

Cancer Patient Experience Survey: Insight Report and League Table 2014



October 2014

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CPES Results: areas of focus

The 2014 Cancer Patient Experience Survey (CPES) demonstrates marginal but consistent improvements across many areas, especially around a) verbal communication, b) written information and c) getting understandable answers as well as having confidence in ward nurses. There are however, some areas where progress is still needed. These are shown below, along with examples of how Macmillan Cancer Support is helping to address these issues.

Care planning:

- Before treatment, 44% of patients 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.

-> 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 consequences of cancer and its treatment.

-> Macmillan's [Recovery Package](#) is a series of key interventions which can greatly improve outcomes for people living with and beyond cancer. The interventions are: Holistic Needs Assessment, Treatment Summary, Cancer Care Review and Health and Wellbeing clinics. These elements are part of an overall support of self management that includes healthy lifestyle, managing consequences of treatment, and information, financial and work support.

Financial support:

- Although improvement has been made since 2010, almost half of patients (46%) who would have liked information about how to get financial help or any benefits are still not receiving any.

-> 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:

- Three in five patients (60%) said that all doctors and nurses asked what name they preferred to be called by.

-> Macmillan is launching a new patient rights product. "Your Cancer Care" is a pocket sized leaflet outlining practical steps to support patients engage in their care and how to complain if things go wrong. It is based on the 8 values in the [Macmillan Values Based Standard](#)[®].

CPES Results: areas of focus

Care co-ordination and transition:

- One in three (34%) mentioned that their GPs and nurses did not support them enough whilst being treated
- Almost two in five (37%) did not feel different professionals worked well together to give them the best possible care.
- For two in five patients (40%), their families or someone close to them were not given all the information they needed to look after them at home.
- 41% were not given enough care and help from health and social services post discharge.

-> Macmillan is currently carrying out research on patients' experiences of care transitions on their cancer journey. By care transitions we mean a change in the place, provider or goal of the care that a person living with cancer is receiving. These changes occur at different stages of the journey, such as after diagnosis, when treatment stops and someone enters survivorship, or end of life. We are interested in how patients experience transitions and touch points, what factors influence their experiences and what impact this has on patients. We are particularly interested in support from primary and community care, and are focusing on health and social care.

10 most improved NHS Trusts, 2014

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 Clinical Network	Number of scores improving	Number of scores falling
The Dudley Group NHS Foundation Trust	West Midlands	14	0
York Teaching Hospital NHS Foundation Trust	Northern England	14	1
University Hospital of South Manchester NHS Foundation Trust	Greater Manchester, Lancashire and South Cumbria	14	1
Luton and Dunstable Hospital NHS Foundation Trust	East Midlands	13	0
Mid Essex Hospital Services NHS Trust	East of England	13	0
Nottingham University Hospitals NHS Trust	East Midlands	13	0
North Bristol NHS Trust	South West	12	0
Portsmouth Hospitals NHS Trust	Wessex	12	1
South Devon Healthcare NHS Foundation Trust	South West	10	0
St George's Healthcare NHS Trust	London	10	0

Source: Analysis by Macmillan Cancer Support based on NHS England's National Cancer Patient Experience Survey 2014

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

10 best and 10 poorest performing NHS trusts in England, 2014

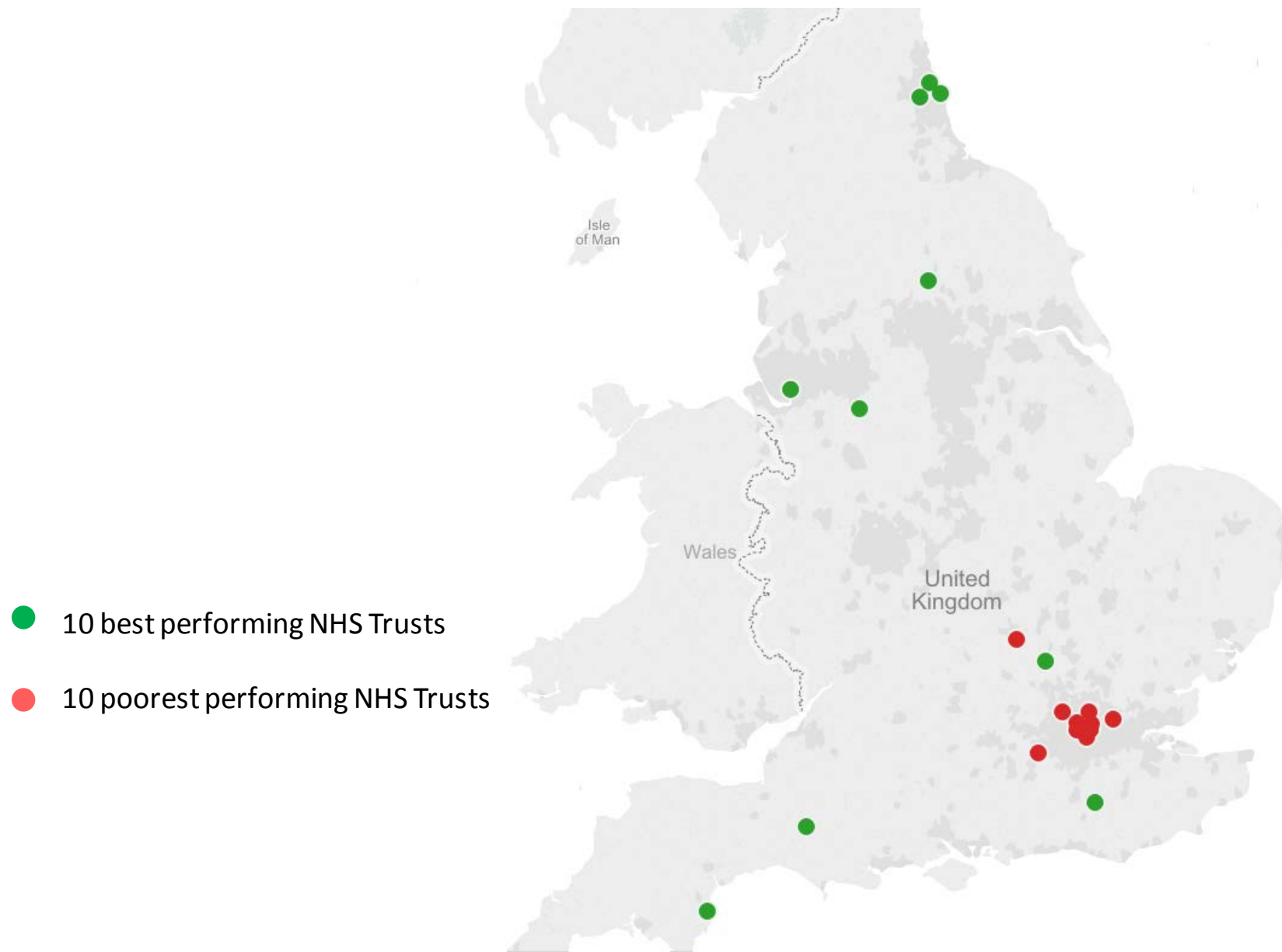
Top 10 best performing trusts - ranked by number of times in top 20%, then number of times in bottom 20%						
Rank	Trust	Strategic Clinical Network	No. of responses	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%	Position in 2013 top ten
1	South Tyneside NHS Foundation Trust	Northern England	106	3	46	3
2	Gateshead Health NHS Foundation Trust	Northern England	344	2	45	1
3	Harrogate and District NHS Foundation Trust	Yorkshire	260	0	44	-
4	St Helens and Knowsley Teaching Hospitals NHS Trust	Cheshire & Mersey	202	1	42	7
5	East Cheshire NHS Trust	Cheshire & Mersey	136	1	41	2
6	Northumbria Healthcare NHS Foundation Trust	Northern England	504	1	40	10
7	South Devon Healthcare NHS Foundation Trust	South West	367	1	38	-
8	Queen Victoria Hospital NHS Foundation Trust	South East	65	4	38	-
9	Yeovil District Hospital NHS Foundation Trust	South West	134	2	37	-
10	Luton and Dunstable Hospital NHS Foundation Trust	East of England	334	0	36	-

Bottom 10 poorest performing trusts - ranked by number of times in the bottom 20%, then number of times in top 20%						
Rank	Trust	Strategic Clinical Network	No. of responses	No. of times the trust falls within bottom 20%	No. of times the trust falls within top 20%	Position in 2013 bottom ten
1	Barts Health NHS Trust	London	888	49	2	2
2	Milton Keynes Hospital NHS Foundation Trust	East Midlands	212	45	0	-
3	Imperial College Healthcare NHS Trust	London	538	44	2	1
4	Homerton University Hospital NHS Foundation Trust	London	36	44	3	-
5	Ashford and St. Peter's Hospitals NHS Foundation Trust	South East	215	42	0	-
6	Barking, Havering and Redbridge University Hospital NHS Trust	London	546	41	1	4
7	Royal National Orthopaedic Hospital NHS Trust	London	68	39	4	-
8	Royal Free London NHS Foundation Trust	London	400	38	2	-
9	North Middlesex University Hospital NHS Trust	London	225	37	1	6
10	King's College Hospital NHS Foundation Trust	London	632	37	0	5

Source: Analysis by Macmillan Cancer Support based on NHS England's National Cancer Patient Experience Survey 2014.

See Annex A for the top 10 and bottom 10 NHS Trusts in 2013.

10 best and 10 poorest performing NHS trusts in England, 2014



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	Haematological
8	Gynaecological
9	Upper Gastrointestinal
10	Brain and central nervous system (CNS)
11	Urological*
12	Sarcoma
13	Other

Overall, brain and CNS, urological, sarcoma 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.

*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 2014



Variation by cancer

Research supported by Macmillan is drilling down on differences in patient experience between different patient groups, including patients with different cancers¹.

University of Cambridge researchers, funded by Macmillan Cancer Support, have conducted additional analysis in understanding the variation in experience between patients with different cancers and characteristics. Given that Patient Experience is a critical dimension of cancer care quality, this is an important first step for designing targeted improvement interventions.

The forthcoming publication is based on the analysis of the 2011/12 English Cancer Patient Experience Survey (n=69,086) using logistic regression to explore inequalities in care experience across 64 survey questions. In addition, the team has calculated a summary measure of variation in patient experience by cancer, and explored inequalities between patients with cancers treated by the same specialist teams.

The findings will be published soon at the European Journal of Cancer Care.

[1] Saunders CL, Abel GA, Lyratzopoulos G. *Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site. Evidence from respondents to the English Cancer Patient Experience Survey.* European Journal of Cancer Care, 2014 (in press)

Key variations: age, primary cancer, recurrence

Age is a factor that can impact patient experience. Younger patients tend to report more negative experiences. By contrast, patients in older age groups tend to give higher scores.

Other factors related to high scores are being treated for the first time for cancer, not being treated for a recurrence and being an inpatient.

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 targeted².

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](#).

² Saunders CL, Abel GA, Lyratzopoulos G. *Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site. Evidence from respondents to the English Cancer Patient Experience Survey*. European Journal of Cancer Care, 2014 (in press)

Key variations: London effect, CNS, Routes to Diagnosis

Cancer patients treated by London hospitals tend to report a less positive experience³.

Research has examined whether this could be due to:

- patient case-mix (as London hospitals serve patients more likely to be young, from ethnic minorities and with rarer cancer types⁴)
- the high number of teaching hospitals (therefore more clinically complex cases) in London

but found that these factors play only a small role.

Other possible reasons could include staffing levels, staff turnover and engagement. These factors are likely to affect the amount of time spent with patients, and relationships between patients and staff.

CNS

The presence of a Clinical Nurse Specialist is shown to have the strongest association with high scores. This is seen as the most important factor for positive patient experience^{5,6}.

Routes to Diagnosis

Patients entering care through an emergency route are much less positive about their care compared with patients who entered their care through a 2 Week Wait pathway or through screening⁴.

3 Saunders CL, Abel GA, Lyratzopoulos G. [What explains worse patient experience in London? Evidence from secondary analysis of the Cancer Patient Experience Survey](#). BMJ Open 2014;4:e004039 doi:10.1136/bmjopen-2013-004039

4 Abel GA, Saunders CL, Lyratzopoulos G. [Cancer patient experience, hospital performance and case mix: evidence from England](#). Future Oncol. 2014;10(9):1589-98.

5 NHS England. Cancer Patient Experience Survey 2014.

6 Griffiths P, Simon M, Richardson A, Corner J. [Is a larger specialist nurse workforce in cancer care associated with better patient experience? Cross-sectional study](#). J Health Serv Research Policy. 2013;18(S1):39-46.

Data notes

NHS England's 2014 National Cancer Patient Experience Survey (CPES), run by Quality Health, provides insights into the care and treatment experienced by cancer patients in 153 NHS hospital trusts across England.

In the 2014 survey, 70,134 cancer patients treated in hospital as day cases or inpatients during September to November 2013 took part. This rendered a 64% response rate from a total sample of 109,760 patients. It is the fourth national CPES; the previous surveys ran in 2010, 2011–12 and 2013.

The national and trust-level survey reports 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 61 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 2013 and 2014 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, 2013

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	Gateshead Health NHS Trust	North East	1	44
2	East Cheshire NHS Trust	North West	2	43
3	South Tyneside NHS Foundation Trust	North East	2	41
4	The Rotherham NHS Foundation Trust	Yorkshire	4	41
5	Liverpool Women's NHS Foundation Trust	North West	6	39
6	Chesterfield Royal Hospital NHS Foundation Trust	East Midlands	3	38
7	St Helens and Knowsley Teaching Hospitals NHS Trust	North West	4	36
8	Bolton NHS Foundation Trust	North West	3	35
9	Papworth Hospital NHS Foundation Trust	Eastern	6	35
10	Northumbria Healthcare NHS Foundation Trust	North East	3	34
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	55	1
2	Barts Health NHS Trust	London	50	1
3	Croydon Health Services NHS Trust	London	43	4
4	Barking, Havering and Redbridge University Hospital NHS Trust	London	42	1
5	King's College Hospital NHS Foundation Trust	London	41	2
6	North Middlesex University Hospital NHS Trust	London	39	1
7	St George's Healthcare NHS Trust	London	39	1
8	Whittington Health	London	37	7
9	The North West London Hospitals NHS Trust	London	36	0
10	The Dudley Group NHS Foundation Trust	West Midlands	33	1