

Better care in my hands



A review of how people are involved
in their care

The Care Quality Commission is the independent regulator of health and adult social care in England.

Our purpose

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

We **register** care providers.

We **monitor, inspect and rate** services.

We **take action to protect people** who use services.

We **speak with our independent voice**, publishing regional and national views of the major quality issues in health and social care.

Our values

Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

Teamwork – learning from each other to be the best we can



Contents

FOREWORD	2
SUMMARY	3
INTRODUCTION	5
1. NATIONAL FINDINGS	11
NATIONAL TRENDS	11
FINDINGS BY SECTOR	12
FINDINGS FOR DIFFERENT POPULATION GROUPS	18
2. GOOD PRACTICE IN INVOLVING PEOPLE	24
CONCLUSIONS AND RECOMMENDATIONS	29
NEXT STEPS	32
ACKNOWLEDGEMENTS	32
REFERENCES	33



Foreword

Enabling people to be more in control of their own care leads to better and often more cost effective outcomes. This is particularly true for those with long-term conditions or people who need to use services more intensively.

This review into how well people are involved in their own care offers insight into the progress and the continued challenges in this vital area. It also gives some practical recommendations for providers, commissioners and system partners to ensure improvements are made in future.

It also comes at a time when there is an opportunity to make real progress in this area, as health and social care services change their models of care to adapt to the changing needs of their populations.

The findings from this study can be used by providers and commissioners of health and social care to understand what CQC expects to

see when we regulate how well services involve people, to learn from good practice, and to focus on what 'enables' people to be involved across the services they use.

Putting people in control of decisions about their care has long been a policy aim. Recent legislation makes it an imperative for those who commission and provide services. We encourage providers of care, bodies that commission services and their partners in the community and voluntary sector to reflect on the inequalities in people's involvement in their care highlighted in this report and to make these policy aims a reality for everyone.

Paul Bate

Executive Director of Strategy and Intelligence
Care Quality Commission



Summary

This report describes the extent and quality of people's involvement in their health and social care. It is based on newly analysed evidence from CQC's national reports and inspection findings, national patient surveys and a literature review. It identifies what enables people and their families to work in partnership with health and social care staff and illustrates this with examples of how people are involved in their care in services we have rated outstanding.

Being involved in your care is an essential characteristic of person-centred care and critical to the move to successful integrated health and care services as set out in the NHS Five Year Forward View and the Care Act. It has benefits for individuals and can lead to savings in services too.

People have a right in law to be involved in their care, as set out in the fundamental standard of 'person-centred care', a standard below which care should never fall. This national standard describes the action that care providers must take to ensure that each person receives appropriate care and treatment based on an assessment of their needs and preferences. CQC can take enforcement action against care providers that do not meet the standard.

National surveys of patients and people using services provide some evidence about the extent to which people feel involved in their care and in decisions about their support and treatment. Recent survey findings suggest that over half those surveyed report feeling definitely

involved in decisions about their health care and treatment, and this includes responses for care in hospitals and in the community. Women who use maternity services are particularly positive about how well they are involved in decisions about their care. We have also identified good practice examples of people being involved in all aspects of their care and decisions about their lives in a range of services we have rated outstanding.

However, the trends in national surveys of patients and people using services over the last five to 10 years highlight there has been little change in people's perceptions of how well they are involved in their health or social care, despite the national drive for person-centred care. In addition, a significant minority of people have consistently reported only feeling involved in their care to some extent or not at all over this period.

Importantly we have found that people with long-term health and care needs are least likely to report feeling involved in their care and in making choices about their daily life. New analysis of national patient survey data highlights that adults and young people with long-term physical and mental health conditions, people with a learning disability and people over 75 years all report feeling less involved in their care than other groups. Further evidence from our analysis of CQC's own thematic and national reviews from the last five years highlights poor practice in this area for these same groups of people, particularly as they move between services.

We have also reported a lack of progress over the last six years in involving people in their care when they are detained under the Mental Health Act. Poor involvement in care is the biggest issue we found in monitoring the use of the Mental Health Act in 2014/15. Our monitoring draws on evidence from people using services and their families and advocates, staff, and patient records.

This report identifies common problems in health and social care services, which can create a 'vicious circle' of poor involvement and which become more significant when people need to use different services or use them for long periods of time. These include:

- failing to regularly assess and monitor people's capacity to make decisions about their care and provide advocacy support
- limited understanding, recording and monitoring of people's wishes and preferences
- inadequate family and carer involvement
- insufficient information and explanation of care and support options.

Given the policy commitments, national standards and movement towards new models of integrated care, there is now an opportunity to make sure people's involvement in their own care becomes embedded in practice – for everyone. To encourage this, our report also presents evidence from services rated outstanding following a CQC inspection since April 2015. These include examples of the good characteristics of involving people in their care, identified from a range of outstanding individual service providers.

Our evidence also repeatedly points to a set of 'enablers' that service providers, commissioners and partners across the local health and care system can put in place to create an 'involving' culture for people using services.

We encourage service providers to focus their efforts on the following enablers that evidence suggests support people to be effectively involved in their care:

- personalised care plans – written with people, for people, and with their wishes and preferences clearly identified and monitored

- the sustained and supported involvement of families and carers in the care of their loved ones
- the coordination of people's involvement in their care as they move between services – for example, through the use of health and care passports and the provision of community and peer support programmes.

We encourage commissioners to ensure new models of care are developed taking account of the enablers to good involvement described in this report. In particular that there is a coordinated approach to the development of:

- accessible information about health and care options and treatment or support for people and their families/carers
- flexible advocacy provision as people use different services
- community and peer support for people to manage their care through programmes with voluntary sector partners.

The development of new models of care provides an opportunity to strengthen people's involvement in more person-centred care.

CQC will use the findings from this report to strengthen our regulation and reporting of people's involvement in their care in specific services. We will explore options to strengthen national survey questions in this area. We will also consider developing a framework to assess people's involvement in care as they move between services and use this in our future thematic reviews and assessments of quality of care for pathways or populations. This will provide more evidence of good practice to encourage providers to improve.

We will work with NHS England, NHS Improvement, Healthwatch England, National Voices and the Social Care Institute for Excellence to encourage the use of an integrated framework for people's involvement in care. This could support providers and commissioners to both meet their duties to involve people, and support the enhanced role of the voluntary and community sector as a partner in new models of care.



Introduction

About this report

This report describes the extent and quality of people's involvement in their own care across all care sectors, drawing on new analysis of national surveys of patients and people using services, CQC's national and thematic reviews and a literature review.

It describes the fundamental standards of people's involvement in their care that apply across all the sectors we regulate, and the key lines of enquiry our inspectors follow when inspecting how well people are involved in their care.

We highlight how people can be involved as 'partners' in their care, using examples from CQC national reviews of the last five years, and from providers of outstanding services, as rated by our new comprehensive inspections in the last year.

The report concludes with our recommendations as to how service commissioners, providers and the voluntary sector can do the same.

This study forms part of a wider programme of CQC work to strengthen our regulation of integrated services, and of people's care across an area and along different care pathways. This in turn will help encourage improvement in the quality of joined-up person-centred care.

Methods

We have analysed evidence from a range of sources for this report. The following methods were used to generate the evidence:

- a literature review (2010 to present of policy and research into people's involvement in health and social care)
- a review of patient survey data from seven national patient surveys from 2005 to 2016 (where possible), the Personal Social Services Adult Social Care Survey 2010-15 and CQC's pre-inspection survey of people using adult social care services (April 2015-March 2016)
- further statistical analysis of six national patient surveys to compare responses of different groups of people (see separate analysis appendix on our [website](#))
- a review of the findings of CQC thematic review reports published since 2012
- a review of other CQC national reports produced for Parliament since 2009 about the state of care in England,¹ the Mental Health Act² and Deprivation of Liberty Safeguards³
- a review of all registered providers rated as outstanding between April 2015 and August 2015 (a total of 96 inspection reports including four NHS trusts, 60 GP practices, and 32 adult social care services that included hospices, care homes and nursing homes).

Definition of involving people in their care

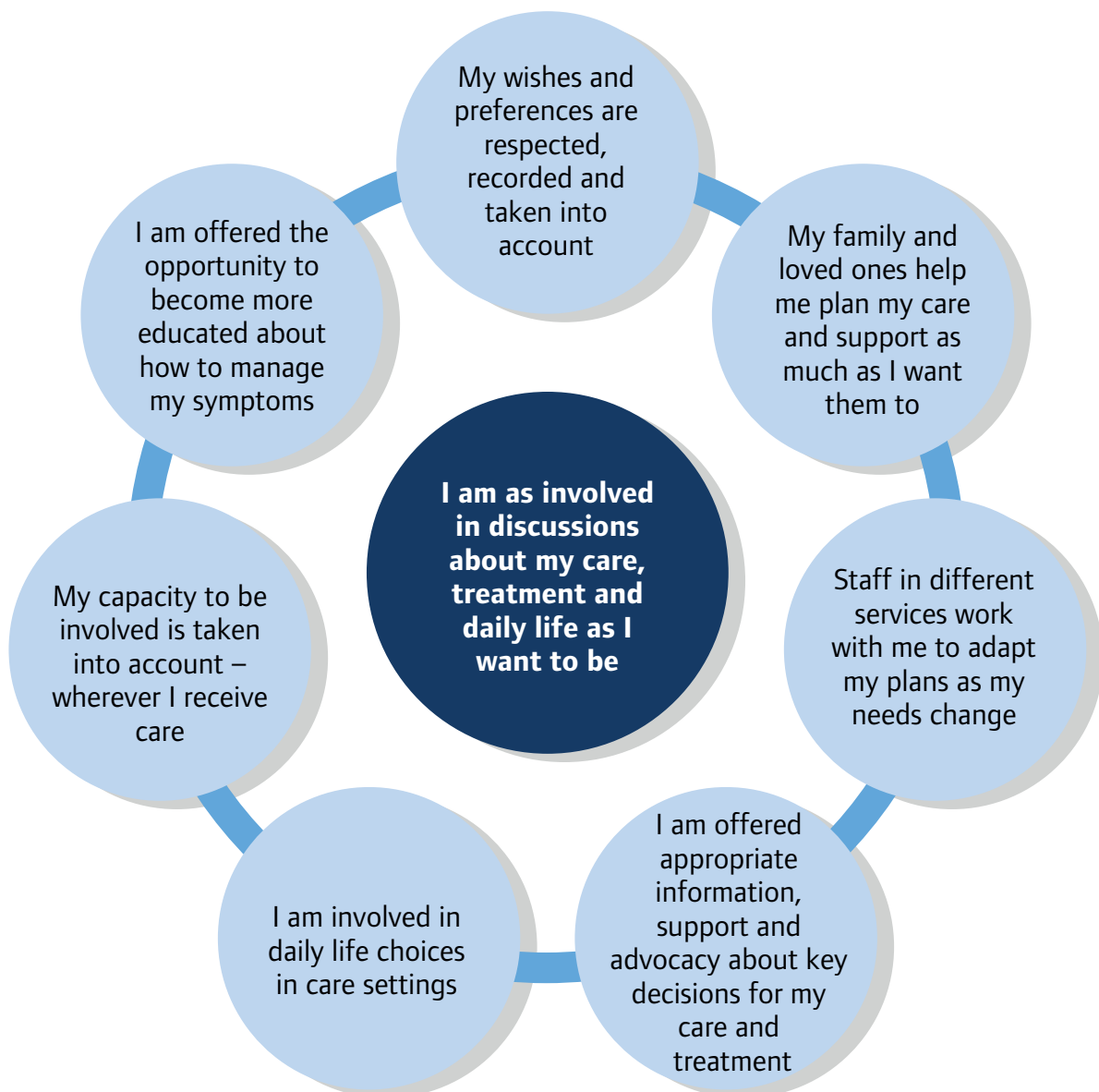
For the purpose of this review, we have taken as our starting point the definition of people’s involvement in their care in the fundamental standard of ‘person-centred care’ and the commitments in the Five Year Forward View for the NHS on people’s involvement in their care.

In 2013, together with 12 other national partners and the Department of Health, CQC made a commitment to encouraging better integrated care. The resulting person-centred care narrative highlights what this means from the perspective of a person using care services:

“I can plan my care with people who work together to understand me and my carer(s), allowing me control, and bringing together services to achieve the outcomes important to me.”⁴

A series of ‘I statements’ to reflect good coordinated care from a person-centred perspective were used as the basis of this shared commitment (FIGURE 1). They were developed by user-led organisations in partnership with people who use services.⁵ We have based our definition of people being involved in their care on these statements.

FIGURE 1: BEING INVOLVED IN YOUR CARE



We recognise that many people do not need to use multiple health and social care services or need long-term care. Someone who uses services occasionally may wish to be involved in their care in different ways, or to a different extent, to someone with a long-term condition or who needs long-term care. However, the I statements reflect the key aspects of ‘being involved’, and provide the starting point for conversations between anyone using health or care services and staff providing care.

The benefits of involving people in their care

A growing body of literature shows that people benefit from being involved in making decisions about their care and in how that care is delivered to meet their needs and wishes.⁶⁻¹⁰ The impacts include:

- improved knowledge of their condition and treatment options
- increased confidence to self-manage aspects of their own care
- increasing the likelihood of keeping to a chosen course of treatment and participating in monitoring and prevention programmes
- improved satisfaction with their care and chosen treatment
- more accurate risk perceptions
- reduced length of hospital stay and readmission rates.

Those in receipt of personal budgets report positive outcomes for feeling independent, in control and positive about their health and wellbeing. Carers also report improved quality of life. The trials of this scheme have also shown a more cost-effective use of treatment – people choosing less costly treatments.¹⁰⁻¹²

Shared decision-making, a process which recognises the expertise that clinicians and patients bring and treats them as equally important, may also lead to people choosing less interventional and less costly treatment, and that involvement in care may lead to reduced hospital admission rates.¹³⁻¹⁷

There is also growing evidence that greater participation in decision-making for those with long-term conditions and for those with higher levels of physical and mental health needs provides cost savings. In a recent study, the charity Nesta concluded that involving patients, their families and communities more directly in the management of long-term conditions reduces admissions to hospital care, which could lead to savings of at least £4.4 billion a year in England.¹⁸

In mental health, there is increasingly evidence that those who feel less in control report lower self-esteem and poorer quality of life, whereas research into shared decision-making around managing medicines has the potential to improve autonomy, choice and health outcomes.^{11,19,20} Other research has found that the greatest benefits from involvement in individual mental health care and treatment are when people agree with the purpose of their care and treatment, have some choice about it and some degree of control over it.²¹

Why involving people matters

Within NHS care there is a long history of policies and initiatives to increase patient rights to choose services, support people to take more control over their own health and to support the rights of patients (Box A). These have combined with a growing movement from people who use services demanding a more open and more equal system of decision-making.⁸

BOX A: INVOLVING PEOPLE IN THEIR CARE – POLICY COMMITMENTS

“You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this.”

NHS Constitution²²

“We will make good on the NHS’ longstanding promise to give patients choice over where and how they receive care. Only half of patients say they were offered a choice of hospitals for their care, and only half of patients say they are as involved as they wish to be in decisions about their care and treatment. We will also introduce integrated personal commissioning (IPC), a new voluntary approach to blending health and social care funding for individuals with complex needs.”

Five Year Forward View²³

“Local authorities must have regard to the importance of the individual participating as fully as possible in decisions relating to their care and support, and being provided with the information and support necessary to enable the individual to participate. In preparing a care and support plan, they must involve the person, their carers and any person the adult asks the authority to involve.”

Care Act 2014²⁴

In recent years this emphasis has increased, for example through a drive for personalised care plans, commissioning models that focus on the needs of individuals, and extensive trialling of personal health budgets. Major reports, such as the Francis Inquiry into the failures at Mid Staffordshire NHS Foundation Trust, have identified people’s involvement in decisions, and those of their family and carers as key to ensuring safe and effective care.²⁵

For the first time, local commissioners of care have been given specific duties to promote the involvement of patients and their carers and representatives in decisions that relate to care and treatment. The 2012 Health and Social Care Act (amending the National Service Act of 2006) specifically separates the duty to involve someone as an individual in their care from duties to inform or consult patients and the public on changes to services or in planning services.^{24,26}

The NHS Five Year Forward View reflects the commitments to a new relationship between the NHS, patients and communities and to increase the direct control patients have over the care that is provided to them. The launch of the vanguard sites for the new care models programme, and the integrated personal commissioning sites in 2015, were heralded as a systems-wide approach to increasing the power that people who use services have over their health and social care.²⁷

Mental health policy has also placed a strong emphasis on a greater partnership between people using services and staff. The recently published Five Year Forward View for Mental Health makes a series of recommendations about improving people’s ability to manage their own conditions and creating greater partnership between people and services in supporting this.¹⁹

There has been a comparable move within adult social care towards greater personal control over resources through direct payments schemes, and a joint ownership of care planning. The Care Act 2014 sets out a range of duties for local authorities to ensure that people’s wishes and preferences are taken into account and that they are better supported to choose their care and how to live their lives.²⁴

Standards for involving people in their care

All health and social care services that CQC regulates are expected to meet the fundamental standards of care introduced in April 2015, based on government regulations. These set the standards below which care should never fall.

Person-centred care is one of the fundamental standards of care (Regulation 9) and includes the key elements expected of care providers to involve someone in their care and treatment – whatever service they use. This includes working in partnership with the person, making any reasonable adjustments and providing support to help them understand and make informed decisions about their care and treatment options, including the extent to which they may wish to manage these options themselves.²⁸

In addition CQC asks five key questions about the quality and safety of care: are services safe, effective, caring, responsive and well-led? We follow key lines of enquiry as part of our assessment, asking whether services involve people in their care, particularly in relation to whether services are caring and well-led. We ask common but tailored questions across all the sectors we regulate. We check:

- whether people who use services and those close to them are involved ‘as partners’ in their care
- how a service supports people to express their views and be actively involved in making decisions about their care, treatment and support
- that people receive personalised care plans that are responsive to their needs
- that people’s needs, wishes and choices are recognised, respected and shared when they move between services, and their individual preferences and needs continue to be met.

The detailed questions we ask for each service type can be found in the links to our provider handbooks for different services (available on our [website](#)).

We also describe what people should expect to see in care services across the health, adult social care and primary care sectors in our characteristics of each rating level. Boxes B and C overleaf summarise what we would expect to see when services are outstanding for involving people in their care and when they are inadequate.

BOX B: CQC'S CHARACTERISTICS OF OUTSTANDING INVOLVEMENT IN CARE

CQC identifies outstanding involvement of individuals where:

- People are truly respected and valued as individuals and are empowered as partners in their care.
- There is a strong, visible person-centred culture.
- Relationships between people who use the service, those close to them and staff are strong, caring and supportive.
- Staff and management are fully committed to working in partnership with people and making this a reality for each person.
- Staff empower people who use the service to have a voice and to realise their potential.
- People's individual preferences and needs are always reflected in how care is delivered.
- The service is exceptional at helping people to express their views so they understand things from their points of view.
- They use creative ways to make sure that people have accessible, tailored and inclusive methods of communication.

BOX C: CQC'S CHARACTERISTICS OF INADEQUATE INVOLVEMENT IN CARE

CQC identifies inadequate involvement of individuals where:

- People are not involved in their care or treatment.
- People do not know how to seek help or are ignored when they do.
- People do not know or do not understand what is going to happen to them during their care.
- People's preferences and choices are not heard or acted on.
- The service does not listen to people or understand how to support them to express their views.
- Staff communication with people with complex needs is poor so they are often not understood. Also, staff do not have access to or understand the different methods of communication that can be used.



1. National findings

National trends

Overall, national surveys of patients and people using services across almost all sectors highlight that, over the last five years, there has been no substantial change in people's reported experiences of being involved in their care. For inpatient care, these trends are found over the last nine years. The one exception is maternity care, where national surveys demonstrate a sustained increase in women reporting greater involvement in their care. Key trends are:

- People's reported involvement in their inpatient care has not changed substantially over the last nine years, according to new trend analysis of national inpatient survey data from 2005 to 2014.²⁹ In 2005, 53% of people reported they definitely felt involved in decisions about their care and treatment, increasing slightly to 57% in 2014.
- The national inpatient survey shows that people's involvement in decisions around discharge from hospital has not changed over the last five years, with just over half of survey respondents saying they definitely felt involved in these decisions.
- Community mental health survey responses from people with a care plan show that the number who felt definitely involved in decisions about their care plans was 57% in 2014 and 56% in 2015.
- People using adult social care services provided by local authorities report very little change in their feeling of control over their daily lives in annual surveys since 2010 (30-32% reporting feeling they have adequate control between 2011 and 2014).
- We have reported consistent concerns regarding people detained under the Mental Health Act experiencing poor involvement in their care over the same period in our Mental Health Act annual reports 2009 to 2014.²
- We have reported on people's experiences of the Deprivation of Liberty Safeguards over the last six years (2009 to 2015).³ This has also consistently raised concerns about the variation in the use of the Safeguards in hospitals and care homes. These result in poor practice where people are not being involved appropriately in decisions about having their liberty deprived, or having an advocate to support best interest decisions being made.

CQC's national thematic reviews

Evidence gathered by CQC in separate national thematic reviews between 2009 and 2015 also highlights a lack of people's involvement in their care for specific groups of people. This includes:

- people over 75
- people with dementia
- young people with complex health needs
- people with a learning disability
- people detained under the Mental Health Act or experiencing a mental health crisis
- those people subject to Deprivation of Liberty Safeguards (see findings by population group below).

Findings by sector

Our analysis of people's responses from national patient surveys, adult social care surveys and CQC's Mental Health Act monitoring highlights that important differences appear to exist about people's involvement in their care when we focus on specific sectors or service areas.

The evidence below draws on the most recent survey data or national reports available. In some cases, it is not possible to make direct comparisons between some of the data from different surveys, as the questions people are asked about involvement in their care differ.

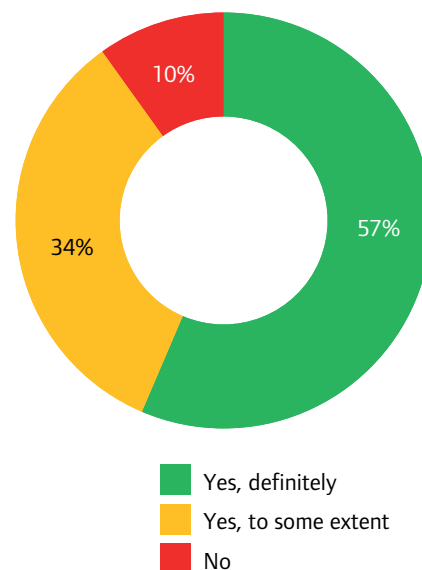
There is variation in the responses at NHS trust level to patient survey questions about people's involvement in their care. This suggests that some trusts are better at involving people in their care than others.

Acute care

People using acute hospital services report mixed experiences of being involved in decisions about their care.

The 2014 inpatient survey found that only just over half of respondents reported they were definitely as involved as they wanted to be.

FIGURE 2: WERE YOU INVOLVED AS MUCH AS YOU WANTED TO BE IN DECISIONS ABOUT YOUR CARE AND TREATMENT? (2014 INPATIENT SURVEY)



Source: National Inpatient Survey 2014.

There are similar levels of responses around people's perceptions of their involvement in A&E services, being offered a choice of hospital, and discharge, from hospital.*

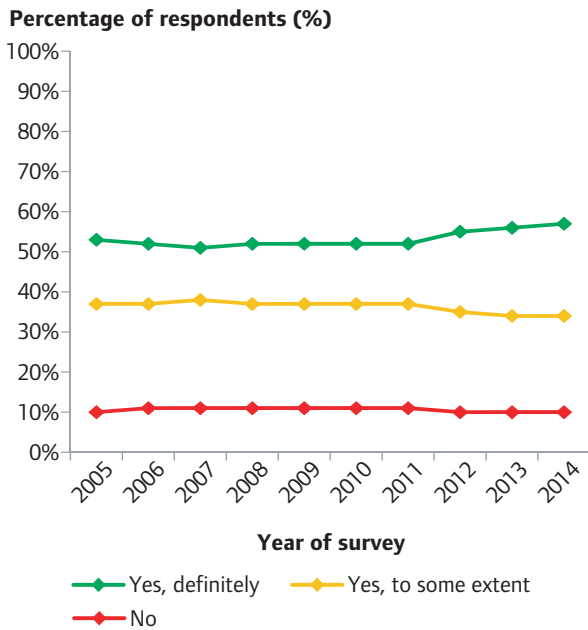
These findings remain relatively unchanged over the last 10 years.

* Responses to the national inpatient survey 2014 show 54% of people reported definitely being involved in decisions about discharge from hospital with 30% saying they were involved to some extent and 16% not at all.

Twenty-seven per cent of people were offered a choice of hospital for their first hospital appointment when they were referred to see a specialist, although 62% said that they did not mind not being offered a choice.

Responses to the national A&E survey 2014 show that 63% of people definitely felt involved as much as they wanted to be in decisions about their care and treatment; 27% felt involved to some extent and 10% reported they were not involved as much as they wanted. Findings are very similar for the last 10 years.

FIGURE 3: WERE YOU INVOLVED AS MUCH AS YOU WANTED TO BE IN DECISIONS ABOUT YOUR CARE AND TREATMENT? (INPATIENT SURVEY 2005-2014)

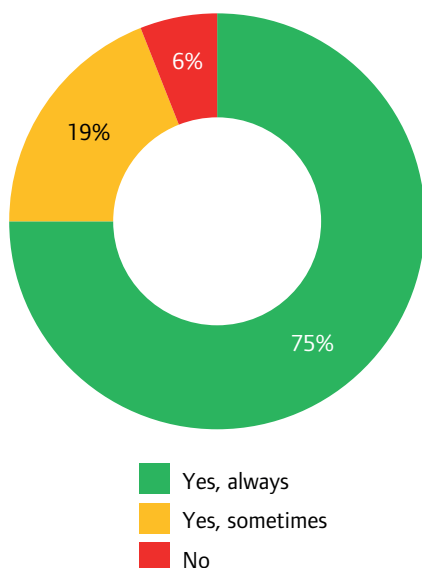


Source: National Inpatient Survey 2005-2014.

Maternity care

Women using maternity services report higher levels of involvement in their care compared to other groups.

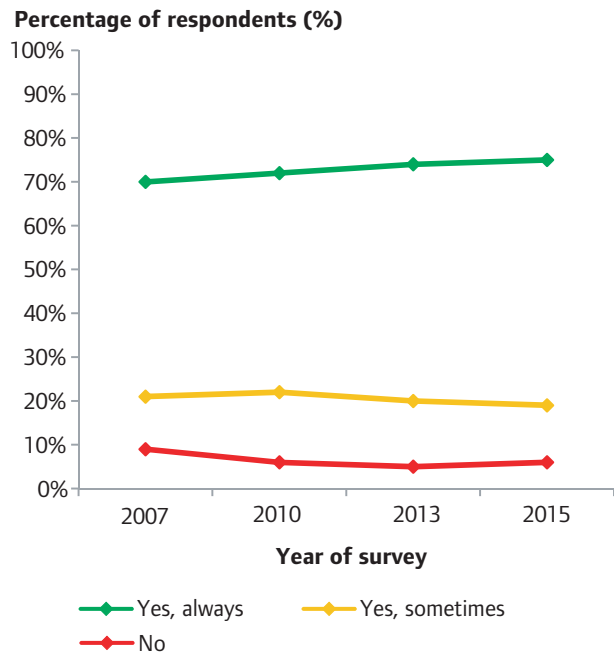
FIGURE 4: THINKING ABOUT YOUR CARE DURING LABOUR AND BIRTH, WERE YOU INVOLVED ENOUGH IN DECISIONS ABOUT YOUR CARE? (NATIONAL MATERNITY SURVEY 2015)



Source: National Maternity Survey 2015

This is part of a significant trend of improvement in responses to this question, from 70% in 2007 to 75% in 2015.

FIGURE 5: THINKING ABOUT YOUR CARE DURING LABOUR AND BIRTH, WERE YOU INVOLVED ENOUGH IN DECISIONS ABOUT YOUR CARE? (NATIONAL MATERNITY SURVEY 2007-2015)



Source: National Maternity Survey 2007-2015

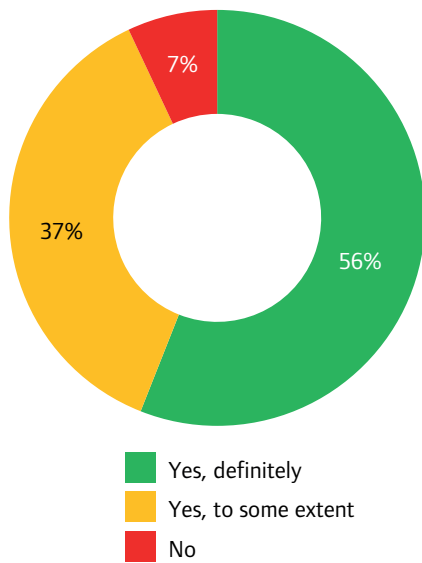
There are similarly positive responses in the 2015 maternity survey around choice about where to give birth, about being involved in decisions about antenatal care, and about partners or family being involved in decisions.*

* Eighty-four per cent of women were offered choices about where to give birth, 78% of women said they were always involved in decisions about their antenatal care, 19% said they were sometimes involved and 4% said they were not involved. Ninety-five per cent of women said that, if their partner or someone else close to them was involved in their care during labour and birth, they were able to be involved as much as they wanted.

Mental health care

People using mental health services report mixed experiences of being involved in decisions about their care.

FIGURE 6: WERE YOU INVOLVED AS MUCH AS YOU WANTED TO BE IN AGREEING WHAT CARE YOU WILL RECEIVE? (COMMUNITY MENTAL HEALTH SURVEY 2015)



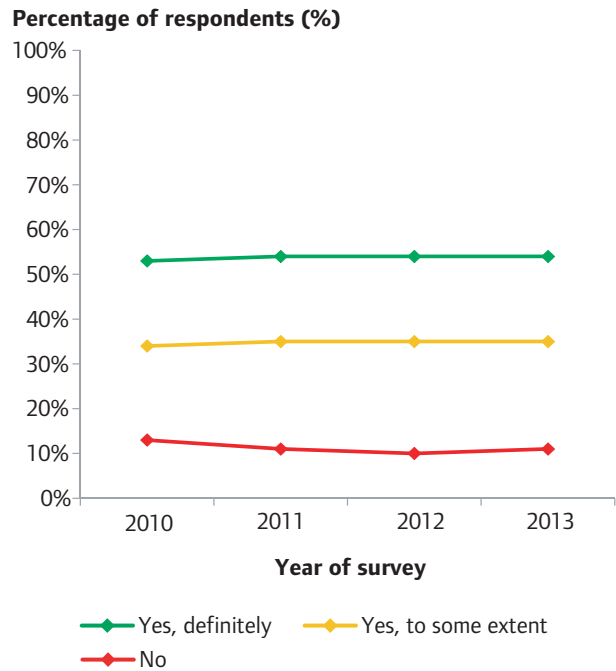
Source: Community Mental Health Survey 2015

This survey also found that:

- 42% of people reported that they had definitely agreed the care they would receive with someone from NHS mental health services, with 23% saying they had not.
- 50% of people reported that they were definitely involved as much as they wanted to be in decisions about which medicines they received.
- 55% of people said they were definitely involved as much as they wanted to be in deciding what treatments or therapies to use.
- 55% of people reported that family members or others close to them were definitely involved in their care as much as they would like, while 17% said their family or those close to them were not involved as much as they wanted them to be.

There has been very little change in the responses over time.*

FIGURE 7: DO YOU THINK YOUR VIEWS WERE TAKEN INTO ACCOUNT WHEN DECIDING WHAT WAS IN YOUR NHS CARE PLAN? (COMMUNITY MENTAL HEALTH SURVEY)



Source: Community Mental Health Survey 2010-2013

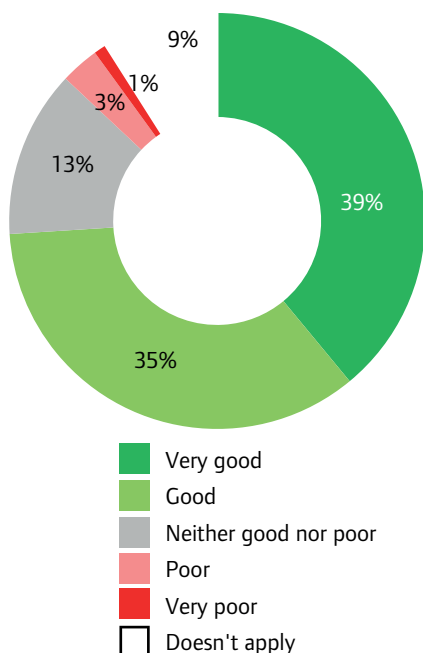
There is evidence over the last five years of poor involvement in care among people detained under the Mental Health Act. This evidence comes from CQC annual reporting on the use of the Mental Health Act. These findings are highlighted on page 21.

* Changes to the survey questions means the findings from 2014 and 2015 are not directly comparable with previous years.

Primary care

There are fewer questions in national patient surveys for primary care services related to people’s involvement in their care. This is an under-developed area of those surveys. Responses to questions related to involvement in this sector provide a mixed picture, such as in the findings from the national GP survey, published in January 2016.

FIGURE 8: LAST TIME YOU SAW OR SPOKE TO A GP FROM YOUR GP SURGERY, HOW GOOD WAS THAT GP AT INVOLVING YOU IN DECISIONS ABOUT YOUR CARE? (GP PATIENT SURVEY JANUARY 2016)

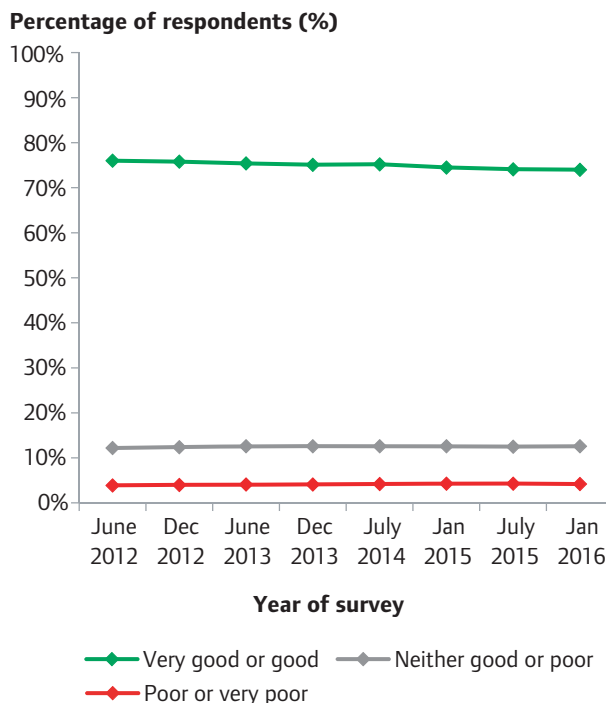


Source: GP Patient Survey January 2016

Sixty-five per cent of those surveyed reported that nurses were very good or good at involving them in decisions about their care.

Only 3% of respondents to the GP patient survey said they had a written care plan. Of those people who had a written care plan, 71% said they had been involved in putting it together, 29% had not, and only 58% said they are involved in regular reviews of this plan.

FIGURE 9: THE LAST TIME YOU SAW OR SPOKE TO A GP FROM YOUR GP SURGERY, HOW GOOD WAS THAT GP AT INVOLVING YOU IN DECISIONS ABOUT YOUR CARE? (GP PATIENT SURVEY)

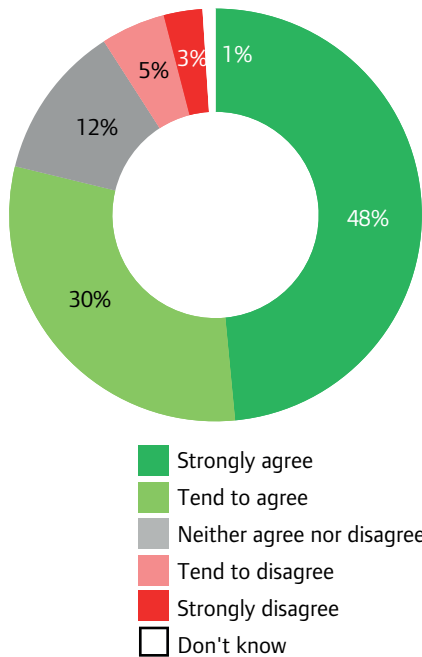


Source: GP Patient Survey 2012-2016

Dentists

People’s experiences of being involved in discussions about treatment options show fairly positive responses, but again the picture is mixed.

FIGURE 10: THE LAST TIME YOU VISITED YOUR DENTIST OR DENTAL CARE PROFESSIONAL, TO WHAT EXTENT DID THE DENTAL PROFESSIONAL DISCUSS THE OPTIONS FOR TREATMENT THOROUGHLY WITH YOU? (GP PATIENT SURVEY)

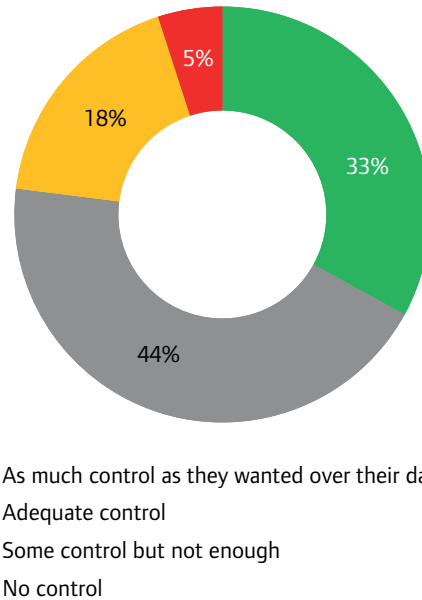


Source: General Dental Council’s Patient and Public Survey 2013

Adult social care

There is less national evidence available about people’s involvement in their care in adult social care settings. The Personal Social Services Adult Social Care Survey 2014/15 provides some evidence about people’s reported control over their daily lives and how easily they can find information and advice.

FIGURE 11: HOW MUCH CONTROL DO YOU HAVE OVER YOUR DAILY LIFE? (PERSONAL SOCIAL SERVICES ADULT SOCIAL CARE SURVEY 2014/15)

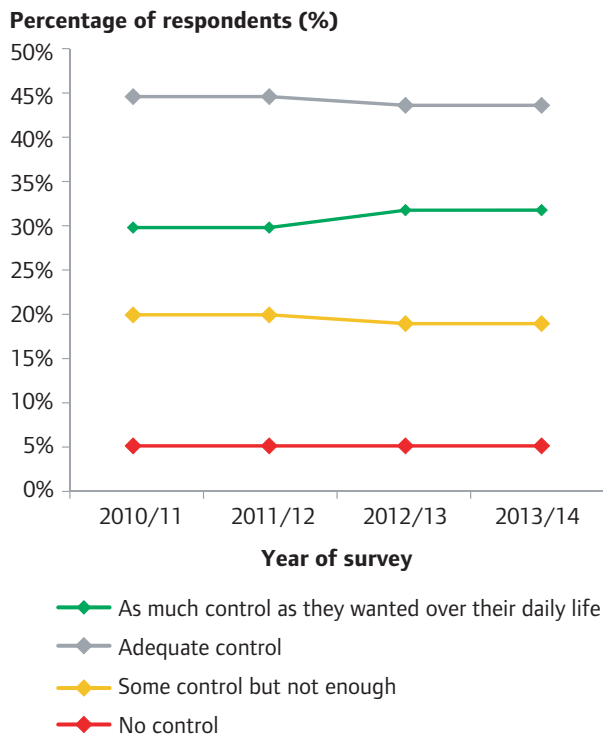


Source: Personal Social Services Adult Social Care Survey 2014/15

In addition, 28% of people said it was very easy to find information and advice about support, services or benefits, while 8% said it was very difficult to find.

Between 2010 and 2014 there was very little change to the responses in a similar survey. The survey is designed to cover all people who use services aged 18 and over in receipt of services funded wholly or in part by social services. It has been running for the last five years. In 2014/15, there were some changes to those people covered by the survey, so direct comparisons cannot be made with previous years.

FIGURE 12: DO YOU HAVE AS MUCH CONTROL OVER YOUR DAILY LIFE AS YOU WANT TO? (PERSONAL SOCIAL SERVICES ADULT SOCIAL CARE SURVEY)



Source: Personal Social Services Adult Social Care Survey 2010-2014

Evidence from CQC's pre-inspection questionnaires of people using adult social care services provide some further evidence. This provides much more positive responses related to people's involvement in decisions about their care. Just over 90% of people questioned as part of CQC's inspections of community adult social care services between April 2015 and March 2016 agreed they were involved in decision-making about their care and support needs.*

Home care

There is no national data available about people's experiences of involvement in their home care services. However CQC's review of home care

* Total number of respondents to CQC's pre-inspection questionnaire of community adult social care services (for inspections scheduled for April 2015 – March 2016) = 22,172

agencies in 2013 inspected 250 home care agencies and found good written information about the services and choices available, and that this was generally explained to people face-to-face.

People were encouraged and supported to express their views and detailed records documented their preferences and choices in many cases.

However, there were concerns about the lack of continuity of care workers and failures to keep people informed about changes to their visits. People felt that they lacked choice about the number of new and unfamiliar care workers who arrived at their home – and that this had an impact on their ongoing involvement and continuity of care.

Lack of involvement of family members and carers was identified as a concern in some services. There was also a lack of involvement in the assessment process and then in the ongoing review of its effectiveness.³⁰

Hospices and end of life care

The 2014 National Survey of Bereaved People found that more than five out of six bereaved people (86%) understood the information provided by health care professionals, but one out of six (16%) disagreed they had time to ask questions with healthcare professionals.

CQC also inspects hospices as part of our adult social care inspection programme. Pre-inspection questionnaires of people using hospice care for inspections between April 2015 and December 2015 showed that 96% agreed they were involved in decision-making about their care, treatment and support needs.**

Further national evidence on people's involvement in their end of life care is available in CQC's new thematic review of inequalities in end of life care.³¹

** Total number of respondents to CQC's pre-inspection questionnaire of hospice services (for inspections scheduled for April – December 2015) = 300

Findings for different population groups

We have found significant differences between certain groups of people using services and their experiences of being involved in their care from analysis of responses across six national patient surveys. These findings are reinforced by evidence from the last six years of CQC thematic reviews, and our monitoring of the Mental Health Act (MHA) and Deprivation of Liberty Safeguards legislation, which provide more details about the experiences of different groups and how they are involved in their care as they use services.

Overall, the findings highlight concerns that people with long-term conditions, people over 75, people with dementia, young people with complex health needs, people with a learning

disability, people detained under the MHA or experiencing a mental health crisis and those people subject to the Deprivation of Liberty Safeguards are not sufficiently involved in making care and treatment plans, or in the choices about the way their care is provided to meet their needs – particularly as they move between health and care services.

These groups of people are likely to be using multiple services over time, and require coordinated involvement in their care. Our evidence shows that they experience a ‘vicious circle’ of poor involvement (FIGURE 13).

These have a greater effect on people’s care and their quality of life as they move between services and when they use services often.

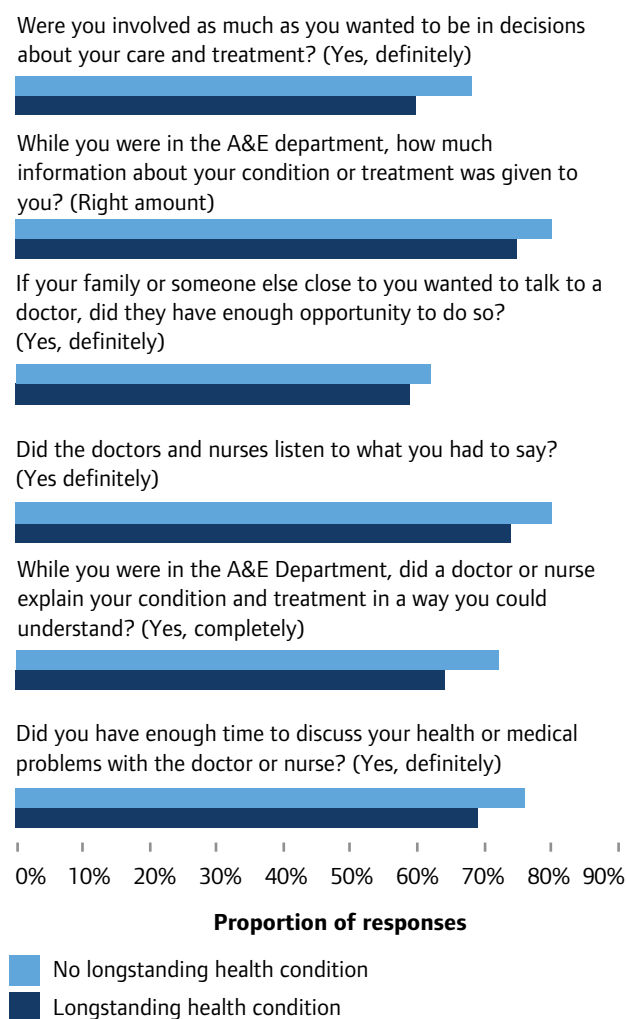
FIGURE 13: THE VICIOUS CIRCLE OF POOR INVOLVEMENT



People with a long-term condition

Responses to the national inpatient, accident & emergency (A&E), maternity and cancer patient experience surveys show that overall, people with long-term conditions consistently report feeling less involved in their care than people who do not have a long-term condition.

FIGURE 14: COMPARISON OF RESPONSES TO 2014 A&E SURVEY BY CONFIRMATION OF A LONGSTANDING HEALTH CONDITION



Source: Accident and Emergency Survey 2014

The exception are responses to the GP patient survey that show people with some long-term conditions feeling slightly more listened to and involved in decisions about their care compared to people who do not have a long-term condition.

BOX D: PEOPLE WITH DEMENTIA

Our 2014 thematic review of care between hospitals and care homes for people with dementia found that 33% of the care homes inspected and 61% of the hospitals inspected were not involving people with dementia or their families in their care or their choices about how to spend their time.

Arrangements to ensure that people with dementia are supported to make decisions about their care were not effectively applied. When people with dementia lack capacity, we found that their freedom could be restricted without proper consideration – due to a lack of understanding about the Mental Health Act.

“Relatives in one care home told us that they were not involved in developing care plans and they did not feel that these accurately reflected their family member’s life history, social or family preferences. In addition, care plans were not up to date and did not provide enough information. As a result, people were sometimes distressed and this was not managed by staff.”

Engagement with some people from Black and minority ethnic communities found that language was a barrier to people accessing information and services, and an area of anxiety for people considering residential care.

One person said, “Poor experiences for me are nobody asking or listening to what I say. People treating me like I cannot think at all anymore. Feeling so disempowered that I feel like nothing.”

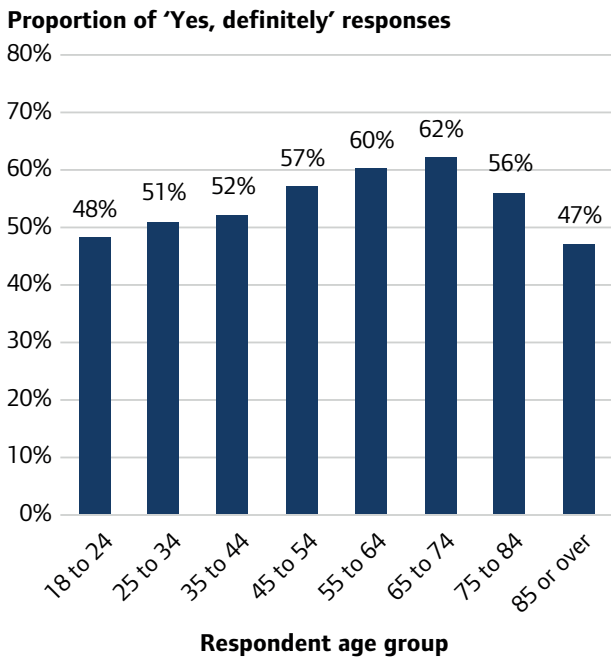
We inspected 129 care homes and 20 hospitals, from 22 local authority areas.³²

Older and younger people

Differences also exist between age groups. Analysis of the national patient surveys shows a general trend in people being more likely to report being involved in their health care as they get older: but only to a certain age. The majority of surveys highlight a significant dip for those in

the final two age groups; people aged over 75 years are less likely to report being involved in their health care.

FIGURE 15: WERE YOU INVOLVED AS MUCH AS YOU WANTED TO BE IN DECISIONS ABOUT YOUR CARE AND TREATMENT? (2014 INPATIENT SURVEY)



Source: National Inpatient Survey 2014

CQC's new thematic review into how well care is joined up for older people will highlight the

latest national evidence about older people's involvement in their care and care planning (due to publish in June 2016).

All the national patient surveys we analysed highlight that the youngest age group (18 to 24 years) feels the least positive about discussing their treatment and care with health professionals and receiving understandable answers and explanations.

The first national survey of children's experiences of healthcare in 2015 found some encouraging findings in relation to the explanations about hospital care that young people were given:

- 91% of 8 to 15 year olds were told what to expect in hospital before a procedure/operation.
- 82% said that hospital staff talked to them about how they were going to care for them in a way that they could understand.

However the survey findings also show:

- 43% of 12 to 15 year olds told us that they were not fully involved in decisions about their care, and 13% said they had no involvement in decisions.
- 20% of parents and carers responding to the children's survey said they did not receive written information about their child's condition or treatment to take home with them.

BOX E: YOUNG PEOPLE WITH COMPLEX HEALTH NEEDS

In our thematic review of young people with complex health needs, only 54% of young people with complex health needs felt they had been involved in planning their transition to adult care and 60% of those who had already transitioned felt they had been involved. We interviewed 180 young people or family members of young people.

For many young people there was no transition planning and no indication of their future wishes, hopes or aspirations. There were many examples of support plans that did not include young people's wishes. Records of capacity to make decisions were generally very poor.

There was inconsistent and often poor information and preparation from children's services for young people and their parents about the changes they could expect as they move into adult services. This led to a lack of understanding of the process of transition.

We saw some health passports during our review, but they were not widely used by those involved in planning with the young person and their family. Families and young people told us one of the most frustrating elements of the transfer to adult services was the need to keep repeating the young person's health needs and history to multiple health teams.³³

Children with a physical disability, a learning disability or a mental health condition responded more negatively to questions about their involvement in care in the children and young people's inpatient and day case survey. Children with these long-term conditions were more likely to be negative about the information provided by staff and the quality of their communications with staff. This included questions about whether staff talked with them when they were worried and whether staff always listened to them. (Children and young people's inpatient and day case survey, 2014)

People with mental health conditions and those detained under the Mental Health Act

We have identified longstanding concerns, reported year on year, of the poor involvement of people who lack capacity, in making decisions about their care and treatment, including people detained under the Mental Health Act (MHA). The level of people's involvement in the care planning process is highlighted in our 2014/15 MHA report:

"The biggest issue we found for patients who were subject to the MHA in 2014/15 was a lack of support to be involved in their care and treatment. This included the information they were given, access to external support such as advocacy and care planning."²

- 25% of 3,836 care records reviewed by CQC did not show that people had been involved at all in developing their care plans. This was similar to the 26% of records with no involvement reported in the 2013/14 MHA report.
- 32% (964 of 3,000) of the patient records examined did not include a capacity assessment for medication when someone was admitted to hospital.
- 171 out of 210 mental health wards surveyed for the report did not keep a record of referrals made to independent mental health advocacy services and 82 wards had not received training on the role of the

independent mental health advocate or how to refer a patient.

Evidence also highlights concerns about the ways people with a mental health condition and their carers are listened to – particularly when people are in crisis:

- Our national patient survey data shows people with mental health conditions report feeling listened to significantly less in accident and emergency departments.
- Findings from a carers' survey in our thematic review of crisis care highlighted concerns about the way carers felt they were listened to and taken seriously as a carer, and whether they were provided with the right information and advice in their situation.³⁴

People with a learning disability

A lack of person-centred care planning was a significant feature in the CQC review of 145 learning disability services in 2012. Lack of involvement of people and their families in the design of their care and as a result lack of control over their needs was significant.

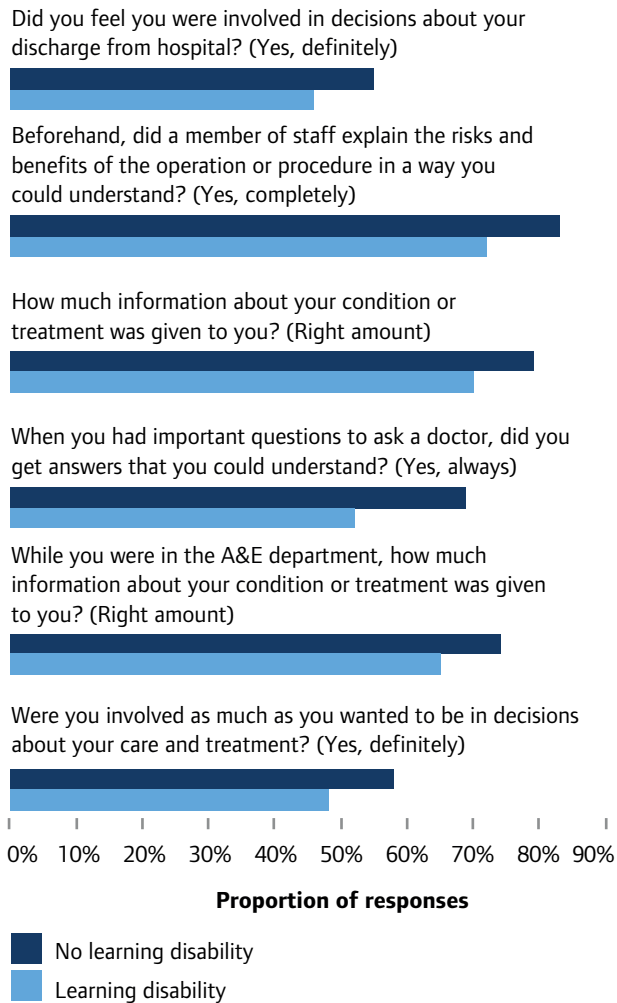
The review found that services lacked information about people's preferences, including likes and dislikes about how care was delivered. Often people were not actively involved in the care planning process. Care plans were not in appropriate or accessible formats in many cases.

None of the care plans we looked at showed evidence of patient, carer or relative involvement and none of the patients had a copy of their care plans. We found that care plans were not routinely being signed by patients to indicate that they had agreed to their treatment. We also found many examples of people unable to access their care plans.

"Staff said when a person was unable to communicate their needs they checked what was recorded in their care plan or referred to the person's family or carers. We found that this did not always happen in practice."³⁵

National surveys also show that people with a learning disability tend to feel less involved in their care.

FIGURE 16: COMPARISON OF RESPONSES TO 2014 INPATIENT SURVEY BY CONFIRMATION OF A LEARNING DISABILITY



Source: National Inpatient Survey 2014

People deprived of their liberties

The Deprivation of Liberty Safeguards were introduced in 2009 and are part of the Mental Capacity Act 2005 (MCA). CQC has reported annually on their use since 2009. The Safeguards are used to protect the rights of people who lack the ability to make certain decisions for themselves and make sure that their freedom is not inappropriately restricted. They do this by helping to make sure that decisions made on their behalf are done so in their best interests, and also by empowering them to make their own decisions wherever possible.

Over the last six years of reporting on the use of the Safeguards, our inspections have consistently found variation in care planning to ensure that people’s best interests are taken into account based on their individual needs (including with involvement of relevant professionals and family members). Our reports highlight the need for providers to ensure the appropriate provision and use of advocacy services to enable people to be involved and to represent their best interests.

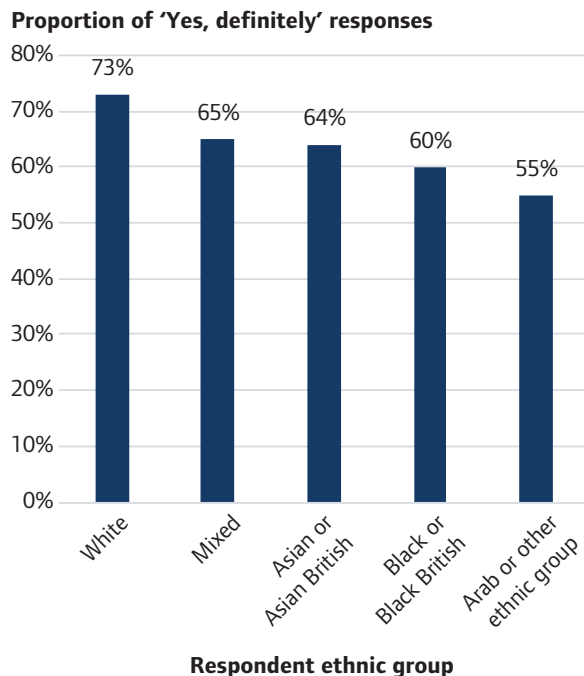
Our 2014/15 report points out that the backlog of applications made by providers to local authorities means that there is a delay in people who may be deprived of their liberty receiving the independent assessments, advocacy and representation provided by local authorities. These are essential to ensuring that people are only deprived of their liberty appropriately and that they receive care which meets their needs and is consistent, as much as possible, with their wishes.

“I was shocked and distressed to say the least; I knew of Deprivation of Liberty Safeguards and the reasons for it but nobody had related this to my son and his respite stays. It was the stuff of nightmares, [that is,] key professionals making decisions and not informing or involving me...”³

People from Black and minority ethnic communities

Responses to the national inpatient, accident & emergency (A&E), GP patient, maternity and cancer patient experience surveys show that overall, people from Black and minority ethnic (BME) groups consistently report feeling less involved in their care compared to white people. They feel less listened to, less involved in decisions, less likely to receive the information they need and less likely to be involved in their care planning across most of the services they use. This is illustrated in figure 17, which shows respondents from ethnic groups other than ‘White’ to the 2014 cancer patient experience survey reported feeling less involved in decisions about their care and treatment.

FIGURE 17: WERE YOU INVOLVED AS MUCH AS YOU WANTED TO BE IN DECISIONS ABOUT YOUR CARE AND TREATMENT? (2014 NATIONAL CANCER PATIENT EXPERIENCE SURVEY)

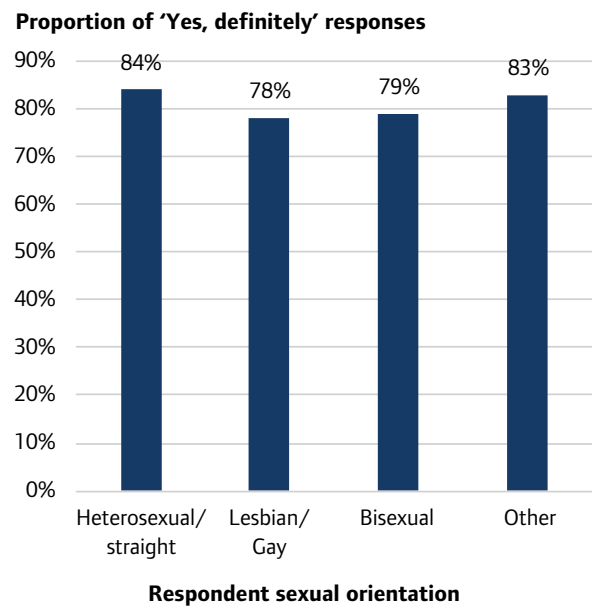


Source: National Cancer Patient Experience Survey 2014

People from lesbian, gay, bisexual and transgender communities

Similar trends were also observed when we analysed people's responses to the national inpatient, accident & emergency (A&E), GP patient, maternity, community mental health and cancer patient experience surveys based on their sexual orientation. Heterosexual people were more likely to report feeling involved in their care compared to lesbian, gay and bisexual people. The GP patient survey results shown in figure 18 illustrate lesbian, gay and bisexual respondents feeling significantly less involved in decisions about their care with their GP.

FIGURE 18: RATING OF GP INVOLVING YOU IN DECISIONS ABOUT YOUR CARE (JULY 2014 GP PATIENT SURVEY)



Source: National GP Survey July 2014



2. Good practice in involving people

Analysis from our literature review, from CQC inspections of outstanding services and evidence from our national thematic reviews has identified a common set of ‘enablers’ that some services put in place to ensure people are involved in their care. There are also wider cross-sector enablers that commissioners and providers can implement so people are involved in their care as they move between services. These will have particular benefits for long-term users of health and social care services and those who need specific support.

We present these alongside good practice examples and quotes from people receiving care, which we have taken from our thematic reports and inspection reports from services rated outstanding since April 2015.

We have grouped these by the ‘I statements’ we have used to define someone’s involvement in their care, to reflect the examples from a person-centred perspective.

I am involved in discussions about my care, treatment and daily life as I want to be

“Nothing is too much trouble, its more than just about the illness, they really care for you.” (Person using a service)

ENABLER

Involving people in all aspects of care is a priority for the organisation and managers take a leadership role, encouraging staff to involve people

INSPECTION REPORT EXAMPLES

“We saw that children and young people were involved as appropriate in decision making on a daily basis about the activities they took part in. This included the type, timing of activities and the way they would like to do them.” (Hospital)

“We saw that people’s preferences and views were reflected, such as the name they preferred to be called and personal care preferences such as, ‘I like to have a shower every day.’ We spoke with this person and they confirmed that they had a daily shower.” (Care home)

“Young people were provided with a copy of their care plan and are asked to sign to say whether they agree or disagree with its contents.” (Children’s mental health service)

My wishes and preferences are respected

“I like the afternoon appointments and staff try to make sure that I get them.”
(Person using outpatients)

ENABLER

There are management systems in place to monitor how people’s wishes and preferences are being acted on

INSPECTION REPORT EXAMPLES

“Hospital staff always reflected individual needs and preferences and ... worked together with other professionals to help overcome obstacles so that people’s daily lives continued despite serious illness...”
(Specialist hospital)

“The main emphasis was that people were at home; they dressed in their preferred clothes and continued to undertake their individual hobbies. We observed people were able to do what they wished, making their own decisions helped and supported by staff. A member of staff we spoke with told us, ‘The residents are not pushed to have a certain routine; we go with the flow so people live the life they choose.’” (Care home)

“We saw people had an opportunity to complete an advanced decision care plan. These clearly told staff what the person wanted to happen and how the person wanted their current and future care to be delivered. For some, these included a ‘Do Not Attempt to Resuscitate’ document. There were also records of family involvement in these decisions.” (Hospice)

My family and loved ones help me plan my care and support

“I am always consulted about everything. The manager and staff keep me informed and we always have a six monthly review meeting when we discuss every aspect of my mother’s care. I find communication to be excellent.”
(Relative of a care home resident)

ENABLER

Services coordinate how they involve people and their families in their care

INSPECTION REPORT EXAMPLES

“The computer system alerted the GPs if a patient was a family carer and identified the patients they cared for. Support groups were run for family carers. Another practice had a priority help line for patients and family carers to contact the practice to discuss care or in case of an urgent enquiry.” (GP practices)

“If a person’s conditions changed in the care home and staff were concerned for their wellbeing the person’s family were contacted. They were told when action had been taken, for example when a GP visit had been requested.” (Care home)

“A relative we spoke with told us they lived a considerable distance from the hospital but they had received a regular daily telephone call updating them of their relative’s progress.” (Specialist hospital)

“There were open discussions where a person had a terminal condition. The family were [invited to] family meetings and the doctor explained everything, encouraging questions.” (Hospital)

Staff in different services work with me to adapt my plans as my needs change

“I have a plan of care; I know where I am going and the staff have been supporting me all the way.”
(Hospital patient)

ENABLER

Key staff work together across services to coordinate people’s involvement in their care

INSPECTION REPORT EXAMPLES

“A hospital passport was completed for each person. If a person needed to go into hospital other professionals would be made aware of people’s preferences regarding their care, support needs and their current treatments that were best for them.” (Care home)

“We were shown examples of personalised care plans that had been agreed between the patient, GP, community matron and other professionals. In one case, the care planning process had improved the patient’s quality of life in terms of their diabetes being better controlled and being less dependent on steroid medication.” (GP practice)

I am offered appropriate information, support and advocacy about key decisions for my care and treatment

“If I struggle reading my care plan my named nurse reads and explains it to me the best he can... it tells about my needs and illnesses and how to look after me. They update my care plan now and again, it depends on how fast I improve.”
(Person with a learning disability)

ENABLER

Tailored and timely accessible information is used to support discussions and the involvement of people and their families

INSPECTION REPORT EXAMPLES

“We observed a member of staff sitting next to a person who had no verbal communication. The staff member was holding the person’s hand and pointing out the various picture meal options available for lunch.” (Care home)

“Accessible information was provided to help patients understand the care available to them... reasonable adjustments were made when required. This included access to longer appointments for people with a learning disability, mental health needs and communication difficulties.” (GP practice)

“During the ward round patients would be given a brief summary of what had been discussed. Patients and their relatives had the opportunity to complete a section titled ‘questions you want answering’ and these would be followed up at the next ward round.” (Hospital)

Patients who spoke with us on the surgical admissions lounge told us they had been given information in a way they could understand and that they had been listened to. One patient said to us, ‘I have been taken through my treatment and have discussed it.’ Another patient said, ‘The doctor explains everything and shows me pictures.’ (Hospital)

“Individual care plans could be hand written to meet needs if required and patients were reminded by telephone in their own language to attend their reviews following receipt of a letter.” (GP practice)

I am involved in daily life choices in care settings

“I take pride in my appearance, I like jewellery that match my outfits. I am probably a bit too fussy, but the staff know this and they never rush me when assisting me to get dressed.”

(Care home resident)

ENABLER

Services are organised to provide continuity of staff working with people using services over time

INSPECTION REPORT EXAMPLES

“Before a resident moved in, the care home found out what their preferences were in terms of how to welcome them, what would make their room more acceptable, and importantly, they agreed to them bringing their cat. Although the Deprivation of Liberty restrictions applied, the home constantly sought ways to lessen the restrictions and enable community involvement for the resident.” (Care home)

“Care staff worked with Mr J and his wife to understand his life story and find out what would make him happier. Mr J had been a firefighter and relished the responsibility of keeping people safe. Care staff supported Mr J to check the environment for safety and standards and also involved him in practical daily tasks. They also found he enjoyed going out for walks and to the pub with a male staff member.” (Care home)

“We observed throughout all four ‘houses’ that people were encouraged to maintain their independence even if there were risks attached to this. We observed staff encouraging people to take a walk if they felt like they wanted to. We saw people being supported to contribute to the menu planning, the activities programme and how they wanted to spend their day.” (Care home)

My capacity to be involved is taken into account – wherever I receive care

“Even the most articulate person, when detained under the MHA, could use help from advocacy in making a complaint, or expressing concerns. It’s difficult to speak up then.”

(Person using mental health services)

ENABLER

There is flexible advocacy provision as people use different services (for people who lack capacity or need support to represent their interests)

INSPECTION REPORT EXAMPLES

“One 17 year old had a continuing healthcare assessment which was very person-centred. His support needs were clearly outlined and recorded in simple language and using his own words. It had a strong focus on his likes, dislikes and wishes. His father told us, ‘The team have worked creatively to expand and enrich his social and practical skills. As a result his ability to join in and socialise with his siblings and peers has grown significantly.’” (Care home)

“An advocate told us that he supported people to make sure their choices were understood and respected at the home, and also at statutory reviews with social services.”

“X was very proud of the work she had done to complete her shared pathway workbooks. She had written in the books in her own words reflecting her level of understanding and the reason for being in hospital. She told us she felt much happier since moving and explained how using the workbooks was helping her to achieve her goal to return to independent living.” (Learning disability inpatient service)

I am offered the opportunity to be more educated about how to manage my condition or care

“I have the same nurse, which is very important to me; she knows my condition and how I am, and has helped to address my pain and nausea; I am totally confident in her and get proper advice and support, which is vital to me.”

(Hospice resident)

ENABLER

People who use services are given training and support to be involved in their care. This includes tailored self-management support tools and programmes, health literacy and coaching programmes and aids for decision-making

There are strong relationships between care providers and the community and voluntary sector – established community and peer support programmes for people to manage their care

INSPECTION REPORT EXAMPLES

“There were opportunities for patients to self-medicate and learn to manage their own medicines as they approached discharge. There was a self-medication protocol in place to make sure this was managed safely.” (Mental health hospital)

“Patients with diabetes received a copy of their health review form and test results prior to attending their review. They also received a written summary of the outcome of their reviews, which helped them to self-manage their condition effectively. They were asked to share their experiences and changes they had made to improve their health and wellbeing, in staff meetings and patient groups as ‘patient’ experts.” (GP practice)

“Women who have a learning disability and [those from the youngest age groups] are provided with a specially developed set of maternity notes called ‘My Maternity Book’. This booklet is used alongside the standard hand held notes to promote understanding and involvement by the woman in her own care and the needs of the unborn and new born baby. (Hospital)



Conclusions and recommendations

Conclusions

The evidence reviewed for this study presents a picture of the extent and quality of people's involvement in their health and social care. It is positive that over half those responding to national patient surveys report feeling definitely involved in decisions about their health care and treatment, and this includes responses for care in hospitals and in the community. Women who use maternity services are particularly positive about how well they are involved in decisions about their care. We have also identified good practice examples of people being involved in all aspects of their care and decisions about their lives, in a range of services we have rated outstanding overall.

However, we have also found almost no change in people's involvement in their health care and social care for the last five years (and longer in acute care). CQC has raised concerns about the lack of involvement of people detained under the Mental Health Act and those deprived of their liberties over the same period.

People needing long-term care and support are the least likely to report being involved in their health care. This includes people with long-term conditions, young people (18 to 24 years) and the oldest age groups surveyed (over 75 years).

People using health and adult care services in the community, including mental health care and their GP, report feeling less involved in their care than people having treatment in hospital.

There is a lack of supported involvement for people who may lack capacity – including young people with complex needs, people with a learning disability, people with mental health needs and people with dementia. The biggest issue for care of people detained under the Mental Health Act is the lack of people's involvement in their care.

For these groups of people their involvement in decisions about care and treatment can be poorly coordinated when they move between hospital, primary care and care services.

The following aspects of people's involvement in their care emerge as areas where most improvement is needed – particularly for people with long-term health and care needs. These are also areas where service providers can work together to coordinate the ways they involve people in their care:

- lack of personalised care plans and passports developed with people to reflect their needs – particularly for people with dementia, people with mental health issues, and people with a learning disability

- a lack of involvement of families and carers in people’s care – particularly for young people and for people with mental health issues
- limited or inconsistent use of advocacy services, peer and community support programmes to support people’s involvement in their care journey and the management of their care.

This report has brought together existing evidence about how well people are involved in their care. Nationally, there is a lack of data on people’s involvement in their care as they move between services and specifically for those using primary and social care. National survey

questions are sector specific and do not currently generate evidence about integrated person-centred care or how people are involved in their care across different services.

Further work is needed to explore the reasons for the differences between NHS trusts, between sectors and between the experiences of different groups of people in how well they are involved in their care.

Evidence of good practice highlights what providers can put in place to drive more sustained and meaningful ways of involving people in their care (see figure 19).

FIGURE 19: WHAT ENABLES SERVICES TO WORK TOGETHER TO INVOLVE PEOPLE IN THEIR CARE?



Recommendations

We encourage providers and commissioners of services, and voluntary sector organisations to work together to ensure health and care services consistently involve people throughout their care and that staff are supported to communicate with and support people and their families to be involved in their care in the ways they wish.

For service providers:

We encourage service providers to focus their efforts on the following enablers that evidence suggests support people to be effectively involved in their care:

- personalised care plans – written with people, for people, and with their wishes and preferences clearly identified and monitored
- the sustained and supported involvement of families and carers in the care of their loved ones
- the coordination of people's involvement in their care as they move between services – for example, through the use of health and care passports and the provision of community and peer support programmes.

For commissioners:

We encourage commissioners to ensure new models of care are developed taking account of the enablers to good involvement described above. In particular that there is a coordinated approach to the development of:

- accessible information about health and care options and treatment or support for people and their families/carers
- flexible advocacy provision as people use different services
- community and peer support for people to manage their care through programmes with voluntary sector partners.

Next steps

In line with the new CQC strategy, CQC will:

Develop a shared view of the quality of people's involvement in their care

- We will work with national partners, including NHS England, NHS Improvement, Healthwatch England, National Voices and the Social Care Institute for Excellence, to support the use of a shared view of good involvement in someone's care.
- We will encourage the use of this shared view through national programmes such as the NHS England vanguard programme, models of integrated personal commissioning and Realising the Value programme.
- We will consider ways of improving our reporting of this aspect of care – to provide more evidence of good practice to encourage providers to improve.

Develop a framework for assessing how well people are involved in their care as they use different services

We will consider developing a framework for assessing people's involvement in their care as part of future thematic reviews, and assessments of quality of care for pathways or populations.

Improve data and indicators

We will explore options to strengthen and coordinate national survey questions in this area, particularly in adult social care and primary care surveys.

Acknowledgements

CQC is grateful to colleagues who provided advice on the development of this report:

- Kings Fund
- National Voices
- NHS England
- Picker Institute
- The Health Foundation.

References

1. Care Quality Commission, **State of Care 2014/15**, 2015
2. Care Quality Commission, **Mental Health Act Annual Report 2014/15**, 2015
3. Care Quality Commission, **Deprivation of Liberty Safeguards 2014/15**, 2015
4. National Collaboration for Integrated Care and Support, **Integrated Care and Support: Our Shared Commitment**, May 2013
5. NHS England, **A Narrative for Person-Centred Coordinated Care**, 2013
6. Coulter, A, **Engaging Patients in Healthcare**, Open University Press, 2011
7. Da Silva, D, **Helping People help themselves, A review of the evidence considering whether it is worthwhile to support self-management**, The Health Foundation, 2011
8. Foot, C, Gilbert, H, Dunn, P, Jabbal, J, Seale, B, Goodrich, J, Buck, D, Taylor, J, **People in control of their own health and social Care, the state of involvement**, The Kings Fund, National Voices, November 2014
9. Richmond Group of Charities and the Kings Fund, **From Vision to Action: Making patient-centred care a reality**, 2012
10. National Voices, **Prioritising person-centred care: supporting self-management: summarising evidence from systematic reviews**, 2014
11. Glendinning, C, Challis, D, Fernandez, J, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Moran, N, Netten, A, Stevens, M and Wilberforce, M, **Evaluation of the Individual Budgets Pilot Programme: Final Report**, Social Policy Research Unit, University of York, 2008
12. Hatton, C, Waters, J, Routledge, M, **National Personal Budgets Survey 2013 Summary**, Think Local Act Personal, 2013
13. Coulter, A and Collins, A, **Making Shared Decision Making a reality: no decision about me, without me**, The Kings Fund, 2011
14. Health Foundation, **Person Centred Care made Simple what everyone should know about person-centred care**, 2014
15. Nunes V, Neilson J, O'Flynn N, Calvert N, Kuntze S, Smithson H, Benson J, Blair J, Bowser A, Clyne W, Crome P, Haddad P, Hemingway S, Horne R, Johnson S, Kelly S, Packham B, Patel M, Steel J, **Clinical Guidelines and Evidence Review for Medicines Adherence: involving patients in decisions about prescribed medicines and supporting adherence**, National Collaborating Centre for Primary Care and Royal College of General Practitioners, 2009
16. Stacey D, Kryworuchko J, Belkora J, Davison BJ, Durand M-A, Eden KB, Hoffman AS, Koerner M, Légaré F, Loiselle M-C, Street RL. 'Coaching and guidance with patient decision aids: a review of theoretical and empirical evidence', **BMC Medical Informatics and Decision Making**, vol 13, suppl 2, p S11, 2013
17. Stevenson FA, Barry CA, Britten N, Barber N, Bradley CP. 'Doctor-patient communication about drugs: the evidence for shared decision making', **Social Science & Medicine**, vol 50,6, 2000
18. Nesta, **The Business Case for People Powered Health**, 2013
19. Mental Health Taskforce, **A report from the independent Mental Health Taskforce to the NHS in England**, (2016)

20. South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, **Recovery is for All. Hope, Agency and Opportunity in Psychiatry. A Position Statement by Consultant Psychiatrists**, 2010
21. NSUN, **Involvement for Influence; 4Pi National Involvement Standards**, 2015
22. Department of Health, **The NHS Constitution: the NHS belongs to us all**, 2013
23. NHS England, **Five Year Forward View**, 2014
24. The Stationery Office, **The Care Act 2014**, (c 7)
25. Francis R, **Report of the Mid Staffordshire NHS Foundation Trust public inquiry**, HC 947, 2013
26. The Stationery Office, **Health and Social Care Act 2012**, (c 7)
27. NHS England, **New Care Models: Vanguards – developing a blueprint for the future of NHS and care services**, 2016
28. Care Quality Commission, **Fundamental standards: Guidance for providers on meeting the regulations**, 2015
29. Care Quality Commission, **National NHS patient survey programme: Trends in the adult inpatient survey 2005-2014**, 2015
30. Care Quality Commission, **Not just a number: home care inspection programme**, 2013
31. Care Quality Commission, **A different ending: Addressing inequalities in end of life care – Overview report**, 2016
32. Care Quality Commission, **Cracks in the pathway: People's experience of dementia care as they move between care homes and hospitals**, 2014
33. Care Quality Commission, **From the pond into the sea: children's transition to adult health services**, 2014
34. Care Quality Commission, **Right here, right now: People's experiences of help, care and support during a mental health crisis**, 2015
35. Care Quality Commission, **Time to listen in NHS hospitals: Dignity and nutrition inspection programme**, 2012

How to contact us

Call us on > 03000 616161

Email us at > enquiries@cqc.org.uk

Look at our website > www.cqc.org.uk

Write to us at >

Care Quality Commission

Citygate

Gallowgate

Newcastle upon Tyne

NE1 4PA



Follow us on Twitter >

@CareQualityComm

Please contact us if you would like this report in another language or format.

