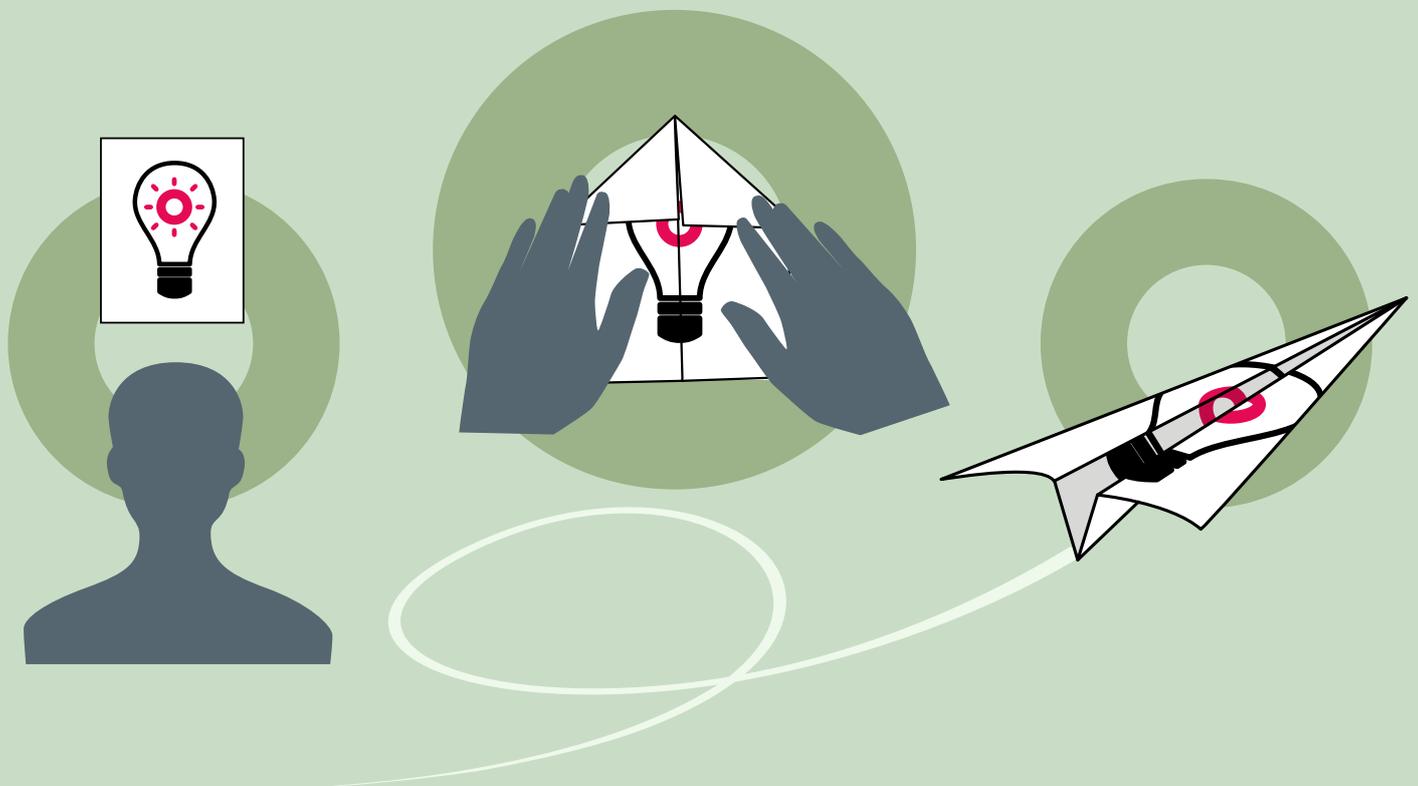


Person-centred care: from ideas to action

Bringing together the evidence on shared decision
making and self-management support

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A note on language and terminology

The field of person-centred care is awash with terminology. As we discuss later in this report, there are myriad concepts and terms used to describe both the broad principles associated with individuals actively participating in their health care, and the specific ways in which participation is enacted and enabled. Many of these terms are contested, some are contentious. Implicit in all are particular ways of understanding patients, professionals and the relationship between them. It is not our intention, nor was it our brief, to resolve this terminological complexity, if indeed this is achievable. Nonetheless, we have sought to use language which reflects an ethos of patients as genuine partners in care, and highlight language and assumptions that detract from or run counter to this.

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Executive summary

Introduction

This report is the product of work which has sought to bring together the evidence on shared decision making and self-management support, with the aim of providing greater coherence and clarity in debates about person-centred care.

For more than ten years, the Health Foundation has been working to promote a more person-centred health care system, where people are supported to make informed decisions about and successfully manage their own health and care, and choose when to invite others to act on their behalf. Shared decision making and self-management support have been important areas of this work.

Shared decision making is a collaborative process through which a health care professional supports a patient to reach a decision about their treatment. The conversation brings together the clinician's expertise, such as the treatment options, risks and benefits, with the areas that the patient knows best: their preferences, personal circumstances, goals, values and beliefs. The approach often involves decision support materials – evidence-based information resources, including patient decision aids, brief decision aids, and option grids – that are designed to help individuals weigh up their options.

Self-management support enables people with long-term conditions to manage their health and wellbeing, day by day, as effectively as possible. It is an active collaborative relationship between patients and health care professionals. Putting it in place involves supporting both patients and health professionals to develop their knowledge, skills and confidence to engage in this new way, as well as ensuring that patients have support before, during and after an appointment.

What did we do?

We undertook the task of 'bringing together' the evidence on four different, but interconnected, issues:

- What is the conceptual relationship between shared decision making and self-management support?
- What is the policy context for person-centred care in the NHS, and where do shared decision making and self-management support sit within this?
- What does the empirical evidence say about the outcomes and impacts of interventions to enact shared decision making and self-management support?
- What works in implementing shared decision making and self-management support into mainstream health care services?

To answer these questions extensive published and grey literature on the above themes were analysed; in-depth interviews with people involved in the design, delivery and/or evaluation of 11 national implementation programmes carried out; and a seminar held with health care professionals, researchers, policy makers and educators to share emerging findings and consider their implications for future policy and practice.

The conceptual relationship

The two concepts have distinct roots and have developed separately. Shared decision making is based on the sharing of evidence-based information, with patients understanding, and then trading-off between, risks. Self-management support has emerged from social models of health and is based upon coaching and supporting incremental achievements towards life goals, with patients using their knowledge, skills and confidence to enact and sustain behaviour change.

However, the task of exploring the relationship between shared decision making and self-management support is not an easy one. There isn't a single agreed definition of either concept and both have narrower and more broadly defined variants. The relationships between the concepts can also vary, from being seen as only loosely related concepts, to being different practices underpinned by the same values or key aspects of person-centred care.

These distinct roots can, therefore, mean that successful implementation into mainstream health and social care services requires different tools and approaches.

The policy context

In all four countries of the UK, person-centred care has become one of the major goals of health policy and recent system reform. Moreover, the definition of what it means to be 'person-centred' is expanding, from a historical focus on listening to patients, to a growing recognition of the active roles that individuals can play as partners in care processes. Both ethical and instrumental cases for person-centred care have been made. The first makes a values-based argument, presenting person-centred care as respecting autonomy and being a good in its own right – the 'right thing to do'. The second justifies person-centred care as a means to achieve better outcomes. Policy makers have tended to link the vision of more engaged and informed patients with improvements in health behaviours, health and wellbeing outcomes, and less (or less costly) service utilisation.

So far, slow progress has been made towards implementing person-centred care. However, our review of the current policy context suggests that it offers some opportunities for embedding shared decision making and self-management support into mainstream services.

Above all, the ever-rising demand for health care services, coupled with a very challenging financial climate, has propelled the issue of large-scale transformation of services from important to imperative. Redesigning care and support for people with long-term conditions, and the broader goal of health and social care integration, are priorities in all four countries of the UK. It is increasingly recognised that the financial sustainability of the NHS requires a reorientation away from traditional, paternalistic models of care to an approach focused on prevention, empowerment and proactive management. The underlying premise is that these new models will be more efficient.

The empirical evidence

Our analysis of the empirical evidence base builds on two previous reviews commissioned by the Health Foundation in 2011 and 2012. Our main aim was to identify any more recent studies – particularly systematic reviews and controlled trials – which might alter the conclusions previously reached. Outcomes were grouped into four main categories:

- self-efficacy (people's motivation and confidence in their own ability), knowledge, experience, empowerment and satisfaction with care
- patient engagement in more 'healthy' behaviours, or general behaviour change
- clinical and quality of life outcomes
- cost and resource implications for health and social services.

Overall, evidence of impact tends to be greatest for self-efficacy and weakest for health care utilisation and cost, although outcomes vary depending on the type of intervention and health condition (or conditions) of the target patient group. Both self-management support and shared decision making interventions generally tend to improve people's knowledge (eg, of their condition or of their treatment options), confidence to participate and satisfaction with their health care. For example, in relation to shared decision making, increased satisfaction can come both from individuals feeling more engaged with decisions about their care, and a sense of having made a 'better' decision.

The evidence base for self-management support and shared decision making, both in terms of their impact and on how they are implemented, continues to grow. However, perhaps inevitably, some of the evidence is contradictory, of variable quality and there are gaps in our knowledge. This partly reflects challenges in designing, implementing and measuring interventions, in identifying and isolating the intervention's 'active ingredients', as well as the difficulty of aggregating data of poor quality or from different and not always fully described methodological approaches.

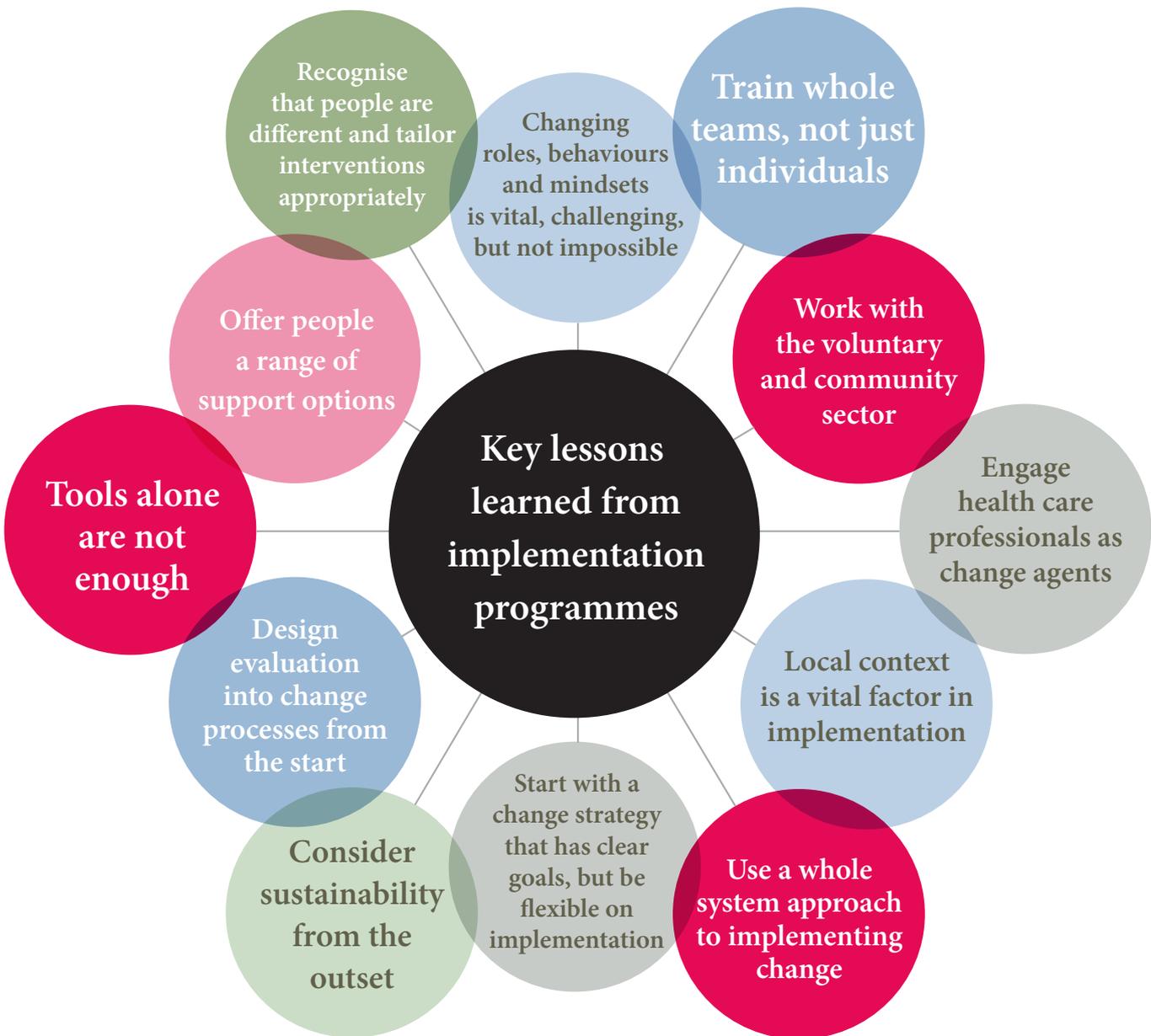
What works?

We examined evidence from eleven large-scale innovation programmes (see Box 5.1 on pages 52–53) that were working to implement shared decision making and self-management support. These programmes represent some of the earliest adopters and innovators in the area of person-centred care in the UK.

The programmes varied in populations, disease areas, providers and interventions. However, despite this diversity, we found some common themes from the programmes and identified a dozen key lessons for those looking to implement self-management support and shared decision making into mainstream care. These are summarised in the figure below and described in the box overleaf.

What works to implement shared decision making and self-management support?

Lessons learned from implementation programmes



What works to implement shared decision making and self-management support? Lessons learned from implementation programmes

Tools alone are not enough. To work, tools should be embedded within a wider change in clinicians' and patients' roles and responsibilities. They also work best when used within a consultation, so that they function as part of a collaborative relationship rather than becoming a substitute for this.

Offer people a range of support options, so they can select to suit their preferences and needs. There is no single best model of self-management support or shared decision making; what works for some will not work for others. The message here is be flexible, and offer a suite of options wherever possible.

Recognise that people are different, and tailor interventions appropriately. Interventions are likely to be most effective when tailored to the patient, professional and condition. Core approaches and tools can be adapted for different groups, and staff value having the flexibility to tailor these so that they are suitable for their particular service.

Changing professional roles, behaviours and mindsets is vital, challenging, but not impossible. Staff may already consider themselves to be practising shared decision making and/or supporting self-management, and therefore not see the need for change. Others may be hesitant about adopting different approaches or find it difficult to change long-established ways of working. It is better to tackle resistance constructively rather than dismiss it, not least because doing so may uncover genuine concerns that need to be addressed to support implementation.

Train whole teams, not just individuals. Training should be delivered to whole teams to help foster collective responsibility for implementation and strengthen peer support and mutual learning. At the same time, individuals within teams may have particular learning and development needs. This suggests that a blend of team-based and more customised skills training may be most beneficial.

Engage health care professionals as change agents. Working with health care professionals as agents – not just targets – of change was identified as a key success factor. There is a range of roles that clinical champions might fulfil, through which peer influence, peer support and peer pressure can be harnessed to bring about the desired change.

Work with the voluntary and community sector. Voluntary and community organisations can offer skills, activities and reach that the health care system cannot. But health care professionals have to know about, value and trust the services provided, and support their patients to access these. Involving voluntary sector organisations as delivery partners may help towards this.

Local context is a vital factor in implementation. Good programme design is important, but success is also shaped by local contextual conditions. Areas where there was a long history of partnership working, established skills for quality and service improvement and/or synergy with other local change programmes often fared better at implementing new models of person-centred care.

Use a whole system approach to implementing change. Embedding self-management support and shared decision making into routine care requires change at every level of the system. Implementing all of this at once can be a very resource hungry process and create a great deal of instability and disruption. An incremental approach that builds on successes is likely to be more effective than attempting wholesale change.

Have a change strategy in place from the start, one that is clear about goals but is flexible on implementation. A 'designed' approach to change needs to be clear about goals, but not overly prescriptive about how these should be achieved. Professionals, teams and services must be able to shape what approaches are adopted and how, and benefit from having the scope to test out and innovate within their own practice.

Consider sustainability from the outset. How changes will be spread and sustained needs to be considered at the outset, and identified actions should be given the same priority as making the changes themselves. New ways of working and successful outcomes should be built into contracts, incentive systems and reward structures – financial levers may be of limited value in bringing about change, but are essential to sustaining it.

Evaluation should be designed into change processes from the start, balancing robustness and feasibility considerations. Staff want to know that the effort they are making to implement change is making a difference; without this, sustaining engagement may be difficult, if not impossible. Measurement can itself trigger behaviour change, by harnessing healthy competition and providing markers of improvement.

Person-centred care: from ideas to action

Chapter 1:

Introduction

Enabling people to be active participants in their health and health care is a major goal of health system reform across the UK. The vast majority of day-to-day care is already undertaken by patients, their families and friends. But the greatest gains will only be achieved if opportunities for active patient involvement are encouraged and supported by health care services. Nothing less than a transformation is required: in the relationship between patients and professionals, and to embed effective tools and techniques to facilitate patient participation into mainstream models of care.

There are many different roles that people can play as active participants in their health care. Two that have received particular attention are associated with shared decision making and self-management: individuals as decision makers and health managers respectively. While both can be seen as elements of a broader person-centred philosophy of care, they have developed – both as concepts and in practice – in rather different ways. Anyone seeking to understand shared decision making and self-management support, how they can be implemented and the outcomes they achieve would have to consult two different bodies of literature and evidence, and make the connections between them for themselves.

A further consequence is that there is confusion about the relationship between these forms of collaborative care.¹ This isn't just a definitional problem; it has very real consequences for implementation too. Efforts to embed shared decision making and self-management support in mainstream care would benefit from knowing whether these are grounded in the same values, behaviours and skill sets (or not). There is also much to be gained from knowing whether the policy and practice environment offers the same drivers and opportunities for change, and if it also presents the same challenges.

1.1 Aims and methods

These issues were the starting point for this project. Our primary aim was to bring together the evidence for shared decision making and self-management support, with the hope of providing greater coherence and clarity in debates about person-centred care. The work we have undertaken to achieve this has been wide-ranging. It recognises that the goal of 'bringing together' raises questions about the extent and nature of relationship between shared decision making and self-management support as defined conceptually, in policy and in practice.

The project comprised four main elements, and this report is organised so that each is addressed in turn. Part 1 looks at:

- the conceptual relationship between shared decision making and self-management support
- the policy and practice environment in which shared decision making and self-management support are being developed
- the evidence base about the impacts of shared decision making and self-management support.

Part 2 explores what has been learned from efforts to implement shared decision making and self-management support into mainstream health care services.

For the first of these elements, we reviewed the conceptual relationship between shared decision making and self-management support. In particular, we were keen to explore whether and how the concepts mapped onto one another in terms of their underpinning values and principles, expectations about patient and professional roles and relationships, and the situations in which each is considered appropriate and/or necessary. Comparison was no easy task because there isn't a single agreed definition of either concept –

both are characterised by a number of more narrowly and broadly defined variants. The consequence of this complexity was a mapping out of several different relationships between the concepts, each driven by different insights from and readings of the literature.

The second element was an examination of the policy and practice environment in which shared decision making and self-management support are being developed. We reviewed policy documents, commentaries and research in order to address the following key questions:

- What is the past, current and expected future context for person-centred care in the NHS? Where do shared decision making and self-management support sit within this context?
- Do the policy drivers and the practice context for person-centred care differ across the four countries of the UK? And if so, how do they differ?
- In what ways does policy act as an enabler, barrier and/or lever to embedding shared decision making and self-management support in mainstream practice?

In policy terms, one thing that shared decision making and self-management support have in common is their promotion as strategies for improving the outcomes and efficiency of health care. With this in mind, a further task was to review the empirical evidence base.

Previous reviews of this kind have typically concluded that the evidence on outcomes is mixed,^{2,3} and we too found this to be the case. So we also sought to unpick the evidence and delve a little further. Our analysis shows how outcomes vary by condition and type of intervention, cautioning against the notion of a one-size-fits-all formula for supporting patient involvement in health care. We also explored the logic of inquiry within interventions research: what kind of outcomes are being targeted, by what means are they assessed and from whose perspective? Our analysis builds on recent work identifying limitations in the design and selection of measures to evaluate the effectiveness of self-management interventions,⁴ and patients' experiences of health care processes more generally.⁵

Finally, we set out to explore what has been learned from efforts to implement shared decision making and self-management support into mainstream health care services. To do so, we reviewed extensive evidence – gathered through documentary sources and in-depth interviews – for eleven implementation programmes (listed in the box below; further details can be found

in Box 5.1 on pages 52–53), including several from the Health Foundation's own portfolio in the area of person-centred care.

The programmes reviewed

- BUPA Health Coaching (BUPA)
- Closing the Gap (The Health Foundation)
- Co-creating Health (The Health Foundation)
- Expert Patients Programme (Expert Patients Programme CIC)
- The Kidney Care Patient Decision Aids Project (NHS Kidney Care)
- MAGIC: Shared Decision Making (The Health Foundation)
- National Cancer Survivorship Initiative (Macmillan Cancer Support, Department of Health and NHS England)
- People Powered Health (NESTA)
- Right Care Shared Decision Making (Department of Health)
- Shine (The Health Foundation)
- Year of Care (Diabetes UK, NHS Diabetes and the Health Foundation)

Our analysis sought to draw out:

- the range and extent of outcomes achieved by the programmes
- learning about and examples of what works
- barriers and enablers to implementation
- lessons for ongoing and future efforts to mainstream shared decision making and self-management support.

Our thinking on the last of these was also shaped by a seminar, hosted by the Health Foundation, where we discussed our emerging findings with health care professionals, researchers, policy makers and educators and together considered their implications for future policy and practice (see Annex 1 for a list of participants). This helped to us to situate the on-the-ground experiences captured through the programmes reviewed in the wider context of complex health care systems and ongoing reform.

We also worked closely with – and benefited greatly from the advice, feedback and insightful contributions of – our partners Professor Judith Hibbard and Professor Mike Bury and a project advisory group (see Annex 2 for membership). The opportunity to share and test out our analysis with leading experts in this area has played a major role in the development of our thinking and the shaping of this report.

Part 1:
**What do we learn from the
conceptual, policy and
research literature?**

Chapter 2:

A conceptual review of self-management support and shared decision making

Shared decision making and self-management support have been largely treated as separate areas of practice and research. This review presents some conceptual considerations of both areas of work, before bringing these together to propose how the concepts may relate to one another.

It is important to note from the outset that the fields of shared decision making and self-management support are both awash with debate. Tensions exist in definition, above all between narrow (influenced by biomedicine and psychology) and broader (influenced by social and relational models of health) understandings of the concepts. Nevertheless, it is possible to trace some consensus in the dominant models.

The way in which these concepts are understood has implications for how interventions are planned, designed and implemented, and ultimately whether they are found to be successful or not. Furthermore, assumptions inherent in the concepts and the translation of these into practice frame patients, professionals and the wider health care system in different roles, through what they ask of each.

2.1 Origins and development of the concepts

Shared decision making and self-management support have largely evolved as separate concepts in different fields. Broadly, self-management support emerged from a set of theoretical propositions and debates, whereas shared decision making has been more strongly influenced by clinical practice.⁶⁻⁸

Clayman and Makoul trace the origins of shared decision making back to a focus on informed consent, framed by bioethical values such as autonomy and respect for patients.^{6,9} As it has developed, shared decision making has often been presented as the

middle ground between a paternalistic model (where professionals make the decision) and what is often referred to as the ‘informed’ model (where the decision is made by the patient).¹⁰ More recent work in the area has sought to develop an understanding of core principles which underpin a ‘shared’ decision. These include the views that information should be unbiased, patient preferences must be considered, pros and cons of different options need to be discussed, and a mutual view on the ‘right’ course of action is desirable (although may not always be possible).⁶

The concept of self-management support has evolved to encompass a wide variety of interventions with different intentions. This is largely a result of various disciplines having contributed to its evolution.⁸ There is an important distinction to make between ‘self-management’ and ‘self-management support’. The former takes account of the fact that individuals are self-managing (to a greater or lesser extent) all the time in their daily lives. Self-management therefore refers to the behaviours that individuals engage in outside of the health care context. ‘Self-management support’ – which is the focus of this report – refers to how individuals are supported in their self-management goals and activities by health care professionals (and others).

Self-management support originated from a social model of health and disability. The voluntary sector and service user groups were influential in the development of lay-led programmes of support. While early models of self-management support were grounded in educational approaches, psychological influences have become more prominent – especially from the late 1990s onwards – with the realisation that behavioural change is not predicted by improvements in knowledge alone.⁸

The psychological concept of self-efficacy has been particularly influential. Defined as confidence in one’s ability to perform given tasks, self-efficacy is

grounded in social cognitive theory.ⁱ Social cognition as an underlying theory can be seen in the many self-management support interventions which focus on problem-solving skills and goal-setting.⁸ An improvement in self-efficacy has been identified as an achievable and measurable outcome for self-management support interventions, but has not been used in the same way for shared decision making.

Shared decision making and self-management support are concepts which both reflect and are shaped by wider trends in health care policy and practice (see Chapter 3). As such, they have been developed alongside – and in some cases have eclipsed or replaced – other concepts to which they are linked. For example, a report by NHS Kidney Care¹¹ illustrates how different ideas have contributed to the evolution of concepts related to self-management. The report tracks generic definitions of ‘self-care’ from the 1970s through to 2011. As a term, ‘self-care’ emerged from the concept of health promotion in the 1970s; in the 1980s, there was increasing recognition of ‘partnership’ with health care professionals; the 1990s saw more emphasis on the continuity of self-care and so-called ‘growth’ models;ⁱⁱ and from 2000 onwards the term ‘self-management’ gained popularity, with a greater focus on long-term conditions and the trend towards more holistic models of care.¹¹

Although ‘self-management’ and ‘self-care’ are often used interchangeably, a distinction between the two concepts can be made. Both can be considered in terms of a continuum (see figure 2.1), with self-care at one end as ‘normal activity’, and self-management an extension of this, being defined as managing ‘ailments’ either with or without the assistance of health care professional.¹² A third concept of ‘shared care’ may fall next along this continuum after self-management. ‘Shared care’ refers to a partnership between health care professionals and patients that supports coping with either acute or long-term conditions.¹²

Concepts related to shared decision making include ‘informed choice’ and ‘informed consent’. Informed choice is said to occur when patients act in accordance with their own values.¹³ Shared decision making and informed choice can also be described as forms of ‘patient involvement’.¹⁴ Where shared decision making describes the process by which a decision is reached, informed choice and informed consent describe aspects of the decision itself. Informed choice can be further understood as a legal construct. It has been noted that in shared decision making a decision can still be uninformed, and that there can be such thing as autonomous dependency or forced independence.¹³ The implications of this are discussed in Section 2.7.

Figure 2.1: Continuum of self-management and shared care



- ⁱ Social cognitive theory is a model of reciprocal causality which emphasises the individual's role in their own development and learning from the social environment. It proposes that internal factors (cognition, emotion, biology), behavioural patterns and environmental events all influence one another. In this model, behaviour is therefore a function of internal and environmental factors, as well as being influenced by outcome expectations and perceived self-efficacy (Bandura, 1986).
- ⁱⁱ This refers to those models based on a theory of personal growth, where people are thought to pass through developmental stages or phases towards achieving ideal self-management skills and behaviour.

2.2 Conceptual inconsistencies

The varied influences on the evolution of shared decision making and self-management support have meant that there is no single definition of either concept.^{6,15,16} This makes comparisons between the two concepts a challenging task.

A systematic review by Makoul and Clayman identified no less than 31 separate concepts used to describe shared decision making.⁹ It was also notable that less than 40% (161 out of 418) of the articles reviewed included a conceptual definition. A lack of conceptual clarity becomes problematic when thinking about how to define and measure outcomes, and in considering how shared decision making can be implemented in practice.⁶ It also makes it more difficult to confidently draw conclusions about relationships with related concepts.

In self-management support, although there is some consensus around the aim to improve skills and confidence to manage long-term conditions, the application of this has varied widely.¹⁶ In particular, there is inconsistency in how interventions have approached self-efficacy as the key concept. Self-efficacy beliefs have either been understood as being related to specific tasks or as general personality traits.

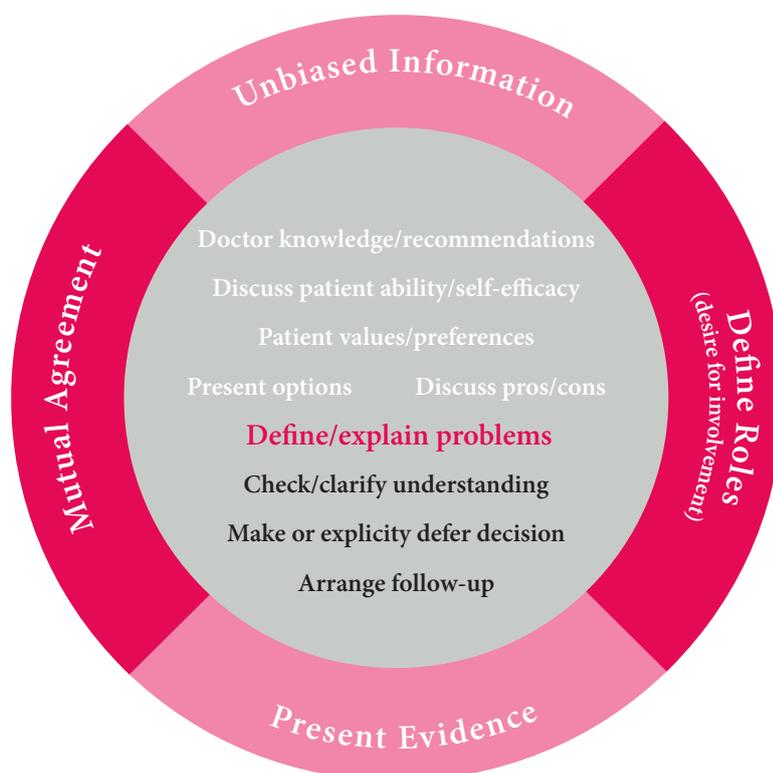
Those interventions that rely on the task-oriented understanding of self-efficacy have been more likely to show improved outcomes. However this has led to some conditions – namely chronic obstructive pulmonary disease and heart failure – perhaps wrongly being deemed as ‘inappropriate’ for self-management support interventions, whereas others (eg diabetes and asthma) are seen as suitable targets.¹⁶

2.3 Core components of the concepts

Despite the lack of conceptual clarity, it is possible to identify core components of shared decision making and self-management support where there is some degree of consensus. This provides a platform from which to explore the similarities and differences between the two.

Makoul and Clayman reviewed 161 articles in order to identify the concepts which were most frequently used to define shared decision making.⁹ References to ‘patient values/preferences’ and ‘options’ were most common, followed by the concept of ‘partnership’. The authors proposed a model of shared decision making built up from those concepts around which there was the most consensus (see Figure 2.2 below).

Figure 2.2: Essential and ideal elements of shared decision making: Makoul and Clayman (2006)



In self-management support, despite the critique of behavioural/individualised approaches (see Section 2.4) the concept of ‘activation’ has become popular in so-called ‘growth models’ of collaborative care. Developed by Judith Hibbard and colleagues, the term ‘activation’ refers to people’s knowledge, skills, ability and willingness to manage their health and health care.¹⁷ Research in this area suggests that activation is developmental, and it has been described in terms of a 4-stage model: people at stage 1 may not yet recognise that they have an important role to play in their health; by stage 4 they have become ‘fully competent managers of their own health’. The popularity of this concept in the self-management literature is partly due to the measurability of activation using the Patient Activation Measure (PAM). Hibbard’s conceptualisation of activation rests on the role of beliefs and knowledge as antecedents to action. Table 2.1 below summarises the four stages, and gives example items from the PAM which are used to assess progress through the stages.

2.4 Conceptual critiques

While there are multiple understandings of the concepts of shared decision making and self-management support, dominant models have nonetheless emerged. Some of these models have been contested on the grounds that:

- they support a narrow focus on the concepts which emphasises a task-oriented approach
- they have a strongly individualised perspective, focusing on patient behaviour and relying on behavioural and psychological concepts at the cost of recognising how social elements may have an influence
- notions of compliance still prevail in what is supposed to be a shift towards enabling patients.

2.4.1 Over-reliance on a transactional perspective

There is a tension between understanding shared decision making and self-management support as being either transactional or relational in nature. A purely transactional process can be more reductionist, with an emphasis on specific tasks to be undertaken to achieve desired ends – for example, using communication skills to elicit a decision. Within this approach a consumerist model may become dominant, with health care professionals and patients representing ‘sellers’ and ‘buyers’ of health care. A more relational perspective, by contrast, emphasises the fluidity of interactions which contribute to an overall relationship between a given health care professional and patient. In this view ‘better’ relationships may be those which utilise health care professionals’ skills of respect, empathy, listening and coaching.

Table 2.1: Four stages of activation: Hibbard et al (2007)

Activation stage	Description	Example items from PAM
1 – Believing the patient role is important	Patients do not yet grasp that they must play an active role in their own health. They are disposed to being passive recipients of care.	<i>When all is said and done, I am the person who is responsible for managing my health condition.</i> <i>Taking an active role in my own health care is the most important factor in determining my health and ability to function.</i>
2 – Developing confidence and knowledge to take action	Patients lack the basic health-related facts or have not connected these facts to a broader understanding of their health or recommended health regimen.	<i>I know the different medical treatment options available for my health condition.</i> <i>I know what each of my prescribed medications does.</i>
3 – Taking health maintaining action	Patients have the key facts and are beginning to take action but may lack confidence and the skills to support their behaviours.	<i>I know how to prevent further problems with my health condition.</i> <i>I have been able to maintain the lifestyle changes for my health that I have made.</i>
4 – Staying as healthy as possible	Patients have adopted new behaviours but may not be able to maintain them in the face of stress or health crisis.	<i>I am confident I can figure out solutions when new situations or problems arise with my health condition.</i> <i>I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.</i>

Arguments for broader conceptualisations, of shared decision making in particular, have been made. A broader conceptualisation advocates a relational perspective, where shared decision making is enacted within ongoing relationships between health care professionals and patients. This opens up a view of shared decision making which sees patient involvement not only in terms of ‘the decision’, but as the whole range of activities and interactions that occur around and support that process, and endure beyond it:

*...patients can be involved not only because of what they say and do to influence a decision, but also by virtue of what they think and feel about their roles, efforts and contributions to decision-making and their relationships with their clinicians.*¹⁸

Narrower conceptualisations, which tend to be strongly task-oriented, rest on the assumption that patients have preferences that can be elicited by medical encounters. This is borne out in practice in the focus on training clinicians in the use of decision aids to ascertain patients’ treatment preferences.¹⁴ The vast majority of decision aids are designed to contain comprehensive information, meaning that they can be used by patients outside the health care context. This may well lead to better decisions from informed patients, but not to more collaborative encounters.¹⁵ It has also been noted that patients do not always have clear and stable preferences.¹⁹ A broader conceptualisation requires recognition of illness, health and choices as dynamic, and also a consideration of the limitations to patient understanding given this fluidity.¹⁹ This recognises that patients do not come with ‘ready-made’ preferences, and that medical encounters may become the testing grounds for working out preferences in a more dialogic way. A central tenet of this proposition is, therefore, that preferences may be ‘co-constructed’ between health care professionals and patients in a process of negotiation and trade-offs.¹⁹

2.4.2 Over-reliance on individual factors

An emerging debate within the field of shared decision making relates to the principle of ‘individual autonomy’. As Epstein and Street note, ‘Shared decision making has often been conceptualized as a process of matching of choices to patients’ values and preferences with the goal of promoting individual autonomy.’²⁰ This can lead towards a more transactional professional–patient

interaction: the professional uses techniques to elicit the patient’s preferences, and the patient is ‘empowered’ to choose between different options that best match those preferences.

However, views of what comprises autonomy have developed over time and the concept of ‘relational autonomy’ is now coming to the fore. Elwyn et al state that ‘at its core, [shared decision making] rests on accepting that individual self-determination is a desirable goal and that clinicians need to support patients to achieve this goal, wherever feasible.’²¹ They go on to describe shared decision making in terms of the key tenets of both self-determination and relational autonomy, as ‘the need to support autonomy by building good relationships, respecting both individual competence and interdependence on others.’ Relational autonomy recognises that information, deliberation and decision making often occur within and are influenced by relationships.²⁰ Attention is drawn to what is ‘shared’ in shared decision making, and co-dependency between the patient and health care professional is valued (although less positive influences – eg mindlessly adopting another’s perspective – are also recognised). The mutuality within a relational understanding of autonomy is also useful to practice, as it avoids the risk of ‘abandoning’ patients to either self-manage or make decisions on their own.

Some models of self-management support have been criticised for a narrow focus; in particular, in terms of the over-reliance on self-efficacy at the cost of broader outcomes of patient enablement. These broader outcomes include the physical, social, emotional and spiritual needs of people living with long-term conditions.^{22,23} Health care may carry ‘symbolic importance’ for patients, and instances where patients feel unsupported or not listened to by health professionals may shape subsequent encounters. The impact of self-management support on patients might therefore be better understood in the wider context of the patient’s social environment, history of health care utilisation and pre-existing relationships with health care professionals.²⁴ Kendall and Rogers present a critique of the Chronic Disease Self-Management Programme (CDSMP), which is widely available throughout the UK in various formats including the Expert Patients Programme (EPP).²³ These authors discuss how the framing of the CDSMP as an approach which promotes a social model of disability is at odds with its dominant outcome of interest: self-efficacy. The focus on self-efficacy promotes a more individualistic understanding of health and wellbeing through its location of responsibility within the individual.

Recent research has also drawn attention to the social context of self-management support, showing that family and social networks play a vital role. A study by Vassilev and colleagues found that some people with long-term conditions had access to wide networks which functioned as everyday sources of practical, emotional and ‘illness-related’ support.²⁵ On the basis of their findings, the authors postulate that people who are able to mobilise diverse relationships in this way ‘have greater access to health-relevant support and are more accessible to interventions and possibly more able to adapt to new health practices.’ In contrast, those in more homogenous networks with strong ties may find it more difficult to adopt behaviour changes.²⁵

2.4.3 Notions of patient compliance

Recent models of self-management support have also been criticised for not moving far away enough from the traditional medical model. Although self-management support interventions originated from social models of health and disability, current approaches have been described as extending the concept of adherence in what begins to look more like medical management rather than self-management support. For example, some professionally-led interventions involve health care professionals supplying self-management strategies and supporting patients to understand and make use of these.²³

Koch et al conducted qualitative research with asthma patients to explore self-management support models.²⁶ They found that an approach akin to the medical model was still dominant in health care practice. Self-management support was framed by the clinical agenda: patients were considered ‘empowered’ when they improved their adherence to professional directions and medical management instructions, and the ultimate aim was for lowering costs.²⁶ This is also reflected in the rhetoric of self-management support interventions which seek to ‘educate’ patients.

2.5 Definitions adopted by the Health Foundation

As we have shown, the literature contains numerous definitions of shared decision making and self-management support. For the purposes of comparison we have used the definitions which have been adopted by the Health Foundation and underpin its work on person-centred care (see Box 2.1). These definitions are comprehensive and incorporate the key concepts rehearsed in the literature: patient participation,

involvement, enablement and collaborative relationships with health care professionals. Both definitions also capture shared decision making and self-management support as both a process and an outcome.

Box 2.1: The definitions of self-management support and shared decision making adopted by the Health Foundation

Self-management support

‘Self-management support is the assistance caregivers give to patients with chronic disease in order to encourage daily decisions that improve health-related behaviours and clinical outcomes. Self-management support may be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership. The purpose of self-management support is to aid and inspire patients to become informed about their conditions and take an active role in their treatment.’²⁷

Shared decision making

‘Shared decision making is a process in which clinicians and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and patients’ informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing patients’ treatment preferences.’²⁸

2.6 Possible relationships between the concepts

Having set out the definitions of shared decision making and self-management support to be used, we now propose several ways in which the two may be related to one another. These relationships will be explored within the context of the broader concepts of patient enablement and person-centred care. Our analysis of the literature identified five possible relationships. Each is described below, followed by a summary and review. We illustrate these relationships with the use of three practice examples, based on real life examples shared with us by three different health care professionals. The examples are not intended to definitively support any relationship over the others. Rather, they are intended to offer a lens through which to consider each of the relationships, as well as illustrating how shared decision making and self-management support concepts translate into, and are achieved in, practice settings.

2.6.1 Relationship 1: They are different concepts, only loosely related

This relationship reflects a view that, although there might be some ways in which shared decision making and self-management support are related, these linkages are limited and they are best treated as different concepts. This relationship therefore emphasises the differences between the two concepts, which rest on a narrow conceptualisation of shared decision making as focused on discrete treatment points in a care pathway. The concepts differ in their origins, the ways in which research has focused on them and their practical application in the health care context. We shall use this section to explore such differences.

Turning to the research literature first, we draw on differences in how both concepts have been approached. As noted earlier, shared decision making has been described as a process by which a decision is made, albeit with the outcome of a treatment preference in mind.²⁸ Most of the essential elements presented in the Makoul and Clayman model (see Figure 2.2 on page 14) describe this process. By comparison, research on self-management support focuses on psychological constructs such as self-efficacy and activation. The premise is that these constructs ‘belong’ to patients, they can be developed or enhanced through interventions, and that this process can lead to behavioural change.

Shared decision making and self-management support evolved from different traditions and differ in the context in which they take place and in the clinical practice outcomes they aim for.²⁹ Frequently the ‘decisions’ which the literature refers to are those taking place within medical encounters, such as decisions about how particular health problems or conditions are treated. In this view, shared decision making is presented as something that occurs within the domain of the health system.

Whereas, if the goal of self-management support is for people to feel more in control of and/or able to manage their health, support for this might come from a number of sources including – but not limited to – health professionals. This is reflected by the fact that self-management support has gained impetus in the voluntary and community sector. The example of Mrs Begum below shows how self-management support can move in and out of the health care context, with patients often self-managing in their daily lives without professional support. In this example the patient draws on support from various sources: from her daughter, friends, personal research, GP and a local voluntary organisation.

Example in practice: 1

Background and patient self-management

Mrs Begum is a 47-year-old woman who has been living with obesity for some time. She developed osteoarthritis many years ago which her GP, Dr Davies, says may be a consequence of the obesity. After talking to her daughter she decided to make some changes to her diet, which had helped her to lose a small amount of weight. Although she sometimes felt she had ‘slip ups’, Mrs Begum was proud of the weight loss she had achieved, and had managed to maintain a steady weight for eight months.

Seeking support for self-management

Mrs Begum felt it was important to talk to Dr Davies about how she could continue to make improvements. She liked to ask questions whenever she saw him, as sometimes the information she read and the advice friends gave her was confusing. She always felt well supported by Dr Davies, who often asked about what else she would like to do to lose weight. She also found it valuable to talk to him about managing the pain in her knees and about the medication she was using.

Impact of a new diagnosis

About a year ago, Mrs Begum was diagnosed with diabetes after what she had thought was a routine blood test. This came as a big shock to her. She felt that she was managing her conditions well, and this new diagnosis seemed to have come out of the blue. She also felt as if the sacrifices she had made to lose some weight had been for nothing. Her confidence plummeted and she started to give up on her dietary changes.

Continuing the self-management journey

A few weeks after the diabetes diagnosis, Dr Davies talked with Mrs Begum about how she was feeling and recommended a group-based self-management programme which was designed specifically for people newly diagnosed with diabetes. Mrs Begum was a little anxious about attending a group programme, but liked the idea that her daughter could attend with her. Being with other people who had diabetes really helped her to come to terms with the diagnosis and to learn more about the condition. She learnt about many things she could do to control her glucose levels, and picked up lots of tips from the other patients. The programme introduced Mrs Begum to the idea of setting herself goals, and she began to increase her weekly physical activity using this technique.

Mrs Begum is now feeling more like she is back on track, and continues to set goals with Dr Davies. She hopes to aim towards more substantial weight loss in the near future.

While differences between shared decision making and self-management support can be found, these may be explained as a historical fact and merely a function of the way the different concepts have evolved. A broader definition of shared decision making, where the emphasis is on a collaborative relationship between patients and health professionals and not just the episodic decisions made by them, suggests a stronger case for conceptual similarity.

2.6.2 Relationship 2: The concepts reflect a continuum

This relationship proposes that the concepts are on a continuum, with one pole representing ‘pure’ self-management and the other representing ‘pure’ shared decision making. This is similar to the conceptualisation presented in Figure 2.1, but differs in terms of a merging of both concepts towards the middle of the continuum, which is represented by a different style of interaction (Figure 2.3).

This relationship is able to account for different definitions of shared decision making. Pole 2 represents a narrower definition of shared decision making, referring strictly to the negotiation of a patient’s preference for treatment in instances where there is more than one option. The central region of the continuum represents a broader definition where shared decision making refers to a different type of relationship between both parties, where collaboration is the focus. In this region there is cross-over with self-management support when this too is characterised by a collaborative relationship. Put bluntly, when there is a genuinely collaborative approach between patients and professionals it may be neither possible nor desirable to identify the specific ‘shared decision making’ and ‘self-management support’ aspects of their interaction.

This contrasts with how self-management is defined at Pole 1, where the emphasis is more narrowly on lifestyle related support which is specifically for patients with

long-term conditions. It is when self-management support and shared decision making are seen in relational (not task-focused) terms that they map onto one another.

Another distinction between the poles may be in terms of different types of interactions, resulting from tensions in how power is held and shared between both parties. Shared decision making can be seen as a shift in power where health care professionals are allowing patients into ‘their domain’. This is inasmuch as clinical decisions have traditionally been within the control of health care professionals who gate-keep the options which can be considered. On the other hand, in self-management support it is the reverse case – patients are allowing health care professionals into their lives, and are able to gate-keep which parts of their lives and lifestyles they want to reveal and subject to external influence. In practice, power sharing is not always comfortable for either party and there will be variations in how different individuals respond to these requirements.

In this relationship the central region is where both concepts interact with one another in a symbiotic fashion: the over-riding ethos of partnership may characterise an ongoing relationship, but may be drawn on to a greater degree when there are specific treatment decisions to be made, or when patients require support to meet their goals towards self-managing their condition. Example in practice 2 (overleaf) depicts shared decision making and self-management support within an ongoing collaborative relationship, and shows how both concepts may support one another. It highlights how shared decision making early in the relationship can function to embed a partnership between a patient and their GP. As trust and respect develop over the course of the relationship, the patient becomes more prepared for self-management support and is able to set and meet incremental goals in collaboration with her GP.

Figure 2.3: Self-management support and shared decision making as poles of the same continuum



Example in practice: 2

Background and diagnosis

Veronika is a 27-year-old single mother. She has been living with depression for seven years, and has seen the same GP, Dr Mason, since she was diagnosed. When Veronika was first diagnosed she was feeling very tired and generally low. She was also quite tearful at times, and felt that she couldn't cope with the stresses of life.

Exploring treatment options

Dr Mason explained some options for treatment. One option was to start treatment with an antidepressant. Dr Mason said that other patients on this medication had said that it helped them to feel more in control of their emotions, less overwhelmed and more able to function on a day-to-day basis. She explained that it could take up to six weeks to feel the effects of the medication, although some patients did report effects sooner.

Dr Mason explained that a second option for treatment was to receive psychological support. She told Veronika about the psychologist based at the practice and said that she could refer her to this service, but that there may be a waiting list. Dr Mason explained that some patients find that psychological support helps them with identifying where they want to make changes in their lives, and with coping strategies. Other people, however, do not find it helpful.

Dr Mason explained that Veronika could either opt for medication, for psychological support or for a combination of both treatments. She also discussed alternative options, such as taking no treatment for now, while monitoring her depression and making some lifestyle changes (for example, becoming more physically active) or seeking support from peer groups. At this point in her life Veronika was not ready to think about making changes in her life, and opted for the medication.

Ongoing relationship

Dr Mason and Veronika met regularly for the next seven years, during which time Veronika continued to take medication on and off. As Dr Mason and Veronika's relationship developed over time, Veronika knew that Dr Mason would not judge her for her choices, and felt that she would not give up on her, despite the recurrent cycle of her depression. They began to set goals together which would be followed up on a monthly basis. They agreed that Dr Mason would send Veronika a reminder text message two weeks after they met, and Veronika felt that this was helpful in keeping her on track with her goals.

Taking the next steps

As Veronika and Dr Mason's relationship developed, Dr Mason began to learn more about Veronika's life. Veronika also grew more confident with setting and meeting goals. Veronika decided that she would like to take up the option of psychological support and accepted a referral from Dr Mason. This treatment option helped Veronika in communicating with her ex-partner, leading to a relationship with him that she was happier with. In her most recent consultation with Dr Mason, Veronika talked about how it was important for her to set a good work ethic for her children, and for the first time spoke about wanting to find a job. Dr Mason put her in touch with some voluntary organisations which could support her with a business idea she had. Veronika is now attending a course at college to become a childminder, and continues to take medication and receive psychological support. She says that she feels more in control of her life, and now has a sense of purpose.

2.6.3 Relationship 3: Shared decision making is a component of self-management support

Another possibility is to see shared decision making as a component of self-management support. This relationship begins with the basic premise that self-management is far reaching and mostly occurs outside of interactions with the health service (see Example in practice 1). People are self-managing in their daily lives, and the support that health services give makes up only a small portion of the whole. Shared decision making, on the other hand, happens at specific points; there are often times in care pathways when decisions are not being made. This is illustrated by both examples 1 and 2.

Mrs Begum is already self-managing with the support of her own social networks, and Veronika makes treatment decisions at specific points (eg at diagnosis, and when she feels ready for an alternative/supplementary option).

This relationship rests on a narrower definition of shared decision making as specific to episodic treatment decisions. This narrow definition excludes the understanding of shared decision making in terms of a collaborative relationship, but does recognise the range of decision-related activities where patient involvement can occur (eg involvement in identification/clarification of the 'problem'). With this view, in contrast to self-management, more of shared decision making takes place within the health care context, although decision

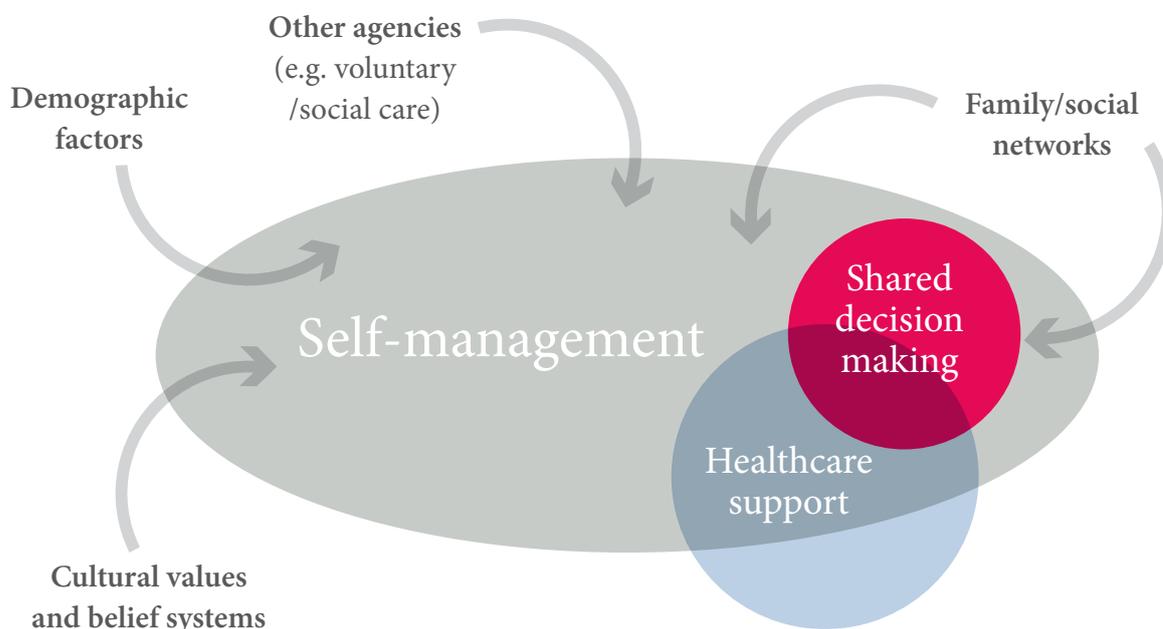
support may also be sought from family and other social networks. Applying this to example 2, Veronika makes decisions with her GP about taking medication and, later, psychological support. However her self-management journey goes beyond the consultation room to her speaking to her ex-partner, seeking support with a business plan and attending college to train as a childminder.

Recognising self-management support as a broader concept which permeates the daily lives of patients opens up an important set of considerations about the support that health care services can provide. Since 'living well' with a long-term condition refers to everything about a given patient's life, the health care system may need to better align with the social elements of self-management. As discussed earlier in this chapter, much research and practice has tended to take a behavioural approach with the focus being on tools and techniques which work to implement change in patient behaviour.²⁵ What might be needed now is a shift

in focus to consider patients' social circumstances and resources. This may include working better with and/or being aware of other agencies and support services that patients might utilise. This is also illustrated in example 2, where the GP is able to engage with Veronika about her work situation and recommend agencies which may be able to support her with her goal in relation to this.

The relationship between shared decision making and self-management support is also influenced by the extent to which these concepts are seen **either** as the broader or underlying principle for collaborative care, **or** as a specific task within that. To illustrate: one view is that the goal of 'collaborative' patient-professional relationships is to enable patients to be more actively in control of their health and conditions.³⁰ In this view, self-management support emerges as the underlying principle and sharing decisions is framed as one means by which more active patient involvement can be fostered.

Figure 2.4: Shared decision making as a component of self-management



2.6.4 Relationship 4: The concepts are different practices underpinned by the same values

This relationship emphasises the common philosophies in which both concepts are grounded. Relationship 1 (the concepts are loosely related) described how shared decision making and self-management support may be very different in practice. However, despite differences, it is possible to identify common principles which underlie both concepts and to locate these principles within the broader approach of patient-centred care. This may be seen in example 2, where the broad approach adopted by Dr Mason is one which respects Veronika's experience of depression, seeks to involve her in decision-making, and supports enablement by encouraging goal-setting and follow-up. In this example self-management support and shared decision-making almost become secondary to these principles which are upheld within an ongoing relationship.

Commonalities between the concepts have already been noted above, and include the importance given by the concepts to patient participation, enablement and collaborative relationships. These principles can be likened to patient-centred care, and all have been used synonymously to describe a shift in health care provision to that which is more aligned to patient expectations, preferences and wishes.

Bodenheimer and colleagues describe the collaborative care model as one which recognises the expertise of both parties in the clinical encounter; where professionals are experts in disease, and patients are experts in their own lives.³⁰ An important feature of collaborative care is therefore 'patient-defined problems', as opposed to problems defined and solutions provided by health care professionals, with which patients are then expected to comply.³⁰ This is also evident in both shared decision making (eg by paying attention to the meaning of various treatment outcomes for patients themselves) and self-management support (eg by supporting patients to reach goals that they have themselves created).

Research has also shown the similarities of both concepts to patient-centred care. Gillespie and colleagues note that patient-centred care has been loosely defined and they explore the different ways by which the concept has been understood.³¹ Their qualitative study with clinicians, managers and patients led them to suggest that, beyond the emphasis on a partnership approach, common understandings also include the health care professional's responsibility

to inform patients, engender trust and promote a holistic model of health. These features bear strong similarities with definitions of shared decision making and self-management support. Patient-centred care, however, goes beyond face-to-face encounters, and also describes patient involvement in the planning and delivery of services,³¹ as we discuss in more detail in the following chapter.

Rogers discusses how, in the field of self-management support, the concept of an idealised 'expert patient' has been associated with patient-centred care in health care consultations, and especially so in primary care.³² Tracing the advent of the expert patient concept to the Wanless review,³³ Rogers discusses the proliferation of terms which have evolved since to frame the individual within patient-centred care. These terms include 'empowered', 'autonomous', 'activated' and 'co-producer'. Similar overlaps have been noted between shared decision making and patient-centred care. In relation to shared decision making, Makoul and Clayman highlight a common ground of constructs including those of 'informed decision making', 'concordance', 'evidence-based patient choice', 'enhanced autonomy' and 'mutual participation'.⁹

Table 2.2 takes the key features of patient 'empowerment' definitions as laid out by McAllister et al.²² It then maps shared decision making and self-management support onto these definitions to show commonality between the two concepts.

2.6.5 Relationship 5: Both concepts are important aspects of person-centred care

Relationship 4 explored commonalities between the two concepts in relation to person-centred care. But it is possible that the relationship with person-centred care is more direct. Relationship 4 can be extended further still to consider shared decision making and self-management support as different aspects of person-centred care. Person-centred care has been used in a number of ways, including within the policy context of integration and coordination of services; in a values-based way (eg promotion of dignity, compassion and respect); and within a body of literature and thinking addressing patient enablement. It is within the last of these that shared decision making and self-management support most directly falls.

Care and support planning may be another important aspect which works with self-management support and shared decision making to provide patient-centred care (see page 40 for a definition and discussion of care and

Table 2.2: Mapping shared decision making and self-management support onto patient empowerment definitions

Features of patient empowerment	Shared decision making	Self-management support
Patients as self-determining agents with some control over their own health and health care	Enacted in interactions where patient preferences are elicited to guide treatment choices	Agenda setting, goal-setting, and goal follow-up within the context of enablement and shared exploration between patients and health care professionals
Conceptualisation of personal control and self-efficacy/self-mastery	More likely in terms of personal control, with patients being able to select their preferred choice from a range of options	The concept of self-efficacy has dominated this field, particularly in relation to patients having the confidence to make behavioural modifications
Individual's capacity to make decisions about their health	Emphasis on information and preparation to enable patients to understand and contribute to decisions	Patient defined problems and solutions to these; strong emphasis on collaborative care planning

support planning). Lhussier and colleagues explore how the three concepts (shared decision making, self-management support, and care and support planning) contribute to person-centred care, concluding that:

*Taken as a whole, these concepts aim to provide patient-centred care and increase involvement in decisions and healthcare.*²⁹

Patient-centredness is described as the foundation for the three concepts in its core principles of equality and power sharing between health care professionals and patients. Where person-centred care reflects the overall goal for the health care professional and patient relationships, shared decision making, self-management support, and care and support planning are seen as building blocks for this approach.²⁹

The three concepts share some key features; for example, they all reflect collaborative approaches, emphasise the achievement of a two-way dialogue between patients and professionals, and recognise the different skills and assets that each party brings. The distinction between the concepts is in terms of the context and their intended outcomes in clinical practice.²⁹ This relationship considers the three concepts as interdependent. However, while all three are constituent parts of person-centred care, there will be situations and settings in practice where some will be more applicable than others.

Figure 2.5 overleaf is an adaptation of the concept map developed by Lhussier and colleagues to show how the three concepts might relate to one another.

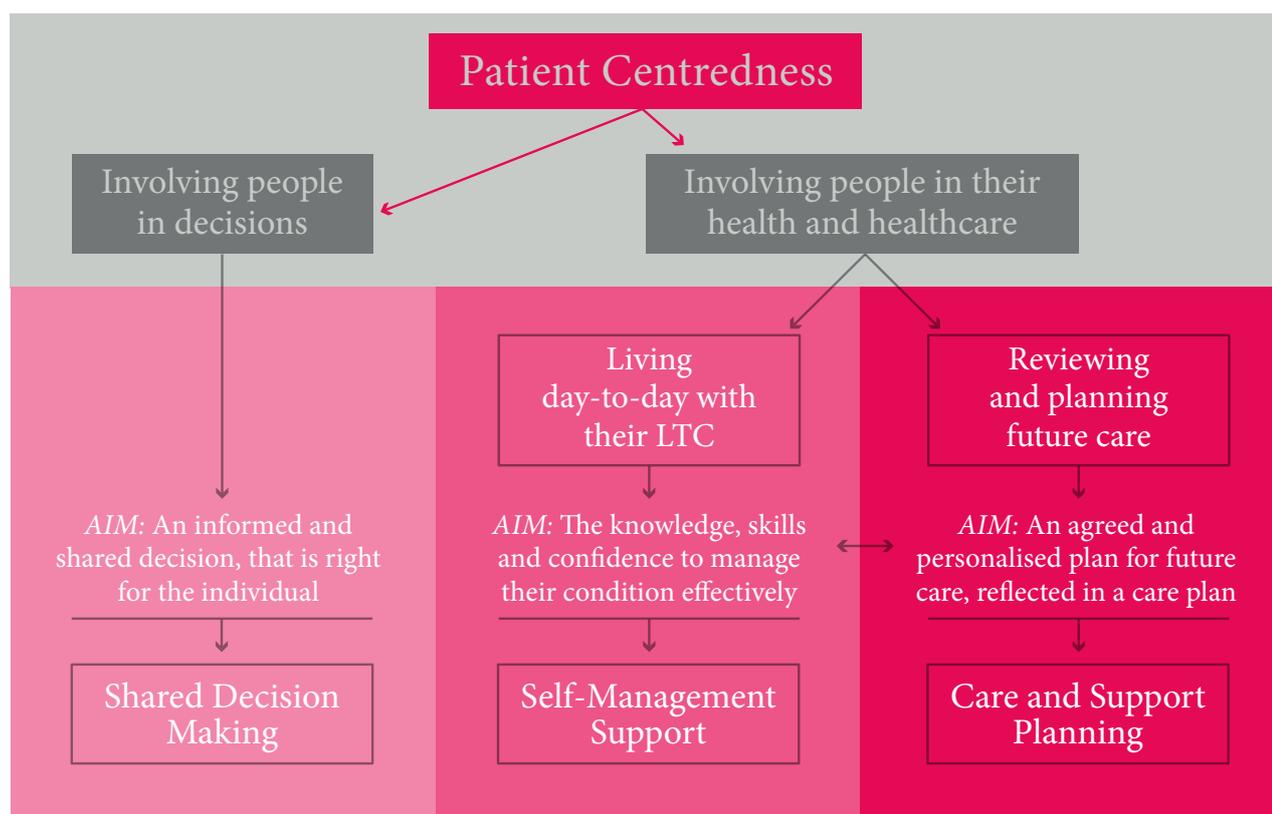
2.6.6 Summary and review of the relationships

The possible relationships between the concepts described above are not intended to be mutually exclusive. Nor are the relationships we have described intended to be a definitive set of possible relationships. It is indeed possible that further relationships may be uncovered by emerging research.

Looking across the literature as a whole, there appears to be least support for the concepts being only loosely related (relationship 1). The various types and sources of evidence we have reviewed for this project all point to differences between the two concepts; equally, they show that there is value in considering them as closely related. Relationships 4 (concepts as different practices underpinned by same values) and 5 (concepts as aspects of person-centred care), and to some extent 2 (concepts as a continuum), all share an emphasis on a collaborative approach to care. Again, there is much support for the view that these concepts are grounded in the broader principles of mutuality and partnership working. Of these three, the literature most strongly supports relationship 5 and its consideration of the concepts as actively contributing to person-centred care. This relationship offers a valuable model for understanding how health care professionals can deliver person-centred care, a concept which is otherwise more abstractly defined.

There is also strong support within the literature for relationship 3 and its view of self-management support as a broader concept which contains shared decision making (as more narrowly defined) within it. In this relationship the arguments for a broader

Figure 2.5: Reframing self-management support, shared decision making, and care and support planning as concepts within patient-centredness



conceptualisation of shared decision making may be relocated to self-management support – ie self-management support represents the relational context within which more focused (and episodic) shared decision making sits. A useful understanding of the linkages between the two concepts may therefore rest in a blend of relationships 3 and 5.

2.7 Implications for patients, professionals and the health system

The relationship between shared decision making and self-management support can also be explored by considering the roles which the concepts envisage for patients, professionals and the health care system.

Taken in their broadest sense – in terms of the principles they share with collaborative and patient-centred care – both concepts rely on patients and professionals being motivated to invest in better quality relationships and improved outcomes. For patients this would mean working in partnership with health care professionals, to be better informed and involved in their care, to share decisions and to contribute to health management. Professionals would need to acquire the appropriate skill set to support this shift and make relevant changes in their practice style.

The role of a supportive health care system is well recognised for implementing sustainable change. In particular, the system would need to support this shift to take place, for example by fostering a conducive culture and creating incentives within current resource constraints. While on one level this may include ongoing training and support to develop new ways of working, system level change would also be beneficial: for example, in terms of how better integrated services may contribute to transforming clinical encounters on the ground. There are also implications for the health care system in terms of considering the balance of cost against outcomes. Cost savings to the system are not an inevitable result of shared decision making and self-management support interventions (as we discuss in Chapter 4), and may not be realised in the short to medium term. A rationale based solely on cost savings may also conflict with the ethos of patient enablement.

Over and above the requirements for collaborative relationships, in practice the concepts may benefit from different sets of skills. Shared decision making relies on the ability to deliberate together over a number of options and negotiate a decision that both parties are willing to follow. Decisions themselves may also differ in complexity. Where some may be relatively narrowly focused on clinical problems, others permeate and have

implications for people's daily lives. This is illustrated in example 2 presented earlier: with the contrast between treatment options for depression and the later decisions that Veronika starts to consider, which relate to her personal relationships and future employment. Of course, these decisions are connected – it is only once she feels her depression is more under control that Veronika is able to approach her 'bigger' life issues.

In order to take account of the wider social context of self-management support and shared decision making, health care professionals also need to be skilled in talking to patients about their lives and what is important to them. In example 2, the GP is able to work with Veronika to set goals which are relevant to her, and towards the later stages in the relationship is able to discuss Veronika's broader life goals of looking for employment. This example illustrates how effective self-management support depends on professionals being skilled in coaching and supporting behaviour change. Equally, it is considered important for patients to be informed, motivated, sometimes to adopt new behaviours, use personal insight and reflection, learn and apply problem-solving skills, etc.

Self-management support also carries implications beyond the patient–professional interaction and formal health care services, due to broader implications that arise from the dominant definitions. While shared decision making pertains to individual points in time where there are specific decisions to be made, components of self-management such as self-monitoring, assessment and behavioural adjustment are ongoing. This also presents challenges for professionals in the support they can give during their time with patients. It opens up a wider view of self-management support as a 'social system', extending the focus well beyond the clinical encounter. This is captured by the Chronic Care Model, which emphasises the mobilisation of community resources, as well as improvements in the organisation and delivery of health services, functioning as an integrated system of support.³⁰

Lastly, the potential both parties already bring to the clinical encounter is important. Self-management in particular is not new. People have always adapted behaviour to take account of health and illness. Health care professionals have also contributed to supporting these adaptations – albeit, not necessarily using the term 'self-management support'. The difference required is in embedding these concepts into routine practice, so that they are more highly valued and patients are more effectively and consistently supported. It is important that self-management is not seen as an entire transfer

of health responsibility to the patient, without support from health care professionals. Instead, the ongoing role for health care professionals is to enable patients to be effective self-managers. This role may require adjustments to align with the different role of the patient as collaborator in the care process.

2.8 Are shared decision making and self-management support interventions suitable for all?

A final set of considerations which are important to understanding shared decision making and self-management support relate to their fluidity: patients might differ from one another in their capabilities and assets, and indeed individual patients may also differ at different points in time. Hibbard and colleagues' concept of patient activation, discussed in Section 2.3, is one way in which these differences have been addressed in the literature.¹⁷ These differences may relate to factors such as health literacy,ⁱⁱⁱ the social circumstances in which individuals live or their psychological and social capacities for involvement. But if the starting point for self-management support and shared decision making is self-determination, then the underlying assumption is that everybody can be enabled to participate in their care, albeit to varying degrees. Differences between individuals and over time mean that tailoring is essential.

Education is a feature of both self-management support and shared decision making. In self-management support interventions this is often in the form of patients learning more about their health condition, and the circumstances that trigger and potential options for managing symptom exacerbation. In shared decision making there is a strong focus on comprehensive 'evidence-based' information provision of options from which patients may choose.

While education – and skills development more widely – may have an important role to play, the way in which this is currently supported appears often to fall short of engaging a wide range of patients. Limitations in the dominant group-based educational model of self-management have been well documented, and it is increasingly recognised that this model is not accessible and/or appealing to all. Indeed, group-based programmes have tended to attract more affluent and educated participants, rather than reflecting the wider

iii 'Health literacy' has been defined by Nutbeam (2009) as 'personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health'.

population of patients;³⁴ although, as we discuss in Part 2 of this report, some recent programmes have found success with tailored group-based programmes for specific cultural or minority groups.

This bias towards more affluent groups has been explained by the focus within conventional educational programmes on self-efficacy; for example, Rogers and colleagues note that:

*An approach which emphasises improvements in self-efficacy may inadvertently sideline the relevance of the existence of social inequalities in chronic illness and the personal experience of chronic illness.*³²

There are additional reasons why this model may not be helpful for all patients with long-term conditions. Unfavourable social comparisons may be reinforced, for some, in group situations. This might help to explain why group-based programmes tend to attract those who are already more effective self-managers, whose values and behaviours are congruent with the view of the 'expert patient' dominant in health policy.³² Hence those who require support most are more likely to be missed by this approach.

Example 3, presented overleaf, depicts a patient who might be described as a very competent and confident self-manager. But it shows how even individuals who are highly engaged in their health care may face challenges when they are faced with new or uncertain situations. The contrast in experience for Michael, between interactions with his GP (with whom he has a long-established relationship) and a cardiologist newly involved in his care, also reflects how context-specific the barriers and enablers to participation can be.

Attempts have been made in both self-management support and shared decision making to account for patient differences: for example, using Hibbard and colleagues' developmental model of activation (see Section 2.3). This offers potential to design tailored interventions for patients at different levels of activation. Research in the United States suggests that tailoring support in this way can improve disease management outcomes.³⁵ There are some parallels with shared decision making. Elwyn and colleagues' conceptualisation of shared decision making emphasises the process of deliberation before a decision is made and acted on.¹⁵ This process may provide the space within which health care professionals might gauge individuals' confidence, willingness and capacity for involvement and adapt their interactions accordingly.

The challenge of accounting for individual differences provides further support for broader conceptualisations of both shared decision making and self-management support, where decisions are co-constructed and support is delivered within the context of collaborative care.

Example in practice: 3

Background and diagnosis

Michael is a 59-year-old man who describes having a good relationship with his GP of 15 years, Dr Patel. Over the years Michael has sought medical advice for numerous physical problems, and has always felt that Dr Patel treats him more like an equal partner than his previous doctors have. Michael has been diabetic for ten years and has welcomed Dr Patel's supportive approach to planning his treatment and discussing his diet. Michael also attends a diabetes clinic at a local hospital and knows the staff there well. He feels he has a good understanding of the health care system, and is confident enough to make his requirements known.

Michael had recently noticed that he was experiencing chest pains whenever he walked uphill. When this had continued for three weeks he decided to go and see Dr Patel. Dr Patel suggested that it could be angina, and referred him to a cardiologist based at a specialist hospital. Michael had never been to this hospital before, and he was feeling slightly anxious about the possibility that he might have angina.

Negotiating collaborative care in a new health care context

Dr Gaynor, the cardiologist, seemed to have a different approach to Dr Patel. Michael thought she was very business-like, and felt slightly unsettled by this. Dr Gaynor confirmed that Michael had angina, and started to talk about the medication she would put him on. Michael wondered what would happen if he didn't take the medication and asked Dr Gaynor about what other options there were. Dr Gaynor explained that there were other options, and asked Michael what he knew already about angina. She answered Michael's questions about the condition and gave him some more useful information that he didn't have. Michael found this discussion helpful, especially when he realised that having angina did not mean that he had a blockage in a coronary artery.

After discussing the condition with Dr Gaynor, Michael asked whether he could try to lose some weight first to see if this would help, before opting to start on the medication. Dr Gaynor agreed that this was one possible course of action, and then discussed the pros and cons of each option with Michael. This information helped Michael to make his final decision: to delay taking medication in favour of making changes to his lifestyle instead. He and Dr Gaynor discussed how he could speak to Dr Patel, who might be able to support Michael with making an action plan for his weight loss.

Chapter 3:

The UK policy context for a more person-centred NHS

In this chapter we report on the evolving policy context for more person-centred health care. While health policy across the UK nations diverges in many respects, all four countries have identified strengthening individual and collective involvement in health care as a key goal. This has spurred efforts to implement support for self-management and, more recently, shared decision making into mainstream services. This process is far from complete, but we can expect to see a continued focus on patients being more actively involved in their health care as services grapple with the challenge of meeting rising demand in an era of limited budgets. As we summarise in the final section, the current context presents both opportunities and risks for the future development of person-centred care.

3.1 Defining person-centred health policy

Across the four countries of the UK, the vision of person- or patient-centred health care has emerged in recent years as a major theme in health policy.³⁶⁻³⁹ The trend – at least rhetorically – has been towards seeing people as active partners in, rather than simply passive recipients of, health care.¹ Despite the often used language of ‘patient-centred’ care, some acknowledgement of the contribution that families and wider social networks make to both health and the provision of health care has also been made. Family carers in particular are increasingly identified as a group with whom professionals and services should collaborate to ensure a more joined up approach to care across formal and informal settings.⁴⁰

It is possible to identify within health policy three broad ways in which person-centred care is being promoted, summarised in Box 3.1

Box 3.1: How health policy is promoting person-centred care

- 1. Improving patient experiences of care:** the patient’s experience is increasingly recognised as a core dimension of health care quality, driving efforts to define, assess and improve health care delivery and outcomes from a service user perspective. The stated goal is often to achieve more holistic care which is respectful, compassionate, dignified and sensitive to the whole person and their needs.
- 2. Individuals participating in their own treatment and care:** at this level, policy has focused on increasing opportunities and support for people to play a more active role in their own health and health care. Specific examples include people self-managing long-term conditions, sharing treatment decisions, participating in care planning and holding a personal budget to purchase their care and support.
- 3. Collective involvement in service design, delivery and improvement:** the push for a stronger public voice in how health services are planned and provided is evident across all four UK countries. This reflects a democratic impulse to foster greater local oversight and accountability, as well as being presented as a vehicle for transforming services by encouraging providers to be more responsive to community-defined needs and priorities.

While all three of these elements are evident in health policy across the UK, it is by no means the case that they have been given equal prominence. Rather, person-centred care tends to be framed and promoted in ways that reflect wider concerns and priorities within the NHS, and therefore has evolved over time.

A good example of this is the recent resurgence of interest in compassionate care, which has been propelled up the policy agenda following several investigations into the care of older people in hospitals and care homes and – above all – publication of the Francis Inquiry into the failings at Mid Staffordshire NHS Foundation

Trust.⁴¹⁻⁴³ The implications for individual and collective forms of involvement were considered in both Robert Francis's report and the government's response to it. Nonetheless, it was the Secretary of State for Health's promise to 'create a culture of compassion with patients' interests at the very heart' which has been most strongly emphasised.⁴⁴ Consequently, in England, actions taken post-Francis have principally focused on overhauling aspects of provider inspection and regulation, workforce training and development (especially in nursing) and the introduction of the Friends and Family Test with the goal of improving patients' experiences of care.

3.2 The ethical and instrumental cases for person-centred care

Broadly, it is possible to identify two different ways in which the case for person-centred care has been made. These different rationales are not mutually exclusive and, indeed, are often combined in practice. Nonetheless, it is useful to distinguish them from one another because each offers a different way of understanding what person-centred care is, why it is important and how success should be defined and assessed.

The first is an ethical or values-based case, presenting person-centred care as a good in its own right and the 'right thing to do'. This is underpinned by the notion that people's rights to participate in and contribute to their own lives, and to wider community life, should be recognised and respected. In relation to health care, this is often expressed as calls for more inclusive and participative approaches, captured by the slogan 'nothing about me, without me'. This phrase originated in the disability movement and has since been used by many service user groups to challenge medical paternalism and push for a shift in the balance of power so that users are recognised as partners in the care process.⁴⁵ At a minimum, partnership calls for an approach in which an individual's needs and views are listened to, valued and taken account of. In recent years, the principle of respect for autonomy has become 'most strongly associated with the idea that patients should be allowed or enabled to make autonomous decisions about their health care.'⁴⁶

By contrast, the instrumentalist case justifies person-centred care as a means to achieve better outcomes. The particular outcomes emphasised vary depending on which element of person-centred care (see Box 3.1) is being promoted. Policy makers generally tend to link the vision of more engaged and informed patients with improvements in health behaviours, health and wellbeing outcomes, and less (or less costly) service

utilisation. This is often how patient involvement is 'sold' to the NHS. So, for example, recent participation guidance issued by NHS England reported that:

*We know that when patients are involved in decisions about their own care and treatment and have more knowledge and confidence, they have better outcomes, follow appropriate drug treatments, avoid over-treatment, and are less likely to be hospitalised... A recent study by Nesta estimated £4.4bn could be saved in the NHS through greater participation and self-management of long term conditions.*⁴⁷

While the policy promotion of person-centred care has been couched in both ethical and instrumental terms, it is the latter which has been given far greater prominence across the UK. However, in Scotland a strong rights-based approach to health and social care – emphasising principles of participation, inclusion, equality and non-discrimination – has recently been put forward by a leading voluntary sector organisation.⁴⁸ There are risks in seeing person-centred care in principally instrumentalist terms. The first is that the intrinsic benefit of people feeling respected, valued and involved in their care can be overlooked in the quest for improved behaviours or reductions in service use. As we discuss in the following chapter, empirical studies of shared decision making and self-management support have shown little impact on health service activity and costs; changes in health behaviours have been reported, but not consistently so. There is a danger of patients being set up to fail if successful participation is narrowly judged in cost terms.

This problem can also affect how person-centred care is implemented in practice. Concerns have been raised that, when driven by the goal of managing health care demand, there is a change in emphasis from professionals working in partnership with the patient, to them transferring responsibility for care onto the patient.⁴⁹ This can be seen in how person-centred care is being developed within the NHS, with far more focus on equipping patients to take on a more active role than on supporting both patients and professionals to engage in more collaborative approaches to care. On this issue, Entwistle and Cribb note that '...caution is needed to ensure that people's legitimate ongoing needs for care from health services are not neglected in the drive to have them do more to help themselves.'⁵⁰

3.3 Tracing the development of person-centred care within UK health policy

In all four UK nations, the aspiration for health services to better understand and be more responsive to people's needs is now well established within health policy. This has been underpinned by the increasing recognition – both in the UK and internationally – that the patient's experience is a key dimension of health care quality.⁴⁵

⁵¹ Although there is a strong drive in England to create and expand opportunities for people to exercise choice, it is the ambition to embed patient voice within the processes of planning, providing and improving care which is the more consistent theme across the nations. So, for example, one of the three foundations of NHS Scotland's quality improvement strategy is:

*...putting people at the heart of our NHS. [This] will mean that our NHS will listen to peoples' views, gather information about their perceptions and personal experience of care and use that information to further improve care.*³⁸

This has resulted in substantial attention and investment being directed at gathering information about patients' health care experiences. This includes national patient survey programmes in both England and Scotland and recent efforts to capture experiences in real time and using a range of methods including online, through social media and using trained volunteers.

But the definition of what it means to be 'person-centred' is expanding, from this longstanding focus on listening to the patients' voices to recognising the active roles that individuals can play as partners in care processes. Both ethical and instrumental arguments are made in support of this. Some emphasise moving away from the paternalistic model of 'professional knows best', highlighting evidence that patients want to be more involved in their care and pointing to the problems that can arise from a lack of involvement.^{1,52} The potential for partnership approaches to bring about more personalised care and engaged patients, and therefore better health and wellbeing outcomes, is also frequently referenced.

The vast majority of day-to-day health management and decision making has always been undertaken by patients, their families and carers – patient involvement is nothing new, despite the policy rhetoric. A good illustration of this is the oft-quoted statistic that a

person with diabetes spends around three hours with a health professional each year, and self-manages their condition for the remainder of this time.⁵³ In many non-urgent situations, decisions about whether, when and – increasingly – how to access health care belong with the patient. The real advance is the acknowledgement that there are several aspects of culture and practice that will need to change to reorient services to the goals of encouraging and enabling involvement. As Gillespie and colleagues point out, 'A patient-centred model of care requires a shift from the traditional notion of the health professional (traditionally the doctor) being the dominant participant, with the patient passive, to one in which power and control are shared.'⁵⁴

Looking across the UK, there are some striking similarities and differences in this ever-evolving policy context. As we noted above, strategies for reforming health services have been consistently framed around the goal of person-centred care, with patient participation often identified as a key priority. The promotion of patient involvement has also been directly linked to the need for a transformation of health services in response to the ever-growing demographic and financial challenges that the NHS faces.

Where the nations differ is in how change is expected to be driven. In England, the commissioner-provider split and market-based mechanisms are foremost, and there has been much interest of late in commissioners' use of financial incentives, contractual levers and payment systems to drive reform. Through the Commissioning for Quality and Innovation (CQUIN) framework, a small proportion (currently set at 2.5%) of providers' income is now tied to the delivery of quality improvements, including better patient experiences of care. The inclusion of shared decision making in commissioning standards and contracts has been proposed,²⁸ and moves to achieve this for self-management support are already underway through initiatives such as the House of Care (see Section 3.3.2 for more information).

There is a somewhat different emphasis in the other nations, where co-operation and partnership – not competition – are the guiding principles for health system governance and reform. In Scotland and Wales especially, the promotion of individual and collective involvement is underpinned by the notion of shared ownership – that is, the NHS **belongs** to patients and the public, who therefore have a right to participate in it. This ethos is reflected in the interest being paid to co-production and asset-based approaches,^{55,56} both of which emphasise a new model for public

service delivery based on collaboration and reciprocal relationships between professionals, service users and their wider social networks.

3.3.1 Shared decision making

A useful place to start tracing the development of shared decision making in policy is the early 1990s and, in particular, the rise of evidence-based medicine (EBM). By focusing attention on treatment outcomes, EBM has shown that many clinical decisions involve treatments with uncertain or differing risks and benefits, for which the available evidence is unable to produce a single best answer. In these cases, where two or more medically acceptable options are available, the ‘right’ treatment decision should be one that takes account of the patient’s circumstances and – as exponents of shared decision making have particularly stressed – their values and preferences.⁵⁷

Also in the early 1990s, the language of individual rights, choice and control was starting to take hold in health policy, as a more explicitly consumerist agenda was put forward for the NHS. Challenges to medical dominance in areas such as maternity care were linked to calls for greater involvement in decision making. For example, the 1993 report *Changing Childbirth* made the case for ‘women-centred’ maternity care, proposing that:

*The woman must be the focus of maternity care. She should be able to feel that she is in control of what is happening to her and able to make decisions about her care, based on her needs, having discussed matters fully with the professionals involved.*⁵⁸

Themes of choice and control have grown increasingly prominent over time, as too has the promotion of patients as decision makers. But involvement in treatment decision making has, at least until relatively recently, been overshadowed by a political agenda dominated by two other choice issues: giving patients more choice over where they receive health care⁵⁹ and encouraging the public to choose healthier lifestyles.³⁶

Much has changed of late in some parts of the UK. In May 2010, a quality improvement strategy for NHS Scotland was published which set out an ambition for ‘Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear

communication **and shared decision-making** [bold added for emphasis].³⁸ In England two months later, the *Equity and excellence* white paper put shared decision making centre stage in the next wave of NHS reform:

*Healthcare systems are in their infancy in putting the experience of the user first, and have barely started to realise the potential of patients as joint providers of their own care and recovery... We intend to put that right. We want the principle of “shared decision-making” to become the norm: no decision about me without me.*¹⁵

The 2012 Health and Social Care Act subsequently created a statutory duty on NHS England and local clinical commissioning groups (CCGs) ‘to promote the involvement of individual patients, and their carers and representatives, in decisions about their treatment and care’. By 2015 it is expected that 80% of CCGs will be commissioning information and support for shared decision making.

Some concerns have been raised – less so concerning the direction of travel and more about how these aspirations and targets will be achieved.⁶⁰ Making ‘no decision about me, without me’ a reality calls for significant changes in clinical training and cultures, and requires both patients and professionals to accept new roles and responsibilities. Implementation, therefore, requires a whole system response and the collaboration of many agencies;⁷ it is not something that CCGs can alone achieve. The same can be said of the implementation of self-management support, to which we now turn.

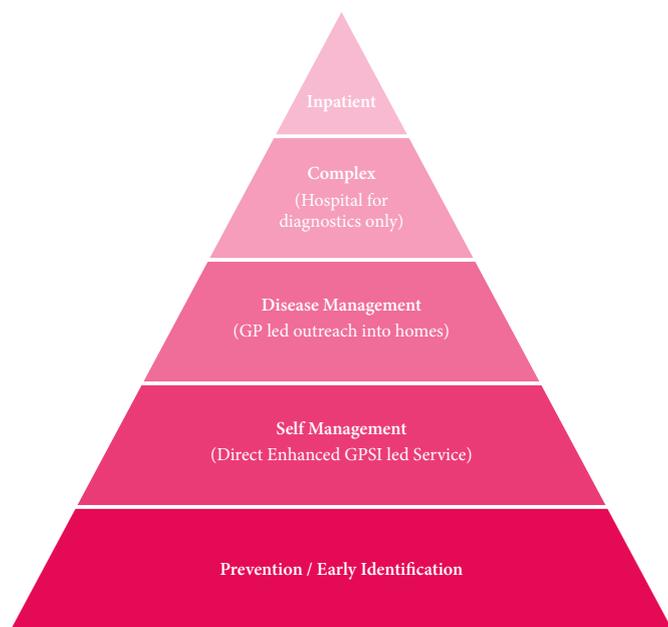
3.3.2 Self-management support

The notion of patients as ‘managers’ of their health and health care has, like shared decision making, evolved over time. Over the past decade, a shift of focus has taken place: from an interest in the broad range of day-to-day health maintenance activities that comprise ‘self-care’, to a more specific set of behaviours that individuals can undertake in order to ‘self-manage’ long-term conditions. Although self-care has not fallen from view completely, current debates tend to almost exclusively concentrate on the management of long-term conditions and the role of individuals and their families in this. This is unsurprising given that the care of people with long-term conditions now consumes around 70% of the health care budget.

Self-management is principally justified in two different, but inter-linked, ways. The first is that long-term conditions are most effectively managed when patients and professionals work in partnership, combining their different skills and expertise.⁶¹ Secondly, reference is made to the growing older population and incidence of long-term conditions, and the increasing demands on health services that result from these trends. In this context, supporting people to become more effective self-managers of their conditions is presented as an essential strategy for managing health care demand and ensuring the long-term sustainability of the NHS as a publicly funded service.^{32,62} A key development in this respect was the Wanless review of the long-term resource requirements of the NHS.³³ The review modelled three future funding scenarios and concluded that the most effective use of resources would depend on the population being ‘fully engaged’ in their own health.³³

All four UK countries have produced virtually identical models of proactive and risk-stratified care for people with long-term conditions; a key element of which is support for self-management.⁶³⁻⁶⁶ As an illustration, the Northern Irish model is shown in Figure 3.1 below. It is acknowledged that self-management is an activity that must be supported. As the Scottish self-management strategy notes, ‘Self management is the responsibility of individuals. However, this does not mean people doing it alone.’⁶⁷

Figure 3.1: Approach to managing long-term conditions: Northern Ireland



Attempts to encourage and enable people to self-manage have generally focused on two main strategies:⁶⁸

- Educational, training and peer-support programmes – such as the Expert Patients Programme (launched in 2001) – that are provided separately from clinical health care consultations and tend to have little connection to the patients’ usual clinical care.
- Approaches to health care consultations in which clinicians put a strong emphasis on supporting people to manage their own conditions rather than rely on the clinician to do this for them.

There has been much discussion about how an ‘enabling’ consultation and patient–professional partnerships for managing long-term conditions can be achieved in practice. Collaborative care and support planning is increasingly seen as the answer to this question. Already an established concept within mental health and end of life care, care planning is now being endorsed by, among others, NHS England, The King’s Fund and the Royal College of General Practitioners.⁶⁹ It has featured prominently in recently policy plans in England. For example, the current NHS Mandate in England sets out a goal that by 2015, ‘everyone with long-term conditions, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions.’

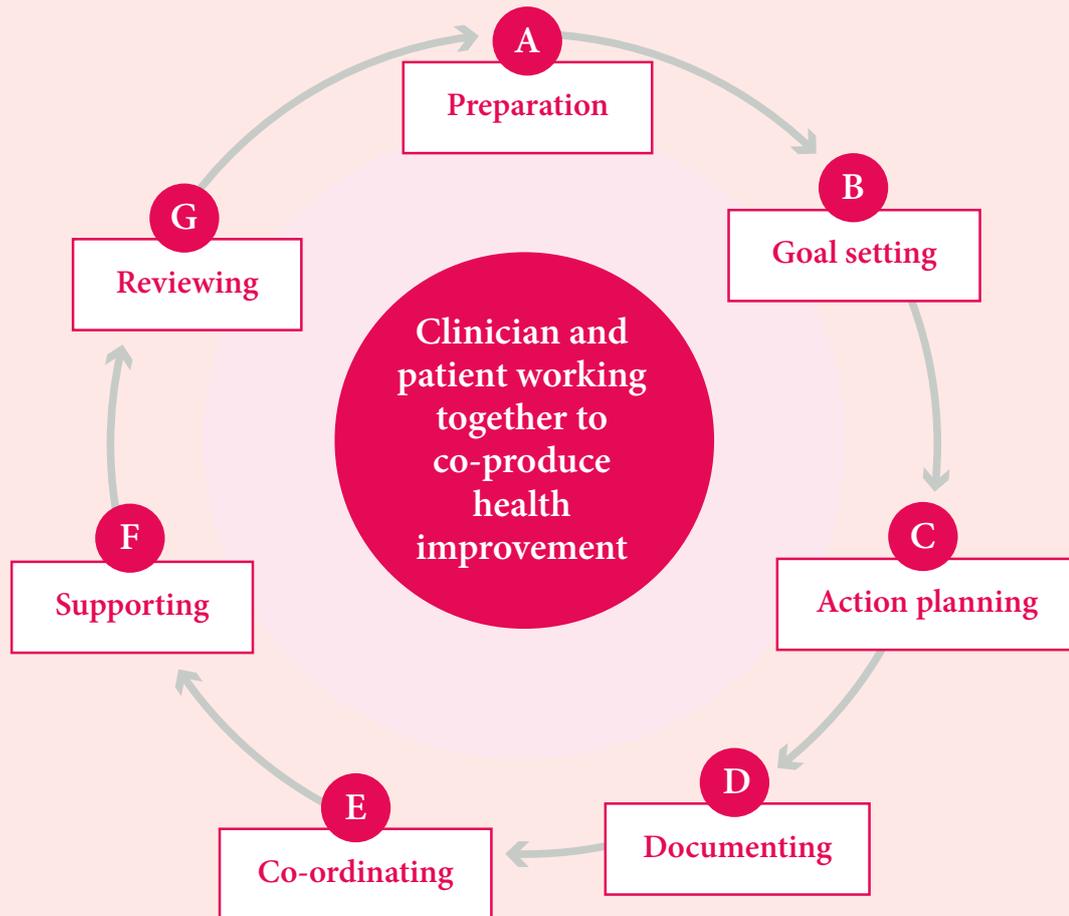
Particular interest has been shown for the House of Care model, which emerged from two of the programmes we review later in this report.⁷⁰ House of Care is a delivery system which aims to embed the care planning process into routine care and link it to population level commissioning in order that individual needs and priorities drive local service planning. The model is being promoted by a national Coalition for Collaborative Care launched in March 2014, with high profile members across health, social care and the voluntary sector. It has also been taken up by NHS England, whose current business plan includes the objective to ‘support the delivery of person-centred co-ordinated care using the House of Care framework.’

What is care planning?

According to Coulter and colleagues:⁷¹

‘Collaborative personalised care planning aims to ensure that individuals’ values and concerns shape the way in which they are supported to live with and self-manage their long-term condition(s). Instead of focusing on a standard set of disease management processes, this approach encourages people with long-term conditions to work with clinicians to determine their specific needs and express informed preferences for treatment, lifestyle change and self-management support. Then, using a decision coaching process, they agree goals and action plans for implementing them, as well as a timetable for reviewing progress.’

They describe care planning as a continuous or cyclical process, involving several steps:



3.4 Parallel trends in social care: personalisation and self-directed care

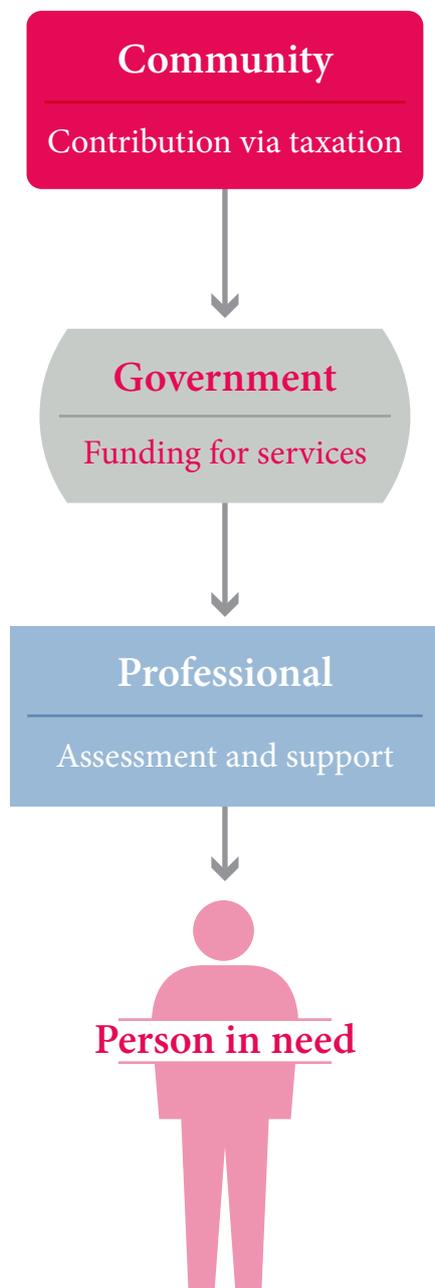
So far we have focused on the trend towards person-centred care in health, but similar developments have also been taking place in social care. Here the concept of ‘personalisation’ has taken hold. Like many of the other concepts included in this report, personalisation has been invested with multiple meanings, nicely captured by Cribb and Owens’s description of it as a ‘wonderfully accommodating orchestrating label’.⁷² The term has political and practical dimensions. Politically,

personalisation emerged from a set of arguments about the limitations of top down public service delivery which was seen as unresponsive, inflexible and increasingly out of touch with a more consumerist and individualised society.⁷²

Service user groups have been particularly vocal in these debates, highlighting the ways in which individuals can be disempowered through problem-oriented approaches that position them as ‘in need’, with professionally controlled assessments and services supplied in response. There are strong parallels between their critique of what is often referred to as the ‘professional gift model’ of welfare (see Figure 3.2 overleaf) and

calls for a more equal balance of power in the health care professional–patient relationship.⁷³ Proponents of personalisation argue that this model fosters reliance on professionals and works against the goals of independence and self-determination.⁷⁴

Figure 3.2: The ‘professional gift’ model of welfare delivery: Duffy (2011)



In practical terms, personalisation has come to represent the idea that services should be tailored to the individual, and the contention that this can only be achieved when people are able to identify their own needs and how these can best be met. There are several ways that this could be achieved in practice. This includes person-centred planning, which was originally championed for and by people with learning disabilities, and has more recently influenced thinking across social care.^{75,76} There are clear similarities with collaborative care planning in health care; for example, both emphasise services being shaped in response to the aspirations and goals that the individual sets for their life. Where person-centred planning differs – and this results from its origins in a social model of disability – is the emphasis on supporting the individual’s inclusion and integration in wider community life. This leads to a focus on both formal and informal networks of support and, because of this, family members and friends are seen as key partners in the planning process.

Echoing debates within health care, it is acknowledged that significant challenges will need to be confronted in moving from services that ‘work for’ people to ones that ‘work with’.^{75,77} Despite the promotion of person-centred planning in learning disability services for well over a decade now, a national review of these services in 2012 concluded that ‘in too many cases care was not person centred; people were fitted into services rather than the service being designed and delivered around them’.⁷⁸

Another mechanism for personalisation, often referred to as self-directed care, involves giving individuals a cash payment or personal budget allocation in lieu of direct service provision. The idea is that direct payments and personal budgets put individuals in control of micro-commissioning their own care and support arrangements and create a financial incentive for services to develop in a more responsive way. This has not been without controversy, with both political and practical objections being raised.⁷⁹ In particular, critics argue that policy makers have focused far more on changing legislature and introducing mechanisms to enable direct payments to be made, and far less on developing sources of information and support to help individuals manage and get the best from their allocation.^{80,81} This suggests a need to integrate the implementation of personal budgets and direct payments with that of person-centred planning. Processes fostering partnership and participation could help to make real the promise of personalised budgets increasing the control that service users have over their care and support.

3.5 Turning policy into practice: where are we now?

Given the longstanding policy promotion of person-centred care, what progress has been made in embedding shared decision making and self-management support into mainstream practice? Here we present evidence from patients' assessments of health care and recent research and policy commentaries.

3.5.1 Evidence from patient reports

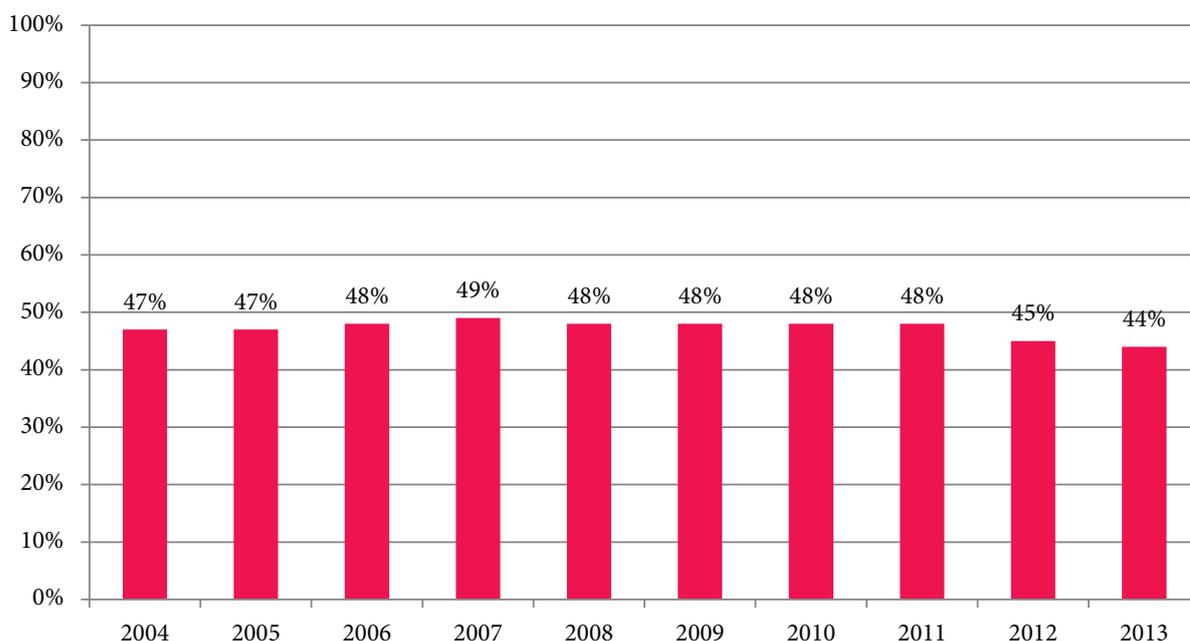
Evidence from patient reports shows that current opportunities for involvement fall short of some people's expectations. For over a decade, around half of all respondents to the national inpatient survey in England have reported wanting more involvement in decisions about their treatment and care (see Figure 3.3 below); a similar proportion of mental health service users also report dissatisfaction with this aspect of their care. This is an issue frequently reported by carers too. For example, a survey of people caring for friends or relatives with dementia found that only 17% were always involved as much as they wanted to be in decision making.⁸² Greater involvement at points of transition – such as discharge from hospital – is a theme common to both patients and carers. For example, 30% of respondents to the 2012 inpatient survey reported having 'some' involvement in decisions about their discharge from hospital, with 16% saying they were not involved at all.

Information to support patients in managing their care is another area for improvement. For example, one in three (33%) respondents in the most recent inpatient survey reported not being given information about what they should do/not do after leaving hospital; well under half (38%) were discharged without fully understanding the possible side effects of medication they had been prescribed.

Experiences of primary care appear to be more positive, although the findings are mixed. Generally, people have reported high levels of trust in GPs and their views on GPs' communication skills are broadly positive,^{83,84} although assessments of communication usually focus on 'listening' and 'explaining', and exclude the more interactive aspects of dialogue. In terms of decision making, social characteristics appear to have a significant influence. Analysis of data from the 2008 English GP survey⁸³ showed that:

- 72% of white respondents reported being involved as much as they wanted to be in decisions about their care, compared to 57% of black or black British respondents and 54% of Asian or Asian British respondents
- 77% of women and 73% of men aged 65 and above reported being involved as much as they wanted to be in decisions about their care, compared to 61% of women and 58% of men aged 16–35.

Figure 3.3: Proportion of inpatients who want more involvement in decisions about their treatment and care



Source: NHS inpatient surveys

The age-related findings should be interpreted with some caution though. What could be seen as evidence that older people are more satisfied with how their care is currently provided might just as easily reflect lower expectations for involvement, or a lack of encouragement to see themselves as active participants in the care process. What also needs to be borne in mind is that social and demographic trends are reshaping the meaning of older age. Now reaching retirement age, the baby boomers are experienced consumers with high expectations who are likely to be far more demanding of the health service than previous generations.⁸⁵

Finally, the UK also fares poorly in international comparisons. A Commonwealth Fund survey of patients and doctors in seven countries found that the UK health system was rated lowest for patient-centred care when assessed against indicators of communication, continuity and feedback, and engagement and patient preferences.⁸⁶

3.5.2 Research and policy commentaries

The conclusions of policy commentators – often made after reviewing evidence from patients’ reports as we have done above – is that slow progress has been made towards implementing person-centred care:

*Patient and public engagement has been on the NHS agenda for many years, but the impact has been disappointing. There have been a great many public consultations, surveys, and one-off initiatives, but the service is still not sufficiently patient-centred. In particular there has been a lack of focus on engaging patients in their own clinical care, despite strong evidence that this could make a real difference to health outcomes.*⁸⁷

The view from many of these commentaries is that there is a need to move beyond standalone – and often unconnected – policy initiatives to a systematic and integrated model for person-centred care. Hence the growing interest in transforming delivery systems through programmes such as the House of Care, and in how more proactive and preventive support for people with long-term conditions can be provided through enhanced community-based services.

Several studies have explored views and experiences from within NHS services. These have provided insight into some of the factors that are likely to affect implementation, including the following:

- Many professionals do not like the term ‘patient-centred care’ and consider it to be ‘management speak’,⁸⁸ while both patients and professionals are unsure what shared decision making actually involves.⁸⁹
- Some professionals mistakenly believe that they are practising in a person-centred way; this seems particularly to be the case in relation to shared decision making, where professionals often think they are sharing decisions more than their patients do.²⁸
- For doctors, there is a tension between a person-centred model of care which requires them to share power and responsibility, and their biomedical identity as a clinical expert and decision-maker;⁹⁰ this is often expressed as concerns about maintaining professional accountability and the duty of care.⁹¹
- Changing long-established ways of working demands time, opportunities and a commitment to developing new skills from frontline professionals, but this may be particularly difficult when services are juggling several competing priorities.³⁴
- Better communication and coordination between services is needed so that decisions and plans are made with patients in a joined up way, and people don’t have to start the process afresh with each different professional involved in their care.⁹¹

3.6 What does the future hold?

In this last section, we explore some of the issues that will shape the ongoing development of person-centred health care in the UK. There are strong drivers to reform the current structure and delivery of health services, which are likely to keep patient experience and involvement high on the policy agenda. But, as we outline below, these drivers present risks as well as opportunities.

3.6.1 The financial context

While NHS spending has largely been protected in real terms in recent years, financial pressures are nonetheless mounting. This is the case across the four UK nations, all of which have identified the need to reconcile limited budgets and rising demand as a fundamental concern. Analysis by the Nuffield Trust of the NHS in

England suggests that there will be a funding shortfall of between £28 and £54 billion – depending on whether current efficiency savings targets are met – by 2021/22.⁹² Against this context, all sectors of the NHS are grappling with how productivity can be improved and demand effectively managed. Addressing the rising costs of care for people with long-term conditions, especially those generated by unplanned and emergency hospital admissions, has emerged as a major area of focus.

This is bringing the issue of self-management of long-term conditions into the spotlight. For example, a recent policy paper by The King's Fund outlining ten priorities for commissioners to deliver financial sustainability put 'active support for self-management' in the top spot.⁶² But there is a danger that this reinforces the view of patient involvement in long-term conditions as a demand management strategy, with efforts to introduce or extend support for self-management driven by system imperatives to contain costs. As Rogers and colleagues have observed, when self-management is explicitly linked to a strategy of demand management, it is the patient's attitudes, behaviours and role that come to be seen as the main targets for change.⁹³ Considerations about patient empowerment and changing clinical cultures can come to be overshadowed by a primary goal that is defined in terms of 'individual self-sufficiency in the hope of a prudent reduction in dependency on health services.'³² As this agenda progresses, it will be important that the issue of self-management does not become uncoupled from broader debates on how patients and professionals can **work together** for a better experience and outcomes.

3.6.2 Health and social care integration

Achieving greater integration – within health and across health and social care – has become a major policy goal across all four UK countries, in part driven by the financial context outlined above.⁹⁴ Much like person-centred care, there are many different definitions and ways of understanding what integration means in practice. Often the vision that is articulated is of professionals and organisations working together effectively to achieve better outcomes **for patients**. Integration of this kind may improve patients' experiences of care, but it overlooks that joint working is something that professionals do with people and their families too. Equally, inasmuch as integration is seen in organisational or structural terms, it may achieve better coordination of services, but not necessarily greater patient involvement in them.

But alternative views of integration are also coming to the fore. Working with service users and patient organisations, National Voices has identified the elements of person-centred coordinated care (see Box 3.2).

Box 3.2: The goals of person-centred coordinated care

- All my needs as a person are assessed.
- My carer/family have their needs recognised and are given support to care for me.
- I am supported to understand my choices and to set and achieve my goals.
- Taken together, my care and support help me live the life I want to the best of my ability.

Source: National Voices (2013)⁹⁵

They have also provided an overall definition:⁹⁵

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.

This definition has been adopted by the 14 national system leading organisations involved in the National Steering Group for Integrated Care and Support, including the Department of Health, NHS England, Public Health England, the Association of Directors of Adult Social Services (ADASS), the Local Government Association, Care Quality Commission and Monitor. It also forms the basis of guidance to local authorities in England, to support the developed of plans for health and social care integration under the Better Care Fund. The question now is whether it will underpin efforts to implement integrated care at a local level. If it does, integration could be a key vehicle for achieving greater patient involvement in decision making and care planning.

3.6.3 Accountability and rewards for person-centred care

Over the last decade, while people's experiences of services have generally improved, slow progress has been made towards the goal of increasing people's involvement in their care. A question arises as to whether the right levers and incentives are in place for the NHS to translate policy aspirations for person-centred care into meaningful action. In all four countries of the UK, health system reform has largely been driven through top down measures including service targets, performance management and

inspection regimes.⁹⁶ Many have suggested that this has led to a situation where ‘what’s measured is what matters.’⁹⁷ Given this, moves to incorporate certain aspects of person-centred care into national frameworks for monitoring and reporting NHS performance should be welcomed. Certainly, this starts to take forward the appeals from the voluntary sector for ‘greater accountability and rewards for patient-centred care.’⁹⁸

Much of the focus so far has been on patients’ experiences of care. In England, patient experience is one of the five domains of the NHS Outcomes Framework, alongside which are evidence-based quality standards for patient experience in adult NHS services and service user experience in mental health. One of the six quality outcomes for the NHS in Scotland is that ‘Everyone has a positive experience of healthcare.’³⁸ However, far less attention has so far been paid to how other goals – for example, to make shared decision making the norm – can be reflected in performance and accountability frameworks.

In England, there is also considerable scope to develop stronger contractual levers and incentives for person-centred care, to drive change at a local level. It is debateable whether the financial incentives and contracting mechanisms currently available to commissioners – such as CQUINs – are sufficient to deliver large-scale and lasting transformation.^{99,100} Instead, a fundamental redesign of NHS payment systems may be required – shifting away from activity-based contracts, to payments which are directly linked to the improvements in the quality and outcomes of care.¹⁰¹ NHS England and Monitor are currently exploring options for developing the NHS payment system, with proposals expected to be published later in 2014.¹⁰²

3.6.4 New models of professionalism

Person-centred care defines new roles and responsibilities for patients and professionals, and necessitates new relationships and ways of working between them. Successful implementation, therefore, requires a fundamental change of culture – to turn the principle of ‘working with’ (not ‘doing for’) into a reality. But cultural change has to come from within the NHS and its workforce; it cannot be successfully imposed on them from outside. As the Health Foundation has previously noted, changing the relationship between people and health professionals:³

...cannot be mandated, specified in a contract or designed into a pay-for-performance system: the participants need to have internalised the ideas and so change their behaviour because they believe it is the right thing to do, not because they have been directed.

Within medicine and other health professions, efforts to define new models of patient-centred professionalism are longstanding. First published in 1995, the General Medical Council’s (GMC) *Good Medical Practice* – which sets out the expectations on doctors who are registered with the GMC – called on doctors to ‘respect the right of patients to be fully involved in decisions about their care.’ Partnership working with patients has featured more prominently in subsequent versions of the guidance, and in recommendations from other leading organisations including the British Medical Association,¹⁰³ Royal College of Physicians¹⁰⁴ and Royal College of Nursing.¹⁰⁵

After several years in development, medical revalidation was launched in December 2012. This requires all UK doctors to periodically demonstrate their fitness to practice. Among medical leaders, there appears to be an assumption that patients should be ‘at the heart of revalidation.’¹⁰⁶ Indeed, the GMC has stated that the core principles of *Good Medical Practice* will underpin revalidation and that patient feedback will inform the process. This opens up the opportunity for revalidation to effect change in the doctor–patient relationship. Whether it does will depend on several factors including the extent to which revalidation supports learning and improvement as opposed to fulfilling a strictly regulatory or clinical governance function,^{106,107} and the weight attached to patient feedback in comparison to other aspects of performance.¹⁰⁸

3.6.5 Developing the workforce

The new models of professionalism which person-centred care call for also need to be embedded in workforce education and development. This is increasingly recognised by professional bodies and educators. For example, a recent commission on the future of nursing education reported that ‘Patient-centred care should be the golden thread that runs through all pre-registration nursing education and continuing professional development.’¹⁰⁹ Assessments of current education and training curricula have shown that these are not adequately preparing health care

professionals to work in partnership with patients. For example, Hasman and colleagues' review of medical education found that:¹¹⁰

While much important work has been done to encourage understanding of the patient's perspective, especially in general practice training, there is still a tendency to encourage trainees to focus on the disease rather than the person, downplaying both the complexity of the doctor-patient encounter and the importance of patients' values, preferences and self-knowledge. An over-emphasis on the technical aspects of care negates the importance of emotional and psychological responses, which are an important part of patients' experience.

They also noted that, while there is an increasing focus on teaching communication skills, this is given relatively little curriculum time and tends to address very specific task-oriented skills such as breaking bad news.

Progressing this issue also requires acknowledging that much learning takes place outside the classroom environment. The idea of the 'hidden curriculum' describes the implicit transmission of values, attitudes and behaviours through professional socialisation and processes of role modelling in workplace settings. In short, what trainees learn through their day-to-day experiences can be as – or even more – influential than formal curriculum content; this has been shown for doctors, surgeons and nurses, among others.¹¹¹ Little is known about how the hidden curriculum specifically affects the development of person-centred care. Haidet and colleagues' US study found that medical students became more doctor-centric and paternalistic in their attitudes as their education progressed from the classroom into clinical settings.¹¹² Efforts to redesign education and training will need to consider all the points at which person-centred values and skills can be learned, and the factors that can detract from or inhibit this.

Chapter 4:

The impacts of shared decision making and self-management support

This chapter provides an overview of empirical evidence on the impacts of shared decision making and self-management support. It is not intended as a stand-alone review of the literature, but rather updates two large-scale evidence reviews published by the Health Foundation in 2011² and 2012.³ In particular, we sought to identify any areas where new evidence has developed or altered the conclusions of these previous reviews. We also attempt to ‘cut’ the evidence differently; where the previous reviews focused on the effectiveness of different interventions, this review focuses on the barriers, facilitators and outcomes for different conditions and illnesses.

Wherever possible, self-management support and shared decision making are considered together. This reflects both the overall aim of this project to ‘bring the evidence together’, but also recognises the inter-relationship between these concepts which we described in Chapter 2. However, where outcomes, barriers or the strength of evidence differs, this is highlighted.

This chapter also contains a critical analysis of the evidence base. Taken as a whole, the evidence for self-management support and shared decision making is variable, and for some outcomes appears to be relatively weak. However, as we discuss, this partly reflects challenges in designing, implementing and measuring interventions, as well as the difficulty of aggregating data of poor quality or from different methodological approaches.

4.1 Methods

As noted above, our aim was to bring up to date two evidence reviews previously published by the Health Foundation. We searched the following databases: MEDLINE, CINAHL, Psychology and Behavioural Sciences Collection, PsychINFO, Social Science Full Text, HMIC, Cochrane Library and the Database of Abstracts of Reviews of Effects. We also carried out a structured internet search and reviewed key organisational websites to identify any further relevant grey literature.

Databases were searched from September 2010 for self-management support literature, and from November 2011 for shared decision making, reflecting the cut-off points of the previous Health Foundation reviews. An initial 67 articles were identified: 39 focused on self-management support, 27 on shared decision making, and one on both. Articles were selected for inclusion in the review based on the standard hierarchy of evidence: prioritising systematic reviews, meta-analyses, randomised controlled trials (RCTs) and controlled trials. Where such studies were not available, other types of evidence were included.

Data were extracted according to a structured template, drawing out information on four main categories of outcome: patient self-efficacy, experience and knowledge; behaviour change; clinical and quality of life; and service utilisation and cost. In addition, we also drew out any wider reflections made about the design, implementation and assessment of self-management support and shared decision making interventions. From this, we developed a critical analysis of the evidence base which is presented at the end of this chapter.

4.2 Outcomes of self-management support and shared decision making programmes

The outcomes of self-management support and shared decision making programmes can be broadly grouped into four categories:

- Patient self-efficacy, experience, knowledge, empowerment and satisfaction with care.
- Patient engagement in more ‘healthy’ behaviours, or general behaviour change.
- Clinical and quality of life outcomes.
- Cost and resource implications for health and social services.

Table 4.1 gives examples of common tools and techniques used to measure outcomes in each of these categories.

These categories build on one another, though the links between them are complex. Behavioural or clinical outcomes are not necessarily more valuable or real than improvements in empowerment; all are important to the patient. Alongside these endpoints are a range of outcomes related to the learning from programme implementation, and continuous improvement and refinement of tools and techniques. These kinds of outcomes will be explored more fully in Chapter 6.

4.2.1 Patient self-efficacy

Almost all interventions look to improve, often as a first step, patient self-efficacy. This is underpinned by the notion that self-efficacy can empower patients and increase their satisfaction with their care, as well as supporting decisions made about it. This is particularly important in self-management support interventions, which to some extent grew out of work on self-efficacy and the realisation that behavioural change is affected by psychological, as well as knowledge-related, factors.⁸

Self-efficacy, often as measured by tools such as the Patient Activation Measure (PAM), can be both a measure of an individual’s willingness and ability to engage, as well as an outcome of it. There is evidence that people who feel empowered and motivated are most likely to self-manage effectively.² Broadly, there is good evidence on the impact of self-management support and shared decision making interventions on self-efficacy, though this evidence varies between conditions. In terms of self-management support, we know that programmes for mental health, arthritis, heart disease, lung disease, diabetes, asthma and stroke can improve self-efficacy.^{2,113,114} Evidence for patients with coronary heart disease is weaker,¹¹⁵ partly due to a lack of methodologically robust studies.

There is uncertainty about the mechanisms by which self-efficacy can be increased. In part, this reflects challenges in measurement and comparison; interventions vary considerably, as do the characteristics of the people they are targeting, both in terms of their condition and personal characteristics (eg the extent to which they are already engaged in their health). There are too many variables between interventions to be able to robustly compare and draw out what works in many cases.

Evidence also suggests that packages which combine different interventions work best, further complicating questions of attribution and comparison.² Increasingly, evidence points to the benefits of using self-efficacy (as measured by activation) to target interventions more effectively. A person’s ability and willingness to respond to a given intervention, as well as what they respond to, will vary according to their stage of activation.^{17,116,117}

Evidence on the long-term sustainability of self-efficacy outcomes remains mixed. In a systematic review of self-management support for diabetes, knowledge was significantly improved at six months, twelve months and two years, but self-management skills, empowerment and self-efficacy outcomes tailed off after the first follow-up

Table 4.1: Examples of common outcomes measures

	Examples of common measures
Self-efficacy	Patient knowledge; satisfaction with care; decisional conflict; empowerment; confidence to self-manage; responsibility for own care; self-efficacy scales
Behaviour change	Self-care behaviour; medication adherence; ability to cope; level of physical activity; diet; decision to screen; measures of patient and clinician involvement (eg the OPTION scale)
Clinical	Quality of life indicators (eg sickness impact profile, SF36); physical functioning; fatigue; locus of control; condition-specific measures
Health care utilisation	Consultation length; hospitalisations; emergency admissions; relapse rates; cost of training programmes; GP attendances

point.¹¹⁸ Similarly, Millard and colleagues' study found no longer-term impact of self-management programmes, despite initial (small) increases in knowledge.¹¹⁹

4.2.2 Decisional conflict, knowledge and satisfaction with care

Evidence suggests that patients who participate in decisions are more satisfied with their care.^{2,3} This increase in satisfaction can come both from individuals feeling more engaged with decisions about their care and from a sense of having made a 'better' decision. It appears that a key factor here is improvements in knowledge and understanding, which can be facilitated by tools such as decision support aids. There is evidence that decision aids are:

- effective for a range of conditions, and in a range of ways. A systematic review suggested that decision aids for pregnant women reduce anxiety, lower decisional conflict, improve knowledge and increase the perception of having made the correct choice.¹²⁰ Similar outcomes are also improved where decision aids are used to support surgical treatment decisions;¹²¹
- practical and effective in some acute or emergency settings. In A&E they were associated with improved knowledge and care satisfaction;¹²² in an intensive care unit, with reduced family member anxiety and distress.¹²³

4.2.3 Behaviour change

Improvements in self-efficacy, satisfaction and engagement with care may lead to individuals changing their behaviour.² However, evidence for this, and the understanding of the precise mechanisms underlying it, is still uncertain. Moreover, behaviours take time to change, and therefore this might not be detected unless outcomes are measured over a longer-term period – which is often not the case. Behaviour change may also occur in ways that are hard to measure.^{2,3} A key issue here is whether behaviour change should be valued as an endpoint in itself, or is deemed successful only insofar as it improves biomedical outcomes.¹²⁴

Generally, evidence around patient behaviour change is stronger for self-management support than for shared decision making. This is unsurprising given that behaviour change is more likely to be targeted by self-management interventions, especially those that are designed to improve self-management knowledge and skills. For shared decision making, the main reported outcomes are medication adherence and

patient participation in decision making. Decision aids are more commonly associated with changes in attitude and knowledge than behaviour.³ A wider range of outcomes is evidenced for self-management support. Systematic reviews have demonstrated that interventions can improve self-care behaviour and the use of self-management strategies.¹²⁵ Those studies which found little or no impact on behaviours were often methodologically poorer than those which found an impact. As with self-efficacy, key in affecting behaviour change was combining multiple support strategies.² Which health behaviours improve vary between studies and conditions. A systematic review of 13 RCTs found that medication adherence improved for schizophrenic patients following self-management education;¹²⁶ however the same improvements were not shown for people who have diabetes, heart disease or are hypertensive.¹²⁷

There have been limited attempts to consider the sustainability of behavioural changes. Millard and colleagues' systematic review of self-management programmes for people living with HIV/AIDS found short-term improvements in psychosocial and behavioural outcomes, but insufficient evidence to confirm whether these improvements were maintained over the longer term.¹¹⁹ More studies with longer-term follow-up periods are needed, as is research to improve our understanding of whether different approaches are needed for behaviour change and to support ongoing behaviour maintenance.

4.2.3.1 Impact on health care professionals' behaviour

Training health care professionals can enhance the effectiveness of interventions. It can also help deal with the problems of reach and sustainability, encountered by programmes which focus on patients alone. However, currently, what works in training health care professionals is not well evidenced.^{2,3} Many of the approaches tested so far have not proved effective. Kennedy and colleagues carried out an RCT evaluation of a practice-level training programme to support a whole system approach to self-management support.³⁴ While attendance rates for the training sessions were generally high, the programme 'did not add noticeable value to existing care for long term conditions' when assessed against a range of outcomes including shared decision making, self-efficacy and enablement.

There is a suggestion that many health care professionals are in favour of shared decision making and self-management support in principle, but find

implementation in practice difficult, for a range of reasons.^{2,3} These include the requirement for a change in behaviours and mindsets from those providing care, concerns about handing over responsibility to patients and the potential for increased consultation time. As much as patients require support to take on new mindsets and behaviours, the same is true of health care professionals.

4.3 Clinical outcomes

Self-management programmes have shown some evidence of improved clinical outcomes, though this varies by intervention and the particular condition targeted, and long-term impact is not well evidenced. The links for shared decision making are less clear; this partly reflects the aims (and potential impacts) of shared decision making programmes.

4.3.1 Clinical outcomes of self-management support

For self-management support interventions, evidence is available of positive clinical outcomes for a range of conditions: arthritis, asthma, diabetes, hypertension, heart disease, heart failure, stroke and cancer.² Findings, though, are not always consistent: either in terms of improvements across a range of clinical outcomes in the same study, or in terms of improvements in the same outcome across different studies. For example, self-management programmes for Type II diabetes have been shown to reduce HbA1c^{iv} and fasting blood glucose, but not mortality, body mass index (BMI), blood pressure or lipid profile.¹¹⁸ Similarly, in a systematic review of self-management for stroke,¹²⁸ six studies showed significant improvements associated with the intervention, and three showed none.

This picture is complicated further when patients have multiple co-morbidities. Co-morbidities may limit individuals' capacity for behaviour change, as they face a greater number of barriers to action. However, there is some evidence that self-management support can lead to improved clinical outcomes, even where patients have a complex mix of conditions and constrained abilities to act on these. A review of self-management support for individuals with co-morbid diabetes and schizophrenia showed improved clinical outcomes (weight, BMI and blood glucose) for inpatients, and a maintenance of BMI for outpatients compared to increases in the control group.¹²⁹

Whether clinical outcomes are sustainable, and what factors might help to sustain them, remains unclear. There is some suggestion that the longer the period of the self-management intervention, the longer the effect tends to last. Others suggest that benefits tend to decrease one to three months after the intervention ceases, irrespective of the length of the intervention.² This complex pattern is confounded by a general lack of evidence, and short follow-up times in most studies. For example, Moss-Morris' trial of an internet-based self-management programme, modelled on cognitive behavioural therapy principles, demonstrated positive clinical outcomes, but with a follow-up of only ten weeks.¹³⁰

4.3.2 Clinical outcomes of shared decision making

The links between shared decision making and clinical outcomes are less clear than for self-management support. This partly reflects shared decision making as a concept. To improve clinical outcomes, shared decision making will have to do one of two things:

- It has to facilitate the patient making a 'better' decision, resulting in a more effective treatment than otherwise would have been selected. Often, this concept of 'better' is not realistic, and patients are choosing between several, equally clinically valid options. They may plausibly choose an intervention which is a better fit for them, thus leading to improved clinical outcomes, but this is not certain. Given by nature this is a personal response, it is very hard to measure, as there is no way to construct a control group; or
- It has to increase the effectiveness of the treatment or course of action selected by increasing ownership of and engagement with the decision, as well as ensuring that the most appropriate ('best') treatment is chosen. However, this assumes patients are taking medications or following courses of action suboptimally, which is hard to measure, and also requires behaviour change, which is inherently hard to achieve.

Nonetheless, where evidence for improved clinical outcomes does exist, this often results from improved adherence to medication – people **are** more likely to follow through with treatments and actions if decisions are mutually agreed.³ Few studies consider the longer-term impacts of shared decision making, even though this is where clinical outcomes might be seen.³

^{iv} HbA1c refers to 'glycated haemoglobin', a measure of blood sugar levels.

4.4 Impacts on health care utilisation

The evidence about the impact of self-management support and shared decision making on health service use and cost-effectiveness is varied. Throughout the evidence, there is an emphasis on seeing outcomes in terms of shifting patterns of health care use, rather than reductions in service utilisation *per se*.^{2,3} Programmes and interventions also tend to avoid overt emphasis on cost-effectiveness.

4.4.1 Impact of self-management support on health care utilisation

There is evidence that self-management programmes can reduce health care utilisation. Several studies included in the 2011 Health Foundation evidence review reported that such programmes can reduce visits to health services by up to 80%. A recent controlled trial of diabetes self-management programmes found that this reduced the odds of hospitalisation and significantly prolonged the time to the first diabetes-related hospitalisation, compared to subjects in the control arm.¹³¹

However, the overall evidence base presents a mixed picture:

- It often demonstrates correlation rather than causation; for example, the evidence shows an association between self-management programmes and reduced hospitalisation rates, but it is not able to demonstrate that improved self-care is the cause of this.²
- The links between people's involvement in their health and utilisation outcomes are complex. For example, Adepoju et al's study showed improvements for patients participating in a self-management programme, but not for those who participated in the programme and had a personal digital assistant (to self-monitor aspects of their health).¹³¹ A recent systematic review of self-management for depression reported inconclusive findings for cost-effectiveness, potentially linked to mixed results on relapse rates.¹¹⁴
- Linked to above, there is still much to be learned about the mechanisms of change, particularly the relationships between self-efficacy, behaviour change, clinical outcomes and resource use. People may go through all those steps, or jump straight from showing improvements in self-efficacy to using health care services less or differently.

For example, an RCT of an e-programme^v for patients with atopic dermatitis found a cost saving of €594 per patient in the first year of treatment, despite no improvement in clinical outcomes.¹³²

This mixed evidence base does not mean that there is no impact on health care utilisation; it may be that changes, where they have taken place, are hard to measure and often beyond the scope and timeframe of any evaluation or study. In addition, as we discuss later in this report, many of the changes in service utilisation are relational changes (ie changes in the way that individuals interact with the health professionals and services); this is not usually taken account of in any conventional analysis of service utilisation patterns.

4.4.2 Impact of shared decision making on health care utilisation

The most evidenced service utilisation outcome for shared decision making is consultation length, but the evidence on this is not conclusive.¹³³ Some studies find that shared decision making takes more time than 'traditional' care, whereas others find that it is feasible within the usual timespan of consultations. There is a suggestion that shared decision making may take more time initially but once health care professionals are accustomed to using the techniques, consultations drop back to previously normal lengths.¹³³ In addition, the evidence cautions against reading off increases in consultation length as a negative outcome. Some studies have shown that longer shared decision making consultations are associated with a better patient experience, and can also reduce the need for further, future consultations, leading to a net reduction in use.^{134,135}

There are also indirect costs of shared decision making; for example, a patient can decide between alternative treatments which may have different costs. There is also a potential reduction in the costs of unnecessary medication and/or improved adherence to medication. While some studies show improvements in treatment adherence associated with reduced costs, others show no change.³

^v The e-programme consisted of an e-consultation, a patient-tailored website, and monitoring and self-management training.

4.5 Outcomes for different conditions

The evidence for self-management support and shared decision making varies considerably between conditions and depends on the outcome considered. Table 4.2 summarises the evidence available. It shows that evidence of impact tends to be greatest for self-efficacy, and weakest for health care utilisation, and that it is variable across conditions. The evidence for both cancer and screening is particularly strong; this mainly relates to the use of decision aids and their ability to facilitate patients making ‘better’ decisions about the complex risks surrounding cancer screening programmes.^{3,136} Mental health care also has a robust evidence base, with several systematic reviews reporting improvements in self-efficacy and behaviour change, though the findings for clinical outcomes and health care utilisation are often more mixed. Evidence for coronary heart disease (CHD) is noticeably weak.

4.5.1 Psychological and physical illnesses

There is some evidence of differences in attitudes and engagement with mental health services, compared to other kinds of service.¹¹³ In particular, mental health conditions can affect patients’ feelings of control, self-efficacy, empowerment and responsibility, potentially making it harder for people to self-manage their condition and share in decision making.³

In addition, treatment for mental health conditions frequently requires individuals to confront difficult issues, such that people can get worse before they get better. They are therefore potentially at greatest risk during their treatment.¹³⁷ Given this, practitioners may be reluctant to encourage self-management. But, as Gillard notes, two key components of self-management and shared decision making programmes – self-control and self-efficacy – are positive outcomes in their own right, as well as being key steps in processes of recovery and rehabilitation.¹³⁷

Table 4.2: Assessment of impact for shared decision making and self-management support, by condition

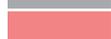
Long-term condition	Self-efficacy	Behaviour change	Clinical outcomes	Health care utilisation
Mental health (excluding schizophrenia)	Satisfaction with care	Evidence of improvement	Evidence of improvement	Some reduction in hospital attendances; mixed evidence around consultation length
	All other elements of self-efficacy			
Schizophrenia	Evidence of improvement	Evidence of improvement	Mixed evidence of improvement	Evidence of improvement
Diabetes	Evidence of improvement	Evidence of improvement	Depends on which clinical outcome is measured	Evidence of improvement
CHD	Limited or no improvement	Evidence of improvement	Evidence of improvement	Evidence of improvement
Stroke	Evidence of improvement	Limited or no improvement	Evidence of improvement	Evidence of improvement
Arthritis/other musculoskeletal	Evidence of improvement	Evidence of improvement	Evidence of improvement	Evidence of improvement
Asthma	Evidence of improvement	Evidence of improvement	Limited or no improvement	Evidence of improvement
Lung disease/COPD	Evidence of improvement	Limited or no improvement	Limited or no improvement	No impact on hospitalisations; some impact on medication use
Pregnancy	Evidence of improvement	Mixed evidence of improvement	Mixed evidence of improvement	Mixed evidence of improvement
Infectious/HIV/AIDS	Evidence of improvement	Short-term only	Short-term only	Mixed evidence of improvement
Screening (Cancer)	Evidence of improvement	Evidence of improvement	Evidence of improvement	Variable impact on consultation length
Cancer	Evidence of improvement	Involvement in decision making	Body image; higher quality decisions	Evidence of improvement

Key

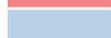
Evidence not reported



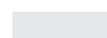
Limited or no improvement



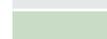
Low to moderate improvement



Mixed evidence of improvement



Evidence of improvement



4.6 Evidence issues

Taken as a whole, the evidence for self-management support and shared decision making is variable, and for some outcomes appears to be relatively weak. But there are several practical and methodological issues that should be considered alongside this evidence, and which might account for the shortcomings in the evidence base that we have sought to highlight above.

Evaluative studies in health care – especially of complex interventions of the kind we are considering here – can confront many different challenges. Where studies do not yield the outcomes expected, it may be that the intervention being tested is not effective. But before reaching this conclusion other explanations ought to be considered and ruled out, for example:

- the intervention or programme was not well designed
- the intervention was not fully or effectively implemented
- the intervention was not evaluated in an appropriate or effective way.

A further issue in relation to the evidence base for shared decision making and self-management support is the sheer diversity it encompasses. Tools, techniques, conditions, participants, settings and research designs vary considerably. Comparing programmes is hard, with reviews and systematic reviews considering a range of interventions which differ greatly in terms of scope and intensity, weakening any aggregate conclusions.

4.7 Design issues

Poor initial programme design can lead to poor outcomes. Self-management support and shared decision making may be effective concepts, but they need supportive infrastructure, training, tools and system redesign in order to work. If these are not designed into a programme, an intervention can fail to achieve results. Particular issues here include:

- the overall programme was not well designed
- the programme did not use appropriate tools or techniques
- the programme did not identify (and therefore target) people who might be expected to benefit most from the intervention.

In sum, programmes have to offer the right type of support, appropriate to the condition and tailored to the people accessing it.

4.7.1 Programme design

A very wide range of initiatives are classified as self-management support and shared decision making, some of which only loosely apply the concepts, tools and techniques. These can have poorer effectiveness, and therefore dilute aggregate findings, as noted by the Health Foundation:³

Some [studies] suggest that the evidence for supporting self-management is only moderate but this is because a wide range of activity is described as ‘self-management support’ and some interventions may be more effective than others.

Aggregating complex programmes – which combine a range of tools, techniques and practice interventions – with those that are simply providing information, will lead to apparently poorer outcomes.

The quality of reporting about the design, targeting and implementation of the interventions being tested is often weak; wider contextual features are often not adequately described. This presents a challenge to those seeking to learn about what works (and also what doesn't), and results in studies that are not replicable. The potential for research to support continuous learning and incremental development is thus also limited.

4.7.2 Selection of tools and techniques

The evidence for which tools and techniques are most effective, for whom, and in what circumstances is varied (see Tables 4.3 and 4.4 on the following pages). It suggests that standalone interventions targeting only patients may have weaker or less sustainable effects than interventions embedded in a wider programme involving – for example – training for professionals and/or a re-modelling of the clinical consultation.^{2,138,139} Indeed, there is evidence to support the notion that a package of multiple support strategies seems to work best.⁵⁸ However, disaggregating the effects of each individual tool and technique can be challenging, as can assessments of whether it was the particular **combination** of tools and techniques offered that was important, compared to merely the **quantity**. Equally, current study designs have limited value in identifying

the incremental value of specific tools and techniques, over and above outcomes that follow from more fundamental changes in consultation style and/or the professional–patient relationship.

Alongside this, there is a suggestion that a wider supportive infrastructure is necessary to sustain effects, be this an infrastructure that helps to embed new

ways of working (eg IT systems) or forms of follow-on support for patients (eg peer networks). Furthermore, which elements of supporting practice are necessary and beneficial will vary according to the tools and techniques used. Some of these success factors are summarised in the tables below. Where programmes have lacked these, it is likely that there will be limits to the outcomes seen.

Table 4.3: Self-management support tools: assessment of impact

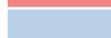
	Tool	Self-efficacy	Behaviour change	Clinical outcomes	Resource use	How effectiveness can be increased
Information	Written information	Low to moderate improvement	Limited or no improvement	Limited or no improvement	Evidence not reported	Combining with educational interventions; making them tailored and personalised
	Electronic information	Evidence of improvement	Limited or no improvement	Mixed evidence of improvement	Evidence not reported	Combining with educational interventions; making them tailored and personalised
Patient empowerment	Decision support tools	Evidence of improvement	Limited or no improvement	Limited or no improvement	Evidence not reported	Nothing noted
	Patient-held records	Mixed evidence of improvement	Limited or no improvement	Limited or no improvement	Evidence not reported	Nothing noted
	Planning and agenda setting	Evidence not reported	Low to moderate improvement	Mixed evidence of improvement	Evidence not reported	Providing care plans; support in primary, rather than secondary care; may be better as a preventative measure, rather than for those with the most severe disease
	Goal setting	Low to moderate improvement	Mixed evidence of improvement	Mixed evidence of improvement	Low to moderate improvement	Regular and proactive follow-up
Behaviour change	Individual education	Low to moderate improvement	Limited or no improvement	Limited or no improvement	Low to moderate improvement	Targeting, specific and long term
	Group education	Evidence of improvement	Low to moderate improvement	Mixed evidence of improvement	Evidence not reported	Focusing on enhancing self-efficacy and combining technical education with more proactive motivation
	Telephone coaching	Evidence of improvement	Mixed evidence of improvement	Mixed evidence of improvement	Low to moderate improvement	Nothing noted
	Work-based support	Evidence not reported	Low to moderate improvement	Evidence not reported	Evidence not reported	Offering the opportunity to practice; tailoring to individuals; offering proactively
	Self-monitoring	Evidence not reported	Evidence not reported	Mixed evidence of improvement	Mixed evidence of improvement	Those most likely to benefit have the most severe disease

Key

Evidence not reported

Limited or no improvement

Low to moderate improvement



Mixed evidence of improvement

Evidence of improvement

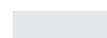


Table 4.4: Shared decision making tools: assessment of impact

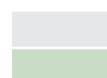
Tool	Self-efficacy	'Better' decision	Behaviour change	Clinical outcomes	Health care utilisation	How effectiveness can be increased
Printed and electronic information	Low to moderate improvement	Limited or no improvement	Limited or no improvement	Limited or no improvement	Evidence not reported	Can improve knowledge, but has no effect on behaviour when used alone; targeted, personalised information is more effective
Patient-held records	Evidence not reported	Evidence not reported	Evidence not reported	Evidence not reported	Evidence not reported	Needs to be an active tool supporting dialogue, not just a passive archive for recording information
Decision aids	Evidence of improvement	Evidence of improvement	Cancer screening	Cancer screening	Evidence not reported	Automatic dissemination works better (rather than relying on the clinician to provide); possibly works better when accompanied by training for clinicians. Research has focused particularly on decision aids for cancer screening, which now have a very strong evidence base.
			All other decisions	All other decisions	Evidence not reported	
Action plans	Evidence not reported	Evidence not reported	Low to moderate improvement	Evidence not reported	Evidence not reported	Suggestion that they are most effective when used as part of a broader programme; possibly work best in primary care settings; generally better for preventative care and/or stable conditions, rather than the most severe disease; jointly setting goals; ongoing follow-up and support
Communication tools	Evidence not reported	Low to moderate improvement	Evidence not reported	Evidence not reported	Evidence not reported	Limited research, often a part of larger interventions
Individual education and coaching	Evidence of improvement	Evidence not reported	Evidence not reported	Evidence not reported	Low to moderate improvement	Limited research reported
Group sessions	Low to moderate improvement	Evidence not reported	Low to moderate improvement	Evidence not reported	Evidence not reported	Limited research reported
Training for health care professionals	Low to moderate improvement	Low to moderate improvement	Evidence not reported	Evidence not reported	Evidence not reported	Most programmes report on outcomes for doctors, rather than considering how professional training programmes impact on patients

Key

Evidence not reported
 Limited or no improvement
 Low to moderate improvement



Mixed evidence of improvement
 Evidence of improvement



4.7.3 Targeting patient groups

A range of factors affect whether patients feel confident and able to self-manage and share decisions about their care. These include their values and preferences, demographic characteristics, health literacy and overall health status, as well as health care professionals' perceptions of these. The relationship between factors and outcomes is complex; patients facing more barriers or who have worse health may have more to gain from a particular intervention. But they may also need different forms or intensities of support.

Certain types of intervention may be more likely to attract those who are already more engaged in their health care. For example, Rogers suggests group-based self-management education programmes – such as those seen in the Expert Patients Programme – tend not to appeal to those who most need the support.³² Group-based interventions are currently the dominant method, which might mean that certain groups are not being reached and outcomes are poorer than they might otherwise be. This also means that programmes may report very positive outcomes, but for a group of people who are uncharacteristic of the wider patient population.

Miles and colleagues' systematic review of self-management interventions for chronic musculoskeletal pain found that self-efficacy was predictive of outcome, irrespective of the intervention.¹²⁵ Interventions which target people based on their level of activation, or 'stage of change',^{vi} appear to be effective. The Health Foundation highlights a number of studies where interventions were successful when targeted in this way.²

4.8 Implementation issues

There are numerous structural and organisational factors which affect implementation of shared decision making and self-management support,^{2,3} including:

- the local and national policy context
- health service and organisational cultures
- leadership support
- the involvement of nurses and allied health professionals, as well as doctors
- training for professionals
- time available

- incentives and disincentives
- supportive practice settings and access to care
- availability and appropriateness of supportive tools.

The wider academic literature base is relatively weak on implementation; this partly reflects how context-specific many of the practical elements of implementation are. That said, there is a large evidence base on how to influence (and sustain) mindset and behaviour change among health care professionals – and which health care professional related factors can limit how successfully a given programme can be implemented. These factors include the following:

- Professionals' perceptions of patients. Professionals' beliefs (and possible biases) will influence whether or not they try to engage a given patient in shared decision making or in managing their own care; some practitioners can assume that particular patients are either unwilling or unable to engage in their own care.^{3,21,140}
- Professional experience and training. Professionals from certain backgrounds may be more accustomed to sharing in decision making than others.^{3,141}
- Training in how to use tools, techniques and theories. Clinicians will not use tools just because they are available. They need to understand them and to buy into the theory behind them.^{2,21,70}
- Perceptions of risks, time and cost. There can be tensions between professionals' desires to respect patient preferences, while ensuring that care is safe and as high quality as possible. This has led some professionals to ask at what point it is acceptable to allow patients to take a medically 'wrong' decision,¹⁴² although such a question assumes not only that there is a 'right' decision to be made but also that the professional knows best. Perceptions of the time and cost implications of self-management support and shared decision making will also influence engagement.³

For interventions to work, professionals must play a central role in facilitating patient involvement in their own care. Practitioner support is often crucial for encouraging and enabling people to engage in decision making, feeling confident about their choices and managing their care.^{2,3} Interventions which combine patient-focused interventions with training for professionals are often most successful.¹³⁹ This is because professionals need to:

vi The trans-theoretical model's 'stages of change' describes behaviour change as a process, whereby individuals progress through a series of stages. These are: pre-contemplation (not ready), contemplation (getting ready), preparation (ready), action, and maintenance.

- be trained and persuaded to use tools, and to understand that they do not already always practise person-centred care^{2,3}
- understand that they make judgements about patients' abilities and willingness to engage, and that these are not always correct^{3,21,140}
- be convinced that shared decision making and self-management support will not cost more, take more time or put patients at risk^{2,3}
- see how self-management support and shared decision making are important to, and can have positive outcomes for, patients.

4.9 Measurement issues

There are a number of challenges to evaluating self-management support and shared decision making, both practical and conceptual. The practical challenges of how to evaluate are covered in the following chapter. The more conceptual challenges are outlined below, and include:

- conceptual clarity over what comprises self-management support and shared decision making
- the scope and scale of impact
- choice and availability of outcome measures.

As we have already discussed in Chapter 2, there is a lack of conceptual clarity over what self-management support and shared decision making are. One systematic review of shared decision making research found that over 40% of intervention studies did not have a clear definition of the concept.⁹ Without this conceptual clarity, defining and measuring potential outcomes – and the logic which might link these outcomes – becomes problematic. There is also a lack of conceptual clarity over some of the outcome measures used. For example, whether improvements in self-efficacy lead to clinical and behavioural outcomes, vice versa, or even both depending on context. There are also problems of additionality. Benefits to patients may be small where usual care already includes a high degree of self-management support, as in stroke or cardiac rehabilitation for example.

Even where concepts are clear and potential benefits measurable, there are still challenges in selecting appropriate and sensitive outcome measures. Firstly, the choice of outcome measure can be led by the prevailing view of what is important for the recovery of a particular condition, rather than what self-management support might plausibly have an impact on. For example, Boger et al's systematic review of outcomes measures in stroke self-management found that the most commonly used indicator was physical function.⁴ They suggest that this reflects a wider assumption within stroke rehabilitation that physical function is key to recovery – despite increasing evidence of the role of psychosocial factors – rather than any evidence that self-management support can result in increased physical function, or that physical function is a desired outcome of such interventions.⁴

This is reflected in the wider literature, where the choice of outcomes (not unreasonably) is often driven by practical concerns about what can be measured and, in the NHS, the kinds of outcomes needed to convince those who pay for and deliver services. Outcome measures which are likely to show some change within the study period are also more likely to be selected.^{2,3} The choice of outcome measure narrows the view of what counts as 'impact' – if the outcome is not appropriate, much of the potential improvement will be lost.

Measurement itself can be very challenging. In shared decision making research, traditional methods such as case note review cannot accurately ascertain whether and how decisions were shared. More observational methods are labour-intensive and can be obtrusive, and health care professional and patient views on the quality and quantity of shared decision making often differ from each other, and from independent observers.^{2,143}

This is compounded by the complex dependencies and causalities related to shared decision making. Patients do not necessarily have a single, stable preference that a consultation can work towards. Indeed, preferences are likely to be co-constructed with health care professionals.¹⁹

Part 2:
**What is the learning from
implementation programmes?**

Chapter 5:

Introduction to Part 2

The main focus of the brief that we were given by the Health Foundation was ‘to investigate and synthesise what has been learnt from efforts to implement self-management support and shared decision making into mainstream health care services.’ In the last decade, there have been numerous initiatives and programmes to develop, pilot and embed shared decision making and self-management support in the UK. Several of these have been supported by the Health Foundation as part of its portfolio of work on person-centred care.

For this review, we have gathered, synthesised and examined evidence from eleven large-scale innovation programmes, five of which were supported by the Health Foundation, and the remaining six led by a range of organisations both within and outside of the NHS

(see Box 5.1 below for a summary of the programmes). Our evidence base comprised over 110 documents including evaluation and project reports, case studies, improvement stories and peer-reviewed articles, supplemented by interviews with 23 people involved in programme design, delivery and/or evaluation. In particular, our analysis sought to draw out:

- the range and extent of outcomes achieved by the programmes
- learning about and examples of what works
- barriers and enablers to implementation
- lessons learned for ongoing and future efforts to mainstream shared decision making and self-management support.

Box 5.1: The programmes reviewed

BUPA Health Coaching (BUPA)

Health coaching to support patients making ‘preference sensitive’ decisions was introduced into BUPA services in 2011. Coaching is primarily provided via telephone by nursing staff, supported by the use of evidence-based decision aids. The evidence we reviewed was from the United States as a UK evaluation was not completed at the time of the project.

www.bupa.co.uk/healthcare-providers/bupa-health-dialog/products-and-solutions/clinical-claims-management-1

Closing the Gap (The Health Foundation)

Two phases of the programme were reviewed: Closing the Gap through Changing Relationships, which aimed to transform the dynamic between people who use health services and those who provide them; and Closing the Gap through Clinical Communities, clinician-led quality improvement programmes in primary, secondary and mental health care.

www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-changing-relationships

www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-clinical-communities

Co-creating Health (The Health Foundation)

This was a two-phase programme aiming to embed self-management support into mainstream health services, involving eight demonstrator sites in England and Scotland. The programme comprised three workstreams: patient self-management support, clinician training (known as the Advanced Development Programme) and a service improvement programme.

www.health.org.uk/areas-of-work/programmes/co-creating-health

Box 5.1: The programmes reviewed

Expert Patients Programme (Expert Patients Programme CIC)

This is a self-management programme for people living with long-term conditions, available across England and Wales. Based on the Chronic Disease Self-Management Programme developed in the USA, it comprises six weekly sessions delivered by volunteer trainers who themselves have experience of living with a long-term condition.

www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/expert-patients-programme.aspx

The Kidney Care Patient Decision Aids Project (NHS Kidney Care)

This programme aimed to embed the use of the End Stage Renal Failure Patient Decision Aids into routine clinical practice. Funding and project management support was provided to 21 renal practices throughout the UK to redesign services to support the use of the decision aid.

[Website not available as NHS Kidney Care is longer in existence]

MAGIC: Shared decision making (The Health Foundation)

This programme ran in one English Trust (Newcastle upon Tyne NHS Foundation Trust) and a Welsh Health Board (Cardiff and Vale University Health Board) until late 2013 and aimed to test how shared decision making approaches can be embedded in different clinical settings.

www.health.org.uk/areas-of-work/programmes/shared-decision-making

National Cancer Survivorship Initiative (Macmillan Cancer Support, Department of Health and NHS England)

Launched in 2007, this programme is exploring a range of new models for delivering cancer care. It comprises several workstreams and projects, one of which is developing and testing interventions to support self-management and exploring how these can be embedded into patient pathways.

www.ncsi.org.uk

People Powered Health (Nesta)

Across six pilot sites, this programme supported partnerships between people and their families, health professionals, and voluntary and community groups to improve outcomes for those living with long-term conditions. It took an asset-based approach and tested out a range of initiatives including social prescribing, time banking, group consultations and personalised care planning.

www.nesta.org.uk/project/people-powered-health

Right Care Shared Decision Making (Department of Health)

Funded through the Department of Health Quality, Innovation, Productivity and Prevention (QIPP) programme, this programme comprised three workstreams focusing on: developing evidence-based decision support tools (delivered by Totally Health); embedding shared decision making in NHS systems and processes (delivered by Capita Business Services); and creating a receptive culture for shared decision making, through training programmes delivered to health care professionals, managers and commissioners (delivered by AQuA).

www.rightcare.nhs.uk

Shine (The Health Foundation)

This ongoing programme provides projects with up to £75,000 of funding and service improvement support to achieve one of three goals, to: support people to take a more active role in their health care; improve the safety of patient care; or improve quality while reducing costs. Our review included only projects focusing on the first of these goals.

www.health.org.uk/areas-of-work/programmes/shine-2014

Year of Care (Diabetes UK, NHS Diabetes and the Health Foundation)

This three-year programme sought to embed collaborative care planning within primary care communities and initially ran in three pilot sites: NHS Tower Hamlets, NHS North of Tyne and NHS Calderdale and Kirklees. It tested out a micro-to-macro model of commissioning, whereby individual patient needs and goals, identified during care planning, drive the commissioning of local services at population level.

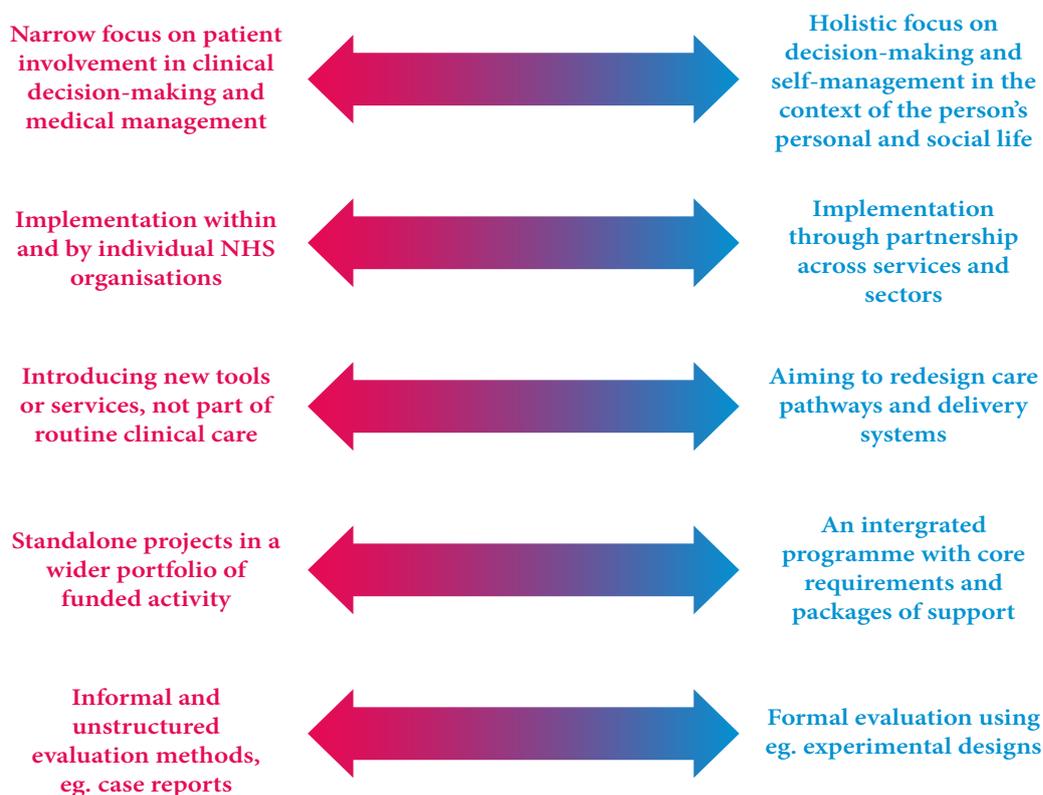
www.health.org.uk/areas-of-work/programmes/year-of-care

5.1 Key characteristics of the programmes reviewed

The programmes (and individual projects within them) vary considerably. There is diversity in terms of their scope and focus, goals, approaches, settings, the nature and level of support provided to individual projects, and the methods used to gather learning and assess impact. Some are more distinctively ‘programmes’ in the sense that they ran for a time-limited period in a selected number of sites; others – such as the *Expert Patients Programme* and *BUPA Health Coaching* – are ongoing and routinely available services. In all cases, health care organisations have been involved in delivery, with wider partnership working a feature of some, but not all.

The main ways in which the programmes vary are illustrated in the Figure 5.1 below, and these differences should be borne in mind when considering the evidence. As the figure shows, differences are not only technical or practical – such as how outcomes were evaluated – but also relate to the philosophies of care underpinning the programme logic and design. Some programmes have focused on the implementation of shared decision making and/or self-management support into clinical processes and relationships (eg *The Kidney Care Patient Decision Aids Project*); others started from a social model of health and sought to connect individual participants with social networks and wider community life (eg *People Powered Health*). In this sense, they reflect many of the different ways of conceptualising shared decision making and self-management support that we outlined in Chapter 2.

Figure 5.1: Key dimensions of variation across the programmes reviewed



The programmes in our review represent some of the earliest adopters and innovators in the area of person-centred care in the UK. There is no ‘off the shelf’ model of shared decision making and self-management support. Instead, and as these programmes provide evidence for, implementation and effectiveness is highly context dependent – what works for one group and in one setting may not for/in others. Many of the programmes sought to provide what Greenhalgh and colleagues call a ‘trialability space’ – an opportunity for experimentation and learning, and chance to adapt and refine over time (with the potential for this to evolve

new and better approaches to implementation).¹⁴⁴ The programmes are often as much concerned with testing theories of change and exploring feasibility and implementation, as they are with the downstream issues of outcomes and sustainability (see Figure 5.2 below).

The diversity of the programmes renders any simple aggregation of learning or outcomes from the evidence reviewed impossible. Rather, what we have principally sought to do is explore key themes and commonalities, as well as highlighting and seeking to account for differences wherever possible.

Figure 5.2: The four main programme aims



Chapter 6:

The impacts of self-management support and shared decision making programmes

This chapter analyses the reported programme outcomes. It does so using the RE-AIM framework. This helps to navigate and demarcate complex outcomes, as well as capturing a broader range of outcomes than just those limited to impact or efficacy. We focus on the **reported outcomes** of projects, with ‘how to’ type questions and lessons learned discussed in subsequent chapters. This is not intended to be a systematic review or analysis; rather it gives a flavour of the kind of outcomes achieved and points to areas where future evaluative work might usefully focus.

The RE-AIM Framework

- **REACH:** eg the number, proportion and diversity of patients reached by the programme/intervention
- **EFFICACY:** eg impact on patient outcomes including knowledge, skills, satisfaction, service use and health status
- **ADOPTION:** eg rates of uptake in practice, degree of penetration across different services and professional groups
- **IMPLEMENTATION:** eg consistency, costs and adaptations made during delivery
- **MAINTENANCE:** eg longer-term efficacy, the extent to which new practices become embedded.

6.1 The comparability of outcome data and the challenges of measuring impact

Few programmes in this review focused their evaluations on impact. Many were still in their early stages and/or took a more exploratory and learning oriented approach, focusing on how to implement self-management support and shared decision making in the NHS (or services more widely). This also partly reflects the scale, objectives and timelines of many of these programmes; most were targeting far-reaching

change in different settings and with different groups of people. Change on this scale is likely to be iterative. A key aim of any evaluation will be identifying and dealing with practical issues. Impacts, particularly at the patient level, are unlikely to be seen straight away. Table 6.1 illustrates the main areas of focus of the 11 programme evaluations: green indicates this was a primary focus; orange, that there was some focus on this; grey, that it was not included in scope and/or not reported.

6.2 Reach

‘Reach’ outcomes relate to the number, proportion and diversity of individuals who are reached by a programme or intervention. It is an assessment both of the scale of delivery, and how effectively it engaged different groups of people. Not all programmes systematically gathered information on the numbers of people engaging in new approaches or accessing new services. Information on reach was mainly collected when it related to targeting specific minority or marginalised groups (see Section 6.2.1).

Some programmes did report the proportions of people engaged, compared to target numbers or target groups. Those that did showed mixed levels of engagement across programmes. For example:

- The *Expert Patients Programme*, which was rolled out nationally, reported poor uptake and attendance, with many PCTs failing to fill their courses.¹⁴⁵
- An average of 76% of people with type 2 diabetes on the registers of practices involved in *Year of Care* were recorded as having at least one care planning consultation in the North of Tyne and Tower Hamlets sites.¹⁴⁶

Table 6.1: Evaluative focus

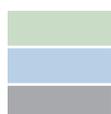
Programme	Implementation/process	Impact	Sustainability
BUPA Health Coaching			
Closing the Gap			
Co-creating Health			Some efforts to look at this, but limited by length of evaluation
Expert Patients Programme			
The Kidney Care Patient Decision Aids Project		Only baseline data is available	
MAGIC: Shared decision making		Some coverage of impact but only in the context of what works	Some coverage of what works in embedding new approaches in health care settings
National Cancer Survivorship Initiative			Some recommendations on this
People Powered Health			Analysis of potential benefits and economic savings of PPH interventions
Right Care Shared Decision Making			Some exploration of this in terms of what works
SHINE			
Year of Care			Some efforts to look at this, but limited by length of evaluation

Key

Primary focus

Some focus

Not in scope/reported



- In *Right Care*, 82% of people across the participating musculoskeletal, maternity and renal clinical pathways were reported as being ‘fully involved in their care’ as a result of shared decision making interventions such as personal decision aids or question prompts.¹⁴⁷

6.2.1 Reaching minority and marginalised groups

The wider literature reports that self-management support and shared decision making programmes have faced a range of problems in reaching minority, marginalised and less engaged groups. This poses a risk that programmes further increase health inequalities, with benefits limited to those whose health and support needs are already better met.

Difficulties engaging diversely were most prominently reported by the earliest programme reviewed here – the *Expert Patients Programme*. Many participating PCTs in the national *Expert Patients Programme* pilot found

that courses were mainly attended by white, middle class women, often the ‘already converted’.¹⁴⁵ *MAGIC* reported similar challenges, with projects finding that they were most likely to engage more affluent, well-educated patients who were internet savvy and who already had strong opinions about their care. The influence of cultural norms and expectations was highlighted; as a nurse in one pilot area explained:

*A lot of [men] have worked down the pits all of their lives. They think they are coming to see the bloke with the bow tie on... and then when they see... a nurse in their clinic and she'd going to feel [their] prostate gland, that's enough to throw them – never mind me asking them to start making decisions.*¹⁴⁸

Programmes have shown a clear evolution in their understanding of these problems. It is now widely recognised that tailoring of activities and services is needed so that they are appropriate, appealing and accessible to diverse groups, including those who may face barriers participating in their care.

For example, *Year of Care*, *The Kidney Care Patient Decision Aids Project* and several Health Foundation programmes, including *Co-creating Health* and *MAGIC*, adopted an iterative approach, identifying and testing solutions for engagement (often at the practice or project level) as they went along. Few programmes have looked in detail at how successful they have been in enhancing their reach through tailoring, thus far. Nonetheless, some key findings include:

- The Tower Hamlets project in *Year of Care* used a range of innovative, bespoke solutions to engage their populations (see Box 6.1). Qualitative evidence suggested that individuals from the Bengali community felt more engaged in their health and health care: ‘Year of Care is a great idea because it is focused around the individual. I’m happy that I get more of a say in my care.’¹⁴⁶ Additionally, clinical outcomes improved over the course of the pilot project.
- Qualitative evidence from *The Kidney Care Patient Decision Aid Project’s* work with minority ethnic groups suggested some success in engaging those who didn’t speak English by working with their family, or using Cultural and Health Information Officers to discuss issues in the patient’s own language.¹⁴⁹
- Phase 1 of *Co-creating Health* found that patients attending self-management courses had lower activation levels (as measured by the PAM) than the population as a whole, suggesting success in reaching those who might stand to benefit most. Various factors are thought to have contributed to this. Primary care professionals were more likely to encourage and refer their patients when clinician training had been targeted at whole practices, rather than individuals, suggesting merit in interventions that foster a sense of collective ownership. The programme also used a wide variety of recruitment methods and, after consulting with the *Expert Patients Programme*, tested out methods for improving attendance including varying practical arrangements and/or the length of sessions, having a tutor call those who did not attend the first session and following up on people who had dropped out.⁶⁰

Box 6.1: Different to reach, not hard to reach: examples of interventions increasing engagement

Both *The Kidney Care Patient Decision Aids Project* and *Year of Care* described a number of practical ways in which they improved engagement across their populations. Interviews with representatives from these programmes identified several key drivers behind positive outcomes:

- Care planning can help to improve both attendance at GP appointments and engagement with self-management programmes:
 - Care planning facilitated a shift away from a paternalistic model of care where people feared being ‘told off’; once they realised it was not like this, individuals were much happier to attend. Without care planning ‘it can feel like an attack, rather than something that’s being shaped to help you’.
 - Care planning was also effective with those who attended GP appointments, but then failed to act on recommendations (Tower Hamlets found this was a particular issue among Bengali men).
 - Again, in line with the wider academic literature, engagement helped people to set more realistic, personal and attainable goals.
- It is not just about translation and interpretation:
 - In *The Kidney Care Patient Decision Aids Project*, the decision aid was not translated into different languages; however, this was not necessarily a problem as patients were generally accompanied to consultations by family members who did speak English and were able to interpret.
 - The interpretation process also helped to engage family members in care planning and decision making. This engagement was key: ‘it’s not just about interpreting... this lady was her mum’s carer, she did all the cooking, the running around, so if you didn’t involve her, you weren’t going to get anywhere.’
- High-quality care is bespoke, and flexibility is key; what works for some groups and individuals will not work for others (see Section 7.2.1).

6.3 Efficacy

Efficacy outcomes relate to how successful a programme is at achieving an impact on patient outcomes. As noted above, assessments of efficacy were often carried out, but typically in the context of a wider set of evaluation questions focused on identifying learning related to implementation and programme sustainability. Even where efficacy outcomes were measured, programmes faced a range of practical and conceptual barriers to doing this effectively, which are discussed below.

Above all, the findings point to the need for methods and tools which can be integrated into routine clinical practice; which are not too onerous for either clinicians or patients to undertake; which balance this need for practicality with the requirement that they are robust; and which capture outcomes which are relevant, not just those which are easy to measure.

6.3.1 Measuring the efficacy of self-management support

Self-management is an ongoing process, not a defined end point. A key challenge with evaluation is, therefore, to try to measure or predict sustained behaviour change and improvements in the ability to self-manage. Practically, it is hard to follow up patients longer term, and attrition is often an issue. It is also difficult to track all of patients' interactions with the health service, particularly without being overly burdensome.

Several programmes (particularly *People Powered Health* and *Year of Care*) highlighted the role of non-traditional providers (NTPs) in supporting people to self-manage, with commissioning models developed to facilitate this. A key challenge was how to measure the impact of these diverse services and interactions, both practically and effectively. This can be illustrated by the following example, given by *Year of Care*.

One woman and her dog

A woman is referred from her GP to an NTP. During her initial goal planning session with the health link worker she identified her main goal to be weight loss, and decided she wanted to increase her physical activity levels to do this. Using an action planning approach, the health link worker gave her the opportunity to think through how she would like to achieve this. She did not want to attend a gym and decided instead to buy a dog. Through the dog walking she reported feeling fitter and losing weight. An added bonus is that she increased her social contacts and confidence by chatting to other dog walkers.

There are two key challenges to measuring outcomes here:

- How to have systems which allow small NTPs (like the link worker in the example) to feed back information on individuals they have supported and the outcomes achieved. Newham CCG is trialling a system which allows NTPs to input information directly into GP systems. Key to any success is minimising the burden on those involved.

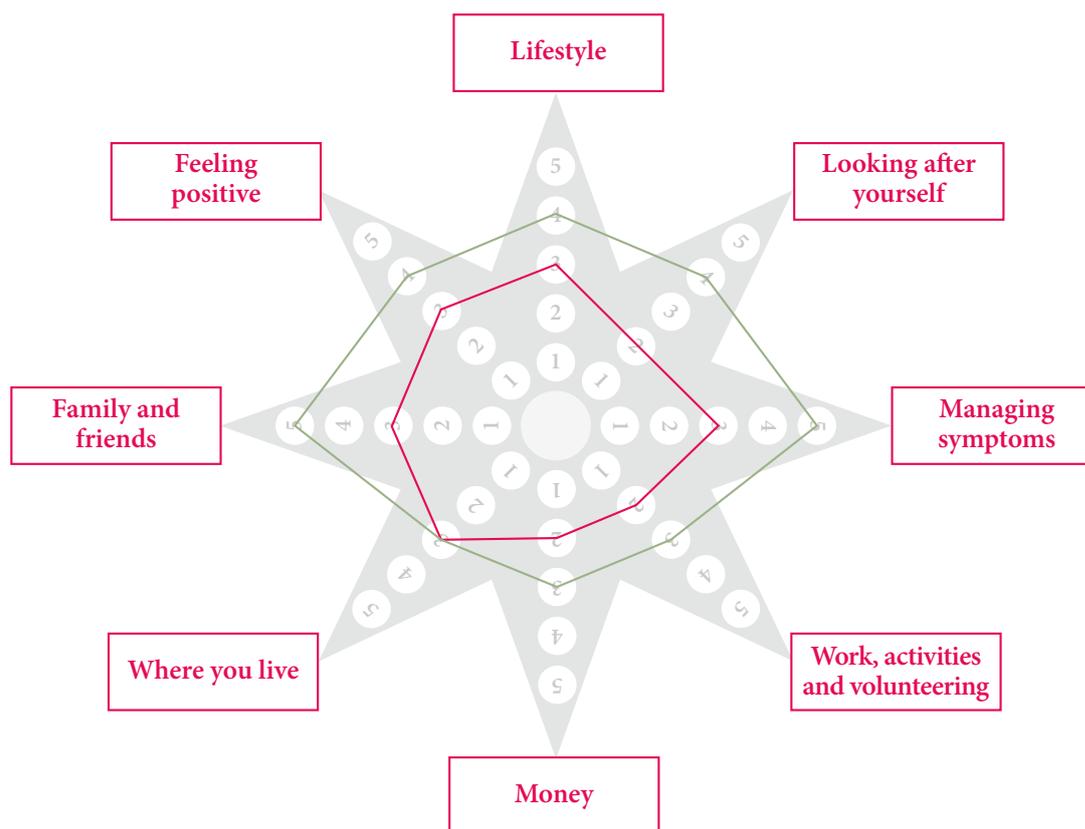
- How to demonstrate success across programmes and populations, and to do so comparatively across diverse interventions and relationships. Interventions that are brief or more social in nature may be unlikely to result in improvements in standard health care measures such as EQ5D (quality of life) or the PAM. One technique used in *Year of Care* is the Outcomes Star (see Figure 6.1 overleaf). This is able to capture a more holistic picture of the health-related, social and emotional benefits to which support from NTPs might help contribute. For example, it includes measures relating to family and friends, feeling positive, and money, as well as one specifically concerning the management of symptoms. The structure of the star allows the scale and range of potential benefits to be assessed.¹⁴⁶

6.3.2 Measuring the efficacy of shared decision making

For shared decision making, the key question is how to measure the quality of the relationship, or encounter, between a health care professional and patient. As discussed in Chapter 2, a successful shared decision making consultation is, by definition, a collaboration. As such, the success of any decision aid or other tool to support patient involvement cannot be measured independently from interventions supporting health care professionals to practice shared decision making; drawing out the relative success of each is difficult.

In addition, traditional evaluative methods such as self-reported questionnaires and rating scales have significant limitations, especially when applied to complex and relational issues such as person-centred care. Many of the programme leads and collaborators we interviewed voiced frustration with such methods in terms of the burden they place on patients and health care professionals (they can be very long and require resources to chase non-respondents). They were also criticised for their inability to capture the full scope of the relationship and relationship changes between patients and health care professionals. It was felt that a move to more qualitative and participatory approaches – including videoing, ethnography, mystery shopping and self-reflection (eg using diaries) – might be helpful; as one person commented, 'dispassionate evaluation isn't the way to do it'.

Figure 6.1: Outcomes Star (www.outcomesstar.org.uk)



6.3.3 The quality of efficacy data

Overall, the quality of efficacy data provided by projects varied greatly, with the majority reporting relatively weak evidence. By ‘weak’ evidence, we do not mean that the programmes had poor efficacy outcomes or a lack of impact; rather, this comment reflects the type and quality of evidence gathered. The key limitations of the efficacy evidence were as follows:

- Projects within overall programmes were very diverse, and aggregation of programme level outcomes was not possible and/or not attempted.
- Either no baseline was established or no follow-up data was collected/analysed, making conclusions about, and the attribution of, impact difficult.
- There was no or limited data collection on programme efficacy or outcomes and/or limited evaluation overall.

Programmes also varied in the type of outcomes they measured. This partly reflects their diversity: programmes (and projects within them) had different target conditions and patient groups; comprised different combinations of patient, health care professional and system interventions; included different models of

support and training; and employed different tools and techniques. Aggregation of results is rarely possible so sample sizes remain small and comparators rare.

Even where interventions (or aspects of interventions) were similar, the way in which outcomes were defined and measured often varied. For example, ‘decisional conflict’ was often used as an outcome measure for shared decision making programmes, but projects and programmes used different tools. These included SURE, CollaboRATE and other unspecified measures. The same tool was also used in different ways across programmes. For example, the PAM was used in some programmes as a tool to segment populations and tailor support, and in others as a way of measuring improvements in self-efficacy. On top of this, sample sizes varied, as did the representativeness of samples (eg some programmes assessed outcomes using survey questionnaires, but had low response rates, so may have biased samples). There was also substantial variation in length of follow-up.

This diversity in both scope and scale of intervention, and robustness and type of outcome measures means comparisons and aggregation between programmes is not feasible. As such, outcomes are not reported exhaustively below; instead, a flavour of the overall efficacy is given.

6.3.4 Efficacy impacts reported by programmes

For continuity, the outcomes will be categorised in the same way as in Chapter 4, which will also allow the evidence to be placed in context of the wider evidence base. This section will therefore consider the available evidence on:

- patient knowledge, self-efficacy and satisfaction with care
- patient engagement in more ‘healthy’ behaviours, or general behaviour change
- clinical and quality of life outcomes
- service utilisation and costs.

A summary of the type of outcomes reported by programmes is shown in Table 6.2. It should not be used to compare the relative success of programmes, as it contains no assessment of the scale of outcome achieved or the robustness of measures used. It is also a summary of all the outcomes achieved at an overall programme level, but outcomes may not have been reported by all the subsidiary projects within a programme or (where reported) may have differed between projects.

6.3.5 Patient knowledge and self-efficacy and satisfaction with care

Improvements in patient experience, self-efficacy and knowledge were the most often reported outcomes, with almost all programmes reporting at least some evidence for these. This fits with the wider literature which reports that almost all interventions look to improve, generally as a first step, patient self-efficacy and knowledge.^{2,3} Improvements in patient experience and satisfaction with care were a target for, and were achieved to some degree by, all eleven programmes. This adds further evidence to support claims that informed and involved patients tend to be happier with their care.

Self-efficacy was more frequently measured in programmes focused on self-management support. Good evidence of improvements in self-efficacy is provided by the *Expert Patients Programme*, which found significantly higher scores for people attending the programme compared to a control group, said to reflect ‘people feeling better about themselves and what they were already doing, as a result of social comparisons and value attributed to sharing of experience in a group setting’.¹⁵⁰ Increased self-efficacy was also reported for *Co-creating Health*, although improvements varied according to condition – effect sizes were relatively small for chronic obstructive pulmonary disease (COPD) and pain, and far larger

Table 6.2: Summary of efficacy data collected by programmes

	Self-efficacy, knowledge, experience, etc	Patient behaviour change	Clinical and quality of life outcomes	Service utilisation and costs
BUPA Health Coaching	Light Green	Light Green	Light Green	Light Green
Closing the Gap	Light Green	Light Green	Light Green	Light Green
Co-creating Health	Light Blue	Grey	Light Blue	Light Green
Expert Patients Programme	Light Green	Red	Light Green	Light Green
The Kidney Care Patient Decision Aids Project	Light Blue	Grey	Grey	Red
MAGIC	Light Green	Light Green	Grey	Grey
National Cancer Survivorship Initiative	Light Green	Grey	Light Green	Light Blue
People Powered Health	Grey	Light Green	Grey	Grey
Right Care	Light Green	Grey	Light Green	Light Green
Shine	Light Green	Light Green	Light Green	Grey
Year of Care	Light Green	Light Green	Light Green	Light Blue

Key

Limited efficacy data reported
Mainly positive efficacy reported



Some positive and some negative efficacy reported
No change reported



for diabetes. Importantly, the greatest improvements were seen for people with lower baseline activation scores and self-reported quality of life.⁶⁰ Findings were similar for the care planning approach tested in *Year of Care*. Evidence for the programme showed ‘a self-reported increase in motivation, confidence and self-efficacy encouraged by the perceived increased level of support from the [health care professional]. For some, there was a recognition that joint commitment from both individuals helped to increase levels of personal responsibility.’¹⁵¹

6.3.6 Patient decision making and decision quality

Shared decision making programmes, particularly those including a decision aid, tended to report patients having an increased understanding of their condition. For example, in *Right Care*, understanding of information among vulnerable pregnant women in the Blackpool project went up from 50% at baseline to 100% at the project end.¹⁵² These increases in understanding led to women feeling they had made better decisions and experienced less decisional conflict (meaning uncertainty about which course of action to take). This reflects findings in the wider literature (see Chapter 4); for example, Say et al’s systematic review showed decision aids for pregnant women improved knowledge, lowered decisional conflict and reduced anxiety.¹²⁰ Similarly in *BUPA Health Coaching*, between 9% and 24% of patients – the rates vary by condition – were reported to have made better health care decisions,¹⁵³ where ‘better’ was assessed in terms of rates of surgery, rather than by patients themselves.

6.3.7 Patient engagement in more healthy behaviours, or general behaviour change

Improvements in patients’ self-efficacy, empowerment and engagement with their care may lead to changes in their behaviour. However, the programmes found very limited evidence of behaviour change. This mainly reflects a lack of measurement of behaviour change outcomes, rather than evidence that it did not occur. Behaviour change was not always an explicit goal or, in some cases, was viewed as a longer-term aim (and therefore out of the scope of evaluation). This was particularly true for shared decision making programmes, where behaviour change was rarely a target.

Programmes were more likely to assess patients’ perceived confidence and motivation to make changes in their health behaviours, typically measured as changes in reported self-efficacy. However, the extent to which improvements in self-efficacy are predictive of actual behaviour change remains uncertain. The relationship between these two outcomes was rarely tested in the programmes reviewed. For example, both *BUPA Health Coaching* and the *National Cancer Survivorship Initiative* reported improvements in patients’ self-management skills and/or perceived ability to manage their condition, but neither tested whether this resulted in the application of these skills, either short or long term.¹⁵³⁻¹⁵⁵

6.3.8 Clinical and quality of life outcomes

A number of projects reported improvements in clinical and quality of life outcomes, including the following:

- HOPE, a self-management support programme which was developed and tested as part of the *National Cancer Survivorship Initiative*, reported improvements in quality of life at twelve months and in hopefulness (a key indicator of psychological health for people in recovery from cancer) at six months.¹⁵⁵
- One of our interviewees reported that *Right Care’s* Pennine MSK project – focusing on shared decision making in musculoskeletal specialities – resulted in a significant increase in quality of life as measured by the EQ5D.
- *Shine’s* STOP! project reported improvements in the management of back pain, reduced disability associated with pain and improved quality of life.¹⁵⁶

As discussed in Chapter 4, clinical improvements are less likely to be a target in shared decision making, where the focus is more often on relational outcomes such as collaboration and engagement. However, where care planning was implemented, for example in *Year of Care*, demonstrable improvements in some clinical outcomes were seen. For example, over the five years that Burn Brae practice (in Northumberland) carried out care planning, weight loss, a fall in blood pressure and a reduction in total cholesterol were all seen.¹⁴⁶ It was proposed that these clinical effects resulted from patients being more motivated and able to manage their own condition, both of which were enhanced through a care planning model which combined shared decision making and self-management support.¹⁴⁶ Comparison

between *Year of Care* sites was not attempted during project evaluation; very few sites provided any quantitative information or analysis on this topic.

Projects within the same programme showed variation in the outcomes achieved. Often, as in *Co-creating Health*, outcome measures varied by location; it is therefore difficult to disentangle why changes happened in one place and not another. The findings available suggest that both context and condition may be part of the explanation. For example, both Torbay and Wandsworth projects focused on depression, but only in Torbay were clinical outcomes consistently improved – suggesting that local context may be a factor.^{60,157} The programme also found that improvements in the primary endpoint (activation, as measured by the PAM) were small for COPD and pain, moderate for depression and large for diabetes, suggesting that target condition may also be a factor.

6.3.9 Service utilisation

Programmes reported a number of challenges in measuring service utilisation. Firstly, it was difficult to measure the whole system impacts of a programme. An intervention may target one area of the health care system (eg primary care, a cardiovascular team), but reductions in service use may well be realised elsewhere in that system (eg in secondary care, in another team). Some interviewees reported that their programmes struggled to take account of these whole system dynamics, and thus may have underestimated their impact. This was a particular problem for people with multiple co-morbidities and mental health problems, who are likely to interact with several sectors of the health service, many of which may not have been within the scope of the programme and/or evaluation.

A subsidiary problem with measuring service utilisation is that the measure used can be somewhat mechanical and fail to effectively measure the positive relational changes that self-management support and shared decision making interventions can have. As one interviewee commented, ‘It [the evaluation] didn’t consider changes in the way people felt about their condition, or how they interacted with the health service’. The following example, provided by a *Co-creating Health* interviewee, illustrates this issue:

Hospitalisation after completing a self-management programme

After completing a self-management programme, a man has an unplanned hospital admission. This is due to the onset of pneumonia, not any underlying health problems, and therefore it is unlikely it could have been prevented by self-management. Aside from this event, the programme completely altered the man’s relationship to his health care, and to his GP and nurse specifically. All three were much more confident in his ability to self-manage, and his GP and nurse were happy to chat through symptoms on the phone and prescribe medication without an appointment.

Assessing the service outcome (the unplanned admission) without understanding the broader context or experiences and relationships of those concerned might create the false impression that the programme had failed in this person’s case.

Despite these challenges, a range of positive impacts on health care utilisation were reported, for example:

- An interviewee reported the impact of shared decision making on the knee/osteoarthritis pathway in *Right Care’s* Oldham project. The intervention resulted in a slowing in the rate of knee surgery growth, compared to the national picture (6% in Oldham compared to 17% nationally).
- *BUPA Health Coaching’s* RCT reported lower medical costs, including a reduction in medical and pharmacy costs by 3.6% (\$7.96 a month), a reduction in hospital admissions by 11.5% and a reduction in inpatient and outpatient surgery attendance of 9.8%.¹⁵³
- *Co-creating Health’s* Ayrshire and Arran project found a fall in average utilisation for all four service-related measures – emergency admissions, hospital outpatient appointments, hospital bed days and out-of-hours contacts – though improvements were only statistically significant for the first two of these.¹⁵⁸ Similarly, in Torbay there was a statistically significant reduction in face-to-face GP appointments when comparing the six months prior to and following attendance of the self-management programme, from 6.7 to 5.1.¹⁵⁹

6.4 Adoption

‘Adoption’ outcomes are quite closely related to reach; however the focus is on engaging health care professionals and services, rather than patients. They consider the rates of uptake in practice: for example, are health care professionals using new skills, have

new approaches been embedded into care pathways and what is the degree of penetration across different services or professional groups?

6.4.1 Adoption by health care professionals

Reaching health care professionals is key to engaging patients in shared decision making and self-management support. Overall, programmes tended to report greater success in getting health care professionals to adopt the tools associated with shared decision making (and to a lesser extent self-management support), compared to making changes in consultation behaviour and style. Health care professionals often thought they were already practising shared decision making. A perceived lack of time and/or motivation to attend training and then put new skills into practice was also commonly reported. We discuss these barriers in more detail below.

Training sessions had some success in changing mindsets and tackling other barriers to change. For example, one of the nurses interviewed from the *MAGIC* programme reported that, prior to participation, they considered themselves to be not merely practising shared decision making, but an advocate of it. Following the programme they realised that their definition of shared decision making was too narrowly limited to informed choice. They subsequently embraced a broader definition based around a partnership approach. This deeper engagement with the philosophy behind shared decision making and care planning, not just the tools and practicalities, was also achieved with some success by *Year of Care* (and was a key target of their training programme).

However, most programmes (and projects within programmes) struggled with engagement. Time was a key issue. One *Right Care* project, Herts Valley, reported that impact was severely limited by a lack of GP involvement – few GPs attended briefings, and those who did often did not pass information on to their colleagues. Shared decision making was felt by some to take too much time:

*We just do the [PSA (prostate specific antigen)] test and hope that it's normal because if it's abnormal then we have more work trying to explain the results.*¹⁶⁰

MAGIC reported that teams often just wanted to implement the decision tools and that training was often attended to confirm existing practice. Similarly, an interviewee from *Co-creating Health* (Ayrshire and Arran project) reported that 'we often had to fight to get more than just the patient element' when rolling out the programme.

Professionals are not a homogenous group and shared decision making and self-management support appears to have greater congruence with some roles than others. During interview, a representative from the *National Cancer Survivorship Initiative* reported that paediatricians, used to working with children and young people in a collaborative way, were more receptive to the underlying ethos of sharing care and responsibility. An interviewee from *Right Care* found that shared decision making had worked best with specialist nurses, physiotherapists and midwives – many of whom were already practising similar techniques. But the findings also suggest that engagement is shaped by wider contextual factors such as clinical leadership, organisational support and prior experience of involvement in improvement programmes. It is not as easy as saying one professional group is receptive, while another is not.

As well as cultural norms, adoption is also mediated by prior skills. One interviewee reported that, while nurses were often receptive and enthusiastic about adopting shared decision making and care planning, most had not been trained in or had opportunities to develop basic consultation skills on which to build.

6.4.2 Adoption by services

Year of Care was one of few programmes to assess the extent of adoption within different services. Spreading the care planning approach to new GP practices within pilot regions was a major aim. The programme reported that the majority of practices in the pilot areas now routinely use the care planning approach; adoption rates range from 97% of practices in Tower Hamlets, 83% in Kirklees, 79% in North Tyneside and 73% in West Northumberland.¹⁴⁶ There was evidence of this 'ripple out' effect – with changes extending beyond early adopters – in several other programmes. This happened both organically and as a result of deliberate strategies and encouragement to stimulate wider adoption by programme teams.

For example, in *Right Care* evidence of positive impacts and the resources on offer encouraged new clinical teams to apply for later rounds of the programme.¹⁴⁷

Ayrshire and Arran retained two staff after the official end of the *Co-creating Health* programme to facilitate wider adoption of self-management approaches to new pathways and conditions including stroke, rheumatology, Parkinson's and telehealth. *Year of Care* has now spread to 22 communities across the country and to long-term conditions other than diabetes.

Where spread happened organically, this tended to reflect health care professionals using the skills and tools they had learned in new settings. For example, in *MAGIC* there was some evidence of health care professionals increasing their general use of shared decision making techniques and tools beyond just the scope of the intervention.¹⁶¹ Similarly, *Co-creating Health's* Wandsworth project reported that the programme:

...seemed to be effecting wider cultural change in the settings, with ADP [advanced development programme] professionals making self-management approaches available to a wider group of patients than just those [recruited onto the programme].¹⁶²

6.5 Implementation

All improvement programmes set out with a theory about how change is going to be brought about, although more often than not this is implicit to the approach rather than explicitly designed into it. Several of the programmes we reviewed sought to explicitly develop and test out theories about how self-management support and shared decision making can be embedded into mainstream services, and much progress has been made. This is the first of the two implementation outcomes that we present below. The second relates to the cost of shared decision making and self-management support, compared to usual care. Overall, with a few exceptions, programmes reported limited information on their costs. Where it was reported, it generally related to specific aspects (eg consultation costs, costs of training programmes) rather than the costs of the programme as a whole.

6.5.1 Theories of change

Over time, an important transition can be seen in how the programmes have understood and sought to bring about change. Early efforts largely focused on developing tools and services to equip patients for

participation. The role to be played by professionals was, in the case of the *Expert Patients Programme* for example, largely limited to signposting patients to the programme and encouraging attendance through referral. The service itself was provided outside of usual clinical care in local community settings. This approach was largely unsuccessful; the evaluators reported that 'The vast majority of health professionals were not engaged by the EPP and few directed their patients to courses', with a particular problem being 'an unwillingness to refer to a system outside of traditional NHS service provision'.⁶³

Addressing the problems encountered by the *Expert Patients Programme* was a key factor in the design of subsequent programmes. For example, a report on the development of the HOPE self-management programme (*National Cancer Survivorship Initiative*) noted that:

Evaluations of the EPP have provided support for the programme's utility, but little engagement from health professionals has been highlighted as a potential limitation... The main reason for this lack of engagement was related to the fact that the programme was not integrated into the NHS, and therefore led to a lack of awareness about it, leading to poorly informed professionals becoming suspicious as to its intent.¹⁵⁵

With this in mind, the HOPE programme was designed to be an integral part of new pathways for follow-up and rehabilitation in cancer, and efforts were made to engage influential local clinicians in its promotion and delivery.

This is one illustration of how programmes have evolved a more holistic approach. Another dimension of this is the shift towards multiple interventions targeting different parts and levels of the health care system. A good example is *Co-creating Health*, which comprised three core elements: a self-management support programme for patients; an advanced development programme for professionals; and a service improvement programme focusing on the systems and processes to embed new approaches into routine care. As the first phase of the programme progressed, it became apparent that the greatest impact came from maximising the synergy and integration of these different elements so they functioned as a coherent

programme. This is captured by the concept of ‘white light’, which *Co-creating Health* has coined to describe its integrated model of change (see Figure 6.2).

Figure 6.2: The Co-creating Health ‘white light’ model



Similar whole system principles underpin the House of Care model, developed and tested in the *Year of Care* and *People Powered Health* programmes. This model comprises four interdependent components: responsive commissioning; engaged and informed patients; organisational and clinical processes; and health and care professionals committed to working in partnership.

6.5.2 Impact of programmes on consultation length

A common barrier to the implementation of shared decision making and self-management support programmes is the belief that they lead to longer consultations, with consequent increases in costs. Several programmes noted that, at least initially, the implementation of shared decision making and self-management support did increase consultation length; this finding did not appear to be affected by the particular conditions or interventions concerned. Our interviews with programme staff yielded the following examples:

- *The Kidney Care Patient Decision Aids Project* reported that initial consultations with patients needed to be around two hours long to fully engage them with the decision aid.

- The *National Cancer Survivorship Initiative* found that a self-management support consultation took twice as long (40 minutes compared to the usual consultation length of 20 minutes).
- One *Year of Care* interviewee found that, for care planning to be effective, consultations needed to be at least half an hour for those with controlled diabetes, and 45 minutes for those with uncontrolled diabetes. However, across the programme as a whole, teams generally found that 20 to 30 minute appointments were sufficient.

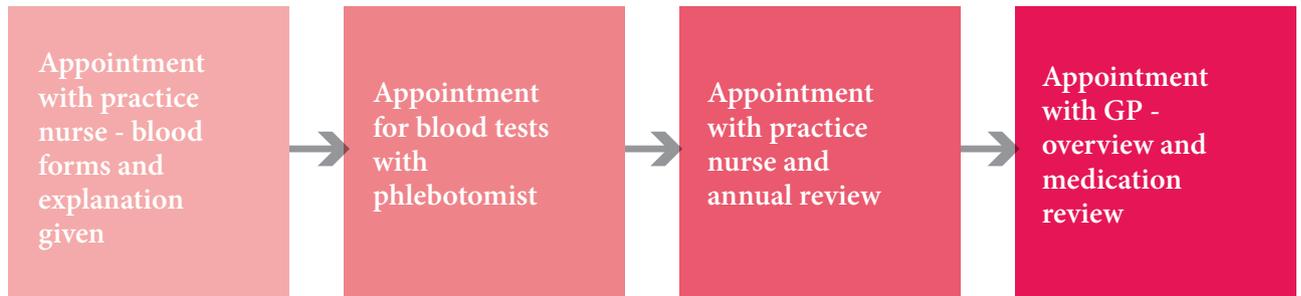
However increases in consultation length were often short term, reducing back to previously normal levels once health care professionals had gained experience of using the skills and tools. Even where increases in consultation length persisted over time, overall costs could still decline. This was either because consultations were more focused and efficient (eg as was reported by the *Right Care* Blackpool project and *Closing the Gap* myRecord project) or achieved through greater use of skill mix. *Year of Care*, for example, makes use of the entire primary health care team, including practice receptionists and health care assistants who play a central role in preparing patients for the care planning consultation and following up with them afterwards. As Figure 6.3 shows, costs were found to be either neutral or reduced, even where patient contact times were greater.

A further finding from *Year of Care* was that preparing patients for care planning consultations – for example, by sending personalised clinical information in advance – increased the likelihood of them initiating conversations with health professionals, but without significantly increasing the consultation time.¹⁶³

A few programmes reported reductions in consultation length. For example, *Right Care* (Blackpool project) found that consultation time was shortened, with the programme saving time on two fronts. Firstly, all options (about choosing parenting classes) were provided as a decision aid, which women could take away to read; they therefore came to the consultation ready to discuss only the options they were most interested in. Secondly, while most women opted for one-to-one parenting support rather than a group-based class (which might initially seem more resource-intensive) overall contact time was lower as participants were more engaged and there was less need for chasing to get people to attend.

Figure 6.3: Costs of Care Planning (Year of Care 2011)

Before care planning



After care planning



Different practices have different working arrangements and have improved their productivity in different ways. Each pair of coloured boxes below represents one practice and records the number of visits a person with diabetes had to make, the time they spent with a healthcare professional and the cost per individual before and after introducing care planning. This includes the cost of increased administrative time.



6.6 Maintenance

Evidence on the sustainability of changes and outcomes achieved was limited, with few programmes conducting longer-term follow-up. An evaluation of the HOPE self-management programme (*National Cancer Survivorship Initiative*) reported that positive patient outcomes – including quality of life, self-efficacy and ability to self-monitor – were maintained at 12 months.¹⁵⁵ In *Co-creating Health* (Torbay project), patients were asked via a postal questionnaire if they still felt they were benefitting from what they had learned in the self-management programme; on a scale of 1-10 the average score was 6.72, indicating ‘good evidence that participants feel that the benefit carries on after the course ends’.¹⁵⁹ In the Ayrshire and Arran project of the same programme, increases in activation were maintained at three months.¹⁵⁸

Several interviewees mentioned a problem with ‘project-itis’, where enthusiasm and support dwindled after programmes (and funding) ended. Those projects which seemed to be the most successful at maintaining and expanding shared decision making and self-management support worked very hard to embed incentives within commissioning systems or, in the case of *Co-creating Health* (Ayrshire and Arran project), maintained a small programme team to support sustainability and spread. A lack of evidence on outcomes was sometimes cited as a barrier. For example, around a third of *Shine* projects failed to secure any additional funding to sustain projects, with the difficulty of demonstrating the impact of preventive services considered a major challenge.¹⁶⁴

Chapter 7:

What works and how?

Knowing what outcomes improvement programmes achieve is one thing; understanding how those outcomes are brought about is another altogether. This is no easy task: the programmes in our review are, as we have already shown, highly complex, typically combining multiple elements, and delivered across diverse groups and settings. Nonetheless, we sought to dig down into the evidence to explore the fundamental question of what works in implementing shared decision making and self-management support.

The purpose of our analysis was to identify the active ingredients within programmes, by which we mean the underlying mechanisms of action by which programmes – or projects within them – effected change. We will describe these ingredients in terms of three interconnected levels:

1. **Tools and techniques** – the specific methods and approaches to support shared decision making and self-management in routine settings that are combined within particular interventions and programmes.
2. **Supporting practice** – factors which support and enable shared decision making and self-management support to be enacted, and tools and techniques to be adopted in routine practice.
3. **Implementation** – features of the overall change strategy that help to achieve and sustain the desired transformation. Within the NHS, this level is often referred to as change management.

Our findings are based on the documentary sources reviewed as well as insights gathered through interviews with programme leaders and contributors. Taken together, these provide tentative indications – rather than definitive evidence – about the ways in which programmes and the elements within them worked.

7.1 Tools and techniques

Key messages

- Tools are only part of the answer. They need to be used to support better consultations. This requires a change in mindset to one which values and is supportive of patients' involvement in their care.
- Well regarded tools include motivational interviewing; goal-setting and action planning; care and support planning; and supporting patient preparedness for consultations.
- Tools and techniques require multiple formats of presentation and delivery to support shared decision making and self-management.

7.1.1 Tools to support changes in culture

While it was possible to identify tools and techniques which were well regarded by programme stakeholders, it was widely understood that tools alone are not enough to implement the changes sought. As one project lead commented, *'the human touch is the biggest thing'*. Programme intentions were not to simply implement new tools, but to use them to support a change in practice and the wider culture to make collaborative care the favoured approach.

In shared decision making, for example, changes in practice can be supported by the use of decision aids, but their use alone does not mean that decisions are being made collaboratively. While a decision aid can act as an important trigger for initiating patient engagement, the extent to which decisions are truly shared depends on the tool being embedded in the consultation, rather than being seen narrowly as a patient resource. This is illustrated by an example from *The Kidney Care Patient Decision Aids Project*; the decision aid presented all possible options for kidney care, including those which may not be clinically possible for some patients. Patients therefore needed

health care professional input in using the decision aid – without this they could not understand which options were open to them. Using decision aids as a patient resource without professional input not only potentially limits the extent to which patients can share decisions but also risks miscommunication and misunderstanding, and ultimately may leave people feeling abandoned.

Most programmes recognised that a change in mindset was imperative, without which tools would have limited effect. The quote below is taken from an interview with a local project lead, and illustrates how patient involvement needs to be made the goal:

[A decision aid] is not the be all and end all, it's a starting point. When we say decision aid it sounds very posh but it's not... sometimes you worry about giving more and more information to patients. But this wasn't like that. This was about involving them in their care, and these (patients) had never been asked before.

Using tools to support better consultations: NHS Redbridge (Shine)

NHS Redbridge introduced individualised information for patients with COPD, in the form of a checklist to take with them to GP consultations. The checklist included information on the costs of service utilisation: for example, the cost of an emergency admission.

Both patients and GPs reported that the checklist was helpful. It improved patients' knowledge, engagement and relationships with GPs. Patients were more willing to prompt their GP for additional information and support; conversely, GPs were made more aware of NICE Quality Standards.

The cost information on the checklist led some patients to make clear links to modifying their self-management behaviour. However a small number reacted negatively, perceiving that the information had been given with the intention of making them feel guilty for using NHS services.

7.1.2 Well-regarded tools and techniques

In determining what works when implementing shared decision making and self-management support, across the programmes reviewed, a number of specific tools and techniques were considered to be useful. Of these, the following were the most commonly cited:

- **Motivational interviewing** – motivational interviewing is a coaching- or counselling-oriented consultation technique which was incorporated into some programmes. Its usefulness was most commonly described in terms of helping to reframe the consultation for one-to-one support and/or to promote and facilitate behaviour change. The demonstration of motivational interviewing in professional training courses provided real-life examples of how behaviour change could be encouraged through a new style of interaction. One interviewee described the use of it as a 'professional life-changing event'.
- **Goal-setting and action planning** – patient interventions underpinned by self-efficacy models were well regarded by the programme team members we spoke to. A sense of accomplishment created by focusing on action and goal attainment was considered to be critical for building confidence and motivation to take action and the ability to sustain it. These techniques tended to be discussed most often in relation to self-management support, and the group setting offered by some support programmes was valued for sharing experiences and reinforcing the techniques among peers.
- **Care and support planning** – these techniques were used to describe a process which works in conjunction with action planning and goal setting. The process of care and support planning was felt to provide a structure for managing consultations. In contrast to the traditional model of clinical practice, it allows patients to set or negotiate the agenda for the consultation, set their own goals and develop a plan for how these will be achieved. These techniques appear to work best when the plan is written down at the end of the process, enabling subsequent reviews of goals and progress towards these. Crucially, care and support planning identifies the responsibilities of both parties, and one interviewee noted that it is 'absolutely key that patients feel that they're listened to, rather than told off'.

- **Preparing patients for consultations** – the value of patients being, and feeling, prepared for consultations was also emphasised. Preparatory activities recognise that collaborative care places demands on patients and therefore they must be properly equipped to participate; they also help to make the best of the (limited) time that patients and professionals spend together. Different forms of preparation were mentioned, including: sending test results prior to the care and support planning consultation; giving patients information to review (and possibly share with others) about different treatment options before a decision is considered; and the provision of tools, such as Ask 3 Questions,^{vii} which help patients to consider what questions they might wish to ask the health care professional they are meeting with.

7.1.3 Design features

The programme review also considered the effectiveness of tools and techniques in terms of design features. Many of the reviewed documents and interviewees noted that it is important to make use of multiple formats, which can enhance both accessibility and appeal.

In shared decision making, paper-based and online tools have been used, both separately and in combination. Flexibility is important; in *BUPA Health Coaching*, patients may be offered decision aids in either paper or online versions, and either version can be discussed with patients over a telephone consultation.

In terms of the content of decision aids, several features were consistently emphasised including evidence-based information, real-life examples and an objective presentation of the possible pros and cons of each option available. Tools can also be made more accessible by the use of diagrams and other visual aids to present risks. It was recognised that a key issue is to ensure comprehensibility for those with limited numeracy skills, although the most effective ways of doing this are not yet clear. A general consensus across the programmes was that decision aids should not be too detailed – there is a balance to be struck between how useful a tool is in practice, and how robust it is. Trade-offs will necessarily have to be made. In the *MAGIC* programme, health care professionals and patients

generally favoured quick and easy to use tools such as option grids and brief decision aids as opposed to more traditional decision aids which are longer in length.

With regard to self-management support, our review confirmed the dominance of group-based educational models, although with some variation in terms of duration and intensity (eg courses ranged from seven weekly sessions to a single four-hour workshop). Some interviewees commented that, while group-based models may be useful for some patients, a greater diversity of approaches is required to widen access to self-management support. One interviewee talked about the need for planning for future generations and exploring the internet as a medium for delivering support. Another suggested that certain conditions – such as diabetes and inflammatory arthritis – are better suited to the model of formal education than others:

There are patients with particular long-term conditions, where they do need to go through some sort of formal education process in order to effectively self-manage – such as diabetes, chronic obstructive airways disease maybe, and inflammatory arthritis. There needs to be a bit of education to back up self-management, you can't self-manage from a position of ignorance or misunderstanding... But I don't think every patient needs that. It needs to be targeted where it will deliver the best outcomes.

Peer support was another popular approach, and several interviewees felt that there was great value in harnessing the power of group effects. Self-management courses in the *Expert Patients Programme* and *Co-creating Health* made use of lay facilitators who themselves had a long-term condition to deliver the courses. The lay role was valued greatly by group participants as they were able to identify with this person. There were also discussions about the value of reciprocity as a mechanism by which patients find peer support helpful and rewarding; as one interviewee commented, 'people want to be reciprocal no matter how ill they are'.

^{vii} Ask 3 Questions was developed as part of the *MAGIC* programme to raise awareness among patients about their role in shared decision making and encourage them to ask three key questions about their health and health care options. For more details and to access the materials, visit: <http://personcentredcare.health.org.uk/resources/ask-3-questions-materials>

7.2 Supporting practice

Key messages

- There is more evidence in favour of tailoring tools and techniques to specific groups of patients than for generic approaches. Patients may require different types of support, depending on their particular condition, the circumstances in which they live, and their readiness and ability to be involved in their care.
- Health care professional training requires a clear message to be communicated to whole teams, and benefits from a practical focus which challenges existing perceptions, mindsets and traditions.
- The voluntary sector has an important role to play in embedding self-management support and shared decision making into mainstream services. The capacity, skills, knowledge and experience of wider support services which voluntary sector organisations can provide has been crucial to the success of some projects in the programmes reviewed.

Three key drivers for embedding shared decision making and self-management support into routine practice emerged from the programme review; each is explored in detail below.

7.2.1 Tailoring approaches

Programmes grappled with how to engage a diverse range of people, beyond those who were 'easier' to reach. In Section 6.2 we described how programme reach tended to be limited unless specific and targeted efforts were made to engage more diversely, including marginalised and minority groups. Some interviewees thought that tailoring was a major factor in increasing patient engagement. Without these efforts, strategies to support self-management and shared decision making risk increasing health inequalities.

The increasing emphasis on tailoring reflects, at least in part, the developmental journey that programmes have taken. Over time, there has been a marked shift away from one-size-fits-all models with recognition that the diversity of patients and circumstances means approaches will have to be varied to ensure all needs and preferences are catered for. Programmes showed that support requirements will differ depending on a host of factors including what patients bring to the encounter in terms of their own expectations, skills and readiness for involvement in their care; their socio-demographic context; and the specific condition or combination of conditions they might have. This has important implications for how shared decision making and self-management support are defined and promoted: they

must be seen as a range of roles and activities along a continuum, rather than a single ideal type that is possible and desirable for all.

In practice, tailoring has tended to take a number of different forms. Approaches have been tailored according to condition, as well as to needs and preferences relating to specific demographic characteristics (eg cultural background, gender, age and literacy levels). Although some programmes made use of generic tools, and a few interviewees thought that generic tools were suitable, many were also supportive of some degree of tailoring in order to make interventions more meaningful to patients (and potentially also to health care professionals).

7.2.1.1 Tailoring by condition

An example of tailoring by condition comes from the *National Cancer Survivorship Initiative*. At the University Hospital Southampton NHS Foundation Trust, self-management support was established as a core feature of redesigned follow-up pathways for patients with testicular and colorectal cancer. The approach included the following key features:

- Embedding self-management support as part of a risk stratified care pathway, identifying care and support packages using the *National Cancer Survivorship Initiative's* Holistic Needs Assessment tool.
- A stratification process to identify which care pathway is right for each patient, based on the level of care needed for the disease, the treatment and the patient's ability to manage (as jointly assessed by the patient and a care professional), and therefore what level of professional involvement will be required. For people with low risk of recurrence, the model of follow-up care *is* supported self-management. This doesn't exclude patients on other pathways from being involved in their care and/or recovery, but recognises the importance of continuing professional input where there are more complex needs and ongoing disease or treatment effects.
- The self-management support intervention included a four-hour workshop, the content of which was tailored to meet the specific needs of the patient group. The workshop was designed to deliver tumour specific information for detection of disease recurrence, as well as promoting self-efficacy, goal-setting and healthy lifestyles.

Findings point to the limitations of the dominant group-based model of self-management support, suggesting this might be better suited to some conditions or patients. One interviewee who discussed this model compared diabetes to chronic pain to show how support and education may require different emphases:

For people with diabetes you need to have a very future-oriented approach to their condition... people are often not symptomatic day to day... they don't have a symptom reminding them to do something different. Whereas for people who have pain, they have a symptom that is urging them to go and seek attention now [interviewee's emphasis]. We should have flexed the programme more to think about ways that people with different conditions live daily... and the different ways they'll want to think about self-management... present-oriented for pain, future-oriented for diabetes.

Elsewhere it has been suggested that early intervention is particularly important for those with chronic pain. Clinical outcomes have been found to be more favourable when intervention takes place before behaviour and thought patterns become established.¹⁵⁶

7.2.1.2 Tailoring for ethnic minority groups

An example of tailoring to better meet the needs of ethnic minority groups came from one GP practice in *Year of Care*, which used Bengali storytelling groups to introduce patients to their diabetes results letter. It acted as a pre-intervention to help individuals (who often had low health literacy and limited English) gain an understanding of their condition and its management to enable informed participation in care and support planning. The group-based storytelling setting facilitated discussion and sharing between attendees, as well as engagement with results letters – harnessing the power of peer support already discussed.

The storytelling was part of a suite of tailored interventions, including the simplification of the results letter itself (including colour-coding for meeting HbA1c targets), and the use of advocates trained in care and support planning approaches to support the involvement of those who could not speak English. Key to its success was its cultural appropriateness – there is a

strong collective emphasis in Bengali culture, and people were comfortable sharing and talking about their own results with others. This example shows that efforts need to be made to engage people in different ways; reaching people from ethnic minority groups requires more than simply translating standard materials into community languages. Providing truly tailored interventions requires understanding the needs, motivations and cultural preferences of particular groups.

7.2.1.3 Tailoring by readiness and ability

Another way to tailor interventions according to individual differences is through addressing patients' readiness and ability to participate in their own care. Confidence and skills vary considerably, as do barriers to participation, so what is possible and desirable for one person may not be the same for another. A few interviewees talked about using the PAM to assess patient readiness and tailor interventions accordingly. Currently, a measurement framework is being developed for the House of Care⁷¹ which will allow for better targeting of interventions by segmenting patients. Services could potentially be varied according to PAM levels, with improvements in outcomes being considered against these levels.

An example of the Shared Haemodialysis Care Model from *Closing the Gap* shows how people can be supported to participate at differing levels according to their skills and confidence. The project provided support for patients to self-manage their own dialysis. There are 14 different care processes in dialysis care which people could potentially be involved in, such as needling and taking blood pressure. In partnership, patients and nurses explored the type and level of involvement that the individual wanted in their care. This enabled them to put together a personalised model of self-management support, where the nurse was able to tailor support and follow-up according to individual needs.

A final point to note here is that health care professionals too are diverse and, like patients, may differ in their ability and readiness to engage in collaborative care. Interventions targeting health care professionals will also require tailoring to maximise effectiveness. This was most notably recognised in relation to training programmes, where a different focus may be needed depending on the skills and capabilities that professionals already have and the learning needs which need to be addressed. Training may need to challenge assumptions about what constitutes shared decision making and self-management support and the

extent to which these are already being practised, as well as offering the opportunity to develop or enhance skills as needed.

There is also evidence that training whole teams together may be more beneficial rather than just equipping individuals. A whole team approach fosters peer support and mutual learning, helping to embed a new organisational culture and ways of working. This question of the right balance between generic and tailored interventions for health care professionals is an area which requires further research attention.

7.2.2 Training for health care professionals

If practice is to be changed so that patients are more involved in their care, strategies will need to include interventions targeting the health care professionals who deliver this care as well as the patients receiving it. Health care professional training is now a recognised component of programmes which aim to implement shared decision making and self-management support into mainstream care. The programme review highlighted four factors which can make health care professional training more effective:

- **Communicate the ‘right’ message** – in the first instance this refers to approaching health care professional training in an open and non-judgmental manner. This may be achieved by maximising peer-to-peer influence: for example, through training being delivered by a colleague who can draw on his/her own experience in practice, rather than by a manager or general trainer.

How the case for shared decision making and self-management support is made is also important. Many interviewees reflected on how important it was to communicate rationale in terms of patient experience and improvements in care; at the same time emphasising that the aim is to build a shared agenda with the patient, not simply transfer responsibility (eg for lifestyle changes) to them. Aims for cost savings or reduction in consultation time should be treated as secondary to this. This is particularly important since reduction in cost and consultation time is not always achieved by such programmes, at least not in the short term.

- **Adopt a holistic approach** – as we noted above, training for whole teams, as opposed to training health care professionals in a ‘scatter gun’ approach, is important. The *Co-creating Health* Phase 2 evaluation¹⁵⁷ notes that health care professionals

who took the training on their own often lacked wider support to make changes in routine care, and found it more difficult to test self-management support in their own practice. As the evaluation of the first phase of the programme reported, training whole teams together is in keeping with the ethos of co-production and reflects the emphasis on multidisciplinary care and assessment for people with long-term conditions.⁶⁰ In the example of the GP practice which tailored an intervention for Bengali people (*Year of Care*), the team which underwent training included those who were advocating and translating for patients as well as the clinical staff. It is also important that health care professional training is not a one-off occurrence. It needs to be complemented by refresher or follow-up sessions and other forms of ongoing support such as mentoring.

- **Maintain a practical focus** – in terms of training content, it appears to be most effective when focused on practical learning. In the programmes reviewed this tended to be achieved through techniques such as role play to practise key skills and working through real life examples. Interviewees talked about how this allowed professionals time to reflect on the relevance to their own practice. One interviewee talked about how using patient testimonies in training had initiated some ‘lightbulb moments’ for those attending: professionals often became more engaged when patients discussed the sense of dignity they felt from being involved in shared care. Some programmes also discussed the merits of involving patients as trainers and, in some cases, this proved to be a powerful method of communicating the importance and benefits of shared decision making and/or self-management support from the patient perspective.
- **Challenge existing perceptions and traditions** – training content also needs to include material which challenges existing perceptions; which might include misperceptions that current practice already fosters shared decision making and self-management support. One interviewee commented that this could be achieved by demonstrating variation in practice:

[We go] through the evidence for shared decision-making and challenge that they do it already. The way you do that is to demonstrate unwarranted variation in treatment pathways, variation in outcome, variation in treatment choice, variation in

spend. And demonstrate that even though most clinicians feel they do it, the evidence is that they don't.

This might also include making explicit the aspects of traditional models of care which are unsupportive of collaborative approaches. For example, the physical arrangement of a consulting room often situates a desk in between patients and health care professionals which can reinforce power differentials and act as a barrier to involvement.

Finally, it was recognised that multiple system-wide interventions are required to fully challenge existing perceptions which are not supportive of collaborative approaches. Interventions include: targeting staff at all levels, including non-clinical staff such as receptionists; equipping future health care professionals by embedding skills development in basic training and education programmes; and focused work with deaneries (now local education and training boards) to ensure closer alignment with workforce development.

7.2.3 Working with the voluntary sector

The voluntary and community sector was noted in several programmes as having an important role to play in embedding self-management support (and to a lesser extent shared decision making) within routine practice. We know from broader research that the provision of holistic care is important for improving patient experience.¹⁶⁵ This requires an understanding of wider factors – such as the social, psychological and cultural circumstances in which people live – which may impact on their health and ability to participate. An understanding of patient needs in terms of these wider factors opens up a role for the voluntary and community sector. The ‘added value’ of the voluntary sector was described by interviewees in terms of the additional skills, knowledge and capacity which they can offer, which is often beyond the scope of mainstream health care services.

The role of the voluntary sector seems especially important for self-management support. One reason for this might be that self-management behaviour permeates patients’ daily lives and choices, whereas shared decision making is confined to specific decision points along a care pathway. The group-based educational model of self-management support is best known for utilising and building voluntary sector capacity. The *Expert Patients Programme* popularised the notion of a volunteer workforce and promoted peer support through its use of lay facilitators. The evaluation

for the programme noted that the training became most quickly established in PCTs which were already running community focused initiatives and where there were direct contacts with local voluntary and community groups.¹⁵⁰

The role of the voluntary and community sector was particularly emphasised in programmes which started from a broader goal of supporting people to live well with long-term conditions, rather than a narrower focus on self-managing health. A good example of this was *People Powered Health*, which developed a model of social prescribing to integrate care and support planning processes in general practice with community-based services and sources of support:

*Social prescribing supports GPs to refer and encourage people to take up activities instead of, or alongside, their medical prescription. This could include going to the gym, joining a reading group, or taking up a hobby. By developing a model to meet the range of needs of patients with long term conditions the project has tried to move away from a disease specific view of long term conditions.*¹⁶⁶

A key factor in the success of social prescribing was the embedding of link workers from voluntary sector organisations into general practices, who acted as the referral point to wider services. As link workers were also generally recruited from the local community, it meant that the advice and support was – in the words of one interviewee – ‘coming from next door rather than higher up’. Link workers had several roles, including:

- giving practical support to help people develop their knowledge, confidence and skills, and working with them to think about the questions they would like to ask at their next GP appointment
- developing a personal health plan with the patient, using motivational interviewing techniques and decision aids to facilitate the individual’s role in the process
- providing advice on local services which may be able to contribute to their health: for example, social groups and exercise classes.

7.3 Implementation

It is clear from the evidence we reviewed that current learning has progressed to recognise that embedding self-management support and shared decision making requires a change in philosophy and practice. The way that change is introduced has an important bearing on whether and how it is accepted, embraced and sustained. Change management in the NHS has

thus become a field of scientific inquiry in itself. Our analysis identified some key features which appear to be important for effective change management when implementing new practices to foster self-management support, shared decision making and collaborative care more generally. These features are shown in Table 7.1 below.

Table 7.1: Implementing change to achieve person-centred care

Effective features	Description
<p>1) Build a shared vision</p>	<p>Programme learning showed that it was valuable to have partners who can work together and develop a shared vision from the start. Interviewees often talked about having the ‘right people round the table’. One interviewee discussed the need for a proactive chief executive or senior lead in shaping a vision for the organisation – someone who ‘really made it their business’ (see also Chapter 8).</p> <p>This vision should articulate the need for change and how the programme aims to achieve this. Many emphasised the importance of a strong quality improvement narrative, linked specifically to the patient experience, and an emphasis on the goal of collaborative care, not just patient involvement. Many interviewees commented that a rationale built purely around cost and efficiencies would not be effective. The phrase ‘it’s about hearts and minds’ was often used to describe how change towards more collaborative care could be implemented in mainstream practice.</p> <p>This feature is also supported in the wider change management literature.^{99,167} Articulating a ‘shared purpose’ for change which is connected to core NHS values is at the centre of the NHS Change Model.</p>
<p>2) Create a strong infrastructure for implementation</p>	<p>Most of the programmes reviewed had a model of centrally supported local projects. Large programmes made up of sometimes quite varied local projects require a supportive infrastructure and robust mechanisms for ensuring accountability. Supportive infrastructure refers to both technical and social aspects of the programme. Management teams need appropriate project management and quality improvement skills, but also require an infrastructure which encourages relationship building, engagement and a sense of momentum as their projects progress.</p> <p>Findings suggested that local projects valued having access to programme resources such as websites, learning resources, networking events and other opportunities to share with and learn from other projects. The way in which a programme team is able to support local infrastructure is also important. This process may start from how local areas are selected. The <i>Right Care</i> programme adopted a tripartite structure to management, where local teams were asked to identify an executive sponsor, clinical lead and project lead. Readiness to adopt change was also assessed through competitive tendering: organisations were asked to complete a questionnaire which included identifying potential barriers to system change.¹⁶⁸</p>
<p>3) Foster local innovation and ownership</p>	<p>There is a balance to be struck between programme goals and management and support for local innovation: if programme management mechanisms are too rigid then enthusiasm and creativity can be stifled. The need for local ownership was frequently emphasised, without which ongoing motivation and sustainability of changes were doubtful. Examples of where local ownership was supported include choices over particular services and pathways to focus on; the design of tools used to implement change; and decisions about which outcomes to assess and how. One interviewee talked about the importance of participating areas being able to choose the pathway to work on, and that this made the programme more relevant to local teams: ‘They were getting something out of it as well.’</p>

Effective features	Description
<p>4) Harness peer power</p>	<p>The culture change required for self-management support and shared decision making is the same: both require a different perspective of the health care professional–patient relationship towards one that supports patient empowerment. As one interviewee commented, ‘even though some of the tools and techniques that you’d use in the consultation are different, the actual basic cultural change, and the relationship change between the clinician and patient is identical.’</p> <p>The power of peer influence in leveraging this change was recognised by many of the programmes. This ranged from the now common mechanism of employing the support of a clinical lead to champion new ways of working, to the value of peer-to-peer training. There were also more informal mechanisms for peer influence including harnessing healthy competition between professionals: for example, by sharing information on outcomes achieved across the different teams and services involved (see also point 7 on evaluation below).</p>
<p>5) Upscale over time</p>	<p>Programme learning suggests that starting small (eg in one clinical area or team) and building on success may be most successful. However, transferability needs to be considered; teams must decide themselves when and how they want to implement service changes, even if this means selective adoption of new approaches at first. Experience seems to be important; teams need to start their own learning journey before they identify where and how they can expand on the changes initially made.</p> <p>Opinions about whether engagement should be made mandatory differed. Some interviewees thought that self-management support and shared decision making cannot be mandated because changing practice should be about winning ‘hearts and minds’. Others thought that a strong ‘must do’ message was important, and that without it change in some parts of the system might never occur. Indeed, there was some evidence that mandated change had acted as a lever to change hearts and minds: for example, in a project in Blackpool (<i>Right Care</i>) a mandated decision grid was at first met with scepticism by the team, but later supported when patients responded to it well (ie, by asking more questions and being more engaged in choices).</p>
<p>6) Work with an incremental model of change</p>	<p>The time taken to implement change should not be underestimated. Interviewees described how change took time and sustained effort. Some of the programmes (for example <i>People Powered Health</i>) were specifically designed as a learning journey. This means that shared decision making and self-management support programmes require an early emphasis on learning, testing out new approaches and making adaptations as required. Where this is the approach, success may therefore be about identifying key lessons and learning from these by maximising levers that have worked well, making changes and avoiding identified pitfalls in future.</p>
<p>7) Evidence is vital at all stages</p>	<p>Most programmes considered evaluation to be an important aspect of the work. Evaluation has many functions. It is used to document change and evidence success, which can motivate people to change and spread innovation. There is also an accountability function in that evaluation demonstrates what has been achieved for the resources (eg, time, funding) invested. However, there is a balance to be struck between collecting data against relevant outcomes and overburdening. It is better to robustly measure fewer outcomes, than to risk poor measurement because of onerous data collection requirements. Evaluation findings can also be used to make a business case for sustaining change. One project lead talked about how she used evidence of reduced cost and service utilisation to influence local commissioners to sustain the project after programme funding ceased.</p> <p>Some projects also found that measurement was an important motivator for change, with one interviewee noting that – in the project they had led – it had triggered changes in professional behaviour by harnessing competition and providing markers of improvement. This suggests that evaluation can function as part of the intervention itself, and is not just useful for producing evidence.</p>

Effective features	Description
<p>8) Sustainability requires early attention</p>	<p>The model of time-limited programme funding has meant that there is often a tendency towards ‘project-itis’. For changes to be sustained beyond the lifetime of a programme, they need to be embedded in a supportive infrastructure. This requires attention at the design stage. Linked to the above point about evaluation, a key consideration is what kind of evidence may be needed to convince those who plan and pay for services to mainstream innovations and continue new models of care. This comes back to the hearts and minds issue we raise above. Programmes recognised the need for good evidence, but some also felt that collaborative care should be promoted as ‘the right thing to do’ (echoing the ethical case for person-centred care that we discussed in Chapter 3).</p> <p>The ‘Influence Model’ (developed by McKinsey – see www.managementexchange.com) identifies ‘reinforcement mechanisms’ as critical to transformational change. This refers to the importance of structures, processes and systems which underpin and facilitate the change being implemented. Two particular reinforcement mechanisms were highlighted in the programmes we reviewed: early engagement with commissioners and a supportive IT infrastructure. We will return to these in the following chapter when enablers and barriers are explored in more detail.</p>

Chapter 8:

Barriers and enablers to embedding shared decision making and self-management support

In this chapter, we explore the contextual factors which act as barriers and enablers to developing and embedding self-management support and shared decision making into mainstream care. It is important to note that our analysis is derived from an evidence base mainly comprised of the views and experiences of programme teams and health care professionals involved in delivery. What follows, therefore, should be seen as the system perspective, and is not necessarily one that patients would recognise or share.

8.1 Health care professional characteristics

Lack of health care professional engagement with interventions for self-management support and shared decision making was one of the most commonly cited barriers. Three main sets of characteristics which may act as barriers to success were discussed by interviewees:

- **Mindsets and preconceptions** include the extent to which health care professionals believe in the philosophy of, or are convinced by rationales given for, involving patients in their own care. Professionals' perceptions about their current practice are also important and can present a barrier to engagement. This is especially so when health care professionals believe that they are already supporting self-management and/or shared decision making, and therefore do not see the need for change. Many of the programmes found that an important learning point achieved from implementing changes was when health care professionals realised in retrospect that they had not already been practising collaborative care.
- **Concerns about risk** may also prevent health care professionals from engaging or developing more supportive attitudes. The health care professionals interviewed discussed the need to 'let go' of a more

paternalistic approach in order to support patient involvement and decision making. The notion of working from the patient's agenda can spur concerns about medical risks and who takes responsibility for these, although evidence from the programmes suggests that these may be unfounded:

..the results do indicate that the attention placed on individuals' goals, rather than biomedical targets did not lead to a deterioration of clinical outcomes – as can be a concern of healthcare professionals¹⁴⁶

The programme design stage does, however, require careful consideration of how different patients can be safely supported to be involved in their care. An example of this came from the *National Cancer Survivorship Initiative* where self-management support was embedded within a risk stratified clinical pathway.

- **Health care professional knowledge of wider support services** was also mentioned as a barrier for embedding collaborative approaches into mainstream care. Put simply, if health care professionals are not aware of supportive services and resources (within and outside the NHS) then they cannot help their patients to access these. This poses a particular challenge to generalist health care professionals such as GPs, given the range of conditions that are managed within primary care. Referring to services outside traditional health care models is particularly relevant to the provision of holistic care. The *People Powered Health* example discussed in the previous chapter suggests that peer navigators and voluntary sector organisations may be better placed to signpost to sources of community-based support than health care professionals.

8.2 Patient characteristics

Patient characteristics which present barriers for embedding changed practice highlight the need for thoughtfully designed interventions and the avoidance of one-size-fits-all strategies. Section 7.1.3 discussed how tailoring and multiple mediums of delivery can support wider patient access and engagement. This section describes a number of characteristics which may be a feature of the daily lives of individual patients and may act as barriers to participation.

- **Demographic characteristics** can influence the extent to which people are able to engage in their health, and can include age, gender, education, ethnicity and socioeconomic status. The barrier most commonly cited by the programmes in our review was deprivation, associated with both greater health needs and increased barriers to participation. Some programmes reported that people living in more affluent areas found it easier to engage with collaborative care initiatives, and there has been growing recognition of the need to target and tailor approaches to less advantaged groups. Emerging evidence on the positive outcomes of tailored approaches (see Section 7.2.1 for more details) cautions against a view that shared decision making and supported self-management are unsuitable for some groups. Indeed, where tailoring is effective, less advantaged groups might benefit more from being engaged in their health care.
- **Skills, knowledge, and confidence** differ markedly from individual to individual, and can be patterned by other characteristics such as socio-economic status. Evidence from the programmes suggests that those living in more affluent areas were more likely to have higher levels of general and IT literacy, and might have already formulated strong opinions about what they want from health care (reported, for example, in *MAGIC* and the *Expert Patients Programme*). This is important given that information and education are central components of many of the approaches used. The use of tools such as the PAM to assess individuals' skills, knowledge and confidence to tailor approaches and packages of support is increasingly supported by the evidence.
- **Beliefs and preferences** also differ from individual to individual, and are shaped by previous health care experiences, a person's knowledge of their own condition as well as their social and cultural background. There are potential tensions in how 'health' and 'decisions' are understood by people

and in models of shared decision making and self-management support. For example, models of self-management put the experience of having a long-term condition centre-stage, and require patients to recognise the need for new behaviours and commit to ongoing management of their health. Despite the focus on positive living, some approaches are underpinned by an illness-based identity which may be inconsistent with how people interpret their health problems and the priority they give to them in the context of their life overall. In this case, accepting the principle of self-management might for some people also mean accepting a new role and identity, and a reorientation in their relationship to their health. The same can be said of shared decision making, where preferences for professionally-led care sit uneasily with the notion of the individual as a partner in the decision making process.

- **Health status and type of condition** may also shape, and potentially limit, opportunities for participation. A desire for an active role may be lower among people who have poorer health, have complex conditions and needs, or who have recently received (and are coming to terms with) a new diagnosis. But there are no straightforward rules – each person will be different, and support and encouragement from wider social networks (eg family and friends) is an important mediating factor. As we discussed in Chapter 7, some interviewees also proposed that current approaches to self-management support and shared decision making are better suited to certain conditions and types of decision. In terms of self-management support, the suggestion was that some kinds of symptoms and behaviour changes are more amenable to the conventional goal setting and action planning approach, and so create positive incentives for patients to self-manage. There was also a sense that partnership can be easier in some circumstances, for example shared decision making may be more straightforward where there are clearly defined alternatives for the patient to consider and where good information is available on the risks and benefits of each.
- **Mental health** appears to be increasingly recognised as an issue for involvement in care generally, and engaging in self-management or shared decision making specifically. Some interviewees described how mental health problems could act as a barrier to people feeling in control of and getting more actively involved in their health. This suggests that psychological and emotional support have a vital role to play in building confidence and capacity

to participate. Some programmes had specifically targeted people with mental illness, with positive outcomes reported – for example – for people with depression in *Co-creating Health*. The key learning here is in relation to programme design and the need to provide opportunities and support which are accessible and beneficial to people with mental health problems.

8.3 Senior level support and ongoing commitment

Senior level support was recognised as a critical enabler by the majority of the programmes reviewed. This was an issue that we focused on in interviews, which helped us to unpack what this should look like in practice. Support at the chief executive or executive lead level is important and some programmes (for example *People Powered Health* and *Right Care*) incorporated this into the funding process, requiring a demonstration of senior support as a pre-requisite for entry into the programme (see Table 7.1). Good chief executive support was described as proactive engagement with and championing of the changes being introduced, not just at the beginning of a programme, but throughout. One interviewee described a proactive chief executive in one of the projects as someone who ‘really made it his business’.

Another crucial component of senior support is clinical leadership. One interviewee noted that this requires more than attendance at steering groups; leaders need to champion changes, articulate the benefits but be mindful and responsive to the concerns that staff may have, and be able to ‘use the right system levers’ to link interventions to broader strategic priorities and goals (see also Section 8.9 below). It was suggested that health care professionals were more receptive to quality improvement initiatives than changes driven for cost-saving purposes, but even championing the former could require a great deal of resilience:

Strong clinical leadership didn't always work well however. It's down to the individual, some are just better at articulating the message. There are a set of core skills that are important: they have to have credibility with their peers, not just the other clinicians, but they need to be able to work right across, and they need to be able to articulate that a good

patient experience is the most important outcome. Having the courage to do this is really important because it can be quite uncomfortable for them.

8.4 Core team to drive change

Change is a time and resource intensive process, especially in complex and dynamic systems such as health care. A core project team was considered by many to be essential to help drive change, mobilise support and offer practical help on the ground to implement new systems and ways of working. But a careful balance needs to be struck between having dedicated support, and fostering an approach that encourages teams and services to assume responsibility for making changes to their own practice and becoming self-sufficient over time. The stability of the team is also a factor; as one interviewee noted, new teams can be suspicious of one another, and high staff turnover can result in limited capacity.

Several interviewees noted that the core team needed to have influencing as well as technical project and change management skills. A good team therefore combines dedicated project staff with supportive (and ideally influential) local professionals and managers. Without the latter, changes were unlikely to be taken up and/or sustained in routine practice. The *Co-creating Health* Phase 2 evaluation notes that self-management support should be visibly practised or actively promoted by ‘a core group of people who have a degree of power and influence and are in a position to effect changes to a service’. In particular, disengagement of people in key roles was noted to have a detrimental effect on junior staff.¹⁶⁹

8.5 Alignment with wider priorities and agendas

As we discussed in Section 7.3, an approach that facilitates local ownership is critical to successful implementation – like patients, professionals are more receptive when they are encouraged and empowered to make changes, rather than directed to do so. This can be easier to achieve where there is a good fit between programme aims and local priorities. For example, the *Year of Care* Tower Hamlets project was able to apply care and support planning to a broader strategic aim to invest in primary care and improve performance on clinical outcomes. Their participation in the programme allowed them to dramatically improve their Quality and

Outcomes Framework indicators for cholesterol and blood pressure; as one interviewee noted, ‘We wanted to put resource into primary care, but we wanted to do it in a way that was going to get used for patient improvement.’

Similarly, *Right Care’s* Blackpool project was able to apply the shared decision making approach to an area which was a particular concern for them – the uptake of parenting support for vulnerable pregnant women:

We thought about what our key issues were, and one was being able to engage vulnerable women in education during the antenatal journey. So we thought we’d look at our parentcraft sessions, and the decision grid showed the pros and cons for different options in terms of location of the education, and whether they wanted one-to-one or group-based support.

Local ownership was also more likely when there was a prior commitment to collaborative working, such that relationships and processes to support change were more established within the system. Programmes that built on previous cross-system working to develop more holistic and person-centred care were – perhaps unsurprisingly – most likely to consider themselves successful.

8.6 IT systems and system capacity

Of all the factors that we identified as barriers to embedding self-management support and shared decision making, it is interesting that IT systems was most commonly cited. While IT alone cannot improve practice, having supportive systems was recognised as crucial to embedding new approaches and ways of working. Tools for self-management support and shared decision making (eg agenda setting, care and support planning, decision aids) need to be embedded into clinical IT systems to regularise and sustain their use. This makes them easier to access and use in a consultation, and means that additional demands are not being placed on health care professionals (especially important in general practice, given the short consultation time available). Having ‘fit for purpose’ IT systems is also important for recording service use, which can provide data to serve monitoring and evaluation purposes, and also support commissioning.

The challenge presented by a non-supportive IT system was noted by one interviewee:

Just couldn’t get it to work... the information flows just weren’t there. This was partly due to the GP software they use, which has no way of capturing people’s goals and actions other than through free text, so they can’t be reported.

Timing is important for maintaining momentum: building an appropriate IT system can take time and requires early investment so that it is available for use soon after training is delivered.

Finally, in terms of system capacity, perceived lack of time was also a commonly cited barrier to staff engagement. There was a widespread view that it is important to protect time while change is being implemented and new skills are learned. This is important for both the core team but also staff more generally. Securing protected time – for example to complete training – is often challenging, and is reliant on establishing senior level support for the change programme. But doing so is important for symbolic as well as practical reasons, in that securing protected time can send a positive message to frontline staff that the improvement and their participation in it is a priority.

8.7 Supportive commissioning and payment systems

A strong theme to emerge from those programmes based in England was that commissioning frameworks are essential to embed collaborative care into mainstream practice. On the whole, commissioning was considered to be a barrier, with tariff-driven models seen to reward activity rather than quality-oriented goals such as patient involvement. Moreover, the annual payment system makes investing in long-term projects – for long-term outcomes – more difficult, and was felt to disincentivise integrated care.

There were several examples of local areas trying to harness commissioning levers to drive and embed change: for example, by developing CQUIN payments or enhanced service specifications (eg Directed Enhanced Services (DES) and Local Enhanced Services (LES) schemes) attached to shared decision making or self-management support. However, Gifford and colleagues guard against over-relying on payment systems to drive the change agenda forward, as this can risk creating perverse incentives.¹⁶⁷ Using

payment systems to support change should therefore be accompanied by an approach which promotes the quality improvement message.

More coordinated approaches to commissioning may be more beneficial, as they are capable of supporting system-wide, not just service-specific, change. For example, in Oldham, Pennine MSK Partnership – who participated in *Right Care* – holds a single bundled contract with local commissioners to provide all rheumatology, orthopaedic and musculoskeletal pain services in the area. This meant that shared decision making could be implemented across the patient pathway, and fostered a more joined up approach because teams and professionals worked together to put the new approaches into practice.¹⁴⁷ In Lambeth and Stockport (*People Powered Health*) ‘collaborative commissioning vehicles’ are bringing together alliances of commissioners and providers across all sectors to work with the community in co-designing and co-delivering services according to the needs and aspirations of the population.

A strong message emerged from these projects about the importance of engaging commissioners from the outset; like clinicians, commissioners may be more willing to contribute to helping make and sustain change if they feel some ownership of it. Local history is important here; where there is already a culture of partnership working these links were easier to utilise. For example, in the Oldham example described above, the project benefitted from the well-established relationship between Pennine MSK Partnership and local commissioners.

8.8 NHS reforms and wider financial climate

Recent NHS reforms and the wider financial climate have created a barrier to implementation in several respects. We were told that structural changes have resulted in fragmentation and a loss of organisational memory due to high staff turnover and changed roles. At the same time, constrained funding in the NHS and the current focus on making efficiency savings appears to have benefitted innovation inasmuch as there is greater recognition of need for system transformation. However, this also presents a risk in that the rationale for change may be understood wholly in terms of cost reduction, rather than improving the quality and experience of patient care. Linked to this, there is some evidence that both patients and health care professionals are questioning the motives of promoting greater patient involvement in care, especially in the current financial

context. The main concern is that the ‘real agenda’ is to cut health care costs by shifting responsibility for certain aspects of care onto patients and their families.

8.9 Maximising national policy levers

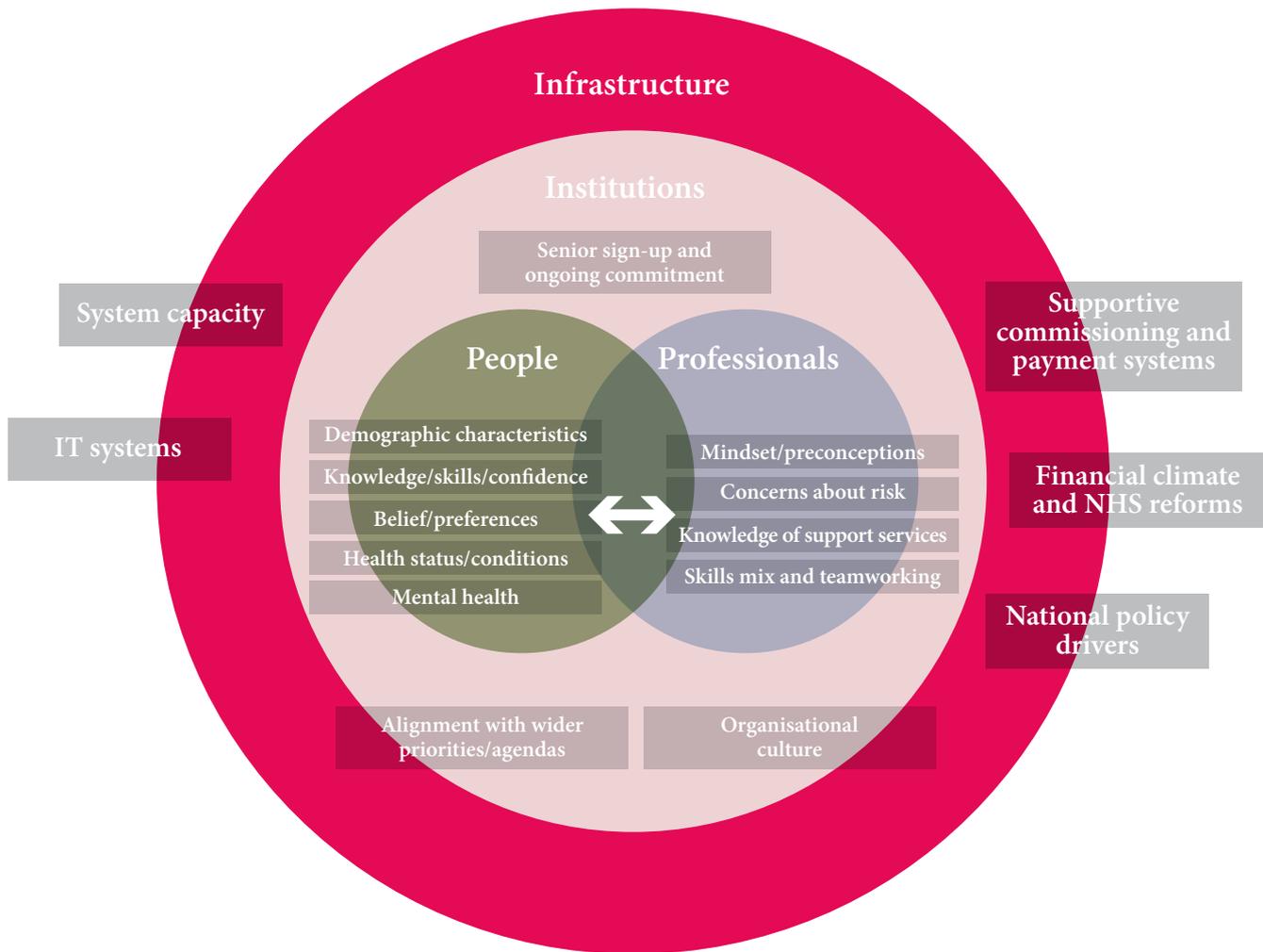
A strong enabler for embedding new approaches into mainstream care is the capacity to draw on the policy context in a way which supports the rationale, implementation and sustainability of change. Some programmes and projects had been able to make use of policy levers in this way, while others talked about lost opportunities. In effect, national policy can provide ‘hooks’ when making the case for change. However, it is important that a range of policy levers are identified to maximise effect: for example, using policy specific to one long-term condition may hamper subsequent spread of changes to other services.

Generally, the current promotion of integrated care was felt to be a particularly useful lever for change. Some argued that self-management support in particular cannot be delivered without integrated working across sectors. The Better Care Fund was commented on as a positive step in the development of models of collaborative care. In its provision of £3.8 billion for closer integration between health and social care, the Fund presents an opportunity for CCGs to work with Health and Wellbeing Boards in particular. One interviewee stated that there was a potential role for Health and Wellbeing Boards in leveraging greater use of community resources to support self-management across local areas.

The new GP contract for 2014/15 was also described as a supportive lever, especially in terms of the new requirement for proactive case management of patients with complex needs. The new contract places developing, sharing and regularly reviewing personalised care plans at the heart of case management. There was a hope that this would translate into increased GP engagement with care and support planning, and that it would lend support to improvement models where changing GP consultations is a feature.

Figure 8.1 summarises the key messages in this section in the form of a taxonomy of barriers and enablers, understood in terms of four different levels: people, professionals, institutions, and infrastructure.

Figure 8.1: Taxonomy of barriers and enablers



Chapter 9:

Lessons learned from the programme review

Given the diversity of programmes and evidence reviewed, and range of issues that we have sought to explore, any simple set of ‘lessons learned’ will – of necessity – be highly selective. Nonetheless, it is possible to identify within our findings some key messages about what helps to embed self-management support and shared decision making into mainstream care.

- **Tools alone are not enough.** To work, tools should be embedded within a wider change in clinicians’ and patients’ roles and responsibilities. They also work best when used within a consultation, so that they function as part of a collaborative relationship rather than becoming a substitute for this. For example, decision aids should be designed with ‘space’ in them to allow time in consultations for discussion and decision making. This suggests that tools need to be introduced carefully and ideally with training to support their use, so that they do not come to be seen by either the patient or health care professional as ‘doing the job’ for them.
- **Offer people a range of support options, so they can select to suit their preferences and needs.** There is no single best model of self-management support or shared decision making; what works for some will not work for others. While this was widely recognised within the programmes reviewed, there was nonetheless a tendency for services to default to certain approaches. In self-management support, the group-based education and skills training model has become predominant across the health service; efforts to facilitate shared decision making are most likely to involve the introduction of patient decision aids. Evidence suggests that these can be effective approaches, but not for all groups, circumstances or outcomes. The message here is be flexible, and offer a suite of options wherever possible.
- **Recognise that people are different, and tailor interventions appropriately.** Interventions to support shared decision making and self-management support are likely to be most effective when tailored to the patient, professional and condition. The notion of tailoring interventions can be a daunting task, implying that a bespoke approach is needed for every different individual and situation concerned. This does not have to be the case. Core approaches and tools can be adapted for different groups, and staff value having the flexibility to tailor so that these are suitable for their particular service. Tailoring must consider patient (and potentially family) needs and preferences too. Many programmes grappled with how to promote shared decision making and self-management to ‘less engaged’ patients. More work needs to be done on this, but a useful starting point is to understand the particular barriers that these patients may face – which may include literacy and language difficulties, a lack of confidence or encouragement to participate and underlying mental health problems.
- **Changing professional roles, behaviours and mindsets is vital, challenging, but not impossible.** Demonstrating the value of shared decision making and self-management to health care professionals is often the first step in them embracing the personal changes that they may need to make. The issue of undoing learned behaviours and mindsets is perennial in debates about person-centred care, service transformation and improvement in the NHS more generally. But it is important to be clear about what needs to be done, and this may not be the same for all concerned. In some cases, staff may already consider themselves to be practising shared decision making and/or supporting self-management, and therefore not see the need for change. This was a key challenge in almost all of the programmes

- reviewed. Emphasising that shared decision making and self-management support are about patient involvement and collaborative care – and providing real-life examples to illustrate what these mean (and look like) in practice – can be helpful. Other staff may be hesitant about adopting different approaches or find it difficult to change long-established ways of working. It is better to tackle resistance constructively rather than dismiss it, not least because doing so may uncover genuine concerns (eg about whether there is sufficient time within consultations to meaningfully involve patients) that need to be addressed to support implementation.
- **Train whole teams, not just individuals.** Training has an important role to play in equipping professionals with the knowledge, confidence and skills for collaborative care. There are still uncertainties about how best to deliver training to health care professionals, but some clear messages emerged from the evidence we reviewed. Above all, training should be delivered to whole teams to help foster collective responsibility for implementation and strengthen peer support and mutual learning. At the same time, individuals within teams may have particular learning and development needs. This suggests that a blend of team-based and more customised skills training may be most beneficial.
 - **Engage health care professionals as change agents.** Working with health care professionals as agents – not just targets – of change was identified as a key success factor across many programmes. There is a range of roles that clinical champions might fulfil, through which peer influence, peer support and peer pressure can be harnessed to bring about the desired change. Training may be best delivered to professionals by a trusted and respected colleague, who can bring shared decision making and self-management support to life and facilitate practical discussions about the issues that may be confronted in trying to implement these into everyday practice.
 - **Work with the voluntary and community sector.** Voluntary and community organisations can offer skills, activities and reach that the health care system cannot. Many provide services that support people to ‘live well’, be that in general, into older age or with a specific long-term condition. Thus they have much to offer, especially in relation to supporting self-management and care and support planning, where their role is increasingly recognised. But there are also barriers. Health care professionals have to know about, value and trust the services provided, and support their patients to access them. Involving voluntary sector organisations as delivery partners may help towards this, as might efforts to include the voluntary sector in local partnership working more generally.
 - **Local context is a vital factor in implementation.** Many of the programmes we reviewed produced evidence showing that the same interventions and approaches, involving the same (or similar) target groups, can sometimes produce different degrees and types of outcome. Good programme design is important, but success is also shaped by the local contextual conditions into which programmes are introduced. Areas where there was a long history of partnership working, established skills for quality and service improvement and/or synergy with other local change programmes often fared better at implementing new models of person-centred care. Equally, the support of local organisational and system leaders helped to create a more receptive environment for implementation. Our findings add to a wider evidence base demonstrating the impact of both ‘hard’ (structural) and ‘soft’ (cultural) factors on the success and sustainability of large-scale change.¹⁷⁰ Not all such factors are amenable to influence, but identifying and working on those which are (not just at the beginning of a change process, but throughout) is likely to enhance effectiveness.
 - **Use a whole system approach to implementing change.** Establishing self-management support and shared decision making as routine features of health care requires engaged and supported patients; skilled and receptive health care professionals; ready access to tools and resources that can be employed to support collaborative care; and systems, processes and incentives that enable all of this to be embedded into mainstream practice. In short, it requires change at every level of the system. Implementing all of this at once can be a very resource hungry process and can create a great deal of instability and disruption (and, therefore, potentially also resistance). Be flexible and allow projects to create their own timescales and stagger some implementation, where appropriate. An incremental approach that builds on successes – however small – is likely to be more effective than attempting wholesale change all at once.
 - **Have a change strategy in place from the start, one that is clear about goals but is flexible on implementation.** New ways of working will not just happen, even where there is a strong rationale and support for person-centred care. Change needs to be planned and designed, and a core project team can be a valuable resource for advising and supporting

implementation and sustaining momentum over time. A ‘designed’ approach to change needs to be clear about the goals, but not overly prescriptive about how they should be achieved. One of the most consistent themes in the review was the importance of local ownership; professionals, teams and services must be able to shape what approaches are adopted and how, and benefit from having the scope to test out and innovate within their own practice. Without this ownership, it is unlikely that any progress made in implementing shared decision making and self-management will be sustained over time.

- **Consider sustainability from the outset.** Most of the programmes reviewed were time limited, and all of these faced the challenge of ‘what comes next’ as they reached the end of their funding. Consideration of how changes will be spread and sustained needs to be given from the very start, and identified actions should be given the same priority as making the changes themselves. Ensuring that shared decision making and self-management support are integrated into routine systems and processes is imperative. It is notable that, of all the barriers that our review identified, inadequate IT systems was the most commonly mentioned. New ways of working and successful outcomes should be built into contracts, incentive systems and reward structures – our findings suggest that financial levers may be of limited value in bringing about change, but are essential to sustaining it.

- **Evaluation should be designed into change processes from the start, balancing robustness and feasibility considerations.** Evidence has a central role to play in driving, supporting and sustaining efforts to embed self-management support and shared decision making into routine services. Staff want to know that the effort they are making to implement change is making a difference; without this, sustaining engagement may be difficult, if not impossible. Measurement can itself trigger behaviour change: professionals and patients are motivated by positive results. Emphasis should be on gathering information to both support ongoing learning and demonstrate impact; but this can place heavy demands on already stretched individuals and resources. Be clear on the intended outcomes from the start, and focus measurement on a selection of them. A small number of outcomes robustly measured is preferable to an extensive evaluation that is poorly carried out. Consideration should be given to how to assess more abstract concepts, such as changes in relationships, as well as longer-term measurement exploring whether effects have been maintained over time. Validated tools can provide a robust measure, and may allow for comparison or benchmarking against other programmes; however, they are also often more costly (due to licensing) and therefore may not be feasible.

Chapter 10:

Conclusion

Many people want to play a more active role in their health care, and there is a growing evidence base showing that well-supported involvement can help to improve the experience, quality and outcomes of that care. The question being grappled with is how the vision of ‘patients as partners’ can be achieved in practice, and what implications this presents for relationships, services and models of care.

Efforts to promote patients’ involvement in their care are increasingly focused on creating opportunities for shared decision making and self-management, with collaborative care planning offering a model for the professional–patient relationship that has the potential to integrate and support both. It is striking that shared decision making and self-management support have largely developed as separate concepts and practices, each with their own distinctive bodies of literature and evidence. This is also reflected in the programmes that we reviewed for this project, the majority of which set out to foster implementation of *either* shared decision making *or* self-management support. This gap is exacerbated when shared decision making and self-management support are seen narrowly as a set of patient-focused techniques, with decision support tools considered critical for the former and mechanisms of behaviour change emphasised for the latter.

So what is the relationship between shared decision making and self-management support? Looking to the conceptual literature for an answer complicates matters further because neither concept has a single commonly agreed definition. In other words, the ‘what’ of shared decision making and self-management support are still in debate, although a consensus about the core features of patient participation in clinical decision making processes does appear to be emerging.

It might be better to address this in another way, from the starting point of a person-centred approach to care. In this approach, patients are listened to, informed, valued, respected and involved, whether that be in episodic clinical decisions or ongoing efforts to manage and live well with long-term conditions. This does not mean to say that shared decision making and self-management support are identical – they aren’t. But our analysis has shown that both are underpinned by the same principles and expectations for respect and collaboration between patients and professionals. And neither can be successful without a more equal distribution of power in the professional–patient relationship and the mainstreaming of approaches that are about ‘working with’ rather than ‘doing for’.

Our review of the current policy context suggests that this offers some welcome drivers and opportunities for bringing about the changes that are needed. The ever rising demand for health care services coupled with a very challenging financial climate has propelled the issue of system transformation from important to imperative. Redesigning care and support for people with long-term conditions, and the broader goal of health and social care integration, are priorities in all four countries of the UK. It is increasingly recognised that the financial sustainability of the NHS requires a reorientation away from traditional, paternalistic models of care to an approach focused on prevention, empowerment and proactive management. Patient involvement has never been higher up the policy agenda or more strongly linked to system reform.

Yet we have also raised concerns, particularly about the goal of more ‘empowered’ patients being promoted and pursued as a cost-saving measure. We can see this happening to a greater extent in relation to self-management, which in recent years has increasingly been framed as a strategy for managing health care demand. No one would dispute that people feeling

more able to manage their health and less dependent on health care professionals to do this for them is a good thing. But self-management is not about patients going it alone; it is about patients and professionals working together for better health, with each bringing valuable skills and knowledge to the partnership. For some, this will mean that service use is different, not less.

This has important implications for how strategies for self-management support and shared decision making are designed and evaluated. Encouraging and equipping patients to be actively involved in their care is necessary, but not sufficient. This is a key lesson from the programmes we reviewed. Over time, these programmes have evolved from a focus on sources of patient support (often delivered outside of clinical settings) to a whole system approach which recognises that, for any aspect of collaborative care to be successful and sustainable, there must be in place:

- engaged and empowered patients
- professionals with the right skills and mindset to work in partnership
- organisational systems and processes that embed new ways of working in routine care, and funding systems that incentivise and reward collaborative care.

It will come as no surprise, then, that another common theme from the programmes was that tools such as decision aids and skills training programmes are not enough. They can support and underpin a collaborative process of care, but will not substitute for it.

All of this suggests that, while implementation will always be a local matter, all parts of the health care system have a role to play in bringing about more person-centred care. One of the main areas of debate in the expert seminar the Health Foundation hosted for this project was the implications of person-centred care for workforce training and development. There was widespread agreement that principles and skills for collaborative care must guide professional training from the outset, but that current curricula fall short of this. The issue of measurement was also prominent, with calls for better tools to assess the outcomes that are most valued by patients and more consideration given to how these can be integrated into clinical consultations. We heard how measuring outcomes can trigger and sustain new behaviours among health care professionals, both by providing evidence that improvements are taking place and harnessing a competitive spirit to do better.

Like all complex changes in health care, embedding shared decision making and self-management support into mainstream services will take time. Much has already been learned from programmes supported by the Health Foundation and others about the factors that contribute to successful implementation and how barriers might be overcome. We hope that our analysis has succeeded in bringing the evidence together in a way that supports ongoing and future efforts.

Annexes

Annex 1:

Participants at the expert seminar

- Dr Alan Nye, Clinical Lead AQUA (Shared Decision Making)
- Dr Anne Kennedy, Principal Research Fellow in Health Sciences, University of Southampton
- Adrian Sieff, Assistant Director, the Health Foundation
- Ben Gershlick, Strategy & Policy Officer, the Health Foundation
- Bridget Turner, Director of Policy & Care Improvement, Diabetes UK
- Dr Charlotte Augst, Richmond Group Partnerships Manager
- Dr Claire Foster, University of Southampton
- Darshan Patel, Research Manager, the Health Foundation
- Dr David Oliver, Fellow at The King's Fund
- Dr Fiona Jones, Reader in Rehabilitation
- Professor Graham Watt, Professor of General Practice, Glasgow University
- Halima Khan, Director of the Public Services Lab, NESTA
- Jo Bibby, Director of Strategy, the Health Foundation
- Jo Ellins, Senior Managing Consultant GHK Consulting Ltd
- Dr Katie Coleman, GP
- Kevin Geddes, Director of Development and Improvement, Health and Social Care Alliance Scotland
- Liza Coffin, Senior Public Affairs Manager, the Health Foundation
- Luke O'Shea, Head of Patient Participation, NHS England
- Margaret Rennocks, NHS Wales Self Care Programme Manager, Public Health Wales.
- Mark Platt, Policy Advisor, Patient & Public Involvement RCN Policy and International
- Dr Nahid Ahmad, Senior Consultant, GHK Consulting Ltd
- Professor Nick Barber, Director of Research, the Health Foundation
- Dr Nick Lewis-Barned, Clinical Fellow, SDM and SMS, Clinical Standards Department, RCP
- Nick Neilson, Coaching for health trainer, the London Deanery
- Peter Davies, Freelance Writer
- Dr Petra Makela, Rehabilitation Physician and Darzi Fellow in Clinical Leadership
- Dr Rebecca Viney, Associate Director Postgraduate GP Education, Coaching & Mentoring Lead, the London Deanery
- Dr Robert Elias, Consultant renal physician, King's College Hospital NHS Foundation Trust
- Dr Sara Demain, NIHR Post-doctoral Research Fellow, University of Southampton
- Sean Maher, Person Centred Health and Care Collaborative, Health Improvement Scotland
- Dr Sue Roberts, Chair Year of Care Partnerships, Northumbria HCFT

Annex 2:

Members of the project advisory group

- Professor Nick Barber, Director of Research, The Health Foundation
- Dr Katie Coleman, GP and Joint Vice-Chair of Islington Clinical Commissioning Group
- Dr Alf Collins, GP and Clinical Associate in Person-Centred Care, The Health Foundation
- Dr Sara Demain, Senior Lecturer, Faculty of Health Sciences, University of Southampton
- Dr Simon Eaton, Consultant Physician and Diabetologist, Northumbria Healthcare NHS Foundation Trust
- Professor Vikki Entwistle, Professor of Health Services Research and Ethics, the University of Aberdeen
- Darshan Patel, Research Manager, The Health Foundation
- Don Redding, Director of Policy, National Voices
- Adrian Sieff, Assistant Director, The Health Foundation
- Emma Walker, Programme Lead for Shared Decision Making, Advancing Quality Alliance (AQuA)

Annex 3:

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We are here to support people working in health care practice and policy to make lasting improvements to health services.

We carry out research and in-depth policy analysis, run improvement programmes to put ideas into practice in the NHS, support and develop leaders and share evidence to encourage wider change.

We want the UK to have a health care system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable.

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