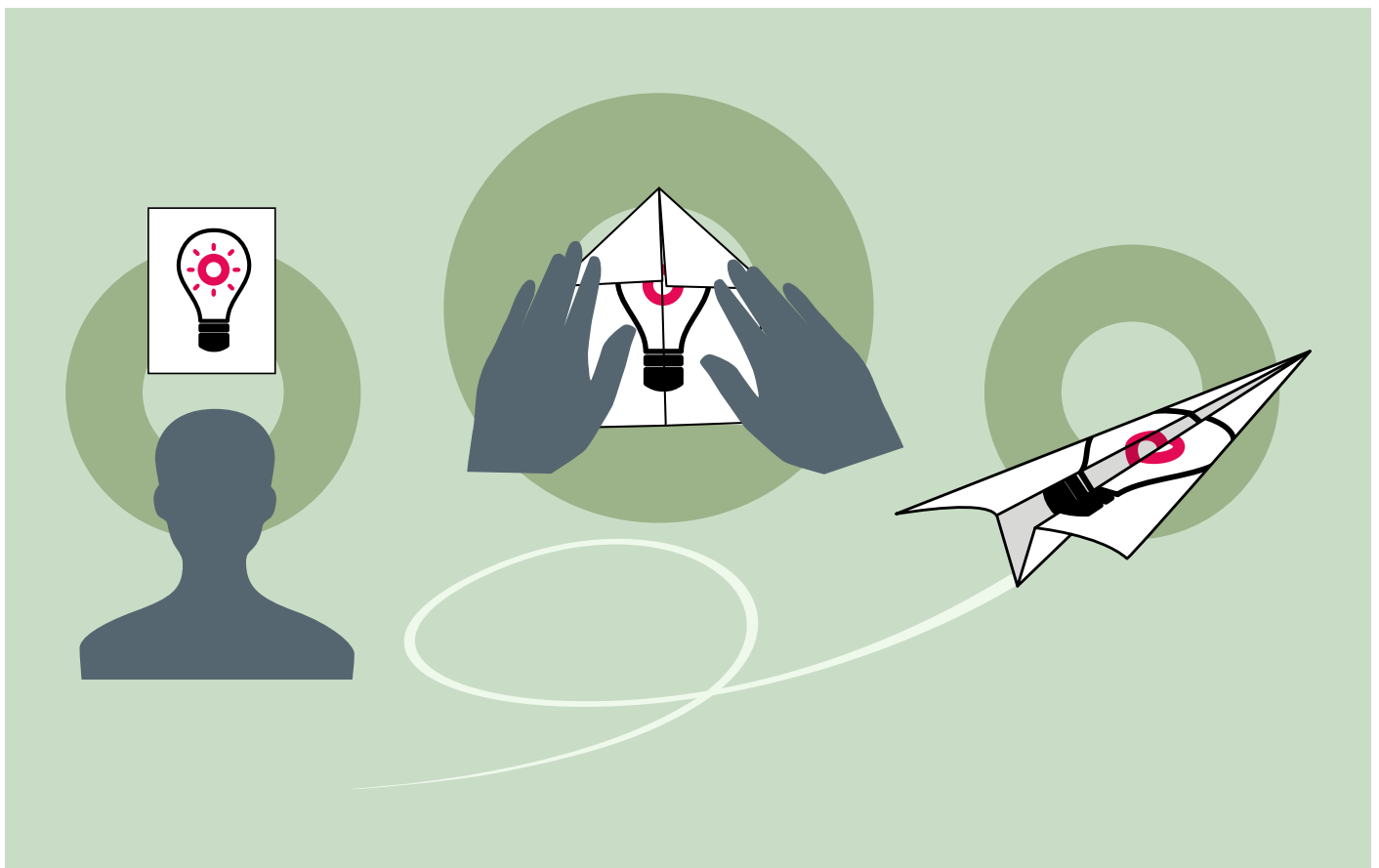# In brief

Person-centred care: from ideas to action

Health Foundation summary and analysis

October 2014

For more information and to download or order the full report, please visit:
www.health.org.uk/pccideasaction

Putting aspirations into practice

In 2013, the Health Foundation commissioned a review to synthesise current knowledge on shared decision making and self-management support and how to make these an integral feature of health care.

The full research report, *Person-centred care: from ideas to action*, draws together and analyses the research, policy, empirical evidence and evidence from programmes. There is also an accompanying learning report, *Ideas into action: person-centred care in practice*, which focuses on how to implement change locally. To download and order these reports, please visit www.health.org.uk/pccideasaction

This 'In brief' looks at the implications of the research for policy makers and those responsible for providing strategic direction to assist them in moving person-centred care and support from an aspiration to an actuality.

The issues considered in document are relevant in the four UK countries. To illustrate our analysis, we have drawn upon the specific roles of those responsible for the strategic oversight, direction and regulation of the health care system in England.

The gap between commitment and practice

There is increasing and welcome recognition that people who use health services can no longer be viewed as passive recipients of care but rather are active co-producers of their own health, including through decisions about whether and what treatments to accept or by taking on day-to-day management of their health and care.

This recognition is manifesting itself in a growing alignment between government, clinical and managerial leaders, patient groups and commentators across the four nations of the UK, behind the aspiration of a more person-centred health service (see Figure 1).

Supporting this aspiration is a growing empirical and practical evidence base – from the work of the Health Foundation and others – on the impact of shared decision making and self-management support, what gets in the way and what needs to be in place to enable them to become normal practice.

Yet there remains a stubborn gap between the commitment to person-centred care and support and the reality on the ground:

– Only around half of people are involved as much as they want to be in decisions about their health care, a figure that has remained stubbornly constant for the past 10 years.

– Only 3% of people living with a long-term condition report involvement in their care plan.

– There are fewer places on self-management programmes available each year than there are people newly diagnosed with a long-term condition.

Why does this gap persist?

It is perhaps not surprising that the gap between commitment and practice exists: person-centred care and support is still novel. It is multifaceted (as shown by Figure 1). It involves, as does any change, asking individuals to change their roles and their behaviours and organisations to change their culture. It is one part of a complex NHS system, where energy is often drawn towards structural change at the expense of quality improvement. It is one of many priorities of professional and system stewards and regulators who have many other priorities on their plate which are more intuitively part of their history and expertise.[1]
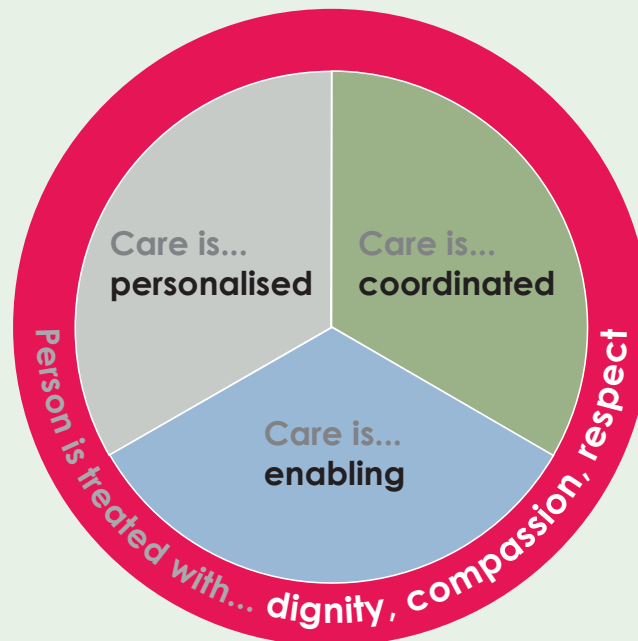
The research draws our attention to a number of barriers, discussed below, that have held back shared decision making and self-management support from becoming 'business as usual'. Paying attention to these points can inform a more coherent and effective approach to implementing person-centred care and support.

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1   By system and professional stewards we mean those public bodies that are responsible for the strategic oversight, direction and regulation of the health care system and the development of health care professionals. This includes central government departments, their arm's length bodies, royal colleges and similar bodies.

Figure 1: What is a person-centred health system?

We can discern four principles of person-centred care and support.

The four principles of person-centred care

Where would we start if care and support were person-centred?

– We would start by understanding what matters to the patient

– Every encounter would be one which embraces the patient as person rather than object

– We would explore their health beliefs, motivations, knowledge, skills, learning styles and familial and social context as well as according to their disease and demography

– Interventions would be targeted and tailored based on these insights to support people where they are at to achieve their goals

– The NHS will measure:

  • how far people's preferences are supported;

  • how confident and able people are to manage their long-term conditions better;

  • the extent to which the NHS has been successful, working in partnership with others such as social care, housing and the voluntary sector, supporting people to achieve their outcomes.

Shared decision making and self-management support are core activities that support the translation of these principles into practice. In particular, they are enabling activities that support people to have agency over their health and decisions about their health care.

Compartmentalised policy

The distinct roots of shared decision making and self-management support can help us understand why they have developed separately in policy, regulation and professional practice. Shared decision making is rooted in sharing evidence-based information and patients[2] having the ability to understand and trade-off between risks. Self-management support is built upon coaching with support for incremental achievements towards life goals and patients having the knowledge, skills and confidence to enact and sustain behaviour change. Where shared decision making is grounded in information being the foundation for making specific and discrete choices, self-management support is more grounded in the capabilities and resourcefulness of patients to problem-solve.

However, in practice, decision making and support are often part of the same encounter. Many encounters will demand of clinicians the ability to flex between the different tools, techniques and skills that have historically been compartmentalised into these disconnected spheres.

Bringing together our thinking and learning on shared decision making and self-management support can help join up policy and its support for practice. Both seek to understand the patient's perspective; both demand that health services engage with a person not their illness or condition; both see patients as assets, with their own unique strengths and resources whose application will determine the outcome of health care.

Simple approach to a complex issue

Person-centred care is a complex arena. It pivots around a relationship between parties with their own histories, identities and purposes. It takes place in an interconnected set of organisations and communities with distinct cultures and social norms.

The capacity for a person to participate in decisions, set and achieve goals or manage their health is therefore not a choice they can enact alone. But the research highlights that policy makers and services have focused their energies on seeking to equip patients to take on a more active role.

Person-centred care is a factor and consequence of the dynamic created by the way care is provided. For people to be more active in their care, more attention therefore needs to be paid to ensuring clinicians, managers, services and systems invite, enable and support an active role.

Knowledge, experience and expertise

A broader focus is beginning to emerge. Health Education England's strategy, *Framework 15,* begins to draw attention to the importance of supporting health care professionals to have the skills and confidence to engage in more collaborative approaches to care.[3] The Care Quality Commission (CQC), NHS England and Monitor are increasingly turning their attention to developing the NHS's infrastructure, capacity and capability to support this new approach. However, these are tentative first steps. These organisations are on their own journey to developing their knowledge and skills in these areas – and do so while being pulled by many other competing demands, facing their own financial constraints and where the pool of expertise to help them on this journey is limited.

Tension in purpose: ethical and instrumental

The research draws our attention to the tension between a rhetoric of person-centred care and support being the right thing to do and its instrumental goal of delivering both better clinical outcomes and less costly health care utilisation. This tension may be inevitable and even healthy in a publicly funded NHS. But a focus on instrumental aims alone can lead to shared decision making, care planning and self-management support being adopted in ways that retain clinical and service control, and so defeat its own purpose.

Tension between complementary purposes in health care

The NHS was set up largely to meet health needs that were out of people's control. In part due to its success in keeping us alive when previously we would have died and in part due to 'lifestyle' diseases, the demands on the NHS today are very different to when it was established. The role of the NHS can no longer solely be to heal us, remove disease and infirmity. Rather, it can help to mitigate the impacts of disability, illness and disease upon our lives and support us to adapt to live our lives optimally.[4]

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2 What we call people who use health services raises hackles: patients, service users, people with lived experience, clients, consumers, all have connotations they may reflect our understanding of person-centred care. This In brief uses patient, recognising that it has inherent within it a history of passivity and disempowerment.

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3   http://hee.nhs.uk/2014/06/03/framework-15-health-education-england-strategic-framework-2014-29/

4   See www.bmj.com/content/343/bmj.d4817

This requires interventions that work within and are coordinated around people's social context from a psychological as well as biomedical standpoint. It means starting with the question 'What matters to you?', rather than 'What's the matter with you?' These sorts of changes in equilibrium don't happen on their own. They need an injection of energy to break the chemical bond which binds a passive patient to paternalistic medicine.

More broadly, it means moving away from an orientation in which the habits and rules of providers and professions come first, to one in which the world is seen through the eyes of the person. It is a radical reframing of roles in which, for example, the clinician's role is to fix to one which builds upon people's strengths and capabilities (see Table 1). Self-management and shared decision making are at the heart of this change.

What are the implications for policy and system stewards?

The challenge that now faces system and professional stewards and regulators is to translate their commitment to person-centred care into specific actions that will create an appropriate and supportive infrastructure, which will in turn facilitate and guide change in practice. While not easy, putting the levers for change in place is an essential step. It will require doing different things as well as doing things differently.

What these different things are and how to do things differently are questions we are all grappling with. Drawing on the research, we set out below our reflections on what actions we think are needed. These thoughts are intended as pointers for deeper exploration: there is no blueprint, no off-the-shelf set of system tools.

Table 1: Shared decision making and self-management support: the changing roles of patients and clinicians

	Current practice	Person-centred care
Roles and beliefs	Patients passive, believe clinician has the answers and will improve their health	People active partners and managers of their health
	Clinical expert gives advice, fixes, cares for and promotes dependency	Clinician cares about, listens and uses expertise to support and enable patient as a partner in decision making and management of their health and care
	Policy and practice assume knowledge creates behaviour change	Policy and practice recognise that knowledge, skills, confidence, self-efficacy and motivation create behaviour change
Model	Primarily medical	Biopsychosocial
	Values clinical outcomes	Values outcomes that matter to people
Who	Workforce = clinicians	Workforce = clinicians + peer support workers + navigators + health coaches + ...
How	Clinician shares results and information during consultation	Person receives results and information at appropriate time to enable them to set their agenda and make their decisions
	Clinical training in 'communication' skills used to enable them to get patients' agreement to clinician determined goals	Clinical training in skills to support people to determine and enact their own goals
	Compliance with clinically determined goals and treatment plans	Collaborative care and support planning with adherence to co-produced goals

A holistic and joined-up approach to change

Person-centred care requires a holistic approach to secure change locally, supported by national enablers in the following three areas:

– Supporting individuals to understand, appraise and apply health information; to be knowledgeable, skilled and confident in managing their health; and to be motivated to become active partners in their health and care.

– Supporting health care professionals to recognise the need and to develop the necessary confidence, skills and knowledge to take on new roles and to work in partnership with patients.

– Building alignment nationally and locally of measurement, processes, financial flows, guidance and regulation to support and encourage these new roles and relationships.

This offers a framework, illustrated by the metaphor of the house of care,[5] for system and professional stewards and regulators to both focus and test their activities.

In addressing each of these areas, we need to recognise the interplay between an individual's personal motivations, the cultural norms within their profession and place of work and the (small-p) political and policy drivers of local NHS systems. Alignment between these individual, social and contextual spheres will support the transformational change in practice that is at the heart of person-centred care.

Policy and system stewards impact across these spheres. For example, education can inform an individual's identity; payments systems focus managers' attention on delivering some outcomes and away from delivering others; professional rewards have a similar impact; CPD can have little impact if it trains individuals in new behaviours and roles in isolation from their peers. Without strong alignment between system stewards in their purpose, policies and practice, we will struggle to achieve a positive and lasting shift to person-centred care.

Supporting individuals

The NHS invests heavily in developing a workforce with clinical knowledge. Yet it expects patients to take on shared decision making, care and support planning and self-management while providing little support to enable them to develop their capabilities to become partners in their own health and care. For people to share decision making and to self-manage more effectively, they need not only information but also motivation, confidence and skills to do so.

Person-centred care: from ideas to action helpfully synthesises the current evidence about those interventions that are most effective in supporting people to take on a role in self-management and shared decision making, and the factors that can influence whether interventions are appropriate and successful. The evidence suggests that packages that combine different interventions work best both in increasing self-efficacy and leading to behaviour change. The report confirmed the findings from the Health Foundation's two previous rapid evidence reviews.[6] These found that proactive interventions or strategies to support self-management and shared decision making were needed – information provision alone was unlikely to be sufficient to motivate ongoing shared decision making or improve self-management behaviours or clinical outcomes. Unsurprisingly, then, the interventions that are most effective are those that take such a proactive approach. These included:

– group-based education and support for people living with long-term conditions

– peer support – both based within NHS organisations and in the community

– health coaching – by appropriately trained clinicians and by non-clinical health coaches.

In addition, the voluntary and community sector offers skills, knowledge and capacity beyond the scope of mainstream services. This could unlock a new resource with the potential to train patients, moving us to scale more quickly.

5   The House of Care developed out of the Year of Care in Diabetes, with care and support planning at its heart. NHS England has developed a House at system level which puts person-centred care at its core. See: www.england.nhs.uk/house-of-care

6   de Silva D. *Helping people help themselves*. The Health Foundation, 2011. www.health.org.uk/publications/evidence-helping-people-help-themselves

    de Silva D. *Helping people share decision making*. The Health Foundation, 2012. www.health.org.uk/publications/helping-people-share-decision-making

    See also www.nationalvoices.org.uk/evidence

Supporting professionals

– **The importance of professional identity**. Clinical practice is driven by a desire to do good. The successes of clinical intervention underpin a belief in the ability of science and medicine to cure illness and disease. However, we may want to reflect on what to 'do good' means as society changes, as modern clinical practice provides multiple ways to address a clinical issue, and creates clinical issues that cannot be addressed, and as a growing proportion of the population live with one or more long-term condition. Professional bodies and others can lead their members in redefining it – perhaps as a duty to support patients to achieve the decision and goal that is right for them, perhaps expanding trainees' early exposure to understanding what 'good' means for patients, and perhaps with greater use of patients as teachers.

– **The importance of practical training**. One of the most common barriers in practice was a lack of recognition of the need to change. 'We already do this' has been found to be a common refrain among health care professionals attending training courses and puzzled when challenged that they do not practise person-centred care. The programmes examined in the research demonstrate the importance of practical training in helping clinicians recognise that they had not been sharing decision making or supporting self-management after all, and to become receptive to how they can do it better.

– **The importance of training teams**. The research highlights the importance of training teams, not individuals. This means everyone will speak the same language, have the same understanding and be motivated towards shared goals: it provides the support infrastructure that enables learning to be translated into practice. This indicates the need for a significant acceleration in multi- or inter-professional training and team training as a far more normal part of development.

– **The importance of starting with clinical leaders**. The hidden curriculum is a powerful force within the NHS. It is not enough to change education and training. Teaching the trainers, who role model behaviour in practice, first will have an impact on both current practice and the training of the next generation. It may also be necessary, in the short term at least, to use train-the-trainer programmes to rapidly expand the number of people able to train their peers.

– **The importance of new roles**. Developing both the capacity and capability of new roles, such as peer workers, health coaches and care navigators who work within and alongside traditional services, highlights the demands of carving out a new training pool from within existing resources. This may lead us back to fruitful partnerships with the voluntary and community sector.

The aspiration of Health Education England's *Framework 15* presents a significant challenge for professional bodies, the education and training stewards and the education sector. A shift in curricula and investment to build a workforce with the skills for the 21st century is needed, developing a workforce that feels as comfortable with shared decision making, self-management support and care and support planning, as it does with clinical diagnosis, drug prescribing and dispensing, and monitoring patients' progress.

A supportive system

A clear message from the programmes that have sought to embed and spread care and support planning, self-management support and shared decision making is the importance of a whole system approach. If systems and processes do not support and align with changes at the individual and clinician level, change is unlikely to be sustained.

This has implications for national policy makers and system stewards about how macro systems and policies need to align around a common purpose and goal if we are to have any chance of reaching tipping point in the spread and adoption of self-management support and shared decision making across the NHS.

The Department of Health, through its role in setting the objectives for the arm's length bodies and in holding them to account, has an important role in creating a clear focus on person-centred care in their priorities.

Equally, in order for system stewards to design their policies, guidelines, inspections and incentives to support and enable shared decision making and self-management support, their own workforce will need to be supported to develop the knowledge, understanding, skills and confidence to develop guidelines, to inspect and to design payment systems which start from the premise of a patient-, not provider- or professional-, focused NHS.

A shared purpose, understanding and language

The way that the policy intents of government and system stewards are framed has a powerful impact on the actions that follow.

We do not yet have the articulation of a coherent, consistent and clear vision of person-centred care which expresses a common understanding. The language of policy often projects a frame in which the health service still ultimately defines the purpose, parameters and practice of how far patients are 'involved' and may serve to unintentionally reinforce a paternalistic and impersonal paradigm in health care.

This is perhaps understandable: as shared decision making and self-management support become more common currency, in conversation at least, they shift from abstract concepts to complex and nuanced constructs. They become messy. If we recognise this, if we seek to understand that our implicit assumptions and habitual behaviours may be grounded in a different worldview, then we can begin to collectively develop a narrative that conveys the true sense of a person-centred health service. This narrative will communicate the holistic approach and multi-layered web of activity necessary to make change happen – developing patients and clinician skills, introducing and embedding new roles and creating a supportive infrastructure.

Shared decision making, care and support planning and self-management support shift the locus of power. This is a fundamental issue to grasp. In shared decision making and self-management support, patients engage services rather than services engaging patients; being 'empowered' means patients having the knowledge, skills and confidence to make decisions about and better manage their health rather than a measure of their adherence to professional directions and medical management instructions. Person-centred care and support is both the purpose and the means of delivering health services, rather than a bolt-on to what may otherwise feel like a clinically-driven, bureaucratically run service.

Putting the person at the heart of regulation, guideline development and payment systems

If we want to deliver value to patients, the four principles of person-centred care (see Figure 1) offer a framework for:

- developing clinical guidelines
- regulation and inspection
- NHS payment systems.

Guidelines

NICE has an aspiration to put person-centred care and support at the heart of its approach. The challenge of shifting from single-disease focused guidelines to take account of multi-morbidities highlights the hard road that lies ahead in reframing the way that guidelines are produced. Building guidelines from a person-centred approach upwards is likely to be even more challenging.

One tool that may help in this shift would be to test all new guidelines against a set of person-centred questions. For example: how do they support patients to manage their own health?; how do they support patients to make decisions about their own health care?; how do they respect the dignity of the person to whom the treatment will be offered? This might help refocus guidelines from clinical, disease-specific pathways, to person-centred pathways. Closer attention could also be paid to the potential for technology appraisals for enabling activities, such as group education and training. NICE could also explore the potential for embedding brief decision aids for shared decision making in clinical guidelines.

Regulation

Turning the aspiration of person-centred care into a programme of action offers a different set of challenges for the system regulators such as the CQC. Currently regulation is based around organisations; but people's care often straddles boundaries between different health care organisations, and increasingly more widely. The regulators could root their inspection regimes around providers' ability to demonstrate how they are enabling care and support planning, shared decision making and self-management support, for example, by how well organisations support people's knowledge, skills and confidence to manage their long-term condition more effectively.

It will be challenging to identify organisations that are giving patients tests or treatments they would not want if they had greater agency over their health and care. Nonetheless, can a health care provider really be fit for purpose if it is over-intervening in people's lives? The Atlas of Variation may be a helpful starting point for enquiry into the extent to which an organisation is oriented to patient needs and wants.

The CQC already carries out thematic reviews in a number of areas such as end of life care and learning disability. A thematic review based on person-centred care might offer a baseline understanding of the person-centredness of organisations; developing the framework for the thematic review might also help tease out the questions and challenges of regulating for person-centred care and support.

Payments, incentives and commissioning

A strong theme to emerge from some of the England-based programmes examined in the research was the place of commissioning and payment frameworks in embedding collaborative care into mainstream practice. On the whole, these were currently seen as a barrier due to a model of payment that rewards activity rather than quality-oriented goals such as patients having the knowledge, skills and confidence to better manage their long-term condition or the agency to share in decision making. The annual cycle
of the payment system and other incentives such as national CQUINs also made it difficult for people to invest in long-term change; something which we know is critical in this area.

Monitor and NHS England have a difficult task ahead in shifting the incentive structure from activity- to outcome-based. An important question to continually bear in mind will be 'What outcomes for whom'? A clinically successful knee operation is only a successful outcome if it enables the patient to better live the life they want to.

Patient Reported Outcome Measures (PROMs) offer a way into thinking about outcomes, but such measures need to reflect the outcomes patients determine are important to them rather than to be a measure of the success of what clinicians or the system determines is important.

It may be helpful to consider if payments for services could be based on outcomes such as:

– improvements in patients' knowledge, skills and confidence;

– the extent to which patients' preferences are being taken into account;

– patients achieving the outcomes that are important to them.

In addition, it may be helpful to think of questions, similar to those suggested in the section on guidelines above, against which new payments can be tested.

Re-prioritisation of applied health research

Self-management support and shared decision making are relative newcomers in applied health care research. Yet they could make a greater impact on health and well-being over the next 20 years than new drugs which add marginally to length of life. More work is needed to address questions such as:

– What interventions work for which people in what circumstances?

– How are brief decision aids best designed and effectively used in a consultation?

– What person-centred care processes do we need to put in place in order to reliably bring about improvements in person-centred outcomes?

– How do we measure those outcomes and use them to drive service improvements?

– How do payment systems support or act as barriers to person-centred care?

NIHR and other research funders have a significant role to play in drawing up and delivering a strategic research agenda for person-centred care. This can directly drive practice. It can also underpin the work of other system stewards, providing the foundations for guideline development, system regulation and professional education and training.

Where to from here?

There is a growing recognition that the NHS cannot continue spending money on prescribing medicines people do not take, undertaking surgery that people wouldn't choose if supported to make decisions in line with their preferences, or providing appointments for people with long-term conditions based on the convenience of the service but unrelated to individuals' needs.

Shared decision making and self-management support may or may not lead to cost savings in all areas of health care. But they should provide better value for whatever money is spent because they drive the NHS to address needs as defined by the people using health services – patients, service users, people with lived experience, clients, consumers or however we want to refer to ourselves – rather than provider defined needs.

The commitment in policy statements by system and professional stewards and regulators is to be welcomed. But shared decision making and self-management support remain marginal in the practice of health care.

The innovators and leaders who have demonstrated their impact in this area and who are operating in a new paradigm remain a minority. If their work is to become widespread, we need to translate the policy intentions into actions that will help drive and embed person-centred care in day-to-day health services. This will be hard work. Person-centred care is complex and it is novel within current care approaches. We lack the bedrock of experience and scale. The transformation to a person-centred care system will therefore require resources to support the types of activities suggested here. Without such practical, focused and forensic leadership, the gap between aspiration and reality will be as wide in 20 years as it has been for the past 20.

The Health Foundation is committed to continuing to support this transformation. We are equally committed to working alongside the system and professional stewards and regulators who hold the challenging responsibility of creating the environment, laying the infrastructure, putting in place the incentives and building capability and capacity that will help close the gap between policy intent and practical reality.