National action for local change: Our Declaration-

Person-centred care for long-term conditions

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Description	This document supports the Five Year Forward View vision for a new relationship with patients, carers and communities and outlines the steps and changes that are needed to ensure that the NHS supports people to gain far greater control of their own care and for the development of new models of care that will ultimately contribute to preventing some LTCs, and improve the quality of life for people who acquire or develop them.
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Document Status

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The National Health Service Commissioning Board was established on 1 October 2012 as an executive non-departmental public body. Since 1 April 2013, the National Health Service Commissioning Board has used the name NHS England for operational purposes.

Promoting equality and addressing health inequalities 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 eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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1 Introduction

A signal of the success in tackling the health problems of the 21st century is the emergence of LTCs as the dominant problem for health and care systems worldwide. Addressing the wider determinants of health along with prevention against infectious diseases, complemented by advances in treatments and technologies means people are living longer and people who once would have died in infancy or youth are living into adulthood.

The changes in life expectancy and advances in treatments and technology however, mean that people are living with conditions that cannot be cured but need to be managed to minimise the impact on their lives and maintain their quality of life. The recent past has also seen this issue become more complex with the emergence and growth of multi-morbidity. More and more people are living with two or more conditions.

The dominance of LTCs and specifically multi-morbidity requires policy and practice to change to meet the needs of the future rather than those of the past. People need to be supported to manage their health, to have more knowledge, skills and confidence to do so and to take more control of their health and lives. Person-centred care sits at the heart of this change.

The Five Year Forward View sets a vision for a new relationship with patients, carers and communities. A vision for an NHS that supports people to gain far greater control of their own care and for the development of new models of care that will ultimately contribute to preventing some LTCs, and improve the quality of life for people who acquire or develop them. For the vision to become a reality, the functions that models of care are required to deliver need to be clear. In addition, the drivers and enablers to support the functions need to be in place and inhibitors removed. Some of these are technocratic but some are about human behaviour: attitudes, mind-sets, values and needs, in both professionals and people with LTCs.

2 Why do we need to change?

There are more than 15 million people living with a long-term physical or mental health condition in England, accounting for over 50% of GP appointments, 64% of all outpatient appointments and over 70% of inpatient bed days[1]. People with multi-morbidity account for 16% of the population but account for 33% of all consultations[2].

With advancements in neonatal and paediatric care, more children are surviving to live with LTCs. Results for England from a Health Behaviour in School-aged Children report found that in 2011 15% of all school students aged 11-15 reported having been diagnosed with a long-term illness, disability or medical condition[3]. Transition is crucial in setting in place the foundations for young people to be responsible for the

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[1] Coalition for Collaborative Care/NHS England (2015) Personalised care and support planning handbook: the journey to person-centred care. NHS England, p.6

[2] University of Bristol

[3] Brooks F, Magnusson J, Klemera E, Spencer N & Morgan A (2011) Health Behaviour in School-Aged Children (HSBC) England National Report. Findings from the 2010 HBSC study for England. Hatfield: University of Hertfordshire

self-management of LTCs for the rest of their lives. However, if not managed appropriately, it can result in disengagement from services and impact on a young person's ability to manage their condition.

Older people are more likely to have frailty, other LTCs and complex care requirements. As a result, older people use a high proportion of NHS resource, for example the number of emergency bed days increases very strongly by age. This ranges from less than 1 million for all age bands under 40, to over 7 million for the age band 85+. As the population ages the challenge for the health and care system will continue to grow. In the next 20 years the number of people over 85 in the UK is predicted to double and nearly treble in the next 30 years[4].

For all that, the average person with a LTC in the UK spends less than four hours a year with a health professional which means that for the remainder of the time, people have to take responsibility for their own care, possibly relying on support from unpaid carers[5].

Whilst there have been pockets of improvement and some examples of excellent local practice, there is an overall lack of progress in fully involving people in their own care. Only around 5% of people with long-term conditions report that they have an agreed written care and support plan[6], and around half of hospital inpatients and one in three people using GP services say that they were not as involved in decisions about their care as much as they wanted to be[7].

Engagement and shared decision-making can only happen if people understand the language that professionals are using. Low health literacy (understanding written or verbal health information) affects around half of the adult working population, which is associated with poorer health outcomes including increased mortality rates in older people[8]. Problems arise with the mismatch between what health and care professionals expect from people through verbal, written or online information and the skills of people, carers and families they aim to assist[9]. A further consideration is that not every person wants the same style or level of decision-making or engagement.

The Patient Activation Measure (PAM) measures the knowledge, skill and confidence a person has in managing their own health and care. Studies provide compelling evidence that people with greater activation scores have better health, better outcomes, improved self-management, and better experience of care and fewer episodes of emergency care[10]. A study on the effect of early palliative care, one of

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[4] National population projections, 2012-based, Office for National Statistics, 2013

[5] Coalition for Collaborative Care/NHS England (2015) Personalised care and support planning handbook: the journey to person-centred care. NHS England, p.6

[6] Coalition for Collaborative Care/NHS England (2015) Personalised care and support planning handbook: the journey to person-centred care. NHS England, p.5

[7] Foot et al (2014) People in control of their own health and care. London: The King's Fund

[8] Koh, H. K. & Rudd, R. E. (2015) The Arc of Health Literacy. JAMA published online August 06, 2015

[9] Royal College of General Practitioners (2014) Health Literacy – Report from an RCGP-led health literacy workshop. London: RCGP

[10] Hibbard, J. & Gilburt, H. (2014) Supporting people to manage their health. An introduction to patient activation. London: Kings Fund

the best examples of person-centred care, found improved experience, reduced use of resources and increased life expectancy[11].

Health and care professionals have a significant role to play in supporting people to self-manage their condition, helping to build patients' skills and confidence and in delivering person-centred care. A study that measured clinician attitudes about the role of patients in healthcare, using the Clinician Support for Patient Activation Measure (CS-PAM) in 2009, found that whilst clinicians strongly endorsed patients following medical advice, they were less likely to endorse patients making independent judgements or actions, or functioning as a member of the care team. The idea that patients should be independent information seekers was endorsed even less[12]. A recent CS-PAM study by NHS England (publish date autumn 2015) found that clinician attitudes have not shifted very much in the last five years.

One of the problems facing the health and care system is the current principle adopted for the delivery model addressing LTCs which is historically condition-based. This makes sense in a medically-driven and directed delivery model that uses an evidence base derived from the study of individual conditions.

The difficulties with such an approach are that it focuses on disease and people's deficits or weaknesses. Physical and mental health conditions are compartmentalised and have to vie for attention and priority. Treatments and care are focused on single conditions, often without considering the effect of on other treatments or diseases an individual may have. Individuals with multiple conditions have to deal with a confusing and complex system, often without any coordination or support. There is often a significant workload imposed on people with many different appointments or contacts with many different part of the system and that affects their ability to work, manage their own health, or play an active role in their community.

The problems caused by this approach has led to the emergence of demand for an alternative, person-centred approach, which not only addresses the needs of an individual but respects the assets that the individual brings to the management of their health: themselves, their social network and the community they live in.

There is good evidence to show that the benefits of actively involving patients in their care include: better decision-making, improved health and health outcomes and better use of resources. What is apparent from the work of National Voices, the concerns voiced by many professionals, and the CS-PAM study is that we have a system that does not support person-centred care, and change is needed.

We need to support the creation of a system that empowers patients and carers, mobilises community resources and fosters strong professional collaboration between expert generalists and specialists. A system where care and support is planned in partnership with people, their carers and professionals, drawing upon the best evidence applied judiciously in line with the values and preferences of the individual with LTCs and their carers.

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[11] Jenner et al (2010) Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer. N Engl J Med 2010; 363:733-742

[12] Hibbard, J. et al (2009). The development and testing of a measure assessing clinician beliefs about patient self-management. Health Expectations, March 2010 13 (1) p65-72

3 Shared ambitions for improving quality and outcomes

It is our ambition that by 2020:

- We will make the NHS the best in Europe at supporting people with long-term health conditions and their carers, to live healthily and independently, with better control over the care they receive, and to transform the experience for those at the end of their life.

- We will use the National Voices definition that was developed by people with LTCs as our definition for person-centred care*

- In order to achieve this we will drive the system and behavioural changes needed to shift from treating the disease to supporting people to live with their condition(s) focussing on the person and delivering what matters to them and their families. Our actions will be supported by the co-creation of plans through clinical, patient and stakeholder engagement.

***Person-centred care has been defined by people themselves 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"

http://www.nationalvoices.org.uk/defining-integrated-care

4 Planning for change together

To understand what is needed to facilitate change and improve person-centred care, clinical leaders, health and care professionals, people with LTCs and carers came together to build a consensus on how to tackle this challenge. This resulted in the production of **"Our Declaration; Person-Centred Care for Long-Term Conditions"** as a system-wide declaration along with **five priorities for action** to turn this narrative for person-centred care into a reality.

The declaration aims to support person-centred care for all people with LTCs; children, young people, adults and carers; from all communities and respects the varying degrees of readiness and support needed for all involved. The declaration, along with the National Voices "I" statements aim to provide a shared narrative to support people working together in partnership to co-produce the changes needed.

5 National priorities to support local change

Turning this narrative for person-centred care into a reality requires national and local action. In developing the declaration five national priorities were identified that build on and compliment other national initiatives and that will support local change to be made.

Five Priorities for Change
More conversations and public campaigns around person-centred care Key to enabling person-centred care will be supporting public expectations and changing professional attitudes. To support people with the behaviours to manage LTCs well requires the right professional behaviours as has already been set out.

The current system does not adequately support either party to proactively engage in positive conversations and relationships based on the delivery and support for person-centred care.

Develop a basket of person-centred improvement measures

People, organisations and systems move in the direction of the questions asked of them. What is measured is, implicitly, one of the most important questions asked of a system. Within the NHS there are a range of measures used. Predominantly, however, they are either condition focused or focused on a particular level within the system e.g. hospital based services. Few measures track journeys of care (the use of the word pathway although helpful creates limiting assumptions as it implies that management of an individual's care is rational and conditional: it isn't – a journey, however, can incorporate many pathways). Measures are predominantly focused on what matters to clinicians and the system rather than beginning with and valuing the measurement of what matters most to an individual.

Incentivise outcomes for person-centred care

The current design and application of incentives in the system does not recognise or reward prevention or anticipatory care. The development of payment for episodes of care has had benefits in clarifying benchmarked costs, supporting activity and delivery of access to finite episodes of care. The detriment, however, in driving the management of long-term condition is that such management is not finite: it requires continuity of care. Incentives across the system are weakly, if at all, linked and therefore do not sustain or properly drive prevention and proactive anticipatory care to the extent required for long term condition management.

Making the case for whole system change to focus on the individual

There is increasing evidence that person-centred care improves value for the system and for the individual. Defining value using quality and cost means that improving effectiveness and safety are important but experience of care is given equal priority. Care and compassion are enhanced by seeing the person, not just a condition. Sackett[13], and latterly Gray[14], moreover defined evidence based practice as the integration of clinical experience, patient values (and preferences), and the best research evidence into the decision-making process for patient care, which person-centred care supports. The principles of person-centred care recognise the assets the individual brings into the consultation. In the 21st century, expectations have changed; digital access to information means the professional is no longer the repository of knowledge and individuals are in a position to take more control of their care and decisions about their care, if they are enabled to do so.

Focus on care and support planning

The key intervention to enable person-centred care is the consultation. There has been the development of clinician-facing tools to support person-centred care in the consultation, and many tools to support people with LTCs to prepare for and be an active partner in the discussion and decision-making process. However, both professionals and people with LTCs are often unaware of these or are unclear about

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[13] Sacket. D.L., Rasen, W.M.C., Gray, J.A.M. & Richardson, W.S. (1996). Evidence-based medicine: what it is and what it isn't. British Medical Journal. 312 (13 January) 71-72

[14] Muir Gray, J.A. (1997). Evidence-based health care: how to make health policy and management decisions. London: Churchill Livingstone

the benefits and how best to use them. The consultation is often based on the medical issue at hand with little time to enter into a discussion about what matters to the person.

6 NHS England’s plans and progress so far on the five priorities

You said…we need to develop a basket of person-centred improvement measures

We have:

- Developed the LTC dashboard that sets out a population level assessment of care for Clinical Commissioning Groups and Local Authorities
- With Public Health England, improved data and intelligence through the Atlas of Variation and Commissioning for Value packs
- Tested use of Patient Activation Measure (PAM) and Clinical Support for Activation Measure (CS-PAM) to assess the level of patient engagement in self-management and levels of clinical support for patient self-management

We are planning to:

- Develop a suite of indicators to measure person-centred care for LTCs
- Continue to improve data quantity and quality to understand current and future delivery of person-centred care including community-based care, care and support for older people and at the end of life
- Support local areas to test metrics and outcomes as part of new care models
- Investigate the barriers and system levers to introducing interventions which support person centred care through the Realising the Value Programme
- Support the wider roll out of Patient Activation Measure
- Publish an evaluation report on how PAM can be used within the NHS, its value to clinicians and commissioners as a tool to support self-management, and the impact of the tool on service provision
- Publish a report on how much clinicians support patient activation and what will help them to better support patients taking an active role in their health and care
- Test how to monitor progress with implementing personal health budgets in terms of numbers, outcomes and experience.

You said…we need to incentivise outcomes for person-centred care

We have:

- Implemented and are supporting roll out of personal health budgets

We are planning to:

- Test individual level commissioning and budgets to incentivise person-centred care through the individual personal commissioning programme
- Review and strengthen the incentives currently available

You said…we need to make the case for whole system change to focus on the individual

We have:

- Improved evidence and implementation to support local commissioning of better

LTC care through production of the LTC Commissioning Toolkit which takes a whole system evidence-based approach to the delivery of person-centred, coordinated care.

We are planning to:

- Develop tools including an economic model, to support commissioners to implement a key set of evidence based approaches to person centred care, including through the Realising the Value programme
- Develop a framework and supporting products for different commissioning models for coordinated care including the use of population diagnostics, modelling tools, capitated budgets, contracting options and risk and reward schemes
- Support the system to recognise and act on the importance of ensuring that patients and the public have access to and are able to act upon high quality, accessible and reliable information related to their condition.
- Develop a collaborative approach to embedding the principles of shared decision making. This will support the development and implementation of patient decision tools, and also support approaches that recognise the changes in professional and patient culture and behaviours required to support shared decision making.
- Test how best to bring together an individual's health and social care funding, and how to give them more control over how this money is used through person-centred care planning and personal budgets through the Integrated Personal Commissioning Programme

You said…we need more conversations and public campaigns around person-centred care

We have:

- Co-founded the Coalition for Collaborative care bringing together people, including people with long-term conditions, and organisations from across the health, social care and voluntary sectors that are committed to implementing the changes needed to improve person centred care for people with long- term conditions
- Developed the declaration for person-centred care.

We are planning to:

- Support engagement in person-centred care through a range of activities including identifying and supporting champions to be national and local change agents
- Continue to be an active partner in the coalition for collaborative care and support their activities.
- Revise and implement the Healthy Ageing Guidance

You said…we need to focus on care and support planning

We have:

- Produced a set of handbooks for commissioners and care practitioners to help them in implementing personalised care and support planning, and further support and resources will be developed including support for patients and carer

We are planning to:

- Develop further commissioning products to support older people with frailty including: Prevention of Frailty; case finding and diagnosis of multi-morbidity and frailty; interventions for low, moderate and severe frailty; development of metrics for care of older people to support commissioners
- Work with Health Education England to develop workforce skills for professionals caring for people with LTCs
- Support enhancement of, and oversee delivery and uptake of the Summary Care Record
- Support expansion of personal health budgets to encourage the wider uptake of care and support planning