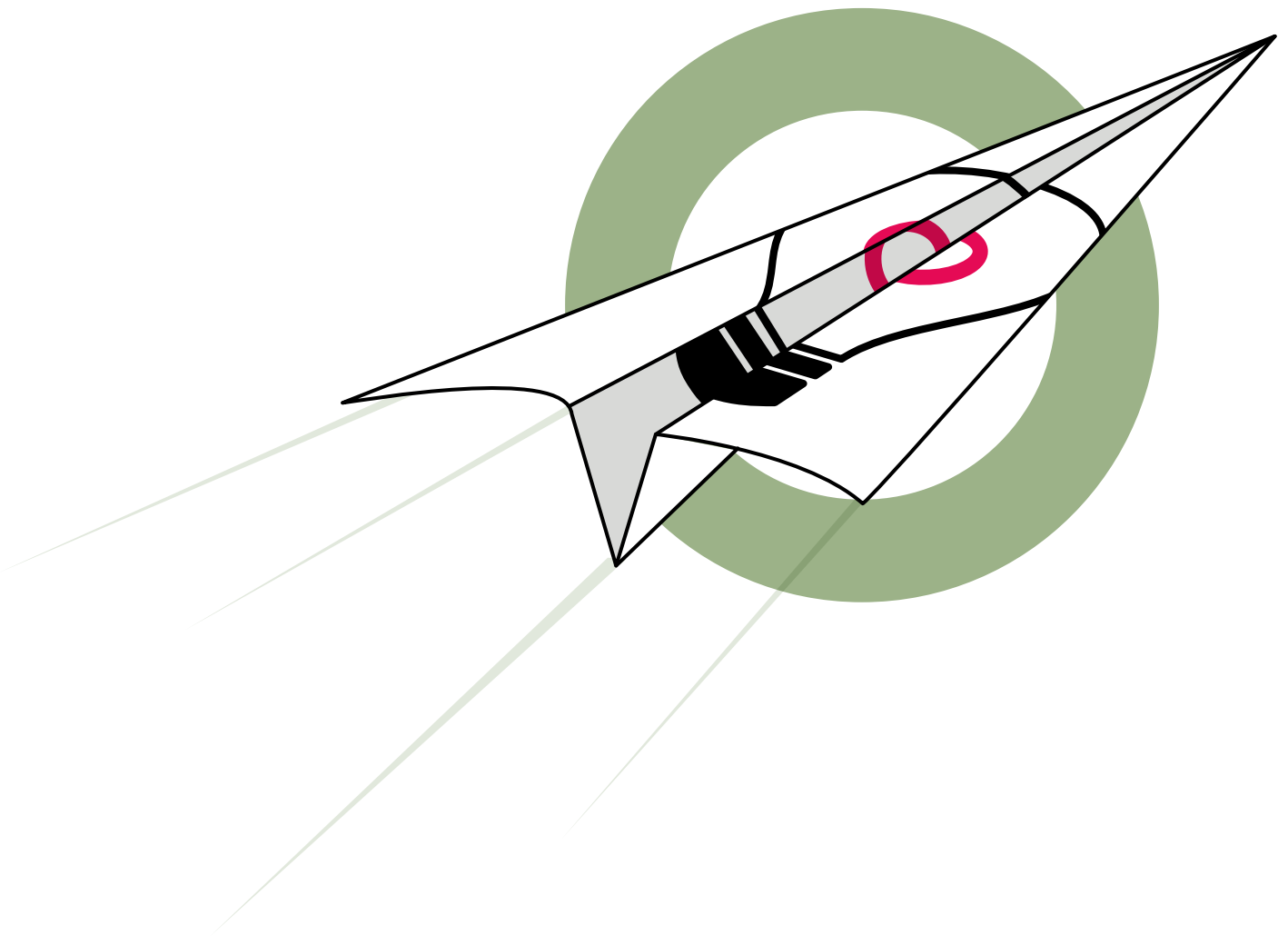


Ideas into action: person-centred care in practice

What to consider when implementing shared
decision making and self-management support



Learning report

October 2014

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We would like to thank the research team from ICF GHK – Dr Nahid Ahmad, Dr Jo Ellins, Holly Krelle and Michael Lawrie – for their work on bringing together the evidence on shared decision making and self-management support, upon which this learning report is based. Their research report, *Person-centred care: from ideas to action*, is also published by the Health Foundation.

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



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Contents

1	Introduction	4
2	What are shared decision making and self-management support?	5
3	Why are shared decision making and self-management support important?	7
4	What works in implementing shared decision making and self-management support?	9
5	Conclusion	16
	Appendix: Programmes reviewed	17

1

Introduction

This report aims to inform health care professionals, commissioners and providers about what to consider when implementing shared decision making and self-management support as part of their drive to make person-centred care a reality.

Shared decision making and self-management support have received particular attention as elements of a broader person-centred philosophy of care. Yet they have developed in different ways, and the relationship between them is complex and can be conceptualised in a range of different ways. This has consequences for implementation. Efforts to introduce both approaches into mainstream care will benefit from understanding the values, behaviours and skills underpinning them – where they are the same and where they are different.

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, our understanding of what it means to be ‘person-centred’ is evolving to encompass recognition of the active roles that individuals can play as partners in their health and health care. Policy focus and emphasis has increasingly encompassed this understanding, leading to a growing interest in the training, infrastructure and incentive implications of shared decision making and self-management support.

This report draws on a broad-ranging Health Foundation research project that set out to bring together the evidence on shared decision making and self-management support.¹ The research team examined and analysed empirical evidence, reviewed policy documents and commentaries and, through documentary sources and in-depth interviews, explored 11 implementation programmes.² These programmes represent some of the UK’s earliest laboratories testing how to get person-centred care into mainstream NHS practice. This report focuses on what the research shows needs to be done to embed shared decision making and self-management support in day-to-day, routine NHS practice.

¹ For full details, see the full research report: Ahmad N, Ellins J, Krelle H, Lawrie M. *Person-centred care: from ideas to action*. The Health Foundation, 2014. www.health.org.uk/pccideasaction

² Details of the programmes reviewed are available in the appendix, on pages 18-19 of this report.

2

What are shared decision making and self-management support?

What are they?

Shared decision making and self-management support have largely evolved as separate concepts in different fields: shared decision making has been influenced by clinical practice while self-management support originated from a social model of health and disability.

Shared decision making supports patients to make a specific decision such as whether or not to have a diagnostic test, take a course of medication, undertake a mental health recovery programme, or to choose between different types of surgery. It 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 helps people develop the knowledge, skills and confidence to manage their own health and/or to recover from an episode of ill health. It encompasses peer-to-peer support, group education programmes (generic or condition-specific, or co-led, including mental health recovery programmes), re-ablement and rehabilitation strategies, motivational interviewing, health coaching and behaviour change or lifestyle counselling.

The two concepts place slightly different emphasis on the role of information in supporting people to either make decisions and/or take actions to do with their health. Shared decision making emphasises supporting patients to understand evidence-based information about treatment probabilities and risk regarding a specific decision. Self-management support emphasises supporting people to incorporate evidence-based health

information into their everyday lives in order to become knowledgeable, confident, everyday problem-solvers.

Both concepts are characterised by:

- health or social care professionals valuing people making decisions and/or taking actions to manage their health
- health or social care professionals working in partnership with people and acting according to the four principles of person-centred care.

How do they relate to person-centred care?

We can discern four principles that underpin person-centred care:

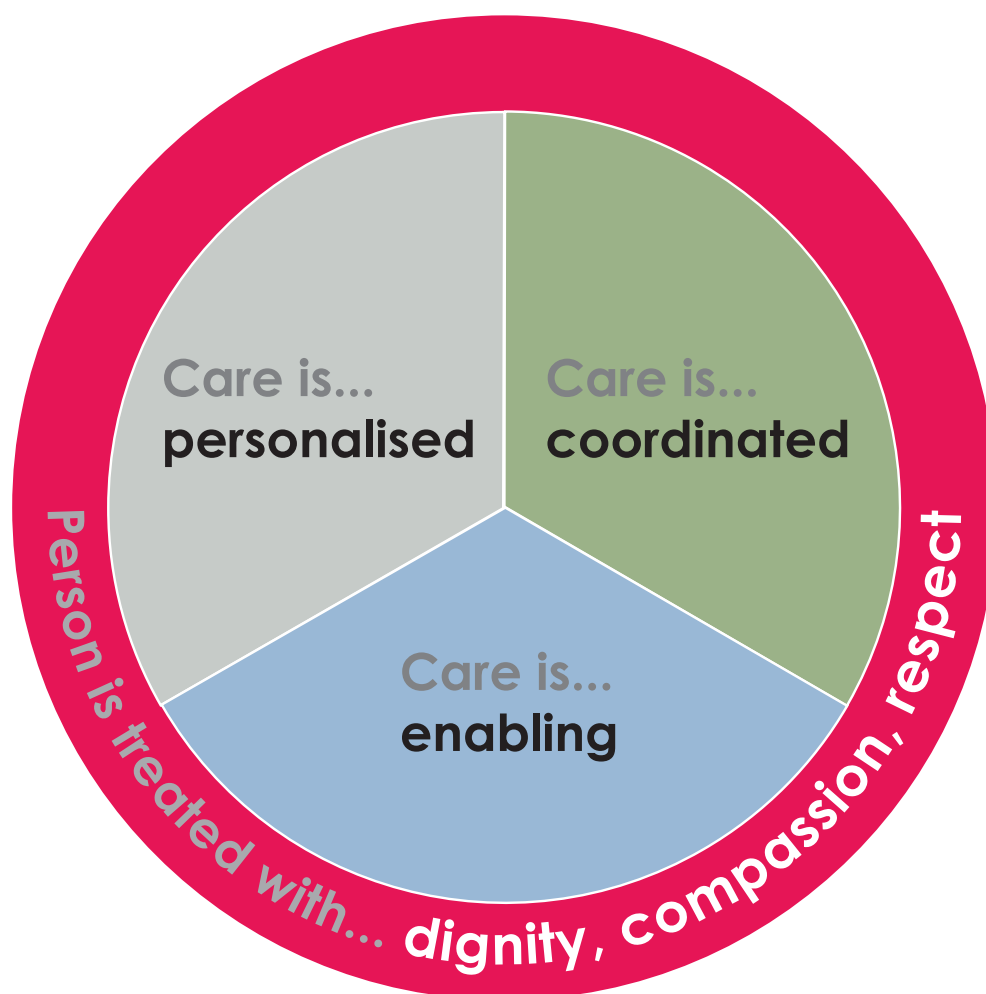
- **Affording people dignity, compassion and respect** – ‘experience standards’ that are basic human rights enshrined in the NHS Constitution.
- **Offering coordinated care, support or treatment** – across multiple episodes and over time; this is critically important at the transitions between services.
- **Offering personalised care, support or treatment** – paying attention to what matters to the individual, their family and carers.
- **Being enabling** – so that people are supported to build on their own capabilities.³

³ Collins A. *Measuring what really matters*. London: The Health Foundation, 2014. www.health.org.uk/publications/measuring-what-really-matters

Putting these principles into practice means carrying out person-centred activities, including shared decision making and self-management support. Self-management support and shared decision making are both enabling activities. They aim to shift the focus from 'What's the matter with you?' to 'What matters to you?'. They also help to ensure that

people are treated as individuals and with dignity, respect and compassion. Supporting people to develop their knowledge, skills and confidence is the primary aim of self-management support, while shared decision making enables people to confidently make specific health-related decisions.

The four principles of person-centred care



3

Why are shared decision making and self-management support important?

What is the case for person-centred care?

Arguments in favour of person-centred care tend, broadly, to be based on ethical or instrumentalist cases. These rationales are not mutually exclusive and are often combined in practice.

The ethical or values-based case presents person-centred care as a good in its own right – the ‘right thing to do’. This is underpinned by the notion that people’s rights to participate in and contribute to their own health and health care, and to wider community life, should be recognised and respected. This is often expressed as calls for more inclusive and participative approaches to health care, represented by the slogan ‘nothing about me, without me’.

By contrast, the instrumentalist case justifies person-centred care as a means to achieve better outcomes. Policy makers 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 person-centred care is ‘sold’ to the NHS.

However, there are risks in seeing person-centred care in principally instrumentalist terms. For example, 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. 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.

What is the evidence for shared decision making and self-management support?

Shared decision making and self-management support can have an impact on outcomes for patients and health services. The types of outcome can be grouped into four broad 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.

There is no hierarchy or exclusivity in these outcome domains: each of them may be important to the patient or to health services.

The Health Foundation has previously undertaken two literature reviews investigating the evidence of whether self-management support⁴ and shared decision making⁵ are worthwhile. As part of their project, the research team investigated if any new evidence had been developed since the reviews were published. They did not find anything that changed the broad conclusions of the original reviews:

⁴ de Silva D. *Helping people help themselves*. London: The Health Foundation, 2011. www.health.org.uk/publications/evidence-helping-people-help-themselves

⁵ de Silva D. *Helping people share decision making*. London: The Health Foundation, 2012. www.health.org.uk/publications/helping-people-share-decision-making

- Evidence suggests that supporting self-management works. Supporting people to look after themselves can improve their motivation, the extent to which they eat well and exercise, their symptoms and clinical outcomes, and can change how they use health services.
- Evidence shows that shared decision making improves patient satisfaction, involvement in their care and knowledge of their condition.

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.⁶ However, perhaps inevitably, some of the evidence is contradictory and 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. A very wide range of initiatives can be classified as self-management support and shared decision making, some of which only loosely apply the concepts, tools and techniques.

For more details and analysis of the evidence base, see the research report *Person-centred care: from ideas to action*.⁷

What is the policy imperative?

Person-centred care has emerged as a major policy theme across the UK. Strengthening people's involvement in health care, and making services more responsive to their needs, is now a key goal in all four home nations (despite divergences in other areas of health policy such as the role of competition in health care provision). This has encouraged efforts to support self-management and shared decision making in mainstream services.

⁶ See also work by National Voices on *Prioritising person-centred care – the evidence*, which summarises the highest quality evidence about what works in a range of components of person-centred care: www.nationalvoices.org.uk/evidence

⁷ Ahmad N, Ellins J, Krelle H, Lawrie M. *Person-centred care: from ideas to action*. The Health Foundation, 2014. www.health.org.uk/pccideasaction

The process is far from complete but, given the drive to reform the current structure and delivery of health services as well as the financial context and integration of health and social care, it seems certain to remain high on the policy agenda.

Currently, shared decision making and self-management support are being promoted within health policy in three key ways:

- **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 the process of making decisions about treatment, participating in care planning and holding a personal budget to purchase their care and support.
- **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.
- **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.

The ways in which person-centred care is framed and promoted tend to reflect wider issues in the NHS, and so have evolved over time. The Health Foundation has produced a timeline showing how person-centred care, particularly shared decision making and self-management support, has developed:

www.health.org.uk/pccimeline

4

What works in implementing shared decision making and self-management support?

Drawing on documentary sources, as well as interviews with programme leaders and contributors, the research team set out to answer the fundamental question of ‘What works in implementing shared decision making and self-management support?’

Their findings suggest that taking account of the context an intervention is introduced into and focusing on the intervention’s active ingredients were particularly important for success.

Contextual factors

The review of shared decision making and self-management support projects identified a number of contextual factors that had the potential to shape the success, or otherwise, of an intervention and its wider adoption.

Health care professional characteristics

Lack of professional engagement with shared decision making or self-management support is a common barrier to successful implementation. Three factors are particularly important:

- **Preconceptions about roles** – Professionals may believe they are already doing it or see no need for change. Realising that things can be done differently may prove a turning point. For example, the *MAGIC* programme evaluation found that a key barrier to clinicians taking part was the perception that they were already making shared decisions with their patients. Adopting an approach which focused on ‘How can we help you do it better?’ proved successful in challenging this perception.

- **Concerns about risk** – Professionals may be concerned about medical risks and who takes responsibility if patients are more involved in decisions about their care. However, the experience of some of the programmes suggests these concerns may be unfounded. For example, the evaluation of the *Year of Care* pilot programme concluded that attention being placed on individual’s goals rather than biomedical targets did not lead to a deterioration of clinical outcomes.
- **Knowledge of wider support services** – Busy professionals, particularly GPs, may need signposting to wider resources in order to direct patients to them. Peers and voluntary sector organisations may be better placed to signpost community-based support.

Patient characteristics

Interventions must be carefully designed to take account of factors in patients’ daily lives that may support or hinder involvement in their care, including:

- socio-demographic characteristics
- skills, knowledge and confidence
- beliefs and preferences
- health status/condition type
- mental health.

Senior level support and commitment

Senior leaders, both clinical and managerial, need to proactively engage with and champion the changes throughout a programme. They need to clearly articulate the benefits, respond to staff concerns and link the interventions being introduced to wider strategic priorities.

Local ownership

Services are likely to be more receptive when they are encouraged and empowered – rather than directed – to change. Local ownership is easier when programme aims and local priorities align. Prior commitment to collaborative working also makes local ownership more likely as relationships and processes are more established in the system.

The importance of local ownership (Year of Care)

Local ownership and decentralised control were important elements of the *Year of Care* programme. Leadership for development of the *Year of Care* concept was left in the hands of the pilot sites after the central team had presented them with five questions to explore and address. The central team also facilitated opportunities for learning with other sites. This raised challenges for ensuring that the central ethos was not lost in the ways it was adapted by local sites but it was seen as important for ensuring local buy-in and ongoing commitment to the programme.

A core team to drive change

A core project team can help drive change, mobilise support and offer practical help. A good team will remain stable and involve supportive and influential local professionals and managers as well as project staff.

Commissioning and payment systems

In England, tariff-driven models seen to reward activity – rather than quality-oriented goals such as person-centred care – can be a barrier. Within this context, local commissioners have some tools they can use to incentivise person-centred care, such as CQUINs (Commissioning for Quality and Innovation) and enhanced GP payments.

Structural change and financial climate

Continual structural changes bring fragmentation and a loss of organisational memory due to high staff turnover and changed roles. Constrained funding and

efficiency savings have prompted greater recognition of the need for system and service redesign. There is a risk that patients and professionals question the motives for promoting greater patient involvement, concerned that the ‘real agenda’ is to cut costs by shifting responsibility onto patients, rather than improve patient experience.

National policy levers

National policy can provide ‘hooks’ when making the case for change. But it is important to identify a range of policy levers to maximise effect: using policy specific to one long-term condition may prevent change spreading to other services. The current promotion of integrated care may be particularly useful.

A holistic approach

Within the local context, taking a holistic approach is an important foundation for successful implementation. A strategic, whole-system approach that works across boundaries, such as those within and between health, social care and the voluntary sector, enables a focus on the person rather than the condition or the service.

A number of the programmes explored how to reframe clinicians’ and patients’ roles: for example, through education and training for clinicians and patients. They also looked at health service activities and how to redesign pathways to incorporate self-management and shared decision making, including through additional or longer appointments or sending patients their test results in advance of a consultation.

Focusing on the active ingredients

The research team identified three levels of ‘active ingredients’ (the underlying mechanisms by which programmes – or projects within them – effected change):

- 1 **Using 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 **Implementing and managing change** – 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.

These levels interrelate – for example, health professionals can be provided with tools, but they will then need training and a supportive context in order to successfully use the tools in everyday practice.

Using tools and techniques

The following tools and techniques for shared decision making and self-management support were commonly used by the programmes:

- **Motivational interviewing** – a coaching-oriented technique that helps ‘reframe’ the consultation for one-to-one support or to promote behaviour change.
- **Agenda-setting, goal-setting, action planning and follow-up** – discussed most in self-management, a sense of accomplishment from focusing on action and goal attainment is critical for building confidence and motivation to take action and sustain it.
- **Collaborative care and support planning** – provides a structure for managing consultations, allowing patients to set or negotiate the agenda, decide goals and plan how to achieve them. They work best when the plan is written down, identifying both parties’ responsibilities and enabling progress reviews.
- **Helping patients prepare for consultations** – involvement places demands on patients, who must be equipped to participate and make the best of limited time. Tools such as options grids⁸ or brief decision aids⁹ are often involved.

Useful steps include sending test results and information about treatment options before consultations, as well as encouraging patients to think about questions to ask.

Using tools and techniques in multiple formats can enhance accessibility and appeal. *BUPA Health Coaching* offers patients paper or online decision aids, either of which can then be used as the basis for discussion in a telephone conversation. Evidence-based information, real-life examples and objectively presenting pros and cons are important elements of content. Visual aids help in describing risks – important for people with limited numeracy. But decision aids should not be too detailed. The *MAGIC* programme’s professionals and patients favoured quick and easy-to-use tools such as options grids or brief decision aids.

Decision aids can support changes in practice, but their use alone does not mean decisions are being made collaboratively. A change in mindset is imperative. Using decision aids without professional input limits patients in sharing decisions, risks miscommunication and misunderstanding, and ultimately may leave people feeling abandoned.

In self-management support, group-based education is by far the most common intervention, although the duration and intensity vary. This model of support can be better suited to people with certain conditions than others. Some of the programmes reviewed argued that more diverse approaches were needed to widen access. Peer support and harnessing the power of group effects are also popular. Lay facilitators were valued by group participants in the *Expert Patients Programme* and the *Co-Creating Health* self-management programme.

For more details and examples of tools, techniques and approaches used in self-management support and shared decision making, see the Health Foundation’s person-centred care resource centre: <http://personcentredcare.health.org.uk>

⁸ www.optiongrid.org

⁹ www.patient.co.uk/decision-aids

Supporting practice

Training professionals, using the voluntary sector and tailoring approaches each have an important role in embedding shared decision making and self-management support into routine practice.

Training professionals

Health care professional training is a recognised part of implementing shared decision making and self-management support. The research suggests a number of factors that can make the training more effective:

- Emphasise the importance of patient experience, improvements in care and building a shared agenda with the patient, not simply transferring responsibility. Cost savings or reduced consultation times should be secondary.
- Maximise peer-to-peer influence by using a colleague who can draw on their experience.
- Focus on practical content and use role play to practise skills and work through real-life examples. Involving patients as trainers can powerfully communicate the benefits of shared decision making and self-management support.

- Train whole teams rather than individuals, who may lack wider support to change routine care and find it difficult to test self-management support in their own practice. Target all staff, including receptionists.
- Embed skills development in basic training and education, working with local education and training boards.
- Counter misperceptions that current practice already fosters shared decision making and self-management support.
- Highlight unhelpful aspects of traditional models: for example, consulting room desks situated between the patient and the professional.

Working with volunteers and the community

The voluntary sector has an important role to play in embedding self-management support and shared decision making into mainstream services. The *Expert Patients Programme* popularised the notion of a volunteer workforce and promoted peer support through its use of lay facilitators. They found that the training became most quickly established in PCTs which were already

Whole-team training at Whittington Health (Co-Creating Health)

In the diabetes department at the Whittington Hospital, the whole of the team was trained from the start in self-management support. This meant that there was a common purpose and hence implementing service changes (such as introducing goal setting with patients prior to appointments) was more easily achieved. This whole-team training in self-management support also took place in the musculoskeletal pain service at the Whittington, which meant that all the clinicians were on board from the beginning.

'You can go to an Advanced Development Programme course and introduce new ways but if done in isolation you slowly drop them off as it is not common practice with the group you have gone back to, it is not being reinforced.' (Physiotherapist)

Having regular team meetings and keeping up communication within the team were seen as key aspects of reinforcing practice change, particularly in relation to sharing and learning from experiences and problem solving. A senior clinician from the respiratory medicine team at Whittington Health described how having all the clinicians trained had led to a 'cultural shift' in the multidisciplinary team.

'And I think a lot of our team work with long-term condition patients over a very long period of time with hugely challenging health and social issues – and I really do think it has changed the culture of our broader multidisciplinary team, I really do... I think it has facilitated a cultural shift among teams.' (Respiratory consultant)

running community focused initiatives and where there were direct contacts with local voluntary and community groups.

The capacity, skills, knowledge and experience of wider support services which voluntary sector organisations can provide was crucial to the success of some projects in the programmes reviewed. This was particularly the case for projects which had a broad goal of supporting people to live well with long-term conditions, rather than a narrower focus on self-managing health.

People Powered Health developed ‘social prescribing’ to integrate care and support planning processes in general practice with community-based services and sources of support. This helps GPs encourage people to take up activities alongside their medical

prescription, such as going to the gym or joining a reading group. Voluntary link workers from the local community were placed in general practices. They developed personal health plans with patients using motivational interviewing techniques and decision guides, as well as advising on local services that could contribute to their health.

Tailoring approaches

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. The programmes reviewed have tailored the interventions in a number of different ways.

Tailoring by condition

As part of the *National Cancer Survivorship Initiative*, University Hospital Southampton Foundation Trust includes self-management support in follow-up pathways for patients with testicular and colorectal cancer.

It identifies which care pathway is right for each patient, based on care needed for the disease, the treatment and the patient’s ability to manage as jointly assessed by the patient and a professional. For people with low risk of recurrence, follow-up care is supported self-management. Patients on other pathways are not excluded from involvement in their care, but continuing professional input is seen as important for more complex needs and ongoing disease or treatment effects.

Self-management support includes a four-hour workshop tailored to meet the patient group’s needs. It was designed to deliver tumour-specific information to detect disease recurrence, as well as promoting self-efficacy, goal-setting and healthy lifestyles.

Tailoring for different groups

One *Year of Care* GP practice used Bengali storytelling groups to introduce patients to their diabetes results letter. This helped individuals who often knew little about health and had limited English to understand their condition so they could take part in care planning. Storytelling prompted discussion and sharing. Other tailored interventions included simplification of the results letter and use of advocates to help non-English speakers. Cultural appropriateness was key to success: Bengali culture has a strong collective emphasis, and people were comfortable sharing and talking about their own results.

Tailoring by readiness and ability

Closing the Gap’s shared haemodialysis care project shows how people can participate according to their skills and confidence. The project supported patients to self-manage their dialysis, which may involve 14 processes such as taking blood pressure and inserting dialysis needles. Patients explored with nurses the involvement they wanted and felt able to take on, enabling them to compile a personalised model of self-management and the nurse to tailor support accordingly.

Implementing and managing change

Shared decision making and self-management support aim to improve the quality of care. It is therefore useful to look at them in the light of other approaches to quality improvement. Earlier research, looking at evaluations of the Health Foundation's improvement programmes, identified 10 persistent challenges to improving quality – and ways to overcome them.¹⁰

Ten challenges to improving quality

- Convincing people that there is a problem.
- Convincing people that the solution chosen is the right one.
- Getting data collection and monitoring systems right.
- Excess ambitions and 'projectness'.
- The organisational context, culture and capacities.
- Tribalism and lack of staff engagement.
- Leadership.
- Balancing carrots and sticks – harnessing commitment through incentives and potential sanctions.
- Securing sustainability.
- Considering the side effects of change.

The way change is introduced is crucial to how it is accepted, embraced and sustained. From the 11 programmes reviewed, the following features of effective change management were identified as key for successful implementation.

- **Building a shared vision** – the need for change and how the programme will achieve it has to be clearly articulated. A strong quality improvement narrative linked to patient experience and collaborative care, not just patient involvement or cost, is important.
- **Creating a strong infrastructure for implementation** – teams need project management and quality improvement skills and require an infrastructure that encourages relationship building, engagement and a sense of momentum

- **Fostering local innovation and ownership** – local ownership includes teams deciding which services and pathways to target, shaping the design of tools to implement change and selecting which outcomes to evaluate and how. Without these, motivation and the sustainability of change can be thrown into doubt.
- **Harnessing peer power** – vital for culture change, peer influence can champion new ways of working and enhance training. Informal mechanisms include harnessing 'healthy competition' between professionals: for example, by sharing information on outcomes.
- **Scaling up over time** – teams must decide for themselves when and how to implement changes, even if this means selective adoption of new approaches at first. Starting small in one clinical area and building on success may be most successful.
- **Introducing change by increments** – change takes time and sustained effort. Programmes need to identify and learn key lessons; maximising what has worked well, making changes and avoiding pitfalls.
- **Providing evidence of success at all stages** – evaluation provides evidence of success by documenting change, which can motivate people to spread innovation and can also be used to make a business case for sustaining changes. It is better to robustly measure fewer outcomes than risk poor measurement because of onerous data collection.¹¹
- **Giving sustainability attention from the start** – to sustain changes beyond a programme's lifetime, the structures, processes and systems that underpin change demand attention from the start. Early engagement with commissioners and a supportive IT infrastructure are particularly important – among the programmes reviewed, IT systems was the most commonly cited barrier to embedding shared decision making and self-management support.

¹⁰ Dixon-Woods M, McNicol S, Martin G. *Overcoming challenges to improving quality*. London: The Health Foundation, 2012. www.health.org.uk/overcoming-challenges

¹¹ Details of the most commonly researched measurement tools and techniques can be found in the report *Helping measure person-centred care*. www.health.org.uk/helpingmeasurepcc

Key lessons from the programmes

The research team identified a number of key lessons about what helps embed self-management support and shared decision making into mainstream care. These are summarised in the following diagram.



5

Conclusion

Many people want to play a more active role in their health care. Growing evidence suggests that approaches aimed at enabling and supporting people to take a more active role in their health and care can improve patient experience, care quality and outcomes.

Much effort to promote person-centred care is focused on shared decision making and self-management, although these have developed as separate concepts and practices.

Neither can succeed unless power is distributed more equally in the professional-patient relationship and collaborative approaches become mainstream.

Collaborative care and support relies on engaged and empowered patients, professionals with the skills and attitudes to work in partnership and organisational systems that embed new ways of working into routine care. Tools such as decision aids and training programmes can help collaborative care and support, but will not substitute for it.

Rising demand for health care and a challenging financial climate have made system transformation imperative. Person-centred care has never been higher up the policy agenda or more strongly linked to system reform. Yet concerns persist about the goal of passing more responsibility to patients being promoted as a cost-saving measure.

All parts of the health care system have a role to play in bringing about more person-centred care. Like all complex changes in health care, embedding shared decision making and self-management support into mainstream services will take time. However, much has already been learned about successful implementation and how barriers can be overcome. Implementing the approaches summarised in this report will help make person-centred care a day-to-day reality for health services and the people that use them.

For more information, see *In Brief: Person-centred care: from ideas to action:* www.health.org.uk/pccideasaction

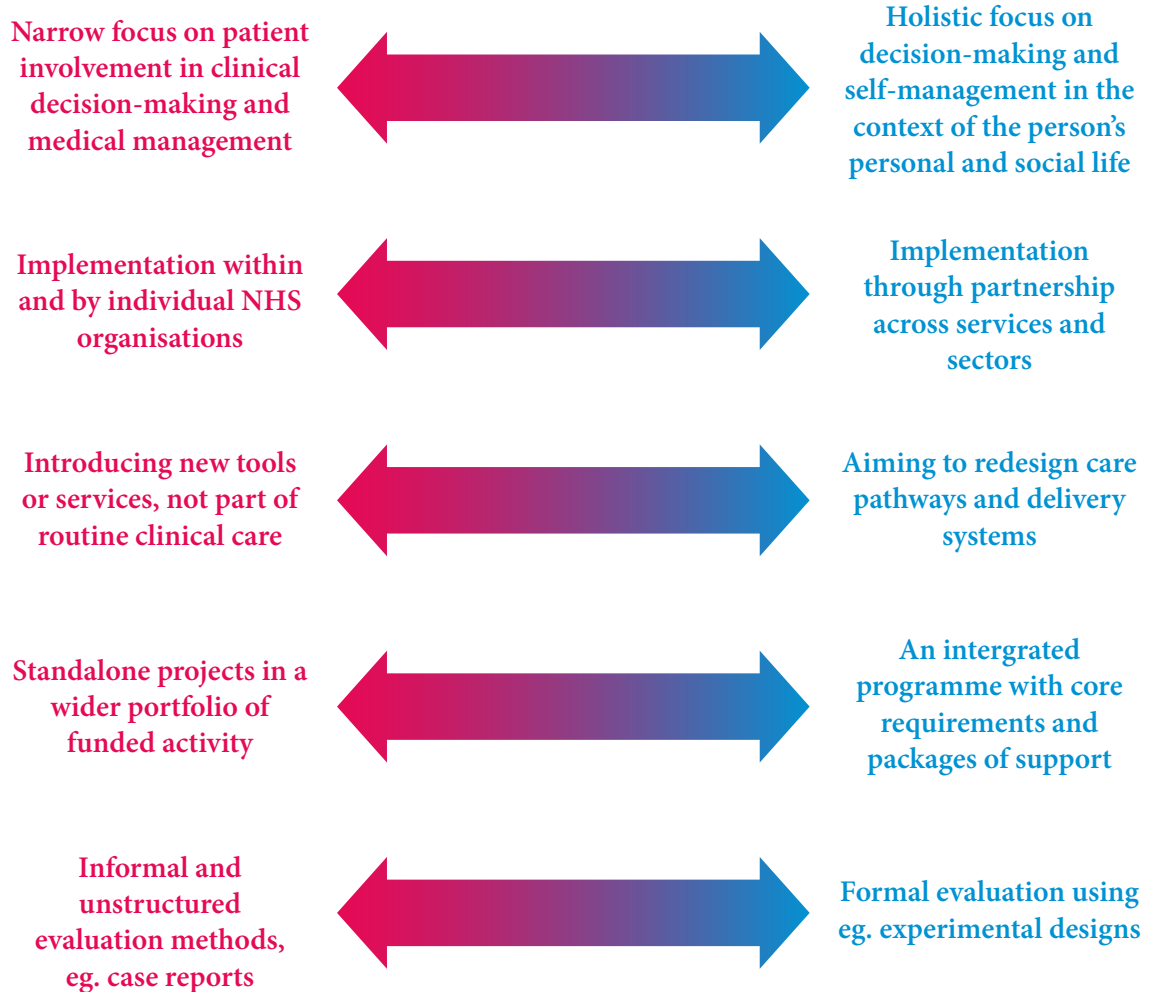
Appendix:

Programmes reviewed

As part of their work, the research team examined projects on shared decision making and self-management support within 11 large-scale improvement programmes (see overleaf). The projects and programmes were diverse in their scope and focus, goals, approaches, settings, the nature and level of their support and methods of assessing impact.

The figure below illustrates the variation between the programmes. It shows that the 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.

Key dimensions of variation across the programmes reviewed



Programmes and projects reviewed

BUPA Health Coaching (BUPA)

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

BUPA introduced health coaching in 2011 to support patients making ‘preference sensitive’ decisions. Nurses provide coaching via telephone using decision aids. The evidence reviewed was from the US as a UK evaluation was not complete.

Closing the Gap (Health Foundation)

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

Closing the Gap through Changing Relationships aimed to transform the dynamic between people using health services and those providing them. *Closing the Gap through Clinical Communities* comprised clinician-led quality improvement programmes in primary, secondary and mental health care.

Co-creating Health (Health Foundation)

www.health.org.uk/cch

A two-phase programme to embed self-management support into mainstream services. It comprised three workstreams: patient self-management support, clinician training and a service improvement programme.

Expert Patients Programme (EPP CIC)

www.nhs.uk/nhsengland/aboutnhsservices/doctors/pages/expert-patients-programme.aspx

A self-management programme for people with long-term conditions, available across England and Wales. Based on a US programme, it comprises six weekly sessions delivered by volunteer trainers with experience of a long-term condition.

Kidney Care Patient Decision Aid (NHS Kidney Care) [website not available as NHS Kidney Care is no longer in existence]

This aimed to embed use of the end-stage renal failure patient decision aid into routine clinical practice; 21 UK renal practices received funding and project management support to redesign services.

MAGIC (Making Good Decisions in Collaboration): Shared Decision Making (Health Foundation)

www.health.org.uk/magic

This programme ran in Newcastle upon Tyne Foundation Trust and Cardiff and Vale University Health Board until late 2013 to test how to embed shared decision making approaches in different clinical settings.

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

www.ncsi.org.uk

Launched in 2007, this programme is exploring new models for delivering cancer care. One workstream is developing and testing interventions to support self-management and examining how to embed them into patient pathways.

People Powered Health (Nesta)

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

Across six sites, this programme supported partnerships between people and their families, health professionals and voluntary and community groups to improve outcomes for those with long-term conditions. Initiatives tested included social prescribing, time banking, group consultations and personalised care planning.

**Right Care Shared Decision Making
(Department of Health)**

www.rightcare.nhs.uk

Funded through the Department of Health Quality, Innovation, Productivity and Prevention (QIPP) programme, workstreams focused on developing evidence-based decision support tools, embedding shared decision making in NHS systems and processes, and creating a receptive culture for shared decision making. It provided training to health care professionals, managers and commissioners.

Shine (Health Foundation)

[www.health.org.uk/areas-of-work/
programmes/shine-2014](http://www.health.org.uk/areas-of-work/programmes/shine-2014)

This ongoing programme gives projects up to £75,000 of funding and service improvement support to achieve one of three goals: supporting people to take a more active role in their health care; improving care safety; and improving quality while reducing costs. Only projects focusing on the first were reviewed.

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

www.yearofcare.co.uk

This three-year programme sought to embed collaborative care planning in primary care and ran in NHS Tower Hamlets, NHS North of Tyne and NHS Calderdale and Kirklees. It tested micro-to-macro commissioning, whereby individual patient needs and goals – identified during care planning – drove commissioning of local services at population level.

The Health Foundation is an independent charity working to improve the quality of health care in the UK.

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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