



Involving people in their own health and care:

Statutory guidance for clinical commissioning groups and NHS England

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Foreword

National surveys tell us that over 40%¹ of people want to be more involved in decisions about their care; this situation has hardly changed in a decade. Similarly 40%² of people living with long term conditions want more support to manage their health and wellbeing on a day to day basis. Indeed, the [Five Year Forward View](#) states that more could be done to involve people in their own health and care, to involve communities and the voluntary sector in improving health and wellbeing and to coordinate and personalise care and support including through personal health budgets.

By involving people in decisions about their health and care we will improve health and wellbeing, improve the quality of care and ensure people make informed use of available healthcare resources. Involving people in their own health and care not only adds value to people's lives, it creates value for the taxpayer. The challenge now is to shift the focus of care and support services from 'what is the matter with you?' towards 'what matters to you?'.



Professor Alf Collins, doctor, commissioner, researcher and national policy advisor in person-centred care.

"With more choice and more control I am able to limit the impact that my multiple conditions have on my life. I can make decisions about my health that give me more opportunities to work, maintain relationships and friendships and continue to do the things that make me happy. This in itself gives me strength to continue to manage my long term conditions."

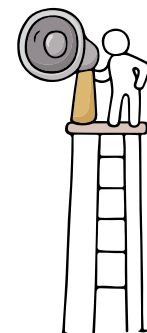
Individual with lived experience

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

[A narrative for person-centred coordinated care.](#)
National Voices 2013

"I want to feel heard and understood. I want to know about my options, and I want to be supported to make a decision based on what matters to me."

A personal view of shared decision making





Summary

Clinical Commissioning Groups (CCGs) and NHS England have a key role to play in ensuring that providers make individuals' personal involvement in their health and care a reality. This guidance supports CCGs and NHS England to fulfil their legal duties to involve people in their health and care, so that people experience better quality care and improved health and wellbeing, and the system makes more efficient use of resources.

The guidance sets out 10 key actions for CCGs and NHS England on how to involve people in their own health and care. These include:

- how to publicise and promote personal health budgets and the choices available to patients and carers
- how CCGs and NHS England assure themselves that providers are enabling involvement
- how CCGs and NHS England are commissioning for involvement.

This guidance has been developed alongside the [‘Patient and public participation in commissioning health and care: statutory guidance for clinical commissioning groups and NHS England.’](#)

To support CCGs and NHS England to address these issues, the key mechanisms for involving people in their own health and care are described, with links to a range of resources, good practice and advice.



Introduction

Purpose and scope

This guidance will help Clinical Commissioning Groups (CCGs) and NHS England to involve people in their own health and care in a meaningful way. It demonstrates the importance of involving people, their carers and families, to improve individuals' health and wellbeing outcomes and the efficiency and effectiveness of health services. It also explains how CCGs and NHS England can meet their legal duties.

Under the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012) CCGs and NHS England have duties to promote the involvement of patients in their own health and care, (sections 14U and 13H respectively). The wording of these duties is set out in appendix A.

This guidance is statutory and CCGs must have regard to it^{3 4}, as must NHS England staff.

The guidance will also be of relevance/interest to:

- patients, carers, and the public
- providers of health and care services, including health and care professionals
- organisations that support commissioning
- health and wellbeing boards
- local authorities
- Healthwatch
- the voluntary community and social enterprise (VCSE) sector
- sustainability and transformation plan partnerships and accountable care systems.



What does involving people in their own health and care mean?

Involving people in their care and treatment means supporting people to manage their own health and wellbeing on a daily basis. It means supporting them to become involved, as much as they want or are able to, in decisions about their care and giving them choice and control over the NHS services they receive. It means focusing on what matters to the individual within the context of their lives, not simply addressing a list of conditions or symptoms to be treated. More specifically, for CCGs and NHS England, it means commissioning services that routinely provide individuals with the information, care and support to determine and achieve the outcomes that matter to them.

Involving individuals in their health and care may range from sharing decisions about one off elective procedures to ongoing care and support for people living with long term conditions or a disability. The amount of control an individual wishes or is able to take in relation to these may vary according to their background, experience, current circumstances and preferences. For example, someone with profound and multiple learning disabilities may find it more difficult to express their needs and preferences. Nevertheless, involvement may be achieved through conversations with those who know them best and who understand and are able to voice their likely preferences.



Ways of involving people in their own health and care

Involving people in their own health and care requires services to shift the focus of support from 'what is the matter with you?' to 'what matters to you?'. Not only does this acknowledge the individual as an expert in their own care, but it also gives people greater choice and control over the care and support they receive. To achieve this a new, more inclusive conversation needs to take place between staff, individuals and their carers. By identifying needs and agreeing together the goals that matter to each person, health and wellbeing needs are better met and people are supported to manage their health, and the impact it has on their lives, more effectively. This section outlines some of the ways in which this changed conversation can be supported.

Personalised care and support planning

Personalised care and support planning is a systematic way of ensuring that individuals living with one or more long term condition are supported through proactive conversations, with their clinician or health and care professionals. These conversations should focus on what matters most to that individual (their personal goals) and the support they need to manage their health and wellbeing. It should be a process of sharing information, identifying medical and non-medical support needs, discussing options, contingency planning, setting goals, documenting the discussion (often in the form of a care plan) and monitoring progress through regular review.

One way of systematically implementing personalised care and support planning is to put in place the '[House of Care](#)' approach.

Example:

Paul has multiple long term conditions including diabetes, heart disease and asthma. His GP organises an appointment for them to discuss his concerns, questions, hopes and aspirations. This also draws on input from other professionals involved in Paul's care. Together they develop a mutual understanding of his preferences, wishes and needs. The discussion is documented in a personalised care and support plan. It sets out the support Paul needs in order to balance all of his physical and mental health needs with what matters to him. He may well access support groups in his local community, health coaching and/or self-management education courses to help him better understand how to maintain his health and wellbeing. He will also learn about the steps to take if his condition deteriorates and where to go for treatment or support, if necessary.



Shared decision making

Shared decision making is a process in which people who experience a change in their health work together with clinicians to select tests, treatments, management or support packages. This is based on the best available evidence and the individual's informed preferences. More specifically, shared decision making is a conversation, or series of conversations, that should include evidence-based information about all reasonable options. This should include all options, including doing nothing, alongside what is known about the risks and benefits of those options, together with decision support and a means for recording and implementing the chosen course of action. In any decision where there is more than one option, the values and preferences of the person, such as their attitude to risk, may be as important as the clinical evidence in choosing which option to follow.

Example:

Indra has back pain that is becoming difficult to manage despite taking regular exercise and pain medication. She wants to understand more about other options, including surgery. She sees a specialist physiotherapist who provides her with a range of options and support, to help her make an informed decision based on the best evidence and her own attitude to the risks and benefits of her options.

Social prescribing

Social prescribing is a way of linking patients in primary care with sources of support in the community. It provides GPs with a non-medical referral option that can operate alongside existing treatments to improve health and wellbeing.

Good practice example:

'[Ways to Wellbeing](#)' is a social prescription service managed by York Centre for Voluntary Service and available through the Priory Medical Group practice. A coordinator connects people who need health and wellbeing support, because of issues such as loneliness and isolation, with activities and services in the community. The coordinator meets with each person and develops a programme of support based on their needs, which is then matched with local services. A recent evaluation of the project showed that 80% of people using social prescriptions experienced a greater sense of wellbeing and 75% had improved confidence. The Priory Medical Group has also reported a decrease of just under 20% in GP appointments from those using the service, freeing up time so that GPs are able to support more patients. [A short film about the project is available on YouTube.](#)



Personal health budgets and integrated personal commissioning

Personal health budgets are a way to improve personal outcomes and experience by giving more choice and control over the care received. They centre on personalised care and support planning and allow people to choose how they prefer to meet their health and wellbeing in personalised ways. Everyone who might benefit from a personal health budget should experience a methodical, coordinated approach to their care and support as described in the [integrated personal commissioning emerging framework](#). Introductory information about personal health budgets and the way they can be managed is available on [NHS Choices](#).

While personal health budgets are relatively new in the NHS, personal budgets in social care have a longer history. Building on the learning from both health and social care and the drive to increase integration across services, Integrated Personal Commissioning (IPC) is an approach to delivering care and support for people with the most complex needs. IPC enables people to join up the funding available for both their health and social care needs, so they experience seamless care and support. IPC is a partnership programme between the NHS and the Local Government Association, developing a personalised model of integrated care for adults, children and young people with high, ongoing care and support needs.

A commitment has been made to providing 50,000 to 100,000 personal health budgets or integrated personal budgets by 2020⁵. This is further supported by expectations outlined in [Transforming Care for People with Learning Disabilities – Next Steps](#) that personal health budgets should also be available to people with a learning disability. [The Five Year Forward View](#) described an additional commitment to introducing integrated personal commissioning. As set out in the IPC Emerging Framework, by 2020 IPC will be a mainstream model of care for around 5% of the population.

Case study:

Mark's life profoundly changed when he was assaulted in 2012, leaving him with permanent brain damage, unable to speak or move independently. He eventually moved out of residential care to live independently in his specially adapted accommodation, thanks to the flexibility of a [personal health budget](#). You can find out more about Mark's experience by [watching this short film](#).



Self-management

Self-management is the term given to a range of approaches that aim to enable people living with long term conditions to manage their own health effectively. Self-management recognises individuals as experts in their own lives, having acquired the skills and knowledge to cope as best they can with their long term condition. Self-management approaches, such as peer support or self-management education, seek to build on this by supporting and enabling people to further develop their skills, knowledge and confidence. By recognising patients as experts in their own health and by providing support to develop understanding and confidence, self-management leads to improved health outcomes, improved patient experience, reductions in unplanned hospital admissions and improved adherence to treatment and medication ⁶.

Example

Amira was working as a teacher when she had a breakdown. Having been prescribed medication, Amira continued to be very ill. After talking with her GP, it was suggested that she attend a peer support knitting group at the local community centre. After a few visits spent scared and quiet in the background, the friendliness and openness of the group drew her in. The equality of relationships built on trust, support and mutual understanding has enabled Amira to engage more and find benefit in talking to others in similar situations whilst taking part in an absorbing activity. Amira is now less reliant on medication to manage her health.



Making health and social care accessible

Everyone should have access to high quality health and care information that enables them to better understand their condition(s). Since August 2016 all organisations that provide NHS care or adult social care are legally required to follow the [Accessible Information Standard](#). The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand. Services are also required to provide additional support where necessary, such as the attendance of a British Sign Language interpreter at appointments. By implementing the standard, people with a disability, impairment or sensory loss are supported to become more informed about their health and more involved in how to manage it effectively.

More generally, [The Information Standard](#) is a certification scheme for any organisation that produces public facing health and care information. Any organisation achieving The Information Standard has undergone a rigorous assessment to check that their information production process generates high quality products. Members of The Information Standard also receive the right to display the Standard's logo on their information. This acts as a quality mark and helps individuals, practitioners and commissioners easily identify reliable, high quality information.

Finally, all organisations should have regard for the health literacy needs of the people who access their services. Health literacy refers to the ability an individual has to access, understand, process and use information and services needed to make decisions about health. This ability may be affected by the individual's personal characteristics, such as their skills, knowledge and confidence, or by external factors such as how easy signage is to understand in a hospital (e.g. x-ray vs radiology).

Example

David recently had a stroke which affected his memory. David's GP practice recognised that the stroke had had an impact on his ability to process, understand and use information. David was given a one to one appointment during which he was asked which of a range of resources he preferred and found easiest to understand. These resources included technical/digital support options. David's preferred options were then logged on his patient record so that all future communications and appointments included the appropriate accessible information. David now feels included, is more confident, better understands his own health needs and has improved health outcomes.



Why is it important to involve people in their own health and care?



Improves health and wellbeing

Improves health and wellbeing

People's lives can be transformed when they feel in control of their health and wellbeing and when they are able to shape their care, support and treatment to fit with what matters to them. When people are involved in decisions about their health and care (such as through personalised care and support planning or shared decision making) they tend to choose care, support or treatment packages that align with their personal preferences and goals. In other words they make decisions and choices that help them optimise their physical and mental health and wellbeing.

Person and community-centred approaches that support people to self manage, help to increase knowledge, skills and confidence to manage their health and wellbeing, improve outcomes, and reduce social isolation and loneliness. A number of approaches should be locally available, including:

- self-management education programmes
- health coaching
- peer support
- group activities such as walking groups
- asset based community approaches.

Access to these approaches via personalised care and support planning should be provided for everyone living with long term conditions or a disability. However, providing access for

people with low levels of knowledge, skills and confidence to manage their health and wellbeing is particularly important as these are the people who have most to gain, and who do indeed gain the most, from personalised support. These approaches support them to recognise and draw on their own resources and those of communities, social networks and statutory services around them.

People with complex needs can benefit from the additional offer of integrated personal commissioning and a personal health budget. Research has shown that people with higher levels of need, who are given greater choice and control through the use of personal health budgets, benefit more than those whose personal health budgets were less flexible⁷.



Improves care and quality

Improves care and quality

Evidence^{8 9} shows that people who are involved in decisions about their health and care tend to:

- report greater satisfaction with the services they receive
- experience less regret about the decisions they have been supported to make and are more likely to say that the decision made were most appropriate for them
- make fewer complaints than those who were not involved in decisions.

Personalised care and support planning and shared decision making reduce unwarranted variation in the provision of care, treatment and support by ensuring that all decisions are informed decisions based on personal preferences^{10 11}. In other words, there is a focus on 'what matters' to individuals, based on the risks and benefits of the available options and the outcomes they are seeking.



Improves financial sustainability and enables the efficient allocation of resources

Improves financial sustainability and enables the efficient allocation of resources

Even people with the most complex of health care needs, such as those with multiple long term conditions, only spend a limited amount of time in direct contact with health and care services. This means it is hugely important that services work to support and empower people to feel confident and able to manage their health effectively in the context of their daily lives. By enabling people to be more involved in their care and providing people with opportunities to increase their skills, knowledge and confidence, people can draw on their own strengths and more effectively self-manage their condition(s).

When it comes to unscheduled care (both within general practice and hospitals), supporting people with long term conditions to develop the knowledge, skills and confidence to manage their health and wellbeing can also reduce uninformed use of urgent and emergency care services¹². Putting a personal health budget in place for people with more complex needs

has also been shown to reduce demand on unscheduled services¹³.

When shared decision making is used across an entire pathway it can ensure that people make the most appropriate use of available resources. It can help reduce overtreatment and may well moderate demand for high risk/high cost procedures. For example, providing a range of treatments including non-medical options, such as walking groups for people with early knee pain through social prescribing, could lead to improved outcomes for individuals and make better use of available resources.

Finally, by understanding what is important to individuals in the decisions they make about their care support and treatment, CCGs and NHS England can gain a better understanding of overall population needs and preferences and use this knowledge to make service commissioning more responsive.



It is a legal duty

Promoting the involvement of people in their own health and care is a key component of CCGs' and NHS England's statutory duties.

Shared decision making and patient choice

Section 14U of the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012) specifically states that CCGs must promote involvement of each individual, their carer and (should there be any) their representatives in decisions relating to the prevention or diagnosis of illness, or their care or treatment.

Section 14V states that CCGs must, in the exercise of their functions, act with a view to enabling individuals to make choices with respect to aspects of health services provided to them.

Legal duty

NHS England is under equivalent legal duties in relation to individual involvement and choice under sections 13H and 13I respectively.

National Health Service Commissioning Board¹⁴ and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 require NHS England and CCGs to give effect to individuals' rights to make choices about who provides their care and treatment.

Precedents established through common law for valid consent mean that people with capacity to make decisions about their care and treatment must be properly advised about their treatment options, and the risks associated with each option, so they can make informed decisions when giving or withholding consent to treatment. In other words, the principles of shared decision making must become the norm.

The Mental Capacity Act 2005 states that people who lack capacity to make decisions about their care and treatment should be involved in such decisions 'so far as practicable'.

More detail on the relevant legal requirements can be found in appendix A.



Personal health budgets and integrated personal commissioning

Since 1 October 2014, adults receiving NHS continuing healthcare and children and young people receiving continuing care have had a right to have a personal health budget. CCGs have a duty to offer and deliver a personal health budget, as set out in the National Health Service Commissioning Board and Clinical Commissioning Group (Responsibilities and Standing Rules) Regulations 2012 (as amended).

Legal duty



What should CCGs and NHS England do in practice?

1. Support patients, carers and representatives

- Inform individuals and provide information they can understand about their right to be involved in and make choices about their care.
- Engage with individuals to learn how involved they are in their care and how they feel they could become more involved.
- Make it easier for patients to access information about their health.
- Make use of existing insight – national surveys and local feedback or research – to understand the views, experiences and preferences of broader communities or individual groups as a context for understanding how this links to what an individual wants and needs. Further information on sources of insight and feedback, such as the [GP Patient Survey](#), and their use in commissioning is available on the [NHS England website](#).
- Require providers to take measures such as those set out above.

2. Publicise and promote personal health budgets

- Publish the local personal health budget offer, setting out where personal health budgets are offered or will be offered and how to get more information.
- Inform people in receipt of continuing healthcare, or children in receipt of continuing care, of their legal right to have a personal health budget.

3. Publicise and promote the choices available to patients

- Publicise and promote awareness of information about the health service providers that people can choose for an elective referral.
- Publicise details and promote awareness of where such information can be found.



Good practice example

Personal health budgets - Holly's story

Holly was a manager for NHS continuing healthcare at Oxford Health NHS Foundation Trust. She and her team of 15 worked with 60 adults with high level care needs who had a personal health budget.

"We first visited people interested in a personal health budget to explain how they might work for them. Sometimes this took time and multiple visits, but it was essential we understood what healthcare outcomes people wanted to achieve. This often revolved around avoiding admission to hospital or residential care. We also discussed what in their traditional care plan was working and not working.

"Traditional care packages lack flexibility; use of agency staff contracted by our local council was compulsory and there was often inconsistency when using agency staff. This was unsettling and detrimental to people's wellbeing. So a key early conversation was whether the person would use their personal health budget to employ their own carers instead. An independent broker from Age UK helped us with this, supporting people with personal health budgets to buy services that met their health outcomes, handling recruitment, dealing with employment issues and providing expert information, including help on managing finances.

"One example is a woman in her thirties who needed day and night support at home. Her carers regularly changed, until she used her personal health budget to employ carers directly. She now has a much better relationship with her carers, whom she sees as friends. Also, the agency staff wore a compulsory uniform, making her feel conspicuous in public. Her new carers don't have to wear uniforms, so she's now comfortable being seen with them.

"Overall, the positive health impact of personal health budgets has been huge, including reduced admissions to hospital and reduced need for crisis management. This is because carers employed directly by people using their personal health budget often get to know a person much better and so can pre-empt problems. Plus, people feel more in control of their lives, feel safer and more confident.

"My main advice to professionals working with personal health budgets for the first time is that, although it can feel a lengthy and daunting process to start with, it is worth it in the end. I can confidently say every single person benefited from moving to personal health budgets. None of them would choose to return to a traditional care package."

[Holly's full story is available on the NHS England website.](#)



4. Commission for involvement

- Introduce requirements and incentives in relation to individual involvement in contracts, service specifications and tenders.
- Consider the need for individual involvement in all aspects of service commissioning, including prevention, diagnosis, care planning, treatment and care management.
- Engage with healthcare providers and professionals to understand what challenges and opportunities they face in involving individuals in their care.
- Co-produce services and pathways with patients, carers and the public to better understand what challenges and opportunities they face in becoming more involved and to create more effective health services.

5. Promote and publicise the involvement of individuals

- Promote the importance of involving people in their own health and care in conversations with staff, providers and the general public.
- Publicise how people can be involved in their own health and care and share good practice.
- Publicise individuals' right to be involved in and make choices about their care.

6. Assure themselves that providers are involving people in their own health and care to an acceptable standard

- Do providers systematically identify and engage with people with long term conditions or disabilities who would benefit from more personalised support, including the offer of integrated personal commissioning or a personal health budget?

This could be through a variety of means, including the use of the [Patient Activation Measure \(PAM\)](#) which identifies individuals according to their level of skills, knowledge and confidence in managing their own health and wellbeing.

- Do providers systematically provide personalised care and support planning for people living with long term conditions or disabilities who would benefit from:
 - a more personalised approach to their care and support
 - and/or more support to develop the knowledge, skills and confidence to manage their health and wellbeing?



- Do providers give people access to their own health records?
- Do providers ensure their clinicians and care professionals systematically share decisions across all care pathways?
- Are providers following the Accessible Information Standard? All organisations that provide NHS care or adult social care are legally required to follow the standard.
- Are the needs of carers being considered? NHS England has produced [commissioning for carers principles](#).
- Are providers aware of the Information Standard? Do they use information from organisations that are members of the Information Standard and are they tailoring information provision to an individual's level of health literacy?
- Are providers offering [meaningful choice to patients](#) when it comes to the provision of care or support services?
- Are providers providing and promoting online patient facing services that support shared decision making, encourage understanding and empower people to make best use of health services?

7. Use and promote tools and resources

[The personalised care and support planning tool](#) by 'Think Local Act Personal' is for health and care leaders, commissioners, planners, clinicians and practitioners.

NHS England has resources available including a [personalised care and support planning handbook](#) and [support materials to promote online services](#).

NHS England has developed a resource pack for commissioners – [Embedding shared decision making](#).

A curated collection of [health literacy resources](#) is available online.



**Good
practice
example**

**Personalised care and support planning in
primary care**

[Year of Care Partnerships](#) provides support and training to organisations and individual general practices to introduce and sustain personalised care and support planning as routine care, using a whole system approach. Through this, CCGs such as Newcastle and Gateshead are supporting practices like Glenpark Medical Centre in Dunston to deliver personalised care and support planning for people with long term conditions, including those with multi-morbidity. The practice recognised that their current approach to care was inefficient for both patients and the practice. By using what matters to the individual as the starting point, involving the whole practice team and focusing on creating a single process, the practice has created a more effective and efficient approach in which staff are enthusiastic and patients feel listened to and supported.

The process enables more productive conversations between healthcare practitioners and patients, with more staff time spent on talking with and listening to the individual and less time on the computer gathering information. Preparing the individual for the conversations is key to this process, as is having effective links to ongoing support through social prescribing and self-management interventions. This means that conversations lead to improved outcomes for the individual.

The feedback has been extremely positive from both staff and patients:

"I got a
chance to ask things
rather than being
asked."

"They were
interested in
how I felt."

"I learned
a lot."



8. Assure themselves that they are commissioning services that match the needs and preferences of their population

- The need to commission services that address what people are saying matters to them and to change/decommission those services that do not.
- The need for supported self care approaches, for example:
 - Commissioning the right mix of generic and condition specific self-management education programmes (face to face or online) to match the needs of their population. [Realising the Value has a range of resources on self-management education.](#)
 - Commissioning health coaching for people living with long term conditions who have low levels of knowledge, skills and confidence to manage their health and wellbeing. [Realising the Value has relevant tools and resources for commissioners](#) and Health Education England (HEE) has developed a [good practice project on health coaching in the east of England.](#)
 - Commissioning peer support and group activities as a core service offer. Realising the Value's [At the heart of health](#) report explores the value of people and communities, in support of the NHS Five Year Forward View.
- The need to utilise local community assets, such as local organisations, groups, activities and resources, in their commissioning to provide a breadth of services that address a variety of health and care needs, such as through social prescribing. For example:
 - Provision of a dedicated contact for individuals and communities such as link workers or [local area coordinators.](#)
 - Working closely with their local authority, local VCSE sector and faith organisations and signposting people to relevant services.
- The need to systematically identify, support and involve carers as described in the [Commitment to Carers.](#)



Good practice example

Bradford Beating Diabetes

Bradford City and Bradford District CCGs wanted to tackle the high prevalence of type 2 diabetes locally. As a result [Bradford Beating Diabetes \(BBD\)](#) was set up to identify people at high risk of developing diabetes and help them reduce this risk by making lifestyle changes. Bradford District Care Foundation Trust (BDCFT) was commissioned to deliver the BBD Diabetes Prevention Programme (DPP).

Health coaches delivered the DPP enabling people to actively participate in reducing their risk of diabetes. Getting the 'right' health coaches was important to enable people without obvious symptoms to be more aware of the risks, become more active and empower people to become healthier and more in control of their health.

Participants were identified by their GP practices and encouraged to take part in the programme. They found out about diabetes, the eatwell guide, being more active and how to set small goals and action plans. Participants found the support of health coaches useful, as the coaches had experience of working on their own health own goals.

Leeds Beckett University evaluated the BBD DPP and found there was a statistically significant decrease in average blood sugar levels after taking part in the programme. Participants' risks had reduced and scores for physical activity, diet, weight, Body Mass Index and waist circumference had all improved.

Four health coaches were recruited, trained and started delivering their own groups whilst still part of their own DPP groups. One of these health coaches, Mumtaz, had not worked before and was a housewife; she attended meetings with national DPP colleagues, a CCG Board meeting and was interviewed by the local news. She was able to put her new found confidence into delivering her groups. Mumtaz said: "Having the right mind set is important; and the prevention programme helped me to gain that. I have understood more about diabetes, its potential complications and how it can be prevented. I'm more aware of what to avoid, and what to do differently to stave off what would otherwise have been inevitable."

Mumtaz has lost weight, reduced her blood sugar levels and is still using the same action plan to continue to make changes. She now voluntarily leads her neighbours in local walks.

The two CCGs and BDCFT worked collaboratively with people, staff and local voluntary and community sector organisations to decide, design tools, deliver and review BBD.



9. Implement a workforce strategy to support health and care professionals to involve people in their own health and care

Involving individuals in managing their health and wellbeing relies on a changed relationship between individuals and professionals. Key to achieving this is ensuring that all those working in health and care have person-centred and community-centred skills, competencies, values and behaviours.

In addition, it means understanding which staff roles would benefit from training in specific approaches that promote the involvement of individuals in their own health and care through:

- personalised care and support planning
- shared decision making
- health coaching
- other forms of partnership working, for example through care coordinator, link worker and health and care navigator roles.

CCGs and NHS England may need to invest in training in these approaches based on HEE's person-centred core skills education and training framework. There are also useful toolkits to help develop a person-centred workforce, such as the [Royal College of General Practitioners' Collaborative Care and Support Planning Toolkit](#) and [HEE's health coaching quality framework](#).



10. Advance equality and reduce health inequalities

Creating the conditions for involving people in their health and wellbeing means proactively reaching out to those who experience the greatest health needs, those who face barriers to access and participation, and those groups protected under the Equality Act 2010. An equality and health inequality analysis can help to identify those groups.

For NHS England staff further information about completing an analysis is available on the intranet. Both NHS England and CCGs can access the [NHS England Equality and Health Inequalities Hub](#) for more information and resources.

Opportunities should be created to ensure fair and equitable access to person-centred care regardless of a person's cultural, linguistic, religious background, communication and accessibility needs. Particular attention should be paid to the needs of those people who are most excluded from traditional services; for example, the homeless, sex workers, recent migrants and Travellers. A holistic approach should be taken which recognises people's lived experience and the range of barriers they experience, rather than tick box approaches to addressing barriers. Conversations between professionals and individuals should be based on principles of mutual respect and listening, understanding and acting on different experiences and perspectives. They should also pay particular regard to people's level of [health literacy](#) which may be a significant barrier to effective involvement in care.

CCGs and NHS England should connect with existing patient, service user and VCSE organisations to reach into, and learn from, diverse communities.

Auditing and monitoring person-centred care planning for people from equalities protected groups supports staff to manage and improve performance in reaching these groups and helps to reduce health inequalities¹⁵ through improved commissioning and accountability. CCGs and NHS England are required to respond to the Public Sector Equality Duty of the Equality Act 2010. Without effective involvement of individuals in their own care, CCGs and NHS England will not be able to respond to the duty in a meaningful way. Staff should use the [Equality Delivery System](#) for the NHS (EDS2), a tool to help deliver better outcomes for people and communities and better working environments, which are personalised.

All organisations that provide NHS care or adult social care are required to follow the [Accessible Information Standard](#), including NHS Trusts and Foundation Trusts, and GP practices. This standard aims to ensure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support, so they can communicate effectively with services.

CCGs and NHS England should have regard to these duties when managing contracts with providers. NHS England has produced [Involving people in their own health and care equality and health inequalities - full analysis and associated resources](#), in relation to this guidance.



Measurement and assurance

There is a number of ways to measure individual involvement and to provide assurance that CCGs and NHS England are meeting their associated legal duties. Examples are outlined below:

- CCGs will be monitored on progress towards meeting their trajectories to expand the uptake of personal health budgets in line with the Mandate commitment⁵. The NHS Operational Planning and Contracting Guidance for 2017-19 sets an aim for CCGs to deliver their share of the Mandate commitment (50,000) by March 2019.
- For 2016/17, NHS England introduced a new [Improvement and Assessment Framework \(IAF\)](#) for CCGs. The framework includes one indicator regarding how supported people with long term conditions feel and one regarding personal health budgets (a headline count of the total number of personal health budgets per 100,000 population). The IAF indicators are published on the comparison website [MyNHS](#), enabling people to see how their local area is performing compared to others, and allowing CCGs to benchmark performance against peers.
- CQUIN 11 in the [National Commissioning Quality and Innovation \(CQUIN\) scheme 2017/19](#) relates to the delivery of personalised care and support planning, whilst the [CQUIN Specialised Scheme 2017-19](#) includes measurement of patient activation for long term conditions.
- CQC regulation 9 specifically states that providers must 'provide support to help [individuals] understand and make informed decisions about their care and treatment options'.
- National surveys, such as the [GP Patient Survey](#) and [Inpatient Survey](#), provide data on how involved individuals feel they are in their health and wellbeing.
- The Care Quality Commission (CQC) have included 'accessible information and communication' as one of their Equality Objectives for 2017-2019. In order to meet this objective, one of their commitments is that, 'From October 2017, all inspection reports include how providers are applying the standard'. Further information about the CQC's Equality Objectives is available from their [website](#).



Appendix A

Legal duty to promote the involvement of each patient

What the law says

Section 14U of the National Health Service Act 2006

- (1) Each CCG must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to
 - (a) the prevention or diagnosis of illness in the patients, or
 - (b) their care or treatment.
- (2) NHS England must publish guidance for CCGs on the discharge of their duties under this section.
- (3) A CCG must have regard to any guidance published by the Board [NHS England] under subsection (2).

13H Duty to promote involvement of each patient

The Board [NHS England] must, in the exercise of its functions, promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to

- (a) the prevention or diagnosis of illness in the patients, or
- (b) their care or treatment.

What the law requires CCGs and NHS England to do

The duty requires CCGs and NHS England to promote the involvement of patients and their carers and representatives in decisions about their own care.

The duty is intended to address the principle of shared decision making – ‘no decision about me without me’.

The duty applies to any decisions at all stages of that individual’s healthcare, from preventative measures, diagnosis of an illness, and any subsequent care and treatment they are offered. Effective involvement of patients in these decisions includes opportunities for patients to take treatment decisions in partnership with health professionals, to be supported to make informed decisions about the management of their care and treatment, and to discuss opportunities for patients to manage their own condition.

The duty to promote patient involvement should be given its ordinary and everyday meaning – to support or actively encourage patients’ participation in decisions about their care. If a CCG or NHS England promotes an approach which is directly contrary to the aim of involving patients, carers or representatives, it is likely to be unlawful. However, otherwise the duty is not prescriptive as to how CCGs and NHS England promote patient involvement. This affords a significant degree of latitude as to how they promote the involvement of patients.



What the law requires healthcare providers to do

Alongside the duty to promote the involvement of patients in their care, healthcare providers and professionals must also involve patients:

- The landmark Supreme Court case of *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 confirms that:
 - Patients are persons holding rights and consumers exercising choices, rather than the passive recipients of the care of the medical profession.
 - Developments in the law, society, technology and professional practice all mean that it is a mistake to view patients as uninformed, incapable of understanding medical matters, or wholly dependent upon a flow of information from doctors.
 - An adult with capacity is entitled to decide which, if any, of the available treatments to undergo, and his/her consent must be obtained before treatment interfering with his/her bodily integrity is undertaken.
 - The doctor is under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in proposed treatment, and of reasonable alternatives.
 - A risk is 'material' if a reasonable person in the patient's position would be likely to attach significance to it, or if the doctor is or should reasonably be aware that their patient would be likely to attach significance to it.

- The Mental Capacity Act 2005 provides a statutory framework for people who lack capacity to make decisions for themselves. The involvement of people who lack (or may lack) capacity is required in accordance with the five statutory principles set out in section 1 of the act. The key principles are:
 - Principle 2: a person is not to be treated as unable to make a decision unless all practicable steps to help him/her have been taken without success. This includes:
 - providing relevant information
 - communicating in an appropriate way
 - making the person feel at ease and
 - supporting the person.
 - Principle 4: An act done, or decision made, for or on behalf of a person who lacks capacity must be done, or made, in his or her best interests. A person trying to work out the best interests of a person who lacks capacity to make a particular decision ('lacks capacity') should try to:
 - encourage participation
 - identify all relevant circumstances
 - find out the person's views
 - avoid discrimination
 - assess whether the person might regain capacity
 - consult other people to see if they have any information about the person's wishes and feelings, beliefs and values.



- Professional guidance requires patient involvement. For example, the General Medical Council's Good Medical Practice (2013) states:
"Work in partnership with patients. Listen to, and respond to, their concerns and preferences. Give patients the information they want or need in a way they can understand. Respect patients' right to reach decisions with you about their treatment and care."
- The [NHS Standard Contract 2017/18](#) and 2018/19 requires providers to provide clear information to service users, that questions are responded to promptly and effectively and actively engage, liaise and communicate with service users in an open and clear manner in accordance with the law and good practice (Service Condition 12). Providers may also have additional obligations agreed locally, for example through local service specifications.
- The right to respect for private life, protected by Article 8 of the European Convention on Human Rights, has been recognised as giving rise to a duty to involve the patient in decisions relating to his/her treatment, in cases such as *Glass v United Kingdom* (2004) and *Tysiac v Poland* (2007), as well as in a number of decisions of courts in the United Kingdom.

Related duties and rights

- The CCG's duty to promote the NHS Constitution (section 14P).
- The CCG's duty as to patient choice (section 14V).
- In respect of a person for whom the CCG considers it

necessary to arrange the provision of NHS continuing healthcare or continuing care for children:

- The person's right to a personal health budget.
- The CCG's duty to publicise and promote the availability of personal health budgets to such a person and their representatives.
- The CCG's duty to provide information, advice and other support to such people and their representatives.

(Part 6A of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012).

- In respect of a person who requires an elective referral:
 - The person's right to a choice of health service provider and clinically appropriate team (led by a named consultant or, in the case of mental health services, a named healthcare professional).
 - The CCG's duty to make arrangements to give effect to the above choices.
 - The CCG's duty to publicise, and promote awareness of, information about health service providers and clinically appropriate teams for the purpose of enabling the person to make the above choices.
 - The CCG's duty to publicise details, and promote awareness, of where the above information can be found.

(Part 8 of the National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012).



References and notes

¹ [CQC inpatient survey 2015](#)

² [GP survey 2016](#)

³ NHS England has the power to publish guidance for CCGs on the discharge of their functions under section 14Z2 of the National Health Service Act 2006. CCGs must have regard to any such guidance published by NHS England. See section 14Z2(4)-(5).

⁴ Having 'regard' means that the guidance should be considered and taken account of. Where the guidance is not followed, this should be justified and the reasons clearly documented.

⁵ [The Government's Mandate to NHS England 2016/17.](#)

⁶ [Active support for self-management](#)

⁷ [Personal Health Budgets Evaluation](#)

⁸ [New approaches to value in health and care](#)

⁹ [Better care in my hands](#)

¹⁰ Coulter A, Entwistle V A, Eccles A, Ryan S, Shepperd S, Perera R. (2014) Personalised care planning for adults with chronic or long-term health conditions, Cochrane Database of Systematic Reviews 2014.

¹¹ Da Silva D. (2012) Helping people share decision making, The Health Foundation.

¹² Improving Population Health Management Strategies: Identifying Patients Who Are More Likely to Be Users of Avoidable Costly Care and Those More Likely to Develop a New Chronic Disease - Judith H. Hibbard, Jessica Greene, Rebecca M. Sacks, Valerie Overton, and Carmen Parrotta. Health Services Research DOI: 10.1111/1475-6773.12545.

¹³ [Personal health budgets evaluation.](#)

¹⁴ NHS England was formally established as the NHS Commissioning Board in October 2012.

¹⁵ [Guidance for NHS Commissioners on Equality and Health Inequalities legal duties.](#)



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