

# Person-centred care in 2017

**Evidence from service users**



National Voices is the coalition of charities that stands for people being in control of their health and care.

We want person-centred care: people having as much control and influence as possible over decisions that affect their own health and care — as patients, carers and members of communities. We want people to be partners in the design of services and partners in research, innovation and improvement.

We help people and organisations to improve the knowledge, understanding, skills and confidence they need to engage more effectively, and to make their approaches more person-centred.

We have expertise in what matters to people relating to health and care, how to involve people, and how to work with the Voluntary Community and Social Enterprise sector.

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This project was generously supported by The Health Foundation.

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## Introduction

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Policy makers have been aspiring to a 'patient-centred NHS' in England for at least 20 years<sup>i</sup>.

In 2008, patient experience became a key part of the national definition of quality in healthcare<sup>ii</sup>; and in 2012 that was codified in law<sup>iii</sup>.

Person-centred care has become an increasingly prominent stated ambition both of national policy and local practice. In 2013, the Department of Health and all the system leading bodies across health and social care in England declared a shared commitment to making 'person-centred coordinated care' the norm<sup>iv</sup>.

What difference, if any, have these stated ambitions made to the experiences of people who need and use services and support? We wanted to know.

National Voices stands for people being in control of their health and care<sup>v</sup>. From 2011 we have been at the forefront of making the case for person-centred care. There is a growing body of evidence that person-centred approaches are important for ensuring the overall quality of care and for improving health and wellbeing outcomes.

## Research scope

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This report attempts to create a snapshot of the extent of person-centred care in the English health and care system, based on how people report their experience of treatment, care and support.

This data can be found — in patches — in surveys of patients and service users.

There have been previous attempts at this task, in reports from Picker Institute Europe [2007]<sup>vi</sup>, The King's Fund/Picker Institute Europe [2015]<sup>vii</sup> and The Health Foundation [2015]<sup>viii</sup>. These looked just at the NHS, through the lens of national patient surveys. We have examined both health and social care, in a context where integrated care has assumed greater importance. And while the national survey data remain our key source, we have drawn on additional evidence.

We found that, while we can report with confidence on some key aspects of person-centred care, on others the data is severely inadequate or absolutely lacking. Our conclusions about what should be measured are therefore at least as important as our findings on what people experience.

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# Executive summary

## Why did we conduct this research?

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Over the last 20 years person-centred care has become an increasingly prominent national ambition. We wanted to know what difference, if any, this has made to the experiences of people who need and use services and support.

## How did we conduct this research?

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We focused on a small number of key ingredients of person-centred care: how people experienced information, communication, participation in decisions, care planning and care coordination. We also looked at family, carers and the varying experiences of particular groups of patients and service users.

## What did we conclude?

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### Person-centred care is inadequately measured

Currently, we cannot fully measure or assess person-centred care across services.

### A mixed picture

From the patchy data available it appears some aspects of person-centred care are being consistently achieved in mainstream services. Others are not, or aren't even being measured.

People's experiences can be highly variable depending which services they use, what their needs are, and who they are.

### Some aspects of person-centred care have improved

Some of the domains that enable person-centred care are being achieved: information and communication in healthcare have improved, and personalisation in adult social care is advanced.

### Progress towards involvement in decisions and being in control

There have been advances towards people being involved in decisions and being in control of their lives and their care, especially for specific groups. In mainstream healthcare and some residential settings the findings are worse, showing that there is still further to go on involvement.

### Progress at risk

Recently, there has been some small but significant deterioration in the indicators for person-centred care in both general practice (2017) and hospital inpatient care (2016).

### Little evidence of personalised care and support planning

Despite it being central to person-centred care, evidence about the extent and quality of personalised care planning is very patchy, but suggests that in most mainstream NHS settings — and in some residential care — it is largely absent.

## **Coordination of care is not measured**

Neither the NHS nor adult social care can demonstrate, from people's reports of their experience, that they are coordinating care around the person.

## **Family involvement is not central, and most carers need better support**

Family involvement appears to remain marginal to the practice and measurement of person-centred care. Some carers have received additional help, but the majority are not getting support for their own needs.

## **Some indications of inequalities**

There is some evidence that certain groups are less likely to report positively on the domains of person-centred care.

## **What are the implications?**

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### **The need for person-centred care to be given greater priority**

These very mixed findings are consistent with person-centred care being an ambition, but not yet a priority. The report to the Chief Executive of NHS England in January 2017 by the People and Communities Board<sup>ix</sup>, chaired by National Voices, included the following recommendations, among others:

- Make person-centred and community based approaches part of normal business
- Make a clear commitment to develop new, simplified, cross sector outcome measures

- Support a small number of super demonstrator sites to develop these approaches at scale
- Commission a pool of VCSE partners able to support local systems to develop person-centred, community focused interventions.

### **The need for a strategic overhaul of measurement**

What matters is what gets measured. Person-centred care is not adequately measured. If it is to become mainstream practice, and be seen to be achieved, the current measures need to evolve.

Our findings suggest it is time for a strategic review and overhaul of person-centred care measures across health and care, based on common outcomes, for the era of integrated and accountable care systems.

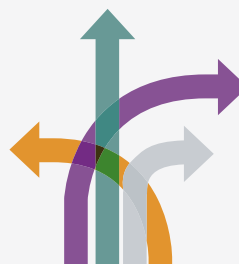
# Key findings

## 1. Person-centred care is inadequately measured.



Currently, we cannot adequately measure or assess person-centred care across services.

## 2. A mixed picture: people's experiences can be highly variable.



From the patchy data available it appears some aspects of person-centred care are being consistently achieved, but people's experiences can be highly variable.

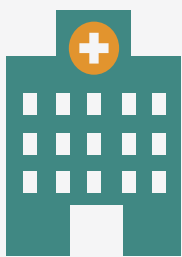
**"Our most cruel failure in how we treat the sick and the aged is the failure to recognise that they have priorities beyond merely being safe and living longer."**

Atul Gawande, surgeon, writer, and Public Health Researcher

**"If I am listened to, my health care becomes a partnership, I am no longer alone in my experience."**

Lissa J Haycock, Senior Peer Trainer, Brighton & Hove Recovery College

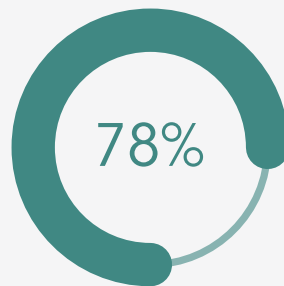
**3. Some aspects of person-centred care have improved.**



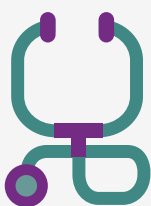
76%

76% of inpatients who had an operation or procedure said that what would happen was 'completely' explained.

**4. Progress towards involvement in decisions and being in control.**

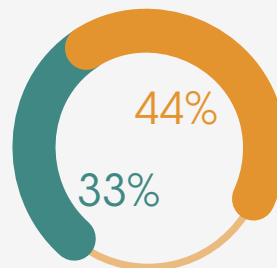


78% of cancer patients were definitely as involved as much as they wanted to be in decisions about their treatment.



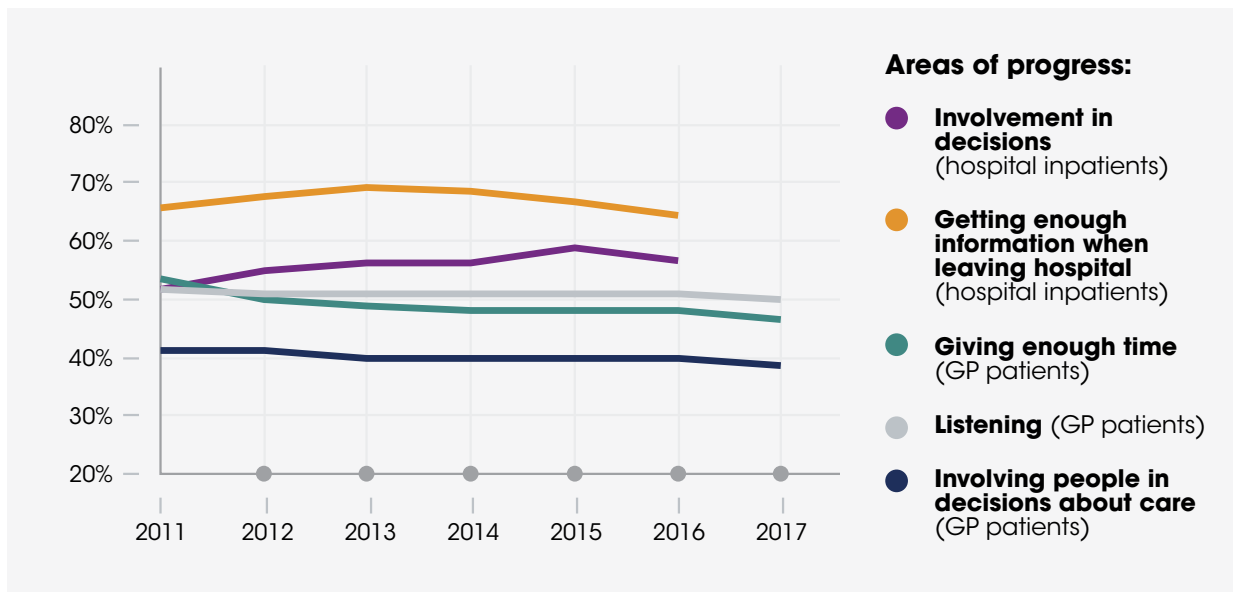
87%

87% of general practice patients said their GP was good at listening to them.



33% of people using adult social care said they had as much control over their daily lives as they wanted; another 44% had 'adequate' control.

## 5. Steady progress is now deteriorating, both for general practice and inpatient care.

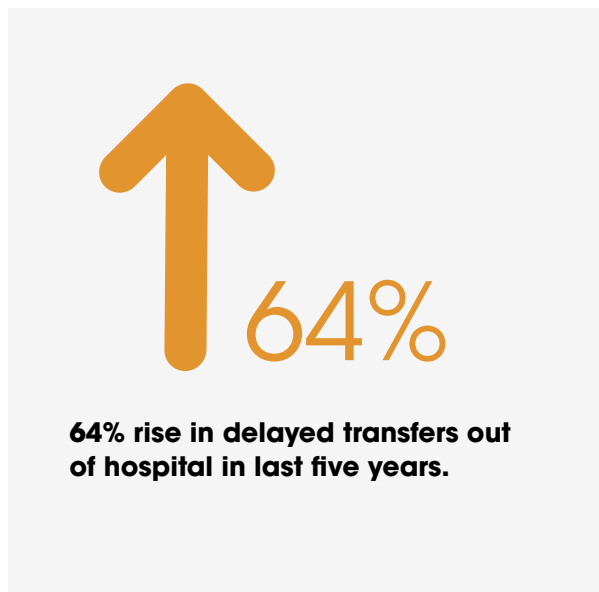


## 6. Little evidence of personalised care and support planning

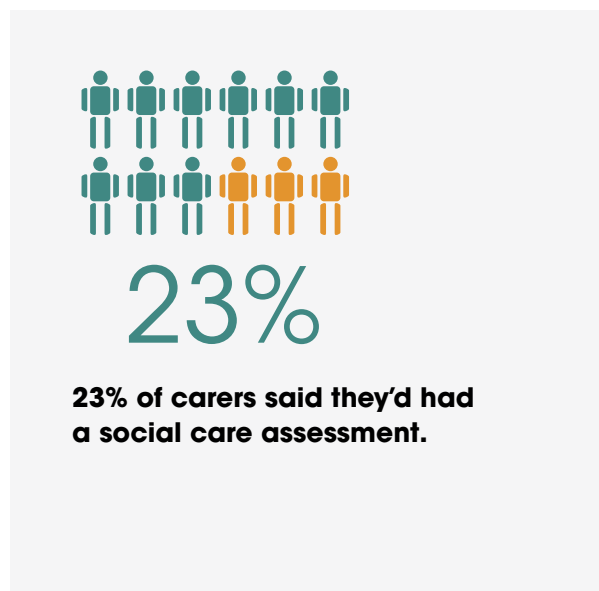
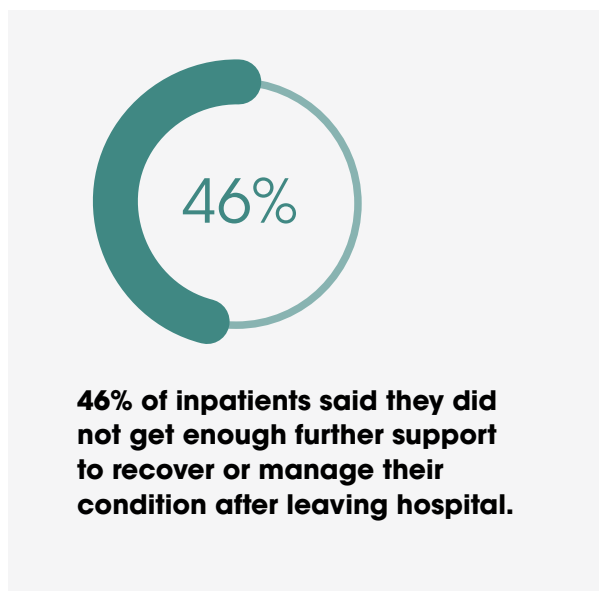
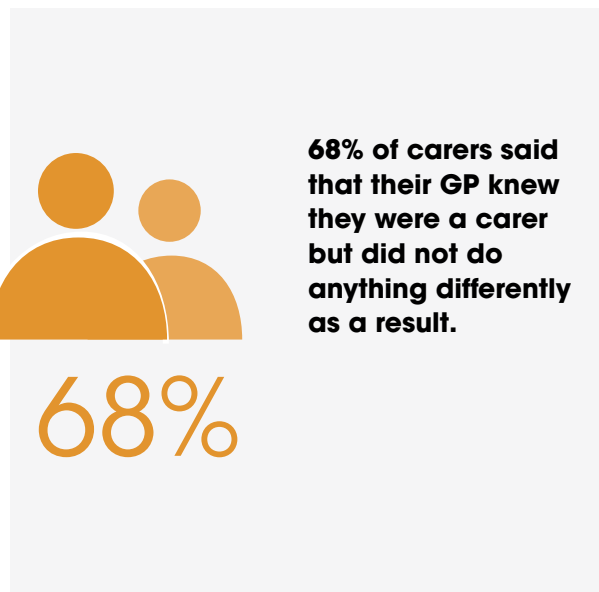




**7.**  
**Coordination  
of care is not  
measured.**

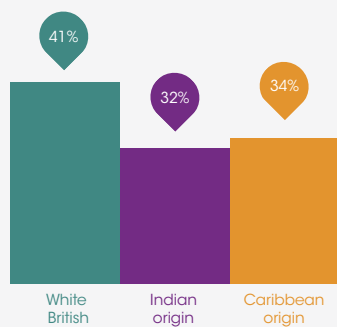


**8.**  
**Family involvement is not  
central, and most carers  
need better support.**

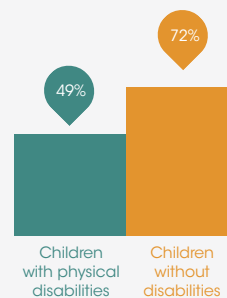


## 9. Some indicators of inequality.

**People who said "my GP was very good at involving me" by ethnicity:**



**Parents of children and young people who said that hospital staff definitely knew how to care for their individual or special needs:**



### The NHS pledges to:

- provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services
- work in partnership with you, your family, carers and representatives
- involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one
- encourage and welcome feedback on your health and care experiences and use this to improve services.

NHS Constitution, 2012

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# About this research

## Methodology

### What is person-centred care?

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There is no single definition of person-centred care, and we have not attempted to create one. Person-centred care is generally understood to mean an approach which is holistic, meets the person's needs and priorities before those of the system or its professionals, engages people in their care as fully as possible, and attempts to support people to take decisions and to be as much in control as possible.

In adult social care, partly in response to the advocacy of service users, 'personalisation' has developed over the last two decades to be recognised as formal mainstream practice.

In healthcare, over the same period, advocates initially emphasised 'patient-centred care'. In the last six years this has evolved into 'person-centred care' for a number of reasons:

- The recognition that staff are people too, and need equally to be engaged in more personalised approaches;
- The word 'patient' symbolises the dependency that personalisation aims to overcome; and
- In an era of increasing integration, 'patient' is the wrong word to describe users of some of these services, such as social care.

There are definitions of person-centred care available. Some aim for comprehensive status by trying to enclose 'all' the features that might be relevant. Among these are:

#### The Picker Principles

These are eight principles set out by the Picker Institute<sup>x</sup>, based on empirical research into what is important to patients. These have formed the basis for further derived definitions, as well as for patient experience measurement systems in the US, UK and parts of Europe. Dating from the 'patient-centred' period, they focus on the receipt of healthcare in formal settings.

#### The Narrative for person-centred coordinated care

In 2013 the Department of Health and all system leading bodies in health and care in England adopted a 'Shared Commitment' to pursue integrated care<sup>xi</sup>. This included a shared 'Narrative' — produced by National Voices and Think Local Act Personal (TLAP) — describing the goal of integration as being 'person-centred coordinated care'; and listing many of the things people would experience if it was achieved<sup>xii</sup>. This covered health, social care and other support, but was produced to define 'integrated care', not to define 'person-centred care', and would be incomplete for the latter objective.

## The World Health Organisation Framework<sup>xiii</sup>

In 2016 all member states agreed the World Health Organisation's Framework for Integrated, People-Centred Health Systems. This includes a 135-word paragraph which stretches the definition beyond both 'patient' and 'person' centred care, to embrace participation in service design, education and support, population health and community resilience.

## The Health Foundation

Other definitions aim to be concise, so as to provide a more useful tool for professionals. For example, The Health Foundation has produced a summary definition which attempts to condense person-centred care into four principles<sup>xiv</sup>:



## Five domains

For the purposes of this report, National Voices has focused on a short range of the most common features of person-centred care that are recognisable from across the 20 years of discussion — and for which indicators might be available (though not in all cases).

We believe the following would be recognised as key aspects of person-centred care by most stakeholders in the system, both at policy and practice levels, and by people who need and use services and support.

- **Information** is the foundation for people to be engaged in their health, care and support. Tailored information — that makes it useful for the individual — is the first step to 'personalisation'. Information may come in many forms, but in care contexts...
- **Communication** between people and staff is the principal way in which information is conveyed, discussed and tailored. More than that, it is the opportunity for the person to surface their own expertise, feelings, values and preferences. Communication should be two-way and as equal as possible. This in turn makes possible...
- **Participation** in decisions as a marker for care that is enabling and empowering, and where people's own values and preferences can be brought to bear. An advanced form of decision making is...
- **Care planning** so that people can consider the future course of their care, treatment and support, and direct it as much as possible. Personalised care and support planning can enable people to identify their goals (for their lives, not just their treatment) and develop a sense of control. People's ability to achieve progress towards these goals is then helped by...
- **Care coordination** so that care and support are built around the individual and their carer(s), with services working together for the outcomes important to the person.

Support and education for self-management is another key domain of person-centred care for people with long-term conditions. We found that there is a lack of good indicators for this domain and therefore, with some reluctance, excluded it from our analysis.

## Main data sources

### The National Health Service (NHS)

Reports from people using NHS services are widely and systematically gathered through the national surveys of patient experience. These include a range of surveys — some annually, some at longer intervals — commissioned by government through the system regulator, the Care Quality Commission (CQC), with the status of official national statistics.

These patient surveys are carried out in single service settings (e.g. hospital inpatients). They are in effect mandatory, so that all such NHS services must complete them. They have a performance management function in that the regulator makes use of them in

**I can plan my care with people who understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.**

'Narrative for person-centred coordinated care: summary statement', National Voices and Think Local Act Personal, 2013

assessments, and Boards are expected to use them for quality improvement.

Other recognised national patient surveys are commissioned by NHS England, including: a regular General Practice Patient Survey commissioned via Ipsos Mori; and occasional national surveys of patients in hospital cancer departments and of bereaved relatives, responding to questions about their loved ones' experience of end of life care (the VOICES survey).

### Adult social care

Reports from people using adult social care and support are gathered in a slightly different way. The Personal Social Services Adult Social Care Survey<sup>1</sup> is carried out via local authorities responsible for social care, and coordinated by NHS Digital (The Health and Social Care Information Centre). Other surveys of people's experience of social care are available, but usually provide limited samples that do not represent all geographical areas or all authorities.

In general, the social care surveys are used to create a 'consumer' feedback function but are not used in performance management.

For this report, we have looked beyond these user surveys to see what other indicators can help to fill out the snapshot. These include:

- Thematic reviews by the CQC which have investigated some particular types of care across service settings (such as end of life care).
- Surveys by National Voices' member charities which touch on aspects of person-centred care for people with particular conditions or groups of conditions.

<sup>1</sup> To be referred to hereafter as the Adult Social Care Survey

- The National Audit of Intermediate Care, organised by an alliance of Royal Colleges, the British Geriatric Society and others, which include measures of service user experience.
- The Personal Budgets Outcome Evaluation Tool (POET) survey of personal budget holders in social care.
- The State of Caring 2017, a survey of carers by Carers UK.
- Other types of indicator (not person-reported) that might show the extent of use of person-centred interventions, such as personal budgets.

A full table of these sources is given at Appendix One.

### **Referencing**

Where we quote from these sources we do not include reference numbers as these would clutter the report.

Where we quote from other sources of information such as previous reports of this kind, they are included in the numbered references.

**'People want to be treated with dignity and respect. They want their care and support to be coordinated so they only have to tell their story once. They want to be treated as individuals — not as a bag of body parts or problems. They want to talk about their priorities; not necessarily ours. They want to know about their options and what is known of the risks, benefits and consequences of all reasonable courses of action that are open to them. In short, they want to be supported to feel as in control as they would wish.'**<sup>xv</sup>

Alf Collins, Clinical Director for Personalised Care, NHS England

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# Person-centred care

## Research findings

### Summary

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We analysed people's reports of their care experiences in the following domains:

- 1. Information**
- 2. Communication**
- 3. Involvement in decisions**
- 4. Care planning**
- 5. Care coordination**

The first three domains are known to correlate strongly with high levels of patient satisfaction<sup>xvi</sup>.

Care planning and care coordination have been less well measured by surveys of people's experiences. However, both are known to be highly significant to the people who make up the modern caseload for health and social care services: people with disabilities, long-term conditions (including mental health conditions), and other forms of higher need. These groups need care over time and from multiple services. Where care planning and coordination are absent, outcomes and experiences will

be worse. This was recognised by the central inclusion of these elements in the national cross-system commitment to integrated care, 2013.

The CQC, in its thematic review of people's involvement in their care, cites care planning, coordination, and the involvement of family members (which we also examine later in the report) as the three biggest enablers that require improvement.

### Note on the reporting of findings

NHS patient survey questions typically offer people response options framed as a strong positive, a partial positive and a negative. For example:

- 'Yes, definitely'
- 'Yes, to some extent'
- 'No'

In this report, we are interested in whether person-centred care is definitely being achieved. This is more meaningful and offers more definitional clarity than 'partial' positive responses, and it is consistent with the level of ambition set out in national policy. Hence, we look for the 'strong positive' rather than the 'partial positive' responses.

## 1. Information

### Why it is important

People cannot act on their health, or health-related issues in their lives, without information. Health literacy — the ability to use information for health-related decisions — is a key factor in population health, since those with the lowest health literacy experience the greatest burden of disease.

Many people struggle to understand information they are given about their condition or medications: between 43% and 61% of English adults do not routinely understand information for health<sup>xvii</sup>.

National patient surveys ask people about information they received while in a particular service setting, and relating to their condition, treatment or procedures.

### National Health Service

In mainstream NHS settings, there are high scores for providing people with information about specific treatments, often with three quarters or more of patients responding positively. For example:

- 76% of inpatients who had an operation or procedure (2016) said that what would happen during their operation was 'completely' explained; 59% said that they were told about how they could expect to feel afterwards.
- 75% of inpatients had the purpose of any medications to take at home completely explained to them.
- 81% of primary care patients (2017) said their GP was good at explaining tests and treatments.

However, in some services for specific groups of patients, scores were lower:

- 62% of women using maternity services (2015) said that they were always given the information and explanations they needed during their postnatal care; almost one in 10 said they did not receive information.
- 54% of people using community mental health services (2016) and who had started a new medicine in the past 12 months said they could completely understand the information they were given about it; with 12% saying they could not understand the information at all.

And there is plenty of room for improvement more generally. For example, among inpatients (2016):

- One quarter (24%) of those admitted via A&E said they were given no information, or not enough, about their condition or treatment.
- One third did not receive any written or printed information about what they should do after leaving hospital.
- Only 38% of those taking medicines



24%

One quarter (24%) of those admitted via A&E said they were given no information, or not enough, about their condition or treatment.



home said they were given a complete explanation of any side effects to watch out for.

## Adult social care

In adult social care the focus is more on how people discover information about services that might be useful to them.

- Only 20% of respondents to the Adult Social Care Survey (2015-16) said it was easy to find information about support services or benefits, with another 33% saying it was 'fairly easy'.
- Only around a quarter of people using personal budgets said that the information they had to make decisions about their support was 'very good'.

## 2. Communication

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### Why it is important

The most important way in which information is transmitted and tailored to the individual is often in communication with staff and professionals.

In many respects, and from the point of view of service users, healthcare *is* this communication. We do not talk about 'using primary care services', but about 'seeing the doctor'.

The national patient surveys ask various questions on communication, not all of which can be incorporated in this report. We have focused on active listening and explaining things clearly, as these are particularly indicative of professionals having the right skills and behaviours for person-centred care.

### 2.a Active listening

In a number of settings, more than three quarters of respondents said that their healthcare professionals demonstrated good listening skills. For example:

- 78% of children and young people felt that staff in hospital listened to them (2015).
- 80% of women who had used maternity services (2015) felt that midwives always listened to them in antenatal consultations, and 77% in postnatal consultations.
- 77% of A&E patients (2014) said that doctors and nurses definitely listened to what they said.
- 70% of people who used community mental health services (2016) said the person they had seen most recently had listened carefully to them.
- 87% of general practice patients (2017) said their GP was good at listening to them.

However, these overall reports can mask some anxieties and deficiencies. Within the general practice figure, for example, only around half of patients said the GP was 'very good' at listening as opposed to 'fairly good'.

Healthwatch England's report on people's experiences of primary care (2015) found that communication was a key area of concern, with people reporting that their GP does not always listen fully, or believe what they have to say. This can lead to some groups not reporting symptoms or issues such as depression.

Although these scores for listening once the person is in contact with a staff member are relatively high, a related question is the extent to which patients have the opportunity and time

for discussions about things that are worrying them.

Here, the scores are weaker:

- 46% of primary care patients (2017) said the GP was 'very good' at making enough time for them.
- 24% of inpatients (2016) said that staff were not always available to them if they had worries or fears.
- 59% of inpatients said they 'always' received enough emotional support from staff.
- 28% of A&E patients (2014) could not answer 'yes, definitely' when asked if they had enough time to discuss a health or medical problem.
- 55% of A&E patients said 'yes, completely' when asked whether, if they had anxieties or fears about their condition or treatment, a doctor or nurse discussed them (with 15% saying no).
- 63% of people who used community mental health services (2016) said they definitely had enough time to discuss their needs and treatment (with 11% saying no).
- 29% of bereaved relatives in the VOICES survey (2015) strongly agreed that their loved one's emotional needs were met near the end of life.

## **2.b Explaining in a way that people can understand**

Patients treated in hospital report that their health and care professionals are very good at explaining their condition, treatment, or medications in a way they can understand.

Among adult hospital inpatients (2016), for example:

- 70% said that if they had an important question to ask a doctor, this was answered in a way they could understand.
- 76% said that what would happen during their operation was 'completely' explained.
- 83% said they had been given a complete explanation of the risks and benefits of their operation or procedure in a way they could understand.

Among children treated in hospital (2014):

- 82% said they were spoken to in a way they could understand.

Strong results are reported in specific hospital departments:

- 83% of cancer patients (2015) who received more than one treatment said that these were explained completely before they started; 73% said that side effects were explained in a way they could understand.
- 78% of people who had been in A&E departments (2014) said that a member of staff explained any tests they needed in a way they understood.
- 89% of women who had used maternity services (2015) reported that they were always spoken to in a way they could understand during antenatal appointments.

For those surveys that are repeated regularly over time, trend data suggests that many of the results for information provision and for communication with staff improved over the decade from 2005 to 2015<sup>xviii</sup>.

### 3. Involvement in decisions

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#### Why it is important

The provision of information, and good communication between people and the staff and professionals they encounter, should provide a basis for people to be as involved as they want to be in decisions about their health, care and treatment.

Involvement in decisions is a central element in any definition of person-centred healthcare, and is strongly correlated to people's satisfaction with their care, treatment and support.

#### National Health Service

In hospital settings, the results for people's involvement in decisions are markedly lower than those for communication about specific tests, treatments and procedures:

- 56% of inpatients (2016) said they were definitely as involved as they wanted to be in decisions about treatments.
- 55% of inpatients said they were definitely as involved as they wanted to be in decisions about discharge (with 15% saying they were not involved).
- 57% of children and young people treated in hospital (2014) said they were as involved as they wanted to be in decisions about their care (with 13% saying they were not involved).
- 63% of A&E patients (2014) said they were definitely involved as much as they wanted in decisions about their care and treatment (with 10% saying they were not involved).

The proportions are similar in other NHS settings:

- 39% of patients in primary care (2017) said their GP was 'very good' at involving them in decisions; for practice nurses the figure was 37%.
- 56% of people who had used community mental health services (2016) were definitely as involved in decisions about treatments or therapies as they wanted to be (with 10% saying they were not involved, but wanted to be).

There are, however, stronger results for some specific groups of service users:

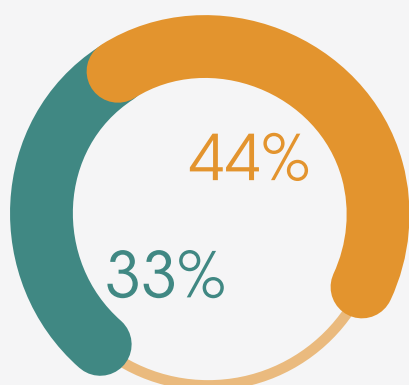
- 78% of cancer patients (2015) were definitely involved as much as they wanted to be in decisions about their treatment.
- 78% of women who had used maternity services (2015) said they were always involved in decisions during their antenatal care; 75% said the same about labour and birth.

#### Adult Social Care

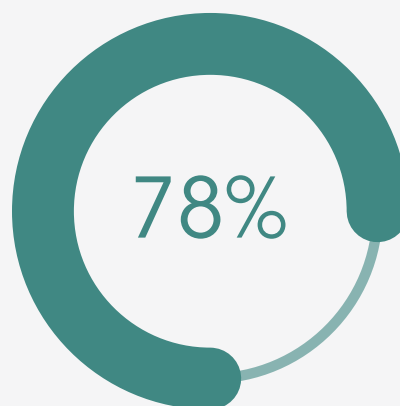
The Adult Social Care survey and the POET survey do not ask about how involved people are in decisions about their care. Their focus is on people achieving 'control' of their daily lives. We cover this in the next section on care planning.

Elsewhere in social care, the CQC's pre-inspection surveys of people using services found that:

- Just over 90% of those using community adult social care said they were involved in decision-making about their care and support needs (April 2015-March 2016).



In adult social care, 33% of people said they had as much control over their daily lives as they wanted; another 44% had 'adequate' control.



78% of cancer patients (2015) were definitely as involved as much as they wanted to be in decisions about their treatment.

- 96% of those using hospice care said that they were involved in decision-making about their care and support needs (April-December 2015).

The CQC also reports a 2013 review of 250 home care agencies, which found that residents were encouraged and supported to express their views, and detailed preferences and choices were documented in many cases.

However, there are also areas for improvement:

- 62% of care homes the CQC inspected did not involve people with dementia, or their families, in care or choices about how to spend their time.

A less favourable picture of decision making in adult social care is in the 2017 TLAP survey, which found that:

- 35% of people said they were always involved as much as they wanted in arranging their care and support (with 16% saying they were rarely or never involved).

### Intermediate care

Intermediate care<sup>2</sup> — in between home and acute hospitals — is a form of care where integrated working between health and care services is prioritised.

The national audit splits this into care provided in three types of settings. When asked if they were as involved in discussions and decisions as they wanted to be, the following proportions said 'yes, definitely':

- 82% of people receiving intermediate care at home
- 65% receiving 'bed-based' care, such as in a community hospital or care home
- 78% receiving re-ablement services

### End of life care

End of life care may involve multiple services being coordinated around the person. The VOICES survey of bereaved relatives (2015) reported that:

<sup>2</sup> The agreed Plain English definition for intermediate care is: "Intermediate care services are provided to patients, usually older people, after leaving hospital or when they are at risk of being sent to hospital. The services offer a link between places such as hospitals and people's homes, and between different areas of the health and social care system — community services, and social care system — community services, hospitals, GPs and social care."

- 75% of bereaved family members said their loved one was as involved as they wanted to be in decisions about their care at the end of life.

However, this did not translate into control over where the person died.

According to survey respondents:

- 81% would have preferred to die at home; 22% actually died at home
- 3% would have preferred to die in hospital; 49% did so
- 7% would have preferred to die in a care home; 24% did so.


## 4. Care Planning

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### Why it is important

Personalised care and support planning<sup>3</sup> is now the single mechanism by which adult social care should assist people to set 'self-defined' goals, consider the range of care and support they might need, and make decisions about how to organise this, such as whether to take a direct payment or personal budget<sup>xix</sup>.

In healthcare, personalised care and support planning can be seen as an extension of the principle of shared



only **3%**  
of people said  
they'd rather  
die in hospital...

... but  
**49%**  
did so.



decision making beyond the choice of specific treatment options, to embrace the person holistically and consider both their clinical and other care and support needs.

Attention to personalised care and support planning has risen significantly in the era of care integration, as it is the most appropriate care design for the groups of people whose outcomes integrated care seeks to improve.

Care planning is potentially appropriate for anyone with a long-term condition, but particularly for those whose care is likely to be more complex, such as people with multiple physical conditions; a combination of physical and mental health conditions; disabilities; cognitive impairments, dementia or frailty; and people approaching the end of life.

However, data on people's access to and use of opportunities for personalised care and support planning are not currently widely collected.

#### **4.a General Practice**

Just over half (54%) of the respondents to the General Practice Patient Survey (2017) identified themselves as having one or more long-term conditions. Of these:

- 3% said they had a written care plan
- 4% were unsure whether they had a care plan in place
- 93% said they did not have a written care plan

This is not an ideal measure. The existence of a plan does not imply that there has been a good planning process. Nor is awareness of having a written plan the same as having been fully involved in creating it.

Of the small percentage of people with long-term conditions who said they had a written plan, 71% said they were involved in putting it together. Hence the proportion of relevant people likely to have had the opportunity for personalised care planning in primary care is probably closer to 2%.

The CQC's thematic review on involvement heard from GPs who said that they did not have enough time to implement tools and undertake care planning in a way that would be meaningful for all their patients.

Against this, the Royal College of GPs' promotional materials for care planning argue that it saves practice time by reducing the need for multiple, reactive appointments.

#### **4.b Acute care**

The Future Hospital Commission set up by the Royal College of Physicians made 11 key recommendations in its 2013 report, including that: 'All patients have a care plan that reflects their specific clinical and support needs.'<sup>xx</sup>

However, the national surveys of hospital patients do not ask questions about care planning or the involvement of people in it. We could find no other useful data to fill this gap.

#### **4.c Intermediate care**

Users of intermediate care services (2015) were asked whether they agreed with the statement: "I was aware of what we were aiming to achieve, e.g. to be mobile at home, to be independent at home, to be able to go out shopping, to understand my health better".

The proportions answering 'yes, definitely' in the three types of care were:

<sup>3</sup> The phrase 'personalised care and support planning' helps to distinguish this type of planning from the one where professionals make care plans (or treatment or management plans) for their patients/clients. The statutory guidance to the Care Act 2014, and the NHS England handbook for care planning, emphasise that this is a process done in equal partnership with the person, to assist them to identify their goals and preferences, and where they should 'own' the resulting plan.

- 98% of people receiving home-based services
- 97% of those receiving bed-based services
- 95% of people receiving re-ablement services

#### **4.d Community mental health services**

There is a recognised Care Programme Approach (CPA) for those with severe mental health needs that emphasises care planning.

There is no specific question about care and support planning in the Community Mental Health survey (2016), but it does ask whether people have 'agreed' their care with someone.

These data should be treated with caution, because the question might encompass everything from care planning, to negotiating a compromise, to acquiescence in decisions made by professionals.

Results are broken down for those who are and are not on the CPA. It is a formal service expectation that people on the CPA should have a comprehensive written care plan.

- 43% of all respondents had definitely agreed their care with someone; while 23% said this had not happened, but they had wanted it to.
- 52% of those on the CPA had agreed their care with someone, compared to 39% of non-CPA recipients.

Among the people who said they had agreed their care with someone:

- 56% were as involved as they wanted to be

- 59% said their personal circumstances were definitely taken into account in planning care.

#### **4.e Health surveys by national charities**

Some National Voices members, which are national charities for people with long-term conditions, have carried out surveys among the people they support.

Unlike the national patient surveys these are not comprehensive (covering all Trusts or GP practices) or representative, but they help to add some light to an under-researched area.

Note that most of these surveys did not ask about personalised care and support planning, but about whether professionals had 'offered' them a care or treatment plan (a less demanding ask, referring to something which should be very common practice).

The Neurological Alliance (2016) found that 82% of respondents said they had not been offered a care plan — up from 72% in 2014.

Within this, further analysis by the Migraine Trust found that 86% of the 1,300 respondents who were migraine patients had not been offered a care plan when receiving specialist neurological care.

The National Ankylosing Spondylitis Society's State of Care Survey (2016) found that:

- 12% of respondents with ankylosing spondylitis, a form of arthritis, had been provided with a written agreed treatment or management plan to help them manage their symptoms
- 55% had received a verbal plan
- 26% had not been provided with a plan

Diabetes UK's Care Survey (2015) suggested that:

- around a third (36%) of people with diabetes have a care plan, developed with their healthcare professional and decided by discussing their individual needs.

The MS Society (2016) found that 7% of people with multiple sclerosis were offered a care plan within the NHS; while 83% were not.

It also found that only 10% of people with MS were offered a care plan for their social care, far lower than the number who said they were receiving some level of local authority-funded support (38%), all of whom should have care plans.

Arthritis Research UK (2014), based on analysis of the GP Patient Survey and the Health Survey for England, found that:

- 12% of people with a musculoskeletal condition had a care plan.

#### **4.f Adult social care**

Although the Care Act 2014 embeds personalised care and support planning in law for people seen in adult social care, there are no national survey data available on this to our knowledge.

The Adult Social Care Survey instead asks about people feeling supported to be 'in control' — reflecting social care's preference for focusing on outcomes rather than process.

- 33% of social care users said they had as much control over their daily life as they wanted, with another 44% saying they had 'adequate' control.
- 89% of all respondents said the care and support they received had helped them to have this control.

The POET survey of personal budget holders (2017) found that:

- 63% said that their care and support had improved their ability to make everyday decisions.
- One third said the choice and control they had over their care and support was 'very good'; 72% in total said it was 'good' or 'very good'.

While these reports are very favourable, there is other evidence to suggest that personalised care planning in adult social care may not always be practised.

The CQC's thematic review of the care of older people, for example, found significant barriers to accessing care planning.

It found that care plans: are commonly seen as actions for health and social care professionals to take; are not always focused on setting out how services and support can help ensure people's goals and preferences are achieved; and may not include information about how people were involved in developing or reviewing their own plans.

Despite a decade or more of work towards 'personalisation', including the drive for widespread use of personal budgets, the CQC still found evidence that some staff are not comfortable with people being able to make independent decisions about their care and support; and that providers tended to make decisions about care plans based on their own priorities rather than those of the person.

In its thematic review of people's involvement in care, the CQC found that in general a lack of personalised care plans, which it described as a key basic enabler of involvement, was one of the key areas for improvement.



## 4.g Personal budgets

Given that there are gaps in the data for people reporting their involvement in care planning, we decided to include the use of personal budgets as a proxy indicator.

The aim of personal budgets in adult social care and now in the NHS is to enable and empower people to take control of decisions about their care and support — to become a commissioner of their own care according to their own goals and preferences. The decision to take a personal budget, and decisions over how to use it, should be based on personalised care and support planning.

The National Audit Office reported on personalisation in adult social care in 2014-15<sup>xxi</sup>. It found that:

- around 500,000 adults with social care needs, and 100,000 carers, were using personal budgets.

The POET survey of adult social care users (2017) found that:

- 51% of personal budget holders said that they could fully or mostly decide how the money in their personal budget was spent; 27% said that they could not (many of whom were people with learning disabilities).
- Around one third said the choice and control they achieved was very good.

Personal health budgets were introduced into the NHS in 2013. In 2016-17, over 15,000 people made use of these. NHS England is seeking to spread their use to around 100,000 people by 2021.

## 5. Coordination of care

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### Why it is important

Increasingly, people are presenting levels of need which challenge silo-based working in adult social care and the NHS.

People living with learning disabilities, frailty, dementia, multiple long-term conditions, mental and physical conditions together, and people near the end of life are likely to need care, support and treatment from a range of services (statutory and community) and professionals. The response can be person-centred only if it wraps around the person, rather than requiring them to pursue many different pathways and/or leaving them unsupported to 'integrate' their own care or that of their loved ones.

Transitions between services are a major cause of sub-optimal care and put outcomes at risk.

Most patient and service user surveys are not designed to capture people's experience of coordination or transitions. In the NHS particularly, the national patient surveys are service specific and ask people about one episode of care in a particular setting.

### 5.a Transitions between hospital and other settings

The most significant 'transition' for many people is going in and out of hospital, and here there are at least some data to indicate what is happening.

The inpatient survey (2016) shows a mixed picture with regard to how well-prepared people are to leave hospital:

- 77% of respondents said they were told who to contact if they were worried after they left hospital.

- 81% said that staff discussed any equipment or adaptations they would need.

However:

- 52% of people knew fully what would happen with their care when they left hospital, while 15% did not know.
- 62% said their family or home situation was definitely taken into account when being discharged.
- 56% said they received enough notice before they left hospital.

- 43% said they were told about danger signals to look for.
- 48% said doctors or nurses gave their family all the information they needed to help care for them at home.

For children and young people who had been treated in hospital (2014):

- 62% said staff definitely told them what would happen after they left hospital; 12% said staff did not tell them
- 69% of parents said staff told them what would happen after their child left hospital.



**69%** of  
parents said staff  
told them what  
would happen  
after their child left  
hospital.

## 5.b End of life care

End of life care is, by definition, coordinated care<sup>xxii</sup>. The VOICES survey of bereaved people (2015) found that:

- 41% reported that during the last three months of their family member's life, care services definitely worked well together; 16% said they did not work well together.
- 31% said that hospital services definitely worked well with GPs and other services outside hospital; 33% said that they did not.

## 5.c Older people's care

The CQC examined older people's experience of integrated care in its thematic review, which looked in depth at how services work together in eight health and wellbeing board areas. It found that:

- Joint working was not mainstream practice
- There were good examples; but often driven by temporary schemes or incentives rather than reflecting a redesign of care
- Services were duplicated
- Different providers did not understand the pressures on each other.

## 5.d Delayed transfers of care (DTOCs)

DTOCs occur when an adult inpatient's treatment is complete and there is no further clinical reason for them to stay in hospital, but their move to another setting (home, care home, community hospital) is held up for a variety of reasons.

DTOCs are recognised as a major cause of sub-optimal care and reduced

outcomes for the person, as well as unnecessary expense to the system for the continued hospital stay. The levels of DTOCs are monitored locally and nationally.

NHS England's statistics<sup>xxiii</sup> show a worsening picture over recent years. In March 2017, 6,622 patients were waiting for transfer at the time of the snapshot view — a 64% increase in five years. Across the month, there were delays totaling 199,260 days — up from 119,736 days five years previously.

It is commonly said that reductions in adult social care over this period have caused this rise, and they have certainly contributed strongly, but official statistics show that delays caused within the NHS remain even more common:

- 55% of delays were attributable to the NHS
- 37% were attributable to social care
- 8% were jointly attributable

The three most common reasons for delays within the NHS were: awaiting the provision of non-acute NHS care; waiting for the person's or family's choice of move to be available; waiting for further assessment(s).



Around  
**500,000**  
adults with social care  
needs, and 100,000  
carers, said they  
were using personal  
budgets.



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# Additional findings

## Further indicators and analysis

### Trends in the most recent data

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In sections 1-3 of these findings we showed strong scores for information and communication in the NHS, and weaker scores for involvement in decisions. We also noted that the long-term trends for these domains had shown them improving.

However, the two most recent and significant surveys of mainstream NHS care tell a different story.

In 2016 the indicators for inpatient care fell, compared to 2015, for the following items:

- Involvement in decisions down 3%
- Involvement in discharge decisions down 1%
- Getting enough information when leaving hospital down 2%
- Being given information about the side effects of medicines to take home down 2%

In 2017 the indicators for general practice consultations fell by 1%, compared to 2016, when looking at whether the GP was 'very good' at each of the following:

- Giving enough time
- Listening
- Explaining tests and treatments

- Involving people in decisions about care
- Treating people with care and concern

In adult social care in 2015-16, most indicators showed no change, or small improvements since the previous year. However, there was a small — 0.5% — increase in the proportion of people who said they had no control over their daily life, and of those who said they had little social contact with people and felt isolated.

While these changes may seem small, they are regarded as statistically significant. Across the millions of users of these services, they represent many thousands of people getting a less person-centred experience than the previous year.

This raises 'red flags' about whether personalised care is beginning to decline as a result of the acknowledged demand and financial pressures on services.

That suspicion may be reinforced by noting that fewer GP patients reported the experience of making an appointment as very good; and that compared to 10 years ago, much higher proportions of the hospital inpatients who responded were admitted as an emergency (61% — up 8% compared to 2006) and/or admitted to critical care areas (24% — up 5% compared to 2006).

In its summaries of inspections (the State of Care reports) published in 2017, the CQC has itself been sounding warning notes about potential falls in quality.

For Adult Social Care, the CQC noted that 26% of services initially rated Good, and which had been re-inspected, had deteriorated<sup>xxiv</sup>. The Chief Inspector said that this, together with the struggle for those with lower ratings to improve, showed that “the danger of adult social care approaching its tipping point has not disappeared”<sup>xxv</sup>.

Reporting on acute hospital care<sup>xxvi</sup>, the CQC described it being on a ‘burning platform’, requiring transformation in the face of increasing difficulties in handling high A&E demand and the consequent challenges for patient flow through the hospital and into efficient discharge<sup>xxvii</sup>.

## Family and carers

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Informal carers, usually family members, are the primary care system. Six million carers, one quarter of whom care full-time, often provide the bulk of a person’s care and support and are their first point of contact for discussions about their conditions and whether to seek further help.

For these reasons, it is important in most forms of care that family and carers are treated as members of the team around the person, and are also listened to, informed and involved in discussions and decisions.

Some but not all of the national surveys ask about this involvement.

### Information

- 48% of inpatients (2016) and 58% of cancer patients (2015) said that their

friends or family had definitely been given the information they needed to look after them after leaving hospital.

- 44% of recently bereaved people strongly agreed that they had understood the information provided to them during their loved one’s care (2015).
- 43% of recently bereaved people agreed that they were kept informed of the person’s care and condition; 14% disagreed or strongly disagreed.

### Listening

- 72% of cancer patients (2015) and 61% of A&E patients (2014) said that if their family wanted to talk to a doctor or nurse they were definitely able to.
- 74% of bereaved people responding to the VOICES survey (2015) said they had a supportive relationship with health professionals; 15% disagreed or strongly disagreed.

### Involvement in decisions

- 55% of people who used community mental health services (2016) reported that their family or friends were as involved as they wanted; 17% said they were not.
- 65% of parents of children treated in hospital (2014) were definitely encouraged to be involved.
- 95% of women said their partners or companions were as involved as they wanted during labour and birth.

### Care coordination

The Carers Survey (2017) reported concerns about discharge:

- 23% of carers said they were not consulted

- 25% said they were consulted but only at the last minute
- 23% said the person was not ready to come home
- 17% said support was not available for them to be at home
- 9% said the person was discharged too early and as a result returned to hospital in the following couple of months.

### **Carers' own care and support needs**

The Carers Survey (2017) found that:

- 23% of carers had been offered a carers' assessment from adult social care, as is their right.
- 19% said that their ability and willingness to provide care was not considered in their assessment or the support they received; another 36% said that these received insufficient consideration.



**69%** of patients who were also carers said their GP knew that they were a carer but did not do anything differently.

- 35% said the support they need to look after their own mental and physical health was considered in the assessment process.

In a health context, the General Practice Patient Survey (2017) found that:

- 69% of patients who were also carers said that their GP knew they were a carer but did not do anything differently as a result; 17% said their GP knows and offers them extra support.

It is difficult to draw conclusions from these patches of data. In particular, it is notable that hospital patient surveys are weak in asking about family and carer involvement.

## Variation and inequalities

In the above sections, we have taken the overall figures from the best available survey data.

But an important question about person-centred care is whether it is equally available to all, or whether some groups of people experience care that is less person-centred than others.

There are many causes of variation in patient experience. For example:

- Geographical location and the quality of the local service can cause experience scores between NHS Trusts or local authorities to vary widely.
- The type of provider: for example, patient experience scores for specialist hospitals are typically stronger than for general acute trusts.
- The extent to which care and resources can be focused onto a specific group. For example, patient experience scores from the cancer

survey are typically stronger, for similar questions, than those for people passing through general inpatient wards.

## But does the quality of person-centred care vary according to who you are?

The CQC's thematic review on involvement included a secondary analysis of a number of patient surveys, and identified variation between different demographic groups. The following groups are less likely to say they are involved in making care and treatment plans than average:

- people with long-term conditions
- people aged over 75
- people with dementia
- young people with complex health needs
- people with a learning disability
- people detained under the Mental Health Act or with mental health conditions
- people subject to deprivation of liberty safeguards

People from some black and minority ethnic communities report being less involved in their care compared to white people, and are less likely to report being listened to, being involved, receiving the information they need, and having the opportunity for care planning across most of the NHS services they use.

In primary care, while 41% of white British respondents said their GP was very good at involving them, this was true for only 32% of people of Indian origin and 34% of people from Black Caribbean backgrounds.



Across all relevant domains, hospital inpatients who also have a mental health condition are less likely to report a positive experience than those with only physical conditions. People who are lesbian, gay, bisexual or transgender have poorer experiences as inpatients, according to a secondary analysis included with the national inpatients survey (2016), especially in relation to emotional support, and coordination; and also less likely to say that GPs were very good at involving them (CQC thematic review of involvement).

With regard to children and young people who were treated in hospital, less than half of those with either physical or learning disabilities said staff definitely knew how to care for their individual needs; compared to 72% of those without disabilities.

### **Additional Note: exclusion**

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In England the worst health outcomes are achieved by people who do not have access to mainstream health services. By definition, excluded groups — such as homeless people, recent migrants, sex workers, Gypsies and Travellers — cannot be included in surveys of people using services.



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# Conclusions

## A summary of the findings

### Person-centred care is inadequately measured

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Currently, we cannot adequately measure or assess person-centred care across services.

In the almost 10 years since 'patient experience' was recognised as a core component of quality, requirements have moved on. For many strategic leaders, professionals and patient groups, and for the emerging new models of integrated and/or accountable care, there is a growing need to know whether services working together are achieving person-centred care.

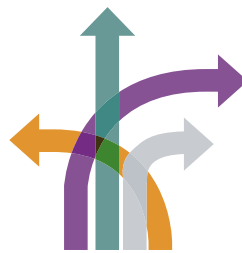


### A mixed picture

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From the patchy data available it appears some aspects of person-centred care are being consistently achieved in mainstream services. Others are not, or aren't even being measured. 'People's experience can be highly variable depending which services they use, what their needs are, and who they are.

We don't have good and consistent ways of measuring person-centred care. For example, we cannot adequately measure or assess person-centred care across the boundaries of settings and services, and there is no direct read across between healthcare and social care.



### Some aspects of person-centred care have improved

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Some of the domains that enable person-centred care are being achieved: information and communication in healthcare have improved, and personalisation in adult social care is advanced.

However, there is also large variation in people's experiences, and there remains great scope for further improvement. For example, most patients coming home from hospital say they did not get a full explanation about the side effects of their medicines, and many people feel there is not enough time and opportunity to discuss matters of concern.



87% of general practice patients said their GP was good at listening to them.



Only 39% of general practice patients said their GP was 'very good' at involving them in decisions.

## Progress towards involvement in decisions and being in control

There has been some improvement in the extent to which people report being involved in health and care decisions and being in control of their lives and their care. Some groups rate their involvement particularly highly, such as cancer patients, intermediate care patients, people near the end of life and women using maternity services.

In mainstream healthcare and some residential settings, people tend to rate their level of involvement lower than the quality of the information and communication they experience. For example, only 39% of general practice patients said their GP was 'very good' at involving them in decisions.

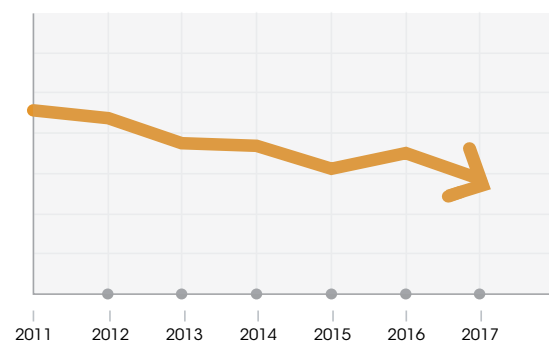
In adult social care there has been a focus on achieving outcomes that are important to people, with the growing use of personal budgets as a means to achieve these. People's experiences of having a personal budget seem largely positive. More generally, the vast majority of survey respondents say that adult social care services and support have enabled them to have more control over their daily lives. However, people in care homes appear to have a less person-centred service, especially if they are living with dementia.

## Progress at risk

Recently, there has been some small but significant deterioration in the indicators for person-centred care in both general practice (2017) and hospital inpatient care (2016).

On all aspects of the general practice consultation — giving enough time, listening, explaining, and involving people in decisions — 1% fewer patients said the GP was 'very good' in 2017 compared to 2016. For hospital inpatients, scores for involvement in decisions, provision of information and follow up care were down in 2016 compared to 2015.

The long-term trend of gradually improving experience in these domains has been interrupted, and this may be due to growing demand and financial pressure on services.



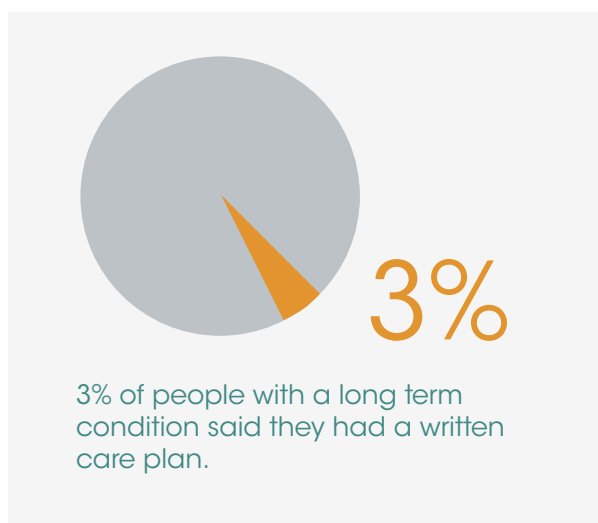
## Little evidence of personalised care and support planning

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Despite it being central to person-centred care, evidence about the extent and quality of personalised care planning is very patchy, but suggests that in most mainstream NHS settings, and in some residential care, it is largely absent.

Strikingly, of the general practice patients who reported having a long-term condition, just 3% reported having a written care plan — and of those, only 71% said they were involved in creating it.

Elsewhere in the NHS, national surveys do not ask sufficient questions to give a clear view. For example, we have no way of understanding whether people in hospitals are taking part in planning their journey of care to align with their own goals, values and preferences.



Surveys carried out by National Voices members suggest that less than 20% of respondents with particular long-term conditions were even offered or provided with a care plan (a lower standard than asking about participation in care planning).

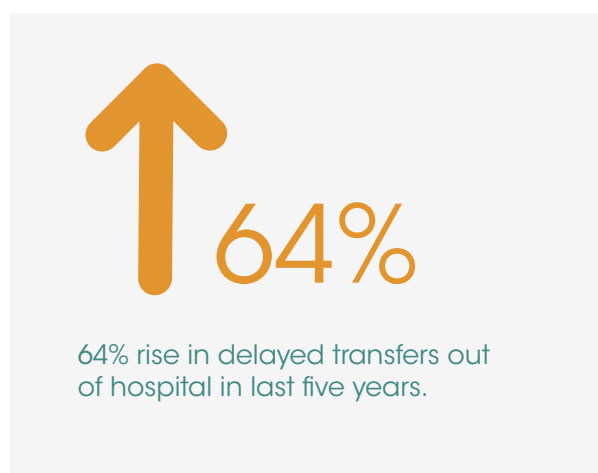
## Coordination of care is not measured

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Neither the NHS nor adult social care can demonstrate, from people's reports of their experience, that they are coordinating care around the person. The data that is available relates largely to hospitals working with other services and on discharges.

The failures of hospital services to work effectively with others appear to be a major, and worsening, cause of poorer outcomes.

There are particular problems with delayed transfers of care from hospital and poor coordination of care at the end of life.



## Family involvement is not central, and most carers need better support

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Family involvement appears to remain marginal to the practice and measurement of person-centred care.

Some carers have received additional help, including a personal budget, but the majority of carers are not getting support for their own needs, even where services know about their caring responsibilities.



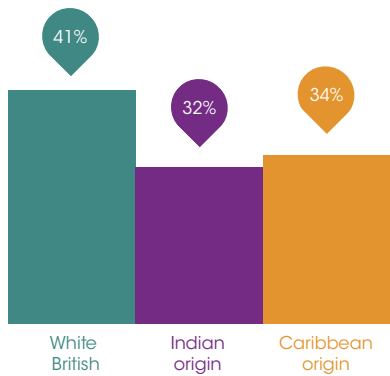
23%

Only 23% of carers said they had had a social care assessment, as is their right.

### Some indications of inequalities

There are initial indications from a small amount of recent secondary analysis of survey results and from CQC thematic reviews that inequalities exist.

People who said "my GP was very good at involving me" by ethnicity:



People who are older than 75, from some black and minority ethnic groups, have learning disabilities, are lesbian, gay, bisexual or transgender, or who present to the NHS with mental as well as physical health conditions, are all less likely to report positively on the domains of person-centred care.

More work is needed to build this area of evidence.



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# The implications

## What needs to happen

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### The need for person-centred care to be given greater priority

These very mixed findings are consistent with person-centred care being an ambition, but not yet a priority. They show a system in which person-centred care is seen more as a 'nice to have' than a 'must have'. In a highly pressured health and care system, staff and leaders may feel that person-centred care is less important than financial control and narrow performance management measures.

A report to the Chief Executive of NHS England in January 2017 by the People and Communities Board, chaired by National Voices, included the following recommendations, among others:

- Make person-centred and community based approaches part of normal business
- Make a clear commitment to develop new, simplified, cross sector outcome measures
- Support a small number of super demonstrator sites to develop these approaches at scale
- Commission a pool of VCSE partners able to support local systems to develop person-centred, community focused interventions.

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### The need for a strategic overhaul of measurement

What matters is what gets measured. Person-centred care is not adequately measured. If it is to become mainstream practice, and be seen to be achieved, the current measures need to evolve.

Our findings suggest it is time for a strategic review and overhaul of person-centred care measures across health and care, based on common outcomes, for the era of integrated and accountable care systems.

Since patient experience was first recognised as a core element of quality in 2008, the needs of people and of the 'system' have moved on. Instead of measurement within service and locational silos, we need to know how services working together are making a difference.

For the people with long-term conditions and higher levels of need, who are now the main caseload for services, the importance of care planning and care coordination have become increasingly recognised, but these are not properly measured.

Elsewhere, National Voices and partners have argued the need for system leaders to revise the complex and overlapping national outcomes frameworks<sup>xxviii</sup>.

We have called for the creation of a simplified, consensual, cross system framework of values and outcomes, based more on wellbeing and quality of life than on specific episodes of care or treatment<sup>xxix</sup>.

In late 2016, Think Local Act Personal secured a shared commitment from all the system leading bodies that included this objective. However, no practical action has resulted.

## **Gaps and requirements that need to be addressed**

### **Common lines of enquiry and question items**

- Align areas of focus and questions across health and adult social care.
- Alignment of the questions in the General Practice Patient Survey with other NHS national patient surveys so that findings become comparable.
- Common questions about the involvement of families/carers in all surveys, to ensure that people are seen as part of their families/informal care systems.
- Alignment would be helped by agreement at strategic level on common desirable outcomes across systems and care settings, based on what matters most to people.

### **Being person-centred**

- For NHS measures, less focus on process (such as making appointments) and more on the content, quality and outcomes of care.
- Building in expectations of a care planning approach for any person with a long-term condition, disability

or complexity; and developing better question sets on care planning for both adult social care and the NHS, to be used across settings.

- Addressing the issue of how to capture people's experience of care coordination — both by asking more and better questions, and by considering surveys that take account of experiences of using multiple rather than single services.

### **Equity**

- Increasing the amount of routine secondary research analysis of the data with regards to variation and inequalities.
- Making this a standard element in survey reports, to assist in tackling population health and health-related inequalities.





## Five Year Forward View

### Chapter Two: What will the future look like? A new relationship with patients and communities

As a first step towards empowering patients we will improve the information to which people have access—not only clinical advice, but also information about their condition and history.

Second, we will do more to support people to manage their own health, staying healthy, making informed choices of treatment, managing conditions and avoiding complications.

A third step is to increase the direct control patients have over the care that is provided to them.

From: Five Year Forward View, 2014

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# Appendix 1

## Data sources

Survey	Year	Population	No. of respondents	Previous years
Adult Inpatient Survey	2016	1,250 patients from each trust who had received care in hospital during July 2016	78	Annual since 2004
General Practice Patients Survey	2017	Surveys of GP patients, returned between 3 January and 31 March 2017. Fieldwork carried out in single wave, while earlier surveys were across two waves. Based on a sample from each GP practice.	808,332	Annual since 2007
Community Mental Health Survey	2016	Those age 18 or over receiving specialist care or treatment for a mental health and seen between 1 September 2015 and 30 November 2015. Separate analysis for those on Care Programme Approach – those with more complex needs.	13,254	2015, 2014
Survey of women's experiences of maternity care	2015	Women who had a live birth in 2015 (over 16 years old)	20,631	2007, 2010, 2013
Personal Social Services Adult Social Care Service User Survey	2015-16	All service users aged 18 and over in receipt, at the point that data are extracted, of long-term support services funded or managed by the social services following a full assessment of need.	73,165	Annual since 2010-11
Children and Young Person's inpatient and day case Survey 2014	2014	Children and young people up to the age of 15 who were admitted to hospital as an inpatient, or for treatment as a day case patient, during July or August 2014.	18,736	N/A

National Survey of Bereaved people (VOICES): England, 2015	2015	Collects information on bereaved people's views on the quality of care provided to a friend or relative in the last three months of life, for England. Data collected between September to December 2015, from a sample of deaths registered between 1 January and 30 April 2015. Very few significant changes from 2015 found.	21,320	Annual 2010 - 2015
Accident and Emergency Survey	2014	Patients aged 16 years and older who attended a major A&E department in January, February or March 2014.	Almost 40,000	
National Cancer Patient Experience Survey	2015	NHS patients aged over 16 with a confirmed primary diagnosis of cancer, discharged from an NH Trust after an inpatient episode or day case attendance for cancer related treatment in April, May and June 2015.	66,086 out of sample of 108,272 eligible patients	
National Audit of Intermediate Care	2015	Within a general clinical audit, patient experience questions were put to a sample of people using services between home and acute hospital, such as rehabilitation and re-ablement services.	12,000 service user responses	
Healthwatch: people's experiences of primary care	2015b	Series of focus groups looking in depth at experience of people from particular patient groups with particular problems, or where less data available, focusing on areas identified in Healthwatch investigation into primary care.		
Healthwatch: Primary Care: A review of local healthwatch reports	2015a	55 local Healthwatches sought views from 11,000 patients, and visited over 550 GP surgeries and other primary care premises.		

TLAP: The Care Act 2014 Survey Results	2017	1,181 respondents aged 18 and over from locations across all nine English regions. 455 were people who needed care and support for themselves, and 643 were carers. 85% of respondents were in receipt of council funding. Respondents were not proportionally representative of those receiving adult social care.	1,181	N/A
MS Society	2016	A survey of people across the UK with MS carried out between February and April 2016.	11,024	
Arthritis Research UK	2014	Data based on analysis of GPPS 2009, 2010, 2011 and the Health Survey for England 2011.		N/A
Neurological Alliance	2017	Online survey via SurveyMonkey, opened on 30 June until 30 September 2016.	7,048	2014
Migraine Trust	2017	Further analysis of the Neurological Alliance data, based on responses from migraine patients.	1,300	N/A
Diabetes UK Care Survey	2015	An online survey run by Diabetes UK between 15 October 2015 and 15 January 2016.	6,850*	N/A
Carers UK 'The State of Caring 2017'	2017	Survey of carers and current carers carried out by Carers UK between March and May 2017. Only current carers were used in this analysis. Survey was across the United Kingdom. 75% of respondents live in England.	6,607	Annual

\* though as not all answered every question, a baseline of 6,702 was used.



# Person-centred care in 2017: evidence from service users

## #personcentred

National Voices is the coalition of charities that stands for people being in control of their health and care.

We want person-centred care: people having as much control and influence as possible over decisions that affect their own health and care — as patients, carers and members of communities. We want people to be partners in the design of services and partners in research, innovation and improvement.



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