

**MACMILLAN  
ATLAS OF  
VARIATION IN**

**CANCER  
PATIENT  
EXPERIENCE**

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# Introduction

Patient experience is one of three markers of quality in the new NHS, alongside clinical effectiveness and patient safety. Following the passage of the Health and Social Care Act in 2012, these three components have been enshrined in law through new duties on NHS organisations to deliver continuous improvements in the quality of services. Under Domain 4 of the NHS Outcomes Framework, NHS England is prioritising improvements in the experiences of patients using services, as measured by the following overarching indicators:

- Patient experience of primary care
- Patient experience of hospital care
- Friends and Family test

The three indicators above are necessarily broad in scope, being designed to cover all disease areas. In cancer as a single disease area, however, much progress has been made prior to the introduction of the NHS Outcomes Framework to measure and improve patient experience:

- In 1999-2000 the Department of Health undertook a large scale national survey of cancer patients involving all NHS trusts in England and covering six different types of cancer, to which over 65,000 cancer patients responded. That survey, published in 2002, provided a baseline

which established patients' experiences and opinions of the quality of services that they received.

- A smaller, follow-up survey was carried out by the National Audit Office together with the Department of Health in 2004, which focused on the four most common cancers.
- The Cancer Reform Strategy of 2007 announced the launch of an annual programme of national cancer patient experience surveys to support service improvement. The first such cancer patient experience survey (CPES) was undertaken in 2010; the survey for 2011-12 was published in August 2012 (to which over 70,000 patients responded); and a third survey was published in September 2013.

The CPES provides the most comprehensive and informative picture of cancer patient experience to date and has generated insights into how cancer services are contributing towards improvements in patient outcomes across each of the five domains. So far, data have only been published at a national level and at provider-level. These data have exposed significant variation in patient experience across England. Macmillan has been working closely with providers to evaluate their performance on

### What does this mean for commissioners?

Why should commissioners, at both a clinical commissioning group (CCG) and NHS England level, seek to play a role in improving patient experience? Firstly, commissioners have a duty to improve health outcomes and patient experience and this has been identified as a key outcome in itself (as measured by Domain 4 of the NHS Outcomes Framework). This is reflected in one of the four national measures that make up the quality premium that will be paid to commissioners in 2014-15<sup>1</sup>.

Secondly, while some important areas of cancer treatment are commissioned at a specialised level (including some specialist surgery, radiotherapy and chemotherapy), many significant aspects of the care pathway are commissioned at CCG level, including early diagnosis, cancer waiting times, care planning, management of common side effects, routine rehabilitation and end of life care.

Thirdly, with the right intelligence, commissioners are well placed to exert influence in this area. By working with providers, commissioners can measure progress, identify areas of weakness and use appropriate levers – from contract management through to financial incentives – to underpin changes enabling providers to deliver the improvements in patient experience that are required.

patient experience and to identify practical steps which they can take to improve the experience of cancer patients. These include ensuring that patients have:

- Improved communication with their healthcare professionals
- Support from a Clinical Nurse Specialist (CNS)
- Support to self-manage, where appropriate
- Access to appropriate information and support
- Timely care

Efforts to improve cancer patient experience have historically targeted providers. This is understandable, given that providers decide how care is organised and delivered and are at the patient interface, directly shaping their experiences of that care in the ways that are outlined above. However, the focus on providers has left a void, both in terms of the evidence that is collected and the action that can be undertaken at a strategic level within the NHS to deliver improved outcomes in this important area of care.

This report, modelled on the Right Care NHS Atlas of Variation in Healthcare series, is the first of its kind to critically appraise trends in cancer patient experience at a commissioner-level. It is based on the latest available data on cancer patient experience broken down by commissioner in which survey responses from the 2011-12 CPES have been aggregated to the PCT of responsibility. At the time of writing, CCG-level data were not publically available. However, the emergence of CCGs from PCT clusters allows today's commissioners to gain important insights into the experiences of cancer patients living in and around their area of oversight. Data on patient experience (including from the 2012-13 CPES) should be published at commissioner level, at the earliest opportunity to further inform the work of CCGs in this important area.

The report is intended to stimulate a discussion about the important role that commissioners can play, working closely with providers, to improve patient experience and – in turn – transform individuals' outcomes.

The purpose of this report is therefore to:

1. Evaluate, at commissioner-level, the extent to which variation exists in England in the quality of patient experience at key touch-points along the patient pathway
2. Explore the relationship between cancer patient experience and other variables at commissioner level, including:
  - the level of deprivation
  - the level of expenditure on cancer services
3. Help commissioners and providers to prioritise action to improve patient experience:
  - Firstly, by evaluating performance against that of their peers to identify where the most urgent improvements are needed
  - Secondly, by identifying the areas of high quality healthcare delivery which are most closely associated with a positive overall experience for cancer patients, in order to focus efforts on changes that matter most to patients
4. Make recommendations to reduce variation in experiences (bringing the majority of scores up to the level of the best) and achieve further improvement in patient experience, by:
  - Identifying potential levers which CCGs should use to drive improvement amongst providers
  - Identifying ways in which NHS England could improve the measurement and reporting of patient experience



# Key findings

## How patients rated their overall experience

- There are marked differences in the quality of patient experience depending on where a patient lives, and specifically, which NHS organisation commissions their care.
- The extent to which patients rated their overall care as either 'excellent' or 'very good' ranged from 71% in Ealing PCT to 90% in Sefton PCT.
- This means that in some parts of England (PCT areas with scores in the bottom quartile) almost one in five patients reported a less than very positive experience of care.

## Overarching vs specific measures of patient experience

- General and overarching measures are of limited use as a stand-alone measure of quality because they provide little insight into the aspects of patient experience which matter the most to patients and, therefore, the parts of the pathway which require the most improvement. Our analysis provides a more complete picture of patient experience which helps commissioners understand when and how to act, by:
  - Pinpointing the specific areas where performance is poor (in case an overarching measure of patient experience masks specific local issues)

- Setting out the areas of healthcare delivery which are most closely associated with a positive experience overall
- An analysis of patient experience across the patient pathway shows significant variations by PCT of responsibility. Based on the measures analysed, the areas that are associated with biggest observable variations in patient experience are:
  - The extent to which patients feel involved in their care (scores ranged from 50% to 76%)
  - The provision of information about self help and support groups (scores ranged from 44% to 77%)
  - The extent to which patients are treated with dignity and respect (scores ranged from 44% to 75%)
  - Provision of information on leaving hospital (scores ranged from 42% to 77%)
  - The extent to which patients are treated as a set of cancer symptoms (scores ranged from 61% to 80%)
- Meaningful patient involvement in decisions about their care is a key priority for quality improvement. This is because the level of patient involvement is associated with significant variation by referring PCT,

it attracts relatively low scores overall compared to other measures of patient experience, and it is an area which has a strong correlation with patients' overall experience of care.

- A number of measures of patient experience attracted particularly low scores overall – such as the provision of financial help, perceptions of the number of nurses on duty and the provision of care after leaving hospital. For these questions, the findings may be confounded either by the lower number of respondents or the fact that some patients reported they were happy not to receive information and support. Commissioners and providers should work together to investigate why scores for these questions are low and take appropriate action improve both response rates and performance where necessary.

### **Exploring variations in deprivation**

- There is a correlation between the level of social deprivation and the overall quality of patient experience reported by patients. In areas with higher levels of social deprivation, patients are less likely to describe their overall experience of cancer care as 'excellent' or 'very good'. This is concerning, given that poor outcomes could serve to exacerbate existing health inequalities.
- The analysis reveals some positive trends in relation to deprivation. For example, people living in areas of higher deprivation are more

likely to be given information on financial support. This shows that some providers are effectively targeting information which could benefit patients living in poorer communities.

- However, it is important for both commissioners and providers to reflect on the impact of cancer on other income groups – including those on middle incomes, who may find it difficult to cope with the financial burden that is associated with a cancer diagnosis – such as maintaining regular payments and meeting existing financial commitments.

### **Exploring variations in expenditure**

- Our analysis showed that the correlation between the level of expenditure on cancer services and the quality of patient experience is very weak.
- The assertion that increased expenditure may lead to improved patient experience is appealing, since additional expenditure may lead to more resources (such as staff) and care being delivered in more convenient settings. However, investment in interventions to improve patient experience (such as better use of information and support for the active engagement of patients) can help to reduce unnecessary healthcare costs and support cost effective use of resources.

- These data show that it is possible to achieve high scores on aspects of patient experience with comparatively low levels of spending. This reflects the relatively low cost of key interventions to improve relational care such as actively involving patients in their care and ensuring that interactions with patients demonstrate dignity and respect.
- Given the current budgetary climate, commissioners should interrogate these patient experience data in relation to spend and identify whether there are any parts of the pathway where investment could be redirected towards either interventions that demonstrate a strong link with overall patient experience; or to areas where performance is comparatively weak compared to peers.

### Geographical variations

- Geographical variations were considered in the context of the location of different types of provider (specialist or general) to see if this has a bearing on the quality of experience.
- PCTs that either host, or neighbour a PCT that hosts, a specialist centre show a mixed picture on patient experience across the nine different patient experience measures analysed.
- There are some instances where the scores of referring PCTs closest to the specialist centres appear higher, such as on core components of clinical care (e.g. perceptions

of whether there were enough nurses on duty). However, the same PCTs score lower on other aspects of care delivery, such as patient involvement and whether patients felt they were treated as a set of cancer symptoms. These trends may be explained by the way that specialist centres are staffed and resourced, as well as by the behaviours associated with individual MDTs.

- Out of all the commissioning areas, referring PCTs in London demonstrate a relatively high level of consistency in patient experience scores across the nine measures analysed. For each measure of patient experience analysed, a majority of London PCTs appear in the bottom two quartiles of patient experience scores.
- Commissioners in London should interrogate their performance on the patient experience measures analysed in this report to draw up a plan of action with providers that tackles the identified challenges in the capital.

### Core areas of healthcare delivery

- Our analysis shows that there are a number of areas of healthcare delivery that have a strong correlation with overall patient experience. Among them:
  - Communication – the way that staff interact with patients
  - Information – the provision of written and verbal explanations about different aspects of their care

- Involvement – the extent to which patients were involved in decisions about their treatment and care
- Integration – how well care and support was coordinated after a patient left hospital and the extent to which whole-person, holistic needs were catered for
- Commissioners should work with providers to develop a plan of action for quality improvement based on:
  - Each of the core areas
  - Areas of patient experience where performance falls short compared to that of their peers and where urgent action is needed
- This will help to ensure that efforts to improve patient experience are effectively targeted and prioritised.

# Summary of recommendations

**Recommendation 1:** NHS England working with Quality Health should publish data on cancer patient experience aggregated to commissioner level on an annual basis to support commissioners to fulfil their statutory duty to secure continuous improvements in the quality of patient experience.

**Recommendation 2:** Public Health England should undertake research into the causes of variations in the experience of cancer patients from different socioeconomic groups and develop recommendations for tackling this.

**Recommendation 3:** Commissioners should interrogate their scores on overall experience and evaluate this against performance on other key patient experience measures to identify the interventions and actions they should require from providers (as part of the service specification) to improve patient experience.

**Recommendation 4:** Commissioners should investigate the relationship between spending on cancer and overall cancer patient experience, and work with providers to identify any inefficiencies or areas of underspend which may have a detrimental impact on patient experience.

**Recommendation 5:** Commissioners should utilise the CPES measure on patient involvement to set out expectations of quality improvement and secure improvements in the performance of providers (e.g. through the use of local incentive payments for percentage improvements in experience) in order to demonstrate action in line with their statutory duties.

**Recommendation 6:** Commissioners should work closely with local providers in areas of poorer performance to identify what steps need to be taken to improve patient involvement, taking into account the demographic profile of the local population.

**Recommendation 7:** Commissioners should consider opportunities to engage with local self help and support groups through the commissioning cycle to support them to fulfil their statutory duties on patient and public involvement.

**Recommendation 8:** Commissioners should require evidence from providers of processes to ensure that all patients are routinely given information about local self help and support groups.

**Recommendation 9:** It is essential that, where appropriate, every person with a cancer diagnosis is given information about how to get financial help from hospital staff.

**Recommendation 10:** Commissioners with relatively low scores in relation to patient perception of staffing levels should critically evaluate whether providers from whom they commission care require additional nursing capacity; need to deploy nurses more effectively; or improve communication and responsiveness of staff with patients.

**Recommendation 11:** Commissioners with relatively low scores should work closely with providers to address identified concerns over nursing capacity, as a priority.

**Recommendation 12:** Quality Health should investigate the reasons why responses to the question on staffing levels are relatively low and consider whether the wording of the question should be changed to make it easier for patients to respond.

**Recommendation 13:** Commissioners should monitor whether patients report that they were treated with dignity and respect, and seek to commission services on the basis of high quality relational care.

**Recommendation 14:** Commissioners should monitor the reasons for cancer patients accessing health services following discharge and work with providers to improve the provision of information and support for self care in order to drive up performance in this area.

**Recommendation 15:** Commissioners should critically evaluate the performance of services that are provided to care for and help cancer patients when they leave hospital, as these services can prevent unnecessary hospital admissions which can be both costly to the NHS and distressing to the patient.

**Recommendation 16:** NHS commissioners should work with local authority commissioners to ensure that there is an integrated, smooth and cost effective link between health and social care services for cancer patients.

**Recommendation 17:** NHS England, in its role as a commissioner, should lead by example and take responsibility for making sure that people experience coordinated care. Strategic clinical networks should prioritise within their cancer workplans the improvement of patient experience at key transition points between services.

**Recommendation 18:** Commissioners should critically appraise their patient experience scores on key staff behaviour measures in the CPES (such as q51 and q69) and in the NHS staff survey to develop a plan to improve the quality of patient-centred care (for example, by using the Macmillan Values Based Standard<sup>®</sup> as a approach for local improvement).

**Recommendation 19:** Commissioners should evaluate scores on the ‘whole-person’ patient experience measure to understand the extent to which providers are upholding the rights in relation to equality and patient-centred care in the NHS Constitution.

**Recommendation 20:** NHS England should ensure that patient experience indicators in national frameworks reflect what is important to cancer patients and drive improvements in care.

**Recommendation 21:** NHS England should hold local commissioners to account for improving cancer patient experience by developing an indicator on cancer patient experience for inclusion in the Clinical Commissioning Group Outcomes Indicator Set.

**Recommendation 22:** Providers should take proactive steps to improve the quality of patient experience across the key areas of communication, information, involvement and integration.

**Recommendation 23:** Commissioners should use the data presented in this report (both on variations and the core areas of care) to develop levers across the commissioning cycle that will help to secure improvements in patient experience.

**Recommendation 24:** Commissioners should use the service specification to stipulate service requirements to improve the quality of patient experience (for example, by requiring providers to ensure an appropriate level of access to a CNS).

**Recommendation 25:** Commissioners should use the service specification to set out quality improvement goals and incentive schemes which require providers to deliver an agreed percentage improvement in priority areas (for example, the proportion of patients feeling involved in decisions).

# Methodology

This report is broken down into two sections:

- A. Mapping of patient experience using nine measures from across the cancer pathway, broken down by commissioner of responsibility, also described as the 'referring PCT'. This is informed by a consideration of the impact of the levels of deprivation and expenditure on cancer services in each commissioning area.
- B. An analysis of the areas of experience that are most strongly correlated with overall cancer patient experience using provider-level data.

**Section A** is based on data from the 2011-12 CPES. This analysis was undertaken using 2011-12 data which was the latest publicly available CPES data, broken down by PCT. At the time of writing, these data were not available by CCG for the most recent year of the survey, 2012-13. It is anticipated that the analysis will be re-run in future years to allow analysis of patient experience scores by current commissioner of responsibility. In the meantime, the findings provide a snapshot of the experiences of patients living in and around CCG areas of oversight to help inform their important work in this area.

Individual patient level data (linked to the referring PCT which incurred

the cost for the treatment and care of the patient) were aggregated to PCT-level. Nine questions were selected for analysis on the basis of one or more of the following criteria:

- They have a positive correlation with overall patient experience (see Section B)
- Measures are associated with specific actions that commissioners and providers can take in order to positively shape experience
- Measures are associated with significant variation among PCTs
- Measures represent the four identified domains of the CPES – provision of information, involvement in decisions, relational care and care transitions
- They help to uncover a picture of performance which spans the patient pathway

Firstly, the PCTs were organised into quartiles according to their score for each patient experience measure. These data were then mapped to illustrate differences in experience for each patient experience measure according to PCT. The colour coding within each map reflects the range of scores achieved for each quartile.

The percentage scores are based on the total number of survey respondents and not the total number of patients



*Question 19: Patient definitely involved in decisions about care and treatment*

*Question 24: Hospital staff gave information about self help and support groups*

*Question 25: Hospital staff gave information about how to get financial help*

*Question 43: Patient felt there were always or nearly always enough nurses on duty*

*Question 51: Patient felt they were always treated with respect and dignity*

*Question 52: Patient felt they were given clear written information about what they should or should not do after leaving hospital*

*Question 55: Patient felt they were definitely given enough care and help from health or social service after leaving hospital*

*Question 69: Patient did not feel that they were treated as 'a set of cancer symptoms' rather than a whole person*

*Question 70: Patient rated their overall care as 'excellent' or 'very good'*

who responded to each question. A number of the questions analysed are associated with a low response rate, which makes the scores appear low (for example, between 30 and 50%). Where low response rates have impacted on scores in this way, it is noted in the analysis.

When interpreting the maps, it is important to recognise that the data

have been aggregated by the referring PCT. This means that patient experience is reflective of the providers from which the PCT has commissioned cancer care, which may or may not be located within the catchment covered by the PCT. It is therefore designed to provide a snapshot of the quality of patient experience in providers over which each PCT has oversight.

**Recommendation 1:** NHS England working with Quality Health should publish data on cancer patient experience aggregated to commissioner level on an annual basis to support commissioners to fulfil their statutory duty to secure continuous improvements in the quality of patient experience.

Section A also sets out the findings of an analysis of the correlation between the nine cancer patient experience measures by PCT and:

- The level of deprivation using the indices of deprivation for 2010 by PCT (these are the latest available indices).
- The level of expenditure on cancer services by PCT using 2010-11 programme budgeting data which is expressed in £m per 100,000 population. Programme budgeting expenditure covers prevention, primary, secondary and urgent and community care, of which over 70% is spent within secondary care settings<sup>2</sup>.

A simple linear regression analysis was used to test the relationship between the PCT scores for each patient experience measure and the deprivation score. The analysis was repeated for the programme budgeting expenditure data. The coefficient of determination ( $R^2$ ) was used to evaluate the strength of the relationship in which one variable is predicted (expenditure or deprivation)

and the other is the predictor (patient experience measure). The strength of the correlation was determined according to the following R values:

R = 0.1 is small ( $R^2$  0.01)

R = 0.3 is moderate ( $R^2$  0.09)

R = 0.5 and above is strong ( $R^2$  0.25)

The findings presented in this report are limited to those measures of patient experience where there was an observed correlation with either deprivation or the level of expenditure. Charts have been used to present these findings. It should be noted that correlation does not infer a causal relationship and further investigation is required to fully understand cause and effect and the impact of other, unmeasured, factors.

Programme budgeting expenditure and indices of deprivation were also mapped by PCT to enable commissioners to pinpoint performance on different aspects of patient experience against these two general measures.

**Section B** presents the findings of an analysis of the relationship between the specific measures of patient experience in the CPES and how cancer patients rate their experience overall. The purpose of the analysis was to understand whether good performance in specific areas of healthcare delivery have a strong correlation with a positive experience overall. To test this, provider-level patient experience scores for every measure in the CPES were plotted against the measure for overall patient experience. This is taken from question 70 of the CPES for 2011-12:

The percentage of cancer patients rating their care 'very good' or 'excellent' in response to the question, 'overall, how would you rate your care? excellent; very good; good; fair; poor'.

A linear regression analysis was used to test the relationship between the overarching measure of patient experience and each of the measures collected through the CPES. The analysis in this report is based on the measures that showed the strongest positive correlation with overall patient experience – R value of 0.5 or more ( $R^2 = 0.3$ ).

However, the findings show that where the links are strongest between particular interventions and overall experience, correlation does not imply causation. In this event further work is needed to verify the extent of any causality.



# SECTION A

## Understanding trends in patient experience by commissioner

This section explores the patterns in patient experience, according to the referring PCT, across a number of patient experience measures which span a cancer patient's journey. The measures are set out in the table overleaf.

Question 19: Patient definitely involved in decisions about care and treatment

Question 24: Hospital staff gave information about self help and support groups

Question 25: Hospital staff gave information about how to get financial help

Question 43: Patient felt there were always or nearly always enough nurses on duty

Question 51: Patient felt they were always treated with respect and dignity

Question 52: Patient felt they were given clear written information about what they should or should not do after leaving hospital

Question 55: Patient felt they were definitely given enough care and help from health or social service after leaving hospital

Question 69: Patient did not feel that they were treated as 'a set of cancer symptoms' rather than a whole person

Question 70: Patient rated their overall care as 'excellent' or 'very good'

Our analysis reflects the understanding that there are, sometimes significant, differences in the quality of cancer patient experience in different hospitals in England, as highlighted in the findings of three national CPES since 2010-11. These findings have thus far been presented at a provider-level. Our analysis is based on an aggregation of patient-level data to the level of the responsible PCT. It helps to inform the work of local commissioners as they seek to secure improvements in outcomes among the providers from which they commission cancer care.

When interpreting these data, it is important to note that cancer services are provided in both general and specialist hospitals. We may assume that the majority of cancer patients living within a particular PCT catchment will be treated at a hospital either within the area of their PCT, or at a hospital that is located in a neighbouring PCT. A patient may also decide to be treated at a hospital that is some distance from their home and hence their referring PCT could be geographically removed from their place of treatment (for example, if they live in the south west and choose to be treated at a specialist centre in London or in the north of England).

Hence, the patient experience scores that are presented here for the 'commissioner of responsibility', or 'referring PCT' reflect the experience of patients living in their area who may have been treated at local or distant hospitals.

# Overall experiences of care

Our analysis of overall patient experience – how patients rated their overall care – shows marked variation by commissioner in England. For those patients who rated their care as either ‘excellent’ or ‘very good’, scores ranged from 71% in Ealing PCT to 90% in Sefton PCT. Although there is significant variation overall, half of all PCTs scored between the small range of 84-87%. While this demonstrates consistency in performance, it also highlights that there is significant room for improvement – in half of all PCTs, over 13-16% of patients did not report that their experience was ‘excellent’ or ‘very good’. Based on 72,000 survey respondents, this equates to thousands of patients who did not report a very positive experience overall.

Map 1 shows the variation by referring commissioners. Analysis of these variations shows that the poorest performance is concentrated within a discrete handful of urban and rural areas. Most notably, performance in London PCTs, which has the highest concentration of general and specialist cancer centres, is consistently in the bottom two quartiles, with the exception of Haringey PCT, Richmond PCT, Croydon PCT and Bromley PCT.

Commissioners in Lincolnshire, North Lancashire, Northamptonshire, Derbyshire and Gloucestershire may wish to explore the reasons why patient experience of their overall care is low compared to that of their peers.

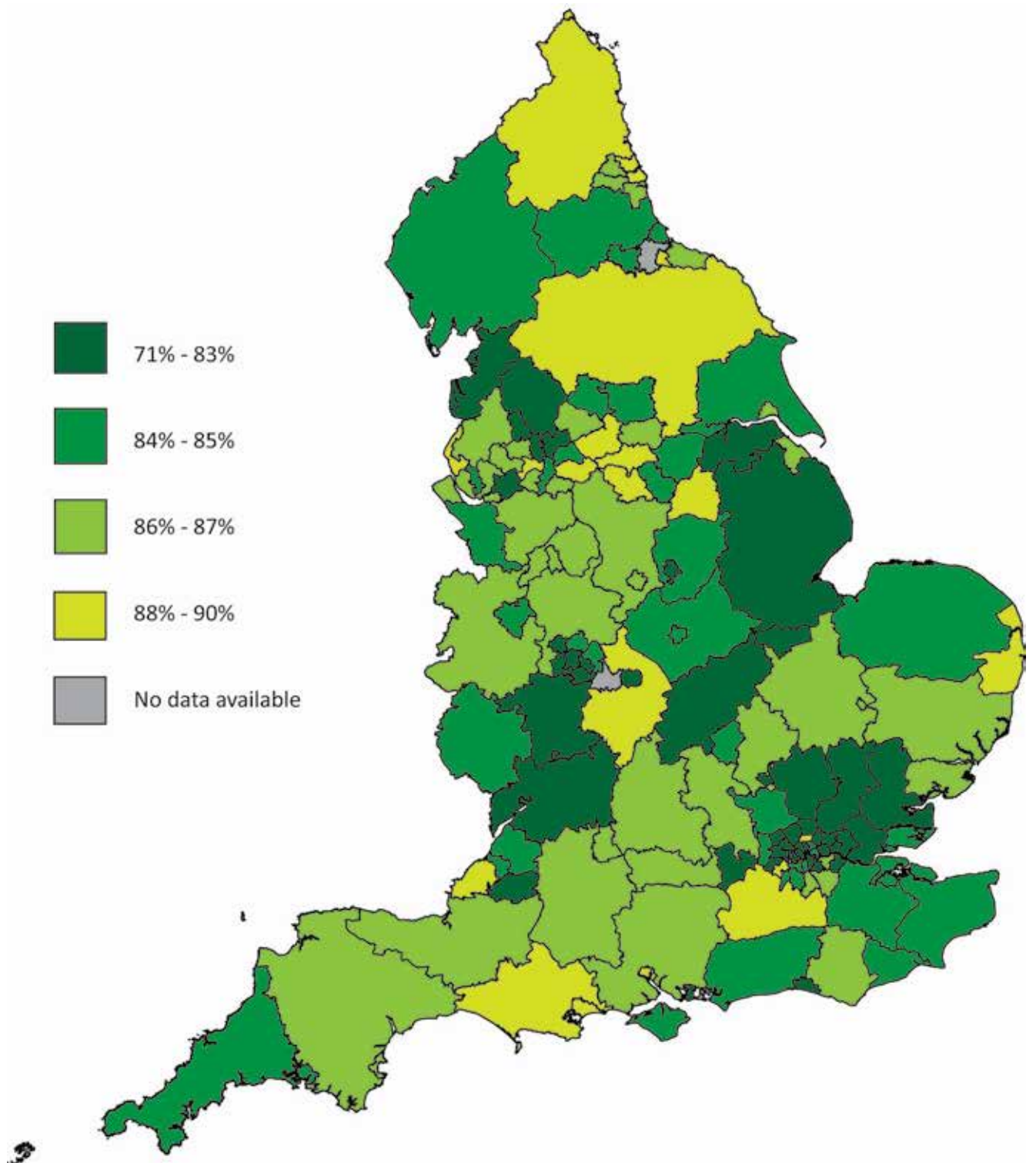
Analysis of the spread of good performance shows that patients referred from PCTs hosting or neighbouring a number of the specialist centres (such as Newcastle, Leeds, Manchester, Bristol) reported more positively, as well as those referred from large rural PCTs such as North Yorkshire and Northumberland. These scores may reflect the combination of treatment excellence (that we may expect from a specialist centre) alongside a compassionate approach to care delivery, that may both contribute to a patient’s overall experience.

However, using the general patient experience measure alone, it is difficult to conclude how providers and commissioners could work towards delivering improvements, given that these data deliberately depict a general and overarching impression of the quality of care.

Hence, our analysis of the individual patient experience measures in this report is instructive in supporting NHS organisations to act to prioritise improvements in patient experience.



**Map 1: Percentage of patients who rated their overall experience of care as 'excellent' or 'very good', by referring PCT<sup>3</sup>**



## Exploring trends in deprivation

Despite the great progress that we have seen in cancer awareness, diagnosis, treatment and support in the past decade, evidence shows that cancer outcomes and experiences are still not uniform across different communities<sup>4</sup>. Levels of deprivation have been identified as an important factor in this. For example, research shows that:

- Cancer incidence and mortality rates are higher in disadvantaged areas
- Those from wealthier areas are more likely to know the major risk factors relating to cancer than those from relatively poor areas
- Disadvantaged communities are less likely to engage in lifestyle behaviours which reduce cancer risk
- There is lower cancer symptom awareness amongst those experiencing deprivation
- Harder to reach groups have unmet needs relating to information, support and services<sup>5</sup>

Given this, we wanted to assess whether the level of deprivation in a local area has an impact on the experience of cancer patients. To test the relationship, we analysed the Index of Multiple Deprivation 2010 data, which are broken down by PCT<sup>6</sup>. These multiple deprivation data are derived from assessing:

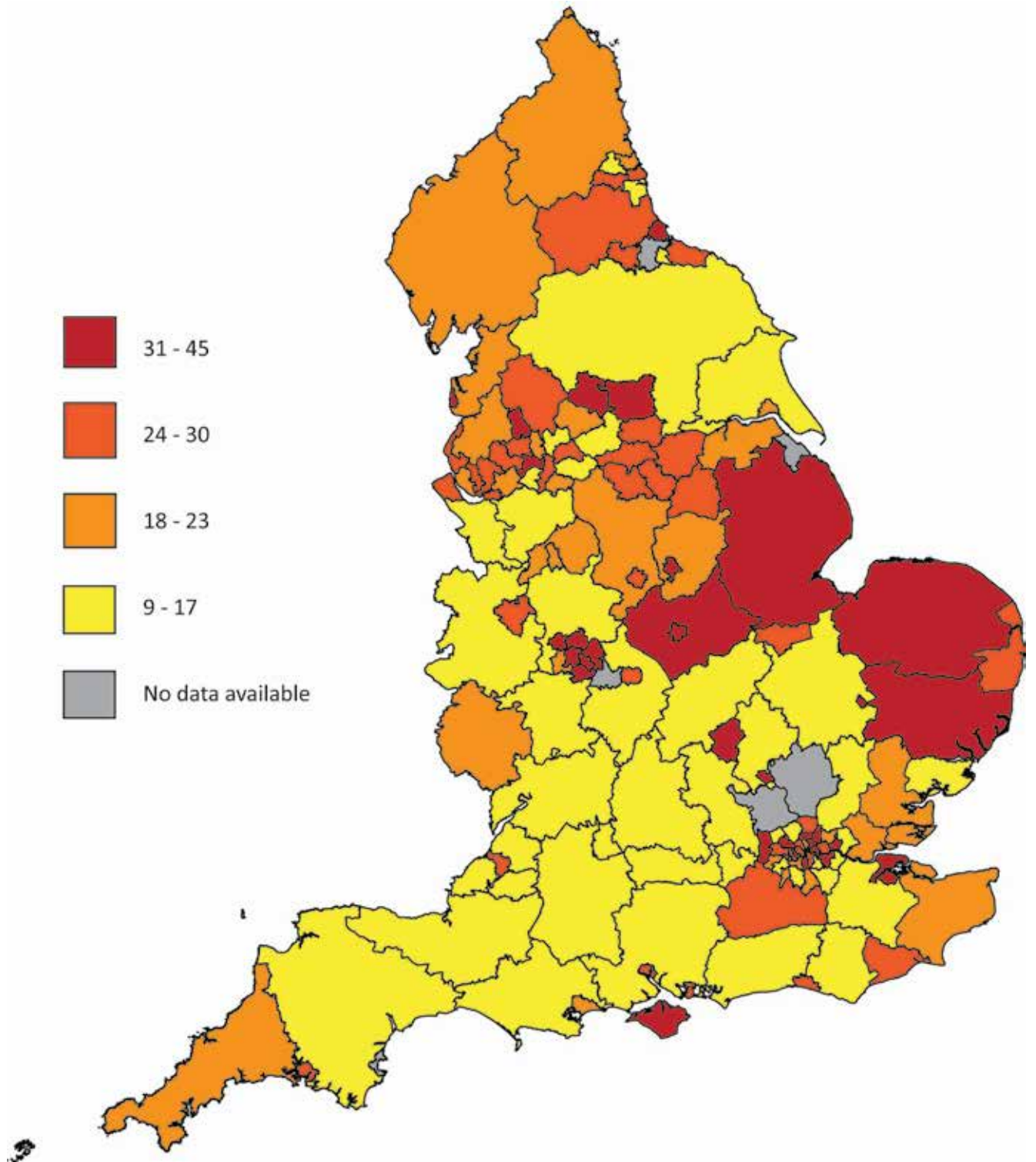
- Income deprivation
- Employment deprivation
- Health deprivation and disability
- Education, training and skills deprivation
- Barriers to housing and social services
- Crime
- Living environment deprivation

Variation in deprivation levels are set out in Map 2. According to these data, the PCT with the highest deprivation levels is Heart of Birmingham Teaching PCT (with a score of 45) and the PCT with the lowest is Surrey PCT (with a score of 9).

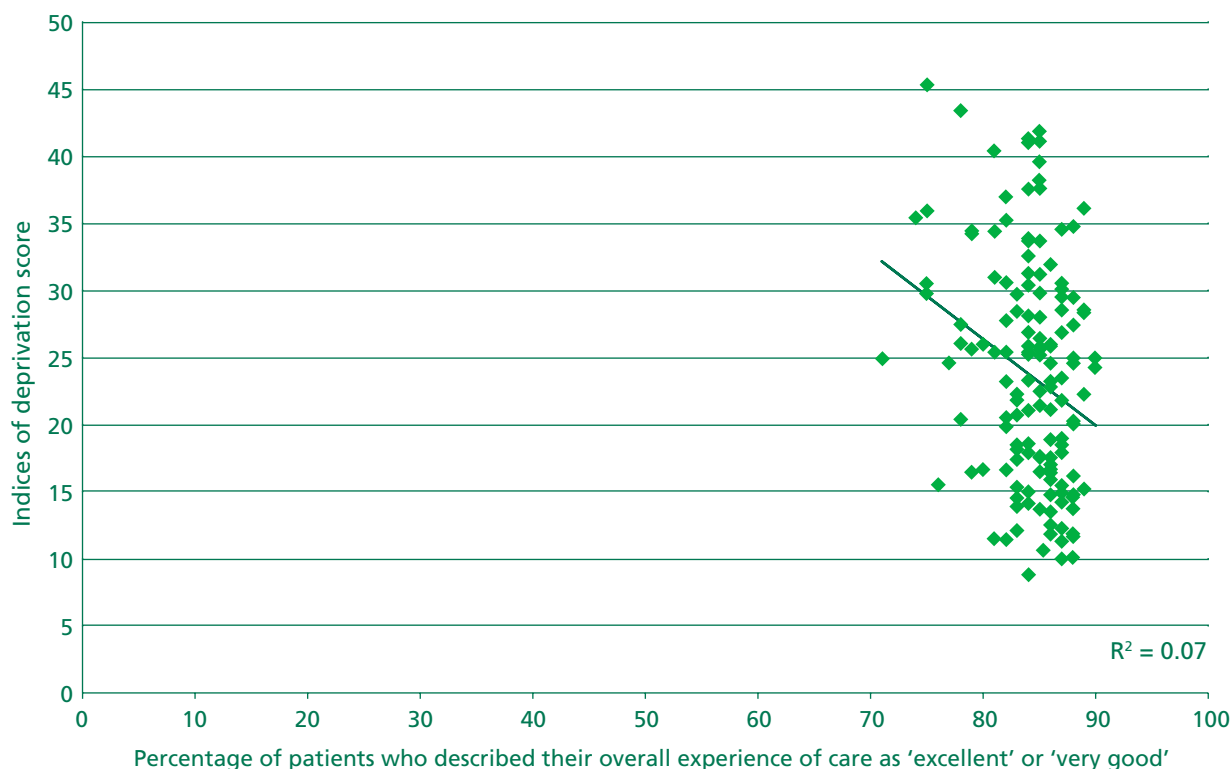
Plotting these deprivation levels against whether patients described their overall care as 'excellent' or 'very good' indicates that there is a small negative correlation, as set out in Chart 1.

Given the evidence set out above about the differences in outcomes and access between those from more or less deprived communities, it is perhaps not surprising that this trend is also reflected in patient experience. For example, if patients from more disadvantaged areas have unmet needs when it comes to information and support, this will be reflected in how they rate their experience of care.

**Map 2: Indices of deprivation by referring PCT<sup>7</sup>**



**Chart 1: Correlation of indices of deprivation<sup>8</sup> and the percentage of patients who rated their overall care as 'excellent' or 'very good'<sup>9</sup>**



There is evidence which suggests that otherwise similar patients from different socio-economic groups are treated differently within the NHS<sup>10</sup>. For example, women with breast cancer from more disadvantaged groups are less likely to receive surgery; fewer patients from deprived areas receive radiotherapy; and those from affluent areas are more likely to die at home<sup>11</sup>. This will clearly impact on patient experience.

The differences in how patients from more disadvantaged areas

are treated requires further exploration. Examining the causes of these variations, for instance whether patients from affluent communities are more likely to ask for the treatment they want, will help inform responses to tackling these inequalities in experience.

**Recommendation 2:** Public Health England should undertake research into the causes of variations in the experience of cancer patients from different socioeconomic groups and develop recommendations for tackling this.

### Exploring trends in spending on cancer services

Map 3 shows the level of programme budgeting expenditure on cancer by PCT per 100,000 of the population. A comparison of Map 1 and Map 3 shows that there are some links between areas of higher spending and higher overall cancer patient experience. This is particularly noticeable in some of the larger rural referring PCTs (such as Northumberland and North Yorkshire, and in the south west of England). This trend – in which lower spending levels are associated with poorer performance – is replicated in some of the urban centres, including London, Greater Manchester and Newcastle.

Interrogation of the map also highlights some areas where the relationship follows an inverse trend. For example, in Swindon PCT (where spending is relatively low, but performance is high) and Worcestershire PCT (where higher spending is associated with poorer performance). Here it will be important for commissioners to identify whether either cost effective approaches to care, or specific inefficiencies, are driving these trends.

The assertion that higher spending on cancer services will lead to a better experience for patients is intuitively appealing. Increased expenditure may lead to more resources (including staff), care delivered in more convenient care settings, better treatments and higher outcomes. However, our analysis of the link between overall

patient experience and expenditure on cancer services revealed that the correlation is very weak ( $R^2 = 0.01$ ).

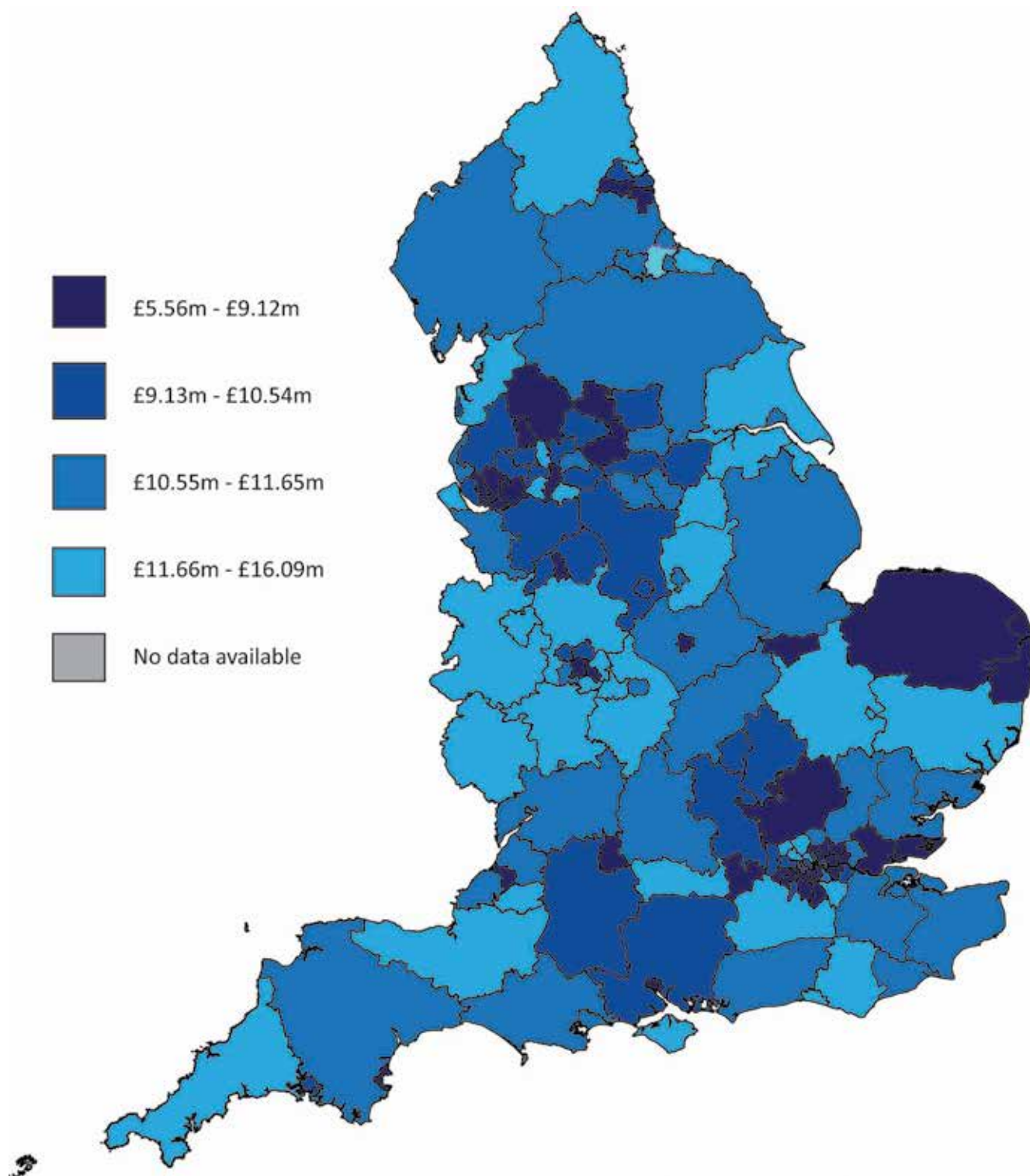
Perhaps this is not surprising, given that a positive experience may be shaped by aspects of care which do not have a significant costs attached to them (for example, such as the way in which a nurse communicates with a patient and the extent to which interactions are based on dignity and respect).

In section B, we explore the areas of healthcare delivery that are most closely associated with a positive overall patient experience in order to illustrate this point.

**Recommendation 3:** Commissioners should interrogate their scores on overall experience and evaluate this against performance on other key patient experience measures to identify the interventions and actions they should require from providers (as part of the service specification) to improve patient experience.

**Recommendation 4:** Commissioners should investigate the relationship between spending on cancer and overall cancer patient experience, and work with providers to identify any inefficiencies or areas of underspend which may have a detrimental impact on patient experience.

**Map 3: Programme budgeting expenditure on cancer by PCT 2011/12**  
(£m per 100,000 population)<sup>12</sup>



# Patient involvement in decisions about treatment and care

The principle of 'no decision about me, without me' is intended to underpin the delivery of treatment and care delivery in the new NHS. Shared decision-making is enshrined as a right in the NHS Constitution and commissioners have a duty to promote the involvement of each patient in decisions which relate to their treatment and care under the Health and Social Care Act 2012.

However, shared decision-making is much more than a legal duty; it contributes to improvements in the quality of care in a number of ways:

- Ensuring that patients are well-informed and can make meaningful choices about their treatment and care
- Helping patients to set realistic care and treatment goals in partnership with clinicians
- Improving concordance with treatment and promoting greater self-care
- Helping to direct limited resources towards the things that matter most to patients

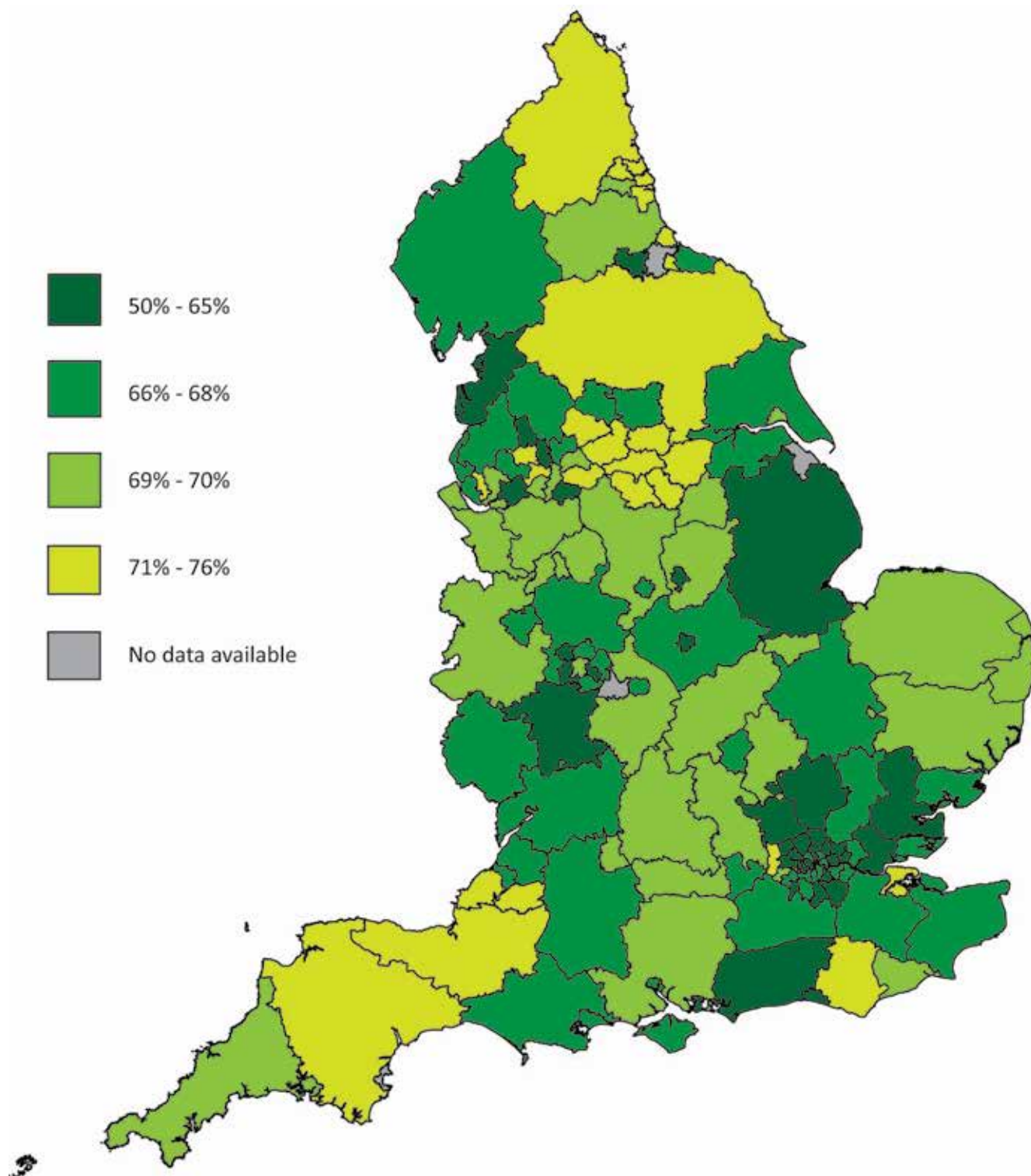
Despite this, the extent to which patients definitely felt involved as much as they wanted to be in decisions about their care and treatment varies significantly depending on where they live. For example, only half of patients living in the catchment for Waltham Forest PCT

who responded to the survey said that they definitely felt involved, compared to 76% in Barnsley PCT. The majority of PCTs achieved scores between 60 and 70% for this measure, which suggests that there is room for improvement.

As shown in Map 4, there is some indication that patients living in more rural areas including Devon and Cornwall, Norfolk, Suffolk, Yorkshire and Northumberland were more likely to report positively on the shared decision-making measure. Patients living in PCTs either covering or neighbouring specialist cancer hospitals in urban centres such as London, Bristol, Cambridge and Leeds, tend to report a relatively poor experience, with scores consistently in the bottom two quartiles across the London area. It is not immediately clear what is causing these differences, but it is likely that clinical culture and the approach of multidisciplinary teams towards patient involvement is likely to shape the quality of patient experience on this particular measure.

Research has shown that younger patients, ethnic minority patients and patients with rectal, ovarian, multiple myeloma and bladder cancer report poorer experiences of involvement in decision making so the specific needs of PCT populations may also be a factor<sup>13</sup>.

**Map 4: Percentage of patients who definitely felt involved as much as they wanted to be in decisions about their care and treatment, by referring PCT<sup>14</sup>**





It is important that both providers and commissioners consider what steps are required to improve the involvement of patients in their treatment and care. Higher levels of patient engagement may help to overcome health inequalities by ensuring that patients are better informed and supported to manage their condition and play a full role in their treatment and their recovery, including through self care.

It is worth noting that our analysis showed no correlation between the patient involvement in decision making and the level of spending. This shows that shared decision-making approaches need not have a cost-impact on services and that approaches to improve the culture of care delivery should not require significant additional resource, but rather be based on a positive commitment to behavioural change at all levels. Moreover, there is some evidence to show that better use of information and actively engaging patients can reduce health utilisation and costs (as well as improving outcomes), for example, through a reduction in unnecessary attendances and more appropriate use of services<sup>15</sup>.

It is beyond the scope of this analysis to identify specific causes which underpin the quality of experience. However, commissioners will want to investigate the particular needs of their local population when considering how best to promote and enhance shared decision-making. It is important, for example, that clinicians use appropriate communication methods to support

the individual characteristics of patients and any additional needs (if a patient has a learning disability, is living with dementia or is less accustomed to a shared decision-making approach, for example<sup>16</sup>).

Commissioners will want assurances that they are fulfilling their statutory duties on patient involvement. However, given that shared decision making relates to the interaction that takes place between a patient and their healthcare professional, it may be difficult for commissioners to exert influence in this area. The CPES measure provides a useful lever for commissioners to prompt action from providers by allowing them to set targets within local agreements and monitor the performance of secondary care providers without the need for an additional data return.

**Recommendation 5:** Commissioners should utilise the CPES measure on patient involvement to set out expectations of quality improvement and secure improvements in the performance of providers (e.g. through the use of local incentive payments for percentage improvements in experience) in order to demonstrate action in line with their statutory duties.

**Recommendation 6:** Commissioners should work closely with local providers in areas of poorer performance to identify what steps need to be taken to improve patient involvement, taking into account the demographic profile of the local population.

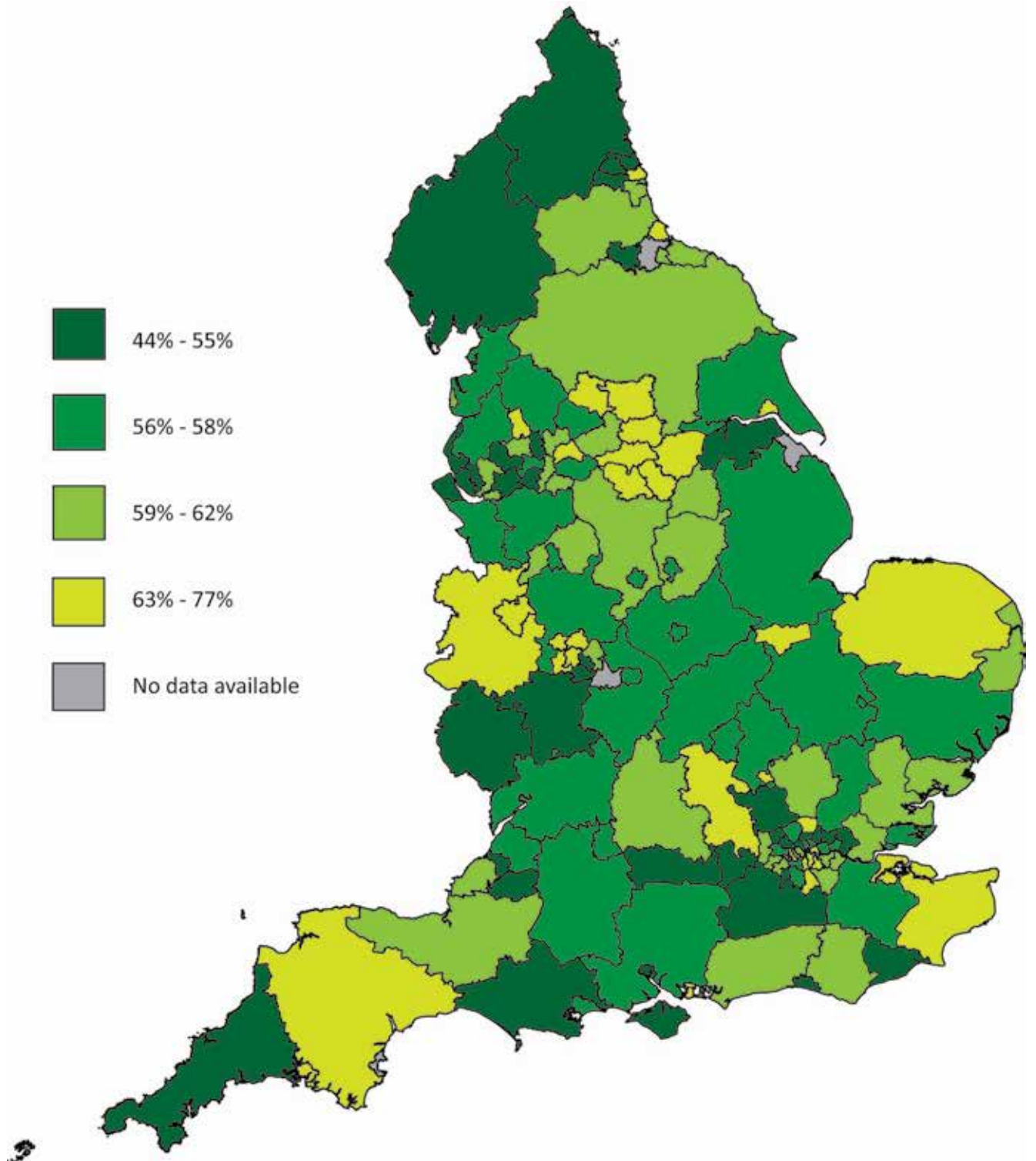
# The provision of information about support or self-help groups

Recent research conducted by Macmillan highlights the importance of providing a package of support that helps people living with cancer and their carers to recover from the emotional and practical effects of treatment as well as the financial problems caused by cancer<sup>17</sup>. Run by volunteers, self help and support groups have a vital role to play by supporting an individual's ability to manage their own condition, and live a healthy and happy life with and beyond cancer.

Despite the value they bring, there is significant geographical variation in the extent to which patients reported that they are able to access information about local support groups. This ranges from around 44% of patients referred from NHS Isle of Wight to 77% of patients referred from NHS Sheffield.

Map 5 shows the variation by commissioner of responsibility across England and illustrates a mixed picture across the country, with higher scores spread relatively evenly between rural and urban areas, and proximity of PCT catchment to general and specialist cancer hospitals. Indeed, recent research conducted by Macmillan showed that the majority of groups described their geographic coverage as 'mixed' supporting some members from urban centres and some from rural areas<sup>18</sup>.

**Map 5: Percentage of patients who said they were given information by hospital staff about support or self-help groups, by referring PCT<sup>19</sup>**



It should be noted that some patients reported that they did not need information about support groups ('it was not necessary') so the findings require careful interpretation since answers other than 'yes' do not necessarily equate to a poor experience. One may still argue that providers should routinely look for opportunities to provide information which patients could find useful on reflection or at a later point in their recovery.

Hence the observed variation can be explained in three main ways:

- The extent to which hospitals are proactively sharing information on self help groups
- The prevalence of local support groups within a patient's local community
- Whether patients are willing to receive (or ask for) information about support groups

Commissioners will want to consider how best to strengthen the relationships between providers and local groups, given the role that groups can play in addressing the complete needs of cancer patients, which may necessarily fall beyond the scope of their formal

NHS treatment and care. By developing a stronger partnership between the public and voluntary sphere, it is possible to extend the care provided to cancer patients beyond hospital wards and clinics cost effectively by drawing on the commitment, skills and support that exists within communities.

**Recommendation 7:** Commissioners should consider opportunities to engage with local self help and support groups through the commissioning cycle to support them to fulfil their statutory duties on patient and public involvement.

**Recommendation 8:** Commissioners should require evidence from providers of processes to ensure that all patients are routinely given information about local self help and support groups.

# The provision of information about how to get financial help

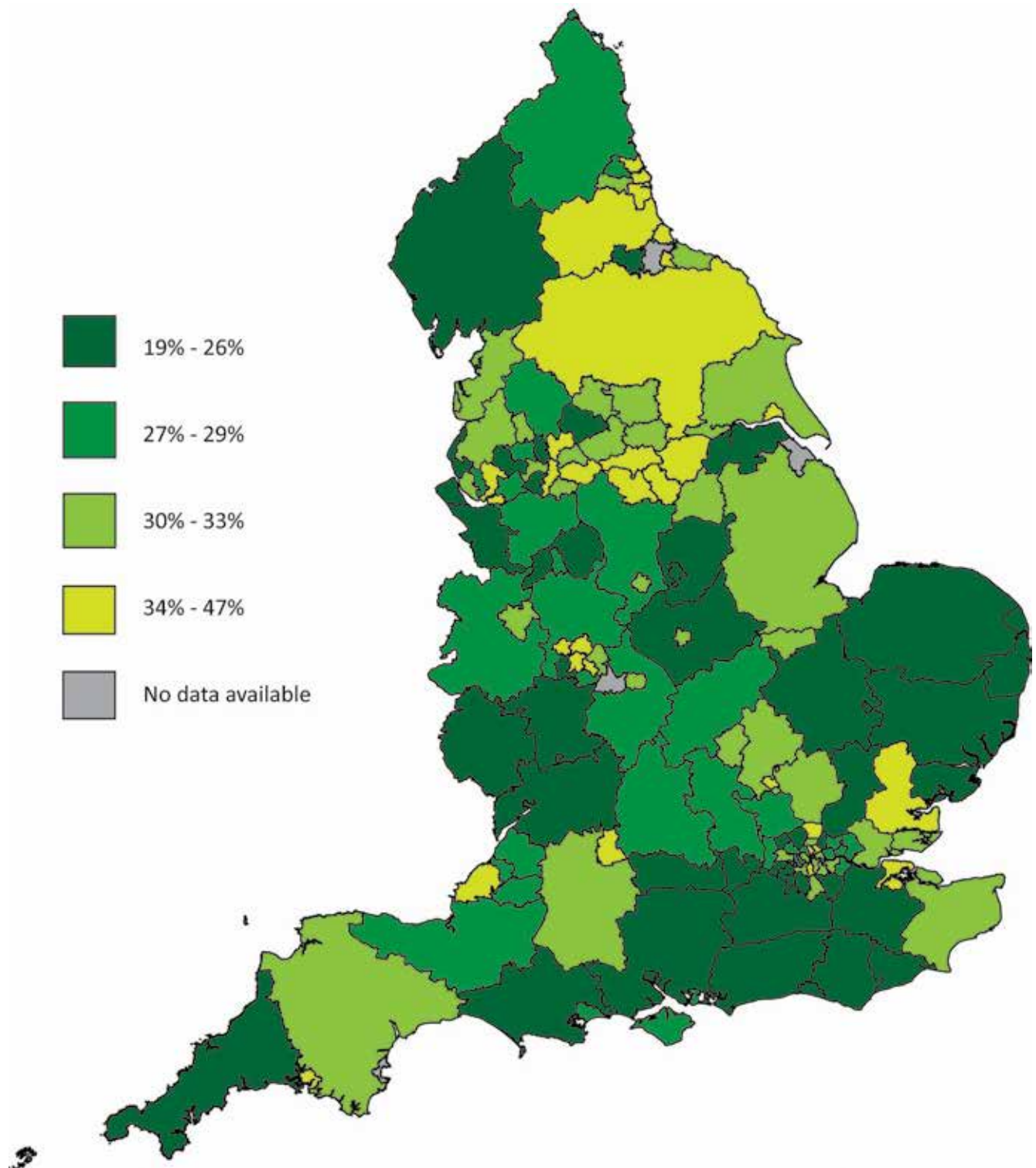
A diagnosis of cancer can lead to financial uncertainty for the person with the diagnosis, their family and carers. Many people find that a diagnosis of cancer can lead to financial difficulties and, therefore, that being given information about financial support can help reduce worry and anxiety.

There was a mixed picture about whether hospital staff gave information about how to get financial help across the country. This varied from 19% of survey respondents in the lowest performing area, to 47% in the highest performing area.

In general, with the exception of some parts of London, more people referred by a PCT in an urban area (with the exception of some parts of London) reported that they were given more information about how to get financial help than those from rural areas. As shown in Map 6, overall, people referred from the East of England, South East Coast and South Central were less likely to have been given information about getting financial help from hospital staff.

Given that the referring PCT is a good indication of where cancer patients live, it is possible to compare this to the indices of deprivation to determine if this may have an impact on whether people are given information about financial help. This correlation is shown in Chart 2.

**Map 6: Percentage of people where hospital staff gave information about how to get financial help, by referring PCT<sup>20</sup>**



**Chart 2: Correlation of indices of deprivation by PCT<sup>21</sup> and the percentage of patients who reported that hospital staff gave information about how to get financial help by PCT<sup>22</sup>**

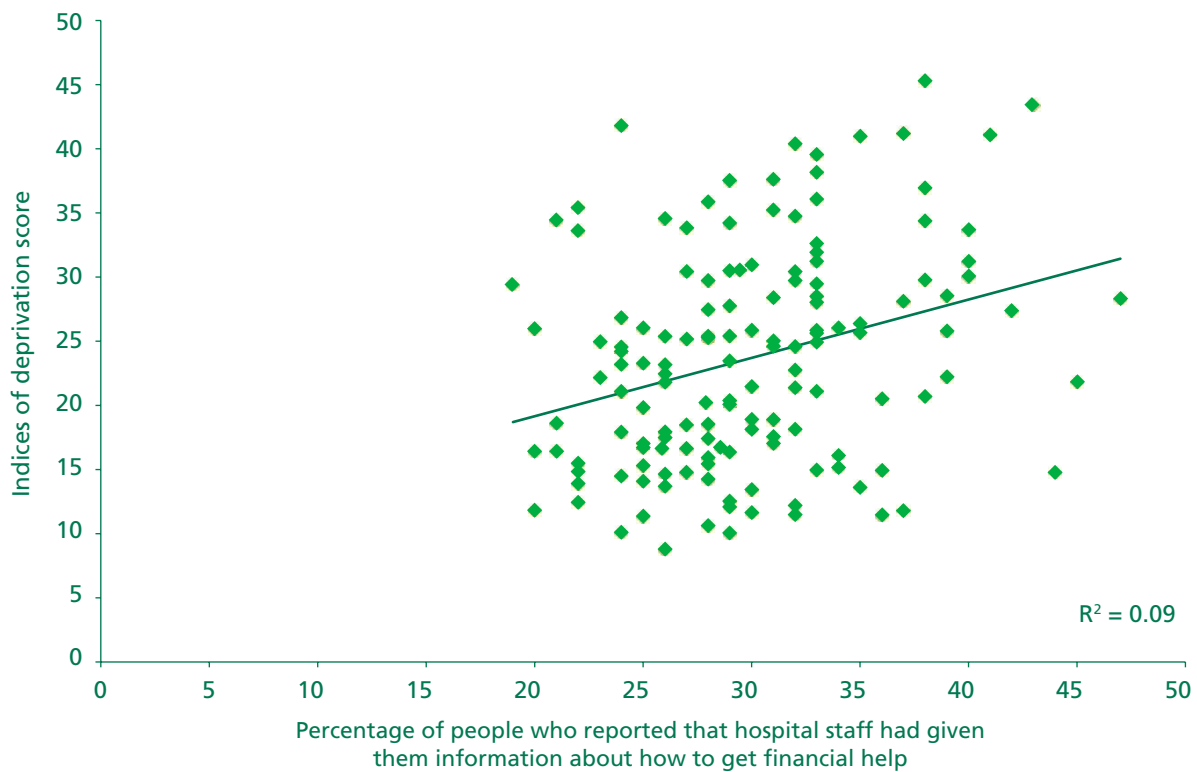


Chart 2 shows that, in general, people who were referred from a more deprived PCT area were more likely to be given information about how to get financial help by hospital staff than those from more affluent areas. This may seem intuitive; however, research published by Macmillan shows that a cancer diagnosis can have a very significant impact on people with middle and higher incomes, if the person affected by cancer or a family member has to give up work, for example<sup>23</sup>.

**Recommendation 9:** It is essential that, where appropriate, every person with a cancer diagnosis is given information about how to get financial help from hospital staff.

# Patient views on whether there were enough nurses on duty

The views of cancer patients on staffing levels are an important measure of patient experience because they reflect perceived (and potentially real) issues about the quality, safety and responsiveness of care. Concerns about whether there are enough nurses on duty can also undermine patient confidence in their treatment and care.

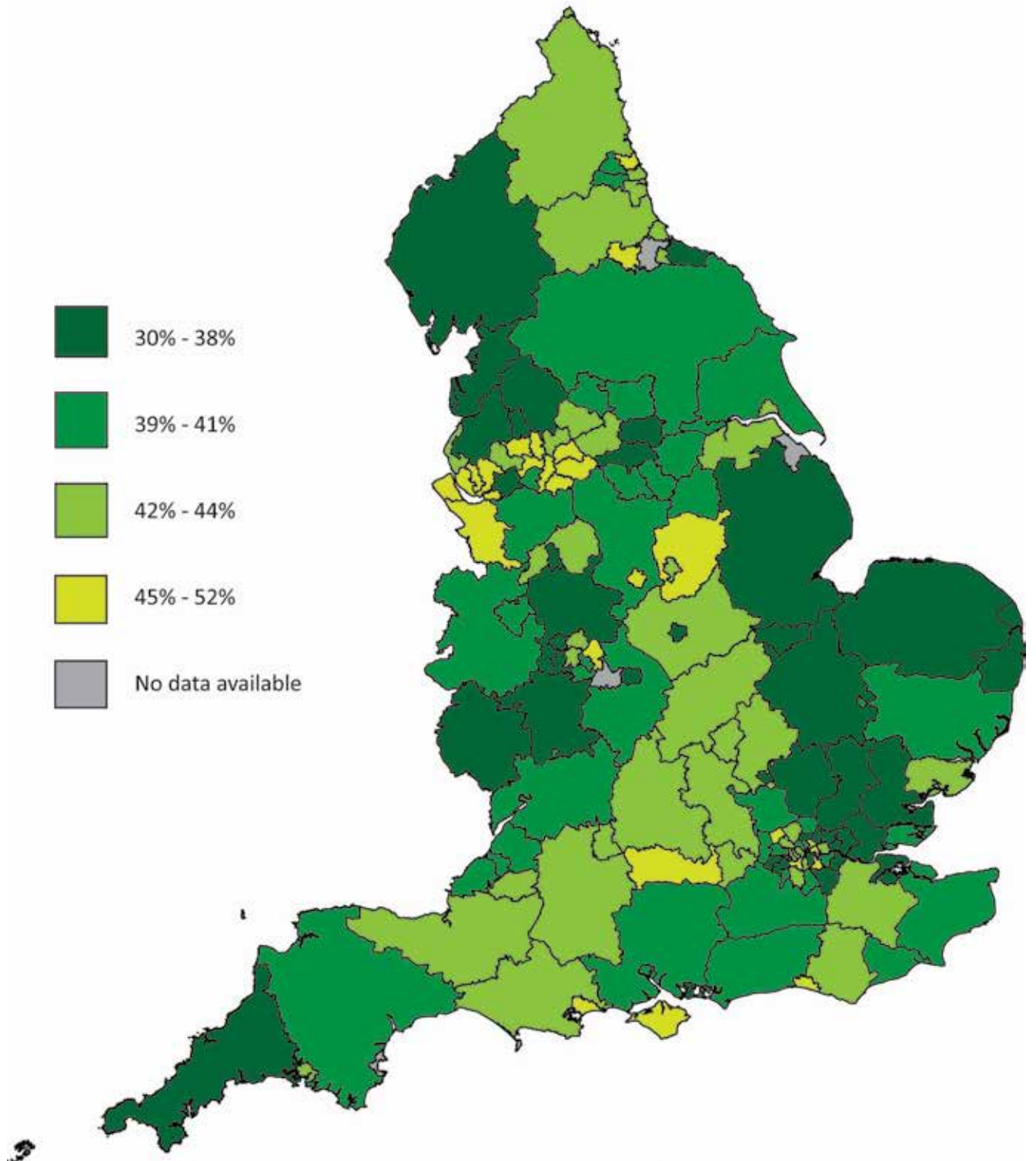
There is a good deal of variation in patient views on staffing levels depending on the commissioner of responsibility. This ranges from 30% in Portsmouth City PCT to 52% in Tower Hamlets PCT. It is important to note that the scores are based on the total number of survey respondents (rather than the proportion of respondents to that particular question). This question attracted a relatively low number of responses which may account for the fact that the scores are low, hence our analysis focuses on the extent of variation rather than the percentage scores.

Map 7 shows that geographically, patient perceptions of staffing levels are very mixed. There is some evidence to suggest that more densely populated areas (such as parts of London, Manchester and Newcastle) are associated with higher performance on this measure, perhaps due to the fact that staffing levels have been effectively planned and resourced to cater for demand.

It may be possible to explain these trends in part by the location of the specialist cancer centres in relation to the commissioner of responsibility. Treatment for cancer is often intensive and requires multiple trips to hospital, often over a number of months. Although larger cancer centres may offer higher staffing levels with clinical, research and teaching expertise, patients may choose to receive their treatment at a local hospital for convenience or to remain in close proximity to family and friends. Map 8 shows poorer experience in more remote areas such as Devon, Cumbria, Lincolnshire, Norfolk, North Lancs, where patients would be required to travel long distances to reach a specialist cancer centre.



**Map 7: Percentage of patients who felt there were always or nearly always enough nurses on duty, by referring PCT<sup>24</sup>**



Our analysis revealed a small correlation between the level of expenditure on cancer services and the extent to which patients felt that there were enough nurses on duty ( $R^2 = 0.04$ ). This might be explained by the fact that staff costs represent a significant proportion of the NHS budgets (around 40%<sup>25</sup>). However, specific analysis of the correlation with staff costs was not possible as expenditure data are not disaggregated in this way at PCT-level. Comparison of the expenditure and patient experience maps shows that in more remote rural PCT catchments such as Norfolk and North Lancashire, lower levels of spending are matched by poorer patient experience which would support the trends described above.

**Recommendation 10:** Commissioners with relatively low scores in relation to patient perception of staffing levels should critically evaluate whether providers from whom they commission care require additional nursing capacity; need to deploy nurses more effectively; or improve communication and responsiveness of staff with patients.

**Recommendation 11:** Commissioners with relatively low scores should work closely with providers to address identified concerns over nursing capacity, as a priority.

**Recommendation 12:** Quality Health should investigate the reasons why responses to the question on staffing levels are relatively low and consider whether the wording of the question should be changed to make it easier for patients to respond.

# Patient and staff interaction

## – respect and dignity

Ensuring that patients are treated with dignity and respect has come under the spotlight in the NHS in recent years. Making sure that patients have a positive experience of relational care and that they are treated with compassion is now considered to be as important as high quality clinical care.

The data from the CPES gives hospitals feedback from cancer patients relating to whether they were treated with dignity and respect during their care. For commissioners, it is vital to know whether the patients they are referring for cancer treatment and care are experiencing this most fundamental right in the NHS.

In the best performing referring area, 75% of patients felt that they were always treated with dignity and respect, compared to 44% in the worst performing referring area. This means that for the worst performing referring PCTs around half of patients (between 44-53%) did not feel that they were treated with dignity and respect at all times. Map 8 shows how the results for this question break down across the country by referring PCT.

Areas in the South East and parts of the North are associated with lower scores on this measure of patient experience compared to people referred from the Midlands and the urban areas around Manchester.

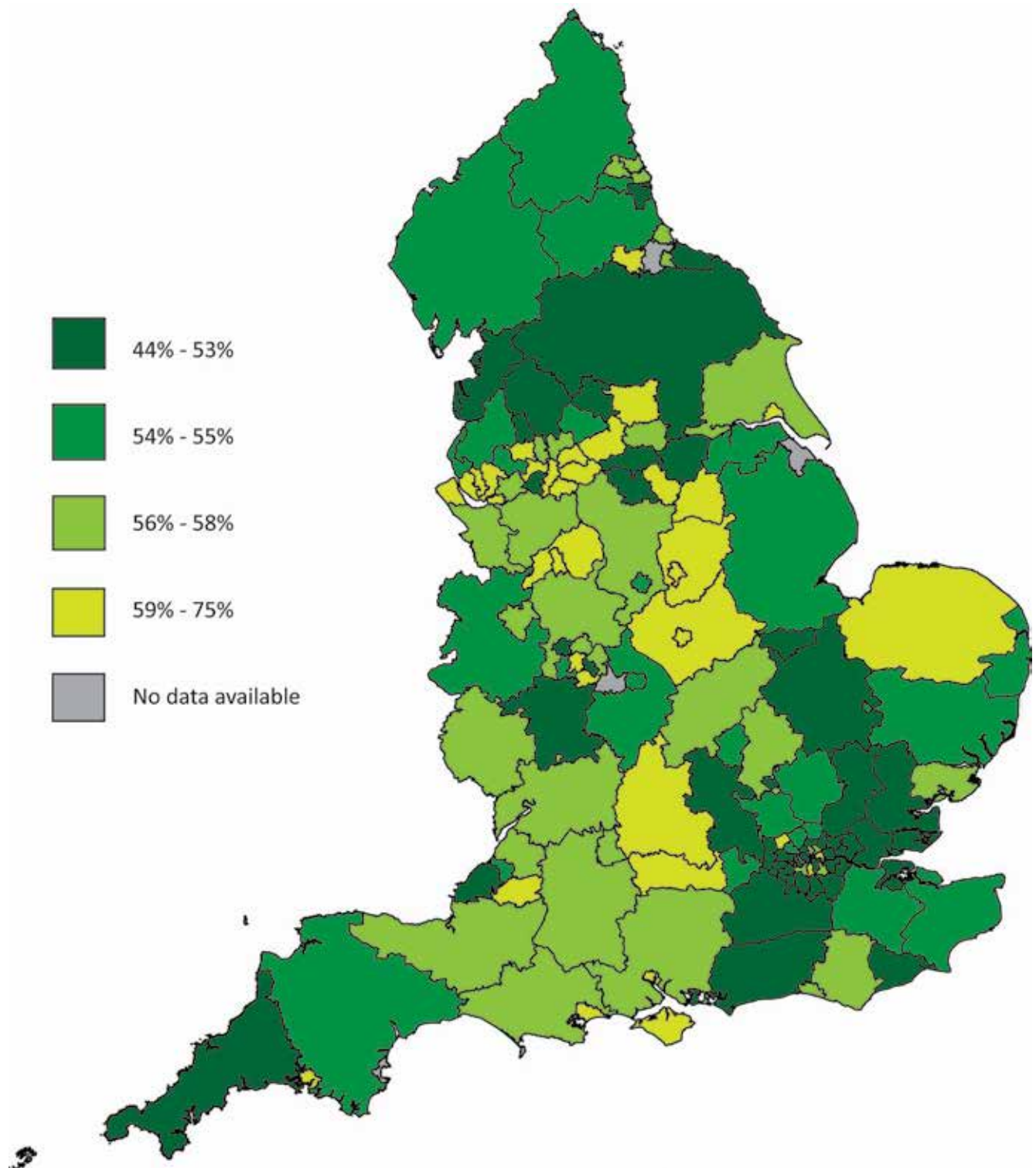
Our analysis revealed that the correlation between whether patients always felt they were treated with dignity and respect and overall spend on cancer is small ( $R^2 = 0.02$ ). This is important because it shows that improving relational aspects of patient experience (treating patients with dignity and respect and improving patient involvement in their care) do not necessarily need to pose significant additional costs, in the way that functional aspects might (such as reducing waiting times for diagnostic tests).

However, to improve performance in this area, providers need to ensure that they are creating positive opportunities for reflective practice, for example, through the use of Schwartz Centre Rounds<sup>®</sup>, to enable professionals from across the MDT to discuss their approach to providing care in challenging scenarios.

Moreover, commissioners should be working with hospitals to develop a values-based approach to care (for example, by using the Macmillan Values Based Standard<sup>®</sup>) which will improve the ability of staff to respond to the individual needs, preferences and expectations of each patient.

**Recommendation 13:** Commissioners should monitor whether patients report that they were treated with dignity and respect, and seek to commission services on the basis of high quality relational care.

**Map 8: Percentage of patients who felt they were always treated with respect and dignity, by referring PCT<sup>26</sup>**



# The provision of information about what patients should do or should not do after leaving hospital

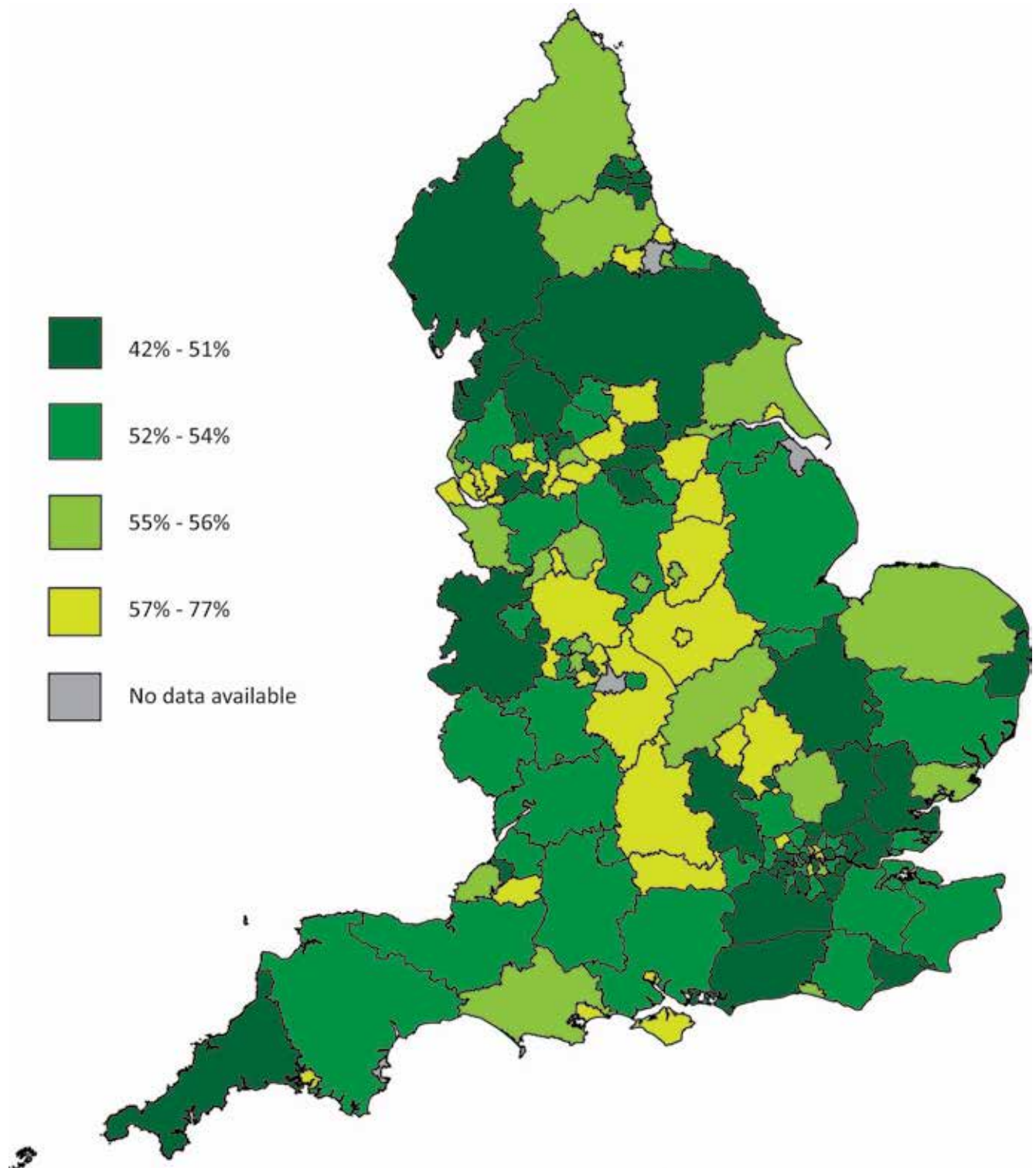
Understanding what to do after leaving hospital is an important part of ensuring patients experience coordinated care, as well as reducing unplanned hospital admissions and the burden on primary care services. It is therefore essential that cancer patients are given clear written information about what they should and should not do after leaving hospital, including support to help them to self-manage.

There is widespread variation in the number of people who reported that they were given clear information about what they should or should not do after leaving hospitals, ranging from 77% in the best performing referring PCT, to 42% in the worst performing referring PCT. The full variation across England is set out in Map 9.

Our analysis showed that there was no observable correlation between the provision of information around discharge and the overall level of spending on cancer services. Given the overall scope of programme budgeting expenditure it is not surprising that there is no visible effect. However, it will be important for commissioners to understand the impact of poor information provision on spending in other parts of the service. This could be achieved through an analysis of primary and secondary care utilisation after discharge and whether these episodes could have been avoided through improved information and engagement of patients in their own recovery.

**Recommendation 14:** Commissioners should monitor the reasons for cancer patients accessing health services following discharge and work with providers to improve the provision of information and support for self care in order to drive up performance in this area.

**Map 9: Percentage of patients who felt they were given clear written information about what they should or should not do after leaving hospital, by referring PCT<sup>27</sup>**



# The provision of care and help from health or social services after leaving hospital

Cancer patients should be able to access high quality care and help at all stages of the pathway. Once treatment episodes are completed, it is important that care and help are effectively coordinated outside hospital, in or around a patient's home.

Ensuring that patients can access integrated care and support after leaving hospital is important for a number of reasons, including:

- Helping patients to achieve high quality clinical outcomes
- Reducing unnecessary healthcare utilisation by supporting improved self care
- Enabling patients to have a positive experience of their care
- Supporting family and carers
- Aligning services so that they are integrated, ensuring that health and social care services can be accessed based on the needs of each individual patient

Given that these services are run outside the control of the hospital, particularly with regard to social care services, it is important to scrutinise performance at the commissioner level.

This is particularly pertinent to NHS commissioners given new duties within the Health and Social Care Act 2012 to promote integrated care. Map 10 shows how scores for this measure of patient experience varied by referring PCT in England.

The map shows that there are variations across England in the proportion of patients saying they were definitely given enough care and help from health or social services. In the best performing referring PCT areas, 43% of patients felt that they had definitely been given enough care and help, but in the worst performing area, only 13% of patients reported this. There is a North-South divide, with patients from referring PCTs in the North more likely to report positively on this important measure of patient experience than those in the South. This shows that there is much more that commissioners in England can do to ensure that services are effectively planned and integrated across health and social care settings, once patients leave hospital.

Considering programme budgeting expenditure in relation to this measure of patient experience is of limited use given that it does not include social care provision funded by local authorities. Hence, local commissioners should work together to review spending and identify whether there are ways to enhance the integration and efficiency of care and help outside hospital, and secure improvements in patient outcomes.

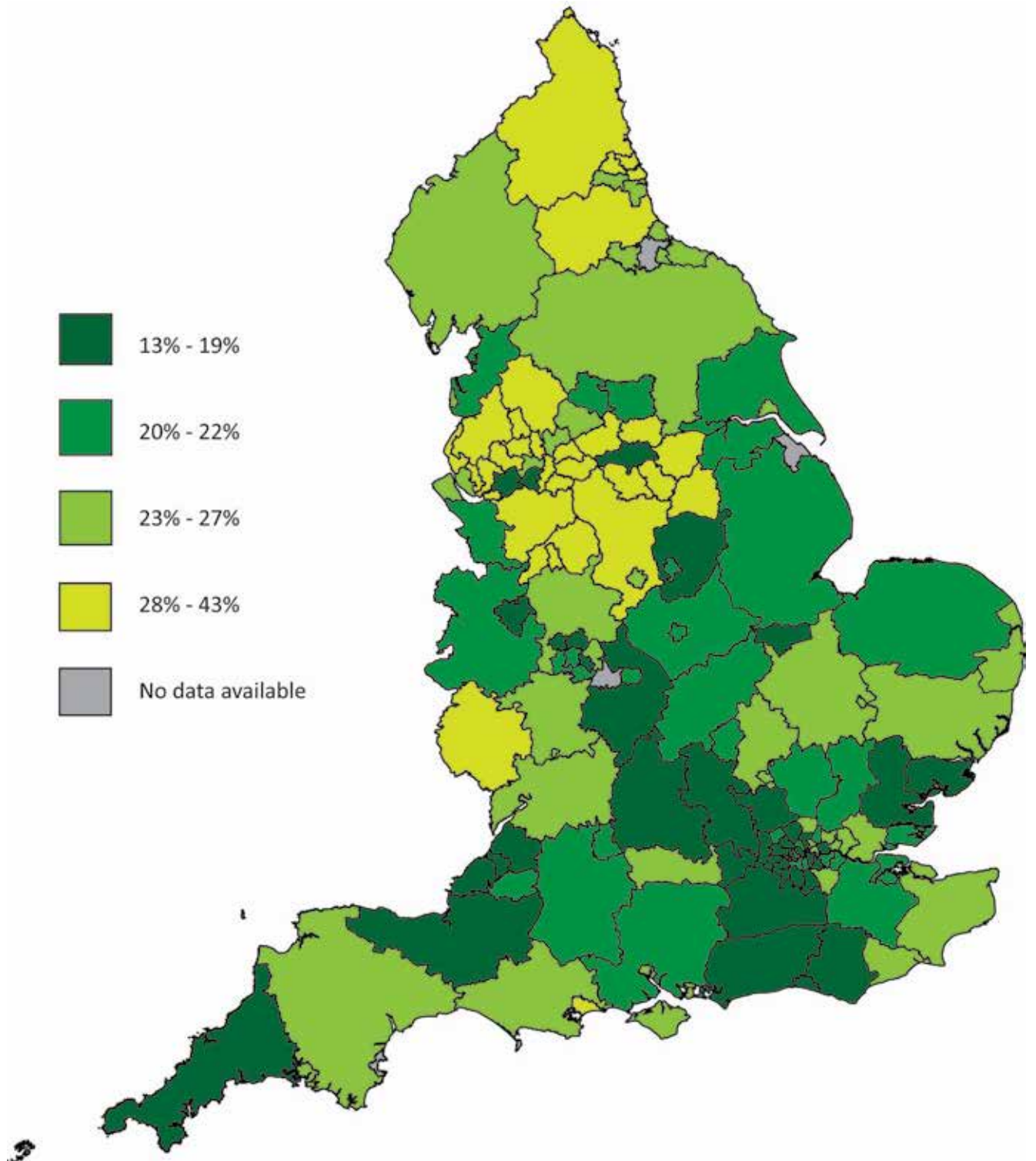
**Recommendation 15:** Commissioners should critically evaluate the performance of services that are provided to care for and help cancer patients when they leave hospital, as these services can prevent unnecessary hospital admissions which can be both costly to the NHS and distressing to the patient.

**Recommendation 16:** NHS commissioners should work with local authority commissioners to ensure that there is an integrated, smooth and cost effective link between health and social care services for cancer patients.

**Recommendation 17:** NHS England, in its role as a commissioner, should lead by example and take responsibility for making sure that people experience coordinated care. Strategic clinical networks should prioritise within their cancer workplans the improvement of patient experience at key transition points between services.



**Map 10: Percentage of cancer patients who felt that they were definitely given enough care and help from health and social services after leaving hospital, by referring PCT<sup>28</sup>**



# Patient and staff interaction – whole-person care

The impact of cancer extends beyond the symptoms of the disease itself and the physical effects of treatment. A cancer diagnosis, the journey through treatment and the process of recovery can be life-changing, affecting the emotional and psychological wellbeing of individuals and relationships with friends and family. As more people are living with and beyond cancer, services increasingly need to respond to a patient's whole needs as a person beyond the disease.

This can mean ensuring that the right services and support are put in place to support holistic needs, or it can be as simple as improving the way that staff interact with patients. This could include calling them by their preferred name, acknowledging them when they communicate that they are in need and recognising how they would prefer to be cared for. In response to these challenges, Macmillan has developed the Macmillan Values Based Standard<sup>®</sup>, which supports staff to address what matters most to patients, as demand on health services and support continues to increase.

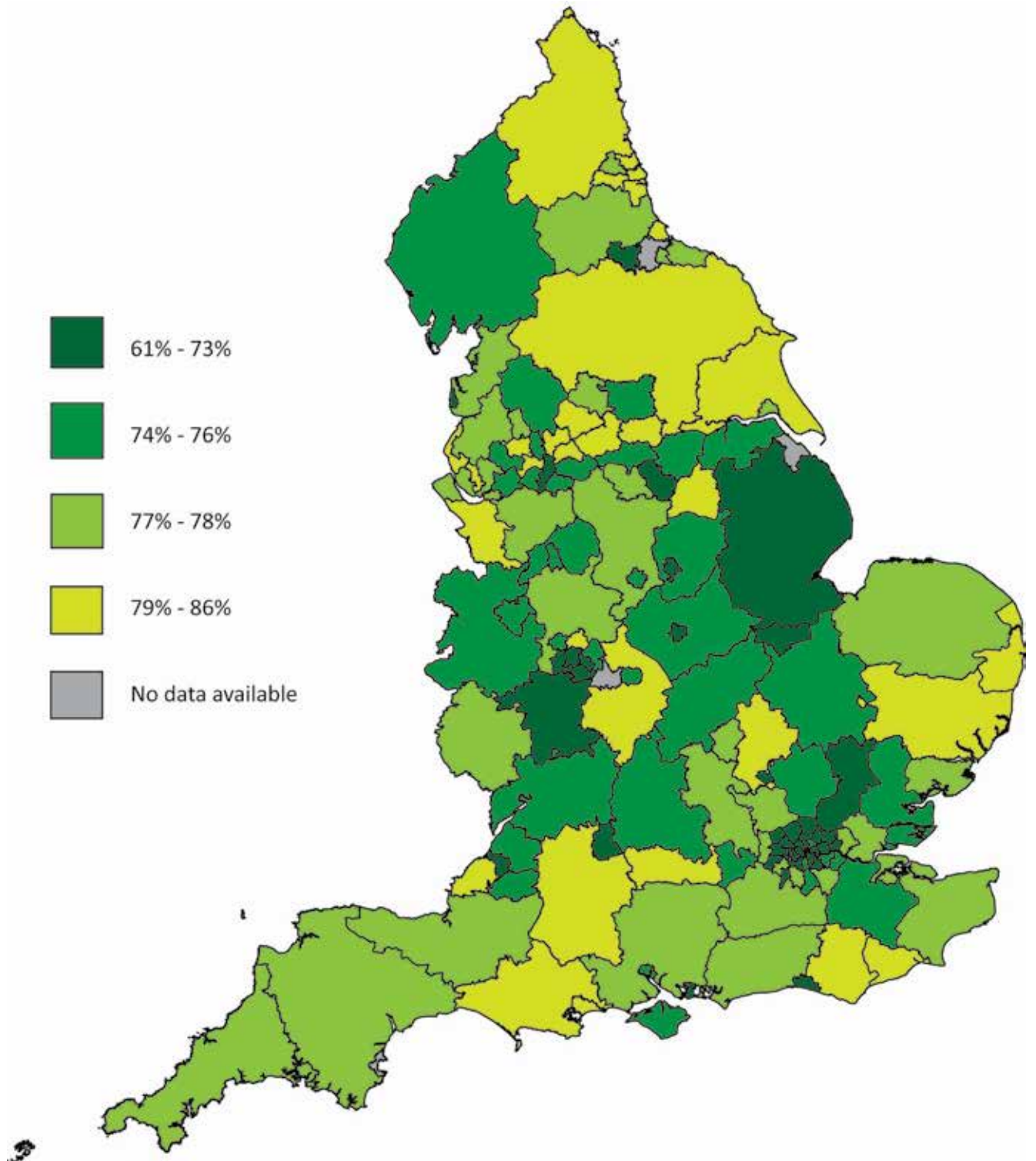
Asking patients what name they would preferred to be called by represents a key marker of the ability of cancer services to deliver care in a

compassionate and responsive way. It is therefore concerning that variation between referring PCT is marked, ranging from 61% in Ealing PCT to 86% in Bassetlaw PCT. This measure is most likely to reflect the clinical culture and behavioural approaches that exist within local cancer teams.

As highlighted in Map 11, the poorest performance is clustered in London – which has the highest density of both specialist cancer centres and district general hospitals. Poorer performance is also linked to other specialist hospitals based in Liverpool, Leeds, Nottingham and Bristol. Although it is difficult to draw firm conclusions about these data, the trends may reflect the focus on achieving clinical excellence, potentially at the expense of patient outcomes concerning relational care.

It is also interesting that referring PCTs covering rural populations tend to report higher patient experience on the 'whole person' measure. This may reflect the patient caseload in less densely populated areas. Lincolnshire PCT stands out as an exception – but is also linked with poorer experience on the measure of staffing levels. Hence it may be that patients felt staff lacked the time and resource to deliver a high standard of compassionate care.

**Map 11: Percentage of cancer patients who said that they were treated as a 'whole person' and not like a set of cancer symptoms, by referring PCT<sup>29</sup>**



Our analysis of the relationship between the 'whole-person' measure of patient experience and the level of deprivation showed a small correlation in which poor performance was associated with a higher level of deprivation ( $R^2 = 0.03$ ). It is important that providers take appropriate steps to ensure that their approach to care delivery helps to break down, rather than entrench, persistent health inequalities.

Our analysis of the relationship with programme budgeting data shows that there is no significant correlation between spending on cancer services and whether patients felt that they were treated as a set of cancer symptoms. This consolidates our previous findings which concern relational care and the interaction between patients and staff. Costs associated with providing ongoing support for reflective practice and investment in improving communication across the MDT are relatively low and remain integral to the wider process of cultural change within NHS organisations in which safe, high quality care is a core priority.

Moreover, it is important to consider the relationship between staff and patient experience. Research undertaken by Picker Institute Europe on behalf of Macmillan showed that across a number of measures, positive patient experience was related to positive staff experience. For example, there was a positive correlation between patient experience and staff reporting that they would recommend

the trust as a place to work or receive treatment, or if they had not suffered any discrimination<sup>30</sup>. Hence commissioners and providers should consider how best to support staff as part of their wider efforts to secure improvements in patient experience.

**Recommendation 18:** Commissioners should critically appraise their patient experience scores on key staff behaviour measures in the CPES (such as q51 and q69) and in the NHS staff survey to develop a plan to improve the quality of patient-centred care (for example, by using the Macmillan Values Based Standard® as an approach for local improvement).

**Recommendation 19:** Commissioners should evaluate scores on the 'whole-person' patient experience measure to understand the extent to which providers are upholding rights in relation to equality and patient-centred care in the NHS Constitution.

# SECTION B

## Which areas of healthcare delivery have the strongest association with overall patient experience?

This section sets out the findings of our analysis of the correlation between each of the measures of patient experience included in the CPES and a measure of how patients rate their experience overall. The overall measure is based on the percentage of patients who rated their overall experience of care as either 'excellent' or 'very good'. This analysis is instructive because it enables commissioners and providers to identify the actions or interventions which have the closest association with overall cancer patient experience, and therefore, it will support them to prioritise efforts to improve outcomes in line with Domain 4 of the NHS Outcomes Framework.

Using these insights together with the data on variations outlined in Section A, helps commissioners to pinpoint:

- The areas of patient experience where performance falls short compared to that of their peers and where urgent action is needed
- The areas of healthcare delivery that commissioners may wish to define, measure, incentivise and reward through the use of commissioning levers in order to improve overall patient experience

This section describes those areas of healthcare delivery where the correlation between the specific measure and the overall measure was strong (as described in the methodology an  $R^2$  value of more than 0.3). Where the correlation was weak or there was no observable correlation, the measures have been disregarded and are not analysed here. The methodology is set out below, using question 44 of the CPES (which had a strong correlation with the overall measure of patient experience).

Question 44 asks '*While you were in hospital did you ever think that the doctors or nurses were deliberately not telling you certain things that you wanted to know?*'. When plotted against the overall measure, there appears to be a very high level of association between the specific measure and patients' overall experience of care, as Chart 3 shows.

While this is not necessarily indicative of cause and effect, it is plausible to hypothesise how perceived honesty would impact on overall experience.

Based on the same method, the following table summarises the themes and specific areas of healthcare delivery where correlation with overall cancer patient experience is the strongest – the 'core areas' of care.

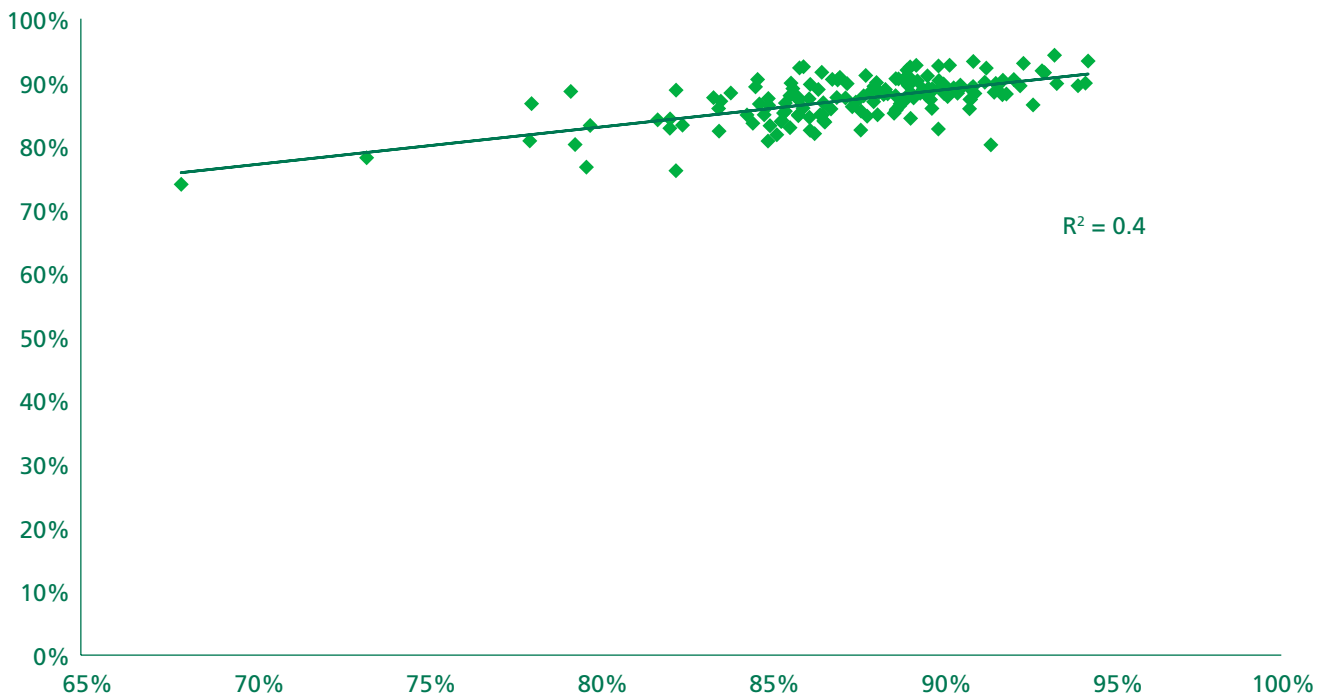
An exploratory factor analysis, to identify an underlying structure by which questions in the CPES can be grouped, identified four key domains: provision of information, involvement in decisions, relational care (communication, respect and dignity) and care transitions which broadly map to the themes identified here<sup>32</sup>.

**Recommendation 20:** NHS England should ensure that patient experience indicators in national frameworks reflect what is important to cancer patients and drive improvements in care.

**Recommendation 21:** NHS England should hold local commissioners to account for improving cancer patient experience by developing an indicator on cancer patient experience for inclusion in the Clinical Commissioning Group Outcomes Indicator Set.

**Recommendation 22:** Providers should take proactive steps to improve the quality of patient experience across the key areas of communication, information, involvement and integration.

**Chart 3: Correlation of a patient answering 'never' when asked if they felt doctors or nurses were deliberately not telling them things they wanted to know<sup>31</sup> (x-axis) and the overall measure (y-axis)**



**Figure 1: Core areas of care**

Theme	Measure	CPES question
Communication	• Being honest with patients and not hiding information	Q44
	• Nurse politeness – not talking about patients as if they weren't there	Q42
	• Giving patients the opportunity to discuss their fears and worries	Q49
	• Ensuring patients receive answers to questions that they understand – particularly from a clinical nurse specialist	Q23
Information	• Giving patients the right amount of information about their condition and treatment	Q67
	• Ensuring patients are given a complete explanation of the purpose of their test	Q6
	• Providing patients with a complete explanation of what would happen during an operation	Q32
Integration	• Coordinating care across hospital and community settings effectively	Q66
	• Caring for the 'whole person' rather than treating patients as a set of cancer symptoms	Q69
Involvement	• Ensuring patients definitely feel involved in decisions about their care	Q19



These insights will help commissioners to secure improvements in the quality of patient experience. They can be translated into specific actions across the commissioning cycle.

**Recommendation 23:** Commissioners should use the data presented in this report (both on variations and the core areas of care) to develop levers across the commissioning cycle that will help to secure improvements in patient experience.

Based on these insights, there are a number of steps that commissioners will want to take to secure improvements in the quality of patient experience.

### Strategic planning

- Commissioners should critically appraise the performance of providers from whom they commission care using the overall patient experience score and scores on the measures which correlate most strongly with overall patient experience (outlined above)
- This can be used to 'diagnose' the state of existing service provision
- This intelligence should be used to inform commissioners' quality improvement plans and create a baseline picture of performance against which progress should be measured periodically over time

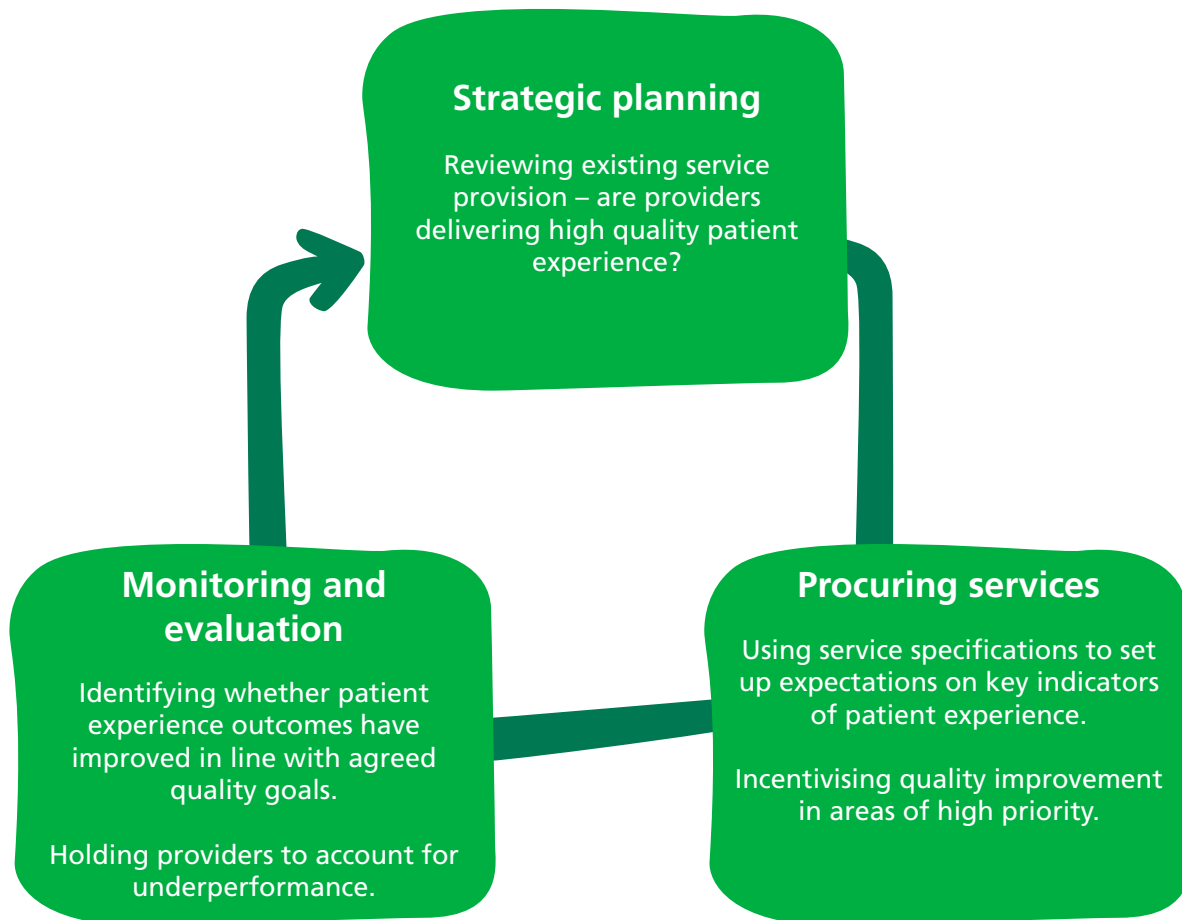
### Procuring services

- Commissioners should set out their expectations of the quality of patient experience as part of the service specification agreed with providers
- It is recommended that each commissioner stipulates a series of service requirements and quality improvement goals
- The requirements and goals should be centred on:
  - The key measures or areas of healthcare delivery where the commissioner scores are relatively low compared to their peers (identified in Section A)
  - The core areas of care which apply to all PCT areas (outlined in Figure 2). A number of recommendations across the core areas are set out below
- Working with the provider, commissioners may wish to identify a number of priority improvement goals which could be established as a local incentive scheme so that an agreed level of improvement achieved over the year is attached to a financial reward

### Monitoring and evaluation

- Commissioners should evaluate the extent to which providers have delivered against service requirements and quality improvement goals and should use sanctions to penalise poor performance where appropriate

**Figure 2: Harnessing insights across the commissioning cycle**



**Figure 3: Suggested service requirements and quality improvement goals to improve patient experience based on core areas**

Theme	Service requirement	Quality improvement goals
Communication	<ul style="list-style-type: none"> <li>• Reflective practice and support to improve MDT communication</li> <li>• Review and secure appropriate level of CNS support based on patient caseload</li> </ul>	<p>Evidence of quality improvement measured by:</p> <p>X % increase in scores on questions 44, 42, 49, 23 using data from the CPES</p> <p>For example, X provider will deliver X% increase in the proportion of patients who reported being able to discuss their fears and worries to be documented in a provider's quality account</p>
Involvement	<ul style="list-style-type: none"> <li>• Implementation of training/programmes to promote patient-centred care and co-creation of interventions (such as the implementation of the Macmillan Values-Based Standard®)</li> <li>• Introduction of processes to secure real-time feedback from patients on the extent to which they feel involved in their care</li> </ul>	<p>Evidence of quality improvement measured by:</p> <p>X % increase in scores on question 19 using data from the CPES</p>
Information	<ul style="list-style-type: none"> <li>• Conduct audit of information provision, working with strategic clinical networks to share examples of good written information and verbal communication</li> </ul>	<p>Evidence of quality improvement measured by:</p> <p>X % increase in scores on questions 67, 6, 32 using data from the CPES</p>
Integration	<ul style="list-style-type: none"> <li>• Allocate key worker to all patients post-discharge to support coordination of care outside hospital</li> <li>• Establish a formal process to ensure that patients are routinely offered information about or signposted to local self help and support groups</li> </ul>	<p>Evidence of quality improvement measured by:</p> <p>X % increase in scores on questions 66 and 69 using data from the CPES</p>

**Recommendation 24:** Commissioners should use the service specification to stipulate service requirements to improve the quality of patient experience (for example, by requiring providers to ensure an appropriate level of access to a CNS).

**Recommendation 25:** Commissioners should use the service specification to set out quality improvement goals and incentive schemes which require providers to deliver an agreed percentage improvement in priority areas (for example, the proportion of patients feeling involved in decisions).

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