The Health Foundation
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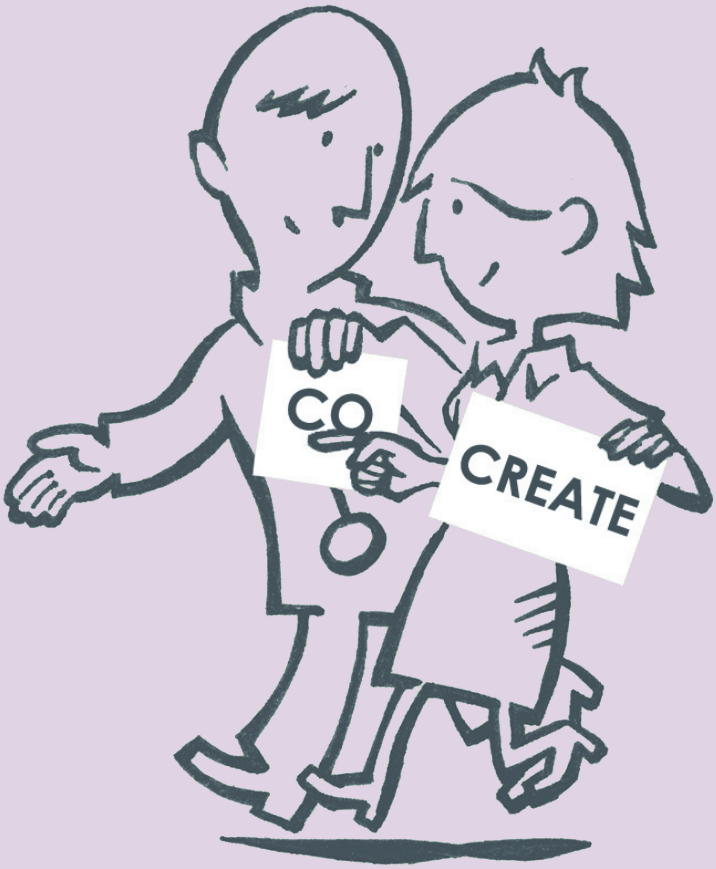
Sustaining and spreading self-management support

Lessons from Co-creating Health phase 2



Evaluation
September 2013

Firefly
Illuminating Research

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Sustaining and spreading self-management support: lessons from Co-creating Health phase 2
is published by the Health Foundation,
90 Long Acre, London WC2E 9RA

Health Foundation commentary

Have you ever tried changing a habit? It's hard. Knowing what you need to change, having the skills and motivation to make the change, the confidence that you can do it and the time all help. Changing the way healthcare is delivered so that patients are supported to more effectively manage their long-term condition is also hard – it involves redefining the role of professionals and patients and putting in place processes and infrastructure that support new ways of working. This is what those who took part in the Health Foundation's Co-creating Health improvement programme sought to do. Why?

Half of GP appointments, and £7 in every £10 spent on health and social care, is spent treating and caring for people living with long-term conditions:[1] people whose lives are suddenly disrupted by a diagnosis whose implications stay with them for the rest of their lives; people who now have to change their habits not out of choice but out of necessity. For these people, the purpose of healthcare is no longer simply to treat and care, it is to support them to manage their own health and healthcare.

There is a large and growing body of evidence that, done properly, a system that supports people with long-term conditions to manage their own health has benefits for the person, their health and for health services.[2]

Creating such a health service requires shifting the habits of healthcare from focusing on managing disease to helping patients stay as healthy as possible. It requires a new understanding of the role of the patient; it demands a new understanding of the role of the clinician; and it needs health systems that have the infrastructure and processes to encourage and facilitate self-management by patients and self-management support by clinicians.

The Health Foundation's Co-creating Health programme offers a tried and tested model to help deliver and sustain these changes. Launched in 2007, the Foundation invested £5m over five years in testing and developing the model to take self-management support from rhetoric to reality.

Co-creating Health is grounded in:

- the Chronic Care Model,[3] which has at its heart a shift from a reactive to a proactive health system
- self-management support,[4] which involves collaborative care and building patients' self-efficacy
- co-production, which emphasises the importance of collaboration between service providers and users in the planning, design, delivery and audit of a public service.[5]

1 https://www.gov.uk/government/policies/improving-quality-of-life-for-people-with-long-term-conditions; http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Healthcare/Longtermconditions/tenthingsyouneedtoknow/index.htm

2 Da Silva D. *Helping People Help Themselves*. The Health Foundation, 2011. www.health.org.uk/publications/evidence-helping-people-help-themselves

3 www.improvingchroniccare.org/?p=The_Chronic_Care_Model&s=2

4 Bodenheimer T, et al. *Helping Patients Manage Their Chronic Conditions*. California Health Care Foundation, 2005. www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/H/PDF%20HelpingPatientsManageTheirChronicConditions.pdf. See also www.health.org.uk/public/cms/75/76/313/551/Co-creating%20health%20briefing%20paper.pdf?realName=vK5jXO.pdf, p.2

5 www.neweconomics.org/publications/entry/co-production

The Co-creating Health model incorporates self-management training for people with long-term conditions, training in self-management support skills for clinicians, and a service improvement programme to put systems and processes in place to support patients and clinicians in their self-management activities. It builds collaboration between clinicians and patients, who deliver training together. At its heart is the combination therapy of shared agenda setting, collaborative goal setting and clinical follow up. As in combination therapy, where a single drug is not sufficient, so here all three interventions need to be delivered in a co-ordinated way.

The evaluation of the first phase of Co-creating Health, published in 2012, demonstrated the programme's positive impacts on patients' confidence, knowledge, self-management skills, condition-specific outcomes and quality of life.[6] This evaluation of the second phase of Co-creating Health seeks to answer the question: what works to embed the Co-creating Health model and to secure its wider uptake within routine healthcare care?

This report's findings are profoundly important to the providers, commissioners and policy makers who are striving to put in place the mechanisms that will transform our health system. Primary amongst the evaluation's conclusions is that there needs to be a strategic, whole-system approach to implementation. This is not about bolting on; it is about fundamentally reframing clinicians' and patients' roles and health service activities.

The report highlights some common features that all those wanting to change their health services – whether because of financial drivers, scarcity of resources or a moral imperative – can learn from.

Through analysis and narrative, the evaluation highlights:

- the benefits of training teams rather than individuals
- the importance of support from senior leadership within the clinical community
- the added value of integrating with concurrent initiatives
- the value of providing support for both patients and clinicians after their initial self-management training as they seek to embed new habits.

The Co-creating Health model can have a profound and positive effect on patients, clinicians and health services. As the evaluation of the second phase of Co-creating Health shows, the journey to change the habits of a reactive, disease-centred healthcare service to a proactive and person-centred health support service was not always an easy one. However, Co-creating Health offers a theoretically robust, well evaluated model with tried and tested training, techniques and tools. And, as the participating sites' work shows, with motivation, knowledge, skill, confidence and effort it is possible to deliver, sustain and spread self-management support – and its rewards can be immensely rich.

The Health Foundation is continuing to work with four of the original Co-creating Health sites as they embed and spread self-management support, and we will carry on sharing the lessons learned. You can sign up to receive updates about our work on person-centred care on our website at www.health.org.uk/updates

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6 Wallace L, et al. Co-creating Health: Evaluation of first phase. The Health Foundation, 2012. www.health.org.uk/publications/co-creating-health-evaluation-phase-1

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Sustaining and spreading self-management support – Lessons from Co-creating Health phase 2

September 2013

Acknowledgements

As with Co-creating Health itself, this evaluation has been a collaborative effort. We would like to thank the project teams in the Co-creating Health sites, in particular the project managers and evaluation leads who kindly helped organise the fieldwork in their areas. We are also indebted to all the lay tutors, patient volunteers and clinicians who contributed to the evaluation.

We are grateful to colleagues in the PriceWaterhouseCoopers/PEAKS team for their advice and practical support, and last but not least to the team at the Health Foundation who worked with us to shape and steer the evaluation.

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Contents

Abbreviations

APR	Assistant Practitioner (Rehabilitation)
CCG	Clinical Commissioning Group
CPD	Continuing Professional Development
COPD	Chronic obstructive pulmonary disease
CQUIN	Commissioning for Quality and Innovation payment framework
DAFNE	Dose Adjustment For Normal Eating
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly-Diagnosed
EPR	Enhanced Pulmonary Rehabilitation course
HIEC	Health Innovations Education Cluster
ICP	Integrated Care Pathway
LES	Local Enhanced Service
NICE	National Institute for Health and Care Excellence
PCT	Primary care trust
PDSA	Plan Do Study Act
PROM	Patient Reported Outcome Measure
QIPP	Quality, Innovation, Productivity, Prevention
QOF	Quality and Outcomes Framework
SCIE	Social Care Institute for Excellence
SHA	Strategic Health Authority

Executive summary

There is evidence that supporting people to self-manage can improve their motivation to look after their health and change the way they use health services. However, although work has been done on interventions centred on the patient, far less work has been done on the way in which clinicians' skills and attitudes can be changed to enable them to support patients in their efforts to self-manage, and there has been little research on how service delivery can be changed to support both patients and clinicians in their self-management activities.

The Health Foundation's Co-creating Health programme was designed to bring together these elements of self-management support and explore what practical steps need to be taken to put them in place in local health economies.

The Co-creating Health programme involved the piloting of an approach to implementing self-management support that comprised:

- self-management training for people with long-term conditions
- training in self-management support skills for clinicians
- a service improvement programme to put systems and processes in place to support patients and clinicians in their self-management activities.

There have been two phases to the Co-creating Health programme. The first phase was implemented over three years and ended in August 2010. It involved eight sites working in pairs on long-term conditions: chronic obstructive pulmonary disease, Type 2 diabetes, depression and musculoskeletal pain.

In January 2011, the second phase began, whereby seven of the sites went on to work on achieving local sustainability of the Co-creating Health approach to implementing self-management support and secure its spread within the original long-term condition and to a wider population within the local health economy.

The evaluation of phase 2 concentrated on how the Co-creating Health model has been spread and sustained.

Sustaining the Co-creating Health model – findings from the Co-creating Health sites

The findings of the evaluation of phase 2 of Co-creating Health show that three broad mechanisms were important in sustaining the Co-creating Health model of self-management support:

1. Co-production

The Co-creating Health model is very much rooted in the principles of co-production. Both the patient and the clinician training course were designed to be co-delivered by a clinical and a lay tutor who was living with a long-term condition.

The evaluation identified a wide range of patient involvement activity, which went well beyond the co-delivery of training, including marketing and promoting Co-creating Health; providing administrative support to the Co-creating Health team; facilitating the involvement of other patients; and supporting wider training activities.

All of the Co-creating Health sites had some kind of mechanism(s) in place to enable patients to shape the development of self-management support, although they varied in terms of how robust these arrangements were.

The co-production element also encompasses peer support, which had developed across the Co-creating Health sites in a number of different ways, including peer support groups and buddy systems that were supported in some way by project staff, as well as more informal activities that patients themselves took more responsibility for, such as walking groups and social groups. Additionally, all Co-creating Health sites have held 'reunions', which in most sites had 'morphed'

into a form of on-going peer support, which is open to anyone coming off a self-management support course.

2. Changing practice amongst clinicians

For self-management support to be sustained, it has to be effectively embedded into routine healthcare, and so there is an implicit requirement for clinicians to alter their practice to support patients effectively in managing their condition.

One of the strongest messages to emerge was the importance of training whole teams, or groups of clinicians from the same service, in order to generate and maintain momentum. A whole-team approach promoted the development of a common language and a common understanding of key self-management support tools, techniques and concepts, which in turn helped to create an environment or culture within teams that was positive about self-management support.

The role of senior or influential clinicians in setting an example by attending self-management support training, changing their practice, supporting new systems and supporting junior staff in the use of their self-management support skills, was very important. At team or service level it influenced other clinicians to do the training and develop or maintain self-management support in their own practice. At an organisation level, senior clinicians played a key role in integrating self-management support into the priorities and strategies of the organisation. Where influential clinicians did not engage, however, this could have a very negative effect, especially on junior staff.

Providing support to clinicians after they have completed their self-management support training is essential if they are to embed self-management support in their practice and sustain it beyond the initial enthusiasm engendered by the training. A range of approaches is needed in order to accommodate different learning styles, the time people have available, the geography of health communities and resources available. In phase 2, these included Action Learning Sets; refresher courses; buddying; one to one support; e-learning; clinical supervision; and supportive systems and processes.

Previous experience of using or learning about skills similar to those developed on the self-management support course made clinicians more receptive to self-management support. Most sites had taken steps to encourage the incorporation of self-management support skills training into medical and healthcare education in their localities, including working with medical schools, Deaneries for GP training schemes and local universities to build it into existing courses and programmes.

3. The patient journey

In their phase 2 plans, all the sites stated that they wished look more strategically at the whole patient journey, and build self-management into care pathways and service improvements in a more robust fashion.

Sites had worked to embed self-management support using tools, templates and IT systems in a variety of ways. This ‘hard-wiring’ helped to reinforce learning amongst clinicians and patients, encourage consistency, and enable monitoring/sharing of information. Examples included patient communication and information tools; promoting a multidisciplinary approach through sharing goal setting information; using IT to promote the self-management skills training; and workforce development.

Some sites had been able to take advantage of local or national initiatives to both raise awareness of Co-creating Health and roll out training, and as a lever for making service improvements or more firmly embedding self-management support into care pathways.

Securing the wider take-up of Co-creating Health

If the Co-creating Health model of self-management support is to be spread (and sustained), both within the existing sites and to other health economies, clinicians and service managers

advocating Co-creating Health will need to be able to 'make the case' within their own organisations, and service providers will have to gain the support of their local commissioners. Whilst the seven Co-creating Health pilot projects were operating in different organisational contexts, they all achieved some 'spread' and a number of common themes emerged in relation to securing the wider take-up of self-management support.

Four of the sites were able to provide some evidence that the Co-creating Health model has the potential to deliver 'value for money'. Showing how the Co-creating Health approach can improve patient experience was also important; and taking steps to influence commissioners through the development of 'business cases', building Co-creating Health into 'bundles' of care and presenting evidence.

To make best use of resources and to work effectively in primary and secondary care, sites began to use both generic and tailored approaches to implementing self-management support; they made connections with existing policies, initiatives and strategies in order to establish wider organisational support and, through this, secured time and resources; enabling input from different stakeholders also helped to promote spread, as did building relationships with external agencies.

Key messages for others looking to adopt the Co-creating Health approach

When the Health Foundation launched Co-creating Health in 2007, the programme represented an important attempt to develop a new and more integrated model of self-management support. The phase 2 evaluation has revealed much about how to sustain and spread the Co-creating Health model of self-management support. In particular, there are three key messages for other health economies looking to adopt the Co-creating Health approach:

Embrace Co-creating Health as a 'whole system' change

Co-creating Health is not a simple 'off the shelf' approach to self-management support – its three interrelated elements are all important and all have to be functioning if Co-creating Health is to have impact. The approach also requires more effort both to understand its integrated approach and to embrace its co-production ethos. Any health economy thinking about adopting the Co-creating Health approach needs to see it as a whole-system change and should take a whole health economy approach, working across secondary, community and primary care services (and the third sector and local authority where appropriate); and across all long-term conditions.

It is also imperative to make the case for the Co-creating Health approach by clearly setting out the benefits of self-management for patients, clinicians and services, and the potential value for money gains for the health economy.

All partners and key stakeholders need to have a common understanding of co-production, and from the outset, co-production should be built into the design and delivery of all self-management support activities

Take a strategic approach to implementation

For a new health economy implementing self-management support, a strategic approach is essential to both make the best use of resources, and to quickly achieve some momentum. In particular, they should build self-management support into local strategies; take opportunities to 'piggy-back' on existing long-term condition initiatives; and use national policies and national quality frameworks as 'levers' for change.

They should also identify ways to support or reinforce self-management support through existing systems and structures, and actively encourage the 'two-way traffic' of ideas.

Part of this is also identifying influential clinicians from across the health economy who can promote self-management support and, from an early stage, developing a network of clinical leaders across all the main specialties working with people with long-term conditions and across primary care

Adopt a targeted but flexible approach to delivery

A flexible approach to the training elements of Co-creating Health is needed, but the wider delivery of self-management support does require a targeted approach in order to achieve the most impact. In particular, it is important to identify the long-term conditions to focus on first, and then look across the whole patient journey to identify the 'hot spots' where self-management support activities are likely to have the most impact.

Targeting self-management support for clinicians on whole teams, or groups of clinicians working in the same services, can help establish a 'critical mass' of trained clinicians in a short timeframe, and make an explicit link between clinician training and service improvement work.

It is important to be flexible and use both generic and condition-specific approaches, according to the needs of different patient groups, the healthcare environment and the geography and demography of the health economy – one size does not fit all.

Lastly, it is important to recognise that the Co-creating Health approach to self-management support is not a 'magic bullet'. It will not be appropriate for some patients and it will not be embraced by all clinicians. Furthermore, it does require some resources both for staff to coordinate the initiative, and to release clinicians for training and other activities.

In return, the Co-creating Health model of self-management support has the potential to fundamentally alter how individual clinicians and healthcare services support people with long-term conditions to manage their own health.

Chapter 1
Introduction

Over the past decade, UK health policy has increasingly highlighted the challenge of supporting and treating the growing number of people living with a long-term health condition. In 2004, the Department of Health estimated that there were around 17.5 million adults living with one or more long-term condition[1]. This has major implications for health services (eg over three quarters of GP consultations and two thirds of emergency admissions relate to long-term conditions). However, it has far greater implications for the people living with long-term illness and their families because most of the care for people with long-term conditions is carried out by the person themselves or family carers.

The Health Foundation's *Helping People Help Themselves* evidence review[2] showed there is evidence that supporting people to self-manage can improve their motivation to look after their health and change how they use health services. However, it also highlighted the fact that: *"Interventions to encourage and support self-management vary considerably in their aims, approaches, content delivery, duration and target group".* Furthermore, much of the self-management research evidence focuses on interventions (ranging from information giving, skills training and decision support, to behaviour change approaches) which are centred on the person with the long-term condition. Far less work has been done (particularly in the UK) on the ways in which clinicians' skills and attitudes can be changed to enable them to support patients in their efforts to self-manage, and very little research has looked at how service delivery can be changed to support both patients and clinicians in their self-management support activities.

The Co-creating Health programme was designed to bring together these elements of self-management support and explore what practical steps would be needed to put them in place in local health economies.

1.1 Self-management support and co-production

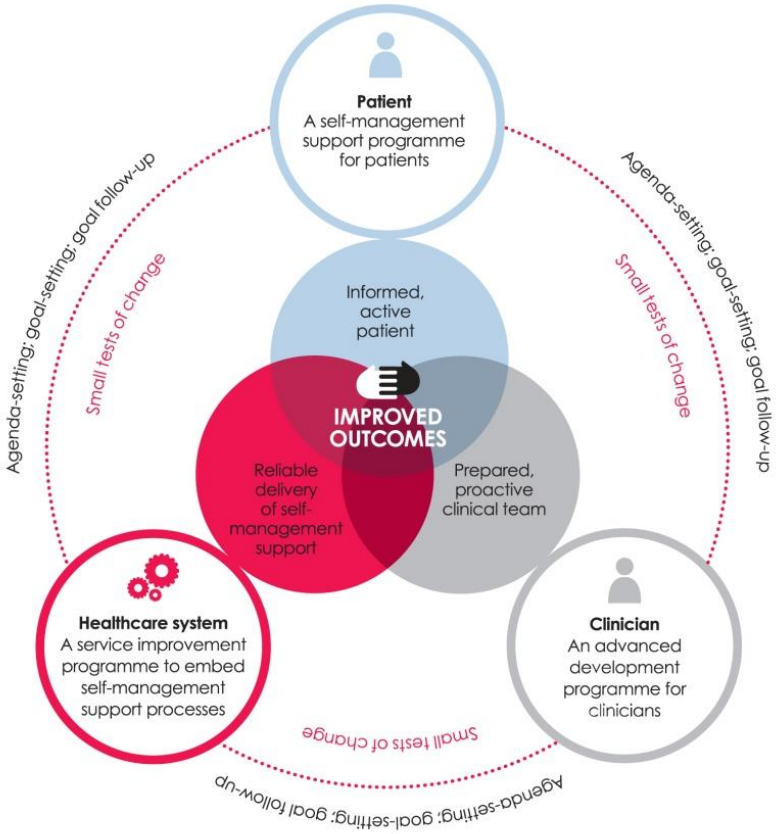
The Co-creating Health model brings together two philosophies – self-management support and co-production. The model piloted an approach to implementing self-management support that comprised three elements:

- self-management training for people with long-term conditions
- training in self-management support skills for clinicians
- a service improvement programme to put systems and processes in place to support patients and clinicians in their self-management activities.

Within each of these elements there was a focus on what are described in Co-creating Health as *'the three enablers'* – agenda setting, goal setting and goal follow up. Figure 1 illustrates how these elements work together.

[1] Department of Health (2004) *Improving chronic disease management* Department of Health, London
[2] Health Foundation (2011) *Helping people help themselves* Health Foundation, London

Figure 1: The Co-creating Health model



The approach to self-management support used in Co-creating Health is based on a definition developed in 2005 by Tom Bodenheimer, Professor of Primary Care at the University of California, San Francisco[3]:

> *"Self-management support is the assistance that caregivers give to people with long-term conditions in order to encourage daily decisions that improve health-related behaviours and clinical outcomes. It can be viewed in two ways:*
>
> - *A portfolio of tools and techniques that help patients choose health behaviours*
> - *A fundamental transformation of the patient-caregiver relationship into a collaborative partnership".*

This definition highlights the importance of both what the patient does for themselves and the role of (professional) caregivers in supporting their efforts. This is reflected in the overall aim of Co-creating Health, ie to support people to take a more active role in managing their health. The programme tried to achieve this aim by building patients' confidence, knowledge and skills to self-manage but also by changing clinical practice and service delivery to support people's self-management efforts.

The Co-creating Health model is also very much rooted in the principles of co-production. Both the patient and clinician training courses were designed to be co-delivered by a clinical tutor and a lay

[3] Bodenheimer T, McGregor K and Sharifi C (2005) *Helping patients manage their chronic conditions* California Healthcare Foundation, Oakland, USA

tutor who was living with a long-term health condition, and the three enablers in effect provided a 'framework' for patients and clinicians to jointly plan their care. Furthermore, as the programme evolved, service user involvement in other activities (eg peer support, redesign of training courses, service reviews) also increased and was seen by some clinicians, managers and patients as one of the most important facets of the programme.

In the research and policy literature, user involvement is now increasingly talked about in terms of 'co-production'. It can be defined in a number of ways, but in a paper for Nesta, Boyle and Harris[4] offer the following definition:

> *"Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change"* (p.11).

However, they also highlight the 'elasticity' of the definition and conceptualisation of co-production, referencing the Social Care Institute for Excellence's (SCIE) co-production research briefing[5]. This briefing outlines how co-production can be understood on a spectrum – in a purely 'descriptive' fashion, where service users are by necessity co-producers of services through, for example, complying with and acting on clinical advice/prescriptions, to a more transformational approach, requiring a transfer of power and control where service users are active partners in planning, delivery, management and governance:

> *"[Co-production] goes well beyond the idea of 'citizen engagement' or 'service user involvement' to foster the principle of equal partnership. It offers to transform the dynamic between the public and public service workers, putting an end to 'them' and 'us'"* (p.12).[6]

Bovaird[7] also provides a framework for understanding service user participation in relation to co-production and in chapter 3 we have used this framework to examine the different ways in which patients have been involved in the design, delivery and development of Co-creating Health.

1.2 Co-creating Health – Phases 1 and 2

There have been two phases to the Co-creating Health programme. The first phase was implemented over three years and ended in August 2010. It involved eight sites working in pairs on four long-term conditions – chronic obstructive pulmonary disease (COPD), Type 2 diabetes, depression and musculoskeletal pain. Each site received funding to support and implement three training and information programmes (which were commissioned centrally by the Health Foundation):

- A Self-Management Programme – to support people with long-term conditions to develop the confidence, knowledge and skills they need to manage their condition while working in partnership with their clinicians.
- An Advanced Development Programme – to support clinicians to develop the skills required to support and motivate people to take an active role in their own health (during phase 2 the programme was renamed the Practitioner Development Programme).

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[4] Boyle, D and Harris, M (2009) *The challenge of co-production* Nesta, London

[5] Needham, C and Carr, S (2007) SCIE research briefing 31. Co-production: an emerging evidence base for adult social care transformation Social Care Institute for Excellence, London

[6] Boyle and Harris (2009) Op cit

[7] Bovaird, T (2007) Beyond engagement and participation: user and community co-production of public services *Public Administration Review* 67(5),846–860

- A Service Improvement Programme – to support the Co-creating Health sites to change and improve the way their health services are designed and operated so that they better support self-management.

Each of these training and information programmes focused on the Co-creating Health 'three enablers': agenda setting, goal setting and goal follow up.

The aim of this first phase of the programme was to *"demonstrate that it is feasible and practical to embed self-management support in routine health services"*, and through doing this achieve measurable improvements in the quality of life of patients with long-term conditions and improve their experience of the healthcare system.

In January 2011, the second phase of Co-creating Health began. Seven of the original Co-creating Health sites went forward to phase 2 (more information about the sites is given in chapter 2). These were:

- Calderdale and Huddersfield NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Guy's and St Thomas' NHS Foundation Trust
- NHS Ayrshire and Arran
- South West London and St George's Mental Health NHS Trust
- Torbay Care Trust and Devon Partnership Trust
- Whittington Health

In phase 2, the sites continued to focus their work around their phase 1 health condition, but also developed plans to spread the Co-creating Health model to at least one other condition and/or new staff or patient groups. Further details of the sites' plans and progress in phase 2 are given in section 2.2. They continued to use the three training and information programmes. However, they were free to develop and commission the Self-Management Programme and Advanced Development Programme (later renamed the Practitioner Development Programme) locally and most sites did so. The Service Improvement Programme was led centrally by PriceWaterhouseCoopers (PwC)/PEAKS. They supported the sites in their service improvement work, in particular focusing on changing structures, processes and behaviours to improve the take up of the 'three enablers' (ie agenda setting, goal setting and goal follow up). To do this they used a collaborative learning model and worked closely with new service improvement technical leads, identified in each site. Phase 2 of Co-creating Health had two primary aims:

- to achieve local sustainability of the Co-creating Health model through the commitment and ownership of local commissioners and providers
- to secure the spread of the Co-creating Health model within the original long-term condition and to a wider population within the local health economy.

There were three supplementary aims which focused on the Health Foundation's wish to promote the spread of the Co-creating Health approach. These were:

- to create a cadre of clinical and non-clinical leaders who would effectively champion the Co-creating Health model across the local health economy and nationally
- to showcase the Co-creating Health model to decision makers at national, system and professional levels
- to create the materials and information of a replicable whole system change programme that others can use.

Responsibility for implementing Co-creating Health 2 in the sites lay with the Local Co-creating Health Implementation Committee, but the day-to-day work was undertaken by a project manager, a clinical lead and other project staff. Implementation arrangements are discussed further in chapter 2.

1.3 Evaluation of Co-creating Health

The Health Foundation has commissioned independent evaluations of both phases of Co-creating Health. The evaluation of phase 1 of Co-creating Health was conducted by a team from the Applied Research Centre in Health and Lifestyle Interventions at Coventry University. It was designed to:

- assess the outcomes of the initiative – the benefits to patients, healthcare professionals, organisations and the healthcare system
- describe how the initiative is delivered and experienced, in order to generate the information needed to make it replicable
- explain how the outcomes were achieved – the critical success factors and barriers.

The phase 1 evaluation was large, complex and quasi-experimental in approach. It used a range of qualitative and quantitative research methods, including staff and patient surveys, interviews, observation of clinical interactions, the patient and clinician development programme and learning events, and analysis of routinely collected clinical and health service utilisation data. The final report from the evaluation is available on the Health Foundation website[8].

In contrast to the outcomes focus of the phase 1 evaluation, the evaluation of phase 2 (Co-creating Health 2) has looked at how the Co-creating Health model has been spread and sustained. The specification for the evaluation identified two main purposes:

- to support sites to carry out their local evaluations (local level evaluation)
- to identify successful approaches to make the Co-creating Health model self-sustaining and to securing the wider uptake of the Co-creating Health approach within the sites (programme level evaluation).

Specifically, the programme evaluation sought to answer the over-arching question:

> *"What works to embed the Co-creating Health model ie to make it self-sustaining, and to secure its wider uptake within routine healthcare care for people with long-term health conditions?"*

1.4 Approach to the phase 2 evaluation

The evaluation began in May 2011 with a three month 'scoping phase'. During this phase, the evaluation team held discussions with key people from the Health Foundation and meetings and telephone discussions with project managers, clinical leads and others from the Co-creating Health site teams. Colleagues from PEAKS and PwC (Technical Provider and Programme Management Office) and from the phase 1 evaluation team at Coventry University also kindly gave up their time to share their thinking and learning from their involvement with the programme so far. In addition, the team examined documents from the sites, and used a number of policy and research papers to inform their thinking. During the scoping phase the evaluation also involved working with the project teams to support the development of their local evaluation plans and

[8] Wallace, L et al (2012) *Co-creating Health: evaluation of first phase* Health Foundation, London. See www.health.org.uk/publications/co-creating-health-evaluation-phase-1/

identify opportunities for the local evaluations and the programme evaluation to complement each other.

At the end of the scoping phase, an evaluation protocol was produced. It built on the original specification for the evaluation, but also took into account the ideas and issues emerging from the scoping work and the local evaluation plans. The protocol was designed to provide a 'route map' for the evaluation of Co-creating Health 2, which would give all those involved, at local and programme level, a common understanding of the focus and structure of the evaluation.

1.4.1 **The local evaluations**

The scoping work (described above) suggested that in phase 1 the sites' approaches to the implementation of the programme were quite 'diffuse'. Project teams worked hard to recruit clinicians to the Advanced Development Programme and patients to the Self-Management Programme, and made progress in implementing the Service Improvement Programme enablers, but these three core element of the Co-creating Health model were not consistently in place (or sufficiently interlinked) in teams, practices and services. For this reason, whilst the phase 1 evaluation was very much focused on outcomes, the results emerging from the evaluation highlight outcomes for clinicians and patients separately, rather than assessing the overall impact of Co-creating Health on services. As a result, the sites did not feel that they had the 'evidence' they needed to convince commissioners and decision-makers that they should invest in the Co-creating Health model of self-management support. All the sites therefore decided to use their local evaluations to assess in some way the impact of Co-creating Health on service use, costs and/or patient experience/outcomes in their local health economies, and from this try to bring together the 'evidence' they needed.

Part of the evaluation team's role was to support the project teams in planning and undertaking their local evaluations. However, project teams were also given funding to support their local evaluation work (£20,000 per site). Four project teams used this funding for 'in-house' evaluation activities and three commissioned external evaluations from local universities (Guy's and St Thomas' NHS Foundation Trust and Whittington Health commissioned a joint evaluation).

All the project teams produced local evaluation reports at the end of the programme. The main purpose of these reports was for the project teams to bring together their findings both for local use and for the Health Foundation. However, the evaluation team have also drawn on material from the local reports, particularly in relation to data on activity, costs and benefits.

1.4.2 **The programme evaluation**

The programme evaluation was structured around five common themes:

Theme 1: Embedding self-management support into care pathways and service delivery
Explored how sites had tried to 'build' self-management support into care pathways or new patterns of service delivery. It looked at the barriers encountered as well as the factors which had facilitated change in an environment where resources are increasingly constrained.

Theme 2: Changing culture and practice amongst clinicians
Examined the strategies the sites used to change culture and practice amongst clinicians in relation to self-management support, including the challenge of sustaining the changes achieved by clinicians who have undertaken the Practitioner Development Programme, and encouraging the take-up of training by new groups of clinicians.

Theme 3: Harnessing patient knowledge and experience
Looked at what was initially seen as a by-product from Co-creating Health: the way organisations have harnessed and used the knowledge, confidence and experience gained by patients through Co-creating Health in order both to sustain self-management support and, more widely, to influence the shape of health services.

Theme 4: Encouraging the take-up of self-management support

Explored the approaches sites used to encourage the spread and take-up of the Co-creating Health model in other localities, patient groups or conditions, in particular the factors which had facilitated or hindered spread and take-up.

Theme 5: Building the business case for Co-creating Health

Sought to understand how sites had tried to demonstrate the impact of the Co-creating Health model of self-management support on the effectiveness of services and/or wider service use and costs, and the approaches they have used to engage commissioners in plans to shift Co-creating Health from a project to the mainstream.

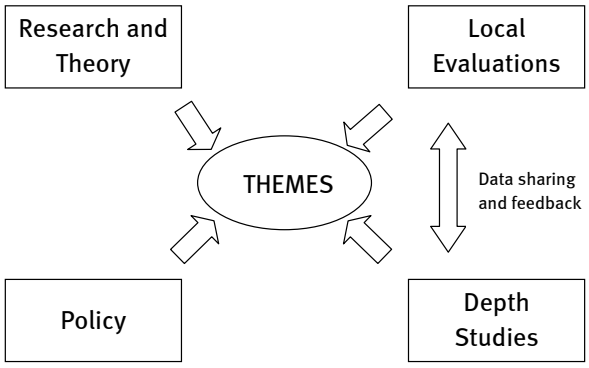
The methods and approaches used to explore these themes are described in section 1.5.

1.5 Methods, analysis and development of the final report

For Themes 1, 2, 3 and 5 (described in section 1.4.2), the evaluation team undertook depth studies. These involved project staff, clinicians and managers from services/practices taking part in Co-creating Health, lay tutors and other patients involved in Co-creating Health, and commissioners from primary care trusts (PCTs)/shadow clinical commissioning groups (CCGs). A range of methods was used, including telephone and face-to-face interviews, discussion groups, surveys, workshop/feedback sessions and examination of local documents. An overview of the methods used in each of the depth studies is provided in the appendix. Four reports were produced from the depth studies. These were used internally by the Health Foundation to provide feedback to programme staff and the sites and key findings from these papers will be available on the Foundation's person-centred care resource centre, which is due to be launched in late 2013.

In the evaluation protocol it was envisaged that the themes would provide the 'structure' for the programme evaluation, analysis and reporting, and would be explored by drawing on depth studies, data/evidence from the local evaluations, and relevant research and policy. Figure 2 illustrates this approach. However, as the evaluation progressed it became apparent that the themes are highly interconnected and so to avoid repetition a slightly different structure was needed for the presentation of findings.

Figure 2: Informing the themes



In early discussions about the evaluation, the evaluation team worked with colleagues at the Health Foundation to consider how it might be informed by evaluation theory. Two considerations were important. Firstly, the overall aim of the programme evaluation in phase 2 was to examine *what works to embed the Co-creating Health model* (in different contexts and with different clinician and patient groups), rather than to evaluate the *impact* of the Co-creating Health model.

Secondly, Co-creating Health as a programme had evolved, and in phase 2 the sites were adapting and applying the interventions and tools in different ways, so a straightforward comparison across the sites was not possible. For this reason, we decided to draw on Pawson and Tilley's work on realist (or realistic) evaluation[9]. In particular, the realist evaluation question they pose (*What works for whom in what circumstances?*) recognised that the Co-creating Health model has evolved and that each of the demonstration sites has its own strategy for making the Co-creating Health model self-sustaining and for securing wider take-up.

Whilst undertaking the analysis of the data gathered from all the strands of the evaluation, we looked at Greenhalgh *et al*'s[10] work on the use of realist evaluation principles in a whole system transformation programme in London. In particular, we found the way in which they identified broad mechanisms of change and underpinning sub-mechanisms very helpful. Building on this, we decided to modify the five original themes, and refocus the analysis and the development of the report around three core 'mechanisms' – building self-management support into the patient journey (which encompasses Theme 1); focusing on changing practice amongst clinicians (Theme 2); and maintaining the co-production ethos (which builds on Theme 3). In addition, we have also considered how the sites addressed the wider take-up of self-management support, and material from Themes 4 and 5 was used to inform this.

Finally, in preparing this report, our main aim has been to highlight the lessons which can be learnt from Co-creating Health, and to set out findings in a way that other health economies can use in their efforts to put self-management support into practice.

1.5.1 Terminology

At the outset, it is perhaps helpful to make a brief note about the terminology used in the report. Where we use the phrase 'Co-creating Health' we are referring specifically to the Co-creating Health programme and projects. We use the phrase 'Co-creating Health model of self-management support' or 'Co-creating Health approach' to refer to an approach to self-management support based on the three elements of Co-creating Health, ie clinician training, patient training and changing the systems. Where we use 'self-management support', we are generally referring to the broader concept of self-management support. Throughout the report we use 'project team' to refer to the core Co-creating Health project teams in the sites (ie the project manager, clinical lead, service improvement technical lead and other staff directly employed as part of the project).

1.5.2 Structure of the report

The report begins with an overview of the Co-creating Health 2 sites, including a description of how they adapted the Co-creating Health model in phase 2. Chapters 3, 4 and 5 focus on sustaining Co-creating Health and consider in turn the importance of maintaining the co-production ethos of the programme, focusing on changing practice amongst clinicians, and building self-management support into the patient journey. In chapter 6 we consider how the wider take-up of Co-creating Health might be secured, and in chapter 7 we highlight the key messages from Co-creating Health phase 2.

[9] Pawson, R and Tilley, N (1997) *Realistic evaluation* Sage, London

[10] Greenhalgh, T, Humphrey, C, Hughes, J, Macfarlane, F, Butler, C and Pawson, R (2009) How do you modernise a health service? A realist evaluation of whole-scale transformation in London *The Milbank Quarterly* 87(2), 391-416

Chapter 2
Overview of the Co-creating Health phase 2 sites

This chapter provides a brief overview of the seven Co-creating Health phase 2 sites. It is important to understand the context within which each of the projects was operating and so it begins with a pen-picture of the sites and a brief description of their plans for phase 2. It goes on to consider how, in phase 2, the sites began to adapt the Co-creating Health model to their local needs and circumstances.

2.1 Site profiles, plans and progress

Seven sites participated in phase 2 of the Co-creating Health programme. Each site continued to work with patients, clinicians and managers in the long-term condition area that had been their focus in phase 1, but extended their work to one or more other long-term condition. All the teams worked across primary and secondary care but the balance in each site varied.

More specifically, in their applications and subsequent project plans, all the project teams described what they hoped to achieve in phase 2 in terms of consolidating and spreading their work in relation to their phase 1 condition, and roll out of the Co-creating Health model of self-management support to other conditions. Monitoring the progress of the sites against their project plans was the job of the Programme Management Office (run by PwC) and so we do not intend to report on this in detail here. However, it is useful to have a broad understanding of what the project teams hoped to achieve, and their successes and disappointments, as this sets the scene for the discussion about spreading self-management support in chapter 6. Below, we provide a short profile of each site and briefly describe their projects' plans and progress in phase 2:

Calderdale and Huddersfield NHS Foundation Trust

Site profile
The Trust serves a population of approximately 400,000, spread across a mixture of urban and rural areas with some significant minority ethnic communities. At the time of the programme, the Trust's catchment area was covered by two PCTs, NHS Calderdale and NHS Kirklees. Calderdale was also one of the Nesta People Powered Health pilot sites.[11]
Co-creating Health focus
The site began by focusing on people with musculoskeletal pain and worked with both secondary care teams and GP practices. In phase 2, the team continued to spread skills and knowledge about self-management support within the musculoskeletal pain services but also started to introduce Co-creating Health for people with COPD.
Co-creating Health phase 2 plans and progress
The team planned to roll out their chronic pain work to more GP practices and extend Co-creating Health to COPD across both primary and secondary care. Achieving spread in primary care proved challenging but Co-creating Health was taken up by some new GP practices and by hospital COPD services in Calderdale and Huddersfield. Therapy staff in the Pain Service had always been enthusiastic about self-management support. In phase 2, all therapy staff across the hospital were offered the Practitioner Development Programme and many also got involved in service improvement work.

[11] See: www.nesta.org.uk/areas_of_work/public_services_lab/health_and_ageing/people_powered_health

Cambridge University Hospitals NHS Foundation Trust

Site profile
The Trust serves the large (c800,000) and growing local population of Cambridgeshire, as well as providing specialist services to a much bigger catchment. NHS Cambridgeshire PCT (and more recently the shadow CCGs) were involved in the programme from the outset.
Co-creating Health focus
The initial focus was on COPD, with the site working with respiratory inpatients and outpatients at Addenbrooke's hospital and with specific GP practices. In phase 2, the team began to extend Co-creating Health (known locally as personal health planning) to people with other long-term conditions, in particular working with staff in community health services.
Co-creating Health phase 2 plans and progress
The focus in phase 2 was on the development of an Enhanced Pulmonary Rehabilitation Course, extending COPD work to a number of target GP practices and rolling out Co-creating Health to the wider respiratory team and diabetes services. In terms of spread, progress in diabetes services was limited, but important, unplanned spread did occur in other areas. In particular, the team worked with both Cambridge Community Service and the Stroke Service.

Guy's and St Thomas' NHS Foundation Trust

Site profile
The Trust concentrated its Co-creating Health work on the communities served by Southwark PCT which had a registered population of approximately 280,000. The population structure of Southwark has a lower proportion of older people and a higher proportion of young and early middle aged people than England as a whole, and is ethnically very mixed. Approximately 50% of housing in Southwark is social housing and the borough has large areas of deprivation with a few pockets of affluence.
Co-creating Health focus
The Co-creating Health project began by focusing on self-management support for people with Type 2 diabetes in Southwark. In phase 2, the team continued to focus on diabetes but Co-creating Health was rolled out to more secondary clinicians and to GP practices in Lambeth.

Co-creating Health phase 2 plans and progress
The plan at Guy's and St Thomas' was to extend their work in diabetes to more GP practices and to spread Co-creating Health to the Podiatry Team and another long-term condition team within the Trust. Overall the team have been successful in spreading clinician training, both in primary care and to other specialties within the Trust but spreading service improvement work and widening the take-up of the Self-Management Programme has been more challenging.

NHS Ayrshire and Arran

Site profile
NHS Ayrshire and Arran serves a population of around 400,000. The area is socio-demographically diverse, with both very rural and remote areas (eg the Isle of Arran), and urban areas with high level of deprivation (eg Irvine and Kilwinning).

Co-creating Health focus
Initially the Co-creating Health team focused on self-management support for people with COPD in secondary care, alongside work with specific GP practices on the Isle of Arran and a number of practices in Ayrshire. In phase 2, the team began to spread Co-creating Health to other long-term conditions and sought to develop a flexible, sustainable and affordable model of self-management support which could be used across their health economy once the Co-creating Health programme ended.
Co-creating Health phase 2 plans and progress
The phase 2 plan for the NHS Ayrshire and Arran team was to extend their work on COPD to a number of target GP practices, but they also wanted to spread Co-creating Health to both the Heart Disease and Diabetes Teams within the hospital. Achieving the level of take up they hoped for amongst the target GP practices proved very difficult. However, progress in the hospital specialties (and linked community staff) was good. Co-creating Health has now been taken up by the Diabetes Team and staff working with heart failure patients. In addition, they are working with the Renal Team and the Parkinson's Disease Team and are developing a practitioner development course for staff working in the HIV and Blood Borne Viruses service.

South West London and St George's Mental Health NHS Trust

Site profile
The Trust has been working with NHS Wandsworth to promote self-management support for people with depression. Wandsworth is one of the largest Greater London boroughs, with around 270,000 residents. The population is also younger and more mobile than the average for England and is ethnically very diverse, with 35% of the population being from black and minority ethnic communities.
Co-creating Health focus
The Co-creating Health project has focused predominantly on people who are being seen in secondary care mental health services, but the team have also been working to promote self-management with the wider community.
Co-creating Health phase 2 plans and progress
In phase 2, the team aimed to spread Co-creating Health to more GP practices across the Trust's catchment area and get six community mental health teams to adopt the Co-creating Health approach. Although some spread was achieved, this site experienced a number of difficulties, including changes in key personnel, which hindered progress.

Torbay Care Trust and Devon Partnership Trust

Site profile
Torbay is a site of contrasts, with areas of affluence but also areas where deprivation is amongst the worst in England. It has a population of around 375,000, with a higher proportion of older people than the average for England as a whole.
Co-creating Health focus
In phase 1, the Co-creating Health team had focused predominantly on people who were being seen in primary care with a diagnosis of depression, with a strong emphasis on their clinician training of GPs and practice nurses. In phase 2, the team continued to spread skills and

knowledge about self-management support across primary care and to other long-term conditions, while also trying to integrate their work with people with depression and clinicians, with the redesign of services.
Co-creating Health phase 2 plans and progress
The strong focus on embedding Co-creating Health in primary care continued to be a priority in phase 2. However, the team also planned to spread Co-creating Health to secondary care mental health services and diabetes services. The work in primary care progressed well, although the level of service improvement work varied between practices. Little progress was made in secondary care mental health services, but self-management courses for people with depression and another long-term condition such as diabetes did take place.

Whittington Health

Site profile
Whittington Health provides integrated acute and community serves to a deprived and ethnically diverse population of around 440,000 in North Central London. For diabetes, the communities served by the Trust perform significantly worse in most performance indicators than the rest of the UK.
Co-creating Health focus
The Co-creating Health team began by working to improve self-management support for people with type 2 diabetes. In phase 2, the focus has been on spreading learning to people with other long-term conditions, in particular pain management and respiratory medicine, whilst continuing to develop their work with GPs in Haringey and Islington.
Co-creating Health phase 2 plans and progress
The plan was to extend the team's work in diabetes services, in particular to the Diabetes Out-Patients Clinic and Community Diabetes Services. However, they also planned to reach a small number of new GP practices and hoped to spread Co-creating Health to the Musculoskeletal Pain Service and COPD. The team were able to make progress in all of these areas (although the work with GP practices had a slow start) and, in addition, they have started to work with clinicians in Respiratory Medicine.

2.2 Local adaptation of the Co-creating Health 'model'

In phase 1, the Co-creating Health 'model' was relatively prescribed. The three training and information programmes were commissioned centrally by the Health Foundation and the content, format and delivery of them was largely the same across all the sites. However, in phase 2, the sites had some freedom (especially in relation to the clinician training) to adapt the programmes to local needs and circumstances, and all the sites did so to some degree. It is important to understand these changes, as they represent one of the ways in which the sites sought to make the Co-creating Health model sustainable in the context of their health economies.

2.2.1 Changes to the self-management programme

The Self-Management Programme was originally developed by the Expert Patients Programme Community Interest Company. The aim of the programme was to give people with long-term conditions the confidence, knowledge and skills needed to manage their condition while working in partnership with their clinicians. It was delivered by a lay tutor and a clinician co-tutor, in seven

three-hour sessions. The table below shows the changes the sites made in phase 2 of the Co-creating Health programme.

Site	Format/Frequency	Content	Delivery
Calderdale and Huddersfield	Self-Management Programme format/frequency largely unchanged. Have recently tested a new approach in the Pain Clinic: selected around 10 patients (who declined full the Self-Management Programme) and ran a mini-Self-Management Programme.	Condition-specific but moving to a more generic content. In the mini-Self-Management Programme: discussed self-management and goal setting with the group plus each patient had a one-to-one session with a clinician.	The Self-Management Programme continues to be co-delivered with lay tutors. The mini-Self-Management Programme was run by a lay tutor, a therapist and a consultant.
Cambridge	The Self-Management Programme has been absorbed into the Enhanced Pulmonary Rehabilitation (EPR) Programme for Patients. The programme comprises 12 x two-hour sessions held twice weekly.	Each EPR session included one hour of supervised exercise and one hour of COPD and self-management education.	EPR sessions are led by a physiotherapist, a physiotherapy assistant and a self-management tutor. There is less of a role for lay tutors, who are now included in just one session.
Ayrshire and Arran	Have developed 'Moving on Together' – a self-management programme for people with any long-term condition. It has six sessions, and is based on the Self-Management Programme.	Five sessions are generic and one is condition-specific.	The Moving on Together programme continues to be co-delivered with lay tutors in a similar manner to Co-creating Health.
Guy's and St Thomas'	Continued in a similar format of weekly three-hour sessions but is over five weeks, not seven.	Contains both generic and condition-specific elements.	The people who deliver DESMOND and DAFNE[12] also deliver the Self-Management Programme. Within diabetes services they have

[12] Education programmes for people with diabetes: DESMOND: Diabetes Education and Self Management for Ongoing and Newly Diagnosed; DAFNE: Dose Adjustment For Normal Eating.

Site	Format/Frequency	Content	Delivery
			had several different programmes and they are now incorporating self-management support into these.
Whittington Health	Continued in a similar format of weekly three-hour sessions over seven weeks.	Contains both generic and condition-specific elements.	The Self-Management Programme has been co-delivered with lay tutors.
Torbay and South Devon	Continued in a similar seven-week format.	The Torbay and South West London project managers worked together to make changes to the Self-Management Programme. This was in part based on changes introduced through the review undertaken by the Health Foundation. Further to this, they have adjusted the content so that the language is more consistent with Practitioner Development Programme. The course they developed is largely generic with the option to adapt/tailor to different long-term conditions.	The Self-Management Programme has been co-delivered with lay tutors. Torbay have secured future funding to continue delivery of the Self-Management Programme, based on the Co-creating Health model.
South West London and St George's	Continued in a similar seven-week format.	See Torbay and South Devon above.	The Self-Management Programme has been co-delivered with lay tutors.

2.2.2 **Changes to the Practitioner Development Programme**

The training programme for clinicians was originally called the Advanced Development Programme. It was developed by Client Focused Evaluation Programmes UK and aimed to support clinicians to develop the skills required to support and motivate people to take an active role in their own health. The Advanced Development Programme was delivered in three four-hour workshops, all led by a clinician tutor and a lay co-tutor. Part way through phase 2, the clinician

training course was re-named the Practitioner Development Programme but, more importantly, sites began to adapt the content, format and delivery of the programme to suit local needs. The role of these changes, in terms of achieving sustainability, is discussed in chapter 4. However, a brief overview of some of the main developments and adaptations is given below:

- **Offering different levels of training to suit different groups of clinicians** eg in Torbay the development of three 'levels' of training: 'gold' which is the full Practitioner Development Programme run over three half days; 'silver' which covers the core elements in one half-day workshop; and 'bronze' which introduces clinicians and other staff to the key ideas and tools in a two-hour session.
- **Reducing the overall time commitment required** eg at Whittington Health, reducing the length of the sessions from three to two hours for GPs and in Cambridge offering the option of an 'in-house' short course (three one-and-a-half-hour sessions).
- **Re-packaging the course to make it more accessible** eg in Ayrshire and Arran, recognising that people have different learning needs, they moved to a much more menu-based approach. They still offer the Practitioner Development Programme in face-to-face workshops, but they also have an e-learning course and run monthly introductory sessions.
- **Offering 'bespoke' courses designed to link clinician training to service objectives** eg in Cambridge they developed a modified course for Cambridge Community Services designed to help deliver Personal Health Planning, a strategic health authority (SHA) priority.
- **'Marketing' the Practitioner Development Programme course in new and interesting ways** eg in Ayrshire and Arran they renamed the Practitioner Development Programme course *Working in Partnership*; in Calderdale and Huddersfield they promoted the programme through the Kirklees Health and Wellbeing Courses public health training programme; and in Cambridge they delivered the Practitioner Development Programme as part of the GP training scheme.

2.2.3 Approach to service improvement

In phase 1, the Service Improvement Programme was provided by Finnamore Management Consultants. It began with a one-day skills-based workshop which introduced participants to quality improvement methods, in particular the Institute for Healthcare Improvement model. This was then followed by team-based use of PDSA (Plan Do Study Act) methods to support teams in the use of the Co-creating Health 'three enablers' ie agenda setting, goal setting and goal follow up. In phase 2, PwC/PEAKS, the technical provider, adopted a more flexible and site-focused approach. Using a collaborative learning model, they supported clinicians and managers in the sites to develop the knowledge, skills and behaviours required to deliver the three enablers. An additional important development was the identification of service improvement technical leads in each site, whose role was to lead and coordinate the service improvement work. However, each site established these roles in different ways and, as is noted in chapter 5, their impact on service delivery did vary.

Chapter 3
Sustaining Co-creating Health – Keep the co-production ethos

Co-production was an important mechanism in establishing and sustaining self-management support. It was underpinned by three sub-mechanisms:

- patients co-delivering self-management support
- patients shaping self-management support
- enabling peer support.

A range of factors which influenced the 'embedding' and sustainability of co-productive activity were identified and can be summarised as: shared understanding of the nature and value of co-productive activity; recognition of the benefits of co-producing self-management support; a supportive infrastructure; and capacity and resources.

Co-production was always an explicit aspect of the Co-creating Health model, both in terms of how it is implemented (specifically through involving lay tutors in the Self-Management and Practitioner Development Programmes), and in terms of desired outcomes (transforming the traditional interaction between clinicians and patients into a more co-productive relationship). The phase 1 evaluation report considered these two aspects and recommended that more attention was given to involving and supporting lay tutors in the provision of the training, and that more post-consultation support should be given to clinicians to promote co-decision making.

The phase 2 evaluation has considered the ways in which Co-creating Health has been co-produced slightly differently. It explored how patient knowledge and experience have been harnessed and the various ways in which patients have supported the implementation of self-management support (well beyond co-tutoring), with the aim of identifying what this means in terms of the sustainability and spread of Co-creating Health. This work provided an opportunity to analyse in some detail the different ways in which Co-creating Health has been co-produced across the seven sites. Only one of the local evaluations explicitly considered this co-productive element, and this was South West London and St George's. Together, the findings of this local report and the fieldwork undertaken for the programme evaluation suggest that co-production is an important mechanism in establishing and sustaining self-management support, and this can be seen in terms of three sub-mechanisms:

- patients co-delivering self-management support
- patients shaping self-management support
- enabling peer support.

These three sub-mechanisms, including the range and type of activity undertaken, are described below, followed by an examination of the co-productive relationships they led to. The factors that facilitated or hindered co-production are also discussed. However, it is helpful to begin by briefly considering the wider policy context the sites are operating within.

Over the past few decades there has been a stronger focus on patient involvement in NHS health policy and guidance. Crawford et al[13] describe the way in which public policy has been articulated in this context and the driving factors, for example: improving the effectiveness of services; improving public perceptions of NHS quality of care; enhancing democracy and accountability and enabling the 'choice' and 'voice' of the health 'consumer'. Co-production is also becoming more influential in shaping the direction of health policy. The Nesta report by Boyle and Harris [14] describes a range of influences that are focusing attention on co-production, including increasing demand, rising expectations and limited budgets. The Prime Minister's 'Big Society' project is very much based on principles of co-production, and there are also related action research programmes (such as Nesta's People Powered Health programme, which one of the sites participated in).

Legislation and guidance for health services on public involvement and engagement have been put in place by successive governments, most recently by the coalition government in England through the Health and Social Care Act (2012). Linked to this, the Department of Health established 'Healthwatch England' in October 2012, and local Healthwatch organisations were more recently launched in April 2013; these replace the existing Local Involvement Networks (LINks) as the main vehicle for public involvement. Guidance and audit requirements have also been issued to PCTs and CCGs on patient participation in Direct Enhanced Services[15], primarily through patient reference groups and surveys.

However, despite commitments made by the UK government over recent years to promote involvement and engagement, service users, patients and the public have questioned what real powers they have to influence change, and have challenged national and local policy makers to implement existing legislation and guidance more effectively. The challenges of implementing public involvement in the context of health were outlined by Baggott[16] in 2005, following changes that the previous government introduced; these included under-resourcing, lack of capacity, complexity and fragmentation. More recently, The NHS Future Forum (following a 'listening exercise' in the course of the Health and Social Care Bill) successfully influenced the government in amending the Bill to improve many of its provisions for 'patient voice', including putting lay representatives as champions of patients onto the boards of CCGs.

Peer support has also been promoted within public policy as part of the personalisation agenda, but predominantly within the mental health sector. The Scottish Government, notably, is making it more high profile across a wider range of chronic conditions, as part of the Social Care (Self-directed support) (Scotland) Bill 2012. Peer support is listed as one of the 'High Impact Changes' issued by the Long Term Conditions Collaborative in 2009: "*We commission peer support groups for people with long term conditions and their carers and provide relevant, accessible information"* (High Impact Change no 3).[17]

[13] Crawford M, Rutter D and Thelwall S (2003) *User Involvement in Change Management; a review of the literature.* A report for NCCSDO

[14] Boyle, D and Harris M (2009) *The Challenge of Co-production*. Nesta, London

[15] Department of Health (2011) Patient Participation directed enhanced services for GMS contract; guidance and audit requirements for 2011/12 – 2012/13, London

[16] Baggott, R. (2005) A Funny thing happened on the way to the forum; reforming public and patient involvement in the NHS in England Public Administration 83; 3 (533-551)

[17] The Scottish Government; Health Delivery Directive Improvement and Support Team (2009) *Long Term Conditions Collaborative; High Impact Changes,* Edinburgh

3.1 Patients co-delivering self-management support

An intrinsic element of the Co-creating Health model is the co-delivery of training (for both the Self-Management and Practitioner Development Programmes) through lay and clinical tutors working together. The evaluation identified a wide range of patient involvement activity which went well beyond this, including:

- **Marketing and promoting Co-creating Health** – this included developing and distributing Co-creating Health marketing and information materials, such as newsletters, leaflets and DVDs; talking to clinicians and students about Co-creating Health; and patients 'telling their stories' in some way or other (eg through accompanying the project manager in promotional work with clinicians, and providing presentations/showcase examples for prospective Self-Management/Practitioner Development Programme participants).
- **Providing administrative support to the Co-creating Health team** – for example by helping with mail-outs and newsletters (see Box 1 below).
- **Facilitating the involvement of other patients** – activities included helping to identify and encourage other patients to act as volunteers, and forging and sustaining links with local voluntary organisations.
- **Supporting wider training activities** – this took various forms, ranging from delivering 'train the trainer' sessions for new lay tutors and mentoring new lay tutors, to facilitating reunions and supporting other peer activities.

Box 1 – The Newsletter Group in Torbay

The initial suggestion for a newsletter came from a member of the Co-creating Health team at a reunion, with a view to producing something that could help keep people interested and motivated in self-management. The Co-creating Health team did not feel that they had the capacity to take it on, so they asked if any people coming to the reunions were interested in taking responsibility for it. At the first meeting the group was facilitated by a member of staff but after that it was self-managed, and a core group of four people have formed The Newsletter Group. Since then they have met regularly and have produced five quarterly Self-Management Programme newsletters.

Group members said they wanted to get involved to continue the impetus of the Self-Management Programme, to keep contact with and support others, and to use it as a vehicle to share information about new service developments or research in the treatment of depression: *"The minute* [T] *mentioned it my mind was whizzing with ideas. I couldn't sleep. I felt motivated to do something."*

The group requests articles from patients and staff, and they produce many features themselves. The group has full editorial control and the final version is 'signed off' and distributed by the Co-creating Health team. Some features are included that are designed to attract readers and encourage them to keep the newsletter for future reference (for example, word searches and recipes), as it carries the dates of future meetings. This was felt to be very important as many patients do not keep diaries. The newsletter is currently only distributed at reunions in hard copy, but the group wanted to find ways that it could be distributed more widely in different formats, and to staff as well as patients. They also wanted to evaluate the newsletter, to explore the responses of patients and see how the newsletter could be improved.

The group meet informally in a person's house and they value this in establishing the tone of the meeting and enabling social contact and peer support. As well as serving to inform others, some of the group members stressed how much they got out of

producing the newsletter: *"I wanted something further. I think it's good for us. It was lovely to get involved. It's definitely done me good."*

One member of the group said she had used her role in this group on her CV and felt it might well have had an impact in her gaining employment.

3.2 Patients shaping self-management support

All of the Co-creating Health sites had some kind of mechanism(s) in place to enable patients to shape the development of self-management support, although they varied in terms of how robust these arrangements were. Some Co-creating Health teams used reunions, peer groups and/or lay tutor groups on an ad hoc basis as 'sounding boards', where in other cases there were more systematic efforts to engage people. Patients were also linked to decision-making arenas – at a minimum patients/lay tutors were members of the Co-creating Health steering group, and in a small number of sites patient representatives were linked to wider strategic forums.

Box 2 – Involvement in Co-creating Health service developments in Guy's and St Thomas'

In Guy's and St Thomas' there is a core group of patients (of about 10) who have been assisting the programme in developing new materials, for example condensing all the existing foot care leaflets into one and restructuring the clinic letters at the hospital to incorporate agenda setting, goal setting and goal follow up. The project manager said that patients help them to make sure they use the right language and plain English.

Patients have also been involved beyond this and the project manager said they always ask patients about new initiatives. *"Staff get so engrossed in what they're doing they don't always consider what's best for patients... We do try to involve them as much as possible."*

The Co-creating Health team have also involved patients in PDSAs and they came up with various suggestions – as a result of this they played a key role in designing 'My Health Plan', which is an aid for people in planning for their appointments. It is an A4 sized paper folded in half, which has space for patients to write down what they want to talk about with their health professional; what the most important thing is that they want to get out of the appointment; their goals and how and when they will achieve them. This is now professionally printed and is used as a service improvement tool in surgeries when they are starting Co-creating Health. The project manager said: *"Patients provide a common-sense view and stop the programme getting caught up in bureaucracy – a fresh-eyed approach. Often the programme will try to make big changes, but actually small changes can bring about huge improvements."*

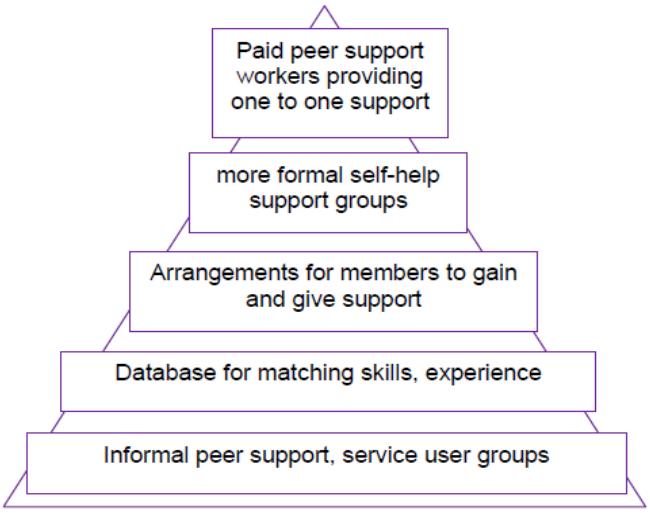
3.3 Enabling peer support

Before describing the type of peer activity in Co-creating Health, it is helpful to consider how peer support has been defined and what value it can bring. Peer support utilises the experience of people who are active service users/patients and carers, including those with past experience. The peer support approach *"assumes that people who have similar experiences can better relate and can consequently offer more authentic empathy and validation"* (Mead and Macneil, quoted in

Repper and Carter[18] p.4). It also has its basis in a 'wellness' model, which focuses on strengths, as opposed to an illness model which places more emphasis on problems that need to be 'fixed'.

Faulkner and Basset[19] illustrate peer support in the form of a pyramid (figure 3), to show the various ways peer support can be harnessed. Using this model, the majority of activity within Co-creating Health could be described as informal, but this suggests a fairly 'healthy' situation given Faulkner and Basset's[20] assertion that there needs to be a strong base of informal peer support for other forms to flourish.

Figure 3: Pyramid of peer support, published in 'Lived Experience Leading the Way' with credit to Rochdale WRAP group



In terms of the benefits of peer support, much of the research evidence available relates to mental health; however, there is increasing focus on the ways in which peer support can be encouraged amongst other patient groups with other health conditions. For example, Dunn et al [21] provide evidence to support the efficacy of peer support programmes for cancer patients and their families, and Brownson and Heisler[22] carried out a review which evidenced a growing body of literature on peer support models in managing diabetes. Repper and Carter's[23] review of peer support literature within mental health also outlines the research evidence concerning the impact of peer support across a number of dimensions (eg admission rates, empowerment, social functioning), and the evidence suggests a range of benefits related to patient outcomes, to volunteer peer supporters, and to health and social care systems.

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[18] Repper J and Carter T (2010) *Using personal experience to support others with similar difficulties* Together-UK, London

[19] Faulkner A and Basset T (2010) *A helping hand: consultations with service users about peer support* Together-UK, London

[20] Faulkner and Basset (2010) Op cit

[21] Dunn, J, Steginga, SK, Rosoman, N, and Millichap, D (2003) A review of peer support in the context of cancer *Journal of Psychosocial Oncology* 2, 55-67

[22] Brownson, CA, and Heisler, M (2009) *The role of peer support in diabetes care and self-management. The Patient—Patient-Centered Outcomes Research* [serial on the Internet] [cited 2011 Dec 1]. Available from: http://adisonline.com/thepatient/Abstract/2009/02010/The_Role_of_Peer_Support_in_Diabetes_Care_and.2.aspx

[23] Repper and Carter (2010) Op cit

It should not be taken for granted that peer support will necessarily have a beneficial impact. The reviews undertaken by Dunn et al and Brownson and Heisler showed a mixed picture in terms of the attributable impact of peer support and shortcomings in the quality of some of the evaluations; more quality research is required to help guide decision-makers. Potential risks are also outlined by Patton and Goodwin[24], for example: dominating /controlling peer supporters; irregular attendance/low membership; sharing of misguided information/ misinformation; underrepresentation of minority groups; and group members dealing with issues at different stages of recovery.

Peer support has developed across the Co-creating Health sites in a number of different ways. This has included peer support groups and buddy systems that were supported in some way by project staff, as well as more informal activities that patients themselves took more responsibility for, such as walking groups and social groups.

Box 3 – The Walking Group inspired by Guy's and St Thomas' Self-Management Programme

Following attendance at Guy's & St Thomas' Self-Management Programme, Mohammed set himself the goal of revitalising a walking group for Asian elders that he had previously initiated. This group now meets weekly and attracts approximately 10 people, mostly males of retirement age who have weight problems and have diabetes (or are at risk of this); many also have cardiovascular problems. They walk for about 40 minutes and stop at an agreed point so that people can go at their own pace. Mohammed said that they always spend 15 minutes or so chatting at the end and having a joke – he saw this as an important part of the health benefit: *"I got this idea from the course. People need to be absorbed in such a way that they forget for a while their own problems and completely relax... Tension causes part of the problem, such as high blood pressure and depression..."*

Mohammed thought that older people were far more likely to be interested in this kind of exercise, as gyms did not feel like welcoming places to them. Plus his walking group provided a really valuable social element to those people who do not go out much.

Additionally, all Co-creating Health sites have held 'reunions'. In most sites the project manager has been primarily responsible for arranging and facilitating these, with lay and clinical tutors involved to varying degrees. However, the majority have found it unsustainable to host on-going reunions that were specific to each Self-Management Programme cohort because it demanded too much time. As a result, in these sites reunion activity has 'morphed' into a form of on-going peer support, which is open to anyone coming off the Self-Management Programme. The reunions serve a variety of functions, including reinforcing goal setting; providing further condition-specific information (in some areas efforts are made to involve external speakers); signposting to related services and reducing social isolation.

When reflecting on the peer support activity in relation to the 'pyramid of peer support' illustrated in figure 3, the majority of activity is clustered around 'informal peer support'. This cluster is not surprising given that peer support activities were not an aim of Co-creating Health and 'informal peer support' includes a range of activity on a group and one-to-one basis. It does suggest a relatively 'healthy' situation when assessed against Faulkner and Basset's[25] assertion that there needs to be a strong base of informal peer support for other forms to flourish. That said, there is

[24] Patton, M and Goodwin, R (2008) *Survivors helping survivors* The Men's Project, California

[25] Faulkner and Basset (2010) Op cit

considerable variation across the sites regarding the level and range of peer activity, and some of the reasons underlying this are explored later in this chapter.

3.4 Types of co-productive relationships

It is valuable to examine this patient shaping and delivering activity in relation to Bovaird's[26] co-production framework (figure 4 overleaf) to help understand more precisely what kind of co-productive relationships have emerged from Co-creating Health.

There was a spectrum of involvement across and within the sites in terms of service delivery. For example, where patient volunteers were responsible for carrying out service delivery functions other than the Practitioner Development/Self-Management Programmes, in some cases this could be described as 'Self-organised community provision' – for example some peer support activities such as the walking group (see Box 3 above). In other peer activities, the project manager had a background support role, and this could be described as 'User/community delivery of services with little formal/professional input', such as the newsletter group in Torbay, described in Box 1 above.

These relationships also appeared to be shifting over time. For example, during phase 1 of Co-creating Health the delivery of the Self-Management Programme could be regarded as fitting into Bovaird's category of *'User co-delivery of professionally designed services'*. In phase 2, most sites appeared to be making some efforts to move towards *'Full co-production'* through greater involvement of service users in the design of the Self-Management Programme. However, Cambridge appears to be returning to more *'Traditional professional service provision'*, as the contribution of patients to the delivery of the Self-Management Programme has markedly diminished. This raises questions about the extent to which the co-productive nature of the training courses can be reduced, whilst being true to the Co-creating Health model.

[26] Bovaird (2007) Op cit

Figure 4: Bovaird's co-production framework

		Responsibility for design of services		
		Professionals as sole service planner	**Professionals and service users/ community as co-planners**	**No professional input into service planning**
Responsibility for delivery of services	**Professionals as sole deliverers**	Traditional professional services provision	Professional service provision but users/communities involved in planning and design	Professionals as sole services deliverers
	Professionals and users/communities as co-deliverers	User co-delivery of professionally designed services	Full co-production	User/community delivery of services with little formal/professional input
	Users/communities as sole deliverers	User/community delivery of professionally planned services	User/community delivery of co-planned or co-designed services	Self-organised community provision

Source: Adapted from Carnegie Trust (2006) 'Commission for Rural Community Development – Beyond Engagement and Participation, user and community co-production of services' by Tony Bovaird, Carnegie Trust[27]

Bovaird made clear that *service planning* covers a range of activities including, for example: design; development; commissioning; monitoring and evaluation. To a greater and lesser extent there was involvement in all of these areas across the sites:

- In relation to *design*, some of the project managers and lay tutors felt that the way in which the Self-Management and Practitioner Development Programmes were initially produced had *"not sent the right message"* (Project Manager) in terms of patient involvement. They were frustrated that in phase 1 the programmes had not been adequately designed in partnership with patients and that the licence restrictions had not enabled or encouraged patients (or staff) to comment on and improve them. In phase 2, all the project teams had been making changes in the design of the courses, but efforts to involve patients in this process have been variable across the sites.
- *Service development* related to Co-creating Health training and service delivery – all the sites had mechanisms for involving lay people, but some were more robust than others. For example, in Calderdale and Huddersfield there was a strong lay tutor group who were routinely involved and consulted, but this was a small cohort of people, making it vulnerable to people being overloaded or dwindling abruptly due to personal circumstances. Other areas developed more diverse systems for involvement, including larger groups of people and more than one group to work with (eg Guy's and St Thomas', Whittington Health, and Ayrshire and Arran all worked with lay tutor groups and reference groups, and consulted with the local

[27] Bovaird notes that for the purpose of clarity he has collapsed various functions into planning and delivery, and in practice "these should be considered to include the full range of potential decision making arenas, such as planning, commissioning, design, managing, delivering, monitoring and evaluating."

voluntary sector). This underlines the need for co-productive activities to be robust and systematic.

- *Service development* activity related to the Service Improvement Programme was focused on commenting on leaflets/promotional material, and several sites said that they struggled to involve patients in broader or more substantial activities. Guy's and St Thomas' appeared to have been able to do the most in this area, and this may link to the fact that they had an established core group of people who had a specific role here (see Box 2 in section 3.2).
- There was little evidence of direct involvement by lay people in *commissioning* in terms of high-level decision making. However, the marketing of Co-creating Health could be regarded as a commissioning issue, and here there was evidence that many sites were co-producing this activity in partnership with patients through, for example, joint visits to practices, giving talks/presentations about Co-creating Health, and making promotional DVDs and leaflets.
- In terms of *monitoring and evaluation*, most sites had some means of capturing the views of patient who had gone through the Self-Management Programme, but these tended to be informal and were not always consistently collated. There was only one site that actively involved patients in carrying out such activities and this was South West London and St George's, where the local evaluation provider employed two service user researchers. This could be described as *'full co-production'* in Bovaird's framework.
- There were other examples of patients being involved in Co-creating Health as employees, for example in Torbay a patient was recruited as part-time administrator, and in Calderdale and Huddersfield a patient was recruited to provide telephone support and administrative help for two hours a week. It is harder to categorise this in terms of Bovaird's co-production framework, which as a model tends to reinforce a professional/patient dichotomy. Many of the people in these roles contributed to the evaluation and said they really valued the 'blurring' of this line. They could have a positively disruptive effect on an 'us and them' mentality, challenging a hierarchical health culture and contributing to culture change.

It is important to remember that many of these co-productive activities were emergent – apart from training delivery, the sites did not embark on Co-creating Health with the specific intention of co-producing it in a number of pre-defined ways, with associated clearly defined outcomes. However, Bovaird's framework is very useful in setting out the various forms that co-production can take. It also raises important questions about particular *types* of co-productive relationships and how they resonate within the Co-creating Health model. It was often stressed by those interviewed that the contribution of patients needed to be more central to Co-creating Health so that it could be more meaningfully co-produced. Many felt that this would improve the quality of delivery, through making it more responsive; providing the unique peer support element that clinicians without such experience could not. One project manager commented that peer support was a *"happy accident"* and several of those interviewed commented that it should have been much more central, both at a strategic level and at a practical level.

Questions remain about the value and impact of particular co-productive relationships. Is the level of professional/patient contribution appropriate to the type of co-productive activity to achieve the best outcome? What exactly are the desired outcomes linked to each activity and are these shared by all stakeholders? Further research and analysis is required to shed light on this, but Bovaird's framework is a valuable tool to help health economies (and of course patients/service users) to broadly 'map' and 'track' different types of co-productive activity – to examine how activities are co-produced and how they perhaps should be co-produced, to effectively implement and sustain self-management support.

Bovaird does stress that co-production is *"not a panacea"* and flags potential problems, such as differences in values and incompatible incentives (p. 856). He also points out that: *"Co-production does not simply involve bi-lateral relationships – usually there are multiple relationships amongst*

public service clients and other stakeholders" (p. 857). There was certainly some evidence (from two of the Co-creating Health sites) that there were tensions around the type of co-produced relationships which are 'allowed' or 'encouraged' by professionals, and where patients wanted to do much more or have more control. This, and other barriers and facilitators are described below.

3.5 Facilitators and barriers to sustaining co-productive activity

Co-productive activity has been unevenly spread across the Co-creating Health sites in relation to patients' involvement in delivering and shaping Co-creating Health and in relation to opportunities for peer support. As indicated above, there is a level of 'happenstance' in engaging enthusiastic, available and able patient volunteers. There are also policy variations across the sites, and it may be no coincidence that the site that particularly stood out in promoting patient involvement and peer support (and where feedback from patient volunteers about the support they received was very positive) is in Scotland (Ayrshire and Arran). The Scottish Government is making peer support more high profile across a wider range of chronic conditions, as part of the Social Care (Self-directed Support) (Scotland) Bill 2012, and peer support is listed as one of the 'High Impact Changes' issued by the Long Term Conditions Collaborative in 2009[28]. Further to this, a range of factors was identified which influenced the 'embedding' and sustainability of co-productive activity. These are outlined below and can be summarised as:

- shared understanding of the nature and value of co-productive activity
- recognition of the benefits of co-producing self-management support
- a supportive infrastructure
- capacity and resources.

3.5.1 Shared understanding of the nature and value of co-productive activity

It was apparent that both within and across sites those involved in Co-creating Health had differing understandings and interpretations of co-production. For example, for some project managers co-production of Co-creating Health appeared to be quite focused on issues directly linked to delivering the Self-Management and Practitioner Development Programmes (eg marketing and promotional work); for others it was about transforming the culture and influencing the wider organisation through the example of involving patients in design and delivery at all levels. These variances are understandable in terms of Boyle and Harris's account of the 'elasticity' of how people define and understand co-production, and they are linked to a range of factors, both individual (eg the background, training and value systems of project managers) and at an organisational level (eg culture, leadership and local priorities). These differences in interpretation highlight the need for more clarity about co-production and what this means in practice for self-management support.

Similarly, the understanding of peer support was uneven within and outside of Co-creating Health teams. Whilst some felt that there was an encouraging and receptive wider culture in their organisations, others thought that much more needed to be done to raise awareness of the potential benefits, especially amongst clinicians. Some believed that a more comprehensive, whole-system approach to encourage and guide people toward different forms of peer support could ultimately contribute to improved patient outcomes. Whilst it was recognised that peer support would not appeal to everybody, it was suggested it should be 'sold' as an integral part of the Co-creating Health package, with the potential benefits more actively 'marketed' to clinicians.

[28] Health Delivery Directive Improvement and Support Team (2009) *Long term conditions collaborative: high impact changes* The Scottish Government, Edinburgh

> *"Peer follow-up was patently missed off from Co-creating Health – there was a belief that we would be training people and they would just get on with it – this was patently not going to work… it is very easy to slip back into old habits…people need to build confidence over time…"* (Project manager)

Some emphasised that there needed to be a culture change within health services more generally in relation to co-production and peer support. Most of the patient volunteers/lay tutors said they did feel treated as equals, but others complained of a continuing 'us and them' mentality within health services. Some felt that there could be a tendency amongst some professionals to assume that lay people would lack professionalism and could not be trusted without very close supervision, or that they were sometimes included in a tokenistic fashion. Calderdale and Huddersfield were involved in the People Powered Health Programme. The project manager felt that there were certainly some synergies here which enabled a more receptive culture around peer support, and one of the Co-creating Health lay tutors was involved in a related working group – but even within this context some of the barriers described above were experienced.

Project managers also described the struggles they sometimes had in gaining clinicians' respect and confidence in lay tutors, and this was particularly apparent in Practitioner Development Programme settings. It is recognised that changing culture is a 'whole system' issue that it is difficult and complex for Co-creating Health teams to manage, but there were encouraging examples where some sites tackled this head-on. The project manager in Ayrshire and Arran described how, in an early Practitioner Development Programme, a few participants had questioned the lay tutor's role and what they could learn from them. The Co-creating Health team felt that this was linked to the limited nature of lay tutor involvement, so they quickly altered the programme to make the lay tutor higher profile rather than lower profile:

> *"From when we took on delivering these programmes ourselves, our patient representatives co-deliver the programme just as they do the Self-Management Programme. We have patients who open up the sessions – it's not the clinician who stands up first. That has become accepted as the way we do things here."* (Project manager)

The project manager felt that this has been effective in helping to shift the culture amongst clinicians, rather than seeing patients as simply in a support role during the training.

3.5.2 Recognition of the benefits of co-producing self-management support

The phase 1 evaluation included some analysis of the benefits of co-tutoring the Self-Management and Practitioner Development Programmes, and drew the conclusion that there is *"a lack of evidence for the impact of co-tutor models on outcomes in patients"* and a need for more research to *"test the comparative value of variations in tutor delivery"*. The phase 2 evaluation was able to go beyond this focus on the Self-Management and Practitioner Development Programmes to explore some of the broader benefits of patient involvement in delivering Co-creating Health that were perceived by both staff and patients. There were three areas where the benefits or value of co-producing self-management support needed to be recognised if it was to be sustained (and spread). These were: self-management support design, development and implementation; benefits to individuals and society; and benefits to the wider organisation.

Benefits to Co-creating Health re-design, development and implementation – Many of those interviewed felt that patient involvement was absolutely central to the Co-creating Health ethos, with a material impact on the positive outcomes that could be achieved. Whilst the phase 1 evaluation could not unequivocally provide evidence for the impact of lay tutoring on patient outcomes, in phase 2 there was a great deal of anecdotal evidence about the power of the lay perspective. Where sites had involved patients in the broader development of Co-creating Health, project managers really valued their contribution; several described how the patient perspective

could not be 'imagined' by professionals and it was vital to gain this directly in order to make Co-creating Health as effective as possible:

> *"As a clinician it's easy to stand back and think what you want or what your outcomes would be but you really have to get feedback from patients who are living with the condition to see what they need and what they expect to get from a programme. If they have been through the ones we have run in the past, they have a really good idea of what we're trying to achieve and what they gained from it."* (Project manager)

Project managers and patient volunteers in particular were of the view that without the input of patient volunteers, the Co-creating Health project could not happen, because there was insufficient capacity to implement it if there was a sole reliance on paid staff. Lay involvement could also shift perceptions. One lay tutor (in the context of depression) described how people witnessing clinicians and patients delivering training together was a very powerful dynamic that could potentially change people's perception of client-professional relationships:

> *"Some Self-Management Programme participants will have a very negative approach to healthcare professionals – some of these feelings are genuinely based on bad experiences and sometimes it is linked to being unwell/negative – many people are wary of health professionals, but when lay tutors and clinicians can be seen working together they can see this is something different – and they can see that they can also have a different relationship with their own health professional."* (Lay tutor)

Benefits to individuals and society – It was clear that patients' skills and confidence could be built through their involvement in SMS. Patients also described how getting involved in Co-creating Health voluntary activity reinforced their own self-management behaviours. As one patient volunteer put it – *"I like the way* [being involved as a Co-creating Health volunteer] *pushes me personally to continue to look at ways to manage depression".* Co-production can also be a vehicle for growing 'human capital' and social networks. During the life of the programme a number of patient representatives/lay tutors and volunteers moved on to gaining employment, and several patients described how their experience in this role had significantly increased their confidence and skills, and sense of their own value.

> *"I've never done anything like this before. I thought I would be a total waste of space. It's motivating me to do something I thoroughly enjoy."* (Patient volunteer)

The evaluation highlighted a number of benefits linked to post-Self-Management Programme peer activity, for example: reinforcing self-management behaviours through peer 'follow-up', and avoiding the programme stopping abruptly; enabling people to prepare for consultations with peers, where people might feel less able to approach a clinician; providing valuable social opportunities and reducing isolation and depression; and extending self-management messages beyond people directly involved in Co-creating Health. This could potentially have significant benefits for 'hard to reach' groups (eg Mohammed's walking group, described in Box 3). The South West London and St George's local evaluation also highlighted a number of benefits linked to the peer element within the Self-Management Programme, concluding:

> *"The opportunity for peer support offered by the group setting of the Self-Management Programme was a highly valued resource for participants, our analysis suggesting that peer support was possibly the most active ingredient supporting goal setting and wider self-management skills acquisition."*

Benefits to the wider organisation – There was a strong view that witnessing co-tutoring and other Co-creating Health patient volunteering activity could help challenge some professionals' perceptions of patients as passive recipients of care, and contribute to culture change (as in the example of Ayrshire and Arran in section 3.5.1). In some sites, the Self-Management Programme was a 'recruiting ground' where people went on to get involved in a wider range of activity linked to the health organisation, for example, as representatives on broader strategic forums. Patient

involvement could also reduce reliance on staff for certain functions, thus reducing costs to the organisation.

3.5.3 **A supportive infrastructure**

Much has been written about supporting volunteers effectively[29] and detailed guidance on supporting volunteers in health services has also been produced by the NHS[30]. There are clearly a number of circumstantial and capacity issues that have influenced the level and type of support to volunteers within Co-creating Health. In all sites, there was a level of informal support to volunteers, through checking how people were and keeping in regular contact. However, there was more variation in terms of access to more formalised support. Staff and patients flagged the risks of lay people undertaking certain roles without a degree of training in basic issues such as confidentiality and listening skills, and they emphasised the need for appropriate training and supervision of volunteers who might be working with potentially vulnerable people. In Ayrshire and Arran, the buddy system described in Box 4 below illustrates the infrastructure that has been developed to ensure that this service runs in a professional and accountable way.

Box 4 – Ayrshire and Arran's buddy system

In Ayrshire and Arran a telephone-based 'Buddy system' has recently been established. Prior to this, informal support was available via the local Breathe Easy Group, but it was felt that more formalised support would be helpful for people who might need some reassurance or encouragement in attending the Self-Management Programme or managing their condition. There is strict guidance that buddies do not give any clinical advice or information.

Anyone with COPD or diabetes can request help and referrals go to the project manager, who matches people with a buddy she feels would provide a good link. Buddying is tightly 'boundaried' with short weekly calls (usually 10-15 minutes) for a specified brief period of time (usually 3-4 sessions). A short form is completed by the buddy after each call to record any issues. Each buddy is issued with a dedicated mobile phone and charges are paid for by the Health Board.

Initial training was provided by Macmillan Cancer Support who are experienced at providing buddy programmes. There are monthly meetings, to enable buddies to share experiences and problem-solve. The project manager is always available, should a buddy need to de-brief following a call.

The buddies described the empathy that they could provide and, although the service is in its early stages, they felt that it was making a real difference to people's lives:

> *"Back in 2008 when I was really ill it would have really helped me, because I became really depressed. I was so bad I became house-bound. I had to work it out with my family and it took a long time.... It [the buddy system] is a great idea and I really hope it takes off."* (Peer supporter with COPD)

One buddy reflected on how he felt when he had an initial diagnosis of COPD and how valuable the buddying role can be at that stage: *"For me it takes me back to the start of my journey, some of the concerns I had and some of the denial I had."*

In most sites, project managers had established links to wider corporate patient and public involvement systems. The nature of this relationship varied, influenced by the project managers'

[29] Crawford, M, Rutter, D and Thelwall, S (2003) *Op Cit*

[30] NHS Employers (2010) *Volunteering pack: volunteering in the NHS* NHS Employers, London

previous role (eg whether they had previous experience of supporting volunteers) and already established links to corporate support systems, eg in South West London and St George's there was a connection with the Trust's Employment Support Service (helping service users back to work), and in Calderdale and Huddersfield the relationship was with the Trust's Volunteer Service. In some areas, links had also been established outside of the health system, for example in Ayrshire and Arran, the project manager tapped into external expertise to support Co-creating Health volunteers, where Macmillan Cancer Support have provided training for Co-creating Health 'buddies' (eg on the role and purpose of buddying/skills development) as they had expertise in this area, and Chest Heart and Stroke Scotland has provided training to support people to become actively involved as patient representatives in the Respiratory Managed Clinical Network. Capitalising on the skills and experience of others in this way can help to provide a more robust and sustainable volunteer base.

However, the level of support/supervision has to be held in fine balance depending on the nature of the activity. This is particularly the case in relation to peer support. Formal peer support (such as a buddy system) obviously requires proper management, but very informal peer activities could not function 'naturally' if they were tightly controlled and monitored – what makes them attractive to some people is precisely the fact that they are not 'part of the system'. Amongst those involved in the evaluation, there were different attitudes towards how peer support should be encouraged and enabled within Co-creating Health and this highlighted some of the dilemmas that project managers have faced in terms of their position in facilitating peer activities. Some have taken a very pragmatic approach, with a member of staff adopting a strong facilitative and organisational role in order to attract and maintain reunions/peer support groups, whilst others resisted this and tried to encourage patients to take more responsibility to organise themselves. The latter approach is in part governed by the knowledge that Co-creating Health funding would cease and needed to be delivered in an affordable way, but also by the belief that this is more in keeping with the philosophy of co-production. Several project managers and lay tutors said they believed that if things are always organised for people they may not be so motivated:

> *"Some people want things laid on for them – self-management is about creating your own activity and motivation."* (Project manager)

They expressed concern that where sites have relied largely on professionally-led peer meetings or on signposting to a local voluntary group, there may be less likelihood of peer support sustaining into the future. It is notable that in one site which had a particularly rich mix of peer support activity, their approach squarely places responsibility on patients to create their own peer support mechanisms, but with the necessary background support to help initiate activity and deal with any problems (see Box 5 below).

Box 5 – Peer support in Calderdale and Huddersfield

In Calderdale and Huddersfield reunions are held as one-off events three months after each round of the Self-Management Programme, facilitated by the clinical and lay tutors. The project manager and administrator help with the practicalities of setting up the reunions and send out reminders, but do not get directly involved in a facilitative role. The venue and tea/coffee is paid for by the Co-creating Health team, but tutors are not paid for this work. To help promote consistency, a 'standard operating procedure' has been developed for the reunions in partnership with the tutors.

As the value of peer support has become increasingly recognised, this is now more routinely addressed and promoted within the Self-Management Programme, and the reunion is a further opportunity for this to be reinforced. People are told about and encouraged to join existing peer activities or initiate new peer activities. There is an ongoing peer-based self-help group which meets weekly (Helping Everyone Living in

Pain [HELP]) and the meeting room in which this is held is funded by the Trust. Other people have set up more informal social activities, such as eating out together regularly. One-to-one peer support is available from some of the lay tutors, who can also be contacted out-of-hours. A buddy system is in the process of development.

3.5.4 **Capacity and resources**

The number of patients involved in co-delivering Co-creating Health varied considerably across sites, and this is significant in terms of representativeness and for sustainability. All project managers were very aware that the people they were trying to involve could be frail or ill, and in two sites project managers said that the condition they were dealing with was a particular limiting factor for involvement – although this did not appear to be borne out in practice, as sites dealing with the same condition had widely varying levels of success in terms of the numbers of patients involved. Two sites relied very much on the efforts of a very small lay tutor group and/or staff who had patient experience and in one particular site there was considerable reliance on using the local voluntary group. However, there were examples where a larger number of patients were involved through a range of channels (see Box 6 below):

Box 6 – The Ayrshire and Arran Reference Group

All patients coming through the Self-Management Programme are asked to join a Patients' Reference Group, which has been operating for the full term of Co-creating Health, and is managed by the Co-creating Health project manager. Currently there is a bank of 40 patients; they do not meet as a group, but are contacted individually through different mechanisms, such as emails and questionnaires, with the purpose of commenting on a wide range of service developments, not just Co-creating Health. Reference group members commented about their role as part of this evaluation and the majority of respondents said their primary motivation in getting involved was to promote self-management amongst other patients and healthcare professionals, and 'to give something back'. It was very clear that they really believed in the efficacy of Co-creating Health from personal experience and wanted to do what they could to ensure it continued.

> *"It's a chance to have input into promoting an environment where self-management principles can be more widely disseminated."*
>
> *"Involving patients is very important to [Co-creating Health's] success."*
>
> *"I have gained my self-confidence back since being involved in Co-creating Health. I hope this will continue."*

The project manager also consults the lay tutor group and the local Breathe Easy group (a local group providing support and information for people with a lung condition), so that a range of views can be captured.

Encouraging and establishing peer support and patient involvement mechanisms and activities clearly demands investment, and capacity and resources for this were somewhat limited within Co-creating Health teams, plus there was a high turnover of project managers in some areas:

> *"Capacity is a huge issue – I do know that this [support to volunteers] is happening at the cost of other areas... and it does take time. There are competing time constraints".*
> (Project manager)

There was also a limited budget within sites to fund activities related to patient involvement and peer support. In many areas lay tutors are paid for co-training but other involvement activities are not paid, and there was a sense that this is unfair and inconsistent. There are also differing

payment policies within Trusts. There was no consensus amongst the lay tutors or Co-creating Health staff interviewed as to how to manage this; some felt 'voluntary' should mean unpaid, but others felt that the important contribution of patients' time/expertise demanded the respect of a financial reward.

None of the sites had fully costed the existing or potential resource requirements for patient involvement and peer activity. Some had set aside funding for specific elements (eg room hire for reunions) but in other sites funding was much more ad hoc. A few of the lay tutors interviewed said they were dismayed and surprised when they had learned there is no dedicated budget for patient involvement and peer support within Co-creating Health funding. Project managers said the lack of a dedicated budget could make it harder to prioritise this work.

The resources required to support volunteers obviously need to be weighed against the potential cost savings. Many of those interviewed stressed that Co-creating Health could not happen without the voluntary time given by lay tutors and patient volunteers. Some went as far as to suggest that Co-creating Health would not be happening in their area (or certainly not on the same scale) without the input of patient volunteers.

Chapter 4
Sustaining Co-creating Health – Focus on changing practice amongst clinicians

For self-management support to be sustained, there is an implicit requirement for clinicians to alter their practice to support patients effectively in managing their condition. Four sub-mechanisms underpinned this:

- targeting whole teams
- utilising influential clinicians
- providing post-Practitioner Development Programme support
- incorporating SMS skills training into medical and healthcare education.

The sites' ability to change practice was affected by a number of facilitators and barriers, including: the extent to which SMS was compatible with clinicians existing approaches and practices; perceptions of the benefits of SMS to patients, clinicians and services; the ease or difficulty of testing and adopting self-management support; and the scope and ability clinicians had to adapt the Co-creating Health model.

For self-management support to be sustained it has be effectively embedded in routine healthcare, and so there is an implicit requirement for clinicians to alter their practice (to a greater or lesser extent) to support patients effectively in managing their condition. The programme evaluation aimed to explore the strategies sites used to enable this change in practice amongst clinicians. It looked at both the challenge of sustaining the changes achieved so far and the take up by new groups of clinicians by finding out what approaches sites used to embed support for self-management in routine clinical practice and create a culture amongst clinicians which was positive about self-management. It also examined which approaches worked best for different groups of clinicians or in different settings.

The phase 2 evaluation has been primarily concerned with how self-management support has spread and been sustained, a key part of which is how clinicians have been encouraged and enabled to change their practice once they have undertaken training in self-management support approaches. From a clinician's perspective, the Co-creating Health model of self-management support is an innovation in their practice. In exploring the approaches the sites have used to change practice amongst clinicians, the evaluation drew on Rogers' Diffusion of Innovation theory[31]. As part of the theory, Rogers describes five 'characteristics' of innovations which affect the successful uptake of an innovation and the rate at which it is adopted. These are:

- **Relative advantage** – the degree to which an innovation is perceived as better than the idea it supersedes.
- **Compatibility** – a measure of the degree to which an innovation is perceived as being compatible with existing values, past experiences and the needs of potential adopters.
- **Complexity** – a measure of the degree to which an innovation is perceived as difficult to understand and use.
- **Trialability** – the degree to which the innovation may be experimented with on a limited basis.

[31] Rogers, EM (1995) *Diffusion of Innovations* New York, Free Press

- **Observability** – the degree to which the results of the innovation are visible to others.

Rogers also discusses the idea of 're-invention', which can be described as the degree to which an innovation is changed or modified by a user in the process of its adoption and implementation.

None of the local evaluations focused specifically on changing practice amongst clinicians, but a number of them elicited clinicians' views on how they perceived their practice would change (or already had changed) as a result of undertaking the Practitioner Development Programme. The findings from the programme evaluation and some of the local evaluation reports suggest that there are a number of sub-mechanisms operating which enable clinicians' practice to change in order to sustain self-management support, ie:

- targeting whole teams
- utilising influential clinicians
- supporting clinicians post-Practitioner Development Programme
- incorporating self-management support skills training into medical and healthcare education.

These are described in the following sections, including the ways in which the sub-mechanisms have been implemented in different sites, the key facilitators for their success and the barriers which have inhibited progress.

4.1 Targeting whole teams

One of the strongest messages to emerge in relation to enabling practice change amongst clinicians was the importance of training whole teams or whole groups of clinicians from the same service, so that everyone involved had a common understanding of self-management support and understood the core tools and techniques. It was felt there was a need to create a *"critical mass"* (ie a proportion or number of clinicians required in a team to ensure that the practice of self-management support is self-supporting and sustainable) of Practitioner Development Programme-trained clinicians within a team or service in order to generate and maintain momentum. Training whole teams in this way could be seen as a way to improve the ease with which self-management support was tested and adopted, ie a way to improve its 'trialability' in terms of Rogers' Diffusion of Innovation theory.

In phase 1 of Co-creating Health, most sites had taken quite a broad-ranging approach to encouraging clinicians to take up the Practitioner Development Programme, which resulted in Practitioner Development Programme-trained clinicians being spread across different locations, practices and teams. This had some benefits; in particular 'seeding' self-management support ideas across the local health economy and allowing 'enthusiasts' from outside the Co-creating Health target conditions to get involved at an early stage. In Torbay, although GP practices were encouraged to send groups of clinicians on the Practitioner Development Programme (so that each practice would have several trained clinicians), their focus was on getting as many practices as possible engaged in some way with Co-creating Health so that self-management support became 'routine'. In two sites (Cambridge and Whittington Health), allowing clinicians from services/conditions that were not in their original plans to undertake the Practitioner Development Programme led to important developments in their self-management support work. However, this open approach also had significant disadvantages and so in phase 2 all the sites moved to a more focused approach to the Practitioner Development Programme, where the majority of staff within a practice or team undertook some level of training. It was seen as important that team members experienced similar training, a common language and a shared understanding of what self-management support was all about. It was about creating a culture shift; focusing training on a whole team or service was thought to be a key feature in achieving this.

The experience of clinicians from one GP practice in Torbay highlights the value of training clinicians as a group. With funding for locum cover, all the GPs and the nurse practitioner in the practice were able to attend the Practitioner Development Programme together. The training for senior clinicians was followed up with shorter training sessions for other clinical staff and the administrative team. This gave the whole team a focus on self-management, which was then reinforced in team meetings and further work on service improvement. As the nurse practitioner explained:

> *"I think the help for me was the three GPs and I all doing the course together, so we were all learning together, changing together, implementing together and evaluating – we were talking about the changes that we'd made and how difficult certain things had been….So for me it was a real positive that we were doing it together and all experiencing those difficulties together."* (Nurse practitioner)

A product of adopting a whole-team approach to training is that it promotes the development of a common language and a common understanding of key self-management support concepts. For example, in the inpatient diabetes service at Guy's and St Thomas' Trust, there was a strong sense that this new common language had changed the tone of clinical meetings. One clinician described the change:

> *"It is interesting how the culture has changed, and the terminology and the words that reflect that culture have changed in the clinical meetings. We have a principals' meeting for example where someone is asked to bring their last clinic notes so they go through every patient. And that's something that we have been doing for a few years and what's been interesting is the questions that people get asked now are not about the HbA1c but did the patient want to do that, what is the patient's goal?"* (Clinician)

The clinical lead also felt that an indicator of the successful adoption of Co-creating Health was the change in the culture of their clinical meetings. The language and focus of their meetings had changed because everyone had been trained in self-management support; instead of focusing narrowly on clinical aspects of care, they were equally concerned with what the patients wanted and what their goals were. Clinicians also noted that this could also lead to small but important shifts in the way they recorded self-management information in their patients' notes. A GP explained:

> *"We write in the notes confidence or motivation 6 out of 10 – so when I see someone* [GP name] *might have seen, I can follow that up – eg last time you thought in relation to giving up smoking, on a scale of 0 to 10 you thought you were 7 out of 10 and you really wanted to get going with this and how do you feel about that now? So you can actually follow up from the previous consultation even if it wasn't with you."* (GP)

In turn, establishing this common language and common understanding helped to create an environment within teams that was positive about self-management support. Adopting the whole-team approach also enabled clinicians to support each other through the process of change (see example below).

Box 7 – Whole-team training at Whittington 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 – *"it's about having key links and people speaking the same language"*.

"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)

Individual clinicians who undertook the Practitioner Development Programme without the rest of their team (or colleagues who worked in the same service) were more at risk of finding it difficult to test out self-management support and work out how it would fit into their practice. There were also dangers in only training one group of clinicians within a team, particularly where the senior clinicians they worked with and who supervised their work had not undertaken the Practitioner Development Programme. A clinician who had experienced this explained:

> *"I think that if I had my time again, I'd come back to the team and say... can we have the lead nurse, lead occupational therapist, lead physiotherapist and let's all sit down and have the training and let's do it with the* [Assistant Practitioners] *as well – let's all do it together and see how as a team we feel this could work with our patients."*
> (Physiotherapist)

4.2 Utilising influential clinicians

There were a number of examples of clinicians within teams/services who had embraced self-management support and, either by visibly practising it or by actively promoting it, had influenced others to do the Practitioner Development Programme and develop self-management support in their own practice. This 'observability' (ie making self-management support visible within the clinical community) is one of the key characteristics described in the Diffusion of Innovation theory which can affect the successful uptake of an innovation. In Whittington Health, the service manager (who was a physiotherapist by background) in the musculoskeletal pain service actively ensured that after she had done the training herself, her whole team did the Practitioner Development Programme to ensure that they were all practising self-management support and working in the same way. She indicated that it was important to have clinicians who *"run with it"* and generate interest – a core group of people who have a degree of power and influence, and are in a position to effect changes to a service.

> *"Get a core group of clinicians so that they can go away and talk about it but you need to get the right people. It's not enough to do the Advanced Development Programme training if you haven't got the power or influence to change the way services might be working."* (Service manager)

Other people from Whittington Health also talked about the importance of influential senior clinicians who had promoted self-management support and encouraged others not only to do the Practitioner Development Programme but also to continue to practise self-management support within their own service. Examples of this were the senior consultants in the respiratory medicine department who were very enthusiastic about self-management support right from the start and had influenced significant numbers of other clinicians to do the training and use it in their practice.

> *"We do meet the consultant in the clinics as well, we work with her quite a lot, any time I have been in her clinic she always highlights that* [self-management support] *and she does it so beautifully so it's always there in the background."* (Respiratory nurse)

The clinical lead from Ayrshire and Arran talked about the importance of having *"people who can spearhead and set an example"* in order to develop and maintain 'observability'. In particular, junior doctors needed to see more senior doctors practising self-management support in order to do it themselves. The clinical lead from Guy's and St Thomas' cited the example of a 'traditional' consultant who had changed his practice substantially following the Practitioner Development Programme and was now leading by example:

> *"We have had some very traditional consultants take part in the Practitioner Development Programme who have said that it changes their practice and one consultant said that by doing it* [using self-management support skills] *himself he was showing his registrars… Some registrars may get this training in medical school but unless they see their seniors doing it they will forget."* (Clinical lead)

Although people did not always explicitly talk about 'leadership', the role of senior clinicians in setting an example by attending the Practitioner Development Programme, changing their practice, supporting new systems and supporting junior staff in the use of their self-management support skills, was very important. This influence was important both at a service/team level and at an organisational level. At a service level, it is about the team *"seeing you use it, hearing, explaining why you are using it"*. At an organisation level, senior clinicians and managers are needed to take self-management support on board and integrate it into the priorities and strategies of the organisation. Where clinicians in key roles did not engage, however, this could have a very negative effect, especially on junior staff.

Some people in the Co-creating Health project teams thought that self-management support 'champions' had been significant in terms of raising the profile of self-management support and enabling it to be embedded into clinicians' everyday practice. In Torbay, clinicians who had become Practitioner Development Programme tutors had taken on the role of champion and were promoting self-management support across the area. In both Calderdale and Huddersfield, and Guy's and St Thomas', local champions had been identified in a number of clinical teams or GP practices as a way of both sustaining and spreading self-management support.

4.3 Supporting clinicians post-Practitioner Development Programme

Providing support to clinicians after they have completed the Practitioner Development Programme is essential if they are to embed self-management support in their practice and sustain it beyond the initial enthusiasm engendered by the training. Within teams, the things which made people feel the environment was supportive of self-management support varied in importance and nature but there were common elements, such as the role of senior clinicians (as

discussed above) and the need for practical steps such as focusing on one aspect of self-management support in monthly team meetings, putting reminders on computer screens, building discussions about the use of self-management support skills and tools into supervision and audit, and changing paperwork to support self-management (see chapter 5 for more about supportive systems). The influence of the wider organisational and policy environment was also important, in particular the extent to which Trusts were generally supportive of self-management, and how it fit with strategic priorities and policy drivers.

It was clear that supporting clinicians to embed self-management support within their normal practice and creating a culture amongst clinicians that was positive about self-management support was essential if it was to be sustained. As one senior clinical manager put it:

> *"It's about sustainability; if we don't support people continually then they'll just do the training programme and then that's it, there's no embedding in it, so it's about trying to continue it as part of what they do in everyday practice."*

A range of approaches to supporting clinicians after their training is needed in order to accommodate different learning styles, the time people have available, the geography of health communities, resources available etc. Most sites had, or were moving towards, a more flexible 'menu-style' approach and many highlighted the need to offer a consistent programme of support. Action Learning Sets had been used in every site in phase 1 of Co-creating Health (when dedicated funding and support were available) but by phase 2, all the sites had stopped using Action Learning Sets to the extent and/or in the way they had been used in phase 1. The main challenge for most sites had been clinicians finding the time to attend them, but cost and tutor time had also been a concern.

The list below describes the types of support available in phase 2:

- **Action Learning Sets** – Although the sites were not using Action Learning Sets to the extent they had been in phase 1, some sites were still using them in a limited form. For example, in Calderdale and Huddersfield, the Action Learning Sets worked well with therapy staff, partly because they used them to link clinicians' training and service improvement work, but they were much less successful with GPs. In Torbay, the phase 1 Action Learning Sets were very active, in part because Torbay Care Trust paid for locum cover for the GPs attending the session, but going forward they recognised that this approach was not sustainable and were looking at other approaches such as e-learning and annual refresher courses.
- **Refresher courses** – A number of sites had developed refresher sessions as an alternative to Action Learning Sets. In Whittington Health, half-day refresher sessions were offered, which picked up a theme or topic from the Practitioner Development Programme and the session was run around it. Other sites were using refresher courses but had often reduced these to one or two a year; again this was mainly because of constraints on clinicians' time.
- **Buddying** – Several sites have established buddying systems. In Ayrshire and Arran, clinicians were offered a Practitioner Development Programme tutor as a buddy. They could get support and advice from their buddy by email and could sit in on one of the buddy's clinics to learn more about putting self-management support skills into practice. In Torbay, the buddies were experienced self-management support clinicians who volunteered to sit in on newly trained Practitioner Development Programme clinicians' consultations and give them feedback.
- **One-to-one support** – In addition to, or instead of, more organised buddying systems, some sites offered one to one support. This was often provided by the clinical development lead, Local Co-creating Health implementation team members or Practitioner Development Programme tutors. However, most recognised that this approach was not sustainable in the long term. In Cambridge, they have been looking at identifying self-management support champions, whilst in Ayrshire and Arran they are linking into the Train the Trainers programme with the aim of having one person in each team of services who can take on this support role.

- **E-learning** – Several sites have recognised the potential of e-learning to support participants post-Practitioner Development Programme. Ayrshire and Arran have developed a flexible programme which clinicians can either go through systematically from start to finish or they can dip into the topics that are most relevant to them. Support is available at any point for any of the modules, and there is also e-learning support post-Practitioner Development Programme for those who have attended the course in a more conventional way. Other sites are exploring how they might use e-learning going forward.
- **Clinical supervision** – It was clear that in some sites, and particularly in inpatient settings and therapy services, clinicians were being supported in their self-management support skills through routine clinical supervision. In the Guy's and St Thomas' diabetes secondary care service, all the consultants have undertaken the Practitioner Development Programme and because they are a teaching hospital, self-management support skills are now being passed on and encouraged in the registrars who pass through the service.
- **Supportive systems and processes** – Clinicians coming out of the Practitioner Development Programme need to be supported to change their practice by the clinical and administrative systems and processes that surround them. As one team manager put it – *"That's how we are moving forward with it really. Building it into team practice rather than it being something else you have to do."*

Looking ahead, sites were very conscious of the need to find ways to sustain self-management support activities after the Co-creating Health 'project' ended. Some sites had modified (or were thinking of modifying) the type of support that was offered to clinicians post-Practitioner Development Programme. These modifications can be seen as akin to Rogers' concept of 're-invention', ie altering aspects of an intervention in order to improve the chances of it being taken up and sustained. In sites where modifications to post-Practitioner Development Programme support had been made, it was mainly because clinicians were unable to commit to lengthy action learning sets or refresher sessions that took time out of their daily work. At the Whittington Health, the uptake of Action Learning Sets was poor so these were replaced with half day refresher sessions. Attendance for these was better but still limited. It was thought that individual clinicians needed to be targeted more but the resources for doing this were limited. In Calderdale and Huddersfield, they changed to a system of offering a 'menu' of options for support post-Practitioner Development Programme; there was a need to adapt what was on offer to suit a range of clinicians. The clinical lead felt it was important to be *"fluid and flexible"* in how support for clinicians was approached. In Ayrshire and Arran, they were also considering changing the way clinicians were supported once they had completed the Practitioner Development Programme:

> *"I think we'll need to find a different model where people probably can spontaneously make contact, I think we favour that model so they can make contact with us by email ideally, to discuss questions, and we'll probably offer follow up of some sort, whether it's email contact, discussion, another group meeting, another practical session...you know, that'll probably be the way forward for us... I think Action Learning Sets, as good as they might be; we didn't find them sustainable really."* (Clinical lead)

4.4 Incorporating self-management support skills training into medical and healthcare education

The phase 1 evaluation found that previous experience of using or learning about skills similar to those developed on the Practitioner Development Programme (eg motivational interviewing, solution-focused therapy and cognitive behavioural therapy) made clinicians more receptive to self-management support. This observation fits with Rogers' concept of 'compatibility'; if a clinician's own ethos fits with that of self-management support, there is more likelihood of it being adopted and sustained in that clinician's practice (see section 4.5.1).

Recognising this, most sites had taken steps to encourage the incorporation of self-management support skills into medical and healthcare education in their localities. They were working with medical schools, Deaneries for GP training schemes and local universities to build self-management support skills training into existing courses and programmes. In some sites this had already been achieved, whilst in others it was still at the planning stage.

In Torbay, the Co-creating Health team had worked with the Pan Peninsula Medical School to build an optional self-management support module into the first year of medical student training. The module took the form of three half-day workshops, very similar to the full Practitioner Development Programme. The Ayrshire and Arran Co-creating Health team had worked with colleagues at the University of the West of Scotland to incorporate Co-creating Health principles into the Respiratory Health Module undertaken by nurses and allied health professionals. In Cambridge, the Co-creating Health team had delivered a number of practitioner development courses for GP training schemes. These took the form of two modules each lasting three to four hours, using the same materials that were used for the Co-creating Health Practitioner Development Programme. The team would like to see self-management support skills training being part of all GP training, but funding would be required and it is not clear who would pay for this addition. There would also be difficulty in fitting additional training in; most schemes only have a set number of training sessions a year and so adding self-management support skills training would mean they would have to drop something else. In Calderdale and Huddersfield, the Practitioner Development Programme had been offered as part of the care planning and consultation skills module of the 'Kirklees Health and Wellbeing Courses' public health training programme. The module was open to all healthcare professionals and had been attended by GPs, practice nurses and community matrons. Whittington Health was working with University College London to adapt the Practitioner Development Programme so that it could be offered as a module on the Health and Medical Sciences MSc course, and at Guy's and St Thomas', the team were working with King's College London to develop a new care planning/self-management support module at postgraduate certificate and Masters levels (levels 6 & 7).

Although these initiatives were mainly in their early stages (and had been, on the whole, somewhat opportunistic because this kind of 'upstream' work was not part of the sites' original plans), it is hoped that as healthcare professionals move through these respective training systems, the principles of self-management support will be 'built in' to their ways of working and hence will lead to a more sustainable future for self-management support.

> *"I would like to see young clinicians, healthcare professionals and social care professionals, who will emerge ready themselves to reshape the organisation, and they enter able to have an influence because they come with that skill set in hand. I think that's...quite critical for developing individuals and organisations for the future. I think that's absolutely essential."* (GP)

4.5 Facilitators and barriers to changing practice

The sites' ability to change practice was affected by a number of facilitators and barriers:

4.5.1 Compatibility with clinicians' approaches and practices

There was some evidence that the extent to which the ethos of self-management support was compatible with clinicians' own philosophies, experiences and practices influenced how open they were to the idea of self-management support, their willingness to undertake the training, and how likely they were to embed and sustain the use of self-management support techniques in their practice. 'Compatibility' is one of the characteristics of innovations described by Rogers which he suggests affects the successful uptake of an innovation.

As noted above, the phase 1 evaluation found that previous experience of, or training in, skills such as motivational interviewing and solution-focused therapy, made clinicians more receptive to self-management support. It was clear that certain groups of clinicians, notably therapy staff, saw self-management support as highly compatible with their training and the way they worked. An outpatient physiotherapist from Whittington Health indicated that self-management support was very compatible with the way that physiotherapists worked in general and that because of this, all the physiotherapists who had undertaken the Practitioner Development Programme had *"embraced"* the use of self-management support. The flipside to this viewpoint, however, was highlighted by a Practitioner Development Programme development lead who said that some people did not see the point of undertaking the training because they were *"doing it already"*. One of the challenges was to encourage them to go ahead with the training in order to see how it could help them improve their techniques of self-management support.

Clinicians whose philosophies fitted with the ethos of self-management support described how their practice had always been to share decisions with patients and to work in a collaborative way, so self-management support just helped them to structure that practice and develop it.

> *"I was interested in self-management because I am always thinking that patients should/could be taking more interest in their health, and would often want to, and are we giving them enough opportunities. So that was my background in wanting to become more involved with it."* (GP)

However, the compatibility of self-management support with some clinicians' practice was also partly related to its flexibility and the way it could be adapted to the clinician's individual circumstances: *"a little suitcase of skills"*.

There were some examples of how introducing self-management support had fitted with the needs of particular services or teams. In Cambridge, the Stroke Service was already looking to improve their approach to goal setting and action planning. The assistant practitioners (rehabilitation) and some therapy staff undertook the Practitioner Development Programme and, with support from the clinical development lead, a new 'patient centred' action planning tool was developed.

The compatibility between the types of patients/clients that clinicians served and the use of self-management support was influential in how likely those clinicians were to change their practice and incorporate self-management support into the way they worked. At Guy's and St Thomas', the clinical lead felt that the nurses in the diabetes department had previously used a philosophically similar approach to self-management support, but they were ready to adopt the use of self-management support because:

> *"The training enabled them to do it in a more efficient and organised way and they were then able to share experience in the way that they speak in meetings so that it is more understandable, it is not seen as a nursing thing, this is a departmental change which is very important".* (Clinical lead)

4.5.2 **Perception of benefit**

Rogers[32] suggests that if there is seen to be a 'relative advantage' in adopting an innovation over current practice then it is more likely to be taken up and used. There was evidence from the evaluation that the majority of clinicians did perceive self-management support to be beneficial to patients, themselves and the services they worked in.

Benefits to patients – Clinicians described many benefits to patients who were supported in self-management, including attending the Self-Management Programme, learning self-management skills which could be used and reused (a 'toolkit' of skills), being able to take control of their own health, set their own agenda and goals and have more say in their treatment (empowerment),

[32] Rogers (1995) Op cit

being listened to more, and increased motivation. A nurse in the respiratory medicine service at Whittington Health described the difference between the successes of the approach they previously used compared to that of the self-management support approach:

> *"Like smoking cessation, you can give them all the products...and they will just go and put the leaflet somewhere. And where you have allowed them to take more interest they can identify the problems and how they can help themselves... It works, it really works because they are able to lay down their expectations, I'm hoping to be able to achieve this, my goal is to be able to be able to walk from A to B, my goal is to wash myself independently, I want to quit smoking completely to help with my breathing."* (Nurse)

Benefits to clinicians – Clinicians could see many advantages for their practice in adopting self-management support techniques, such as improved consultation skills, more options in their consultation 'toolkits', more focused consultations (and therefore, sometimes, shorter consultations), a framework to work within, more confidence and certainty in their role, improved communication with patients/improved listening skills, greater awareness of patients' needs and more receptivity to their ideas, change in practice across the board, more openness to change in general, possible reduction in prescribing and possible reduction in number of consultations for those patients who self-manage.

> *"Before, I was working with the patient and I thought it was more of me, imposing my ideas on the patient but having done it* [the Practitioner Development Programme]*, it's more allowing the patient to tell me what they want or what they expect, what they are hoping to achieve, if they are concerned with a problem...what are they hoping to come out of the consultation. And how I can support them or help them. It has changed the way I approach those consultations."* (Respiratory Nurse)

Benefits to services – There were also thought to be benefits of adopting self-management support to the services and teams that clinicians worked in, including providing a common language/focus for the team, changing the way the multidisciplinary team approaches patient care, putting a greater emphasis on viewing care provision through the lens of the 'patient journey', giving the opportunity to look at systems more critically and hence introduce improvements, and using the technique of agenda-setting at a practice level to streamline patient appointments.

Box 8 – Benefits of self-management support in a Paignton GP practice

The population served by the practice is quite socially deprived and has a high incidence of depression. The GPs in the practice were keen to look at new ways of helping these patients and self-management support fitted the bill. Having the option of sending patients on the Self-Management Programme, whilst also practising self-management support in consultations and introducing service improvement changes, has benefited the patients, the clinicians and the practice.

"I think from a practice point of view it's achieved the focus of self-management as a team and it's a common language we all use and everybody's on board... I think as a team it's been good and for the patients it's been good and they've been able to develop some things like a patient library and some work on our website, which is going to benefit – has benefited – the patients in equipping them to do a lot of thinking themselves before they approach us." (GP)

The patients' library has been seen as very beneficial, not only for patients with depression but those with other problems that might be amenable to self-management.

> *"But what did go well for me, and I think the practice, was our library. We bought a stock of books around depression and anxiety, eating problems, smoking, weight issues – a lot of self-management books – to enable somebody to go away with a book on, say, depression or anxiety, knowing that somebody else has felt that way... I've found the library books good. Not everybody wants to be engaged, cerebral. But it's nice to be able to say 'would you like to read a book around how you're feeling, what you're feeling?', and to be able to give them that option."* (Nurse practitioner)

4.5.3 **Ease or difficulty of testing and adopting self-management support**

There was some evidence that it was more likely that clinicians would change their practice and build self-management support into their way of working if it was possible to introduce changes easily by having the opportunity to 'trial' the initiative in a manageable way (as suggested by Rogers' concept of 'trialability'). In Torbay, one of the factors which led to successful trialling of self-management support in GP practices was the introduction of a Local Enhanced Service (LES) payment to support related service improvement. This gave clinicians an incentive to focus on service improvement and remain engaged.

> *"I think it* [the LES] *was a carrot to get it started. Individually, I think we'd all started to think about it and to change our consultation methods slightly and then when the LES came up, it was an opportunity to involve the practice nurse team, and also to involve the receptionists..."* (GP)

With the support of the service improvement lead, the practices were expected to introduce small changes each month as part of their service improvement work. This approach enabled different interventions to be trialled on a small scale and made it easier and more manageable for clinicians to incorporate them into their practice:

> *"Having a monthly action to do was quite helpful, in that every month, we had to focus on what we were going to do next – because it's quite easy to let things slip and you carry on and perhaps get into different bad habits than you were in before. But having to do something different every month, and report back, was good for us."* (GP)

The phased introduction of the three elements of the Co-creating Health approach to self-management support (ie patient self-management, clinician support for self-management and service support for self-management) in Torbay meant that it was easier for clinicians to incorporate the change into their practice. In the Paignton GP practice (see Box 8 in section 4.5.2), the three different elements of the Co-creating Health programme were put in place consecutively, ie the availability of the Self-Management Programme preceded the clinicians attending the Practitioner Development Programme which preceded the service improvement work (under the auspices of a LES). It also happened over a period of a few years so there was time to build up the number of patients who had done the Self-Management Programme, consolidate the clinicians' self-management support skills and embed service changes in a structured, non-hurried manner. As the lead GP explained: *"We were quite lucky in having those three almost consecutive years of one reinforcing the next".*

Although this approach was successful in Torbay, it should not be assumed that this 'sequencing' of the three elements is always going to be the most successful method of introducing self-management support; different situations and contexts may require different approaches. In some situations resources may dictate that not all the elements are implemented at the same time, but care should be taken that they are not so widely spaced chronologically that the impact is diluted (see section 5.4 for more on the introduction of service improvement changes in relation to the other aspects of self-management support).

Conversely, where problems were encountered in practising self-management support at a clinical level because of the difficulty of introducing the three elements of Co-creating Health in tandem, this acted as a barrier to implementing and embedding self-management support amongst clinicians. The evaluation of phase 1 reported that this had been a difficulty across the sites, and the evidence from phase 2 seems to indicate that this continued to be a stumbling block for clinicians and services. Rogers suggests[33] that the 'complexity' of an innovation (ie how easy or difficult it is to adopt in practice) affects the success of its uptake and continued implementation, and this seems to be reflected in the experience of some of the sites.

In a number of teams/services, only one element of the three had been implemented (usually clinicians undertaking the Practitioner Development Programme) and some clinicians were attempting to practise self-management support without even being aware of the possibility of their patients undertaking the Self-Management Programme or of service improvement activity. Sometimes there was also confusion about how these different elements might work together. However, many felt that self-management support could not work properly if patients were not able to access training for themselves. Furthermore, it was important for Practitioner Development Programme-trained clinicians to be able to refer patients to a Self-Management Programme course so that they could get positive feedback on the value of self-management support to patients:

> *"There has got to be support in an area for patients to have some sort of self-management programme….you can have all the skills you like and you can be as welcoming as you like but you have got to provide patients skills too so that they can be getting on with their own stuff. The Practitioner Development Programme has to be just one part of it. For too long we have gone on with Practitioner Development Programme being THE part of it."*
> (Lead Practitioner Development Programme tutor/Diabetes Specialist Nurse)

In addition, patients can help to drive the change in clinicians' thinking and practice, by explaining how self-management had affected them and expecting clinicians to work with them in a different way. As one GP put it: *"There needs to be a lot more story-telling by patients who have achieved change in order to influence clinicians."*

4.5.4 **Scope and ability to adapt the Co-creating Health model**

In response to a need for the Practitioner Development Programme to be more manageable (in terms of the time commitment) for clinicians to complete and more tailored to groups of clinicians' specific needs, a number of the sites altered their clinician training programme. As with the example of sites modifying their support to clinicians post-Practitioner Development Programme (see section 4.3 above), these alterations fit in with Rogers' concept of 're-invention'. The greatest changes were probably made in Torbay where instead of just one Practitioner Development Programme they introduced three 'levels' of training: 'gold' 'silver' and 'bronze' (see section 2.2.2). This approach has enabled a wide range of staff (including receptionists and healthcare assistants) working in GP practices across Torbay to gain an understanding of self-management support. In particular, key groups such as practice nurses, who may not have been given the time to do the full Practitioner Development Programme, have been able to undertake 'silver' level training. Revising the programme in Torbay was seen partly as a practical decision to overcome the inability of some clinicians to do the full training and partly as a response to a belief that the programme contained some repetition and could be streamlined. In the Cambridge stroke service they have cut down the programme to a series of three one-and-a-half-hour sessions so that it can be delivered 'in house'. This is in response to a large number of staff rotating into the service for a period of only a few months – it would be very difficult to deliver the full training to all of these clinicians. In other sites, the programme has also been shortened: at Whittington Health, the length of the sessions for the programme has been cut down from three to two hours for some GPs.

[33] Rogers (1995) Op cit

In Cambridge, the content of the Practitioner Development Programme has been changed in order to *"adapt the training to the challenges and priorities of different teams"*. This was felt to be necessary because it was becoming increasingly difficult to recruit to a stand-alone course; they needed to be able to address teams' different priorities. Flexibility is also being added to the programme being offered to clinicians from the musculoskeletal pain service at Whittington Health in order to match the needs of the service. A GP from South West London, who is also a Practitioner Development Programme tutor, felt that it was important to be able to adapt the programme to one's own locality and population because, although there are similarities between areas, there are also differences. Other sites have also 're-packaged' the course to make it more accessible. In Ayrshire and Arran the feedback they gathered from clinicians in phase 1 showed that *"one size doesn't fit all – people learn differently"* and so they moved to a much more menu-based approach. They still offer the Practitioner Development Programme in face-to-face workshops, but they also have an e-learning course and run monthly introductory sessions.

Although some sites have found it necessary to adapt and/or cut down the Practitioner Development Programme in order to fit in with clinicians' priorities and schedules, there was some concern expressed that the impact of the programme could be watered down if the training did not include all the elements, in particular those that were more interactive and enabled clinicians to 'practise' the skills. It is not possible to judge yet if this is being borne out in reality, but some sites clearly felt that there was a trade-off to be made whereby having a shorter/more easily accessed course which led to more clinicians being trained outweighed concerns about the depth of the training.

Chapter 5
Sustaining Co-creating Health – Build self-management support into the patient journey

Building on the work of the technical provider, the programme evaluation explored if and how sites were embedding and sustaining self-management support across the whole patient journey. Specifically four important sub-mechanisms were identified:

- using tools, templates and IT systems to reinforce self-management support
- building on existing initiatives
- working across different sectors and with partners
- targeting and sequencing service improvement work.

A range of factors was identified which influenced the extent to which self-management support was 'hard-wired' into the patient journey. These were: national policy and quality improvement frameworks; team capacity and access to support; leadership and organisational culture; and information systems.

In phase 1 of Co-creating Health, the Service Improvement Programme focused on the use of the Co-creating Health 'three enablers', ie agenda setting, goal setting and goal follow up. Although teams were encouraged to adopt PDSA to support the use of the three enablers, the emphasis in service improvement terms was on the individual interaction between the clinician and the patient. This was based on the assumption that clinical consultations provide an important opportunity for clinicians to support patients in their self-management efforts, through co-produced decisions and plans. The phase 1 evaluation showed that *"co-production* [in decision making and planning] *was not confidently and consistently applied as routine"*. The reasons for this were complex, but the evaluation team noted that whilst many clinicians were using agenda setting, the task of incorporating the interactive package of the three enablers in consultations was seen as time consuming and impractical for many clinicians. For secondary care clinicians in particular it was often difficult to undertake goal follow-up when their consultations were several weeks or months apart.

In phase 2, the technical provider (PwC/PEAKS) adopted a more flexible and site-focused approach. Using a collaborative learning model, they supported clinicians and managers in the sites to develop the knowledge, skills and behaviours required to deliver the three enablers. They continued to use PDSA methods, but working with the new service improvement technical leads, whose role was to lead and coordinate the service improvement work in the sites, they encouraged teams to make modest service improvements which would facilitate and encourage self-management support. Key learning from the service improvement work is available on the web-based self-management support resource centre set up by the Health Foundation[34].
It is clear that in phase 2, all the sites made progress in changing aspects of service delivery or systems in order to facilitate or reinforce self-management support. These ranged from the development of tools and templates designed to prompt or sustain self-management (eg Personal Health Plans in Cambridge, and My Health Plan in Ayrshire and Arran and Guy's and St Thomas' Trust), to changes to IT systems to remind clinicians about agenda setting, goal setting or goal

[34] http://selfmanagementsupport.health.org.uk/

follow-up (eg SystmOne templates developed in Calderdale and Huddersfield to enable goals set with community teams to be seen by other health professionals) or to encourage them to use techniques learned on the Practitioner Development Programme (eg pop-up reminders on information systems in Torbay and Whittington Health). However, whilst valuable, most of these changes focused on a specific aspect of service delivery or a particular clinician/patient interaction, rather than looking more strategically at the whole patient journey.

Interestingly, at the start of the Co-creating Health programme, key stakeholders saw the potential for embedding self-management support into care pathways. The phase 1 evaluation reported:

> *"The opportunity for Co-creating Health to support process or pathway redesign was cited by both PCT and provider trust CEOs in year 1, but it is clear this aspect of Co-creating Health was not developed at any site."*

In their proposals and spread plans for phase 2 of Co-creating Health, all of the sites made clear their desire to build self-management into care pathways and service improvements in a more robust fashion. In particular, there is an emphasis on embedding change related to the specified condition; on ensuring more connectivity across health and care sectors; and on influencing care pathways for other long-term conditions.

It is perhaps helpful to say something here about what is meant by the term 'care pathway' and how it has been used in the context of Co-creating Health. Put simply, a care pathway should *"support treating the right patient at the right time and in the right way"* [35]. Generally, the Co-creating Health sites have used the term 'care pathway' more loosely to describe the 'patient journey' through the whole or part of a care system, for a particular condition. However, a care pathway can also be something which is robustly evidenced-based and systematic in nature; these tend to be termed Integrated Care Pathways (ICPs). There are many definitions of ICPs – the European Pathway Association states that:

> *"A care pathway aims to improve the continuity and coordination of care received by patients from various professions and organisations across the continuum of care in order to improve patient outcomes, safety and satisfaction and make the best use of resources"*[36].

ICPs differ from 'guidelines' and 'protocols' because there is more emphasis on forming a multidisciplinary, locally-agreed, evidence-based plan. However, the evidence base for the effectiveness of ICPs is not clear; a systematic review of ICPs in 2009[37] states that *"the evidence to support their use is equivocal and understanding of their 'active ingredients' poor".* Notwithstanding this, there is now increasing emphasis in the NHS on ICPs. The *NHS Outcomes Framework 2012/13*[38] emphasises collaboration and integration, and promotes the development and use of quality measures along with ICPs through which CCGs can commission integrated care packages from a range of local providers. In relation to long-term conditions, National Institute for Health and Care Excellence (NICE) guidance on long-term conditions such as COPD and diabetes have promoted and informed the development of ICPs – but by-and-large these focus on clinical aspects of delivery/decision making. More generic ICPs for long-term conditions are now being promoted in England/Wales (for example, through the NHS Improvement Programme)[39], and

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[35] *On care pathways* Bandolier Forum, July 2003. Available at: www.medicine.ox.ac.uk/bandolier/Extraforbando/Forum2.pdf

[36] European Pathway Association *Clinical/Care Pathways*. Available at: www.e-p-a.org/index2.html

[37] Allen D, Gillen E, Rixson L (2009) *The effectiveness of integrated care pathways for adults and children in health care settings: a systematic review* JBI Reports 2009; 7(3): 80

[38] Department of Health (2011) *NHS Outcomes Framework 2012/13* Department of Health, London

[39] Department of Health (2012) *Effective pathways for long term conditions* Department of Health, London

through NHS Scotland[40]. Generally the Co-creating Health sites have used the term 'care pathway' more loosely to describe the 'patient journey' through whole or part of a care system, for a particular condition.

Interestingly, whilst much of the national work on long-term conditions does consider how *self-care* amongst patients can and should be encouraged and promoted across all parts of the pathway of care (eg Self-Care – A Real Choice; Self-Care Support – A Practical Option[41]), there is little consideration of how this relates to *self-management support,* and the systems and processes that need to be put in place to embed self-management support along the care pathway. The programme evaluation provided an opportunity to build on the work of the technical provider to explore if and how the sites had been able to build self-management support into aspects or stages of the patient journey, and consider what had helped or hindered progress. Specifically we identified four important sub-mechanisms for embedding and sustaining self-management support across the whole patient journey:

- using tools, templates and IT systems to reinforce self-management support
- building on existing initiatives
- working across different sectors and with partners
- targeting and sequencing service improvement work.

Each of these is considered in more detail below, followed by an analysis of factors that have facilitated the sites efforts and the barriers which have inhibited progress.

5.1 Use tools, templates and IT systems to reinforce self-management support

It was clear that changing tools and systems so that they underpin self-management support was often difficult, and ensuring such changes were robust and widely accepted was even harder. A quote from the Cambridge local evaluation report illustrates this:

> *"Working with the APRs* [Assistant Practitioners (Rehabilitation)] *in the stroke unit demonstrated a high level of personal engagement with service improvement where it was integrated with the training. The APRs developed and refined an action planning form while they were learning the skills and were able to review their experiences of the form in the training sessions. This was evaluated very positively by the APRs... However, there were challenges in integrating the use of the form into the wider rehabilitation processes in the unit."*

However, sites had worked to embed self-management support through tools and systems in a variety of ways. Several contributors emphasised the importance of this 'hard-wiring' in order to embed and reinforce learning amongst clinicians and patients, encourage consistency, and enable monitoring/sharing of information. Some examples are briefly outlined below:

- **Patient communication and information –** Several sites had developed templates that patients could use to prompt or sustain their self-management activities (eg 'Personal Health Plans' in Cambridge and 'My Health Plan' in Ayrshire and Arran and Guy's and St Thomas'). Others routinely informed patients about their results in advance of appointments (eg in Cambridge and Whittington Health) and helped people prepare for consultations (eg 'Your Appointment' forms in Torbay). Increasingly, sites were finding ways to routinely inform patients about self-

[40] Scottish Government Long Term Conditions Collaborative (2010) *Improving Care Pathways* The Scottish Government, Edinburgh

[41] Department of Health (2005) *Self-Care – A Real Choice; Self-Care Support – A Practical Option* Department of Health, London

management resources (eg downloadable apps for smart phones; publicising links to self-help websites; and the creation of self-management libraries in GP practices in Torbay), including signposting them to peer support post-Self-Management Programme (eg in Calderdale and Huddersfield). Some were using different media to communicate with patients (eg a GP in the Whittington Health site uses the nhs.net account for the practice to send texts to patients two weeks after agreed goal-setting. Most patients are happy for her to send the texts and liked the system; she has found this a very powerful method of follow up).

- **Promoting a multidisciplinary approach –** A number of sites described arrangements for routinely sharing individual goal-setting information within multidisciplinary team meetings (Cambridge). Others were sharing goal-setting information through IT systems (eg in Calderdale and Huddersfield, SystmOne templates enabled the goals set with community teams to be seen by other clinical professionals).
- **Using IT to promote the Self-Management and Practitioner Development Programmes –** Both Guy's and St Thomas', and Ayrshire and Arran have developed e-learning practitioner development modules for clinicians, and in Ayrshire and Arran they are developing on-screen prompts to remind and encourage clinicians to refer patients to the Self-Management Programme: *"It won't just come up at diagnosis – it will be attached to the patient's records and will flag up every time they are in the practice".*
- **Workforce development –** A few sites had created pop-up reminders on information systems to encourage clinicians to use techniques learned on the Practitioner Development Programme (eg in Torbay and Whittington Health). In Calderdale and Huddersfield they had also incorporated self-management support into job descriptions and recruitment processes, for example, by asking applicants at interviews about their approach to SMS.

5.2 Building on existing initiatives

It was clear that some sites, particularly those focusing on diabetes and COPD, had been able to take advantage of local or national initiatives, not only to raise awareness of Co-creating Health and roll out training, but as a lever for making service improvements or more firmly embedding self-management support into care pathways. Indeed, a few contributors felt that piggy-backing on other initiative was one of the keys to sustainability:

> *"If you're going to sustain something, you can't develop a whole new programme – it has to become part of other initiatives. You have to be on the lookout all the time for other things that you can be part of. It may be different in other areas, but in London there are lots of opportunities to tap into."*

The Diabetes Modernisation Initiative is a good example here. Both of the sites that had focused on diabetes were encouraged by the profile that self-management had achieved and some of the system changes that have been introduced as a result. At Guy's and St Thomas', they changed the patient pathways and developed guidelines for GPs on the back of this initiative. The project manager explained how one of the targets of the Diabetes Modernisation Initiative, to set up guidelines for GPs and Co-creating Health, has been a key driver. Another of the Diabetes Modernisation Initiative targets was to have 100% of newly-diagnosed people with diabetes doing self-management training, so they all go through this pathway now, as the Self-Management Programme is a designated follow up to DESMOND. The project manager said that being part of a wider programme has been really valuable in promoting a more consistent approach:

> *"What is important is that everyone is being given the same information and it is the same structure across Lambeth and Southwark. It has given direction to GPs."*

In Ayrshire and Arran, the Health Board obtained European funding to develop a telehealth care programme for people with long-term conditions. The Co-creating Health team have been working with the telehealth team to build self-management support into the telehealth care pathway for patients with COPD. They recognised that for people with these conditions to make the most of the equipment they were being provided with, they would need the skills and confidence to self-manage. It was agreed that all patients with COPD going onto the telehealth care programme should be invited to attend a self-management programme being delivered in the locality, before getting the telehealth equipment.

In some areas there were well-established condition-based programmes, and efforts had gone into making strong links with these or even combining them, such as the development of the Enhanced Pulmonary Rehabilitation Programme in Cambridge. Here a member of the Co-creating Health Team described how self-management principles have been absorbed into an existing rehabilitation programme – they have not changed the care pathway, but she believed that the quality of provision had been improved and that it may eventually change referral patterns:

> *"What we haven't done is advertise it externally as an alternative – it's just 'this is the gold standard in this area and this is what you get'. So I don't think it's necessarily had an impact on recruitment but one of the things moving forward which we'll look at is whether it encourages people to send a different type of patient on to this programme. So I think if we can get this going more fully, then I think that is one of the questions we'd be asking."*

5.3 Work across sectors and with partners

Changing care pathways demands working with a range of different partners and in different health sectors, and there were many examples of how sites had approached this. In some instances the focus had been on establishing common approaches, which cut across health sectors or teams. At Guy's and St Thomas', the work in diabetes services has cut across hospital and community clinics (in both Lambeth and Southwark). Clinicians in both areas have been using 'My Health Plan' (agenda and goal setting tool) in consultations and the majority of clinicians in both areas have done the Practitioner Development Programme so *"they're all using the same language".* The South West London and St George's Co-creating Health team had established links with Wandsworth's 'virtual ward'. The service provides support at home to people (with a range of long-term conditions as well as mental health needs) who might otherwise be admitted to an acute hospital ward. As part of this initiative, the Practitioner Development Programme has been delivered to community matrons, who are using goal setting in their practice.

Other sites are building wider links. In Calderdale and Huddersfield, the Co-creating Health team are starting to work with other agencies as part of developing a more 'whole systems' approach, including building on existing community, third sector and local authority structures. However, both the project manager and the associate medical director explained that, with hindsight, they wished they had made these links sooner. In particular, they were quite a long way into the project when they realised the local authority had expertise and knowledge they could draw on. Guy's and St Thomas' have also been working through other agencies to spread self-management support, eg the Health Innovations Education Cluster (HIEC) for SE Thames to promote the fact that self-management support should be part of the whole care pathway. Also, as part of the HIEC, they were able to support the inclusion of self-management principles into the training for GPs.

5.4 Target and sequence service improvement work

The phase 1 evaluation report noted that in many sites there had been a relatively 'untargeted' approach to delivering Self-Management and Practitioner Development Programmes. This not only

inhibited the development of the patient/clinician relationship in terms of supported self-management, it also limited the opportunities for service improvement work, as not all staff within teams or service areas were familiar with the Co-creating Health concept. During phase 2, all the sites had adopted a more targeted approach to delivering training, focusing on whole teams, or on groups of people working within distinct parts of the care pathway. The advantages of this approach for changing practice amongst clinicians are discussed in chapter 4. However, it was clear that this approach also benefited from the promotion of service improvement work.

Some service improvement work was undertaken through formal arrangements or specific initiatives. For example, in South West London and St George's, the project manager worked in partnership with a Well Being Practitioner (who was Co-creating Health trained and a Practitioner Development Programme tutor) to try and embed changes within the Practitioner's Community Mental Health Team. The Well Being Practitioner was given dedicated time to support this work and, together with the team, she and the project manager made a number of operational changes, such as introducing SMART[42] tools for goal setting and adjusting relevant paperwork. Similarly (as was noted in chapter 4), Torbay provided practical support and agreed to make LES payments to six GP practices who agreed to undertake service improvement work which would reinforce their self-management support activities. However, many of the smaller changes that teams and services had made happened because people had undertaken the Practitioner Development Programme and had been inspired by the Co-creating Health approach. This internal ownership was very important, but people also needed to be encouraged to think systematically about where to focus their service improvement efforts, and there were examples from the sites of more systematic approaches. Again in Torbay, primary care teams were given the opportunity to 'process map' and identify areas for change, with the support of an external facilitator.

There were differing views about when teams or groups of clinicians should start thinking about service improvement work related to self-management support, and when to provide support for this. Many contributors felt that service improvement work should begin as soon as possible after people had been through the Practitioner Development Programme, and some felt this should have been a more explicit part of the Co-creating Health model. Others suggested that service improvement has to be considered at a very early stage, possibly even before clinicians did the Practitioner Development Programme.

> *"You can do the training but the service has to be able to change with it. You need to evaluate where your service is first, eg Do major changes need to be made in order to incorporate self-management? What is the service delivery like? What is the operational framework like?"*

As the Co-creating Health project drew to a close, a number of senior stakeholders from across the sites reflected on how the service improvement process, as a facet of the Co-creating Health model, had or needed to change. They felt that the early focus on the three enablers had encouraged quite a myopic approach to service improvement. To sustain Co-creating Health, sites should think through required changes on a more 'whole systems' basis and consider how specific Service Improvement Programme activities might relate to broader service or quality improvement work across the organisation. Linked to this, they highlighted the importance of a strategic approach to service improvement activity which looked at the whole patient journey from the patient's perspective, and targeted service improvement resources and activity on the places or steps on the journey where changes would have the most impact in terms of supporting clinicians' practice or patients' behaviour. As one senior manager put it:

> *"Step back – don't make changes. Look at what gets in the way of patients having a collaborative relationship with their clinician. Identify the barriers."*

[42] An acronym for a commonly used approach to making changes – Specific, Measurable, Achievable, Realistic, and in a specific Timeframe.

5.5 Facilitators and barriers to building self-management support into the patient journey

A range of factors was identified which influenced the extent to which self-management support was 'hard-wired' into the patient journey. These are summarised here as:

- national policy and quality improvement frameworks
- team capacity and access to support
- leadership and organisational culture
- information systems.

5.5.1 National policy and quality improvement frameworks

Over the last decade, NHS quality improvement programmes have positioned patient centeredness and patient involvement, as well as self-management interventions for long-term conditions, within several government initiatives – for example, NICE Quality Standards, Patient Recorded Outcome Measures (PROMs), Quality Accounts, and the Quality and Outcomes framework (QOF). QOF was introduced to primary care in 2004 as part of the General Medical Services Contract and is a voluntary incentive scheme for GP practices in the UK, rewarding them for how well they care for patients. QOF is used across the four nations of the UK.

The Commissioning for Quality and Innovation (CQUIN) framework was introduced by the Department of Health (England) in April 2009 as a national framework for locally agreed quality improvement schemes, and a major driver for commissioners in England is the government's Quality, Innovation, Productivity, Prevention (QIPP) agenda. This is a programme designed to improve quality and increase cost-effectiveness to provide £15 to £20bn of efficiency savings by 2014/15[43]. In Scotland, each year the Scottish government agrees a suite of national NHS performance targets known as HEAT targets (Health Improvement; Efficiency and Governance; Access to Service, and Treatment appropriate to individuals). Healthcare Improvement Scotland is a health body formed on 1 April 2011. Created by the Public Services Reform (Scotland) Act 2010, it has a support and scrutiny role in relation to quality and service improvement.

These main service improvement policy drivers were generally regarded as useful means of making Co-creating Health more high profile, and as vehicles to encourage clinicians to adopt Co-creating Health and to embed service improvements. Many practitioners said it was a valuable exercise to make these links:

> *"Hooking this onto QOF and QIPP has been essential to help give it some priority. If you do this, it in effect delivers this aspect demanded of QOF – it made it easier for them."*

However, some contributors (notably in mental health) were more guarded in terms of the ultimate benefits of these policy drivers, and the extent to which they have embedded improvements. One said: *"Whilst linking changes to QIPP and QOF helped, and could enable access to wider income streams, Co-creating Health was still seen as extra work."* A senior clinician, (also within mental health) described how Co-creating Health has been linked to CQUIN targets concerning individual patient's recovery goals, and a template has been developed for this for clinicians to use. But, he said:

> *"CQUIN targets were largely financially driven. Procedures are in place to make these changes sustainable – ie filling the form in – but the training to support this has not been regarded as high priority. Ninety per cent of patients now have recovery goals and this*

[43] NHS Information Centre. *Supporting QIPP.* http://www.improvement.nhs.uk/Default.aspx?alias=www.improvement.nhs.uk/qipp

> *can be reported, but it is questionable whether care is more meaningful or safer or whether there is more confidence amongst staff in using this approach."*

This clinician said that he tried to use CQUIN as a vehicle to insist on the Practitioner Development Programme but the Trust did not want to do this – partly because of the costs, but also because in his view they did not recognise the necessary behaviour change required: *"They just saw it in process terms – completing a form".* Another contributor in mental health was concerned to see stronger policy initiatives related to self-management: *"There needs to be NICE guidance – or Payment by Results and specific CQUIN targets, otherwise it will be given no attention or priority – it's just seen as an add-on".* By contrast, a GP in Whittington Health reflected on how complementary Co-creating Health is to the current policy environment:

> *"Co-creating Health has been a real catalyst in this work. Embedding self-management support into practice is a central part of the new Health and Social Care Bill and a number of things are coming together at the moment to allow it to happen more proactively."*

5.5.2 **Team capacity and access to support**

Capacity for development work within the Co-creating Health teams has been a critical influence on the extent and nature of service improvement work. At a practical level, it must not be forgotten that in many sites there were several changes to Co-creating Health team personnel (with, for example, seven different project managers in one area), which had a somewhat compromising effect on sites' ability to engage clinicians and promote change in a consistent way.

Sites also set up the Co-creating Health teams in different ways, and the amount of dedicated support for service improvement work, and the skill base and capacity of the teams varied somewhat. It was clear that service improvement work had been very limited, where dedicated support was not in place, for example where the project manager was expected to cover multiple roles, and supporting clinical staff had little capacity to offer much in the way of 'hands-on' support. However, most Co-creating Health teams included people who had dedicated time/expertise for service improvement activities during phase 2 of the evaluation. For example, in Torbay an external service improvement consultant has been funded part-time to work with the GP practices involved in Co-creating Health – she felt that her role had been critical in providing the necessary expertise and focus for promoting change within primary care practices. In Ayrshire and Arran, a practitioner within the Co-creating Health team has had specific responsibility for service improvement work, and did not get directly involved in any of the training. She described how she has been able to offer advice as Co-creating Health has rolled out to other areas:

> *"As long as they don't want us to do everything, then we'll work with them because what we're trying to do is to sustain this by creating capacity within services that will embed that as part of what they just do and they can keep it going and we can co-ordinate on quality assurance aspects and give that support. But the limitations on this are just based on whether people want to get involved or not.... We'll do what we can to give people the support that they need, but what we're quite clear about from the beginning is that we won't do it for them."*

It is not clear how all of the sites will be able to continue this support after Co-creating Health funding has ceased, but certainly an intention remains in Ayrshire and Arran to maintain the type of support described above, and Cambridge have established a Centre for Self-Management Support as a centre of expertise to develop this work further.

Another significant issue is the fact that many sites did not feel they had fully 'embedded' the Self-Management and Practitioner Development Programmes within the first phase of Co-creating Health. Frustrations were expressed about the rigidity of the training modules, and about the lack of patient and staff involvement in developing them. As a result of this, much of project staff time during phase 2 of Co-creating Health has been spent adjusting the training modules and marketing/delivering them in different ways, and to different groups of people. Also, staff in some

sites felt there was a lack of clear evidence of the impact of Co-creating Health from the phase 1 evaluation report, and this resulted in project staff putting their energies into gathering evidence of impact. To a greater or lesser extent across projects, these were factors which resulted in reduced capacity for a systematic approach to considering how self-management could be more effectively linked to care pathways/service improvements. Furthermore, given the profile of Co-creating Health and the seniority of some of the stakeholders involved in the sites, there was scope to tap into a wider skill base within the organisation and potentially have a much greater impact on the evidence-based redesign of care pathways.

5.5.3 **Leadership and organisational culture**

Influential clinicians who had the power and authority to promote self-management support were one of the keys to making changes to services and care pathways. In particular, it is the combination of leadership and 'position power'. For example, in Cambridge, the leadership and authority of the clinical lead was highlighted as a key factor in getting self-management more embedded into the COPD care pathway: *"It's the fact that it's led by* [the Clinical Lead]*, that it's part of the integrated pathway, and he's interested in getting us in and he talks to colleagues*". As was noted in section 4.2, in Whittington Health the head of the Musculoskeletal Pain Service (who was also a clinician) heard about the Practitioner Development Programme for diabetes clinicians and undertook the programme to learn more. Following this, she encouraged the whole Musculoskeletal Pain Service team to embrace self-management support and, over a period of about six months, all members of the team attended the programme. This has ultimately influenced the development of a new pain pathway. Part of the assessment process has been cut out because practitioners are relating to patients in a different way, and this has resulted in more time being spent actually talking to patients about their care and self-management. One contributor stressed the importance of the range of people in key positions who need to be 'on board':

> *"The changes have to be owned by the people who are responsible for the service, ie the budget holder, senior clinicians and managers – the ones who are accountable."*

By contrast, in some sites the difficulties of leadership and culture were mentioned as one of the main barriers to embedding the Co-creating Health approach into care pathways and service delivery. Contributors from one site described this happening on a number of levels. A clinical lead said that even though he was in a relatively senior position, those involved in implementing Co-creating Health were not directly accountable to him so he lacked the power to make things happen; an enthusiastic executive sponsor left post during the life of the project and one of the clinical leads commented that: *"We never really recovered from that"*; and there was a perceived lack of knowledge about, and support for, the Co-creating Health approach at Trust board level and within the local CCG. One of the clinical leads commented that without such top-level support it was almost impossible to introduce changes.

Aside from designated clinical leads, most other leaders emerged as the projects progressed, often as a result of attending the Practitioner Development Programme and being inspired by Co-creating Health to roll it out in their practice or service (as in some of the examples above). In the later stages of Co-creating Health, Calderdale and Huddersfield decided that a more strategic approach was required, creating leads across clinical divisions (as outlined in section 6.2.2).

There was general recognition that creating a culture receptive of self-management support was not easy and would take time. Several contributors stressed the importance of taking the time to get 'buy-in' from teams; to get them to accept and promote changes in service delivery; to increase awareness of the importance of putting patients at the heart of care; and to develop new ways of relating to patients – these were sometimes described as the *"softer skills"* of self-management support. The two quotes below illustrate these issues:

"There's a whole load of 'letting go' that's difficult for clinicians – you know, 'If I do that to a patient, and they take the wrong thing, or they do the wrong thing, then am I clinically responsible?' Some people believe it doesn't work. Some people use it as a form, so not understanding the concept of embedding and teaching the tools, and actually that the PHP [personal health plan] is just the platform – it's not the thing itself – it's not self-management."

"It's [Co-creating Health] fundamentally changed the way they work with patients and the way they expect their team to work with patients. It's much more collaborative."

5.5.4 **Information systems**

Making changes to information systems is a functional but often essential component of changing service delivery and care pathways. In some sites this has proved to be a barrier to progress, and there were only a few examples of success. Some contributors expressed concern that service improvement might be lost if changes were not sufficiently embedded in this way, for example, in Cambridge they faced the not untypical problem of GP practices using different IT systems:

"We have a slightly different problem with the system here because GPs are on 2 different systems so it's difficult to put a self-management flag on to EMIS [44] or SystmOne – and actually we've got one of our cluster GPs working on that as we speak."

Nonetheless, some sites had been able to introduce changes, for example, in Ayrshire and Arran most GPs use the same system and the project manager described how patients will have a tag on their records to prompt the GP to check if they have been offered a self-management programme:

"So that becomes a routine prompt to allow people to recognise that we are encouraging people to be supported to manage their own condition and that there are opportunities for them to refer people into that programme. It won't just come up at diagnosis – it will be attached to the patient's records and will flag up every time they are in the practice, so over the lifetime of their diagnosis, it should flag up."

As this rolls out, the project manager said it will be possible to link it to specific long-term conditions:

"As we spread to the different specialties, we'll then be able to say to the IT people to add this on to the people who have a record of stroke, or whatever it might be. So that then becomes systematic and it's not reliant on some people finding out and some not."

There was another positive example in Guy's and St Thomas' where the new EMIS template has changed practice:

"Nothing changes behaviour of GPs and practice nurses like the template in front of them changing."

The complexity of the IT 'context' and the ability to take advantage of any electronic templates/systems in development is likely to have a material impact on both the ability to reinforce change and the pace of change.

[44] EMIS and SystmOne are GP practice information systems.

Chapter 6
Securing the wider take-up of Co-Creating Health

All seven Co-creating Health pilot projects achieved some 'spread'. A number of common themes emerged in relation to securing the wider take-up of self-management support which can be grouped under two broad headings:

- **Making the 'business case' for the Co-creating Health model of self-management support** – including: evidence that the Co-creating Health model has the potential to deliver 'value for money'; showing how the Co-creating Health approach can improve patients experiences; and taking steps to influence commissioners through the development of 'business cases', building Co-creating Health into 'bundles' of care and presenting evidence.
- **Adopting a strategic approach** – using both generic and tailored approaches to implementing SMS; making connections with existing policies, initiatives and strategies to establish wider organisational support; enabling input from different stakeholders and building relationships with external agencies, to help promote spread.

As a model for self-management support, Co-creating Health is not easy to spread. Its three interrelated elements – self-management training for patients; self-management support training for clinicians and service improvement activities (to support and reinforce the first two elements) – all have to be in place for the model to work as intended. More effort is required on the part of clinicians, service managers and commissioners to understand and embrace this integrated approach to SMS, and some resources are needed to support its implementation. Furthermore, the emphasis on co-production can be challenging for some clinicians, and practically difficult for some patient groups. However, if the Co-creating Health approach to self-management support can be established at a systemic level, it offers the opportunity to fundamentally alter how people with long-term conditions are supported to manage their own health.

All the Co-creating Health phase 2 sites faced real challenges in spreading the Co-creating Health approach to self-management support during the relatively short lifetime of their projects. However, they all made some progress, either in spreading 'vertically' along the patient journey for a particular condition or spreading 'horizontally' to other long-term conditions. Some sites also took steps to widen access to the Self-Management Programme through targeting 'harder to reach' patient groups.

If the Co-creating Health model of self-management support is to be spread (and sustained), both within the existing sites and to other health economies, clinicians and service managers advocating Co-creating Health will need to be able to 'make the case' within their own organisations, and service providers will have to gain the support of their local commissioners. They will need to present the anticipated costs and benefits (to patients and services) of the Co-creating Health approach compared to other self-management support options, and some may even need to convince their commissioners of the need for any kind of self-management support.

Whilst the seven Co-creating Health projects were operating in different organisational contexts, a number of common themes emerged in relation to securing the wider take-up of self-management support, which are considered in this chapter under the headings of:

- Making the 'business case' for the Co-creating Health model of self-management support

- Adopting a strategic approach

6.1 Making the 'business case' for the Co-creating Health model of self-management support

Here we draw on the evidence available from the sites in relation to value for money and patient experience, and also reflect on ways in which sites have been able to influence commissioners.

6.1.1 Effectiveness, efficiency, economy and equity

As was noted in chapter 1, the focus in the phase 2 programme evaluation was on how Co-creating Health had been sustained and spread, not on its impact. However, in their local evaluations all the sites decided in some way to assess the impact of Co-creating Health on service use, costs and patient experience or clinical outcomes. Here we draw on a full cross-site analysis of the findings from the local evaluations to show how sites had begun to demonstrate that Co-creating Health represented 'value for money'. In particular, we consider three of the four value for money dimensions identified by the National Audit Office[45]: Effectiveness ('spending wisely'), Efficiency ('spending well'), Economy ('spending less') and Equity ('spending fairly').

Four of the sites (two had a joint evaluation) were able to provide useful and relatively robust evidence that the Co-creating Health model has the potential to deliver value for money in supporting people with long-term conditions. Extracts from their local evaluation reports illustrate the key findings:

Guy's and St Thomas' Foundation Trust and Whittington Health – effectiveness:

> *"We were able to show a clinically-significant improvement in diabetes control in patients who attended the Self-Management Programme with a poor starting HbA1c[46]. The reduction in HbA1c of 0.6% (in those with a starting HbA1c of over 7.5%) if sustained will have a significant impact on reducing the risk of diabetic complications. This is of particular importance given that diabetic complications are the major cause of patient morbidity and the chief source of great cost to the NHS in diabetes management.*
>
> *It is further important to note that this degree of HbA1c improvement is similar to that reported with the newer antidiabetic drugs being developed and launched. For example, there has been a huge growth in the use of DPP-4 inhibitors (Dipeptidylpeptidase-4) over the last 2 years. The most used agent, Sitagliptin, gives a mean reduction in HbA1c of 0.61% at the usual treatment dose of 100 mg daily. A year of treatment with Sitagliptim will cost the NHS £434. In comparison, the Self-Management Programme will give a similar reduction in HbA1c, but will also give the patient the skills to manage the other multiple co-morbidities and long-term conditions they are struggling with."*

Torbay – efficiency:

> *"Completing the Self-Management Programme is associated with a decreased level of psychiatric symptomatology and an increased level of the participant's confidence to self-manage their illness.*

[45] See, for example, http://www.nao.org.uk/successful-commissioning/successful-commissioning-home/general-principles/value-for-money/assessing-value-for-money/

[46] HbA1c or glycated haemoglobin: Haemoglobin is a natural component of red blood cells; it is renewed every 8-12 weeks. Glucose in the blood sticks to haemoglobin, so the higher the glucose level, each hour and day, the more sticks to haemoglobin. This forms HbA1c or glycated haemoglobin, which can be measured. The higher the average blood sugars, the higher the HbA1c result. The HbA1c of a person without diabetes is 4.2% - 6.2%. Blood glucose control close to this level has been shown to prevent and lower the risks of serious diabetes complications. The NHS QOF sets 7.5% as a cut-off for better control.

> *This increase in confidence is significantly correlated with the reduction in psychiatric symptoms.*
>
> *The self-management programme for depression has a similar rate of successful response as the standard talking therapy available locally on the NHS, but at a lower financial cost.*
>
> *Completing the Self-Management Programme is associated with a significantly reduced number of primary care contacts in the six months after the course as compared to the six months before.*
>
> *Utilising the Co-creating Health model in primary care is associated with a decreased number of psychiatric secondary service referrals."*

NHS Ayrshire and Arran – economy:

> *"The MoT* [Moving on Together] *self-management programme for patients in conjunction with the WiP* [Working in Partnership] *e-learning programme for clinicians appears to offer significant benefits for the patients involved. Not only do they gain confidence to self-manage their condition, but they are also less likely to have to attend the hospital or visit their GP on a regular basis. This benefit is achieved at quite a minimal cost in comparison with the cost savings that it is shown could be achieved in the long run through service usage. The lower year-on-year costs of the new service compared to the current service, as well as the significant benefits achieved, therefore suggest that this intervention is cost-effective."*

There was less evidence of value for money in relation to 'equity', as this had not been a particular focus of the local evaluations. Several project managers spoke of barriers to access including language difficulties, patients in full-time employment being unavailable, and patients' additional health problems, which need to be addressed. However, in practice, there were some good examples of peer networks spreading self-management support to typically 'hard to reach' groups, as outlined in chapter 3.

Further to this, whilst no sites had costed its impact, many project managers were of the view that Co-creating Health would not have been able to be delivered on the same scale without the co-produced nature of Co-creating Health and the significant contributions of lay tutors. Whilst there is a cost involved in recruiting and supporting patient volunteers, the financial and wider benefits to the organisation are far-reaching.

6.1.2 Patient experience

Both the phase 1 evaluation report and the phase 2 local evaluation reports have explored specific patient outcomes (eg patient activation) and the benefits of the co-produced nature of Co-creating Health have been briefly discussed in chapter 3. These are clearly very important in making the case for Co-creating Health. However, it is also useful to highlight the benefits of improved patient experience, both for their intrinsic value and because of patient experience being given an increasingly high profile in government policy. For example, in 2012 NICE issued guidance on this[47], drawing attention to the importance of self-care for people with long-term conditions as a part of improving this area of patient care.

Several of the local evaluation reports discussed patients' experiences of the Self-Management Programme and a few touched on the impact of clinician and training service improvements on patients' experiences in different contexts. Feedback from patients about the Self-Management Programme was very positive – they valued the self-management skills they had developed on the course, but there was some evidence that the scope to use tools such as agenda setting and goal

[47] NICE Guidance (2012) *Patient experience in adult NHS services; improving the experience of care for people using NHS services.* National Institute for Health and Care Excellence, London.

setting was in part dependent on clinicians also knowing about them and having time to use them in consultations. The South West London and St George's local evaluation noted that patients with depression particularly liked the opportunities for peer support, both during the course and afterwards, and the fact that the Co-creating Health approach provided scope to address other long-term conditions that they may have.

There were relatively few examples of patients' experiences of service improvement, but the Cambridge local evaluation did report on patients' experiences of using their Personal Health Plan. Some patients had simply kept it for reference, but others had used it to prepare for appointments with health professionals; as an information resource; to address knowledge gaps; to help think about problems; and for recording contact numbers. A few had shared with family and friends as a way of helping them understand their condition and how they were trying to manage it. They concluded that the Personal Health Plan may be a useful tool for some patients, especially where its use is encouraged by the patients' clinicians, but it should not be assumed that it will facilitate self-management behaviour for everyone.

Perhaps one of the most important messages to emerge from both the local and programme evaluation in terms of patient experience was the need to acknowledge that the Co-creating Health approach to self-management support, in particular training patients in groups, will not be right for everyone. Some patients may not have the personal resources or skills to immediately embrace it and will need additional support[48]. Others may dislike group activities or be too ill to travel to take up training. In making the case for Co-creating Health it needs to be recognised that there may need to be some degree of targeting or selection in order to maximise impact and make the best use of resources.

6.1.3 Influencing commissioners

During the life of Co-creating Health there have been huge policy shifts in relation to commissioning, which have affected the Co-creating Health sites in England. Some practitioners expressed frustration at the uncertainty and organisational change during the life of Co-creating Health and this has halted progress in some areas. It has also affected partnership working: *"Everything came to a standstill"* (Project manager).

With the introduction of CCGs in England, some concerns were expressed about the potential impact of this, where there was a perceived risk that necessary strategic support for this kind of work could become fractured from self-management training delivery, or that self-management is purely seen by commissioners as a training function, with little regard for the importance of related service improvement work. One project manager stressed the need to forge a shared understanding of Co-creating Health and improve the knowledge base of commissioners: "*There is no shared understanding now due to all the changes".* It remains to be seen how commissioning of care in England by CCGs might impact on the ability of the Co-creating Health sites (and, in the future, other health economies) to develop and implement self-management across care pathways, and as part of a 'whole systems' approach.

A Mandate[49] has recently been produced by the Department of Health for the new NHS Commissioning Board (launched April 2013; now called NHS England) which includes an objective for the Board to ensure that "*by 2015 far more people will have developed the knowledge, skills and confidence to manage their own health, so they can live their lives to the full"* with a related indicator (2.1: Proportion of people supported to manage their own condition). It is not yet clear

[48] Greene, J and Hibbard, JH (2011) Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes *Journal of General Internal Medicine* [published online Nov 30]. See www.commonwealthfund.org/Publications/In-Brief/2012/Feb/Why-Does-Patient-Activation-Matter.aspx

[49] Department of Health (2012) *A Mandate from the Government to the NHS Commissioning Board April 2013-March 2015.* Department of Health, London

how this will be specifically implemented and measured, or the priority it will be given, but it is potentially a useful lever through which to advance self-care programmes.

There was also evidence that practitioners are thinking strategically about where to embed Co-creating Health. For example, in Guy's and St Thomas', self-management training for patients is being linked to Lambeth Early Intervention and Prevention Scheme (LEIPS). Whilst such shifts will be influenced by a range of factors and may well have positive outcomes, they beg questions about whether elements of Co-creating Health might be located in perceived 'safe' places in order to attract funding, which might risk eroding some of the proven benefits of Co-creating Health and jeopardise a 'whole system' approach.

In Scotland, there is no provider/commissioner split, and the project manager in Ayrshire and Arran felt this was to their advantage:

> *"It helps not having commissioners and providers, in that you can look across the health economy and think 'Is this just going to make sense for this group of our patients?'. You're not thinking you've got to make a case to have somebody 'buy it'... if we've got an idea to go and do something, you might meet resistance from someone, but there are no other barriers there. In terms of 'dos' and 'don'ts', we're an integrated Board but with GPs as contractors – and they may choose not to do something – but it's because they choose not to, rather than having a particular structure that prevents them speaking to them and having a particular process to go through."*

There is also a more high-profile link between self-management and long-term conditions in Scotland; in 2008 a Self-Management Strategy for Long Term Conditions in Scotland[50] was published by the Long Term Conditions Alliance Scotland; this was fully supported by the Scottish Government who have also linked self-care to their HEAT targets (referred to in section 5.5.1).

The commissioners (both PCT managers and GPs involved with their CCGs) who contributed to the evaluation recognised the role of self-management support in reducing pressure on services for people with long-term conditions. They also understood the potential benefits for patients and acknowledged that national policy (and usually local strategy) supported self-management initiatives. However, their understanding of what effective self-management support 'looks like' was mixed and some commissioners were unsure about how to commission it. This was partly because in the field of patient self-management training, there are a number of programmes for commissioners to choose from, some of which are generic (eg Expert Patient Programme courses) and some disease specific (eg DESMOND and DAFNE for diabetes and the Pulmonary Rehabilitation Course for COPD). In commissioning terms, Co-creating Health is a more complex option because commissioners have to both understand the benefits of the three elements of the Co-creating Health model (ie the Self-Management Programme, Practitioner Development Programme and Service Improvement Programme) and be willing to commission them all, *and* understand the implications of its co-produced nature.

Commissioners face a number of 'investment dilemmas' in relation to Co-creating Health:

- The Co-creating Health approach requires clinician training, which is not part of most other self-management approaches. As such, there is both a cost and a clinician 'buy in' issue.
- To achieve significant take-up of Co-creating Health in primary care could involve funding for locum cover and possibly incentives for service improvement work.
- It's not clear how these 'incentives' (eg LES, QOF points) for primary care will be commissioned in the new commissioning environment.

[50] Long Term Conditions Alliance Scotland (2008) *Gaun Yersel: The Self-Management Strategy for Long Term Conditions in Scotland*

- Is a 'pick and mix' approach possible or appropriate, ie can commissioners choose elements from the different self-management schemes, for example an existing Pulmonary Rehabilitation Course for patients and a new Practitioner Development Programme for clinicians?
- Many commissioners are balancing the desire to 'invest to save' with need for investments to show 'in year' savings. Self-management support may show some short-term benefits but it is not a quick fix.
- It is not clear how the co-produced nature of Co-creating Health can be commissioned whilst ensuring this can be firmly linked to corporate infrastructures.

Whilst there is good evidence available nationally and internationally about the benefits to patients and services of self-management support, commissioners involved with Co-creating Health were often still looking for local evidence that the Co-creating Health model was effective and/or cost effective. A few had wholly unrealistic expectation about the kind of evidence that could be generated (eg 'gold standard' RCT type evidence) by a pilot programme and the only option for sites was to challenge this head on. Generally, the key things which appeared to influence commissioners were:

- Reductions or positive changes in clinical activity (eg fewer GP consultations, more effective/appropriate use of medication, fewer A&E attendances), which could be short and long term, and big and small, but ideally with associated cost savings.
- Improvements in clinical indicators (eg HbA1c for diabetes; 6 Minute Walk Test for COPD; PHQ9 depression score) known to lead to improved management of the condition and potential reductions in clinical activity.
- Higher levels of patient satisfaction with services and improved quality of life.

Sites were approaching these commissioning (or in Scotland investment) challenges in a number of ways. A few had developed formal 'business/investment cases' for Co-creating Health with different delivery options. A number were trying to build Co-creating Health into long-term condition pathways as part of a 'bundle' of care and/or embedding self-management support activities into routine care by professionals. All were trying to continue the use of lay tutors for patient training and/or volunteers for peer support, but the extent of this varied considerably. A few were looking for continued funding for Co-creating Health activities through 'special' funds, eg Innovation Fund.

6.2 Adopting a strategic approach

As has been noted in earlier chapters, progress in phase 1 was in part hampered by quite an unfocused approach to implementation, especially in relation to clinician training and service improvement. In phase 2, the sites which had made most progress in terms of spread had adopted more strategic approaches, looking in detail at the ways in which the training is delivered, and – at a broader level – how it is woven into the key strategies and policies of the organisation, working in partnership with others, and with the necessary support in place. This section describes how this was being achieved.

6.2.1 Flexibility: using generic and tailored approaches

Co-creating Health was piloted on the basis of a single condition within each site, with the aim of spreading it to other conditions during phase 2. For all sites, this raised the issue of whether to implement Co-creating Health in more generic ways. There is no straightforward resolution to this, particularly in light of the fact that a generic approach makes more sense in primary care, yet secondary care services are generally organised around medical or surgical specialisms. There is

also the issue of economies of scale. Rolling out self-management support in defined specialist areas is time consuming and there are several functions where a more 'organisational' approach will not only reduce duplication of effort, but arguably be more efficient and effective in terms of accessing corporate support systems (such as supporting and training patient volunteers) and in adopting a more strategic approach to service improvement. Sites have addressed this issue in a number of ways, for example:

- In Ayrshire and Arran, the Self-Management Programme has been adjusted so that five sessions are generic and one is dedicated to the relevant condition. Most other sites have also adopted a similar approach.
- In working with whole teams, sites were able not only to create a 'critical mass' as a means of promoting change more effectively, but also to tailor the Practitioner Development Programme and service improvement work to the needs and priorities of the team – for example, adopting more generic approaches within primary care services (eg Torbay) and working with specialist teams in secondary care services
- In Calderdale and Huddersfield, patient volunteers/lay tutors with different long-term conditions were training and meeting together, and lay tutors were getting involved in delivering 'train the trainer' sessions across conditions.

These flexible approaches also help to address the problem of working with patients with co-morbidities, as it reduces the risk of self-management support operating in 'silos'. Further to this, many of the patients and lay tutors who were interviewed also thought that there could be some merit in a more generic approach in their role as lay tutors in the Self-Management /Practitioner Development Programmes, and in other patient involvement functions. There was enthusiasm about the possibility of broadening the volunteer base across other conditions, where people could act as mentors and contribute to volunteer training activities.

Also, many of the lay tutors and patient volunteers felt that the skills and experience they had acquired were transferable (eg general self-management principles, listening skills) and the majority felt that they could usefully talk to people with other conditions because so much of it centres on the practicalities of living with a long-term condition (eg coming to terms with fear, dealing with the reactions of other people, coping with isolation and depression, understanding the impact on families, dealing with health professionals). They said that it was the clinicians who brought the specific medical perspective, but in their view this was often only a small part of what people needed to gain from self-management courses. This viewpoint has a strong resonance with the social model of disability, which defines disability as being created by barriers in society, as opposed to the medical model, which defines disability on the basis of people's impairment or health condition.[51]

> *"The issues that come up in the courses, they are about life in general.... There's a light bulb moment, you're not on your own, and you realise the difficulties other people have. If you give them the skills it continues beyond the life of the course. The common ground is the long-term condition and its living life and realising you have to get on with it." (*Patient volunteer*)*

Most Co-creating Health sites were moving towards a generic model, with scope to tailor accordingly. An exception was Cambridge where, at least for COPD patients, they have linked training to the Enhanced Pulmonary Rehabilitation programme. It is questionable whether such an approach can provide an effective base for roll-out of self-management across other long-term conditions.

[51] For a fuller description of the social model of disability, see information provided by the Office for Disability Issues: http://odi.dwp.gov.uk/about-the-odi/the-social-model.php

6.2.2 Making connections with existing policies, initiatives and strategies

It is clear that where sites have been most successful in securing the wider take-up of self-management support, it has been against a backdrop of local organisational support, and through making connections to existing structures and initiatives. Sites tried different approaches to move on from a piecemeal approach, which had hampered progress in the early stages of Co-creating Health, and this has manifested itself in different ways across the sites. For example:

- Some sites have focused on ensuring that self-management support is incorporated into their organisation's strategy and policy documents. In Torbay, self-management support is now a strategic priority for the Trust and is an intrinsic element of the long-term conditions strategy. This has been largely due to the efforts of the Co-creating Health project manager in relation to her linking role with the local CCG.
- As noted in chapter 5, other initiatives already being developed in the organisation (such as Diabetes Modernisation Initiative) were being used to increase the uptake and spread of self-management support.
- In Calderdale and Huddersfield, they aimed to spread self-management support across all the clinical divisions in the Trust and, therefore, instead of having just one clinical lead for Co-creating Health, they appointed a self-management support clinical lead in every division (eg medicine, surgery).
- Sites have also dovetailed with local priorities by utilising LESs as incentives, for example at Whittington Health, self-management support has been incorporated into their new Diabetes LES for Islington and it has also been written into their clinical commissioning LES. Their multidisciplinary team case-conferencing LES, which is in the process of development, also aims to encourage the implementation of self-management support in primary care.
- In Cambridge, the Co-creating Health team worked with Cambridge Community Services NHS Trust in order to support roll-out of self-management support:

  > *"And I suppose fundamentally that we got another part of the* [Health economy] *on board…. Cambridge Community Services, which provides something like pulmonary rehabilitation, and we managed to get permission to train all their specialist nursing staff with motivational interviewing skills, so we provided a whole load of training programmes across about 90 staff… On the back of that we got into the pulmonary rehabilitation programme, so delivery is through that training programme."* (Project Manager/Patient Development Lead)

Quality improvement arrangements (driven by policy initiatives such as QIPP, QOF and CQUIN) were generally seen as valuable vehicles to encourage clinicians to adopt Co-creating Health within their practice and to promote service improvement work (as outlined in chapter 5). In Calderdale and Huddersfield, the Trust's Quality Improvement Strategy, which highlighted the importance of the underlying principles of self-management support, had been very useful in encouraging the uptake of Co-creating Health. However, there was some concern that although these existing quality improvement structures were useful as incentives for clinicians to adopt self-management support, and also enabled access to wider income streams, there was still a problem in terms of Co-creating Health being seen as extra work which clinicians did not have the time or resources to implement (see section 6.2.3). In addition, if the organisation did not recognise the value of self-management support in relation to quality improvement targets, then it was difficult to make headway in the take-up of Co-creating Health. So making shifts in culture and understanding were regarded as vital.

6.2.3 Time and resources

Where there has been success in securing the wider uptake of self-management support in the sites, it has only been possible through the input of dedicated time by project staff (both

professional and lay) and clinicians, alongside the availability of a range of resources, such as the provision of backfill monies and venues for marketing events/training, and to nurture peer support.

It is clear that there is a need for a co-ordinating role to ensure that self-management support is linked into strategies and systems within the organisation and to ensure that opportunities for spread which could be built upon are recognised. The project manager role has been invaluable in this regard for the life of Co-creating Health, and in order for self-management support to continue to spread and become embedded within organisations, and to promote co-production and peer support as part of this change. There will continue to be a need for this kind of role, although its emphasis would need to change as it becomes part of 'core business'. As noted in previous chapters, in those sites where there have been problems in relation to the project manager role (either through lack of effectiveness of individuals or multiple changes of post-holder), the ability to look for opportunities and work towards embedding and spreading self-management support has been hampered.

Where there are the resources in terms of personnel, it is essential that these are nurtured and supported. Project management staff, lay tutors, peer support volunteers and clinicians alike all require back-up and supervision (be that formal or informal) to ensure they do not take on too much (see chapter 3 for more in relation to support for lay staff and volunteers).

In order for self-management support to spread within organisations there is inevitably a need for clinicians to make time to undertake the training and work on embedding the change in their practice. However, this time commitment does not necessarily have to be prohibitive and, in some cases, Co-creating Health project teams have introduced changes to the clinician training programme to make it more manageable for clinicians (see section 2.2.2). Indeed, as mentioned in chapter 4, some clinicians believed that as they continued to use and embed self-management support skills into their consultations, so their consultations became more focused and hence, potentially, shorter.

Financial incentives have been used successfully in some sites to encourage the wider take-up of Co-creating Health and to engage new teams and services; for example, payments to fund backfill locum cover in primary care. As mentioned in section 4.5.3, LES payments to GP practices in Torbay were considered the catalyst which enabled service improvements to be made and kept clinicians focused on maintaining changes in their practice. There is some doubt, however, as to whether financial incentives are helpful in the long term as they may imply that self-management support is an 'added extra', and not something that is part and parcel of what clinicians should be doing anyway.

6.2.4 Enabling 'multiple voices'

Evidence of progress amongst the sites suggests that a managed approach to leading change, and enabling input from key stakeholders helps to promote spread:

Clinical leaders: By its nature Co-creating Health was a pilot programme and so the local teams had to focus their efforts. All agreed that in the early days there were advantages to working with clinicians who already had an interest in self-management support, or with teams where some self-management support 'good practice' was already taking place. However, as those involved in the programme reflected on how their sites had progressed, many highlighted the need to develop a network of clinical leaders across all the main specialties working with people with long-term conditions (as is now happening in Calderdale and Huddersfield) and across primary care. As was noted in chapters 4 and 5, influential clinical leaders played a vital role in 'promoting' self-management support, but some contributors felt that they should have taken a more systemic approach to spreading Co-creating Health.

Middle managers and support staff: These are often a forgotten group in clinically-focused initiatives, and yet sites were beginning to recognise the importance of their ability to 'oil the

wheels' of self-management support. This could be through their practical interface with patients or through bringing particular skills (for example, marketing, IT, evaluation, service improvement).

Patient representation: As chapter 3 emphasised, co-production is at the heart of the Co-creating Health approach to self-management support. As such, lay tutors and patient representatives are central to spreading Co-creating Health, whether through influencing other patients, showing clinicians how their patients can benefit from self-management support, or generally promoting Co-creating Health and helping to shape its development. Sites varied in their capacity to engage and support patient volunteers and in the priority they gave to this work. There were risks evident in a couple of sites, where there was over-reliance on a very small number of patient representatives. The strongest networks were evident where there were multiple opportunities for patient involvement and patient representation, with links to related corporate systems and third sector organisations (for example as in Ayrshire and Arran).

6.2.5 Building relationships

Building relationships with external agencies has been key to the delivery of Co-creating Health, as evidenced in chapters 3 and 5. Most of the Co-creating Health sites made efforts to build links with the local voluntary sector in marketing and implementing Co-creating Health, and this was fundamental to promoting effective patient involvement and enabling Co-creating Health to be co-produced. Building such relationships is also fundamental to the spread of Co-creating Health, and there were several examples of partnerships that had helped to achieve this in the sites. Most had worked in association with local deaneries or other training providers, to promote 'upstream' development initiatives (see section 4.4), and some had formed other partnerships (eg see section 5.3 for Guy's and St Thomas' work with the Health Innovations Education Cluster for SE Thames). There were fewer examples of partnerships with local authorities, but some sites (such as Calderdale and Huddersfield) were starting to see the benefits of this in their efforts to establish a more 'whole systems' approach to self-management support. There were also some unexpected and innovative examples of partnerships, for example, Guy's and St Thomas' initiated a walking group in association with the local Ramblers Association; they also carried out an open day in a local health food shop and through this developed contact with people they may not have identified through medical routes.

In particular, the need to forge partnerships was highlighted in relation to equalities issues, where developing/capitalising on relationships with local black and minority ethnic groups, and community organisations was regarded as pre-requisite to engaging traditionally underrepresented communities. Several commentators highlighted that forming and nurturing these networks was resource intensive and (whilst such action was highlighted in some spread plans) they regretted not having sufficient time to commit to this work. However, given there is considerable evidence that many traditionally underrepresented communities are more likely to experience long-term conditions, there needs to be more focus and priority on spreading self-management support through such relationships, and on working through corporate equalities infrastructures to help achieve this.

Chapter 7
Key messages from Co-creating Health phase 2

When the Co-creating Health programme began five years ago it represented an important attempt to develop a new and more integrated model of self-management support. In its first phase, the programme sought to test the feasibility of embedding this new model into routine health services, and to examine whether it could deliver improvements in both patients' quality of life and their experience of healthcare service. The phase 1 evaluation did show that Co-creating Health was able to deliver improved outcomes for patients. However, at the end of phase 1, and perhaps because of the complex nature of the programme, there was still much to learn about how to sustain and spread the Co-creating Health model of self-management support. This was the focus of Co-creating Health phase 2.

In the preceding chapters of this report we have set out what has been learned from the seven pilot sites about both sustaining and spreading Co-creating Health. Clearly each Co-creating Health project was operating in a different environment; they had varying levels of skill and support within their organisations; they were focusing on a range of long-term conditions; and had different ambitions and plans for spreading Co-creating Health. Nevertheless, a number of common factors emerged which together and in different ways appear critical to sustaining and spreading Co-creating Health. These 'mechanism' and 'sub-mechanisms', and the facilitators and barriers which influenced them, are described in detail in chapters 3, 4, 5 and 6.

In this final chapter we consider the lessons from Co-creating Health phase 2 from the perspective of a new health economy looking to adopt the Co-creating Health approach to self-management and suggest that there are three key messages to share:

- Message 1 – Embrace Co-creating Health as a 'whole system' change
- Message 2 – Take a strategic approach to implementation
- Message 3 – Adopt a targeted but flexible approach to delivery

7.1 Message 1 – Embrace Co-creating Health as a 'whole system' change

Co-creating Health is not a simple 'off the shelf' approach to self-management support. As was noted in chapter 6, its three interrelated elements (self-management training for patients; self-management support training for clinicians and service improvement activities) are all important and all have to be functioning if Co-creating Health is to achieve its impact. The approach also requires more effort on the part of clinicians, service managers and commissioners both to understand its integrated approach and to embrace its co-production ethos. As such, any health economy thinking about adopting the Co-creating Health approach to self-management support needs to see it as a whole system change. In particular they should:

- take a whole health economy approach, working across secondary, community and primary care services (and the third sector and local authority where appropriate); and across all long-term conditions
- make the case for the Co-creating Health approach by clearly setting out the benefits of self-management for patients, clinicians and services, and the potential value for money gains for the health economy
- ensure that all partners and key stakeholders have a common understanding of co-production, and that from the outset co-production is built into the design and delivery of all self-management support activities.

7.2 Message 2 – Take a strategic approach to implementation

From the start of the programme, the Health Foundation worked hard to establish support for Co-creating Health amongst stakeholders working at a strategic level in the host organisations. However, by their nature, the Co-creating Health projects were pilots, designed to test the Co-creating Health model in a small slice of their health economy and so it was not feasible for them to take a fully strategic approach to implementation. For a new health economy implementing self-management support a strategic approach is essential to both make the best use of resources and to quickly achieve some momentum. In particular they should:

- build self-management support into local strategies; take opportunities to 'piggy-back' on existing long-term condition initiatives; and use national policies (related to long-term conditions, self-management, patient involvement, patient experience), and national quality frameworks as 'levers' for change
- identify ways to support or reinforce self-management support through existing systems and structures (eg quality improvement networks, patient involvement structures, personnel systems, care pathway development) and actively encourage the 'two way traffic' of ideas
- identify influential clinicians from across the health economy who can promote self-management support, and from an early stage, develop a network of clinical leaders across all the main specialties working with people with long-term conditions and across primary care.

7.3 Message 3 – Adopt a targeted but flexible approach to delivery

Co-creating Health began by often taking quite a broad approach to recruiting clinicians to the Practitioner Development Programme but using a condition-specific focus for the Self-Management Programme. By the end of phase 2, most sites were moving to the opposite of this – a focused approach to training clinicians and generic patient training. In practice, a flexible approach to the training elements of Co-creating Health is needed. However, the wider delivery of self-management support does require a targeted approach in order to achieve the most impact. In particular, those looking to implement self-management support should:

- identify the long-term conditions to focus on first and then look across the whole patient journey to identify the 'hot spots' where self-management support by clinicians, changes in service delivery or self-management training for patient are likely to have the most impact
- target self-management support for clinicians in whole teams or groups of clinicians working in the same services to establish a 'critical mass' of trained clinicians in a short timeframe, and make an explicit link between clinician training and service improvement work
- be flexible and use both generic and condition-specific approaches according to the needs of different patient groups (eg the nature of the patients' condition, the communities they come from), the healthcare environment, and the geography and demography of the health economy – one size does not fit all.

Lastly, it is important to recognise that the Co-creating Health approach to self-management support is not a 'magic bullet'. It will not be appropriate for some patients either because of their illness, their personal circumstances or their outlook, and it will not be embraced by all clinicians working with people with long-term conditions. Furthermore, it does require some resources both for staff to co-ordinate the initiative, organise training, assist service improvement work and recruit/support lay tutors and volunteers, and to release clinicians for training and other activities. In return, the Co-creating Health model of self-management support has the potential to fundamentally alter how individual clinicians and healthcare services support people with long-term conditions to manage their own health.

Appendix A - Overview of depth study methods

Depth Study 1: Embedding self-management support into care pathways and service delivery

The main outputs from the service improvement work undertaken by PWC/Peaks (who acted as technical provider for the Co-creating Health programme) were reviewed, and colleagues from PWC/PEAKS shared their observations about this theme with the evaluation team. The ideas and issues emerging from this review were used to inform and provide a focus for a series of interviews with clinicians and managers from across all seven sites who were in some way involved in developing/influencing care pathways or service delivery (eg project managers, clinical leads, service improvement leads). In total, 14 interviews were conducted between November 2012 and January 2013. They were undertaken by telephone using a semi-structured topic guide, designed to gauge the amount and type of activity related to the key themes, and to elicit views on perceived benefits and factors affecting viability and sustainability. The fieldwork was also informed by exploration of relevant literature/policy related to service improvement and the development of care pathways.

Depth Study 2: Changing culture and practice amongst clinicians

The study had three main stages: i) initial interviews to 'map' the approaches being used by the sites to change culture and practice amongst clinicians; ii) more in-depth field work in three sites to explore new or innovative approaches, approaches with the potential to be rolled out and scaled up, and/or approaches which appear to have worked well with particular groups of clinicians; iii) a short email survey to find out more about the 'up-stream' work sites had been doing to encourage the incorporation of self-management support skills into medical and healthcare education in their localities. Each of these stages is described in more detail below. In addition we carried out a brief examination of literature relevant to this theme.

Mapping approaches to Practitioner Development Programme take up and post- programme support

The study began with a small number (n=14) of one-to-one interviews with the clinical leads and other key people (eg clinician development leads) in each site. These took place between February and April 2012 and aimed to understand what approaches the sites have been using to:

- support clinicians who have completed the Practitioner Development Programme to use, develop and share their skills in supporting patients to self-manage
- encourage new groups of clinicians to undertake the Practitioner Development Programme and/or get involved in other self-management related activities.

The material from the interviews was initially used for a short briefing report for the Co-creating Health sites and Health Foundation colleagues, but has also been drawn upon for this report. In addition, it was used to identify examples of interesting approaches from which wider lessons might be learnt.

Follow-up work in three sites

From the information gathered in the first stage of the study, we identified sites which appeared to have adopted interesting approaches to changing culture and practice, and then we chose three locations for more in-depth work. These were:

- two GP practices in Torbay
- the Stroke Service in Cambridge
- a cross-section of services/groups of clinicians in Whittington Health.

The fieldwork took place between July and October 2012, and in each of these locations we used a mix of focus groups (n=2 with 10 participants in total) and interviews with clinicians and managers (n=10) to explore:

- what has worked well about the approach and why
- the barriers encountered and how these were overcome
- examples of the ways in which clinicians have been influenced or supported to develop their practice
- any practical issues to be considered in rolling out the approach.

Survey of work with medical and healthcare education providers/in-house training programmes

In late summer 2012 we sent an email survey to the Co-creating Health project managers/evaluation leads (six of whom responded) asking them to gather brief information in response to the following three questions:

- Have you been doing any work to encourage the incorporation of self-management support skills into medical and healthcare education in your localities?
- If you have, what form has this work taken?
- Has there been any work done to incorporate self-management support skills into your trust's/organisation's overall training programme/regular training sessions?

Depth Study 3: Harnessing patient knowledge and experience

Depth Study 3 has been informed by field work with a range of staff and patients (in total 46 people), which took place in two stages:

- Stage one included scoping work through semi-structured interviews with project staff and lay tutors across all the Co-creating Health sites.
- Stage two focused on areas of good/innovative practice flagged in stage one, and gathered patient volunteer perspectives through individual and focus group activity.

The initial scoping work across all sites took place between November 2011 and January 2012. Information was gathered through 15 interviews with key staff/personnel across the Co-creating Health sites. These included:

- Four Co-creating Health project staff, one clinical lead, and three leads supporting patient self-management. Two of these also acted in the capacity of lay tutors.
- Seven lay tutors. One of these was also employed in a salaried administrative role for Co-creating Health.

Thirteen interviews took place over the phone and two were face-to-face, using a semi-structured topic guide. The interviews were designed to gauge the amount and type of activity related to the key themes of patient involvement and peer support, and to elicit views on perceived benefits and factors affecting viability and sustainability. Following this scoping work an interim report was produced in March 2012.

The second stage of field work with patients was carried out between March and May 2012. This took place in four sites where the scoping work had suggested good practice and innovative approaches to harnessing patient knowledge and experience, and where it was practical to talk to people within the required timescales. The field work included 31 patients who were involved in the following ways:

- a focus group with four ex-Self-Management Programme participants who are taking full responsibility for producing a Self-Management Programme newsletter
- a focus group with four lay tutors who are involved in a wide range of peer support and involvement activities outside of their Self-Management/Practitioner Development Programme tutoring role
- a postal questionnaire of 37 patients involved in a local reference group, which drew a response of 14 people (38%)
- telephone interviews with eight out of 10 people who are active in a newly-established telephone 'buddy' system
- a telephone interview with a patient founder/organiser of a walking group.

The discussions with patients focused on the kinds of activities they were involved in; what helped and inhibited these activities; what difference they felt their function made to the delivery and sustainability of Co-creating Health, and their views on harnessing patient knowledge and experience in the delivery of Co-creating Health.

The depth study was also informed by exploration of relevant literature relating to peer support, patient involvement and co-production, and by the policy context in England and Scotland, with consideration of how this might impact on sites' ability to promote and implement peer support and patient involvement.

Theme 4: Encouraging the take-up of self-management support

A separate depth study was not undertaken for theme 4. As the evaluation progressed it became apparent that 'spread' could not be achieved without first sustaining the Co-creating Health approach in the original target conditions and services. As a consequence, much of the data being generated in the depth studies 1, 2 and 3 could be drawn on for this theme. However, the evaluation team did review each of the site's original Co-creating Health 2 plans and then conducted short follow-up telephone calls with the project manager and/or clinical lead from each site, in which they were asked to reflect on the 'spread' achieved in their site and the factors which had helped or hindered their progress.

Theme 5: Building the business case for Co-creating Health

The findings from this study will be available on the Health Foundation's person-centred care resource centre, which is due to launch in late 2013 (see www.health.org.uk). They bring together the cost and activity data presented in some of the local evaluation reports to consider the economic evidence and approaches other health economies may wish to use in developing the case for self-management support.

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