



# Snapshot

## *Co-creating Health*

---

*Building new relationships between people with long-term conditions and a supportive health service*

---

*Identify Innovate Demonstrate Encourage*

# What are we doing?

---

*We know that people with long term conditions can improve their health and have a better quality of life by taking a more active role in managing their own condition. But to do this, people need to develop their confidence and skills in self management. They also need expert support and motivation from skilled clinicians. Finally, they need a healthcare system that operates very differently – one whose organising principle is helping people to be an active partner in their health.*

*Co-creating Health is the Health Foundation's improvement programme that helps people with long term conditions take control of their health and supports them to self manage.*

# WHY IS SELF MANAGEMENT SUPPORT IMPORTANT?

The Health Foundation's Co-creating Health programme aims to embed self management support within mainstream health services. We are learning about how routine care can be redesigned and commissioned to provide a supportive and personalised approach for people with long term conditions.

## The challenge

It is estimated that over two thirds of all healthcare resources in the UK are spent treating people with long term conditions. These are conditions such as diabetes, depression, heart disease and arthritis, which can be controlled by medication or other therapy, but not cured.

With an ageing population and rising levels of obesity, these figures are predicted to grow. However, the NHS is under increasing pressure to improve quality and reduce costs.

## Meeting the challenge

Co-creating Health has the power to help the NHS meet the challenge ahead – to improve the quality of health services, increase personalisation and also reduce costs.

### – No decision about me without me:

The 2010 NHS white paper, *Equity and Excellence: Liberating the NHS*, sets out that people with long term conditions should be engaged in

making shared decisions about their own care. Co-creating Health can help healthcare organisations by providing a practical programme to make this ambition a reality.

### – A better healthcare experience:

All healthcare organisations are seeking to improve the experiences of people who use their services and will be increasingly assessed in this area. Many people with long term conditions say that they are not provided with the support they need to help themselves and that their current contact with healthcare professionals is demotivating. Co-creating Health creates high levels of satisfaction and a much improved healthcare experience.

### – Personalisation, choice and control:

By supporting clinicians to shift from being 'experts who care for and do to' to 'enablers who advise and support' we can increase people's choice and control. Co-creating Health helps people to move from being passive recipients of care to taking an active role in their health and care in collaboration with clinicians.

### – Responding to the challenging

**economic climate:** Research shows that self management support can bring about changes in how people use health services. In particular, the evidence is that self management support leads to fewer crises and in-patient admissions and can improve adherence to medication. Co-creating Health has begun to show such results in our phase one demonstration sites.

# WHAT IS CO-CREATING HEALTH?

The Health Foundation wants to see self management support become a core part of how health services are provided in the NHS. However, we know this will require a whole-system approach to change.

That's why we have invested over £7.5 million in our Co-creating Health programme, aiming to transform care for people with long term conditions.

Since 2007 we have been working with eight NHS sites to demonstrate the best way to establish self management support at the heart of mainstream healthcare. Spanning primary and secondary care, the sites have been working in pairs to focus on one of four clinical areas: chronic obstructive pulmonary disease (COPD), depression, diabetes and long term musculoskeletal pain.

## The sites are:

### Diabetes:

- Whittington Hospital, NHS Islington and NHS Haringey
- Guy's and St Thomas' NHS Foundation Trust

### Depression:

- Torbay Care Trust and Devon Partnership Trust
- South West London and St George's Mental Health NHS Trust

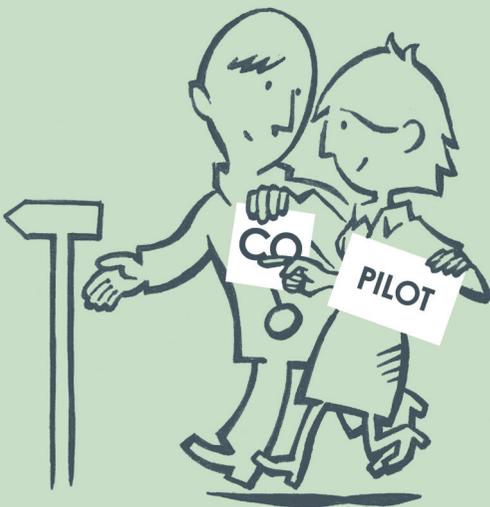
### COPD:

- NHS Ayrshire and Arran
- Cambridge University Hospitals NHS Foundation Trust

### Musculoskeletal pain:

- Calderdale and Huddersfield NHS Foundation Trust
- North Bristol NHS Trust (involved in phase one only)

Read more about the sites' work:  
[www.health.org.uk/cch](http://www.health.org.uk/cch)



# The approach

Research has shown that supporting people to manage their health better improves their quality of life, improves clinical outcomes and reduces the pressure on the health system.

For example, supporting someone with diabetes to stay healthy, lose weight and follow the right diet will reduce the likelihood of associated health problems or emergency admissions to hospital. Self management support also gives the person with the condition more confidence and control and improves their well-being and quality of life significantly.

But effectively managing a long term condition requires people to make difficult lifestyle and behaviour changes. Research shows clearly that providing information alone is not enough to help people maintain motivation through these changes. More active goal setting and approaches that help behavioural change are needed.

*‘Clinical staff at all levels feel they are no longer just treating “a patient”... some of them feel a huge sense of satisfaction that they’ve really improved that person’s life, not just the clinical treatment.’*

NHS Chief Executive

Co-creating Health has distilled the evidence about what works to support self management into a clear set of skills and practices. It teaches clinicians how to support self management by incorporating three key processes into their routine practice.

- 1 Agenda-setting** – the consultation focuses on an individual’s priorities and concerns.
- 2 Goal setting** – the individual works with the clinician to agree what they will focus on to address these concerns eg by deciding to increase exercise, stop smoking or change diet.
- 3 Goal follow up** – the clinician arranges for someone to make contact with the individual within 14 days to check progress with the agreed goals.

Engaging people in this way is proven to significantly improve clinical outcomes. It is a simple concept, but one that requires a fundamental change in approach from health professionals and from the health system as a whole.

This is because it means moving away from the traditional relationship between ‘passive patients’ and ‘expert health professionals’ to one where both parties work together as active partners.

This approach recognises that while clinicians are experts about treatment options, the individual is an expert about his or her own personal experience of their condition, constraints on changing their lifestyle, social circumstances, personal values and attitude to risk.

## Phase one: testing the model, building skills and evidence

The first phase of the Co-creating Health programme ran from 2007–10. It focused on testing Co-creating Health's innovative model of whole system change. Within sites, the teams focused on building skills and knowledge around self management with clinicians and people with long term conditions.

Following the Co-creating Health model, three development and improvement programmes were delivered across all sites.

- **Advanced Development Programme (ADP) for Clinicians** – helping clinicians to develop the knowledge and skills to support people to self manage effectively.
- **Self Management Programme (SMP) for people with long term conditions**
  - supporting people to develop the knowledge and skills they need to manage their own condition and work in effective partnership with their clinicians.
- **Service Improvement Programme (SIP)** – supporting people with long term conditions and healthcare professionals to work together to identify and implement new approaches to health service delivery that will enable people to take a more active role in their own health.

## Phase two: sustaining and spreading the approach

In January 2011 we moved into the second phase of the programme, which will run until August 2012.

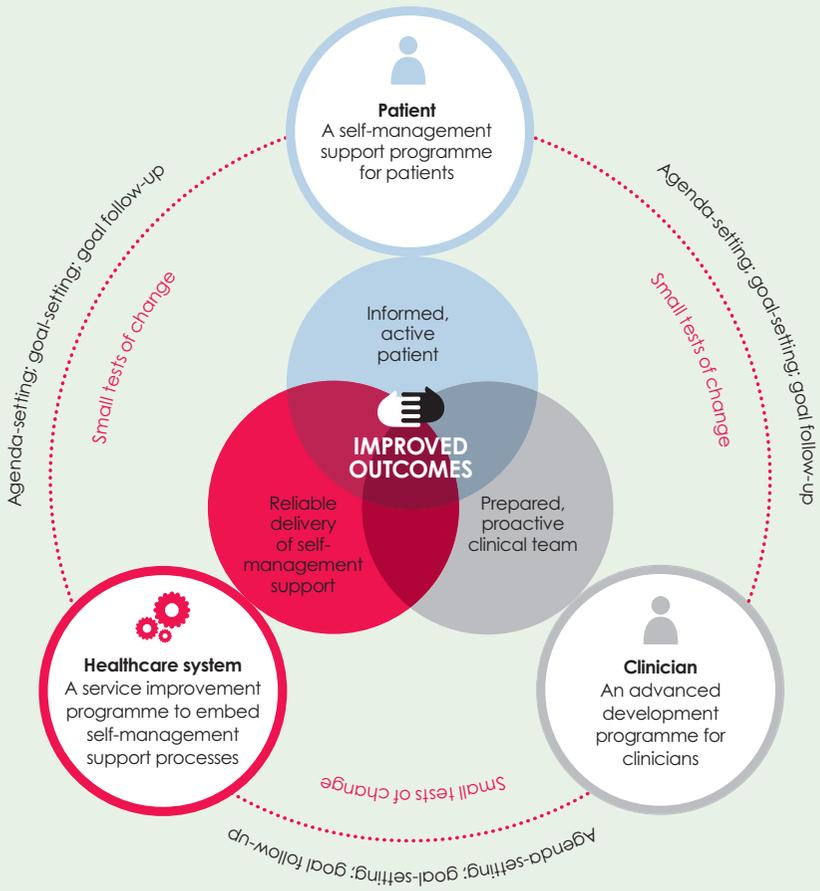
During phase two we will work with our sites to:

- achieve local sustainability of the Co-creating Health model through the commitment and ownership of local commissioners and providers
- secure the spread of the Co-creating Health model to a wider population.

We also want to promote the spread of the Co-creating Health model by:

- creating a group of clinical and non-clinical leaders who will champion Co-creating Health
- showcasing our work and learning to decision makers at all levels, from central government to local health service management and frontline clinicians
- developing materials and information that will support and enable others to adopt the Co-creating Health model.

## Co-creating Health: a self management support programme



*‘Co-creating Health has been a significant catalyst in terms of the organisational culture and what the board is now expecting the clinicians to deliver.’*

NHS Chief Executive

# THE IMPACT OF CO-CREATING HEALTH

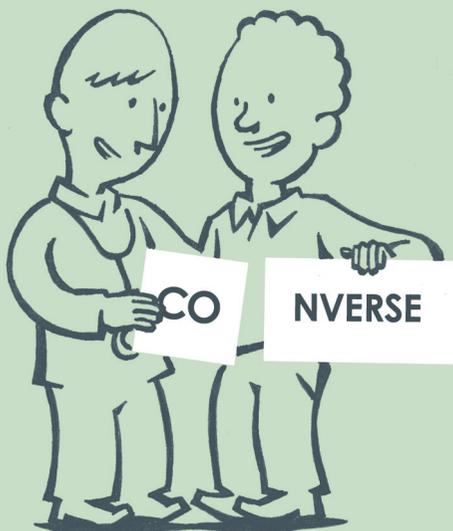
Co-creating Health has had a transformational impact on the lives of people living with long term conditions and has also transformed the practice of clinical staff.

Having completed the Advanced Development Programme, clinicians commonly report an increased motivation to improve their practice, greater belief that improvement is possible, increased job satisfaction and a greater sense that they are now 'helping people' in a way that reflects why they came into healthcare.

After attending the Self Management Programme, people with long term conditions report statistically significant changes to their quality of life. They say they have a more constructive attitude to their condition, more positive emotional well being and are now using self management skills and techniques.

Impact examples:

- In Wandsworth, people living with depression used significantly fewer consultant appointments and bed days and had reduced anxiety and depression.
- In Haringey and Islington, people living with diabetes had improved clinical outcomes (glucose control, lipids and renal function) over one year.
- In Torbay, people living with depression were less likely to have consultations with specialists at the mental health trust.
- Several sites have reported reduced DNA (did not attend) rates for appointments, particularly where individuals had received agenda-setting prompts prior to their appointments.



## How self management helped me

*Person living with depression:* ‘I’ve had a long history of depressive episodes since my teens, including some really serious breakdowns and two suicide attempts. Joining the Self Management Programme was a fantastic breakthrough.

We learnt some really practical skills over those seven weeks and you could pick and choose the bits that felt helpful to you. Like creating an action plan in your personal life, which made perfect sense to me. You do it every day of the week when you work, why wouldn’t you do it in your ordinary life?

Just recently I had my annual care review with my consultant and community psychiatric nurse, and we agreed I can be discharged to my GP. We’re also talking about reducing my medication to nothing within the next year. Seven years ago that would have been unimaginable. I thought I would be on heavy medication forever. For me being discharged is a huge deal, like winning an Olympic medal!’

*Person living with diabetes:* ‘Self management means I really do look after myself much better. I can make my own decisions, like do I take this tablet, which makes me feel awful but lowers my blood sugar level? Or do I just do the work [to reduce my blood sugar] myself? I know how to do that now. That’s made a huge difference to my confidence and has made me much more proactive with things like exercise and healthy eating.’

## The clinician’s view

*Community matron:* ‘As a community matron I support people with long term conditions. I took part in the Advanced Development Programme and it has really helped me communicate better with my patients and see better results.

It taught me how to really listen to patients and allow them to set the agenda. It’s a change from the traditional approach where you visit a patient and say “okay, today we’re going to do this...”, and the patient says “okay, you’re the boss”. We used to wonder why that wasn’t working.

Now I use agenda setting with my patients and I start by asking “what do you want us to do today?” Patients appreciate this different approach because you are giving them the power. You work out the goals and the steps together and they are empowered to carry on and work on it on their own. So you may need to visit a bit more at first, but in the long run you need to visit less often. And my patients know I’m there for them whenever they need me.’

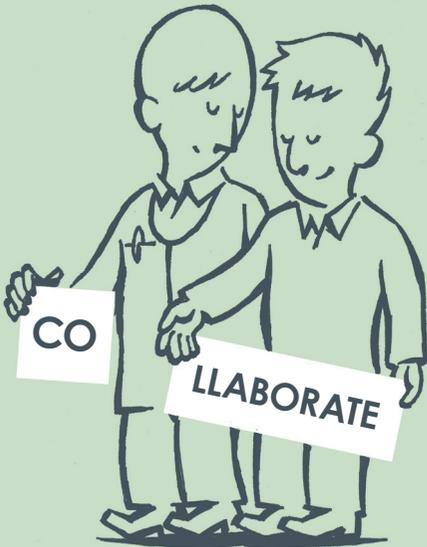
*Clinician:* ‘It’s been great to be involved. I’ve found the service improvement tools that Co-creating Health is teaching really interesting and applicable to all other areas – the idea that you can try out small changes quickly and easily and assess their effectiveness as you go along. It’s been a really liberating approach.’

# Learning so far

---

*The Health Foundation co-designed Co-creating Health through an 18-month process of research, consultation and co-production with experts. We then partnered with eight health economies to test and develop the innovative model that we had created. The next section highlights our learning from the first phase of Co-creating Health.*

---



# ESTABLISHING THE PROGRAMME

We found that Co-creating Health requires time at the outset to establish the framework for effective delivery:

- **Align the visions of clinicians, managers and commissioners across organisational boundaries.**

Implementing Co-creating Health requires partnership work between primary and secondary care, commissioning bodies and lay representatives. Everyone needs to share a local vision and strategy for the care of people with long term conditions. All key players must understand and fully own the aims and desired outcomes of the programme.

- **Frame the programme within the current national and local policy context.** Co-creating Health directly helps health economies to deliver on key priorities, including shared decision making, personalisation, care planning and making savings on care for people with long term conditions. Framing the programme with national and local priorities helps organisations build a case for self management support.

- **Create a strong infrastructure for implementation.** It's important to establish clear and effective programme leadership and management structures, and handle Co-creating Health as a project. Each of the demonstration sites recruited a full-time project manager, who is accountable to a formal steering group. Executive sponsors have also been crucial, at a high enough level to ensure commitment and support across participating organisations.

- **Deliver a single integrated quality improvement programme.**

We found that a staggered approach meant that the three programmes (self management, clinician development and service improvement) were not all at equal stages of development and effectiveness. Co-creating Health needs to be designed and delivered as one integrated programme, with strong operational links between each of the components.

- **Personal stories of success** from both people with long term conditions and healthcare professional provide invaluable insights and encouragement to people participating in the programme, particularly those who are sceptical about the benefits of self management support.

*Everyone needs to share a local vision and strategy for the care of people with long term conditions.*

# IMPROVING CLINICAL PRACTICE

It takes time and effort to encourage clinicians to change, to share skills, and to sustain change over time. As a result, Co-creating Health is largely an experiential programme where people make their own individual journeys of learning and transition.

- **Local clinical champions**, who promote the value of the approach and advocate its feasibility among their peers, are essential. To be authentic champions of self management support, it is particularly critical that clinical leaders attend the Advanced Development Programme and experiment with changes in their own clinical practice.
- **Engaging whole practices and clinical teams rather than individuals** is the best way to support sustainable change. Initially demonstration sites attempted to engage clinicians from a wide range of clinical settings. Over time we learnt that impact was greater when we focused on whole teams who can support each other and share a common aim.
- **Tailoring the Advanced Development Programme to local needs** has helped sites to engage clinicians in the programme. Changes have included focusing on how the programme supports staff to manage existing pressures and offering in-house sessions for general practice teams. However, the core content is derived from the evidence base and is therefore used in all sites.

- **Follow-up support to help clinicians** embed and sustain the skills that they have learnt is critical. Successful strategies include one to one coaching, action learning sets and prompts such as reminder cards and prompts on their electronic record systems.
- **Avoid unnecessary admin.** Clinicians are more likely to test changes in their practice if the processes involved are not overly bureaucratic and tools are available such as electronic templates that can incorporate goal setting, agenda setting and follow up.

---

## Chief executive's view

*Acute Trust Chief Executive:*

‘The benefit for the organisation is that we’ve been able to showcase Co-creating Health in the organisation through the pain team... we’ve made it very clear from the top team that this is the preferred model for how we move forward around the care of all patients with long term conditions.’

*Commissioning organisation Chief Executive:*

‘I will never forget... hearing the patients themselves [speak] in the most powerful way. I think that the kind of learning that you get from that on a personal basis is immense...you carry them with you throughout everything you do really. We have shown our Board the new interaction between patient and clinician. We let them actually observe Co-creating Health in action. The board was very, very excited.’

## HELPING PEOPLE TO IMPROVE THEIR HEALTH

- **Build the Self Management Programme (SMP) into care pathways** for people with long term conditions. It is important to distinguish between SMP and structured education courses that focus more on building knowledge and skills particular to each condition (such as DAFNE and DESMOND for diabetes). These courses are complementary but not substitutes for each other. In phase two we will look at integrating into care pathways.
- **People are more likely to attend the Self Management Programme** if they are encouraged to do so by their clinician. Well advertised programmes, available at different times and days and taster sessions have also been successful in boosting participation.
- **Reunions for people who have attended the self management programme** encourage people to continue using their skills and further develop their confidence and motivation.

## CHANGING THE SYSTEM

Through the service improvement part of Co-creating Health, demonstration sites have been redesigning services in order to integrate self management support into routine NHS care. They have been using the quality improvement tools, including the PDSA cycle – Plan Do Study Act – to test and implement small scale changes that will support clinicians and individuals.

- **Service improvement experience and expertise are needed to make real progress.** In phase one, we provided demonstration sites with work-based support from quality improvement consultants. In phase two, sites will draw on existing improvement expertise from within their organisations.
- **Demonstrate to clinicians how service improvement helps** them with the adoption of new clinical skills. All participating clinicians need to understand the totality of the commitment and how the various aspects of the programme reinforce each other.
- **Go straight to implementation where a change is already proven.** At the start we needed to test everything. In future, teams will be able to learn from the testing that has already been done and experience quick wins by using proven models and tools. These include giving agenda-setting prompts, sharing test results before appointments and using templates for clinicians to record goals and goal follow-up arrangements.

# Key priorities

As we continue into phase two of our Co-creating Health programme, our priorities are to:

**Showcase our work and spread the word:** We want to encourage local commissioners and providers to take up the Co-creating Health model and ensure self management support is provided to everyone with a long term condition.

**Lead and inspire:** We want to create a group of inspiring clinical and managerial leaders who will champion the Co-creating Health approach. It is vital that these senior leaders are active, visible and willing to share their own personal journey of transition.

**Deliver an integrated quality improvement programme:** Learning from phase one, we are focusing on delivering Co-creating Health as a single integrated programme so that our work with clinicians, individuals and services all come together for maximum impact.

**Work in partnership to align vision, policy and practice:** We will work with our partners across the health sector to help professional and patient organisations, providers and commissioners, and policy-makers nationally and locally to understand how the Co-creating Health model can support their objectives.

**Provide materials and resources:** We want to support and enable others to adopt the Co-creating Health model. We will develop a brand new suite of materials and resources that reflect all of the learning gained in phase one.

**Spread further within our initial demonstration sites:** Finally, we will continue to support our initial demonstration sites with their pioneering work to embed the Co-creating Health model in long term conditions care across their health economies.

# How to get involved?

- 
- Sign up for e-updates on our improvement programmes and long term conditions to receive the latest news and updates on our work: [www.health.org.uk/updates](http://www.health.org.uk/updates)
  - Read more about self management support: [www.health.org.uk/sms](http://www.health.org.uk/sms)
  - Read more first-hand experiences from clinicians and people with long term conditions who have taken part in the Co-creating Health programme: [www.health.org.uk/cch](http://www.health.org.uk/cch)

*Find out what is going on to improve self management support in your local area and consider how you could get involved.*

***You can find out more at [www.health.org.uk](http://www.health.org.uk) or email us at [info@health.org.uk](mailto:info@health.org.uk)***

---

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

We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable. We believe that in order to achieve this, health services need to continually improve the way they work.

We are here to inspire and create the space for people to make lasting improvements to health services.

Working at every level of the healthcare system, we aim to develop the technical skills, leadership, capacity, knowledge, and the will for change, that are essential for real and lasting improvement.

The Health Foundation  
90 Long Acre  
London WC2E 9RA  
T 020 7257 8000  
F 020 7257 8001  
E [info@health.org.uk](mailto:info@health.org.uk)

Registered charity number: 286967  
Registered company number: 1714937

**[www.health.org.uk](http://www.health.org.uk)**

Follow us on Twitter:  
**[www.twitter/HealthFdn](https://twitter.com/HealthFdn)**

16 Co-creating Health