



# **Personalised care and support planning handbook:**

**The journey to person-centred care**

**Core Information**

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Equality and diversity are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have given due regard to the need to:

- Reduce health inequalities in access and outcomes of healthcare services and to integrate services where this might reduce health inequalities
- Eliminate discrimination, harassment and victimisation
- Advance equality of opportunity and foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it.

## Contents

<b>Part 1: Introduction to the handbook.....</b>	<b>5</b>
Foreword .....	5
1.1. Introduction.....	6
1.2. Purpose of this handbook.....	7
1.3. The House of Care .....	9
<b>Part 2: What is personalised care and support planning? .....</b>	<b>11</b>
2.1. What is personalised care and support planning? .....	11
2.3. Principles of Care and Support Planning.....	13
2.4. Care and Support Planning in relation to the ‘care plan’ .....	13
2.5. Terminology.....	14
2.6. A single holistic care and support planning discussion and plan .....	14
2.7. What are the intended outcomes of personalised care and support planning? .....	15
2.8. How is personalised care and support planning different? .....	16
<b>Part 3: The case for change.....</b>	<b>18</b>
3.1. Introduction.....	18
3.2. Making the case for change.....	18
3.3. Demonstrating a robust model of personalised care and support planning .....	21
3.4. The current position.....	24
3.5. What are the incentives and drivers to deliver personalised care and support planning, how does it fit with other initiatives? .....	24
<b>Glossary of terms.....</b>	<b>28</b>
<b>Additional resources.....</b>	<b>34</b>
<b>References.....</b>	<b>34</b>

## Part 1: Introduction to the handbook

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### Foreword

The NHS Five Year Forward View sets out the vision for the future NHS including a new relationship with patients and communities that supports people to gain far greater control of their own care when they need health services. Personalised care and support planning will be a key part of this shift. While not a new concept, it is increasingly important to recognise the assets and value that patients, carers and communities can bring to help deliver more effective, person-centred and sustainable care for people with long-term conditions.

Personalised care and support planning is an essential prerequisite for helping people living with long term conditions. It transforms their experience from a largely reactive service, which responds when something goes wrong, to a more helpful proactive service, centred on the needs of each individual patient. As one member of the Coalition for Collaborative Care's co-production advisory group puts it:



It means professionals seeing me as a whole person not simply focussing on a list of conditions to be treated. It means designing my health care and support in partnership with me to help me manage my own health and live the life I want.

Although this approach has been adopted effectively in some local health economies across the country, the GP Patient Survey suggests that only a minority of people, including those with long-term conditions have an agreed care plan.

We believe this will improve as more professionals, organisations and communities recognise the benefits of personalised care and support planning in human, clinical, social and economic terms. The Coalition for Collaborative Care which was launched in November 2014, is an alliance of people and organisations across health, social care and the voluntary sector, which is encouraging uptake of this approach by building a national movement for a new deal for people with long term conditions and by supporting those involved to create the conditions for change. This includes evidence of benefit, workforce development, and incentives.

This handbook provides an introduction to personalised care and support planning. It contains and links to practical guidance, case studies and theory on how to introduce personalised care and support planning. This is an evolving area and more work is needed to help address some of the gaps, particularly in gathering more evidence on the impact of personalised care and support planning and exploring new roles and models of care. Nevertheless, we hope that this will be a useful document to support business planning and to encourage reflection and innovation for local approaches to implementation.

Professor Sir Bruce Keogh  
National Medical Director  
NHS England

Professor Nigel Mathers  
Chair  
Coalition for Collaborative Care

## 1.1. Introduction



Personalised care and support planning encourages care professionals and people with long-term conditions and their carers to work together to clarify and understand what is important to that individual. They agree goals, identify support needs, develop and implement action plans, and monitor progress. This is a planned and continuous process, not a one-off event.

Coalition for Collaborative Care, 2014

Care for people with long-term conditions (LTCs) forms a significant part of the health and social care system. There are over 15 million people living with a long-term condition in England. This includes both physical and mental health conditions such as arthritis, asthma, COPD, depression, dementia, diabetes and many more. These are conditions which cannot at present be cured but can be managed or improved through person-centred approaches that deliver the right care for that individual no matter what their condition(s) to ensure that they are involved in managing their condition(s), receive the care they need to live and die well, and that both they and their carers feel supported to maintain a good quality of life. Support might relate to learning new skills, changes in behaviour, access to community support, as well as medication and traditional treatment or therapies.

The number of people with one long term condition is projected to be relatively stable over the next ten years. However, those with multiple LTCs are set to rise to 2.9 million in 2018 from 1.9 million in 2008<sup>1</sup>.

Consultations with people with LTCs account for more than 50% of GP appointments, 64% of all outpatient appointments, and over 70% of inpatient bed days. £7 from every £10 of health and social care spend is targeted towards this 30% of the population in England.<sup>2</sup> However, the average person with a long term condition in the UK spends no more than three or four hours a year with a health professional<sup>3</sup>. The rest of the time, people have to take responsibility for managing their own care, perhaps relying on unpaid carers such as family and friends<sup>4</sup>.

Personalised care and support **planning** is a **process** in which the person with a long-term condition is an active and equal partner. The process should normally be recorded in a personalised care and support **plan**: but this plan is only of value if the **process** has taken place effectively.

Evidence shows that personalised care and support planning can lead to the most appropriate use of limited healthcare resources. People who are engaged in their health and care are more likely to receive care and treatment that is appropriate to them; to take up appropriate prevention services (such as regular screening); and to adopt more healthy behaviour. By sustaining successful self-management, and by anticipating and making explicit provision for possible crises and emergencies, personalised care and support planning may also help to reduce the use of urgent and emergency care.

While the concept of personalised care and support planning has been part of the rhetoric of the engaged patient and a commitment from central government for many years, implementation remains patchy. This needs to change and quickly.

The [GP Patient Survey](#) January 2016 gives us the latest national picture of whether patients have, and are using, care plans. Although 53.6% of patients completing the survey said they have a long standing health condition, only 3.3% of people who answered the survey have a written care plan.<sup>5</sup> Of these patients, only 71% say that they helped to put the plan together - leaving over a quarter of cases where it appears that, even though there is a written care plan, the care and support planning process has not taken place.

## 1.2. Purpose of this handbook

The [NHS Mandate 2016/17](#)<sup>6</sup> includes an expectation (Objective 2) that people are empowered to shape and manage their own health and care and make meaningful choices, especially people with long term conditions and people receiving end-of-life care. This can be better achieved through personalised care and support planning

In addition the Care Act 2014 sets out requirements for care and support planning for anyone with assessed needs and greater integration across health and social care<sup>7</sup>.

The handbook is aimed at commissioners and care practitioners (i.e. not just health and care professionals, but also other non-clinical and volunteer roles), and is intended to set out what personalised care and support planning is, and how to deliver it. It will show how personalised care and support planning fits within the wider context of person-centred care and can be used as a system enabler to help provide more proactive and co-ordinated care for people with long-term conditions and better support for self-management.

The handbook will be of relevance and interest to health and social care commissioners, including those in Clinical Commissioning Groups, Local Authorities, Area Teams, Public Health, Strategic Clinical Networks, and Specialised Commissioning when designing strategies for long-term conditions and developing service specifications and contracts with providers. It will be of particular help to GP practices, CCGs and Area Teams in relation to the current Enhanced Service in the GP contract for Avoiding Unplanned Admissions where personalised care planning is a key component.

Personalised care and support planning can be delivered in any number of situations where there is a dialogue between care practitioners (including non-clinical and voluntary staff) and patients and carers. This handbook can therefore be applied to a number of provider settings and will also be a useful resource for care practitioners in delivering personalised care and support planning.

Guidance on care and support planning aimed at people living with long-term conditions and their carers already exists, and this handbook is intended to complement this by giving commissioners and practitioners more information. See box below for more information on the National Voices guide to care and support planning. Linked [Care Act practice guidance](#) was published in October 2014.



## What does personalised care and support planning mean for patients and carers?

In 2013-14, National Voices, a coalition of health and social care charities, worked with a wide range of people who use services to develop a common understanding of what is meant by care and support planning. Their [guide](#)<sup>8</sup> provides an introduction to care and support planning, introduces the 4 steps of the approach and sets out what should happen at each step: prepare, discuss, document, and review.

National Voices, working with Think Local Act Personal and others, have also produced a [narrative for person-centred, co-ordinated care](#)<sup>9</sup> which helps define what 'integrated care' means to service users and demonstrates the pivotal role of effective, personalised care and support planning.

The narrative was co-produced with people using services, patients, carers and their organisations. From the perspective of the person using services, person-centred, coordinated care is defined as:

“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.”

The narrative provides the basis for this handbook on personalised care and support planning. Since the narrative was published, a partnership for transforming personalised health and care [Think Local Act Personal](#), have produced a range of very useful resources for people, carers and care professionals, including a [planning tool](#) for person-centred care.

This handbook pulls together learning from a number of organisations and programmes that have been working on personalised care and support planning, support for self-management, and person-centred care, including National Voices, Royal College of General Practitioners, and in particular, draws on learning from the [Year of Care Programme](#) which has developed and extensively tested models of care and support planning and provides important success criteria for implementation. These organisations came together with others to form the [Coalition for Collaborative Care](#), which was launched in November 2014 to support the national shift towards person centred collaborative care.

Personalised care and support planning is currently delivered in many different ways and it is important that approaches are locally designed to ensure they work best for all the people involved. Whilst this document is intended to help build understanding, it is not intended to be prescriptive.

The document provides core information with two linked documents giving supplementary information which will be of particular interest to [commissioners](#) or [practitioners](#) as they develop their local offers. There are complementary handbooks on [Using case finding and risk stratification](#) and [Multidisciplinary team development](#).



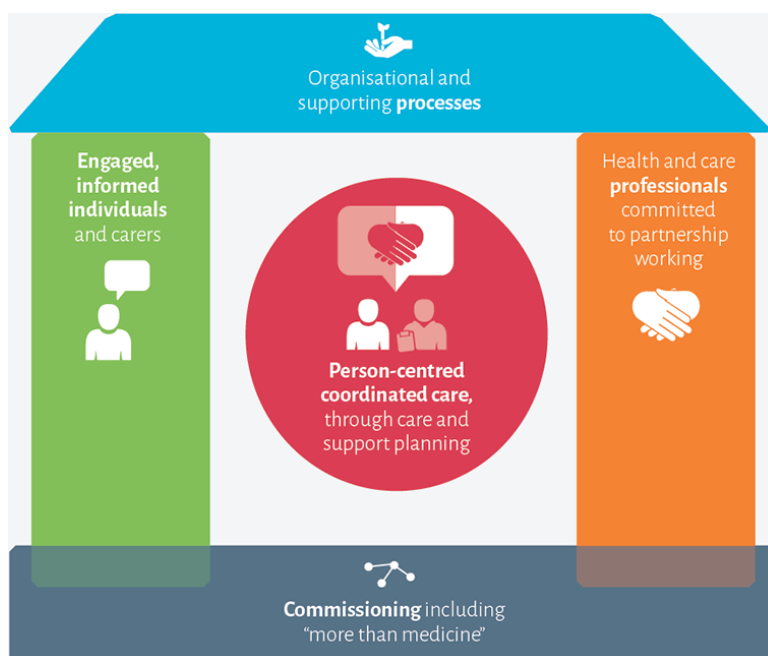
These resources have been co-produced with representatives from commissioning organisations, care practitioners, patients, carers, and policy experts. NHS England and Coalition for Collaborative Care would like to thank these individual and organisations for their valuable input and expertise.

Personalised care and support planning is an evolving area and comments on this document, as well as examples of local approaches, are welcome and should be sent to [england.patientsincontrol@nhs.net](mailto:england.patientsincontrol@nhs.net).

### 1.3. The House of Care

At the level of the individual, the care and support planning process is a systematic way of ensuring that individuals living with one or more long-term conditions, their carers and their health and social care professionals have more productive conversations, focussed on what matters to them and are able to play a much bigger role in planning their own care. These changed conversations do not happen on their own or by luck. A significant number of supporting factors need to be in place, and this can include complex changes to long-established ways of working.

The ‘House of Care’ is part of a wider LTCs framework for thinking about this. It is often referred to as a “whole-system” approach: all the elements need to be in place for change to happen. The diagram and text below sets out more detail of the House of Care approach.



The House of Care

The House of Care is a visual representation of the elements that need to be in place to deliver person-centred, coordinated care through personalised care and support planning:

- individuals and carers are supported to be active and engaged in discussions about their care and support, with relevant and accessible information to help them make decisions
- health and care professionals committed to working in partnership with patients and with each other
- systems in place to support organisational processes and organise resources effectively
- having a whole-system approach to commissioning health and care services

Where this approach has been used it has brought benefits for people with long-term conditions and for frontline staff. It links traditional clinical care with support for self-management; helps to better coordinate health and social care; and emphasises the importance of linking people with 'More than Medicine' services such as community activities and social networks that build confidence and provide support in their daily lives.

The House of Care illustrates the importance and interdependence of each element. If one element is weak or missing the structure is not fit for purpose. It can act as:

- a checklist – highlighting what needs to be in place
- a metaphor – emphasising that personalised care and support planning is complex and that all the components need to be in place to make it a success
- a flexible framework – guiding each local community to build a stable house designed round the needs of local people

The House of Care approach is based on international evidence and best practice experience in the UK<sup>10</sup>, and was developed by grassroots teams as part of the Year of Care Programme.<sup>11</sup> The [House of Care toolkit](#) provides links to a number of resources to help in designing and building local approaches to the House of Care.

## Part 2: What is personalised care and support planning?

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“Each time I get a greater understanding of my condition and understand more about how I can go about maintaining and improving it.”

Person with a long term condition

“I know what is going on now which is a relief. I do feel more in charge both during the consultation and in managing my condition.”

Person with diabetes



### 2.1. What is personalised care and support planning?

The overarching aim of personalised care and support planning is to support people who live with long-term conditions, to develop the knowledge, skills and confidence to manage their own health, care and wellbeing. People live with their conditions and/or disability every day and make decisions about how to manage them. Over time, they learn what works best for them, what information, care and support they need and how it fits into their life. As well as helping improve quality of life, this can help improve patient safety and prevent unplanned care, in particular hospitalisations for these people.

Personalised care and support planning is a systematic way of ensuring that individuals living with one or more long-term condition (LTC) and their health and care professionals have more productive and equal conversations, focused on what matters most to that individual. It is a collaborative process between equals, whereby people with health and care needs, along with their family and/or carer, work together with care practitioners to discuss:

- what is important to them, setting goals they want to work towards
- things they can do to live well and stay well (and for some people, dying well)
- what support they need for self-management; agreeing actions they can take for themselves
- what care and support they might need from others and how this can best fit in with the rest of their lives
- what good support looks like to them as an individual
- preparing for the future, including making choices and stating in advance preferences for care at the end of their life (where relevant and appropriate)

#### Who is it for?

Whilst personalised care and support planning is often discussed in relation to people with long-term physical and mental health conditions, it can be beneficial to anyone with ongoing health and care needs including for example, older people at risk of frailty, people

undergoing rehabilitation or reablement, those receiving treatment for cancer, or people with complex needs receiving care and support from a number of different agencies e.g. people with substance misuse problems.

The process can be particularly beneficial to people with multiple long-term conditions by helping to consider the interdependencies between different conditions and the collective impact this can have on their wider health and wellbeing. Rather than considering each condition in isolation, personalised care and support planning takes a more holistic approach, starting with what is most important to the individual.

Whilst personalised care and support planning could be beneficial to many people, services will need to consider how best to introduce and extend their local offer. In addition to this handbook, NHS England has produced a complementary resource on [using case finding and risk stratification](#) which outlines some of the tools which can be used to identify priority patient groups.

## **Who is involved?**

The people involved in care and support planning conversations may vary; sometimes the conversation might be facilitated by a health or social care practitioner such as a GP, social worker, nurse practitioner, occupational therapist or community nurse. Alternatively, the conversation may be with a volunteer, peer supporter, advocate or other non-clinical role who can help the individual to think through what is important to them and prepare them for interactions with care professionals. The focus of these conversations will likely be influenced by the knowledge, skills and experience of the person facilitating. Commissioners will need to consider what type of conversation and which roles would work best for individuals and their carers.

The inclusion of unpaid carers, such as family members or friends as the people involved in the individual's immediate support network is very important. The practical and emotional support that they provide, as well as their perspective on the individual's health and care should be captured in the discussion. Carers may also have health and care needs that need to be considered. Care and support arrangements might be dependent on carer's involvement, particularly where they have a guardianship role or the individual does not have capacity to make decisions, and therefore, the commitment and agreement of carers or parents may be vital to the design and implementation of plans. Throughout this handbook, the inclusion of carers should be considered alongside the needs of the individual at the heart of the personalised care and support planning process.

Additional people may also need to be involved in the discussion, for example, it may be helpful to have more than one care practitioner contributing. Or the individual may have particular communication or access requirements which mean they would like additional support during the discussion. The person at the heart of the care plan should give consent for others to be involved; and there should be safeguarding principles embedded to ensure that there is no conflict of interest between the person and the person(s) they wish to involve.

## 2.3. Principles of Care and Support Planning

In 2013-14, National Voices, a coalition of health and social care charities, worked in collaboration with a wide range of partners and people who use services to develop a common understanding about what is meant by care and support planning<sup>12</sup>. They highlight the four main steps of the care and support planning process and have identified a number of principles to help ensure that the process is truly person-centred. These principles should be at the heart of any changes in process, systems, skills, behaviours and attitudes.

### 1. Prepare

- Starts from the point of view of the person and their carer
- Gathers necessary information and makes it available upfront
- Builds in time to reflect and consider options

### 2. Discuss

- Takes a partnership approach
- Focuses on staying well and living well (and for some, it will also mean dying well)
- Identifies the actions that a person can take
- Identifies what care and/or support might be needed from others

### 3. Document

- The main points from discussions are written up, included as part of the person's health and/or social care records, and owned by the person and shared, with explicit consent.

### 4. Review

- Considers options for follow up and sets a date for review

These principles need to be fully understood by everyone involved in the care planning process and provide a framework for the practical guidance on delivering personalised care and support planning outlined in [Part 5](#). For further information from the patient/carer perspective, please see the [National Voices Guide to Care and Support Planning](#).

## 2.4. Care and Support Planning in relation to the 'care plan'

Personalised care and support planning focuses on the conversation between the individual, their carer and the care practitioner (or supporter). The key points of these discussions are then recorded as the person's agreed 'care and support plan'.

There are many different terms for care plans used across different care settings and for different conditions and purposes. A few examples are given below:

- Advance care plan which makes clear a person's wishes in anticipation of a deterioration in their condition in the future and their preferences for end of life care
- Discharge plans for people being discharged from hospitals or other care settings
- Education, health and care plan for children and young people with special educational needs and disabilities
- Emergency health care plans or crisis care plans

- Health action plans for people with learning disabilities
- Mental health recovery plans
- Person-centred care plan – often used in social care.

Whatever the plan is called, the aim should be for a single plan to be developed that includes all aspects of an individual's health, wellbeing and life.

The setting for the care planning conversation and the focus, purpose, format and content of the plan can all vary, but a personalised approach and the skills required to facilitate this kind of collaborative discussion, can be used in any setting. The principles outlined in 2.3 can be applied so that the care planning discussion focuses on what is important to the individual and their carer and how best to achieve the outcomes they want to work towards. As people's needs change, the details of their care and support might change, and the focus of their care plan might change, but the approach should still be the same.

## **2.5. Terminology**

There are a number of different terms which could be used when discussing personalised care and support planning. The main shift from using the term 'care planning' is to recognise that this is different from traditional treatment planning. Terms such as 'collaborative', 'person-centred', 'individualised' and 'holistic' could equally be used to reflect that the conversation relies on equal input from the individual and the care practitioner(s), and looks at the individual's health and care needs within the wider context of their lives.

We refer to 'care and support' to signal that people need more than medicines or clinical treatments; social, psychological needs and support to do things for themselves and links to community based support are equally important. Of course there will be times when people's needs do need to be met by healthcare services and therefore whilst there is a shift away from a purely medical model, it is still a key part of the discussion.

The glossary at the end of this document provides further details about the different terminology used within this handbook.

## **2.6. A single holistic care and support planning discussion and plan**

Personalised care and support plans should be developed in conjunction with other plans that the individual may have, for example where the person is receiving both Local Authority provided care and support and NHS health care. For children and young people with special educational needs and disabilities, the plan will also need to cover education in order to produce an Education, Health & Care plan. All of the individual's needs and outcomes should be considered together and ideally, attempts should be made to combine plans (and the planning process) to support the individual and avoid duplicating process or introducing multiple monitoring regimes. Healthcare services and Local Authorities would then need to establish a 'lead' organisation who would undertake monitoring and assurance of the combined plan, or put in place joint accountability mechanisms.

The Care Act 2014 states that "Local authorities should not develop plans in isolation from other plans...and should have regard to all of the person's needs and outcomes when developing a plan, rather than just their care and support needs. The local authority should attempt to establish where other plans are present, or are being conducted and seek to combine plans, if appropriate. This should be considered early on in the planning process (at the same time as considering the person's needs and how they can be met in a holistic way) to ensure that the package of care and support is developed in a way that fits with what support is already being received or developed." It also says, "particular consideration should be given to ensuring that health and care planning processes are aligned, coherent and streamlined, to avoid confusing the person with two different systems."

## **2.7. What are the intended outcomes of personalised care and support planning?**

The process of discussing a person's care and support needs, goals and actions can help people to:

- Understand their condition(s) or disability better
- Feel more confident and able to manage their own health and care
- Take an equal role with professional partners in decision making
- Understand the options available to them
- Be as independent as possible
- Play a more active role in managing their condition and get recognition and support from professionals in this role
- Prevent a deterioration in their condition or symptoms
- Build on their strengths and feel supported in doing or achieving what matters to them, which may include the role of their carer
- Recognise trigger points and early warning signs
- Understand when to seek help and where from
- Maintain social connections, have opportunities to learn new skills and being able to contribute back the community
- Transition more smoothly between different services, such as between children & young people's services and adult services
- Where appropriate, consider the use of a personal health budget to help meet their needs

In considering outcomes as part of personalised care and support planning, the discussion should be focused on what is being aimed for, from the individual's perspective, and in specific terms what will be working better, be maintained or be avoided. Outcomes should not be about services, treatments or therapy. The intended outcomes from the care planning process will usually fall under one of the following<sup>13</sup>:

- Change in health and wellbeing, including physical, psychological, or psychosocial health
- Change in capabilities for managing condition
- Change in health-related behaviours (secondary)
- Change in use of health services (secondary)

Here are some examples of personal outcomes:

- To better manage my pain relief so I don't wake up at night
- To stay in my house as long as possible
- To stop taking anti-depressants because I don't like the side-effects
- To learn how to cook healthy meals that the whole family will enjoy
- To have the same person caring for me from 9am-3pm so my parents can go to work and do not need to be at home for staff changeovers
- To meet new people in my local area so I don't have to travel into the centre of town
- To receive end of life care at the hospice close to where my sister lives

People with LTCs are in charge of their own lives and self-management of their condition and are the primary decision makers about the actions they take in relation to the management of their condition. Personalised care and support planning encourages an honest conversation about the knowledge, skills and confidence that individuals have to self-manage their condition. From time to time, people may need traditional, specific interventions from care services, but the majority of the time, they will be managing their condition themselves and may need help and support to do this effectively to maintain a good quality of life and to avoid any deterioration in their condition.

The goals and actions identified in the personalised care and support plan will often focus on self-management strategies and any additional support they might need. For example, some common self-management strategies include<sup>14</sup>:

- Recognising and responding to symptoms
- Using medicine
- Responding to acute episodes and emergencies
- Managing nutrition, diet and exercise
- Giving up smoking
- Using relaxation and stress reduction
- Interacting with health care providers
- Seeking information and using community resources
- Adapting to work
- Managing relations with significant others
- Managing emotions

## **2.8. How is personalised care and support planning different?**

The term 'care planning' has been used for many years in many different settings. The approach of 'personalised' care and support planning as a collaborative and person-centred process is distinctly different. It is NOT about any of the things below:

- developing a traditional treatment plan for individual services;
- a process intended purely to aid health and care practitioners in making decisions about an individual's care and treatment;
- single disease pathways; whilst services might choose to prioritise patients with particular conditions, the care planning discussion should look at all their physical and mental health and care needs, particularly where the individual has more than one condition.
- solely about traditional medical solutions,



- a one-off 5 minute conversation;
- something which can be prepared by the care practitioner and the patient agrees to;
- a tick box exercise which results in a standardised plan that can be copied and used for any individual with a particular condition or similar circumstances.

## Part 3: The case for change

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“We stand of the cusp of a revolution in the role that patients – and also communities – will play in their own health and care. Harnessing what I’ve called this renewable energy is potentially the make it or break-it difference between the NHS being sustainable or not.”

[Speech](#) to the NHS Confederation Conference (June 2014)  
Simon Stevens, Chief Executive, NHS England

### 3.1. Introduction

This section will look at the evidence and rationale for *why* care services should deliver personalised care and support planning. It looks at the wider policy context and movements towards person-centred care and how personalised care and support planning can act as an enabler to delivering more personalised approaches that recognise the assets of patients, carers and communities, providing a more proactive approach to care.

### 3.2. Making the case for change

Personalised care and support planning is part of a much bigger picture of delivering person-centred care. It acts as a system pre-condition for providing support for self-management and for this reason it can be difficult to isolate the evidence of impact. A recent, comprehensive review of personalised care planning<sup>15</sup> established that when done well care planning can be effective in improving the quality of life of people and reducing unplanned admissions. However, there remain gaps in evidence, particularly around the financial impact of introducing personalised care and support planning, and further work is needed to truly understand the value of personalised care and support planning for individuals’ health and wellbeing; the value to care services in terms of resource use; and the value for society (social, economic and environmental). NHS England has commissioned a research programme under the title of ‘Realising the Value: a new relationship with patients and communities’ to further investigate these dimensions in relation to delivering person-centred care, and to help develop tools to support commissioners to increase the support available for self-management. Realising the Value is designed to identify and scale key person and community centred approaches, by building the evidence base at the same time as developing tools, resources and networks to support their spread.

#### 3.2.1. The future of care for people with long-term conditions

Over the next two decades, shifts in demographics and disease management will result in a greater proportion of people than ever before, living well into their eighth and ninth decades of life. The majority of these people will also be living with at least one long term condition. Ensuring their care is well managed over the long term, including the approach to the end of their lives, will become an increasing challenge for the NHS.

The Five Year Future View<sup>16</sup> emphasises that caring for these needs requires a partnership with patients over the long term rather than providing single, unconnected ‘episodes’ of care. There is strong consensus that the NHS needs to shift towards a more preventative, proactive and personalised approach, with much greater involvement of individuals and communities in their own health and care. The vision is to offer the following through a person-centred approach to long term condition care:

- Individuals are supported to be in control of their care
- People are treated as a whole person with their physical and mental health care needs treated equally and appropriately
- Community based care is appropriately aligned with hospital care so it is personal, accessible, responsive and delivers what individuals need
- Health and social care information is used to plan individual patient care and population level services
- Continuity of care is based around the individual not organisations.

The reality however is not as simple – establishing new community based services focussing on person-centred, coordinated care, is sometimes seen as time-consuming, and may challenge existing professional boundaries. Fundamental to addressing the challenges ahead will be supporting commissioners and wider primary care to move from the status quo and find cost-effective solutions to managing long term conditions in the community. These solutions need to put the person, rather than their condition, at the centre of care and recognise patients, carers, and communities as sources of renewable energy that support good care.

### **3.2.2. The move towards person-centred care**

Supporting people in their own health and care is not just the right thing to do; there are also strong health and economic arguments for doing this now.

1. People are arguably the greatest untapped resource within the NHS, as they manage their health and care on their own, the vast majority of the time<sup>17</sup>.
2. People who are more ‘active’ in relation to their health and wellbeing– who understand their role in the care process and have the knowledge skills and confidence to take on that role – are more likely to choose preventative and healthy behaviours and have better outcomes and lower costs<sup>18</sup>.
3. People can be supported to take an active role. Approaches that tailor support to the person’s level of activation that build skills and confidence, and use peer-support have a positive impact on activation as well as other key outcomes. People who start at the lowest levels of ‘activation’ tend to improve the most, indicating that these approaches can challenge health inequalities<sup>19</sup>.
4. The communities we live and work in and the quality of relationships we have with other people are in themselves important wider determinants of health and wellbeing<sup>20</sup>. Communities can be harnessed to improve health and wellbeing and reduce health inequalities<sup>21</sup>. Commissioning using an asset-based approach allows the NHS to access the wealth of experience and practical skills, knowledge, capacity and passion of local people, and to exploit the potential for communities to become equal partners in their care.

The Cochrane Review on personalised care planning<sup>22</sup> found that personalised care planning plus appropriate follow-up support leads to improvements in certain indicators of physical, psychological, and subjective health status, and people's capability to self-manage their condition (self-efficacy). The studies showed that the effects were greater when it included preparation, record-sharing, care coordination and review, involved more intensive support from health professionals, and was integrated into routine care.


A review of care planning research by NHS Kidney Care<sup>23</sup> (2011) reports a positive correlation between patient participation in decision making and satisfaction with care received. The studies also demonstrated that decision support systems that help health care professionals to elicit patient preferences and incorporate them into their care plan helped to improve patient care experience and health outcomes.

Personalised care and support planning provides an essential gateway to discussing the interventions and support that might work best for the individual. There is a great deal of positive evidence around self-management, and personalised care and support planning should be seen as a gateway to providing support for self-management. A review by The Health Foundation in 2011 showed that supporting self-management can have benefits for people's attitudes and behaviours, quality of life, clinical symptoms and use of healthcare resources<sup>24</sup> but that interventions work best when implemented as part of wider initiatives to improve care such as educating practitioners, applying best evidence, and using technology, decision aids and community partnerships effectively.

The components of the interventions that were found to work well to support self-management included:

- involving people in decision making
- developing care plans as a partnership between service users and professionals
- setting goals and reviewing progress
- helping people to monitor their symptoms and know when to take appropriate action
- providing opportunities to share and learn from other service users.

Part of the support that people with LTCs might need and discuss during personalised care and support planning, goes beyond medical support. This is covered in more detail in section 4.5. 'More than medicine' refers to a range of social interventions that build on and complement clinical care to help deliver improved health outcomes. These interventions usually focus on supporting long-term behaviour change, improving wellbeing, building social networks of support and helping people to better manage their condition.



“The NHS in England could realise savings of at least £4.4 billion a year if it adopted People Powered Health innovations that involve patients, their families and communities more directly in the management of long term health conditions. These savings are based on the most reliable evidence and represent a 7 per cent reduction in terms of reduced A&E attendance, planned and unplanned admissions, and outpatient admissions.”

Nesta, 2013<sup>25</sup>

Although there is growing evidence about the role and benefit of social capital and social connections on health, the significant risks posed by a lack of social relationships is still not widely recognised. One study<sup>26</sup> found that social relationships (with friends, family, neighbours or colleagues) significantly increase our odds of survival. Social isolation and loneliness is a major public health issue associated with higher risks of mortality and morbidity. Interventions based on community engagement can be such a powerful tool for tackling health issues. Community engagement and outreach as well as peer support programmes can be extremely effective at promoting behaviour change and better management of long term conditions.

### **3.3. Demonstrating a robust model of personalised care and support planning**

The Year of Care programme<sup>27</sup> has been one of the most significant programmes to explore what is required to effectively deliver personalised care and support planning. The initial focus was on care for people with diabetes, but has subsequently been applied to other long term conditions and multi-morbidities. The programme offers a detailed understanding of implementation across health communities, along with linkages to effective micro- to macro-commissioning.

Learning from the pilot stage found improvements for people, professionals and practices - people reported improved experience of care and real changes in self-care behaviour; professionals reported improved knowledge, skills and greater job satisfaction; while practices reported improvements in team work and productivity.

The Year of Care programme identified a number of benefits in implementing personalised care and support planning:

#### **Benefits to people with long term conditions**

- Involvement in decisions about their care
- A better understanding of their condition
- Respect for and recognition of their everyday work to self-manage
- Tailored support to increase confidence and skills in self-management
- Consistency and continuity of care – the person with the condition is the most consistent provider of their own care
- A central role in service planning, and agreeing what local care should look like
- Information and signposting to local support services

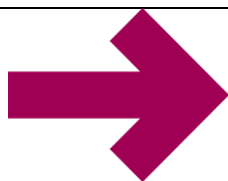
#### **Benefits to clinicians**

- More satisfying consultations
- Commissioning influenced by genuine clinical data
- Services commissioned that people with LTCs will use
- Better outcomes for people with LTCs
- A new and interesting skill set
- A lever to improve clinical IT and drive quality improvement
- Less inappropriate use of medication

## Benefits to commissioners

- Greater value for money, as services provided meet individual needs, deliver improved health outcomes and reduce medicine wastage
- A positive impact on other local and national drivers, such as reducing acute admissions and improving the patient experience
- Complete fit with QIPP
- Provides information needed to commission services that people want and clinicians value
- A detailed understanding of pathways and costs as the basis of new local currency
- A stimulus to the whole healthcare community to redesign services for LTCs, ensuring the right care is provided, in the right place, at the right time, by people with the right skills, with the right funds
- Provides a long term, sustainable approach to reducing the burden of LTCs on local resources

The Year of Care programme demonstrated that person-centred approaches not only benefit the individual, but can also lead to improvements for care professionals and commissioners. The programme continues to demonstrate improved satisfaction with care and the care process for both patients and clinicians.



### **Case study: Year of Care approach to care and support planning at Holmside Medical Group**

Holmside, a 9000 person, inner city practice in the West end of Newcastle wanted to look at better ways of supporting their patients with long term conditions through introducing care and support planning.

Working with the Year of Care Partnership they mapped out what would be needed to administer the new way of working and the training needs of staff. They invited the YOC team to a whole practice meeting to look together at the case for change and the implications for the practice if everyone on their QOF registers was included. With GP support and joint leadership from nursing and administration they worked as an entire practice team to reorganise systems, develop resources, identify new roles, develop staff and provide training.

They introduced a more coordinated, personalised approach based on a care and support planning process. This focuses on what matters to each person in their daily lives, what they would like to achieve and what support is needed; all brought together in a single process and plan, however many 'conditions' the person may have.

Some of the administrative processes that they used at Holmside included:

- Creating a birth month register of LTC patients, divided into practice agreed groups according to conditions and number of conditions each person has
- Lead GP reviews each group where different processes might be involved such as those with mental health issues or dementia or the housebound; to ensure that the care and support planning process is right for each person and the right people are involved
- People within the groups are sent a personalised letter tailored to their needs, and an invitation to attend an initial appointment with the healthcare assistant if tests or examinations are needed as part of the preparation stage

- Test results and/or reflective prompts are then sent to them , merged into letters with explanations, encouraging reflection prior to the care planning consultation itself
- Care planning consultations are booked as double appointments either with a nurse or GP
- Information about the new way of working is widely available throughout the practice, flagged up by receptionists and discussed by the Healthcare assistant.

These changes required staff to take on new roles:

- Administrative staff were trained to be able to guide patients and enquirers about the system, make appointments in the right way at the right time, and make sure it works for each person
- Healthcare assistants were trained in specific clinical tasks to help with examinations and tests and played a key role in explaining the care planning process and roles to patients, encouraging people to be more actively involved in discussions. They might also signpost people to supportive community activities.
- The nursing team used consultation skills to identify what was important to each person, building empathy, listening and gently challenging, and supporting the person to find solutions and practical actions. In addition, practice nurses needed to have a good understanding of the main issues for different conditions or know where to go to for advice. This was supported through training on specific topics.
- GPs provide ongoing support and supervision to the nursing team. They lead the care planning process for particular groups of individuals and people with complex issues. They were initially sceptical about introducing the changes but now wholeheartedly support the programme.
- Nurses and GPs attended Year of Care core care and support planning training to better understand the philosophy and skills required and the Year of Care team kept in touch to continue providing support.

Through introducing this more co-ordinated, personalised approach, the practice found that people were more involved in the care and support planning process as well as with their own health, with some shorter consultation lengths and greater systematic use of the phone. The practice found team work improved and everyone found it a better way to work.

The nurse practitioner (NP) has identified some critical success factors. These include:

- Training in care planning to get the right ethos and consultation style
- Regular team meetings to improve the service as quickly as possible
- Robust templates for both the health care assistant and practice nurse
- Regular training sessions for HCA/PN
- Having a dedicated admin team for support and systems development
- Having a dedicated lead nurse to go to with all issues whether clinical/admin.
- A whole team approach

Comments that the practice gathered in their feedback

“...thank you so much, without you ... my life and lifestyle would be very different the one I now enjoy” (person with LTCs)

“You build relationships ... and then see results!” (nurse practitioner)

For further details, please contact [Year of Care Partnerships](#)

### **3.4. The current position**

Despite the policy messages and the growing evidence, both nationally and internationally, of the benefits of care and support planning there still remains significant gaps, with many people living with long term conditions reporting that they are not involved in their care as much as they would like to be.

In a recent survey by the Institute for Public Policy Research (IPPR)<sup>28</sup> with over 2,500 people with long-term conditions, over three-quarters of respondents (77%) felt that more of their healthcare could and should be managed independently at home – but they said that a lack of support and information was holding them back from doing so. Most people (56%) thought that a healthcare plan would be useful, and people who were offered healthcare plans were much more likely to report satisfaction with the management of their condition (91%, compared to 63% of all respondents).

The [GP Patient Survey](#) (January 2016) gives us a national picture of whether patients have, and are using, care plans. Although 53.6% of patients completing the survey said they have a long standing health condition, only 3.3% of people who answered the survey have a written care plan. Of the people who have a care plan, 67% say that they use it to manage their day-to-day health, which suggests that two thirds find having a written care plan to be beneficial. However, 29% say that they did not help put the plan together. Two years on, this still reflects the results of a National Audit of Intermediate Care<sup>29</sup> which found that 25-30% of service users reported little involvement in the development of their care and support plans.

The GP Patient survey also found that of all patients who said they had a written care plan, 58% said it was regularly reviewed by the GP, nurse or other health professional. Over a quarter of these patients (27.9%) said that their plan was not regularly reviewed and 14% did not know whether it was reviewed or not.

### **3.5. What are the incentives and drivers to deliver personalised care and support planning, how does it fit with other initiatives?**

The importance of person-centred care, personalisation, support for self-management and personalised care planning have been highlighted in numerous policy documents over the past decade. This shows that whilst there is a consistent vision, challenges remain. However, with personalised care and support planning running through the various policy documents, incentives and drivers, it is clear that offering personalised care and support planning would help to achieve a number of different requirements at the same time.

#### **3.5.1. Long-term conditions**

The [NHS Mandate 2016/17](#)<sup>30</sup> includes an expectation (Objective 2) that people are empowered to shape and manage their own health and care and make meaningful choices, especially people with long term conditions and people receiving end-of-life care. This can be better achieved through personalised care and support planning.



### Other incentives and drivers to deliver personalised care and support planning:

- The [Urgent & Emergency Care Review](#)<sup>31</sup> recognises the importance of supporting people to self-care in order to prevent the deterioration of conditions and the need for urgent help. It also recognised the need to “accelerate the development of comprehensive and standardised care planning, so that important information about a patient’s conditions, their values and future wishes are known to relevant healthcare professionals.” Latest information on the review is available [here](#).
- From October 2014, people eligible for NHS continuing healthcare and children and young people’s continuing care have had the right to a [personal health budget](#), including a direct payment for healthcare. The NHS Mandate 2016/17 includes a goal that 50-100,000 people should have a personal health budget or integrated personal budget (up from current estimate of 4,000). Co-produced, personalised care and support planning is at the heart of making personal health budgets work well.
- 50 [new care model](#) and vanguard sites across England, have been chosen to take forward the Five Year Forward View. Among these are multi-speciality community providers, new models to enhance care in care homes and vanguards which focus on integrated primary and acute care systems.

#### 3.5.2. Specific conditions or groups of individuals

- **Learning Disability** - The [CIPOLD review](#) in 2013 highlighted that the quality and effectiveness of health and social care given to people with learning disabilities has been shown to be deficient in a number of ways and that premature deaths could be avoided by improving the quality of the healthcare they receive. The review recommended the introduction of patient held records, standardisation of annual health checks, and that advanced health and care planning for people with a learning disability should be prioritised.
- **Mental Health** - The [Care Programme Approach](#)<sup>32</sup> is the national framework for mental health services assessment, care planning, review, care co-ordination, and service user and carer involvement focused on recovery.
- **End of life care** – [One Chance to Get it Right](#) produced by the Leadership Alliance for the Care of Dying People focuses on five priorities for care of the dying person. Priority 5 relates to the agreement and delivery of a plan of care for the individual who is expected to die within days to hours. Advanced care planning should be seen as part of the care and support planning continuum<sup>33</sup>. Advance care planning with those who are in the last year(s) of life has been an important component of end of life care since the publication of the national End of Life Care Strategy in 2008. It is identified in NHS England’s [Actions for End of Life Care: 2014-16](#)<sup>34</sup> and in the more recent National Voices ‘[Ambitions](#) for Palliative and End of Life Care’.

#### 3.5.3. NHS Contracts

- The [NHS Standard Contract](#) specifies service conditions related to personalised care planning and shared decision making (SC10).

- As part of the GP contract, GP practices can sign up to deliver the [Enhanced Service for Avoiding Unplanned Admissions](#) which was extended to April 2016. The Enhanced Service requires GP practices to identify patients who are at high risk of unplanned admission and manage them appropriately with the aid of risk stratification tools, a case management register, personalised care plans and improved same day telephone access.
- The [Enhanced Service for Facilitating timely diagnosis and support for people of Dementia](#) 2015/16 encourages GP practices to identify patients at clinical risk of dementia, offer an assessment to detect for possible signs of dementia in those at risk, offer a referral for diagnosis where dementia is suspected and in the case of a diagnosis, provide advanced care planning in line with the individual's wishes.
- The Learning Disabilities Health Check Scheme Enhanced Service for 2014/15 encouraged GP practices to identify all patients aged 14 and over with learning disabilities, to maintain a learning disabilities 'health check' register and offer them an annual health check, which included producing a health action plan.

#### 3.5.4. Integrated care

- In 2016/17, the [Better Care Fund](#) (BCF) will be a mandated minimum of £3.9bn to be deployed locally on health and social care through pooled budget arrangements between local authorities and CCGs.
- The [Integrated Personal Commissioning Programme](#) was introduced in July 2014, when NHS England announced plans to pool funding for key groups across local authorities, CCGs and specialised commissioning. The key aims were to test new commissioning and funding models including joined-up capitated funding approaches, and to explore how individuals can have more control over how the funding is used through personalised care and support planning.
- The NHS, local authorities and health professionals have a number of obligations and statutory duties in relation to the [special educational needs and disability \(SEND\) reforms](#) in the Children and Families Act 2014. The reforms are focused on outcomes for children and young people and how education, health and social care can help children and young people achieve their outcomes. Individual outcomes should be discussed and recorded in an Education, Health and Care plan. The [Making it Personal](#) guides produced by 'Kids' help to explain what this means to commissioners, providers and families.
- The National Collaboration on Integrated Care and Support, which includes the Department of Health, NHS England, and the Care Quality Commission, published [Integrated Care and Support: Our Shared Commitment](#) which outlines commitments at a national level and expectations of local areas.

#### 3.5.5. Social care

- The [Care Act 2014](#) sets out a modern legislative framework for social care, creating a strong focus on wellbeing and prevention. Section 24 of the Act gives local authorities a new legal responsibility to prepare a care and support plan for an adult

when it is required to meet needs, or decides to do so. Section 25 sets out in more detail what information should be included in the plan and who should be involved in its preparation. Section 27 creates a duty on the local authority both to generally keep plans under review and to respond to reasonable requests from the adult to whom the plan relates. 'Think Local Act Personal' has published [guidance on personal care and support planning](#) and separate guidance on joined up planning across health and care. There are also support materials available [Skills for Care](#).

### 3.5.6. Carers

- To help do more to identify, support and recognise the vital role of carers, since 2013 NHS England has been working with carers and their organisations to develop a series of [commitments to carers](#). NHS England see these commitments as the start of a journey and will continue to work with carers. Supporting people to provide better care and to stay well themselves will contribute to better lives for those needing care and more effective use of NHS resources. As part of this commitment, NHS England worked with partners including carers organisations, to publish 10 Commissioning for Carers [Principles](#) in 2015.

### 3.5.7. Other

- A personalised approach to care planning is included in quality statements for the [NICE Quality Standards](#) for a number of long term conditions including chronic kidney disease, diabetes in adults, asthma, dementia, end of life for adults, epilepsies in adults, and epilepsies in children and young people.
- The [NHS Constitution](#) includes the right “to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers.” And also the commitment “to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one”.

### 3.5.8. The Five Year Forward View

Delivering the Five Year Forward View Planning Guidance for 2016/17 <sup>35</sup> sets out expectations that in local 'Sustainability and Transformation Plans' new models of care and GP practices will plan to provide enhanced GP services, (including evening and weekend access) and same-day GP appointments for all over 75s who need them. There is also an expectation that in 2016/17, GP practices and new care models will make progress on integration of health and social care, integrated urgent and emergency care, and electronic record sharing. Among technology targets set out for the NHS and partners, it is expected that a minimum of 10 per cent of patients will be actively accessing primary care services online or through apps, and there will be a significant increase in patient access to and use of the electronic health record. All these factors can contribute to improving personalised care and support planning.

## Glossary of terms

Term	Definition
Advocacy	A process of supporting and enabling people to express their views and concerns, access information and services, defend and promote their rights and responsibilities, and explore choices and options. An advocate is someone you trust who is willing to act on your behalf as well as someone who can work well with other members of your healthcare team such as your doctors and nurses.
Alliance contracting	An alliance contract is a contractual arrangement between the commissioner(s) and an alliance of parties who deliver the project or service. There is a risk share across all parties and collective ownership of opportunities and responsibilities associated with delivery of the whole project or service. An alliance contract creates a collaborative environment without the need for new organisational forms. By having one alliance contract, all parties are working to the same outcomes and are signed up to the same success measures and principles, rather than an individual organisation's position.
Asset-based approach	An asset-based approach seeks to mobilise the skills, capacities or resources available to individuals and communities which could enable them to gain more control over their lives and circumstances. Assets could include the practical skills, capacity and knowledge of local residents; the passions and interests of local people that give the energy to change; the networks and connections in a community; the effectiveness of local community and voluntary associations; and the resources of public, private and third sector organisations that are available to support a community
Capitated funding approaches	A capitation is the amount of health service funds to be assigned to a person for the service in question, for the time period in question, subject to any national budget constraints. Capitations are usually varied according to an individual's personal and social characteristics, using a process known as risk adjustment. In most nations, the intention is that the risk-adjusted capitation should represent an unbiased estimate of the expected costs of the citizen to the health care plan over the chosen time period (typically one year)
Care co-ordination	Involves deliberately organising patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care. This means that the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and that this information is used to provide safe, appropriate, and effective care to the patient.
Care pathway	Lead the healthcare commissioner, provider or clinician through the entire care process and patient experience for a given clinical condition – one that displays the clinical steps linked together along a timeline that structures the entire care process. Care pathways have locally agreed standards based on evidence where available to help a person with a specific condition or diagnosis move progressively through the clinical experience.
Carer	Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.
Case finding	A systematic or opportunistic process that identifies a specific population segment (e.g. people with COPD) from a larger population for a specific purpose. For example, 'Flu vaccination

<b>Term</b>	<b>Definition</b>
Case management	The process of planning, coordinating, managing and reviewing the care of an individual. There are different models of case management in chronic care. However, the broad principle is to assign each person a 'case manager' to assess patients' needs; develop a care plan arrange suitable care; monitor the quality of care; and maintain contact with the person and their family.
Co-commissioning	Different commissioning bodies aligning strategies whilst retaining direct responsibility for resources.
Continuity of care	Arrangements in place that ensure any health, care and support arrangement/intervention is carried out to ensure the least disruption to the service user/ patient.
CQUIN	Commissioning for Quality and Innovation – The <a href="#">CQUIN payment framework</a> enables commissioners to reward excellence, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals. -
Direct payments	One way of managing a personal health budget is a direct payment where money is given directly to an individual or their representative for the management of their NHS care. This option became legal on 1 August 2013 and is in addition to the pre-existing legal options for managing a personal health budget - by the NHS, or through a third party.
Education, health and care plans	Based on an assessment of the child's needs in education, health and care, EHC plans replaced statements of Special Educational Needs (SEN) from September 2014
Health Action Plan	A personal plan about what an individual with a learning disability can do to be healthy. It details the actions needed to maintain and improve the health of the individual, and any help needed to accomplish these. It is a mechanism to link the individual and the range of supports they need if they are to have better health. Health Action Plans need to be supported by wider changes that assist and sustain this individual approach.
Health literacy	The ability of a person to obtain, process, and understand health information and services needed to make sound health decisions.
Holistic needs assessment	A process of gathering information from an individual in order to inform discussion, that focusses on the whole person. Their entire well-being is discussed – physical, emotional, spiritual, mental, social, and environmental needs.
Integration	Integration involves joined up, coordinated health and social care that is planned and organised around the needs and preferences of the individual, their carer and family. This may also involve integration with other services for example education or housing.
Intervention	In the context of this document, interventions are considered to be activities, programmes, or offers of support which enable people to have a more active role in their own care, or to experience improved outcomes, such as education programmes, information to support decision making, or peer support. This is distinct from medical interventions which might include drugs or treatments to improve, maintain or assess a person's health.
Lack of capacity	As defined in the Mental Capacity Act 2005 "...a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain" .

<b>Term</b>	<b>Definition</b>
Lasting power of attorney	A legal document that enables a person to appoint people (“attorneys”) to make decisions on their behalf. It could be used if the person concerned became unable to make their own decisions. There are two types of lasting power of attorney, health and welfare, and property and financial affairs.
Link workers	Provide a signposting or facilitator role and act as a bridge between healthcare services and community services. They help people to understand what options are available to them in their local area.
Long term or chronic conditions	These are conditions which cannot at present be cured but can be managed or improved through person-centred approaches that support developing new skills, changing behaviours, access to community support, as well as medication and traditional treatments or therapies.
‘More than medicine’	Refers to a range of social interventions that build on and complement clinical care to help deliver improved health outcomes. These interventions usually focus on supporting long-term behaviour change, improving wellbeing, building social networks of support and helping people to better manage their condition.
Motivational interviewing	A form of collaborative conversation for strengthening a person's own motivation and commitment to change. It is a person-centered counselling style for addressing the common problem of ambivalence about change by paying particular attention to the language of change. It is designed to strengthen an individual's motivation for and movement toward a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion.
Multidisciplinary team working	Involves appropriately utilising knowledge, skills and best practice from multiple disciplines and across service provider boundaries, e.g. health, social care or voluntary and private sector providers to redefine, re-scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s).
Multi-morbidity	Multimorbidity is defined as the co-occurrence of two or more chronic medical conditions in one person.
NHS Continuing Health Care	A package of care that is arranged and funded solely by the NHS for individuals who are not in hospital who have complex ongoing healthcare needs.
Non-traditional providers	Non-traditional providers include charities, community groups and social enterprises. They are different to mainstream, statutory health service providers.
Patient activation	Defined as an individual’s knowledge, skill, and confidence for managing their health and health care. A behavioural concept which captures a number of core components of patient involvement, each of which is important for active engagement and participation.
Patient Activation Measure (PAM)	The PAM contains a series of 13 statements designed to assess the extent of a patient’s activation. These statements are about beliefs, confidence in the management of health-related tasks and self-assessed knowledge.
Patient decision aids	Specially designed information resources that help people make decisions about difficult healthcare options, such as which treatment they feel will be best suited to their needs and preferences. They enable patients to feel more involved in a shared decision making process with their healthcare professional.

<b>Term</b>	<b>Definition</b>
Peer support	Where people with shared experiences come together to offer empathy, understanding and mutual help. It can range from informal, social support, to more formalised programmes where individuals might be referred to a peer support worker who is trained to help people plan how to manage their health and wellbeing.
Personal budgets	<p>The up-front total amount of funding allocated by a particular service (social care/health/education) to meet the assessed support needs of a particular individual. Users can choose to take this funding as a direct payment or ask someone else to manage the money on their behalf, or a combination of the two.</p> <p>A personal budget is used to purchase the services and support required by the individual to meet their specific requirements and to live a more independent life, in line with their support plan.</p>
Personal health budgets	An amount of money to support individual's identified healthcare and wellbeing needs, planned and agreed between them, or their representative, and their local NHS team. At the centre of a personal health budget is a care plan. The plan sets out the individual's personal health and wellbeing needs, the health outcomes they want to achieve, the amount of money in the budget and how they are going to spend it. Personal health budgets can be used to pay for a wide range of items and services, including therapies, personal care and equipment, allowing individuals to have more choice and control over the health services and care they receive.
Personalisation	Recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support. Personalised approaches involve enabling people to identify their own needs and make choices about how and when they are supported to live their lives.
Person-centred care	<p>To an individual it means "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." (National Voices, narrative for person-centred care)</p> <p>Patients are equal partners with health professionals in planning, developing and assessing care to ensure it is most appropriate to their needs. It involves putting individuals and their families at the heart of all decisions and requires a different kind of interaction between patients and healthcare professionals.</p>
Pooled budgets	Combine funds from different organisations to purchase integrated support to achieve shared outcomes. This will enable organisations to build on previous joint working experience in order to purchase truly integrated care services.
Reablement	A short term service which involves typically, six weeks of intensive home-based support to help people recover independence following crisis or hospital discharge. It involves the use of focused support and therapy to help people regain daily living skills and become able do things for themselves again after an illness or accident. It can also include the provision of equipment and aids to help people live more independently in their own homes.
Rehabilitation	A multidisciplinary process which supports the individual to achieve their maximum potential to function physically, socially and psychologically through support and intervention.

<b>Term</b>	<b>Definition</b>
Risk enablement	Concerned with managing risks effectively to enable choice and control and finding a balance between the need to protect vulnerable people and promoting the rights of the individual. Individuals will be allowed to take informed risks if they understand their responsibilities and the implications of their choices.
Risk stratification	A systematic process that identifies a population at higher risk of a specified outcome, e.g. unscheduled admission to hospital, from people with a lower risk.
Safeguarding	The process of protecting people's health, wellbeing and human rights, and enabling them to live free from harm, abuse and neglect. It applies to children and to vulnerable adults. Where abuse is suspected or alleged, then safeguarding procedures can be used by organisations and services to make sure that a consistent and comprehensive response is provided.
Self care	Includes the actions people take for themselves, their children and their families to stay fit and healthy, from knowing when and how to take medicines and treating minor ailments, to seeking help when you need it.
Self-management support	Enables and encourages people with long-term conditions to develop the knowledge, skills and confidence to more effectively manage their health and wellbeing. Self-management can include finding out more about your condition; learning new skills and tools to help you manage your health; working in partnership with health care professionals; taking charge of your health care; choosing what is right for you; and getting support from other people in a similar situation.
Shared decision making	The process by which a patient and their healthcare professional reach a decision together about treatment options and next steps. It requires patients and professionals to understand what is important to each other when choosing a treatment, weighing up clinical evidence and individual preferences.
Social capital	Refers to the institutions, relationships, and norms that shape the quality and quantity of a society's social interactions.
Social prescribing	It's about connecting people to non-medical sources of support in their local community that may help meet particular needs, or that can help to prevent worsening health for people with existing LTCs and reduce costly interventions in specialist care.
Structured education programmes	Programmes that provide people with the education and support they need to enable them to manage their condition in a structured way, typically including a curriculum or course with trained educators and an agreed quality assurance process. The programmes will help people learn about making lifestyle changes, managing medication, and monitoring symptoms. This term is particularly used in Diabetes e.g. DAPHNE and DESMOND courses.
Telecare	Services that enable people, especially older and more vulnerable individuals, to live independently and securely in their own home. It includes services that incorporate personal and environmental sensors in the home, and remotely, that enable people to remain safe and independent in their own home for longer.
Telehealth	Often referred to as remote patient monitoring – refers to services that use various point-of-care technologies to monitor a patient's physiological status and health conditions. - Typically, it involves electronic sensors or equipment



Term	Definition
	that monitors vital health signs remotely from home or while on the move. Readings are automatically transmitted to an appropriately trained person who can monitor the health vital signs and make decisions about potential interventions in real time, without the patient needing to attend a clinic.
Transition	The process of preparing, planning and moving from one care setting or package to another. Often refers to young people with long-term conditions or care needs and their families moving from children's to adult services or into independent living. Plans need to be in place to ensure coordination and continuity of care.
Unmet needs	Where care and support needs have been identified but cannot be addressed due to treatments or services being unavailable, inadequate or unsuitable
Voluntary and community sector (VCS)	Sometimes referred to as the third sector, VCS is a common umbrella term for organisations such as charities, third sector organisations, not-for-profit organisations, community groups, social enterprises, civil society organisations and non-governmental organisations.
Wellbeing	A broad concept that in simple terms can be defined as feeling good and functioning well. Wellbeing can cover various elements of a person's life from their own subjective evaluation. For example, it could include personal dignity (including treatment of the individual with respect); physical and mental health and emotional wellbeing; protection from abuse and neglect; control by the individual over day-to-day life (including over care and support provided and the way it is provided); participation in work, education, training or recreation; social and economic wellbeing; domestic, family and personal relationships; suitability of living accommodation; and the individual's contribution to society.
Whole systems	Whole systems approaches involve identifying the various components of a system and assessing the nature of the links and relationships between each of them rather than focusing on only one element. Systems consist of people, structures, and processes that work together.

## Additional resources

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National Voices and the National Palliative and End of Life Care Partnership (Sept 2015)  
*Ambitions for Palliative and End of Life Care*  
<http://www.nationalvoices.org.uk/node/579>

Arthritis Research UK (2014) *Care planning and musculoskeletal health* -  
<http://www.arthritisresearchuk.org/policy-and-public-affairs/policy-priorities-and-projects/musculoskeletal-health-services/care-planning.aspx>

Helen Sanderson Associates – One Page Profiles  
<http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/one-page-profiles.aspx>

NHS England *Integrated Personal Commissioning Prospectus* (2014)  
<https://www.england.nhs.uk/2014/09/ipc-prospectus/>

NHS IQ - Pinterest board for end of life care and advance care planning resources  
<http://www.pinterest.com/nhsiq/end-of-life-care/>

NHS Midlands & East video *A personal approach – to healthcare professionals*  
<http://www.youtube.com/watch?v=MsyYhib-sAs>

Personal health budgets resources on care planning -  
<https://www.england.nhs.uk/healthbudgets/>

QISMET have a database of providers of structured self management programmes –  
[http://qismet.org.uk/providers\\_database](http://qismet.org.uk/providers_database)

Think Local Act Personal (TLAP) (2015) Tools for supporting integrated care for people with health and social care needs <http://www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/>

Royal College of General Practitioners (2015) 'Stepping Forward' commissioning principles for collaborative care and support planning  
<http://www.rcgp.org.uk/~media/Files/CIRC/Quality-Improvement/RCGP-Stepping-Forward-2016.ashx>

NHS Benchmarking Network *National Audit of Intermediate Care* (2015)  
<http://www.nhsbenchmarking.nhs.uk/partnership-projects/National-Audit-of-Intermediate-Care/year-four.php>

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- <sup>4</sup> National Voices (2014) *Prioritising person-centred care – the evidence* [www.nationalvoices.org.uk/evidence](http://www.nationalvoices.org.uk/evidence)
- <sup>5</sup> NHS England (January 2016) *GP patient survey – national summary reports* <https://gp-patient.co.uk/surveys-and-reports>
- <sup>6</sup> Department of Health (Dec 2015) *The Government's mandate to NHS England for 2016/17* <https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017>
- <sup>7</sup> Department of Health (2014) *Care and support statutory guidance* [www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation](http://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation)
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