are more likely to have been provided with a written care plan.

Women also tend to report more negative experiences of care across most elements of experience, however the size of this effect is smaller than differences found by age, ethnicity and cancer. Whilst some differences by socio-economic group exist, these are fairly small and inconsistent.

These inequalities may reflect differing needs and expectations by different patient groups, or differences in quality of the care that is delivered, potentially because of preconceived ideas on the part of healthcare professionals. Where patients with different cancers are at risk of reporting more negative experiences, factors could include variations in the treatment burden and prognosis, as well as the way that different specialities are resourced. Whatever the cause, these differences point to groups who have a greater need and indicate where improvement efforts can be targeted.

Experiences of discrimination and inequality in cancer care, as told by cancer survivors and carers, are described in Macmillan's report [Walking into the unknown](#).

[1] The Asian category includes Indian, Pakistani, Bangladeshi, or 'other' Asian.

## Data notes

NHS England's National Cancer Patient Experience Survey (CPES), run by Quality Health, provides insights into the care and treatment experienced by cancer patients in 155 NHS hospital trusts across England.

In the 2012–13 survey, 68,737 cancer patients treated in hospital as day cases or inpatients during September to November 2012 took part. This is the third national CPES; the previous surveys ran in 2011–12 and 2010.

The national and trust-level survey report can be found on the [Quality Health website](#).

### **Notes on the top, bottom and most improved analysis:**

The 10 best performing NHS trusts are ranked based on the number of questions where their scores fell within the top 20% of all trusts, then further ranked by the number of questions where their scores fell within the bottom 20% of all trusts (i.e. the trusts with the highest number of questions in the green category, further ranked by the lowest number of questions in the red category).

The 10 poorest performing NHS trusts are ranked based on the number of questions where their scores fell within the bottom 20% of all trusts and are further ranked by the number of questions where their scores fell within the top 20% of all trusts (i.e. the trusts with the highest number of questions in the red category when looking at the trust-level reports, further ranked by the lowest number of questions in the green category). The remaining trusts were not ranked. There were 63 scored questions in total which were included in the ranking.

The 10 most improved NHS trusts were ranked based on the number of questions where their scores had shown a statistically significant improvement between the 2011–12 and 2012–13 surveys. The 10 most improved NHS trusts are those whose scores had improved on the highest number of questions, further ranked by those with the lowest number of questions where scores had shown a statistically significant fall.

Counts of questions scoring the top or bottom 20% for each trust are based on raw data. Due to rounding differences counts may not match those in the trust reports.

Caveat: Many trusts saw improvement on a smaller number of questions than the trusts listed in the top ten. Among these trusts there may be those who have made a larger scale of improvement in percentage terms. However the method we have used only takes into account the number of questions with improved scores, rather than the percentage change in the scores.

### **Notes on the tumour group ranking:**

There were 37 questions that identified significant differences in responses for patients with different tumour groups. For each question tumour groups were ranked according to their average score (ranked from 1 for the highest score to 13 for the lowest). An average rank for all 37 questions was then calculated for each tumour group to determine an overall ranking.

# 10 best and 10 poorest performing NHS trusts in England, 2011–12

Rank, Trust, SHA, Number of questions falling into the top/bottom 20%

Top 10 best performing trusts - ranked by number of times in top 20%, then number of times in bottom 20%				
Rank	Trust	Strategic health authority	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%
1	Harrogate and District NHS Foundation Trust	Yorks & Humber	0	55
2	South Tyneside NHS Foundation Trust	North East	1	55
3	Papworth Hospital NHS Foundation Trust	East of England	3	46
4	Northumbria Healthcare NHS Foundation Trust	North East	0	44
5	Gateshead Heath NHS Foundation Trust	North East	1	42
6	Chesterfield Royal Hospital NHS Foundation Trust	East Midlands	3	37
7	Barnsley Hospital NHS Foundation Trust	Yorks & Humber	4	37
8	St Helens and Knowsley Teaching Hospitals NHS Trust	North West	3	36
9	Liverpool Heart and Chest Hospital NHS Foundation Trust	North West	6	36
10	Tameside Hospital NHS Foundation Trust	North West	2	35
Bottom 10 poorest performing trusts - ranked by number of times in the bottom 20%, then number of times in top 20%				
Rank	Trust	Strategic health authority	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%
1	Imperial College Healthcare NHS Trust	London	56	1
2	Whipps Cross University Hospital NHS Trust	London	50	1
3	King's College Hospital NHS Foundation Trust	London	45	2
4	The Princess Alexandra Hospital NHS Trust	East of England	42	4
5	North West London Hospitals NHS Trust	London	41	0
6	University College Hospital London NHS Foundation Trust	London	41	2
7	Ealing Hospital NHS Trust	London	41	4
8	Newham University NHS Trust	London	40	3
9	Barking, Havering and Redbridge University Hospitals NHS Trust	London	39	1
10	North Middlesex University Hospital Trust	London	38	3