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Is the NHS becoming more person-centred?

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This is one of a series of overviews looking at key areas of quality: safety, waiting times, mental health, person-centred care and international comparisons.

See: www.health.org.uk/qualityoverview

5%

Only 5% of people with a long-term condition have a written care plan

This overview examines how the NHS in England has performed over this parliament in relation to indicators that reflect person-centred care. We consider a range of measures including: dignity, respect and compassion; patient involvement in decisions; support for self-management and care planning.*

Key points

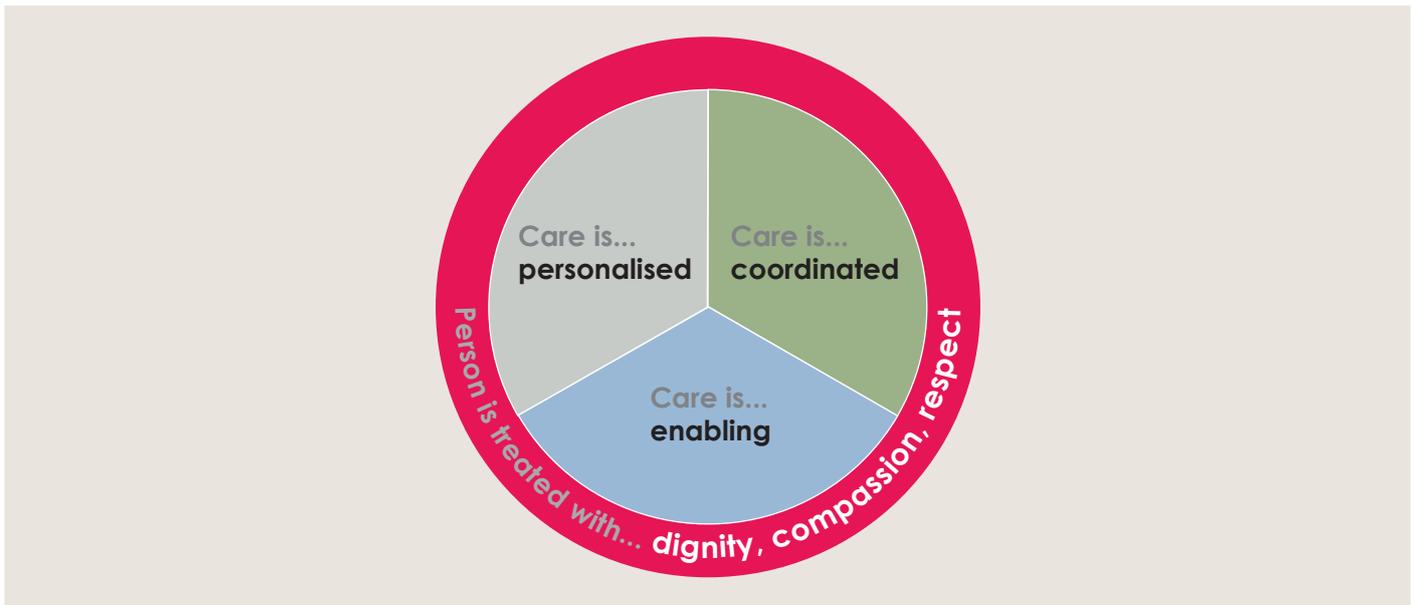
- **Successive governments, since at least 2000, have made a commitment to person-centred care.** The serious failings in care at Mid Staffordshire NHS Foundation Trust and the current government's early commitment to the principle of 'no decision about me without me' have underpinned the focus on person-centred aspects of care during this parliament.
- **National measurement of person-centred care is conducted through NHS surveys.** These surveys give an indication of how the NHS is performing in some areas, such as treating patients with dignity and respect. However, in others, such as coordination of care, there are very few national measures to draw on, so we do not know how well health and care services are performing.
- **While there are signs of improvement in some areas of person-centred care, in many others there has been no real improvement over the last five years.** For example, the percentage of patients who reported that a nurse spoke in front of them as if they were not there has reduced but there has been no change in the 16 percent of patients who say they are not involved in decisions about their discharge from hospital.
- **In some key areas, there remains a large gap between the ambition to have a health service that is person-centred and the reality of patients' experience.** Only 5% of people with a long-term condition have a written care plan and almost 20% of inpatients say they are not always treated with dignity and respect.

* The Picker Institute published a paper in 2007 titled *Is the NHS becoming more patient-centred?* Although this overview covers similar ground, it is not an update to the Picker paper. For the full paper see Richards N, Coulter A. *Is the NHS becoming more patient-centred?* Picker Institute, 2007. www.yearofcare.co.uk/sites/default/files/pdfs/99_Trends_2007_final%5B1%5D.pdf

What is person-centred care?

There is no single definition of person-centred care; this is one of the reasons why measuring and judging progress is difficult. The Health Foundation has developed a framework that sets out four principles of person-centred care.¹ There are also a number of person-centred care activities, such as personalised care and support planning, self-management support and shared decision making. These activities can ensure that services reliably deliver the person-centred care and support principles.²

Figure 1: Four principles of person-centred care³



Common person-centred care terms

- **Self-management support:** An approach to enabling people with long-term conditions to manage their health on a day-to-day basis. Self-management support acknowledges that people frequently make decisions about their health and care and supports people to develop the knowledge, skills and confidence they need. Examples include structured group education programmes, health coaching and motivational interviewing.
- **Shared decision making:** A collaborative process through which a health care professional supports a patient to reach a decision about a specific course of action. It can help prepare individuals before a consultation by encouraging them to think about the questions they want to ask. It often involves decision support materials designed to help individuals weigh up their options, such as information resources, patient decision aids, brief decision aids and option grids.
- **Personalised care and support planning:** A way of supporting people with long-term conditions and disabilities to work together with their health care professionals to plan their care. The process involves exploring what matters to the person; identifying the best treatment, care and support; and supporting them to set goals and think about actions they can take to reach them.
- **Personalisation:** Providing health services that are tailored to the needs and aspirations of each individual, not standardised to their condition, age, or other characteristic. What is important to the person receiving care and their family is discussed and forms the basis of their treatment and care.
- **Coordination:** Organising services so that transitions and information sharing between settings and professionals are coordinated and seamless.
- **Enablement:** An ill-defined term but it is generally accepted that it describes the degree to which people feel supported to develop their own unique range of capabilities.

Person-centred care in context

Ensuring that people using health and care services are treated with dignity, compassion and respect should be an ‘always event’ – yet we know that this is not the case. The exposure of serious failings in care in particular settings, including Mid Staffordshire NHS Foundation Trust,⁴ Winterbourne View⁵ and, most recently, Morecambe Bay⁶ puts the results from the national surveys into stark perspective. The fact that over 80% of inpatients say they are treated with dignity and respect at all times could be cause for complacency, until one realises that this means that one in five patients are not always treated with dignity and respect.

Commitments to some or all of the principles of person-centred care have been explicit aims of all UK governments since the *NHS Plan* was published in 2000.

Patients and service users want to plan their care with people who work together to understand them and their carers, put them in control and coordinate and deliver services to achieve the best outcomes for them.⁷ There is a growing body of evidence showing that person-centred care activities, such as self-management support and shared decision making, can contribute to improvements in a range of areas including patient experience, care quality and health outcomes.^{8,9}

Commitments to some or all of the principles of person-centred care have been explicit aims of all UK governments since the *NHS Plan* was published in 2000. Over the current parliament, an increasing emphasis has been placed on choice of treatment (represented in the principle of ‘no decision about me without me’), recognising the patient’s role in managing their own health and care and ensuring that care is personalised and coordinated around the needs of individual patients and carers (often called ‘integrated care’).

Figure 2: Timeline of English policy commitments to person-centred care in the current parliament



This overview highlights performance in relation to a number of person-centred principles that are measured in the current national datasets. We mostly use data from surveys of hospital inpatients and patients registered with a general practice but include data from other surveys with cancer patients and those using community mental health services, where these provide useful comparisons.

National data on person-centred care

National surveys

Currently, the main data about person-centred care in the NHS are collected through a series of national surveys including some that are condition-specific. One of the main strengths of the national surveys is their large sample size:

Survey	Most recently conducted	Sample size (people)
Adult inpatient survey ¹⁵	2013	62,400
Adult outpatient survey ¹⁶	2011	More than 72,000
GP patient survey ¹⁷	2014	881,183
A&E survey ¹⁸	2014	Almost 40,000
National cancer patient experience survey ¹⁹	2014	70,141
Community mental health survey ²⁰	2014	More than 13,500

In addition, there have been five million friends and family test surveys completed since April 2013 (see 'The friends and family test' below).

There are significant limitations in the existing survey data:

- Common questions across different surveys (for example, about dignity and respect and involvement in decisions) may not be comparable between different services and populations, or over time. This is due to variations in response options and the wording of questions, as well as data weighting.
- Most surveys look at single points in time such as the last time a person was admitted to hospital or saw a GP. However, some aspects of person-centred care, such as coordination, need to be considered over time, across services and using multiple measures.
- Survey data is collected in different health care settings and at different organisational levels. For instance, the GP Patient Survey is collected at practice level, while the adult inpatient survey is collected at the level of provider trusts. In the latter case, the raw data cannot be used to drive micro-system improvement (eg, at the level of a ward or a team) because it is not attributable to that level of the system. Even where surveys can and do highlight data that could be used for micro-system improvement, the evidence that this happens systematically is not strong.²¹

The friends and family test

The friends and family test (FFT) is a single question survey that asks patients whether they would recommend the NHS service they have used to friends and family who need similar treatment or care. It was introduced in 2013 and is used across a range of health care settings.

A review of the FFT published in July 2014 found that the FFT was performing well as a tool for service improvement.²² 85% of trusts said that they were using it to improve patient experience and 78% reported that it has increased emphasis by their organisation on patient experience in their trust. However, the review concluded that the role of the FFT in the performance

management of trusts – for example, by providing a transparent headline metric that can compare trusts with each other – is currently limited. We have, therefore, not used FFT data in this overview.

Measures of person-centred care

Being treated with dignity, respect and compassion

The inpatient, outpatient, cancer patient experience and community mental health surveys all include a general question about whether people feel they were treated with dignity and respect.

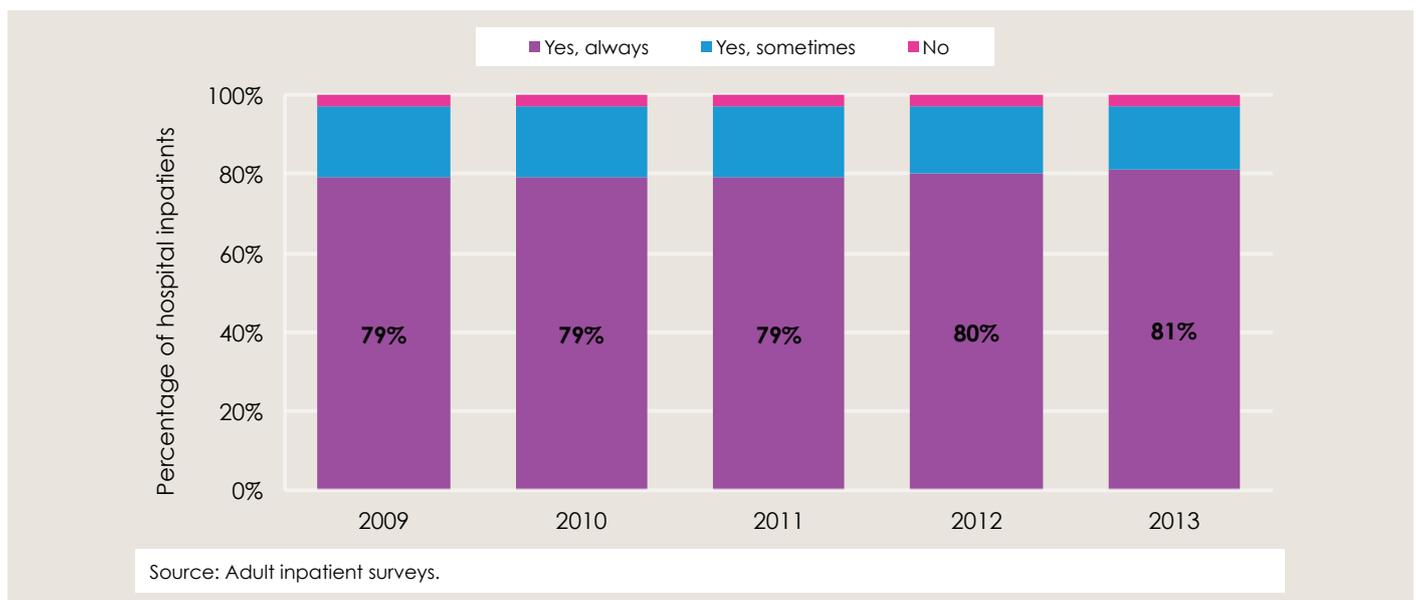
The majority of respondents consistently reported that they were treated with dignity and respect at all times. In the most recent surveys, 89% of outpatients (2011)¹⁶ and 81% of inpatients (2013)¹⁵ agreed with this statement. This leaves more than one in 10 outpatients and nearly one in five inpatients feeling they were not treated with dignity and respect some or all of the time.

In comparison, the National Cancer Experience Survey asks patients who have had an operation or overnight stay in hospital whether they were treated with dignity and respect. In 2013, 84% of respondents said they were always treated with dignity and respect – up from 82% in 2010.

1 in 5

One in five inpatients felt they were not treated with dignity and respect some or all of the time

Figure 3: Extent to which hospital inpatients felt that, overall, they were treated with dignity and respect while they were in hospital



The GP survey asks instead about how good the GP or nurse was at ‘treating you with care and concern’. The majority of respondents state that they were good or very good (91% for nurses and 85% for GPs in 2014). However, as with many of the indicators of person-centred care, results vary across organisations (figure 4).

Figure 4: Percentage of patients who felt that, last time they saw or spoke to a GP from their GP surgery, their GP was good at treating them with care or concern, by clinical commissioning group

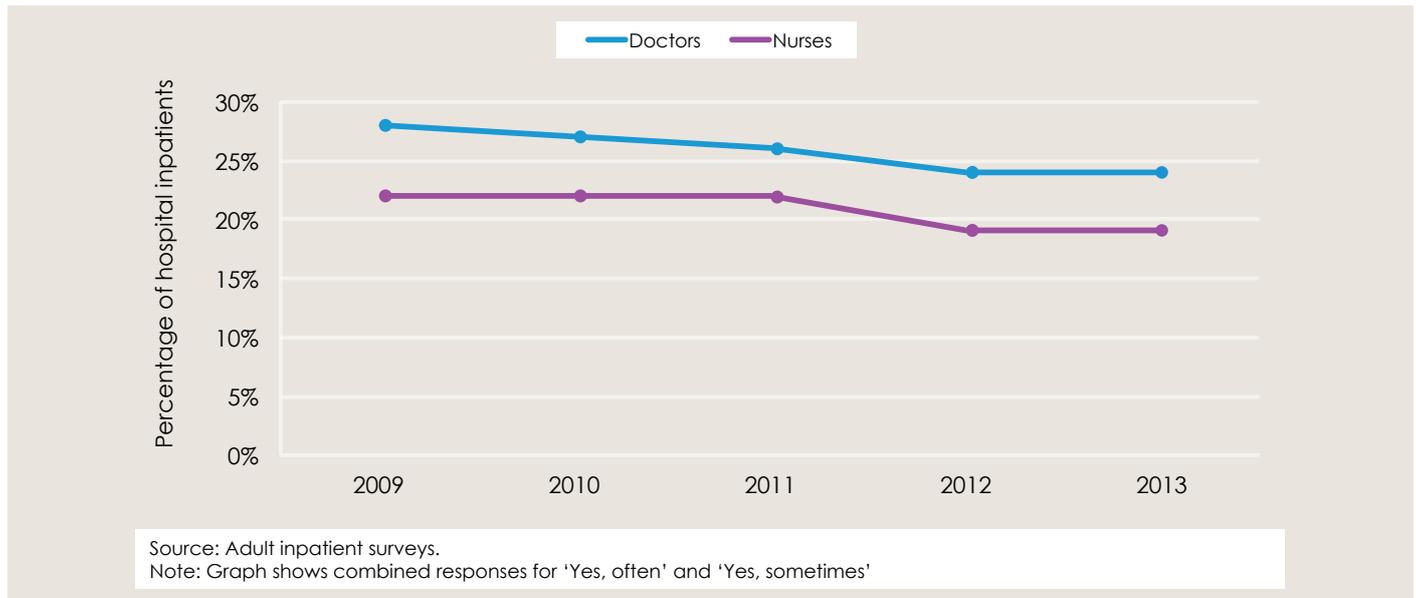


Source: GP patient survey 2014.
Note: graphs show combined 'good' and 'very good' responses

Positive responses to general questions like these may be due in part to gratitude bias (where feelings of gratitude may inhibit negative responses and promote positive ones) – this bias is more likely to affect indicators that rely on summary assessment rather than more objective questions.²³ There are a number of more objective questions in the various surveys that could be considered ‘proxy’ measures for dignity, respect and compassion. Responses to these more specific questions are often – although not always – less positive than the answers to the general or overarching question.

For example, nearly one in four patients reported that during their recent stay in hospital, doctors spoke in front of them as if they weren’t there, and one in five felt the same about nurses (figure 5, page 7). The surveys suggest that, since 2009, the number of patients reporting that a doctor or nurse spoke in front of them as if they weren’t there has reduced, from 27% to 24% for doctors and 22% to 19% for nurses. We do not know the reason for this change or whether it constitutes a real trend that will be sustained over time.

Figure 5: Percentage of hospital inpatients who reported that doctors or nurses spoke in front of them as if they weren't there

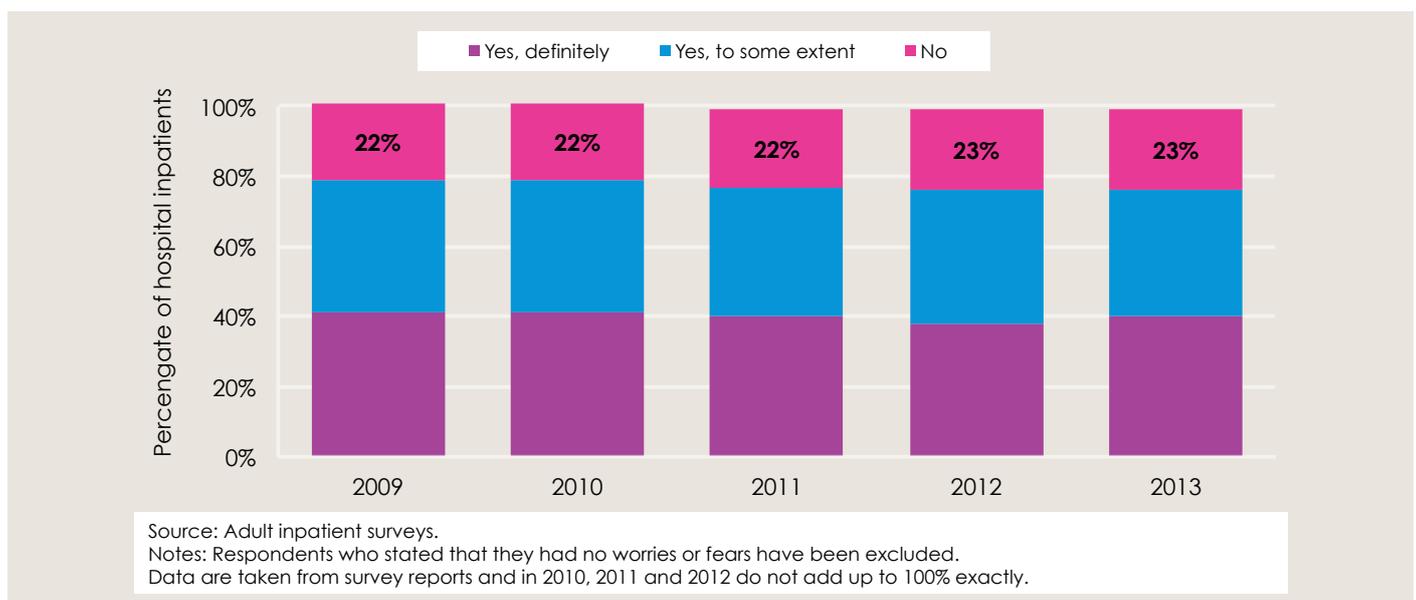


Both the inpatient and cancer patient experience surveys ask questions about whether people found someone to speak to about any worries or concerns.

Only 40% of inpatients in 2013, who said they had worries or concerns, definitely found someone to speak to about them (figure 6). This is the same as the level reported in 2010, at the beginning of the current parliament.

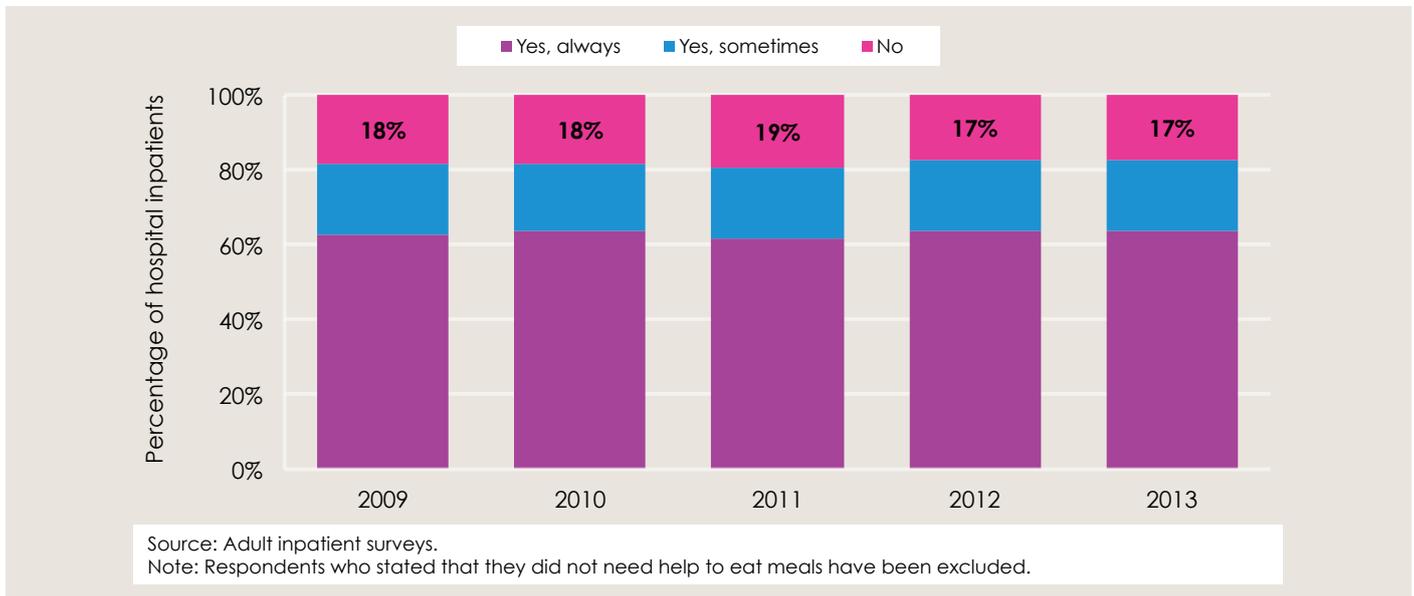
In comparison, 65% of cancer patients who had an operation or spent a night in hospital, and who said they had worries or fears, reported that they were able to discuss these as much as they wanted. A further 22% said they were able to do this most of the time.

Figure 6: Extent to which hospital inpatients found a hospital staff member to talk to about their worries and fears



Other questions look at physical aspects of care such as privacy, and provision of food and drink. Over a third of inpatient survey respondents who said they needed help to eat their meals reported that they did not always get this assistance (figure 7).

Figure 7: Extent to which hospital inpatients felt they got enough help from staff to eat their meals



The Care Quality Commission (CQC) conducted themed inspections in 2011 (100 hospitals)²⁴ and 2012 (50 hospitals)²⁵ looking at the extent to which older people were treated with dignity, were involved in decision making and had their nutrition and hydration needs met. The 2012 review concluded that:

'most of the hospitals we inspected were caring for people with dignity, treating them with respect, and supporting them to make sure their nutritional needs were met.'

However, underlying this overall finding was a very mixed picture. For example, while more hospitals were meeting the standards in relation to nutrition and assistance with eating and drinking (88% of hospitals, up from 83% the previous year), the review found fewer hospitals where patients were always treated with dignity and where people felt their privacy and independence were respected (82% of hospitals, down from 88% in 2011).

The CQC also publishes an annual *State of care* report that describes the main findings from its inspection programmes and surveys across health care and adult social care. The latest report from 2013/14 highlights variations across trusts for indicators of person-centred care, but also variations in the experiences of different groups of people.²⁶ For example, in both the 2011 inpatient survey and the 2012 A&E survey, people with a long-term condition – particularly a mental health condition – were less likely to report that they were treated with dignity and respect than those without.

Events at Mid Staffordshire NHS Foundation Trust and other places remind us that dignity, respect and compassion are not areas the NHS can afford to ignore

Events at Mid Staffordshire NHS Foundation Trust, Winterbourne View care home and other places remind us that this is not an area the NHS can afford to ignore. We need to continually measure and improve how health and care services treat those using them. The factors that impact on this are multiple. As well as measuring patient experience, we must pay attention to staff experience and wellbeing, which also impact on patient experience, and explore ways to triangulate available data at an organisational level.²⁷ Events at Morecambe Bay in particular, highlight the harm that can be caused when an organisational culture exists that fails to have regard for the users of services, let alone putting them at the centre.

Experiencing personalised care

Personalisation describes an approach that treats patients as individuals, rather than simply as a set of symptoms or diagnoses. It seeks to address 'what matters' to them, both in the moment (personal experience) and across time (personal outcome). While the national surveys incorporate items that resonate with the personalisation agenda, no survey contains a range of questions that measure the extent to which we elicit patients' preferences, or captures the experience and outcomes of personalisation as described above. It is therefore currently not possible to comment on the degree to which personalisation is indeed occurring in the NHS.

Being involved in decisions

Decisions about care and treatment

There is agreement across the major political parties that the NHS should support patients to become involved in decisions about their care or treatment. Shared decision making is also a core theme in the NHS Mandate¹² and the NHS Constitution.¹³ Evidence shows that patients who have support to make decisions about their care and treatment, in partnership with health professionals, are more satisfied with their care and are more likely to choose treatments based on their values and preferences rather than those of their clinician. They also tend to choose less invasive and costly treatments.⁹

An October 2011 survey of 5,000 people in England, commissioned by the Department of Health, found that four in every five respondents wanted more choice in how they were treated.²⁸

Most of the national patient surveys ask a question or questions about the extent to which people have felt involved in decisions about their care. The data are not comparable because wording or response options vary across surveys, but within each survey it is possible to see whether involvement in decisions has improved over time (provided sampling and methods have remained consistent).

Figures 8–11 on the following pages gives examples of the extent to which patients have felt involved in their care.

Patients who have support to make decisions about their care and treatment are more satisfied with their care

Figure 8: Extent to which hospital inpatients felt they were involved as much as they wanted in decisions about their care and treatment

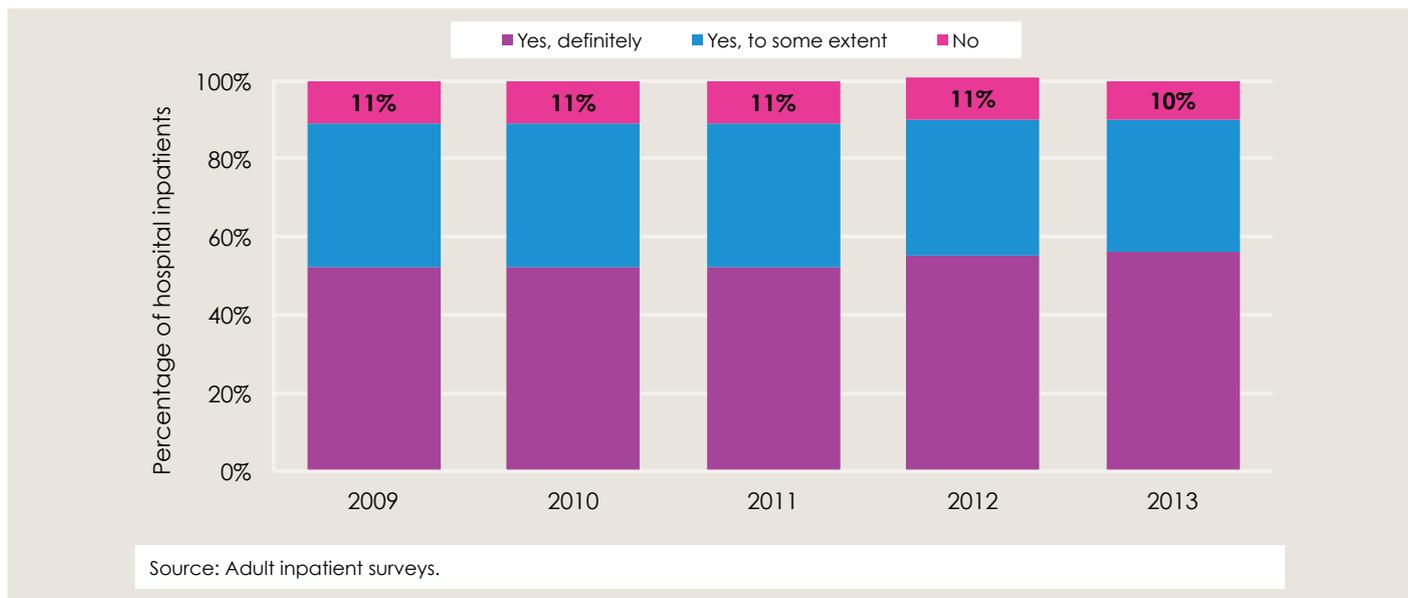


Figure 9: Extent to which cancer patients were involved as much as they wanted to be in decisions about their care and treatment

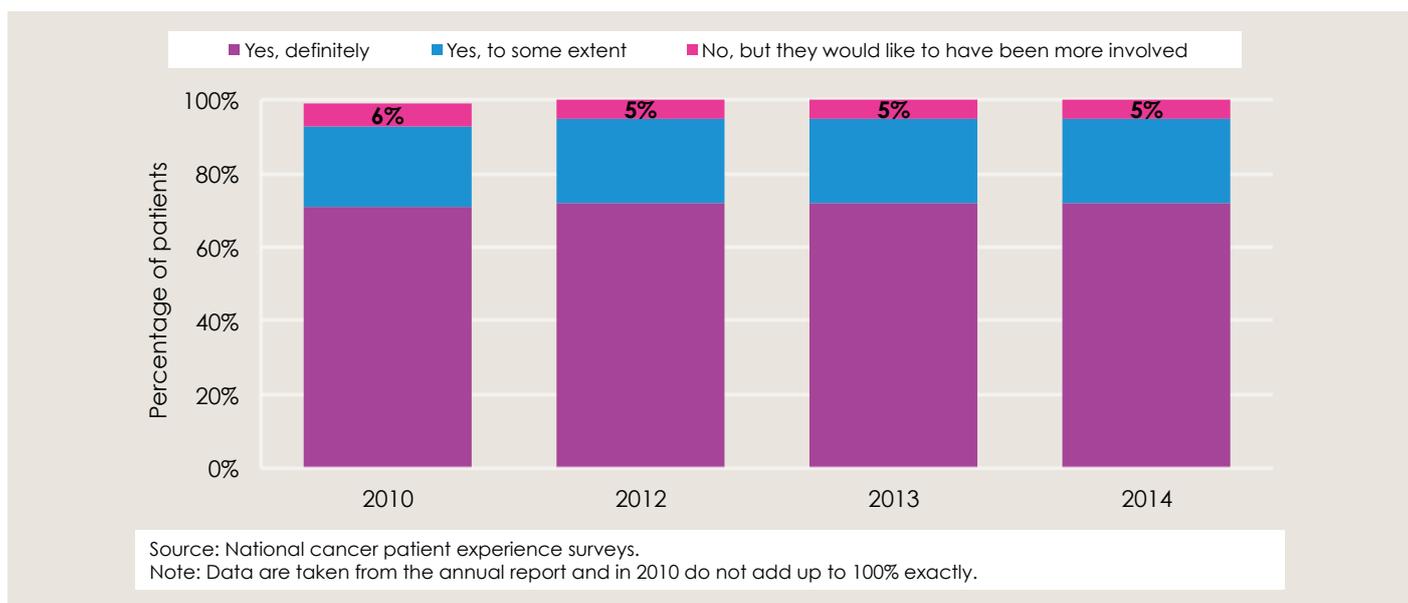
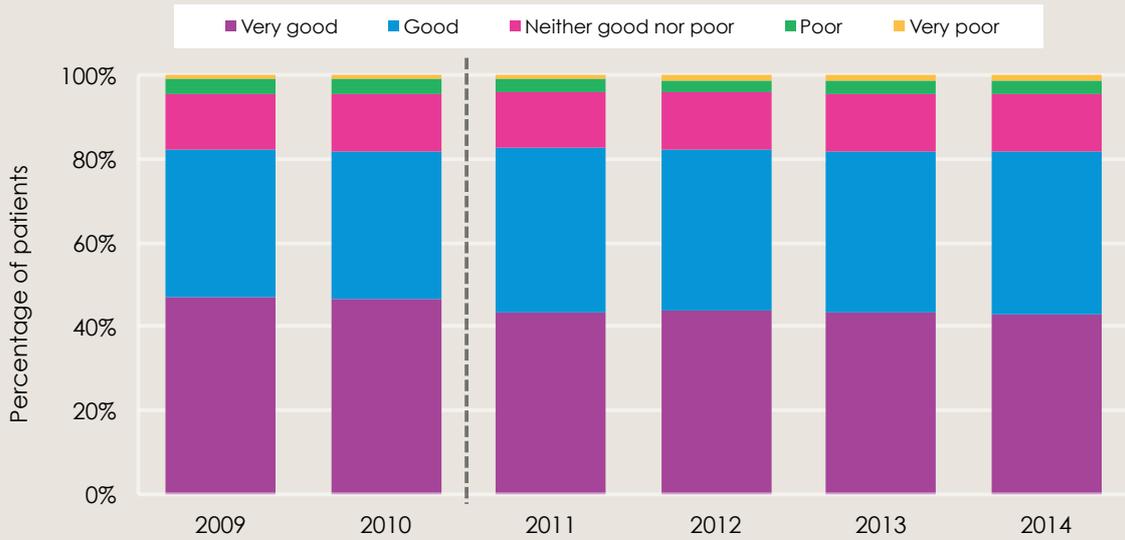


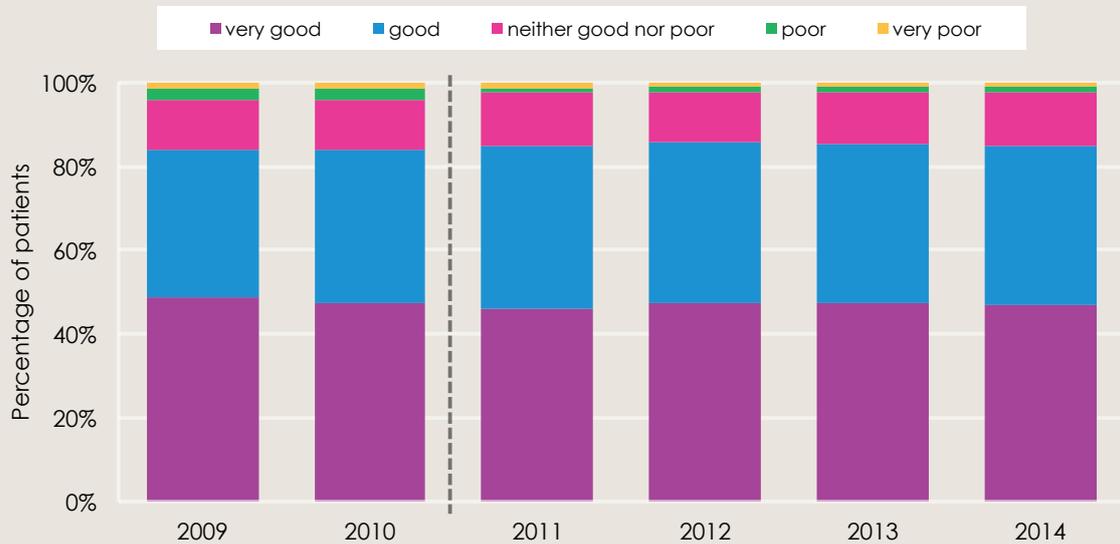
Figure 10: Extent to which patients felt that the last GP they saw or spoke to was good at involving them in decisions about their care



Source: GP patient surveys.

Notes: The vertical black line indicates a change in the survey response weighting. Data before and after 2011 are therefore not directly comparable. Two data collections were made per year, except for 2011 when data were only collected in the second half of the year.

Figure 11: Extent to which patients felt that the last nurse they saw or spoke to from their GP surgery was good at involving them in decisions about their care



Source: GP patient survey.

Notes: The vertical black line indicates a change in the survey response weighting. Data before and after 2011 are therefore not directly comparable. Two data collections were made per year, except for 2011 when data were only collected in the second half of the year.

56%

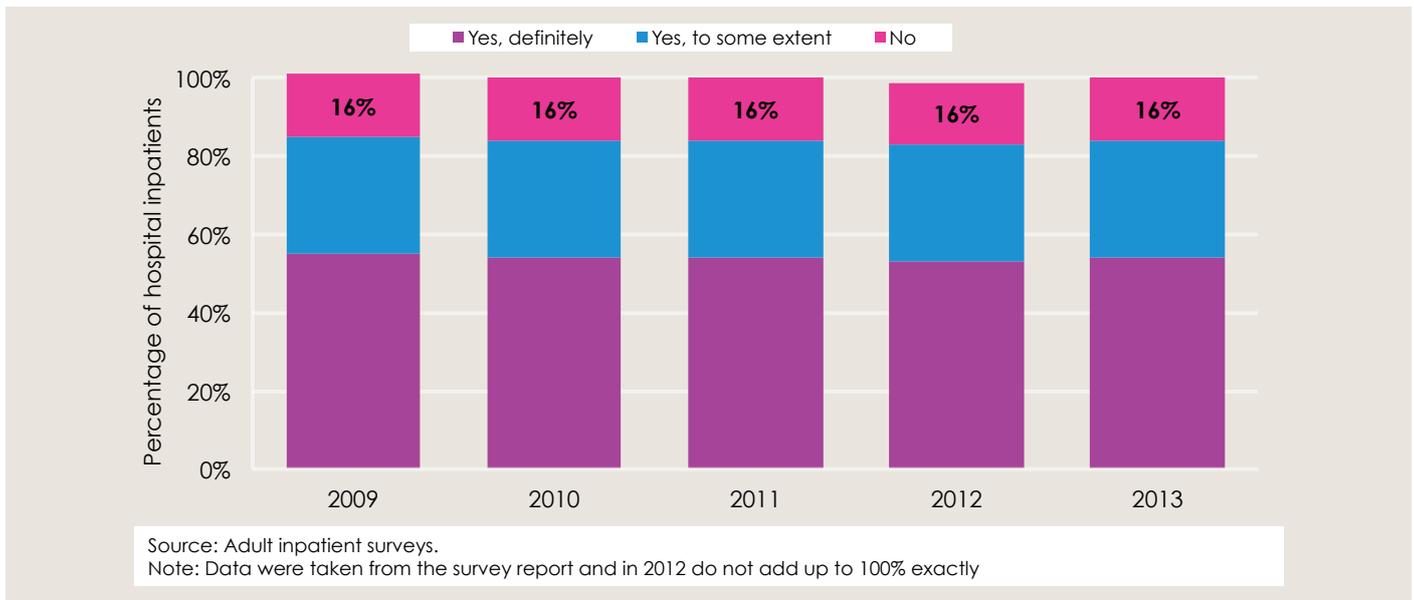
In 2013, 56% of inpatients reported that they were involved in decisions about their care and treatment as much as they wanted to be

The percentage of inpatients who report they were involved as much as they wanted to be in decisions about their care and treatment has risen from 52% in 2009 to 56% in 2013 (figure 8, page 10). This means that more than four in 10 inpatients want more involvement in decisions about their care and treatment. A higher proportion of cancer patients report that they are involved as much as they want to be in decisions (72% in 2014 – figure 9, page 10). The majority of respondents to the GP survey also rate their GP or nurse as good or very good at involving them in decisions (figures 10 and 11, page 11).

Decisions about discharge

Discharge is an area of NHS services that is often highlighted as requiring improvement. Specific areas for improvement include the length of time that medically fit patients wait for discharge and the quality of the information given to patients and relatives about what will happen when they go home.²⁹ This is also true for involvement in discharge decisions. Nearly half of patients consistently report that they are not fully involved in decisions about their discharge from hospital (figure 12). This has not changed over this parliament.

Figure 12: Extent to which hospital inpatients felt involved in decisions about their discharge from hospital



Experiencing coordinated care

We currently have no meaningful national data on whether people experience coordinated, joined up care,³⁰ and yet this is a major focus of a number of government initiatives under the banner of ‘integration’, including the Better Care Fund and the Integration Pioneer programme.

The national datasets are patchy on coordination indicators. Some, like the cancer patient experience and community mental health surveys, have more indicators that cover this area, including questions such as whether patients or service users have someone responsible for coordinating their care, whether hospital and community staff work well together and whether GPs are given enough information about a person’s care and treatment.

There are currently no meaningful national data on whether people experience coordinated, joined up care

The government recognises the gap and is seeking to address the lack of data, including commissioning new questions to insert into the national surveys. But finding a feasible way of measuring people's experience of integrated care, including identifying the target population for whom this will be meaningful, is proving difficult and slow.²³ In the meantime, many local areas working to deliver integrated care are developing their own measures. This may prove more fruitful for supporting local service improvement although a core set of national measures will also be necessary to compare organisations and to benchmark progress over time.³¹

The CQC has also signaled that looking at how care is safely coordinated around patients will be an increasing area of focus in coming years.²⁶ In 2015, the CQC will be conducting a thematic review of coordinated care, and it has already started to look across care sectors in areas such as dementia care, diabetes and the transition of young people with complex needs to adult services. This work may help us to start building a better understanding of the extent to which people experience care coordinated around their needs, although it will be some time before we can see whether this is improving.

Supporting people with long-term conditions

More than 15 million people in England live with one or more long-term conditions. On average, someone living with a long-term condition spends three hours per year in contact with health and social care services and the remaining 8,757 hours managing their own health and care.³² In order for people to do this effectively, they need their contacts with health and social care services to work with them to plan their care around their goals and to support them to enact this plan. Personalised care and support planning and self-management support are two key ways in which services can do this.

Personalised care and support planning

The NHS mandate includes a clear commitment that everyone with at least one long-term condition will be offered a personalised care plan reflecting their preferences and agreed decisions.¹²

The care and support planning process identifies the support the individual needs to enable them to assert their preferences. It also sets out what support will be in place to enable them to take agency over their health and care. A recent Cochrane review defined personalised care planning as:

'an anticipatory (forward-looking), negotiated discussion or series of discussions between a patient and a health professional (perhaps with other professional or family members present) to clarify goals, options and preferences and develop an agreed plan of action based on this mutual understanding.'³³

Although the GP survey includes a set of questions about planning care, they do not formally measure these key ingredients of care planning outlined above and have only been asked in the surveys in their current form since 2013. So, we can only look at progress in this area by looking at the available proxy measures that focus on a written care plan. However, even based on these measures, we seem to be a long way from the stated policy objective.

Only 5% of people with a long-term condition said they had a written care plan in 2014 (figure 13). More than one in four of these patients said they were not involved in putting the plan together (figure 14), and more than one in three did not review their care plan regularly with a health care professional (figure 15). This suggests that personalised care planning is not taking place.

Notably, the results from this survey suggest that those patients with a long-term condition who helped to put their care plan together are more likely to report that they use it to manage their day-to-day health than when they are not involved (79% compared with 51%) (figure 16).

Figure 13: Percentage of patients with a long-term condition who had a written care plan

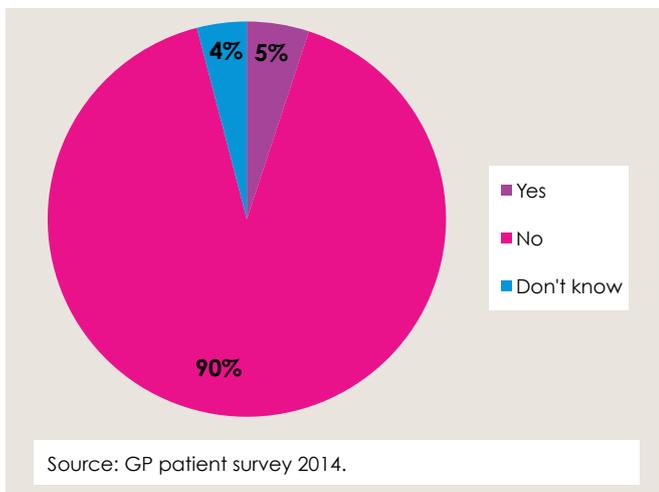


Figure 14: Percentage of patients with a long-term condition and written care plan who helped to put together their written care plan

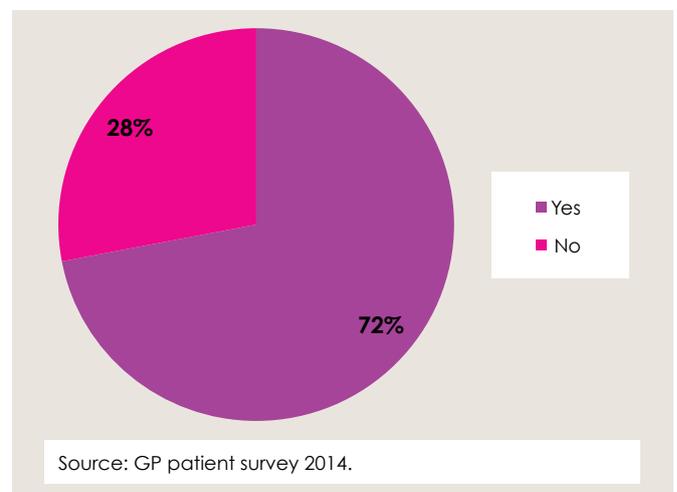


Figure 15: Percentage of patients with a long-term condition and written care plan who reported that their GP, nurse or other health professional reviewed their written care plan regularly with them

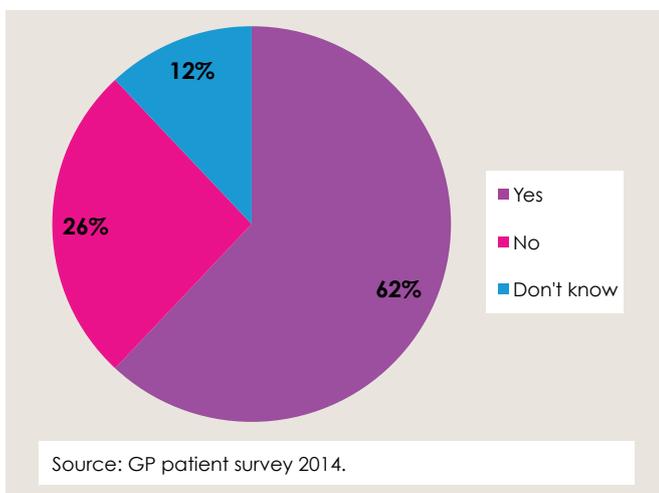
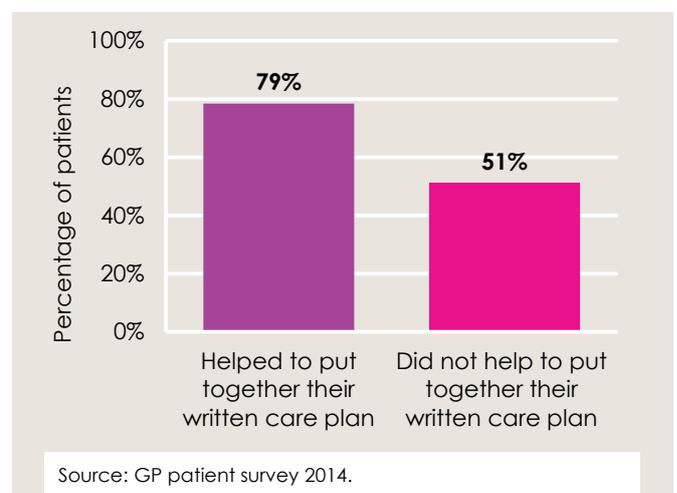


Figure 16: Percentage of patients with a long-term condition and written care plan who used the plan to help manage their health day-to-day, by those who did and did not help to put their care plan together



There is clearly a need for the GP survey to include indicators of high quality personalised care planning in its dataset. These were added to the 2014 Community Mental Health Survey, which now places more emphasis on the process of care planning than on the production of the written care plan.

Support to self-manage

The 2014 GP patient survey asked:

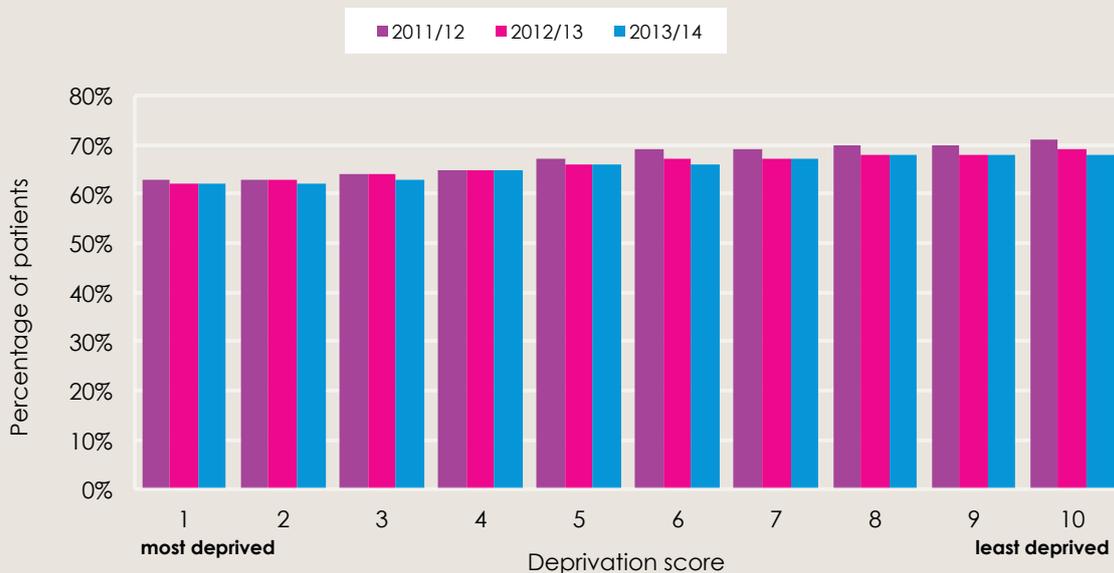
'In the last 6 months, have you had enough support from local services or organisations (not just health services) to help you to manage your long-term health condition(s)?'

Those who come from the most deprived areas feel less supported to manage their long-term conditions

Of those who needed support, just under 50% said they had 'definitely' received enough support to manage their long-term condition; 32% said they had 'to some extent'; 16% felt they had not received enough support. It is difficult to interpret exactly what it means for someone to have received 'enough' support 'to some extent', but we can conclude that a substantial proportion of people did not feel adequately supported to manage their long-term condition.

Even more strikingly, the GP Patient Survey data indicate that those who come from the most deprived areas feel less supported to manage their long-term conditions (figure 18). Given that the most socially deprived segments of our population already tend to have the worst health outcomes,³⁴ we would expect the NHS to provide more, not less, support for people living in the most deprived areas.

Figure 17: Percentage of patients that had enough support from local services or organisations to help manage their long-term condition(s) in the last six months, by deprivation score



Source: Health and Social Care Information Centre, with original data from the GP patient survey.
 Notes: These data include all patients, including those who reported they did not need such support. Graph shows combined 'Yes, definitely' and 'Yes, to some extent' responses. These data have been weighted by the Health and Social Care Information Centre, which uses a different approach to GP Patient Survey weighting. Additionally, the data have been grouped into one-year periods using data across years from summer to summer, rather than winter to winter. The area in which each respondent lives is used to derive a deprivation score.

Conclusion

Over this parliament, key developments, such as a new legal duty to involve patients in their care, have brought person-centred care into even sharper focus. Our ability to measure person-centred care is lagging behind this intent. We currently have a patchwork of measures that tell us something about how person-centred the NHS is, but do not give us a comprehensive picture.

Where we do have measures, there remains significant room for improvement. While there has been some progress in some measures over the past five years, this is limited and patchy. We have yet to see substantial and sustained change. For example:

- **Involvement:** the proportion of adult inpatients who felt that they were involved as much as they would like to be in decisions about their care has improved over this parliament. However, more than two in five people are still not involved in decisions as much as they would like to be and nearly half of patients are not being fully involved in decisions about their discharge.
- **Supporting:** people living with long-term conditions in the most deprived areas appear to be receiving less support than those in more affluent neighbourhoods to manage their health and care.
- **Coordination:** there is a strong perception that care is not coordinated, which has driven government to introduce policy and initiatives such as the Integration Pioneers and the Better Care Fund to improve this. However, we do not have measures to tell us whether the NHS is getting better at coordinating patients' care or not.
- **Dignity, compassion and respect:** the numbers who say that doctors and nurses speak in front of them as if they are not there has decreased, but over a third of people who needed help with their meal in hospital did not receive it and 1 in 5 inpatients are not always treated with dignity and respect.

The NHS is unlikely to make sustained and meaningful progress on meeting person-centred policy aims until we have the right measures in each of the dimensions of person-centred care.

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