

Evidence:

Co-creating Health: Evaluation of first phase



*An independent evaluation of the Health Foundation's
Co-creating Health improvement programme*

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Identify Innovate Demonstrate Encourage

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Foreword

The Health Foundation is pleased to publish this report, which details the findings from an independent evaluation of phase 1 of our Co-creating Health self-management support improvement programme. Self-management support is the assistance caregivers provide to people with long-term conditions in order to encourage daily decisions that improve health-related behaviours and clinical outcomes.¹

The report was written by the evaluators, the Applied Research Centre in Health and Lifestyle Interventions at Coventry University.

For over a decade now, policy has been consistently moving towards providing greater support for people to manage their own health. This has been driven by a broad shift away from the traditional model of healthcare to one that promotes greater choice and control and more personalised care. The policy direction has also been driven by the demands on healthcare from the rising number of people living with long-term conditions, particularly those with multiple long-term conditions.

In this context, there is an appetite at all levels of the NHS to understand how to effectively support self-management and how to integrate it into existing NHS systems.

There is already an established evidence base to show that self-management support can improve the quality of life and clinical outcomes of people with long-term conditions, and also help them make more informed decisions about accessing health services. However there is still a need for more evidence, and its effective communication, to demonstrate the impact of self-management support.

The first phase of the Co-creating Health improvement programme was a three year initiative in eight sites across the UK that aimed to demonstrate the impact, on clinicians and patients alike, of integrating self-management support into routine care for people with long-term conditions. The evaluation of the programme, reported here, provides valuable insights into what worked and the further challenges health systems need to address in order to support people to develop confidence in managing their long-term condition(s) themselves.

We would like to thank everybody who participated in and contributed to the programme for their effort and commitment.

Adrian Sieff
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¹ Bodenheimer T. *Helping patients manage their chronic conditions* 2005

Health Foundation commentary

What is self-management support and why is it important?

Around 18 million people in the UK live with a long-term condition such as diabetes, depression, heart disease or arthritis, and this number is expected to double by 2030. Someone with a long-term condition spends on average 3 hours each year in contact with a healthcare professional and 8757 hours looking after themselves. People are already managing their conditions but much more could be done to support those with long-term conditions to do this more effectively.

As well as having a lasting impact on people's quality of life and wider health outcomes, this support can lead to improved health outcomes and improved levels of patient activation. Patient activation refers to a person's ability to manage their health and healthcare. As well as exhibiting general health-promoting behaviours, people with higher levels of activation are also more likely to adopt healthy behaviours specific to their particular long-term condition(s). For instance, more-activated people with diabetes are more likely to keep a glucose journal and more-activated people with arthritis are more likely to exercise. Improved activation is therefore the first, pivotal step on the road to the optimal management of any long-term condition.

However, supporting people to manage their healthcare requires changes in the way healthcare is delivered. There needs to be greater emphasis

on understanding the motivations and challenges people face in adopting health-promoting behaviours. Health professionals need to recognise and support the autonomy people exercise in managing their own condition and consider how public services can support people to care for themselves effectively on a day-to-day basis.

What was Co-creating Health (phase 1)?

The first phase of the Co-creating Health improvement programme ran in eight sites over three years, starting in 2007. Each site focused on one of four clinical services – long-term pain management, depression, diabetes or chronic obstructive pulmonary disease (COPD). The overall aim of the programme was to support people to take a more active role in managing their health. It did this by building their confidence, knowledge and skills to self-manage, which were supported by changes in clinical practice and service delivery. Co-creating Health piloted an approach to implementing self-management support that comprised three components:

- The Self-Management Support Programme (SMP): A patient education programme for people with long-term conditions, supporting them to develop the knowledge, skills and confidence they need to manage their own condition and work in effective partnership with their clinicians.

- The Advanced Development Programme (ADP): A skills training programme for clinicians, helping them to develop the knowledge, skills and confidence to support people living with long-term conditions to self-manage effectively.
- The Service Improvement Programme (SIP): A programme to put systems and processes in place that support people to manage their own health.

The Health Foundation identified three enablers to self-management: agenda-setting, goal-setting and follow-up. Each of the three components focused on how these enablers can be incorporated into everyday practice for patients, clinicians and services.

What are the lessons from the evaluation?

Clinicians and managers seeking to embed self-management support should take note of our practical learning about how to put in place systems to support patients to play a more active role in management of their care:

- **The self-management support programme for patients improved the activation and quality of life of people with long-term conditions.** This improved activation is particularly noteworthy because the SMP was successful at recruiting people who were on average less activated than others with the same condition within the health economy. It also recruited people from the hardest-to-reach groups that do not usually attend such programmes. The evaluation also shows that people living with diabetes, depression and long-term pain who participated in the programme had improved quality of life. These improvements were at least comparable to, and in some aspects superior to, those achieved by patients participating in other self-management programmes.
- **Adopting self-management approaches requires long-term behaviour change, and the interventions to achieve these also need to be long-term.** The successful implementation of self-management support requires initial training programmes for both clinicians and people with long-term conditions to be followed up with ongoing support. The evaluation identifies which techniques appear to be most effective and points the way for future testing of different models of support, such as buddying systems, telephone coaching and peer support.
- **Self-management support must be normalised into existing ways of working within health economies.** It cannot be an ‘add-on’ but needs to be embedded within care pathways and commissioning contracts. It needs to be led by those ultimately responsible for planning and delivering care for people with long-term conditions in each health economy, transcending condition-specific clinical teams and individual enthusiasts.
- **Techniques to support self-management, including agenda-setting and goal-setting, were well received and implemented following training.** Implementing goal follow-up, however, proved significantly more challenging and there was poor implementation. This was largely because it required significant changes to the clinical micro system, and indeed the broader delivery system, in order to embed changes in practice and behaviour.
- **Co-delivery is an important way of changing patients’ and clinicians’ perceptions.** There were benefits from having every training course, whether for clinicians or people with long-term conditions, jointly facilitated by a healthcare professional and someone living with the condition, working in equal partnership. This innovative co-delivery model is identified as an important way of changing patient and clinician perceptions of their role in healthcare.

Limitations and challenges

The independent evaluation of Co-creating Health provides valuable and generalisable insights into the effectiveness and impact of the patient education (SMP) and clinical skills training (ADP) components. It also provides some important observations on the conditions necessary for successful implementation of service improvement (SIP). During the first phase of the programme, the sites were not able to fully integrate the three components and it was therefore not possible, over the lifetime of the evaluation, to assess their combined impact.

Prior to Co-creating Health, very little work had been done in the UK, and not a great deal more overseas, to test methods of developing clinicians' skills in supporting self-management. This is a young and emerging area of research and practice. Co-creating Health's ADP training course was designed to equip clinicians to better understand and explore motivations and barriers to health-promoting behaviours and to support the development of practical strategies to increase people's capacity to manage their own health. There was evidence from the evaluation that clinicians who completed the course increased their use of techniques to support self-management and that their confidence to do so increased. However, the sample size studied was small and larger samples of clinicians are required to confirm the findings.

It would be naive to conclude that changing models of professional practice, from one where the health professional is the expert advisor to one where they see themselves as co-creating health with their patients, is simply achieved through training. The evaluation illustrates the genuine constraints upon clinicians in making this shift. Through this work we have developed a rich picture of professionals' legitimate concerns about what it means in practice to change their clinical approach. There are real and perceived dilemmas about risk, patient safety and the professional's own risk management which may constrain their ability and willingness to adopt self-management support and other patient-centred practices.

Next steps

This evaluation of the first phase of Co-creating Health, together with learning from other improvement programmes and our *Helping people help themselves* evidence review, signal that the following issues need to be addressed.

- Measuring, and increasing, patient activation – the ability of people to manage their own long-term condition. Higher activation levels are associated with lower levels of unmet need for healthcare and greater support from healthcare providers. Activation also brings benefits for use of health services beyond long-term conditions.
- Embedding programmes that support people to develop their health literacy and the confidence to act as equal partners in their care and treatment in local care patient pathways.
- Embedding the skills and tools for clinicians to act as enablers and coaches who can support people to manage their long-term condition in training at undergraduate and postgraduate education and continuing professional development (CPD).

Underlining all the conclusions reached by this evaluation is the recognition that there needs to be a long-term approach to implementation. The Health Foundation has funded a second phase of the Co-creating Health programme, which will continue in seven of the phase 1 sites until the end of 2012. Through this second phase we are building on phase 1, filling the gaps in our knowledge about how to make the Co-creating Health model work in practice and constantly improving our interventions. In 2011, we commissioned Firefly Research and Evaluation Ltd to carry out an evaluation of the phase 2 programme. They are using qualitative methods to identify successful approaches to making the Co-creating Health model self-sustaining and to securing wider take-up.

The interventions in phase 2 have been developed to reflect the findings from the phase 1 evaluation. Since the evaluation was completed, we have:

- updated and revised the clinician development programme
- commissioned a similar revision of the self-management programme for patients, to develop it into a modular and flexible format which will be made freely available to the NHS
- developed a change package to support redesign of services around self-management support.

We are constantly sharing new resources and evidence through our popular Self-management support resource centre (www.health.org.uk/sms) and will share our learning from the evaluation of phase 2 during 2013.

The lessons from Co-creating Health also feed into the Health Foundation's wider work on improving the quality of healthcare. This evaluation was included in a synthesis of learning from 14 Health Foundation improvement programme evaluations, led by Professor Dixon-Woods of the University of Leicester and published in an April 2012 report called *Overcoming challenges to improving quality* (www.health.org.uk/overcoming-challenges).

The report identifies ten key challenges to improvement that consistently emerged in the programmes evaluated, and suggests ways to overcome them. The findings are shaping both how we support individual improvement programmes, as well as the wider strategic focus of our work.

Over the coming year, we will continue to work with clinicians, educators, patients and others to develop a deeper understanding of what it means to be a health professional in a modern healthcare system. We will be opening up a debate about how doctors' relationships with patients are changing. We will also be publishing a range of primary and secondary research, exploring how changing this relationship can improve the quality of healthcare in the 21st century.

Conclusion

No one could argue with the principle that health services should be supporting people with long-term conditions to manage their health more effectively. Achieving this in practice remains a challenge. Co-creating Health has worked at the frontline to develop practical wisdom, materials and strategies to translate the rhetoric of involvement and engagement into reality.

Already 70% of NHS spend is taken up by the 30% of the population with long-term conditions. Reducing people's dependence on health professionals and increasing their sense of control and wellbeing is a more intelligent and effective way of working: self-management support can be delivered within routine healthcare. It must be central to the health service of the future.

Co-creating Health Evaluation of first phase



Co-creating Health Evaluation of First Phase Executive Summary

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CCH 1 Evaluation Report – Executive Summary

The evaluation of The Health Foundation's Co-creating Health (CCH) phase one programme was commissioned in 2007 and conducted by Coventry University's Applied Research Centre in Health & Lifestyles Interventions. This executive summary presents an overview of CCH, the headline findings and key recommendations for improving the implementation of the CCH model in services in the future.

Co-Creating Health

The CCH model was developed as a result of important policy drivers in the UK, and consistent with those in other countries, supporting the integration of self-management support into mainstream healthcare provision. The programme design was based on some psychological theories of how people learn and develop motivation to make lifestyle changes. A further programme design feature was co-production between patients and clinicians, in designing CCH at site level and in a co-delivery of training programmes.

The Co-creating Health Programme was launched by The Health Foundation in November 2007 with phase one of the programme ending in September 2010. Its overall aim when launched was to... “*demonstrate that increased self-management by patients with long-term conditions, appropriately supported, leads to improved health outcomes*”.

The programme was designed to transform the patient-clinician interaction through the integration of three support programmes. Together, these programmes were intended to be a fully integrated programme, which would improve clinicians' skills in shared decision-making and communication, enhance the self-management ability of people with long term conditions, and improve the effectiveness of health service organisations and their delivery to facilitate a more active role for patients in managing their health and care.

The three integrated support programmes delivered by CCH were an Advanced Development Programme (ADP) for clinicians, a Self-Management support Programme (SMP) for people living with a long term condition (LTC) and a Service Improvement Programme (SIP) focusing on system changes.

Together these programmes focused on the implementation of three specific self-management support (SMS) tools; agreeing an agenda for change, setting behavioural goals for change, and agreeing goal follow-up. These are referred to as the ‘three enablers’.

In addition, CCH focused on four LTCs: chronic obstructive pulmonary disease (COPD), depression, diabetes, and musculoskeletal pain across eight NHS sites (demonstration sites) with two sites each focusing on the same condition.

The programme goals for CCH included achieving change for patients, clinicians and services, as well as building capacity to continue to develop and improve the programme. The goal for patients was to improve their quality of life and well being, and their health as measured by condition specific indicators. Importantly, CCH aimed to develop their knowledge, skills and confidence to self-manage their condition (patient activation). Further, CCH aimed to transform the relationship between the patient and the clinician to a

collaborative partnership in which clinicians adopt self-management support (SMS) practices including routinely using the three enablers and improve patient satisfaction with services. Together, these changes were aimed at achieving better, more appropriate utilisation of healthcare resources. Finally, CCH aimed to build capacity and capability to sustain these changes and make them the norm beyond the demonstration phase.

In 2010 Health Foundation extended the CCH programme to a second phase which ends in August 2012 and focuses on the sustainability and wider uptake of the CCH model.

The Evaluation

The evaluation of Co-creating Health (Phase one) was conducted by Coventry University. The evaluation was commissioned to answer four main evaluation questions:

1. To what extent do key outcomes improve for patients involved in the self-management activities of Co-creating Health?
2. To what extent do clinicians increase the range and use of practices (including the three enablers) to support self-management as a result of Co-creating Health?
3. Does Co-creating Health use co productive methods of delivery? Does Co-creating Health support more co-productive interactions between patients and clinicians?
4. What lessons are there for integrating CCH into the wider organisation?

A mixed methods approach was used to obtain both qualitative information (via text, interviews, and observations) and quantitative information (via surveys and health outcome data). The summative aspects of the evaluation answered questions about whether the initiative worked or not, for whom and why. The formative aspects of the evaluation sought to provide ongoing feedback on key aspects of learning or good practice. The programme evaluation included testing the counter factual by undertaking evaluation activities, measurements and having comparator sites with the same four conditions. Evaluation of programme theory was undertaken by elaborating key assumptions and testing these were evident and in use with the intended and the unintended effects.

The relationship between the CCH1 programme goals, the evaluation methods and the key findings are presented in figure 1 below.

Figure 1: CCH Programme Goals, Evaluation Methods and Key Findings

CCH programme goals	Evaluation methods/data collection ¹	Key findings
Self management support programmes will improve health and well being for patients; improved patient activation, (knowledge, skills and confidence to manage); improved quality of life (QoL) and improved condition specific health indicators.	Surveys with patients attending SMPs, and of patients in the pathway of care not attending SMPs, and in comparator sites. Interviews with SMP attendees and drop outs, SMP tutors, patients and clinicians. Interviews with senior stakeholders, observation by site reporters.	Evidence of improved activation, and use of self management skills, with some improvement in condition specific outcomes and quality of life. No impact on patients who did not attend SMPs.
Clinicians adopting self-management support (SMS) practices and routinely using the three enablers.	Surveys with Clinicians attending ADPs, and of Clinicians in the pathway of care not attending ADPs, and in comparator sites. Interviews with ADP tutors, ADP attendees and drop outs, other clinicians and patients. Interviews with senior stakeholders, observation by site reporters. Secondary analysis of Service Improvement Programme data, and ADP course exit measures. Videotaped observation of consultations with clinician and patient exit ratings.	Evidence of improved use of the three enablers, weak evidence for improved use of a wider range of SMS skills. Weak evidence for the application of the skills in routine clinical practice. No impact on Clinicians who did not attend ADPs.
Change the relationship between patient and clinician to a collaborative partnership in which patients and clinicians identify a shared agenda, set goals and agree a plan for goal follow-up (three enablers), and patient satisfaction with services.	Document analysis of teaching materials, Observations of courses. Secondary analysis of Service Improvement Programme data, and ADP course exit measures. Videotaped observation of consultations with clinician and patient exit ratings.	Evidence of co tutor activity being positively regarded by most tutors and participants. Application of the 3 enablers showed more use of agenda setting, some goal setting, with few instances of goal follow up. Evidence of warm, supportive consultation communication styles.
Introduce changes which are sustainable through building capacity and capability.	Document analysis, programme performance data, interviews with clinicians, patients and senior stakeholders in sites.	Tutor capability requires ongoing development and quality assurance, reliance on small number of key people, requirement for planned approach to future tutor workforce, delivery to include more flexible formats, and support for post course skill consolidation. Establish links to trust HR, training and governance procedures.
Better, more appropriate utilisation of resources. No increase in consultation time overall, reduction in numbers of follow-up appointments and emergency visits to A&E. Patients accessing other non-NHS resources.	Evaluation of routinely collected NHS data.	Insufficient data linkage between CCH inputs and patient related healthcare use, problems in data access, quality of data, insufficient numbers of patients involved in CCH activity to justify these analyses.

¹ See Technical Appendix 6 for the evaluation design and methods.

Key Findings

Patient outcomes

The new model of condition specific SMPs delivered by lay and clinician co tutors achieved high levels of patient completion (attended ≥ 5 sessions). The evaluation found that the SMP provided participants with the knowledge, skills and confidence to become better self-managers and those improvements in key outcomes were a function of the techniques learnt on the SMP and the experience of learning these techniques in a supportive group environment.

We found that patients who had attended most or all of the SMP group sessions, irrespective of condition, were on average significantly more activated, that is, they were more motivated and confident to self manage. This is a particularly striking given that SMP participants were, on average, relatively *less* activated than the majority of other patients with the same condition in their health economy.

This relates to the finding that CCH sites were relatively more successful than other comparable UK self-management programmes run by the Expert Patient Programme in¹ recruiting patients who do not traditionally attend SMPs (e.g. men, black and minority ethnic patients and patients of lower socio-economic status).

SMP outcomes were comparable to, and in some aspects superior to, other programmes used in the UK¹ and in other countries.^{2,3}

- Patients who were younger, more anxious,¹ less activated,² and had poorer quality³ of life made the best gains in terms of activation.
- Patients whose main LTC was depression reported significant improvements in depression,^{1,IV} anxiety,¹ health status^{III} and quality of life^{III} after the SMP.
- Patients whose main LTC was pain reported improvements in their pain symptoms,^V confidence to manage their pain,^{VI} health status^{III} and anxiety¹ and depression.¹
- COPD patients significantly improved their mastery over their condition.^{VII}
- Diabetes patients significantly improved their diabetes specific quality of life.^{VIII}

All participants, irrespective of condition, were significantly better at some aspects of self-managing their condition,^{IX} with depression and diabetes patients in particular improving in more self-management domains than pain and COPD patients. We also sampled patients who had not been on the SMP but were receiving the same local routine care as those who did attend it. We found there was no evidence of impact of CCH on patients in the pathway of care who did not attend SMPs.

Clinician reported changes in their practices

There is limited evidence that clinicians who attended the ADP increased their reported use of a wide range of practices in self-management support, as the sample size for paired data from the same clinicians before and after the ADP was small and may have been biased towards those most likely to report positive effects of the course, since those who dropped out would not respond to surveys. There is stronger evidence that these clinicians reported improvements in the use of the three enablers, and some evidence that their confidence in a wider set of self-management support practices also improved.

The largest proportion of those who attended the ADP were doctors and the majority of these were GPs. Doctors started with the lowest pre ADP use of clinical self-management skills and the three enablers relative to other professions, and they made proportionately the greatest gains. Clinicians who were allied health professionals and psychologists were more likely to report practicing self-management support and the use of the enablers particularly goal follow-up after completing the ADP. Nurses were more likely to use them than doctors. The sub set of nurses who worked across primary and secondary care are likely to be clinical specialists for whom self-management support may have been in their basic training and may well be in their current job role. Secondary care clinicians are least likely to use the consultation to support or arrange goal follow-up, even after attending the ADP. Alternatives to be explored in future programmes would be supporting self-management through goal follow-up within the secondary care team and in collaboration with general practice.

Supporting co-production

Co-production was well evidenced in the delivery of CCH, via patient and clinician involvement in the conduct of the demonstration site activity and in co tutoring of programmes. Sites were generally convinced of the value of co tutoring, but sought ways to modify course content and delivery to customise the courses to local circumstances. Evidencing these modifications , and continuing to measure course outcomes with robust research based measures and measures linked to NHS performance metrics, will be important in demonstrating the value of the CCH model.

We draw conclusions based on all sources of data, from the surveys, interviews, service improvement measures, and consultation observations of expert clinicians with their patients. These data showed that of the three enablers, the easiest and most often used was agenda setting, with less goal setting and action planning and very little goal follow-up. Exit ratings from consultations tended to show patients felt valued and supported by clinicians, but these measures are open to many biases, and were used in CCH mainly for training purposes not evaluation. Interviews and direct observations showed that clinicians, particularly those whose job role, and prior training have not supported the use of these co production skills in consultations, require more support to develop and apply these skills in routine practice. Video analysis of consultations of experienced ADP trained clinicians and tutors showed evidence of a range of co-productive skills by this small sub set of champions for the ADP, although the use of the three enablers was not widely evident even in these consultations.

Supporting the application of co-productive self-management skills of clinicians into practice will require further programme design of mechanisms to support skill development and implementation, such as coaching, video or audio taped feedback of real consultations, and the use of robust patient and clinician exit measures. Supporting co-productive consultation skills by patients will similarly require modification of the content of the SMP and mechanisms for supporting the application of new skills for subsequent healthcare consultations, for example via health coaching, and skills practice at SMP reunions.

The integration of the ADP, SMP and SIP was sub-optimal, meaning the assumed synergistic effects were not programmed to occur and could not be evidenced. However, there was

recognition of the importance of achieving changes in clinician practices and the design of services to support self-management of LTCs, with many innovations underway at the completion of this phase.

Lessons for integration in the wider organisation

While CCH is broadly in line with national policies promoting self care, in this first phase, it was managed and delivered very much as a stand-alone project and not linked well with the Quality, Innovation, Productivity and Prevention (QIPP) programme, or drives towards personalisation or mutuality at programme or at site level. Local policies and procedures to embed the support practices were not being used in a coherent way to normalise the new model. However, there were some examples where sites were beginning to use systems such as appraisal and revalidation to support clinician commitment to learning and using these new practices. There was also some evidence of sites planning to achieve more integrated approaches to planning and delivering self care for LTC across trust boundaries.

Senior level leadership of CCH was established as a key success factor for CCH at the outset by the Health Foundation. Several processes, such as VIP visits and feedback via national forums involving CEOs, were very effective in securing this commitment throughout this first phase. At site level there was over reliance on a small number of champions, who often took on many roles. Awareness of the need to translate executive director “buy in” into securing the resources within organisations to support site level leaders, was an important learning point for all sites.

The Programme as a whole, and most of the trusts in the demonstration sites, did not have clear aims for CCH, articulate them, and measure them in a meaningful way to track progress and measure achievements. This meant that the strong executive level commitment was not reliably translated into resourcing local staff to develop the CCH model as routine in existing services and out the CCH model into other services.

Challenges for the Evaluation

A consequence of the emergent nature of the programme theory, and the co-production approach to developing the programmes with the technical providers, was that the measurement for performance (monitoring programme inputs and throughput) was not planned in advance. The evaluation was only one of the data collection activities required of CCH sites, alongside quality improvement data used to self-assess progress and programme management data required to ensure that the programme was on track operationally. Some site staff felt burdened at times by the differing types of measurement, and it affected their willingness to recruit participants for evaluation activities.

The emergent nature of CCH meant that there was not an optimal approach to achieving maximum synergy between the three programmes. This overlapping combination was known as “White Light”. The importance of proactive planning and targeting of the programmes in order to achieve this synergy became clear about mid-way through the first phase of CCH. Consequently in the latter half of the programme, sites began to test strategies for delivering the holistic, integrated CCH model to specific clinical teams and general practices. The impact of this for the evaluation was that whilst it was possible to

assess the impact of each of the three component parts of CCH independently, it was not possible to identify the impact of all 3 interventions in combination because such combined delivery was being achieved only on a small scale in some sites by the end of Phase 1.

A further consequence of the emergent nature of CCH was that there were no mechanisms in place to ensure the sites could record if patients were accessing teams and clinicians who had been part of the Service Improvement Programme (SIP) or the Advanced clinician Development Programme (ADP). Clinicians were also not able to have direct knowledge of whether their patient was taking part in the Self-Management Programme (SMP). There was also no means of recording the occurrence of the combined effects of all three programmes, on individual patients. Therefore the evaluation could not establish which programmes were impacting on patient outcomes and services (the “dose of CCH”). Further, it was not possible to link CCH activity to the use of routine NHS data on service use and service recorded clinical outcomes.

The evaluation of the impact of CCH on service redesign was difficult to establish. CCH sites did not have a “diagnostic” phase as part of Quality Improvement (QI) activities and consequently no baseline data was collected before the Service Improvement Programme started. The data that was used was limited to the improvement measures being collected by the teams and provided to the evaluators via the technical provider. The evaluation method therefore consisted of secondary analysis of this data and was not able to draw any wider conclusions about the impact of the Service Improvement Programme. For this reason, this report does not include any detailed analysis of the impact of the Service Improvement Programme. A Technical Report has however been presented to The Health Foundation with some evaluation findings from the Service Improvement Programme, as well as a separate Technical Report on the use of NHS datasets for evaluation purposes.

The evaluation findings presented in this summary (and full report, along with Technical Appendices) are for Phase One of the programme only; they reflect all data collected up to February 2011. Phase Two is running until August 2012.

Recommendations: Executive Summary

Given the findings above the evaluation of CCH (phase one) has six recommendations to support the implementation and integration of self-management programmes more widely. Further recommendations are given at the end of each of the report chapters on the CCH programme components, and are provided in total at the end of the Main Report.

Supporting Integration within the wider organisation

- **Fit with local policy and care pathways:** Future self-management programmes should be designed to readily fit with policies that transcend specific condition pathways. The outcomes chosen should include those which are readily evidenced at the local level as contributing to these policies via the implementation of the programme in the pathways as they are described and measured by commissioners.
- **Making the business case with the right data:** A complex multilevel programme requires agreed aims along with means of measuring and communicating the progress of the programme and its impact. Where possible the measures include those already in use in the healthcare system to promote comparison with other initiatives, and to

enable comparison between services as the new model of service is rolled out to new pathways. Such data is essential to support business cases for investment.

- **Normalisation within existing procedures:** Future self-management programmes should be planned to integrate with and be supported by policies and procedures that embed the intervention into the way the organisation habitually operates including systems of workforce planning, job plans, appraisal, staff remuneration, re-accreditation and governance.
- **Executive Leadership:** Senior leaders such as CEOs should be involved targeting the resources of a new SMS programme where they believe there will be most gain. It follows that they have a key role to play in defining the programme aims, outcomes and measures so they are able to make decisions about future investment and disinvestment.

Supporting Implementation

- **Targeting limited resources more effectively:** Recruitment strategies for self-management programmes could be targeted to meet commissioners' local health needs analysis in order to reach those most in need. This will also ensure local clinicians (particularly those trained in self-management support skills) are more active recruiters to the programme. For example with the SMP, the targeting of resources would also mean that alternative models of provision could be explored (such as varying session length, frequency, and format of delivery to include digital media DVDs, Web and phone based applications), as well as on line social networking. The latter are particularly suited to younger participants.
- **Ongoing support and tailored training for clinicians:** To build on the initial gains in competence in using SMS skills developed from attending courses such as the ADP, we recommend that ongoing development for clinicians is provided, for example by coaching, to consolidate and refresh these skills, and that the provision is based on an analysis of individual and team training needs. For example, future training courses for clinicians using the ADP model would benefit from using well designed post consultation exit ratings by both the clinician and patient, and/or tutor facilitated feedback on videotaped consultations to enable clinicians to gain feedback on their skills in real clinical practice.
- **Embedding co-productive practice:** Building competent practice in co-productive consultation skills by clinicians requires organisational support and a planned approach to skill development, which is likely to include using direct observation of clinical consultations and coaching from clinician tutors. Support for patients to participate co-productively in consultations may require a much greater content on this topic in the SMP as well as coaching and feedback offered over a period after the SMP, perhaps via recapping experiences at reunions or via ongoing support groups or web forums.

Footnote:

Self-management evaluation papers

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Outcome measures

I Zigmond AS, Snaith RP. The hospital anxiety depression scale. *Acta Psychiatr Scand* 1983;67:361-370.

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Page of Contents

CCH 1 Evaluation Report – Executive Summary.....	2
Recommendations: Executive Summary	8
Footnote:.....	10
Self-management evaluation papers	10
Outcome measures	10
Co-Creating Health: Introduction to the Programme and Evaluation	13
Question 1: To what extent do key outcomes improve for patients involved in the self-management activities of Co-creating Health?	24
a) Did the SMP manuals have content relevant for improving key patient outcomes?.....	26
b) Did the SMP deliver content relevant to improving the key patient outcomes?.....	26
c) Did the SMP improve key patient outcomes?.....	28
d) What was the experience of SMP participants and tutors?	51
e) What was the reach of the SMP, and how could this be improved?.....	58
Recommendations: Question 1	61
Question 2: To what extent do clinicians increase the range and use of practices (including the three enablers) to support self-management as a result of Co-creating Health?	63
a) Did the ADP have content relevant to increasing practices (including the three enablers) to support self-management?.....	65
b) Did the ADP teach the content relevant to increasing practices to support self-management in ways that motivated clinicians?	66
c) What is the evidence that the ADP increased practices to support self-management (including three enablers) and improved motivation to support self-management? Who benefited from the ADP training?.	68
d) What are the lessons from the use of the ADP in CCH for how the training of clinicians in SMS practices be improved?	85
Recommendations: Question 2	92
Question 3: Does Co-creating Health use co-productive methods of delivery? Does Co-creating Health support more co-productive interactions between patients and clinicians?	94
a) What is the evidence that the CCH initiative was delivered in ways that maximise co-production?	96
b) What is the evidence that the programme delivery was experienced as co-productive?.....	99
c) Is there evidence that the ADP and SMP courses in the CCH initiative were designed to support productive interactions between patients and clinicians? Was co-production built in to other CCH activities?.....	103
d) Is there evidence that the programme resulted in observable changes in co-productive consultation practices, and how might programmes support co productive consultations in future?.....	105
Recommendations: Question 3	112
Question 4: What lessons are there for integrating CCH into the wider organisation?	113
a) Were there clear and communicated aims and measures of progress, and success available to site leaders? How can systems of measurement assist implementation in other services?	115

b) Is there a "fit" with the strategic aims and culture, as well as national policies, local strategies and commissioners' priorities? How can the model of service support of these priorities and policies?	117
c) Did trusts have the policies and procedures to support the model become integrated across the wider organisation? How can this be achieved in future?	122
Recommendations: Question 4	126
Report Conclusions	127
Report Recommendations.....	132
References.....	136
Glossary.....	143

Separate Appendix for Question 1 to Question 3 Data Tables

Question 1 Appendix.....	4
Question 2 Appendix.....	12
Question 3 Appendix.....	28

Co-Creating Health: Introduction to the Programme and Evaluation

Overview of the Programme

In this opening chapter we describe the aims and objectives of the Co-creating Health (CCH) Programme, the design of the CCH programme, its context, key assumptions and evidence. We then briefly outline the evaluation approach design and methods.

The Co-Creating Health Programme

The Health Foundation's (THF) Co-creating Health (CCH) Programme was launched in November 2007. The final on site activity ceased September 2010 and the final data collection ended in February 2011. It is important to note that the CCH programme has two phases, this evaluation reports on phase one of the programme only.

The aim of CCH (phase one) was to:"demonstrate that increased self-management by patients with long-term conditions, appropriately supported, leads to improved health outcomes" (ITT for Evaluation of CCH, 2006)

The programme was designed to transform the patient-clinician interaction through the integration of three support programmes to:

- Improve clinicians' skills in shared decision-making and communication.
- Enhance self-management ability of people with long term conditions.
- Improve the effectiveness of health service organisations and delivery to facilitate a more active role for patients in managing their health and care.

The three integrated support programmes delivered by CCH were an Advanced Development Programme (ADP) for clinicians, a Self-Management support Programme (SMP) for people living with a long term condition (LTC) and a Service Improvement Programme (SIP) focusing on system changes. Together these programmes focused on the implementation of three specific self-management support (SMS) tools. These are shared agenda setting, collaborative goal setting and goal follow-up. These are referred to as the three enablers throughout this report. In December 2008, the National Support Team (NST), which comprised senior members of the Technical Providers (TPs) and evaluation team, the Programme Office (PO) and members of The Health Foundation agreed high level Programme Goals that support the programme to achieve these outcomes. These are summarised below:

CCH Programme Goals

- Improve health and well being for patients; improved patient activation, (knowledge, skills and confidence to manage); improved quality of life (QoL) and improved condition specific health indicators
- Change the relationship between patient and clinician to a collaborative partnership in which patients and clinicians identify a shared agenda, set goals and agree a plan for goal follow-up (three enablers), and patient satisfaction with services

- Clinicians adopting self-management support (SMS) practices and routinely using the three enablers
- Introduce changes which are sustainable through building capacity and capability
- Better, more appropriate utilisation of resources. No increase in consultation time overall, reduction in numbers of follow-up appointments and emergency visits to A&E. Patients accessing other non-NHS resources (Source: CCH National Support Team, 2008)

CCH focused on four LTCs: chronic obstructive pulmonary disease (COPD), depression, diabetes, and musculoskeletal pain across eight NHS sites with two sites each focusing on the same condition. These are referred to as the demonstration sites throughout this report.

Figure 1: Demonstration sites by condition

Condition	Trusts
COPD	NHS Ayrshire and Arran Cambridgeshire Primary Care Trust & Cambridge University Hospitals NHS Foundation Trust
DEPRESSION	Wandsworth Teaching Primary Care Trust & South West London and St George's Mental Health NHS Torbay Care Trust & Devon Partnership Trust
DIABETES	Southwark Health and Social Care Trust & Guy's and St Thomas' NHS Foundation Trust Islington and Haringey Primary Care Trusts & The Whittington NHS Hospital Trust
PAIN	Calderdale and Kirklees Primary Care Trusts & Calderdale and Huddersfield NHS Foundation Trust Bristol Primary Care Trust & North Bristol NHS Trust

CCH Programmes

CCH took a whole system approach to embed self-management support within mainstream health services. This included integrated provision of support for a period of three years, delivered in collaboration with eight competitively selected sites (healthcare economies), combining primary and secondary/tertiary care providers of healthcare around one selected condition.

The Health Foundation commissioned three technical providers (TPs) to offer the three programmes at each site.

Expert Patients Programme Community Interest Company (EPPCIC) provided the patient Self-Management Programme (SMP). This is a group programme with a lay and a clinician co tutor taking place in seven three hour sessions for around 12 participants. Client-Focused Evaluations Programme UK (CFEP UK) provided the Advanced Development Programme (ADP) for clinicians. This is a group training programme of three four hour workshops lead by a clinician and a lay co tutor, and includes use of patient survey feedback and optional action learning sets.

Finnamore Management Consultants (FMC) provided the service improvement programme (SIP). This comprised a one day skills based workshop to introduce Quality Improvement methods, and in particular the Institute for Healthcare Improvement (IHI) model for improvement, followed by clinical team based use of PDSA (Plan Do Study Act) methods to support the introduction of the three enablers into services.

It is worth noting that in 2010, the Health Foundation extended the CCH programme to a second phase (ending August 2012). The main aim of the phase two programme being to achieve local sustainability of the CCH model beyond the Health Foundation's direct investment through the commitment and ownership of local commissioners and providers.

The extension therefore aims:

- To create a cadre of clinical and non-clinical leaders who effectively champion the CCH model across the local health economy and nationally.
- To showcase the CCH model to decision makers at national, system and professional levels.
- To secure the spread of the CCH model within the original long term condition and to a wider population within their local health economy as agreed by each site (e.g. this could be to another long term condition or a hard to reach population).
- To create the materials and information of a replicable whole system change programme that others can use.

As mentioned above this evaluation only reports on phase one of the programme which ran from November 2007 September 2010.

The context to Co-Creating Health

The CCH model was developed as a result of some important policy drivers, and was based on some psychological theories, key assumptions of change processes, and evidence from other programmes for the application and use of self-management support in healthcare. Below we outline some of the key evidence and policies.

Co creating Health in relation to the UK policy context 2007-11

A key feature of CCH was the policy context around self-management in the UK in 2007. Demographic changes, especially the growth in the ageing population, have created escalating demands for healthcare worldwide. Lord Darzi¹ reported that by 2031, the population over the age of 75 will be 8.2 million. LTCs currently affect more than 17 million people in the UK and they fill 80% of consultations in primary care, 60% of hospital bed days and two-thirds of emergency admissions.² It is recognised that health care professionals and the system of health care they operate within are not supporting patients adequately. The 2006 DH White Paper³ promised an increase in self-management training for people living with a LTC from 12,000 to over 100,000 course places by 2012. In this period, NHS quality improvement programmes positioned patient centeredness and patient involvement, as well as self-management interventions for LTCs at the heart of government initiatives.⁴

In 2006-7, the Health Foundation sought to develop a national quality improvement demonstration programme to influence UK health policy on services for people with long term conditions, by testing processes that would support self care, patient empowerment

and participation in healthcare consultations and recognising the importance of support provided by clinicians and services. The CCH self-management support principles fit with the latest NHS policy White Paper, Equity and excellence: Liberating the NHS (2010),⁵ which emphasises the importance of shared decision-making for clinical consultations (“no decision about me without me”). The existing Quality, Innovation, Productivity and Prevention (QIPP) also focuses the NHS on increasing self-care and the use of new technologies for people with long-term conditions.

Self-management – the approach and evidence

The Health Foundation adopted Bodenheimer's definition of supported self-management.⁶

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

Bodenheimer et al⁷ maintain that self-management complements traditional patient education. The provision of information is an important part of self-management, however, self-management differs because of its focus on the patient's own agenda, improving problem solving skills, and improving confidence (self-efficacy) to use those skills in coping with a broad range of consequences of living with a LTC. Bodenheimer et al⁷ believe that a crucial feature of self-management interventions are patient generated goals and action plans.

A recent review for the Health Foundation of almost 600 studies showed that self-management can lead to improvements in patients' quality of life, clinical outcomes and health service use. Improved self-management and behaviour change was more likely to occur in interventions which included collaboration between patients and clinicians and included information and education alongside behaviour change strategies such as goal setting, action planning and follow-up.⁸

The Health Foundation commissioned EPPCIC to develop a new SMP for CCH. The template for the SMP was Professor Kate Lorig's Chronic Disease Self-Management Course (CDSMC), which has an established evidence base⁹ and is currently being used in 30 countries to provide self-management training to LTC patients. Lorig and colleagues pioneered the use of lay leaders (people with a LTC) as co deliverers. In the UK, the CDSMC, which was rolled out nationally by the Department of Health in 2007, is known as the Expert Patient Programme (EPP). A systematic review and meta-analysis involving nearly 7,500 LTC patients who attended lay-led SMPs reported small improvements in several outcomes such as self-efficacy, depression, pain, disability, fatigue, self-rated health, aerobic exercise, cognitive symptom management.¹⁰ The largest UK RCT of the CDSMC showed improvements in energy, self-efficacy and other psychosocial outcomes and that it was cost-effective.¹¹

Co-Tutor model

The early successes of programmes with lay and clinician co tutors in Australia supported the model of co tutoring proposed by the Health Foundation.¹² The underlying assumptions of co tutoring are that each has their respective expertise to offer, and that co tutoring offers opportunities for learning by seeing the tutors act co-productively, a form of learning by observing known as role modelling.¹³ In this first phase of CCH, co tutoring was also applied to the ADP, which builds on models of patient lead training of healthcare clinicians.¹⁴ Coulter and Ellins¹⁵ maintain that if health care professionals undermine patients' coping skills, the health care professionals can expect to see patients utilising their services more often. Given the limited contact that healthcare professionals have with patients, it is important that the interaction is as productive as possible with both parties maximising the opportunity for successful self-management and clinical outcomes.

The Health Foundation recognised that one of the limitations of self-management policy and research in the UK has been the over emphasis on providing training to patients without either providing training to clinicians to support patients' self-management behaviours or making service improvements to embed self-management within service provision. This has led to limited outcomes for patients who can quickly lose the confidence and motivation to self-manage when faced with unresponsive and unsupportive clinicians and services. CCH is set within the Wagner chronic care model (CCM).¹⁶ According to Wagner et al:¹⁷ "*High quality chronic illness care is characterised by productive interactions between practice team and patients that consistently provide the assessments, support for self-management, optimisation of therapy and follow-up associated with good outcomes.*"

Some of the initial evidence which the CCM was based upon included a Cochrane Collaboration review of 41 service redesign studies in diabetes care in the USA. The results showed that comprehensive and multi component interventions (which included one or more of the following elements, decision support, delivery system design, information systems, and self-management support), were more successful in improving patient and process outcomes.¹⁸ Complex interventions that only target providers' behaviour did not change patient outcomes, unless accompanied by interventions directed at patients.¹⁸ All five studies in the review which involved all four interventions had positive outcomes on patients and process outcomes.¹⁹

According to the CCM model, one of the main tasks for health services is to support self-management. This is an important task and needs to be embedded in a system which includes activated patients, prepared clinicians and a responsive and flexible administrative structure. CCH was developed to focus on interventions to influence self-management by patients directly, and via the consultations with their clinicians.

Productive interactions and the three enablers

Productive interactions are underpinned by the use of three self-management support tools known in CCH as the three enablers: agenda setting, goal setting and follow-up. These are defined in the Glossary. The programmes in CCH introduced change processes which were developed to implement the three enablers. The first enabler, agenda setting, supports patients and clinicians to collaboratively agree the aims of each consultation, the purpose of which is to clarify and establish the patient's motivations and interests in order that the

clinician can help formulate and support patient selected goals, which are more likely to excite and motivate the patient. There are few studies which have looked at agenda setting in isolation from other self-management activities such as goal setting and action planning.

The second enabler is goal setting. The goals should be patient generated and important to the patient. Specific goals are described as action plans which involve the clinician and patient specifying a course of action to achieve the goal (the what, when, where and how often). Bodenheimer and Handley²⁰ reviewed 8 studies in the USA and found that in nearly all studies goal setting improved patient outcomes. Follow-up encourages regular reinforcement of the goals set by patients. Evidence shows that goal follow-up is linked to successful goal attainment and can either be conducted in clinic,²¹ via telephone²²⁻²⁴ email^{25,26} and can be automated.²⁷

In order help a person identify and understand the consequences of their lifestyle choices on their health, and assist in thinking about options for change, clinicians have been trained to use motivational interviewing (MI) to support the use of self-management support skills in their consultations with patients with long term conditions. MI is a client-centred, directive method for enhancing motivation to change by exploring and resolving ambivalence.²⁸

MI embraces a collaborative type of clinician-patient consultation and its main goal is behavioural change.²⁹ MI has been used in supporting LTC patients to make behavioural changes,³⁰⁻³² and encourages collaboration between the patient and clinician, in which change is elicited rather than imposed.²⁸ MI comprises four general principles: expressing empathy (establishing and building the relationship), developing discrepancy (explore values/goals), roll with resistance (support autonomy/choice-avoid arguing for change) and supporting self-efficacy (build skills/ agree small goals).²⁸ These skills overlap with and complement the clinical consultation skills required to provide SMS and include: establishing an empathic clinician-patient relationship, joint agenda setting for each consultation, collaborative goal setting, exploring ambivalence about change, using problem-solving skills, using systemic tools to support goals' follow-up. These approaches underpinned the design of the Advanced clinician Development Programme (ADP).

Social Learning Theory

Both the SMP and ADP are grounded in social learning theory.¹³ The courses aim to develop attendees' confidence (self-efficacy) and skills for self-management behaviours and self-management support skills respectively on the SMP and ADP. On the CDSMC confidence to perform self-management behaviours is achieved through four efficacy enhancing strategies: skills mastery (goal setting, action planning and problem solving), social modelling (observing peers model target behaviours), social persuasion (group feedback and encouragement) and reinterpretation of symptoms. Evaluations of the CDSMC consistently report improvements in self-efficacy¹⁰ and that other patient outcomes are predicted by self-efficacy. Participants frequently report using and finding beneficial the three of the efficacy enhancing techniques (skills mastery, social modelling and social persuasion).³³⁻³⁵

Patient Activation

Patient activation is similar to self efficacy and refers to the extent that patients are motivated and using self-management support skills in their lives. The concept of patient activation describes a series of four developmental stages that LTC patients proceed ("journey") through to become skilled self managers.³⁶ Informed and activated patients who are able to collaborate in their care are central to the Chronic Care Model. Patients who are least activated are less likely to engage in self-management behaviours and self-management support should be tailored for these patients to include small, realistic and achievable goals to foster success and increase motivation to take on more complex self-management behaviours. Hibbard³⁷ suggests that self-management support for patients at Stages 1 and 2 should focus on self-awareness and setting small goals, whereas patients at Stages 3 and 4 can be encouraged to perform clinically meaningful behaviours. Activities planned in CCH such as co-tutor role modelling and learning from the success of peers, goal setting, goal review, problem solving, vicarious learning, instillation of hope, information exchange, both through the formal activity content and the informal exchange between the participants, would be expected to contribute to activation.

The key assumptions of Co creating Health (CCH)

The Health Foundation set out to achieve an integrated programme of self-management support, taking the learning achieved across the range of research and models of provision to demonstrate what could be achieved in the UK National Health Service. In so doing, the Health Foundation used a deliberately emergent and collaborative approach to developing programme theory throughout the life of the programme.

Key assumptions for the programme are:

1. The use of the three enablers is essential by patients for their everyday self-management, and clinicians can learn to use service tools and communication skills in consultations to support patients to use these enablers.
2. Learning can be enhanced by role modelling- so co tutors who demonstrate how they apply the enablers themselves will enhance skill acquisition and confidence to apply the skills.
3. The greatest programme effects will be shown where there is integration between the three programmes affecting simultaneously patients, clinicians and services as they impact on the consultation. This can be described as integration, i.e. processes working synergistically together to make a coherent programme. It can be referred to as a strategic intent to focus all aspects of the programme on teams or parts of a pathway, which is referred to as the "White Light".

The evaluation approach and design

The aim of CCH phase one was to improve key patient outcomes by embedding a range of self-management support. The programme was not fully prescribed at the outset but had a significant degree of flexibility in how it evolved and was implemented. The experimental and emergent nature of the programme was reflected in some aspects of the evaluation design.

The commissioned evaluation by Coventry University's Applied Research Centre in Health & Lifestyles Interventions was summative and formative, methodologically pluralistic using

mixed methods to obtain qualitative (text and observations) and quantitative (numerical) information. The summative evaluation answered questions about whether the initiative worked or not, for whom and why. The formative evaluation sought to provide ongoing feedback on the learning from the evaluation as it unfolded. The focus of the evaluation was to extract learning that could assist the spread of successful practice alongside assessing the impact of the programme of interventions, where there was good evidence supporting the use of the constituent parts.

Evaluation measurement included

Outcome Evaluation: What was the “worth” of the intervention i.e. did the programme achieve the overall programme goals? This included outcomes such as quality of life for patients, and clinicians’ confidence to provide self-management support (SMS).

Theory-Driven Evaluation: Why does CCH lead to the observed impacts and outcomes? This is the elicitation of the implicit causal models of the programme and how they are intended to impact on the overall programme objective.

Process Evaluation: We planned to discover how the initiative produced the observed outcomes.

There was one integrated evaluation, making use of both cross sectional and longitudinal (repeated measures) data collection. The evaluation design takes account of the emergent nature of the programme, and made provisions to estimate the counterfactual (what would have happened had the initiative not taken place) through the use of comparison sites matched by clinical condition. Neither the sites, nor the sites’ clinicians and patients were selected using randomisation.

The measurement methods included surveys of patients and clinicians using standardised psychological measures, interviews, non participant observations, participant observation by site reporters, and analysis of NHS data. The full method and datasets are described in the Technical Appendix 6- Evaluation Methods, Datasets and Theory of CCH. See Figure 3 describing how the evaluation methods addressed the five programme goals and the key findings.

In order to measure the counterfactual, four comparator sites were selected (See Figure 2). In comparator sites a similar set of evaluation activities took place to those in demonstration sites. This comprised the surveys and interviews of patients and clinicians on the pathway of care were conducted in the early phase of CCH and repeated in the final year. Also, there were interviews with senior stakeholders at these times. In the same way as the demonstration sites, the comparator sites also had “site reporters” who conducted observations and interviews to capture activities of the site in their approaches to self management support. Comparator sites also provided data on healthcare use of patients in the condition evaluated in the site.

Figure2: Demonstration sites by condition

Condition	Trusts
DEPRESSION AND DIABETES	Coventry and Warwickshire Partnership Trust, University Hospitals Coventry and Warwickshire NHS Trust, NHS Warwickshire PCT and NHS Coventry PCT.
COPD AND PAIN	Isle of Wight Healthcare NHS Trust.

Figure 3: CCH Programme Goals, Evaluation Methods and Key Findings

CCH programme goals	Evaluation methods/data collection ^{II}	Key findings
Self management support programmes will improve health and well being for patients; improved patient activation, (knowledge, skills and confidence to manage); improved quality of life (QoL) and improved condition specific health indicators.	Surveys with patients attending SMPs, and of patients in the pathway of care not attending SMPs, and in comparator sites. Interviews with SMP attendees and drop outs, SMP tutors, patients and clinicians. Interviews with senior stakeholders, observation by site reporters.	Evidence of improved activation, and use of self management skills, with some improvement in condition specific outcomes and quality of life. No impact on patients who did not attend SMPs.
Clinicians adopting self-management support (SMS) practices and routinely using the three enablers.	Surveys with Clinicians attending ADPs, and of Clinicians in the pathway of care not attending ADPs, and in comparator sites. Interviews with ADP tutors, ADP attendees and drop outs, other clinicians and patients. Interviews with senior stakeholders, observation by site reporters. Secondary analysis of Service Improvement Programme data, and ADP course exit measures. Videotaped observation of consultations with clinician and patient exit ratings.	Evidence of improved use of the three enablers, weak evidence for improved use of a wider range of SMS skills. Weak evidence for the application of the skills in routine clinical practice. No impact on Clinicians who did not attend ADPs.
Change the relationship between patient and clinician to a collaborative partnership in which patients and clinicians identify a shared agenda, set goals and agree a plan for goal follow-up (three enablers), and patient satisfaction with services.	Document analysis of teaching materials, Observations of courses. Secondary analysis of Service Improvement Programme data, and ADP course exit measures. Videotaped observation of consultations with clinician and patient exit ratings.	Evidence of co tutor activity being positively regarded by most tutors and participants. Application of the 3 enablers showed more use of agenda setting, some goal setting, with few instances of goal follow up. Evidence of warm, supportive consultation communication styles.
Introduce changes which are sustainable through building capacity and capability.	Document analysis, programme performance data, interviews with clinicians, patients and senior stakeholders in sites.	Tutor capability requires ongoing development and quality assurance, reliance on small number of key people, requirement for planned approach to future tutor workforce, delivery to include more flexible formats, and support for post course skill consolidation. Establish links to trust HR, training and governance procedures.
Better, more appropriate utilisation of resources. No increase in consultation time overall, reduction in numbers of follow-up appointments and emergency visits to A&E. Patients accessing other non-NHS resources.	Evaluation of routinely collected NHS data.	Insufficient data linkage between CCH inputs and patient related healthcare use, problems in data access, quality of data, insufficient numbers of patients involved in CCH activity to justify these analyses.

^{II} See Technical Appendix 6 for the evaluation design and methods.

Data on the delivery of the CCH programme, the throughput of its three elements and other metrics are described in more detail in the Technical Appendix-6.

Challenges for the evaluation

A consequence of the emergent nature of the programme theory, and the co-production approach to developing the programmes with the technical providers, was that the measurement for performance (monitoring programme inputs and throughput) was not planned in advance. Site staff also felt burdened at times by both types of measurement.

A further challenge for the evaluation was that the CCH programme was not designed at the outset to achieve maximum synergy between the three programmes. That is, the programme assumed that a key way of achieving supported self-management is by the interaction with clinicians, particularly via co-productive consultations of the patient and the clinician and the clinical team, with the provision of services that support self-management (e.g. by having agenda setting aids in place prior to consultations). This overlapping combination was known as “White Light”. Mechanisms to ensure the programme acted synergistically, i.e. there was a strong focus of CCH in particular teams, who would not only carry out service improvement, but also attend the clinician training, and refer patients to the self-management programme did not begin to be addressed until mid way through this phase of CCH. We found, for example, that recruitment to SMPs, ADPs and SIP work were often occurring in different parts of the pathway or geographically in distant areas.

A further consequence of the emergent nature of CCH was that there were no mechanisms in place to ensure the sites could record if patients were accessing teams and clinicians who had been part of the Service Improvement Programme (SIP) or the Advanced Development Programme for clinicians (ADP). Clinicians were also not able to have direct knowledge of whether their patient was taking part in the Self-Management Programme (SMP). Patients would not be aware if their services and clinicians were part of this new approach which supported self-management, and so may have felt inhibited in attempting to discuss their self-management issues taught via the SMP. There was also no means of recording the occurrence for individual patients of the combined effects of all three programmes; and so establishing which patients, clinicians and services were impacting on patient outcomes and services (the “dose of CCH”) could not be evaluated.

The evaluation of the impact of CCH on service redesign was particularly challenging. The sites were expected to choose in which teams and services the QI activities took place and began immediately with no “diagnostic” phase, which might not only have targeted SIP activities more appropriately, but would have afforded a “baseline” measurement period to be undertaken independently by the evaluation team. The evaluation consisted of secondary analysis of the technical provider’s performance data which focussed on process measures (amount of PDSA cycles undertaken for example), which had no measurement of the impact of the activities on service outcomes, as well as senior stakeholders’ views of SIP. Technical Reports have been presented to The Health Foundation on the use of NHS datasets (healthcare use) and the evaluation of the Service Improvement Programme.

Overview of evaluation questions

The evaluation findings presented in this report are structured to answer the following four questions posed by The Health Foundation and which reflect the broad programme goals:

1. To what extent do key outcomes improve for patients involved in the self-management activities of Co-creating Health?
2. To what extent do clinicians increase the range and use of practices (including the three enablers) to support self-management as a result of Co-creating Health?
3. Does Co-creating Health support more "co-productive interactions" between patients and clinicians?
4. What lessons are there for integrating CCH into the wider organisation?

The chapters (Introduction to the programme and evaluation, questions 1-4) are presented with sub questions, suggested by the evaluation team derived from models of Implementation Science as described in the Chapter addressing question 4.

Question 1: To what extent do key outcomes improve for patients involved in the self-management activities of Co-creating Health?

Introduction

The overall aim of CCH was to achieve measurable improvements in patients' activation, quality of life, psychological distress, self-management ability and experiences of their care by embedding self-management support within mainstream health services. One of the ways to achieve this was through the provision of a group-based, self-management programme which patients attended to become more knowledgeable about their condition and become more confident to use self-management skills. The three CCH programme inputs were intended to be combined to achieve this goal, for reasons outlined in the introduction of the report. This chapter will focus on the outcomes for the self-management programme (SMP).

This section of the report describes the content and format of the SMP and then focuses on what impact the SMP had on improving key patient outcomes such as patient activation, health status, health-related quality of life, psychological distress and self-management skills, by answering the following questions:

- a) Did the SMP manuals have content relevant for improving the key patient outcomes?*
- b) Did the SMP deliver content relevant to improving the key patient outcomes?*
- c) Did the SMP improve the key patient outcomes?*
- d) What was the experience of SMP participants and tutors?*
- e) What was the reach of the SMP, and how could this be improved?*

This chapter begins by identifying the headline findings and goes on to examine each of the sub-questions above in more detail. We provide our discussion and conclusions at the end. There is a Question 1 Appendix, and further data in the Q1 Technical Appendix.

Headline Findings

- The SMP manual contains many behaviour change techniques, some of which (such as goal setting) are extremely important and relevant to managing a LTC and have a good evidence base for improving key outcomes. There is only one activity of 20 minutes duration in the SMP which provides specific training in the use of the three enablers within a clinical consultation.
- The SMP was consistently delivered as set out in the manual indicating high programme fidelity, which increases the confidence that any improvements in participant outcomes can be attributed to the course. However, rigid adherence to the course manual and inflexibility at responding to individual concerns impacted negatively on the course experiences for some participants and tutors.

- We found that patients who had attended most or all of the SMP group sessions, irrespective of condition, were on average significantly more activated, that is, they were more motivated and confident to self manage. Patients whose main LTC was depression reported significant improvements in depression, anxiety, health status and quality of life after the SMP. Patients whose main LTC was pain reported improvements in their pain symptoms, confidence to manage their pain, health status and anxiety and depression. COPD patients significantly improved their mastery over their condition. Diabetes patients significantly improved their diabetes specific quality of life. Participants, irrespective of condition, were significantly better at some aspects of self-managing their condition, with depression and diabetes patients in particular improving in more self-management domains than pain and COPD patients.
- Participants described how they benefitted from learning how to self-manage within a positive and supportive group environment. Activated participants found the motivation and commitment to become better self-managers. Goal setting in particular was an important technique which participants found useful for initiating self-management behaviours. Participants valued the input from both the clinician and lay tutors with the former providing the clinical knowledge and reassurance and the latter the inspirational role modelling.
- The patients, who did not directly experience the SMP in the demonstration sites, did not benefit from the effects of CCH which might have impacted on them via contact with clinicians and services.

Self-management Programme (SMP) for patients

Development of the SMP

As described in the Introduction the structure and the content of SMP was partly based on the Expert Patient Programme (EPP). However, there are important differences. The EPP is a generic programme, which has been criticised as a “one size fits all” approach³⁸ to managing LTCs. The CCH SMPs are essentially four condition specific programmes, which are supplemented by generic core modules and activities (e.g. goal setting, problem solving, and relaxation). The condition specific information and activities were provided by clinician and lay experts from the sites. Also compared to the EPP, the SMP has a greater focus on positive psychology techniques (e.g. gratitude activity), motivational interviewing techniques (e.g. use of importance rating scales as well as confidence rating scales), identifying and challenging unhelpful beliefs (e.g. experiencing pain is a signal to stop exercising) and a greater acknowledgement of the role of the psychological and social impact of living with a LTC.

Patients attending the SMP received a self-management handbook and participated in a range of activities and discussions designed primarily to increase patient activation. The SMP content includes topics such as defining self-management, goal setting, action planning and follow-up, agenda-setting, making the most of successful consultations with health practitioners, symptom scanning, communication with family/friends and exercise. Behavioural and cognitive techniques such as relaxation, distraction, managing fatigue and medication, problem-solving and positive self-talk are also covered, as are more condition

specific activities such as stretching (pain), managing breathlessness (COPD), monitoring diabetes at home, and warding off depression (identifying and controlling thought triggers).

a) Did the SMP manuals have content relevant for improving key patient outcomes?

Evidence

In order to establish whether the SMP had content that was relevant to enhancing the key patient outcomes we examined the content of the SMP manuals using a theory-linked behaviour change technique taxonomy checklist.³⁹

Findings

The SMP manual contains 27 (out of a possible 40) behaviour change techniques (Q1 Appendix Table 1) including those that have a strong evidence base such as goal setting, action planning and problem solving.⁴⁰ The CCH programme logic assumes the three enablers (agenda setting, goal setting and follow-up) are a crucial component of each of the three programmes (SMP, ADP and SIP). The SMP manual placed a strong emphasis on teaching patient skills in setting, monitoring and following up goals, which feature in each of 7 weekly sessions. But these are often set within the context of generic lifestyle self-management (e.g. diet, relaxation, exercise), rather than LTC self-management (e.g. medication management, pain control). There is only one optional activity of 20 minutes duration in the SMP in session 6 which provides specific training in the use of the three enablers within a clinical consultation involving two role plays. Further, one of our researchers noted after observing SMP tutor training and through discussions with tutors that coverage of the three enablers had been only briefly covered and that some tutors were unable to recall what these were. These issues are explored in more depth in question 3, and in the first CCH Evaluation Themed Paper.⁴¹

Discussion

The SMP manual contains many behaviour change techniques, and it is important to the programme's likely impact that goal setting features prominently throughout the SMP manual. Many of these behaviour change techniques are amongst those identified in the behaviour change techniques taxonomy.³⁹ However, it is important to note that a recent review suggested that more focused behaviour change interventions involving about eight techniques may be more effective than interventions combining a large number of different techniques.⁴⁰ Our review shows that there is limited content in the SMP manual relating specifically to applying the three enablers within a clinical consultation.

b) Did the SMP deliver content relevant to improving the key patient outcomes?

Evidence:

We conducted non participant observations of 44 SMP sessions across all eight sites combining ethnographic field notes and the Self-Determination Theory (SDT)⁴² rating scale to assess the content, style of tutor presentation and delivery and the engagement of participants. The underlying SDT theory describes how delivery style can influence the motivation of participants to translate their learning into practice. The SDT rating findings

are presented in the Co-production chapter (question 3). We also analysed interview data with SMP participants and SMP lay and clinician tutors.

Findings

Programme fidelity:

Our observations found that tutors delivered the SMP activities and techniques as set out in the manual thus demonstrating high levels of programme fidelity (i.e. the extent to which the SMP was delivered as set out in the manual). Participants were taught several key behaviour change behaviour change techniques, including problem solving, pacing, goal setting and action planning.

"Well, I wouldn't be sitting here today talking to you if it wasn't for the self-management programme which taught us techniques to use like planning and pacing, goal setting, problem solving that I found very helpful indeed. And it got me back into society as you may say again, rather than being stuck at home." (LOCCHIT patient representative, COPD site, Year 3)

Throughout the three years of the project, lay and clinician tutors showed little knowledge of the three enablers and how they related to the wider CCH programme goals such as service improvement and co-production in clinical consultations.

"I know some of the people we've seen since they did the self-management courses sound as if they've never heard of agenda-setting, not everyone, but some people certainly didn't retain it at all...I think the whole working with your health professional thing wasn't done well really in the self-management programme." (SMP clinician tutor)

Scripted delivery style:

There were some concerns raised by the research team, site reporters, participants and tutors over the scripted delivery style of the SMP. On occasions, tutors were unable to adopt a flexible approach to accommodating participants' wishes to discuss in more depth issues they deemed to be important. For some participants this was the reason they stopped attending the SMP. This scripted approach may account for SMP tutors being less able to demonstrate good interpersonal skills and encouraging participant autonomy compared to providing structure as described in the Co-production chapter (question 3).

"Overall the session was delivered as set out in the manual, however most of it was delivered by reading from the script." (SMP observation, COPD site)

"Observations of the SMP and tutor training have been that tutors are very reliant on the course manuals when delivering, to the detriment of effective delivery/engagement with course participants." (SMP observation, Pain site)

"I found it too boring, the tutors kept ongoing over and over the same thing." (SMP drop out who attended first 3 sessions, Diabetes site)

"It was very task orientated and not person orientated, and I don't know if that was, it certainly wasn't right for me." (SMP dropout who attended the first and the third session, Depression site)

Our observations of the SMP and those of the site reporters found that in some cases the SMP “*felt very controlling and left little room for creativity and individuality*” (*Pain Site Report*). SMPs at The Whittington site were extended by 30 minutes per session to permit greater discussion on some topics.

Discussion

Setting manageable, graded goals, which increase in difficulty as competence increases are the basis of mastery learning, the primary process by which self-efficacy is enhanced.¹³ Control theory states that goal setting, progress monitoring, feedback and goal revision are important self-regulatory processes.⁴³ We found that SMP participants described the benefit of these techniques for helping them manage their LTC.

SMP tutor training and tutor accreditation places a strong emphasis on attaining and demonstrating competencies in delivering all the activities within the constraints of a highly structured, manualised protocol. We found that some SMP tutors were so focused on adherence to the manual that at times this became detrimental to the enjoyment and experience of participants. This may reflect lack of skill and confidence in tutors.

There are some disadvantages to manualization of behaviour and emotion focussed programmes. It has been found, for example, that manualization of cognitive behaviour therapy programmes can have a negative impact on the relationship between the tutors and participants and can result in negative impact on outcomes and satisfaction.⁴⁴ This is consistent with research on other self-management courses delivered by EPPCIC outside of CCH^{33,45,46}. This body of research on generic (i.e. not condition specific) self-management courses were also characterised by delivery which is highly prescriptive and formally structured. The research found that some of the most relevant and pressing psychological, emotional and social problems were not dealt with in any substantive depth, and, although the exchange of ideas and support was highly valued it was not always possible as discussions were curtailed. Wilson et al⁴⁵ observational study of the EPP programmes raised some very important points, which mirror Davidson's⁴⁷ comments about the EPP's ability to deliver sustained change while superficially covering so many self-management activities and techniques. Kennedy et al⁴⁶ have also highlighted the importance of self-management programme participants having the opportunity to tell their story of living and coping with a LTC. They found that participants who were allowed to tell their stories within the group reported that they had gained more than those who were not able to tell their stories.

c) Did the SMP improve key patient outcomes?

Data Sources

Patients who did not attend the SMP:

We collected patient self-report questionnaire data from patients who did not attend the SMP on the eight demonstration sites but who could have benefitted from contact with clinicians and services involved in CCH. We analysed Year 1 and Year 3 survey data^{III} to

^{III} We started Year 1 data collection soon after introducing CCH in demonstration sites (March 2008) and completed it in September 2009. Year 3 data were collected between April and November 2010. At the same time we collected data from CCH comparison sites. It was assumed that introducing CCH in demonstration sites would result in improving patient outcomes in Year 3 when compared to Year 1 results. However when interpreting the results it needs to be noted that Year

examine whether key patient outcomes improved during the three years of the programme delivery. These data were compared using independent t-tests against comparison sites where no CCH programmes were delivered.

Analysis of surveys from patients who completed the SMP (attended 5-7 sessions):

Analysis of pre and 6 months follow up SMP questionnaire data was undertaken to answer whether attending the SMP influenced patient outcomes. We surveyed patients (using paper questionnaires) three times: at baseline during the first SMP session (T1), 6 months after the start of the SMP (T3); and 12 months after attending the SMP (T4). T4 (12 month) data collection was still ongoing at the end of this phase of CCH and the findings are not reported here. SMP participants also completed a post-course questionnaire (T2) during the last session (week 7) where they anonymously rated the quality of the delivery and their experience of the course. Mean changes from baseline to 6 months follow-up were compared for each condition separately using related t-tests. The analysis was conducted on participants who completed the SMP (i.e. attended at least 5 sessions) and who completed a baseline and 6 month follow-up questionnaire. The primary outcome measure was patient activation. We conducted a regression analysis to find out what factors predict improvements in patient activation. The level of statistical significance was set at 5%. Where it is reported that there was a significant improvement this means that it is unlikely that the improvement occurred by chance. In addition to reporting the statistical significance of the findings we also, where there is information available, report whether the improvements are important and the effect sizes of the improvements. Boundaries recommended by Cohen⁴⁸ were used to determine small (0.2), moderate (0.5) and large effect sizes (0.8).

Interviews:

SMP participants and tutors were also interviewed for their experiences of attending and delivering the SMP respectively. Data were analysed using Framework Analysis,⁴⁹ which was developed in the context of applied policy research to produce outcomes or recommendations. Framework analysis is often used where there are specific issues being addressed and where some themes are generated from a priori issues identified in the research questions, however, it is flexible enough to allow other themes to emerge from the data. An investigation of the mechanisms by which improvements in outcomes occur is largely lacking from self-management research.^{11,50} Our interview schedules were deliberately designed to address this important issue and we present the qualitative data in this report where it plausibly provides an explanation for some of the improvement in the outcome measures we found.

SMP participant characteristics:

The Q1 Appendix Table 2 shows the returns from surveys before and after the SMP. The number of surveys returned before the course was 1170 and at 6 months follow-up (from the start of the SMP) there were 568/1170 (49%) returns and at 12 months there were 228 (19%) returns (some 6 month and 12 month follow-up data collection was ongoing at February 2011). Where we could establish direct pairing of data from participants who

¹ data collection was extended and covered the first and partially the second year of the programme hence it does not reflect a true baseline. It is likely that some changes resulting from introducing CCH were already present during the second year of the programme so presented results may not reflect the actual outcomes in relation to patient outcomes.

completed pre course and 6 month surveys and who attended at least 5 SMP sessions (defined as SMP completers), there were 476 matched surveys in total. The numbers for each condition were as follows:

- COPD (N=100)
- Pain (N=146)
- Diabetes (N=117)
- Depression (N=113)

The questionnaire return rate at 6 months is lower than we have achieved in other self-management evaluations (e.g. 83% in Barlow et al⁵¹ and 80% in Barlow et al⁵²). We are unsure as to the exact reasons why this lower rate occurred and can only speculate that all the other CCH activities which took place on sites were given greater focus and perceived importance, and that this might have been unwittingly transmitted through to SMP participants.

Characteristics of participants who returned 6 months follow-up questionnaires:

COPD patients were significantly more likely to respond at 6 months follow-up compared to patients from the other three conditions. Participants who did not respond at 6 months follow-up tended to be significantly younger (mean age 54 years vs. 59 years) and have poorer health status (mean 0.46 vs. 0.51 on the EQ5D Index health status scale). There were no other demographic (age, sex, ethnicity, house ownership, living arrangements, education, employment, co morbidity) or generic outcome (patient activation, health status, quality of life, depression) differences between participants who responded and those who did not respond at 6 months follow-up.

Characteristics of participants who enrolled on the SMP and completed baseline questionnaires:

The characteristics of the 1170 participants who enrolled on the SMP and completed a pre course (baseline) questionnaire are presented in Table 1 below. Participants were on average 56.3 years of age, predominantly white ethnicity (81.3%) and female (64.1%). Overall, nearly two thirds (60.6%) owned their own home and nearly a third lived alone (32.2%). Less than a quarter (24.2%) was in full or part time employment. Nearly a third (30.7%) left education under 16 years of age, and just over a quarter (28.3%) was educated post 19 years of age. More than two-thirds (68.4%) had a co-morbid condition.

Nearly two-thirds (62.6%) of participants were at the lowest stages of patient activation (Stages 1-2) and there were more pain and depression patients compared to COPD and diabetes patients in these lower stages (Table 3 below). The comparable figure for Year 1 demonstration site patients who did not attend the SMP was 45.9% (see Q1 Technical Appendix). This figure is similar (44.0%) to LTC patients who took part in large (N=2,121) national telephone survey measuring patient activation.⁵³

Nearly a half of all SMP patients (48.9%) were at risk of probable clinical anxiety (HADS Anxiety sub scale) and nearly a third (30.4%) at risk of probable clinical depression (HADS Depression sub scale) and of not surprisingly there were more depression patients at risk compared to the other three conditions (See Table 1 below). The comparable figure for Year

1 demonstration site patients who did not attend the SMP was 32.4% for anxiety and 21.6% for depression (see Q1 Technical Appendix).

Approximately three-quarters (72-75%) of all participants experienced “some” or “extreme” problems with carrying out usual activities, pain/discomfort and anxiety/depression (EQ-5D measure). Over a half (59%) of all participants experienced mobility problems and nearly a third (31%) experienced self-care problems (Table 1 below).

Table 1: Patients' characteristics enrolling on the SMP and who returned a baseline questionnaire (N=1170)

Characteristics	All (n=1170)	COPD (n=205)	Musculoskeletal pain (n=366)	Diabetes (n=285)	Depression (n=314)
Age: Mean (SD=standard deviation)	56.3(14.6)	68.3(9.3)	52.32(13.1)	62.3(11.1)	48.2(14.8)
	%	%	%	%	%
Gender:					
Male	35.9	44.1	25.8	48.7	30.7
Female	64.1	55.9	74.2	51.3	69.3
Ethnic origin:					
White	81.3	95.7	92.1	44.5	91.6
Accommodation:					
Owner occupier	60.6	67.9	72.4	45.6	56.5
Living arrangements					
Live alone	32.2	34.8	20.2	36.6	40.4
Age left education:					
Below 16 years	30.7	57.6	27.2	27.1	20.9
16-18 years	41.0	27.7	51.9	30.9	45.5
≥19	28.3	14.7	20.9	42.0	33.6
Employment:					
FT/PT	24.2	7.8	25.6	23.9	34.3
Other (retired, housewife/husband, student)	75.8	92.2	74.4	76.1	65.7
Co morbidity	64.8	70.5	63.6	72.7	55.6
Outcome measures					
PAMS Activation stages ^{IV} ↑ = better	%	%	%	%	%
Stage 1	34.5	22.8	40.2	21.5	47.0
Stage 2	28.1	27.7	27.4	33.2	24.8
Stage 3	24.1	29.2	19.9	30.9	19.5
Stage 4	13.3	20.3	12.5	14.5	8.6
HADS Anxiety ≥ 11 ^V	48.9	29.6	55.7	23.2	76.5
HADS Depression ≥ 11	30.4	17.2	35.5	11.6	49.8
EQ-5D (Some/extreme problems)					
Mobility	58.8	75.5	86.8	42.2	29.9
Self-care	31.1	32.5	53.6	14.7	18.4
Usual activities	71.8	79.5	94.1	39.6	69.4
Pain/discomfort	74.5	77.0	100.0	66.2	51.1
Anxiety/depression	71.5	58.1	77.2	46.6	94.8

IV There are 4 developmental, sequential stages of patient activation with later stages indicating more activated, (i.e. more effective self-managers) (Stage 1) believing the patient role is important, (Stage 2) having the confidence and knowledge necessary to take action, (Stage 3) actually taking action to maintain and improve one's health, and (Stage 4) staying the course even under stress.

V A score of ≥11 on the HADS is the recommended cut-off value for detecting probable mood disorder

SMP completion rates:

Table 2 shows the completion rates for the SMP, defined as the proportion of patients attending five or more course sessions. Completion rates averaged 72% across all sites and ranged from a low of 66% (Depression) to a high of 75% (Diabetes).

Table 2 SMP completion rates

Sessions Attended	ALL (N=1123)* (Number, %)	COPD (N=197)	Pain (N=362)	Diabetes N=265)	Depression (N=299)
0	22 (2.0)	1 (0.5)	1 (1.1)	5 (1.9)	12 (4.0)
1	99 (8.2)	20 (10.2)	27 (7.5)	18 (6.8)	27 (9.0)
2	85 (7.6)	15 (7.6)	24 (6.6)	17 (6.4)	29 (9.7)
3	64 (5.7)	9 (4.6)	20 (5.5)	15 (5.7)	20 (6.7)
4	55 (4.9)	11 (5.6)	19 (5.2)	12 (4.5)	13 (4.3)
5	149 (12.7)	19 (9.6)	50 (13.8)	40 (15.1)	40 (13.4)
6	280 (24.9)	44 (22.3)	95 (26.2)	63 (23.8)	78 (26.1)
7	376 (33.5)	78 (39.6)	123 (34.0)	95 (35.8)	80 (26.8)
Completers (5-7 sessions)	805 (72%)	141 (72%)	268 (74%)	198 (75%)	198 (66%)

* Missing data for 47 participants

Characteristics of participants who completed the SMP:

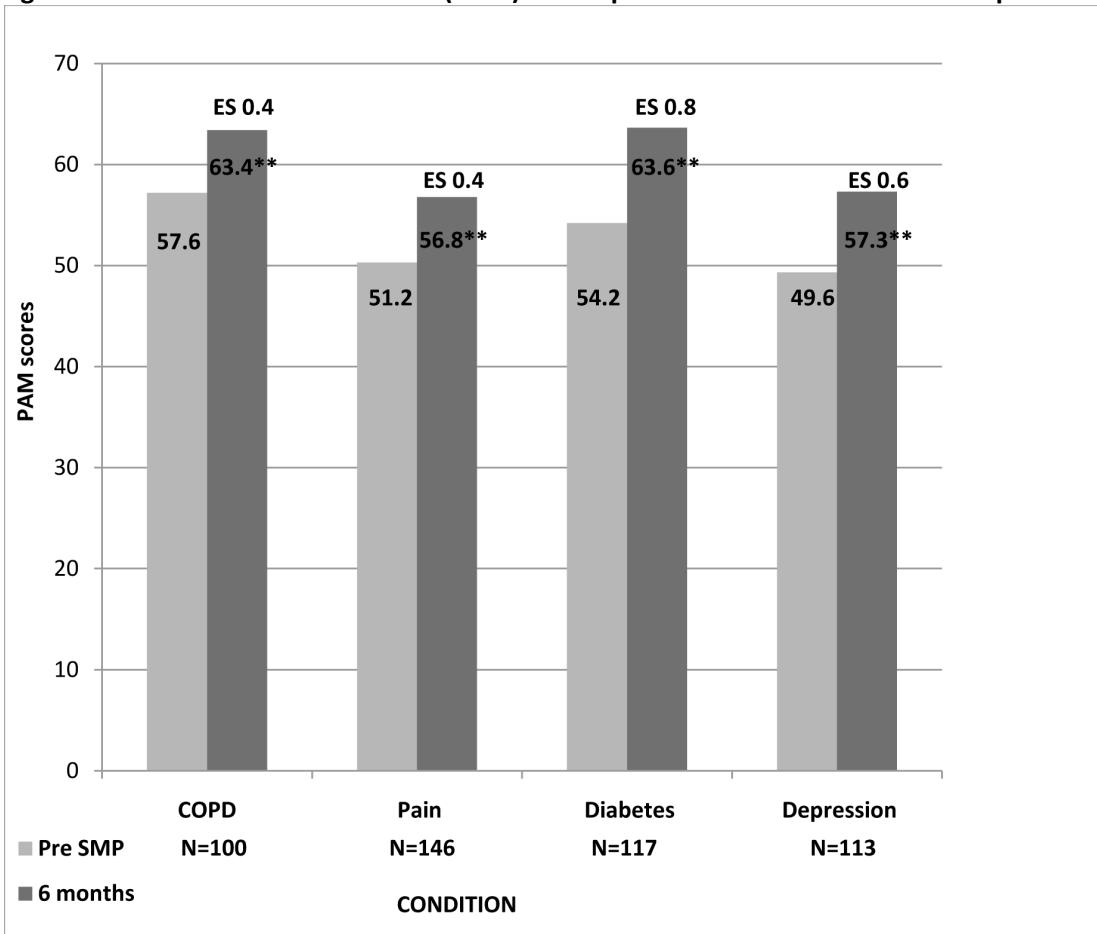
Participants who completed the SMP tended to be significantly older (mean age 59 years compared to 55 years) and significantly less anxious (mean 10.0 compared to 10.9) and significantly less depressed (mean 8.0 compared to 8.6) than those who dropped out of the SMP (attended 0-4 sessions). These findings are confounded with the lower completion rates among depression patients (66% compared to CCH average of 72%), who also tended to be younger, more depressed and anxious. There were no other demographic differences on variables of gender, ethnicity, house ownership, living arrangements, education, employment, co morbidity, or generic outcomes (patient activation, health status, quality of life), between participants who completed the SMP and those participants who did complete the SMP. We conclude that participants who drop out of the SMP are likely to be younger and experience higher levels of psychological distress compared to participants who complete the SMP.

Findings

Do patients who attend the SMP show improvements in activation?

In this study we measured this outcome using the Patient Activation Measure (PAM).⁵⁴ Participants who completed the SMP (attended 5-7 sessions), showed significant improvements in activation 6 months after attending. This pattern of improvement was consistent across all conditions (Figure 4 below and Q1 Appendix Table 3 for breakdown by condition). The effects sizes ranged from small for COPD and pain, (0.4), moderate for depression (0.6) to large for diabetes (0.8). A difference of 4 points on the PAM is meaningful as this difference differentiates between patients who engage in self-management behaviours and those who do not.^{37,55,56} All 4 conditions averaged an improvement in more than 4 points at 6 months follow-up.

Figure 4 Patient Activation Measure (PAM) scores pre SMP and 6 months follow-up



Patient Activation Measure (0-100↑ =better). ** $P < .001$, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

The PAM scale measures 4 developmental, sequential stages of patient activation with later stages indicating more activated, (i.e. more effective self-managers).

- Stage 1: believing the patient role is important
- Stage 2: having the confidence and knowledge necessary to take action
- Stage 3: actually taking action to maintain and improve one's health
- Stage 4: staying the course even under stress.

Figures 5 to 8 below and Q1 Appendix Table 4 show that there were more patients at the highest activation stage (Stage 4) and fewer at the lowest activation stage (Stage 1) at 6 months follow-up compared to baseline, irrespective of condition.

Figure 5 Patient Activation stages for COPD patients before the SMP and 6 months follow-up

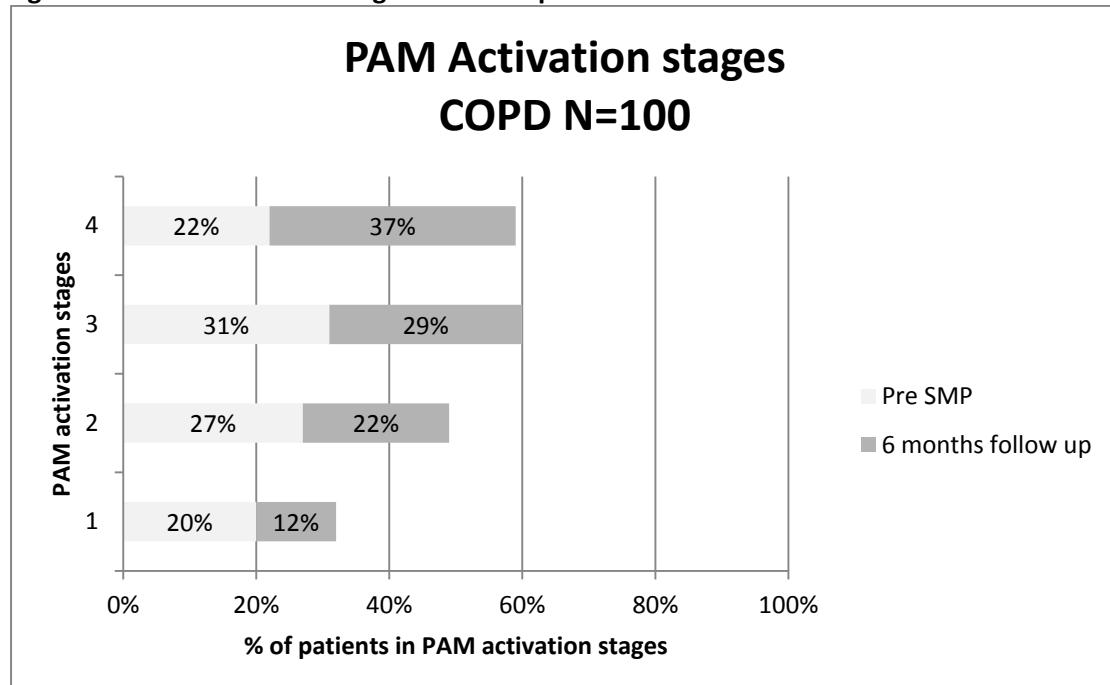


Figure 6 Patient Activation stages for pain patients before the SMP and 6 months follow-up

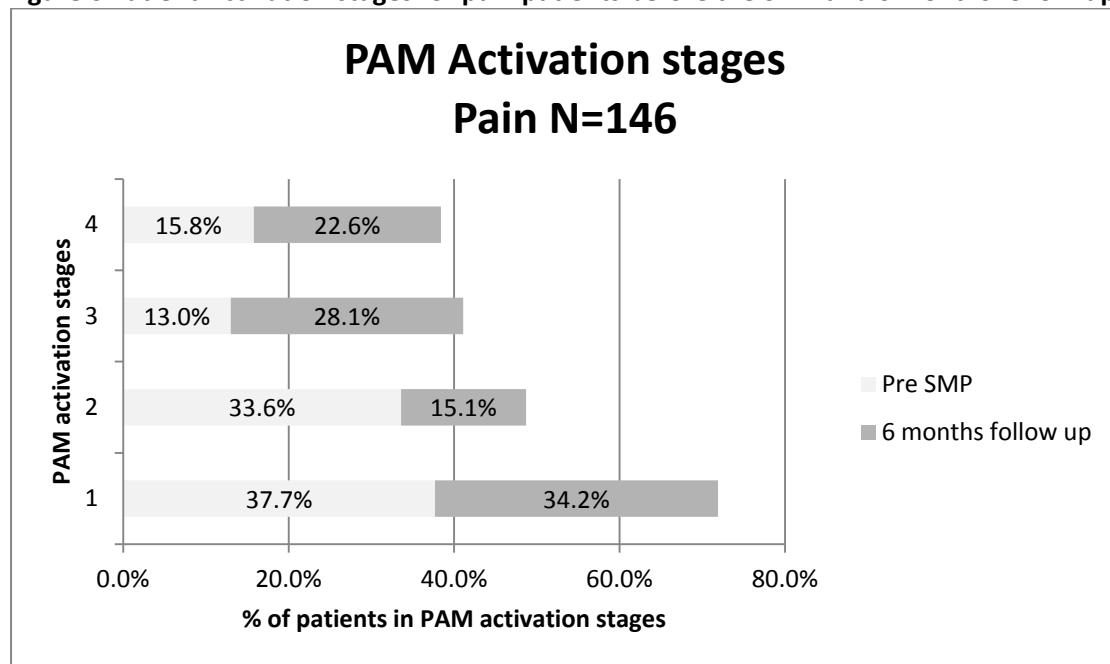


Figure 7 Patient Activation stages for diabetes patients before the SMP and 6 months follow-up

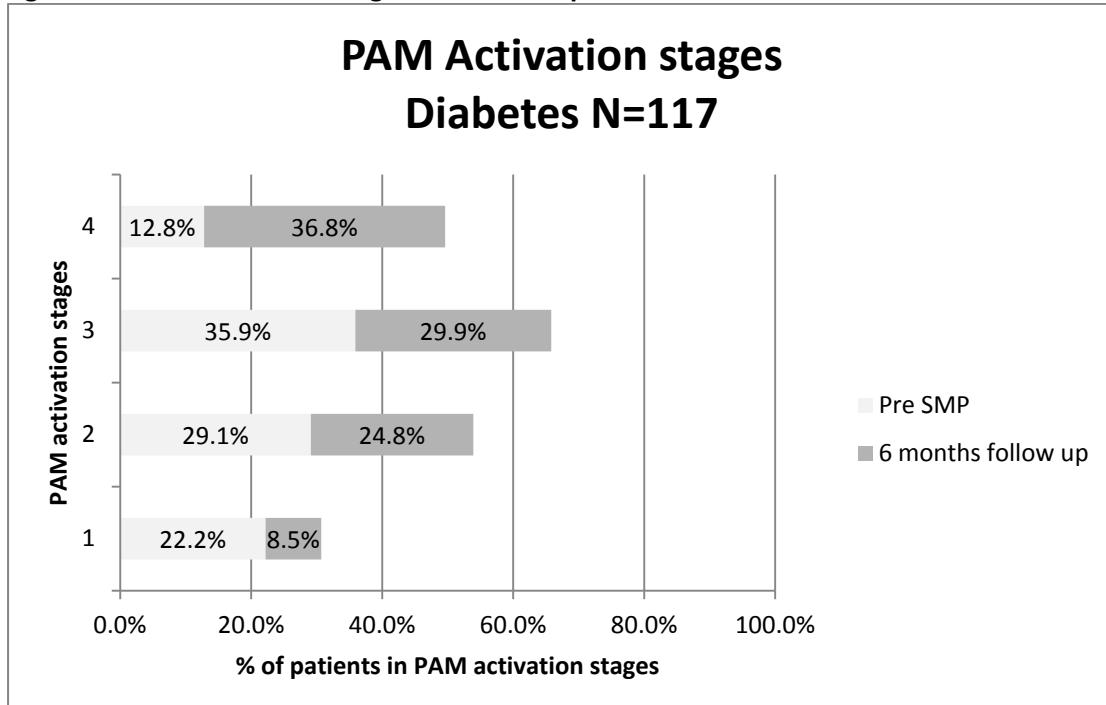
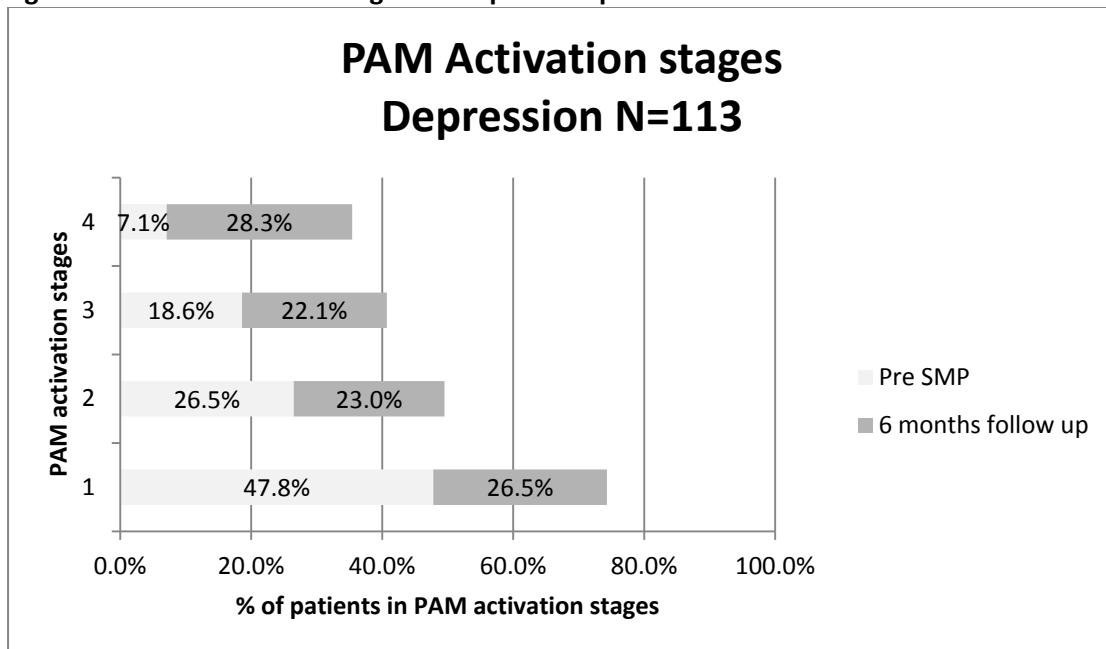


Figure 8 Patient Activation stages for depression patients before the SMP and 6 months follow-up



What factors were associated with improvements in patient activation?

We looked at whether the following factors were associated with improvements in patient activation using a regression model. Patients' age, sex, ethnicity, home ownership, and baseline health status, quality of life ,anxiety, depression and patient activation score were included in the model. The results showed that patients who were younger, more anxious, had a poorer quality of life and who were lower in activation at baseline experienced the greatest change in patient activation at 6 months follow-up (See Q1 Technical Appendix for details). Similar findings have been reported by patients attending the EPP, where low levels

of self-efficacy and health-related quality of life at baseline predicted improvements in self-efficacy 6 months later.⁵⁷

The interviews confirm that SMP course participants increased their knowledge of their LTC and how best to manage it was derived through a combination of the formal learning and teaching resources and informal exchanges with other participants through the group discussions.

"I enjoyed the course. It opened my eyes and gave me a lot more information [about COPD] than what I would have otherwise got. And the books, I received a lot of literature, and that helped me as well." (SMP completer, COPD site)

"It was really good once a week to go with a group of people who were in a similar situation and with the same condition sharing their experiences, trying different things out and it was absolutely fantastic." (Diabetes SMP tutor, Tell me more interviews)

"Because we're a wee bit more educated now, the SMP gave you that wee bit more confidence that you could cope." (SMP completer, COPD site)

The participants found goal setting to be an invaluable skill in helping participants to take greater control of their lives and become more active and energised.

"Goals that you can set yourself that will help you move forward, things that perhaps you weren't previously able to do, that you can actually sort of see yourself achieving now as you move through the course." (SMP completer, Depression site)

"The goal settings and the action plans when they come back and do this follow-up, you see how eager they are to tell them, to tell the whole class that they've done it, or done a little bit more as well. You know, it's changing these negative thoughts into positive and it, and it works so well." (LOCCHIT Patient Representative, Pain site, Year 3)

"It [goal setting] motivated you to say "right I'll go next week and see how I get on and see what's happening." (SMP completer, COPD site)

Participants described how the increased knowledge led to improved confidence to manage their LTC.

"It did impact on my confidence because now I actually know what I'm supposed to be doing. You know, the thing I've been burying my head in the sand about." (SMP completer, Diabetes site)

For some participants this increase in confidence was due to the positive role modelling and inspiration provided by other course participants and tutors.

"Well it galvanised me, it got me going. I think I pulled myself out of a hole and decided that I was going to do it. Like the lay person [tutor], she'd obviously taken charge of her illness, and I thought well I can do that, I'm not a wimp." (SMP completer, COPD site)

"Six months ago I wouldn't have been able to sit and talk to you like this, you know. I'd feel sorry for myself, but I think now my confidence is coming out you know, and it's because of the SMP" (SMP completer, Depression site)

In summary, irrespective of condition, participants were more activated after attending the SMP and those who were younger, with a poorer quality of life more anxious and least activated at baseline improved the most. Information combined with goal setting as instrumental in improving activation.

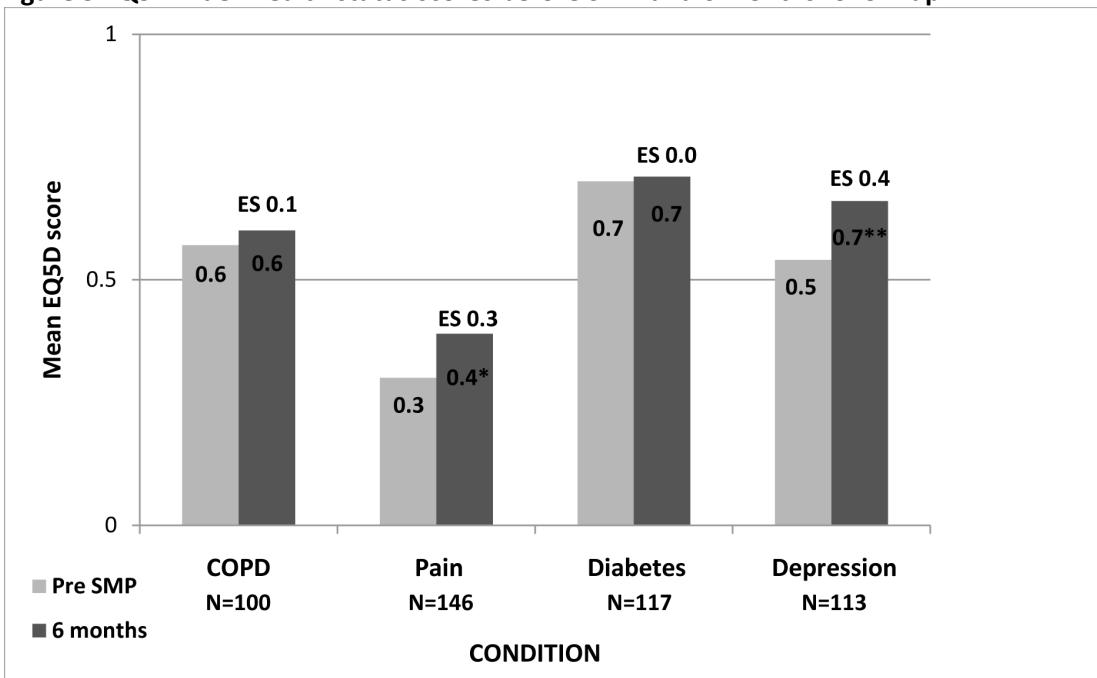
Do patients who attend the SMP show improved health status and health-related quality of life?

The programme logic assumes that the SMP provides patients with training in self-management skills within a supportive and facilitative group setting which leads to improvements in activation and confidence which in turn impacts on health status and health-related quality of life.

Health status:

Only pain and depression patients reported significant improvements in health status. The effects size was small (0.3 and 0.4 for pain and depression patients respectively) (See Figure 9 below and Q1 Appendix Table 3 for breakdown by condition).

Figure 9 EQ5D index health status scores before SMP and 6 months follow-up



EQ5D index Health Status (0-1↑ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

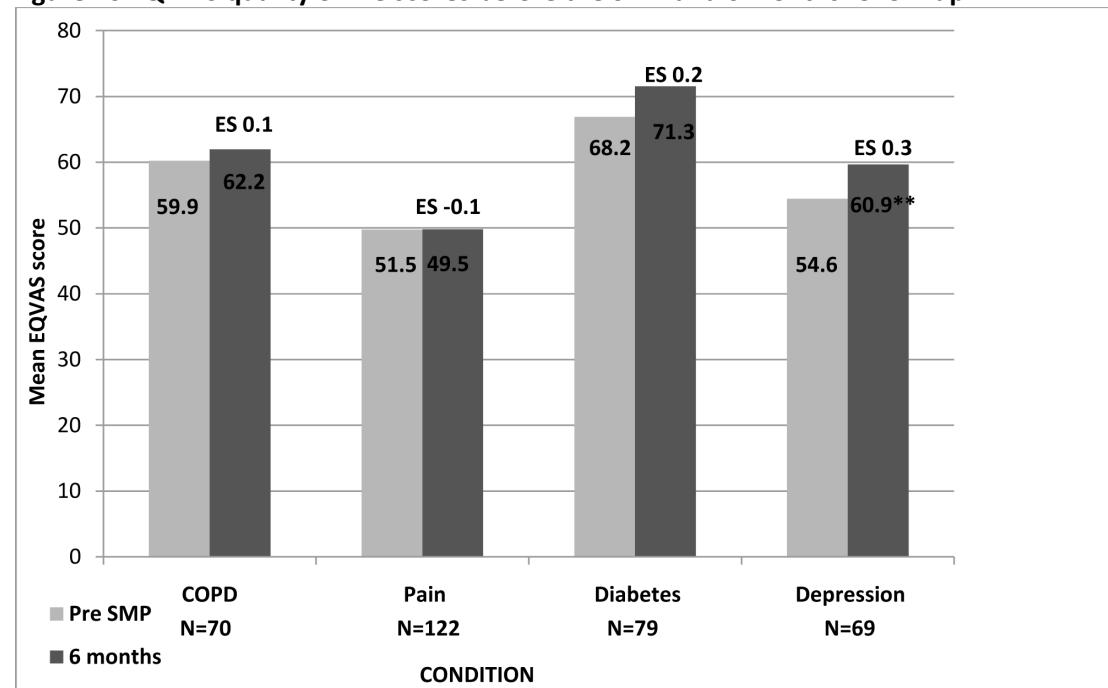
This depression patient described during the interview how the SMP had helped build a more positive, resilient outlook and a determination to start "living again."

"Well as I said it opens my mind to living again, I mustn't give up you know. Like, I was a year ago, I was very down you know, but it opens my mind to, to carry on living for myself again." (*SMP completer, Depression site*)

Health-related quality of life:

Only depression site participants showed significant improvements in quality of life 6 months after attending the SMP. The effect size was small (0.3) (See Figure 10 below and Q1 Appendix Table 3 for breakdown by condition).

Figure 10 EQ VAS quality of life scores before the SMP and 6 months follow-up



EQ5D VAS quality of life (0-100↑ =better). * $P<.01$, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

We examined interview data for the experience of tutors. The account below from an SMP tutor describes how through his continued social contact with SMP participants he has witnessed the enduring impact the course has had on participants' quality of life through reengaging with previously abandoned activities.

"I've also seen a better standard of life for the majority of the people that have been on the courses that I've run. I'm in touch with them all the time and they keep getting in touch, and dropping messages about what they've been doing, things they haven't done for years, it's unbelievable some of the stories they tell me." (LOCCHIT Patient Representative, Pain site, Year 3 and SMP tutor)

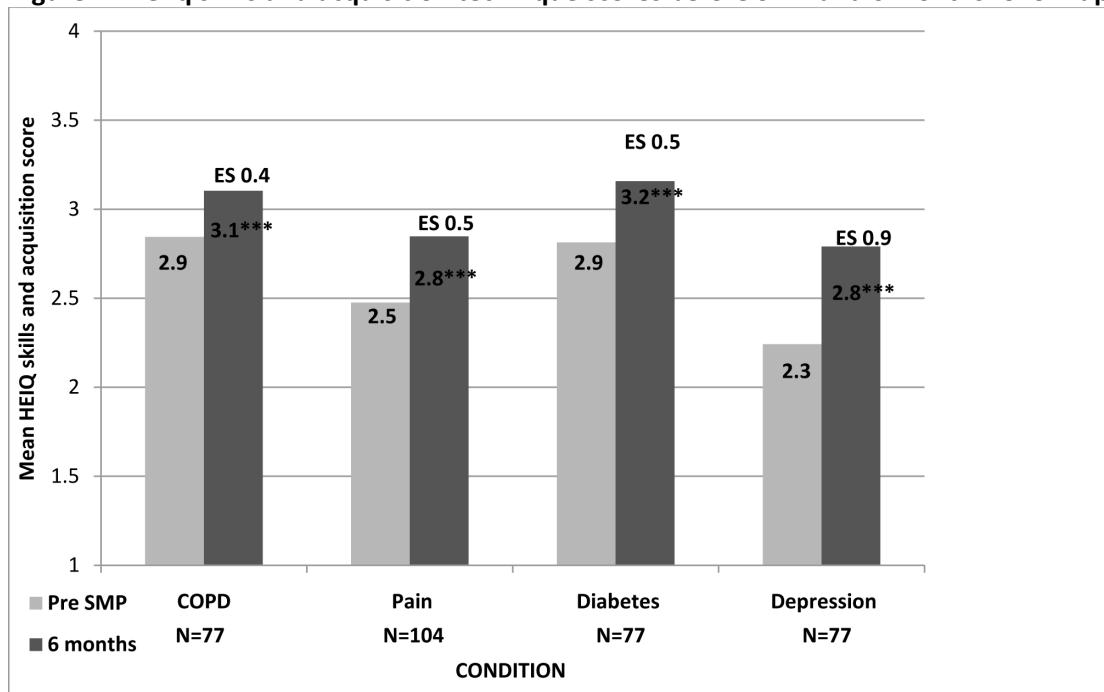
In summary, it was pain and depression site patients only who tended to show significant improvements in health-related quality of life and/or health status. This may be partly a consequence of having lower scores (poorer health) at baseline compared to COPD and diabetes patients and thus having greater potential for improvement.

Do patients who attend the SMP show improvements in self-management ability?

Skills and technique acquisition:

Participants across all 4 conditions reported significant improvements on the self-management domain of *skills and technique acquisition*. The effect sizes ranged from small (0.4) for COPD patients to moderate for (0.5) for pain and diabetes patients to large (0.9) for depression participants (See Figure 11 below and Q1 Appendix Table 5 for breakdown by condition).

Figure 11 hei-q skills and acquisition technique scores before SMP and 6 months follow-up



hei-q self-management scale (1-4, ↑ =better). **P=<.001, t -test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

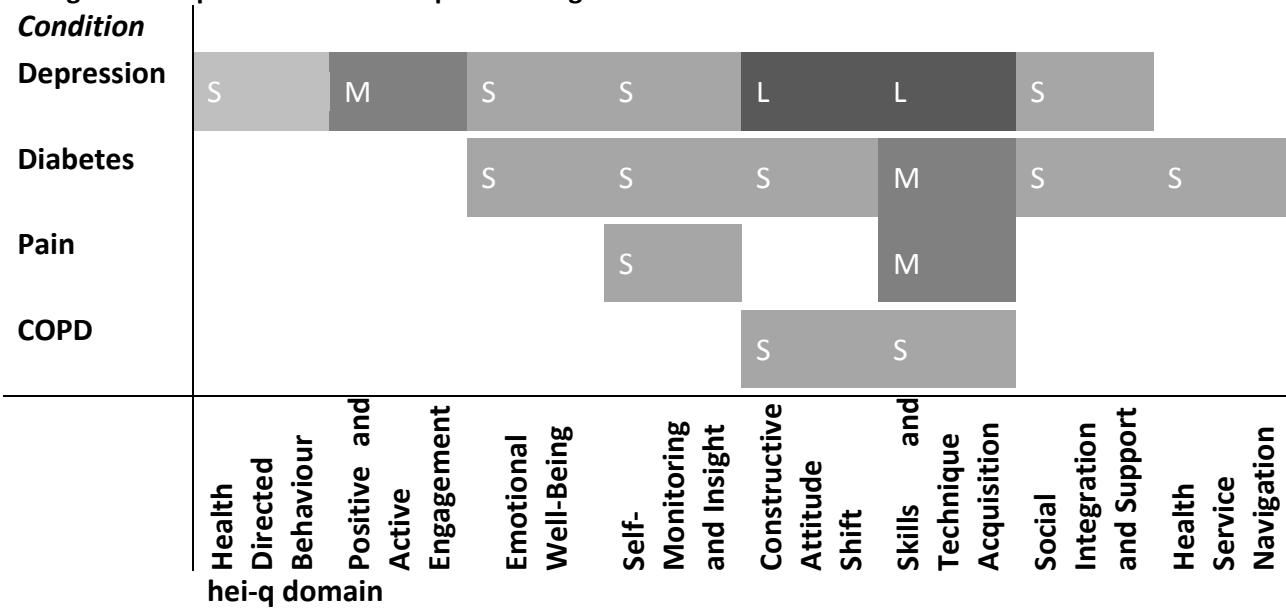
Interviews showed that patients were able to apply the skills and techniques that they learnt on the SMP to other areas of their lives.

"The skills that I learnt, especially on the SMP- that was the real key for me – has transferred itself into other areas of my life, for instance, just dealing with problems with people – the idea of breaking problems down into manageable chunks, knowing when I need to ask for help". (Tell Me More Interview participant, Depression site)

"Pacing activity, working out what you can do even on your worst day was very useful". (SMP completer interviewed by Bristol Site Reporter)

Figure 12 shows that in addition to improving on *skills and technique acquisition*, COPD and pain participants improved on only one other domain known as *constructive attitude shift* and *self-monitoring and insight* respectively. Diabetes participants significantly improved on 6 out of 8 domains with the exceptions being *health directed behaviour* and *positive and active engagement in life*. Depression participants significantly improved on 7 out 8 self-management domains (See Figure 12 and Q1 Appendix Table 5 for breakdown by condition).

Figure 12 Improvements in hei-q self-management domains



Key to Figure:

Shaded area = statistically significant improvement

S = Small Effect size (0.2)

M = Moderate Effect size (0.5)

L = Large effect size (0.8)

The *Health service navigation* subscale of the hei-q assesses participants' understanding of and ability to interact collaboratively with a range of health service professionals and providers. It also assesses participants' ability to communicate more confidently with their doctors and get their needs met. The three enablers are relevant to how patients can engage in co-productive self-management with clinicians. Only diabetes patients reported significant improvements in this domain. Some of the qualitative findings showed that SMP participants and tutors showed limited understanding of the three enablers "*I am trying to remember what they are*" (Lay SMP tutor, COPD site) Several did not recollect the shared agenda setting role-play exercise in session 6 ("*I've forgotten which session that was.*" Clinician SMP tutor, COPD site), or how this activity related to the wider aims and purpose of CCH. As described in our first themed paper⁴¹ there was little evidence that participants applied the three enablers in clinical consultations. Our ratings of the SMP manual showed that there was insufficient focus on training patients to collaborate effectively with their health care team which were confirmed by our observations of the SMP and interviews with tutors and participants (See question 3).

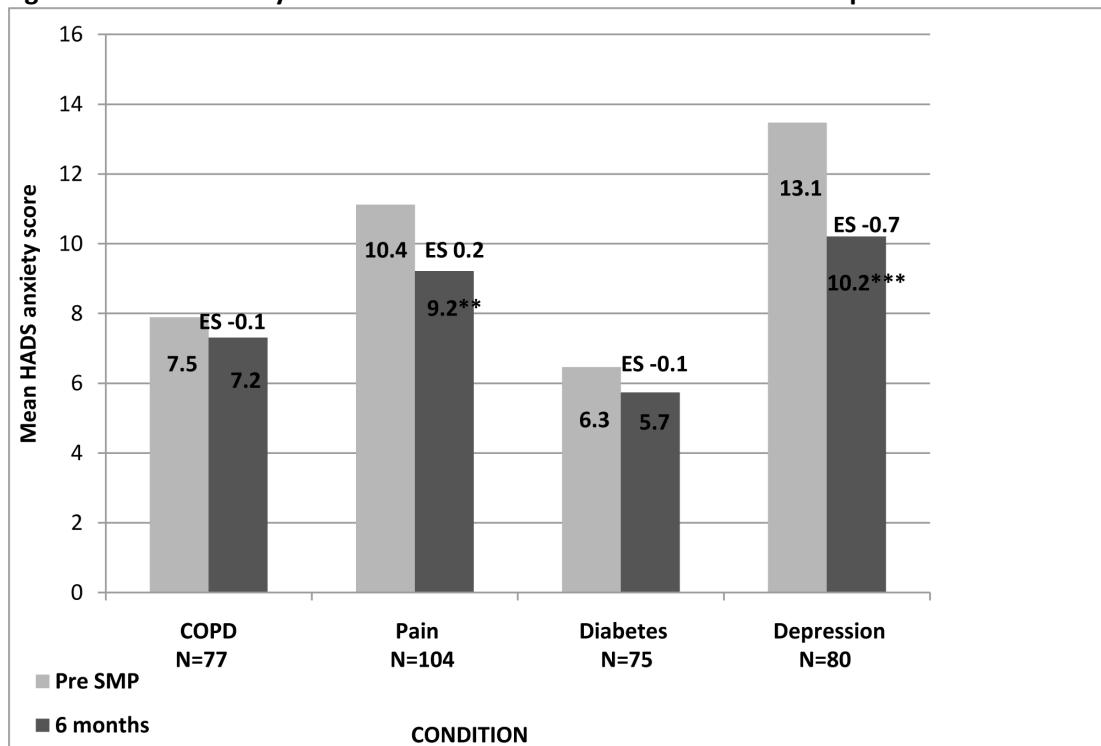
In summary, depression and diabetes patients reported using more self-management skills after attending the SMP. Ability to work more collaboratively with health care providers was not improved for COPD pain and depression patients.

Do patients who attend the SMP show improvements in anxiety and depression?

Pain and depression patients were significantly less anxious and depressed 6 months after starting the SMP. There were moderate effect sizes for anxiety (0.7) and depression (0.6) for

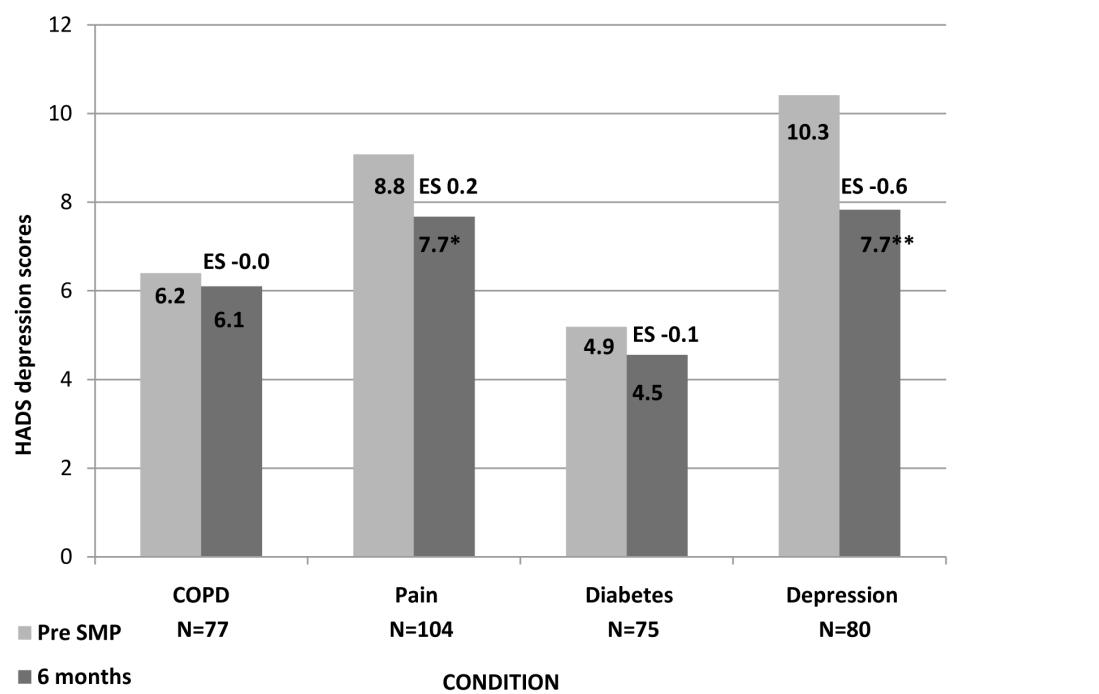
depression site patients and small effect sizes for pain site patients (0.2) (See Figure 13 below and Q1 Appendix Table 3 for breakdown by condition). The minimal important difference of the Hospital Anxiety Depression Scale HADS is approximately 1.5 points in COPD patients. It is not known whether this figure generalizes to patients with other LTCs. Only depression patients improved by an average of more than 1.5 points.

Figure 13 HADS anxiety scores before the SMP and 6 months follow-up



HADS anxiety (0-21; ↓ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

Figure 14 Hospital Anxiety Depression: anxiety scores before SMP and 6 months follow-up



HADS depression (0-21; ↓ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

From our interviews we noted that many patients described how being with similar others helped them to combat feelings of shame, isolation and stigma which are all factors which maintain and exacerbate depression. Reconnecting and identifying with similar others is a powerful group curative factor which Yalom⁵⁸ has labelled *universality* a “welcome to the human race” experience. The following accounts are from a pain patient and depression patient respectively.

“You learned stuff from other people and what they’re going through and you realise that they’re exactly the same as you. We also had a good laugh which was the main thing.” (SMP completer, Pain site)

“There is a lot of discrimination out there and you do almost feel rejected by society especially if you’re not working and stuff, and you know, with depression there is that sort of self loathing and all the rest of it, so down on yourself. Whereas, being in the group that dilutes that, and as I say you get back, you reconnect with the human race basically, and you draw strength from each other. I just always think of people on the Co-Creating Health as very courageous people”. (SMP completer, Depression site)

In summary, it was pain site and depression site patients only who showed significant improvements in mental health problems. This is partly a consequence of pain and depression patients having higher HADS scores (poorer mental health) at baseline compared to COPD and diabetes patients and thus having greater potential for improvement.

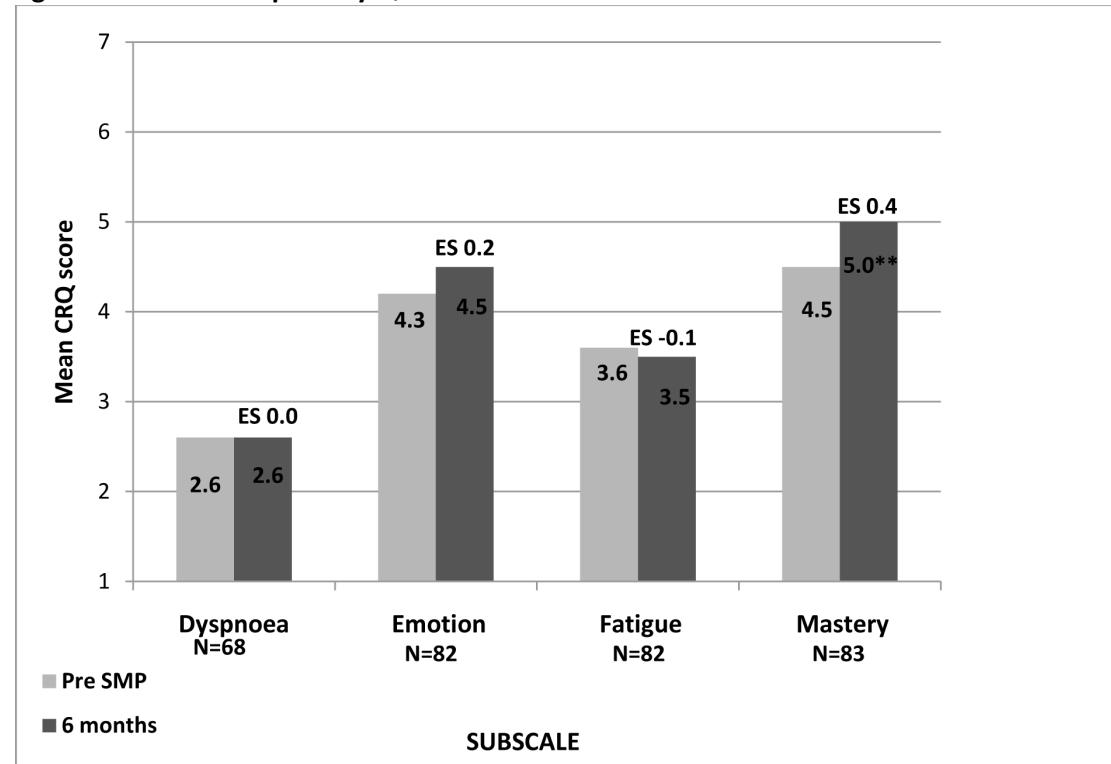
Do patients who attend the SMP show improvements in self-report of their condition?

For each of the four conditions there was at least one condition specific self report measure used in all surveys.

Chronic Obstructive Pulmonary Disorder (COPD):

COPD patients who completed the SMP reported a significant improvement in their confidence to manage their condition (mastery) (small effect size 0.4). There were no significant improvements in COPD-related fatigue, emotional wellbeing or dyspnoea (breathlessness) (See Figure 15 below and Q1 Appendix Table 6 for details).

Figure 15 Chronic Respiratory Questionnaire scores before the SMP and 6 months follow-up



CRQ-SR (1-7↑ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

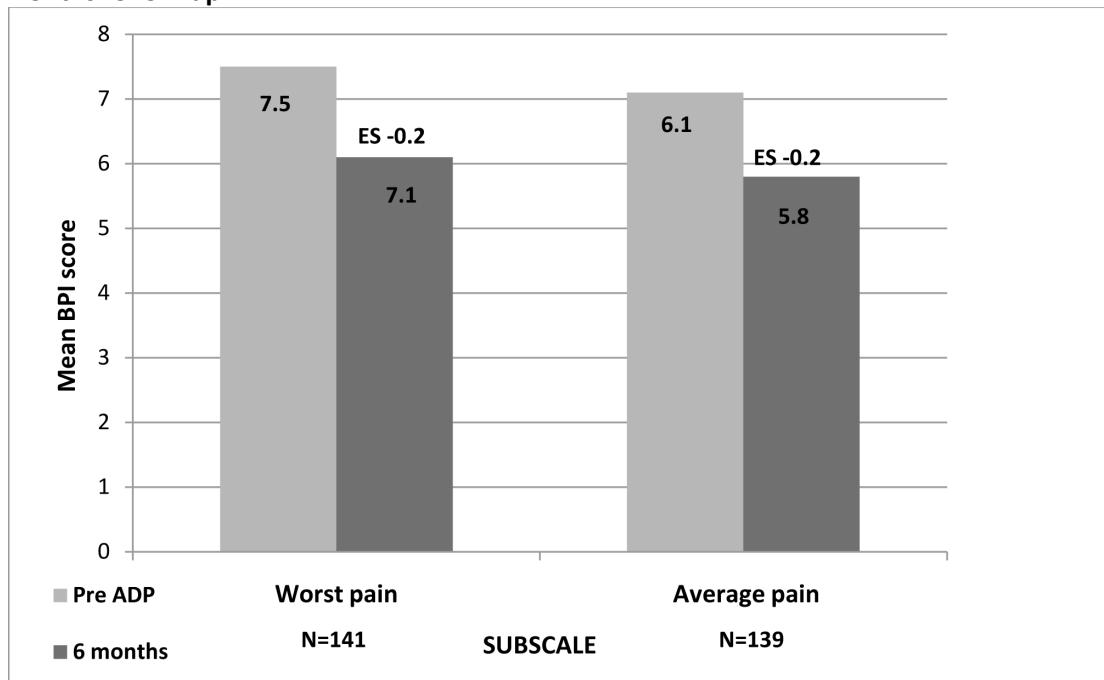
In our interviews, several COPD participants described using a broad range of self-management skills to cope better including taking medication, using an inhaler, not going out in bad weather, healthy eating and accepting their condition.

"I think you have to try and help yourself as well as having the proper medication. I don't do anything foolish, like weather wise if it's not good then I don't go out, things like that. I try to eat properly, you just live with what you've got and you try your best." (SMP completer, COPD site)

Pain:

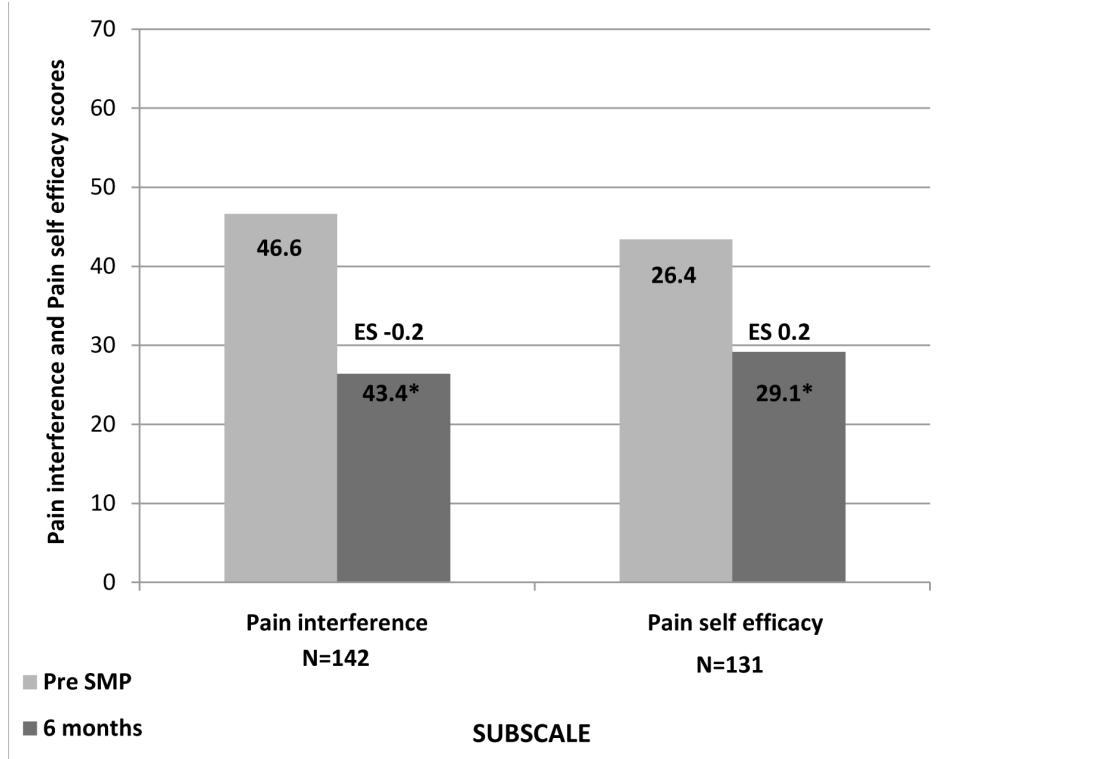
Pain patients reported significant improvements in the worst pain they had experienced (small effect size 0.2, (See Figure 16 below Q1 Appendix Table 6 for details) and the extent to which pain interfered with their lives (small effect size 0.2) and in their confidence in their ability to cope with a range of social, leisure and household chores despite their pain (small effect size 0.2).

Figure 16 Brief Pain Inventory (BPI) worst pain and average pain scores: before the SMP and 6 months follow-up



BPI (0-10; ↓ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

Figure 17 Brief Pain Inventory (BPI): pain interference scores and pain self-efficacy scores: before the SMP and 6 months follow-up



BPI pain interference scores (0-70; ↓ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8). Pain self-efficacy (0 -60; ↑ = better) **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5).

A pain patient described how attending the SMP and having to set weekly goals provided her with the motivation and energy to join a local swimming group and how the swimming has enabled her to cope with her pain.

"I do it about what twice or three times a week which is good. It's a case of having energy. When a person's in a lot of pain, you deal with the pain first, when really you're supposed to exercise through it, and it's damn hard to do that, it really is. So you need to re-programme your body to get it going. But once you get going it goes quite well."

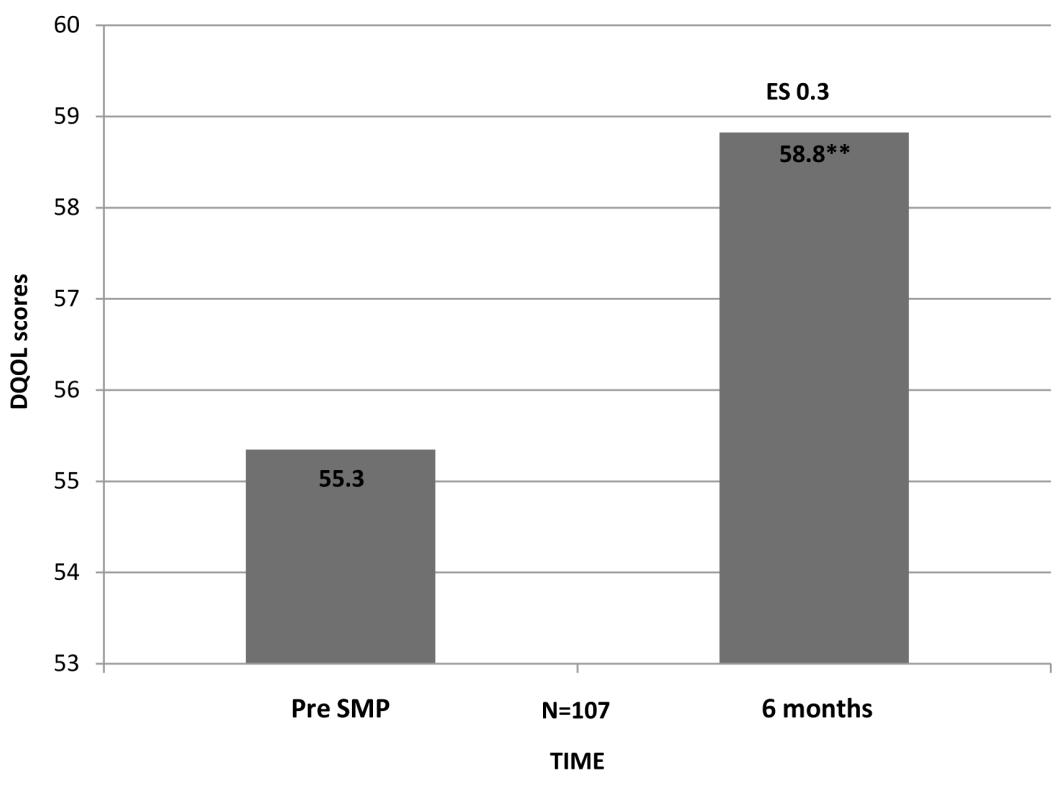
From our interviews, we also found an example of how one pain patient used planning to minimise the likelihood of pain interfering with her activities

"It just taught you to say, right, I'm having a good day but because I'm having a good day today doesn't mean I've got to go and clean the house top to bottom. Because if I do, I'll have another four or five days as bad days. It taught you to level out your activities. That was a good help."

Diabetes:

Diabetes patients reported a significant improvement in the diabetes-related quality of life (small effect size, 0.3). (See Figure 18 and Q1 Appendix Table 6 for details).

Figure 18 Diabetes quality of life scores pre SMP and 6 months follow-up



Diabetes quality of life scores (15 -75; ↑ = better) **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5).

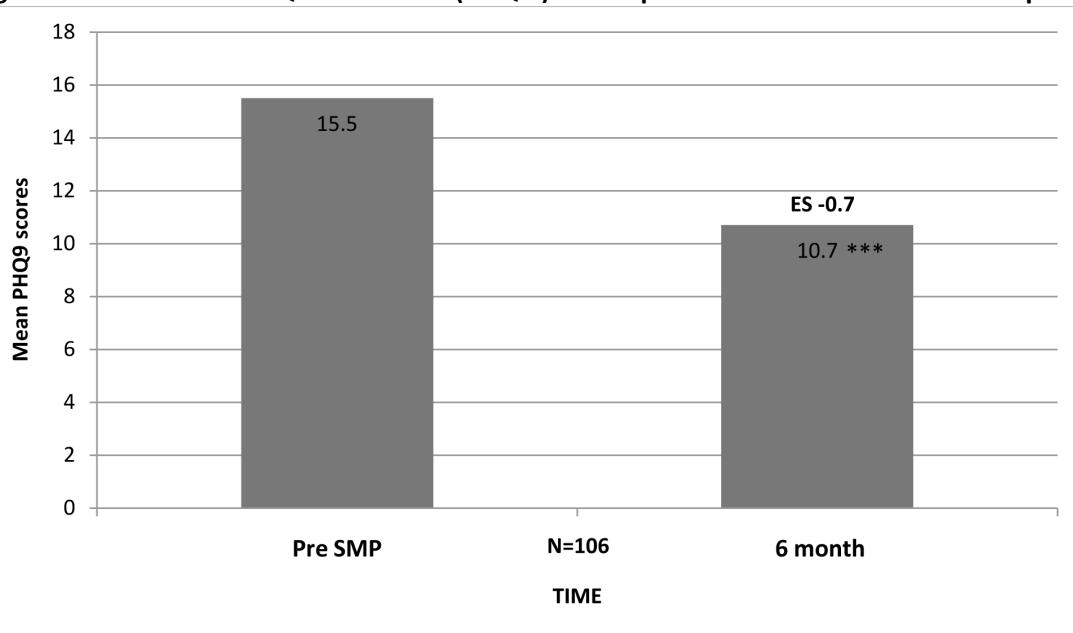
Our interviews with diabetes patients showed how, for some participants, the SMP provided new information about diabetes symptoms and it also provided the impetus and motivation to ensure that they continued to self-manage.

"Listening to other people who were getting different symptoms, or the same symptoms that we all get but I hadn't associated them with diabetes. So like constant dry mouth, leg aches, it was only when I heard that that over the past year that I have noticed that my walking really slowed me down and I just put that down to aging but now I know that it's not the case.. I gained awareness, general awareness, a kick up the back side really, to stop you from getting complacent" (SMP completer, Diabetes site).

Depression:

Depression site patients were significantly less depressed after attending the SMP (moderate effect size, 0.7). (See Figure 19 below and Q1 Appendix Table 6 for details). The mean difference in PHQ-9 scores was 4.8. A 5-point difference in PHQ-9 scores is advocated as the minimal clinically important difference for individual change.⁵⁹

Figure 19 Patient Health Questionnaire (PHQ-9) scores pre SMP and 6 months follow-up



PHQ-9 (0-27; ↓ =better). **P=<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).

We observed from our interviews that the SMP provided a safe environment for some depression patients to begin to socialise again, initially with other SMP participants, and then other people with depression outside of the SMP and then gradually gaining the confidence to meet up with friends.

"It was through the co-creating SMP that I started to socialise again, but I'm socialising with people with depression at the moment and just slowly venturing out to sort of picking up seeing my friends." (SMP completer, depression site)

In summary, participants, irrespective of condition, showed improvements on some condition specific outcomes such as mastery (COPD patients), pain symptoms, pain interference and self-efficacy (pain patients), quality of life (diabetes patients) and depression (depression patients).

The findings reported above are those from the 6 months follow-up. Twelve months follow-up data are not presented in this report due to ongoing data collection. A preliminary analysis of the data we have currently collected (N=228) shows there are no significant changes in any of the outcomes, between 6 months and 12 months follow-up.

Discussion

SMP participants:

Generally, patients enrolling on the SMP tended to be less activated and more anxious and depressed compared to patients in the pathway of care. This is an encouraging finding because it suggests that patients, who self-referred or who were referred onto the SMP by their healthcare provider, were those who were more likely to need self-management training the most and were the most likely to benefit. Compared to other UK self-management programmes¹¹ more men, ethnic minorities, people who lived alone, who had no educational qualifications and did not own their own homes attended the SMP. This suggests that the SMP was relatively successful at recruiting participants who traditionally do not attend self-management programmes.

Patient activation:

Irrespective of condition, participants who completed the SMP reported greater knowledge, skills and confidence (activation) to manage their LTC. There were more patients at the highest activation stage (Stage 4) and fewer at the lowest activation stage (Stage 1) after attending the SMP. Hibbard³⁷ suggests that patients at Stages 1 and 2 tend to focus on self-awareness and setting small goals, whereas patients at Stages 3 and 4 are more likely to perform clinically meaningful behaviours. The ADP teaches clinicians to recognise patients' activation levels and to provide tailored SMS depending on where the patient is on the journey to becoming better self-managers.

The mean improvement in the PAM score ranged from the lowest 5.6 (pain patients) to 9.4 (diabetes patients) (Q1 Appendix, Table 3) this compares to a 4.7 mean improvement reported by patients attending a similar self-management programme (Lorig's Chronic Disease Self-Management Course) in the United States (USA).⁵⁴ A tailored telephone coaching intervention in the USA for people living with a LTC recorded an average 4.6 point PAM improvement. Other research has shown that activated patients are more likely to participate in collaborative decision-making with their clinicians, and they report improved health-related behaviours, clinical outcomes and they adhere to physical therapy.^{60,61}

Participants' condition did not predict improvements in patient activation. Participants who were younger, more anxious, less activated, with a poorer quality of life at baseline improved their activation the most. Similarly, Reeves et al⁵⁷ found that EPP participants who at baseline were low in self-efficacy, had lower health related quality of life and were

younger tended to improve the most. We found that younger patients were also more likely to drop out the SMP.

The condition specific measures, which are conceptually similar to patient activation, namely the pain self-efficacy measure and the mastery subscale of the CRQ-R, confirmed that attending the SMP resulted in improvements in participants' confidence to self-manage pain and COPD related problems respectively. Several researchers have questioned the importance and relevance of self-efficacy in managing a LTC as it perpetuates and favours an individual behavioural response to health challenges, which might be better addressed through an acknowledgement of the important roles that family, social and material resources have on self-management and health outcomes.⁶²⁻⁶⁵ Further, the importance of improved self-efficacy relative to other outcomes, such as improved quality of life and symptoms to LTC patients has been questioned.¹¹ However, a recent study showed that UK participants who attended the EPP rated self-efficacy as an important outcome and were willing to trade decrements in quality of life for improvements in self-efficacy.⁶⁶

In summary, patients reported moderate to large improvements in patient activation and this finding compares favourably with other self-management programmes(Chronic Disease Self-Management Course, Arthritis Self-Management Programme)⁶⁷, which tend to show small to moderate improvements in conceptually similar outcomes (e.g. self-efficacy).

Health status and quality of life:

Pain and depression patients enjoyed better health status after attending the SMP. Only depression patients enjoyed a significantly improved quality of life as measured by the generic EQ VAS. Two other self-management studies^{51,68} similarly found no improvement using the EQ VAS among arthritis and COPD patients respectively. A recent meta-analysis⁶⁷ of Professor Kate Lorig's Stanford University arthritis self-management programmes (ASMP) and generic chronic disease self-management course (CDSMC) suggested that improvements in quality of life might take longer (i.e. > 12 months) to emerge compared to other outcomes such as self-efficacy. Further, it has been suggested that some generic measures may not be sensitive enough to adequately capture quality of life improvements after attending self-management programmes.⁶⁹ We found that the diabetes specific quality of life measure (DQOL) but not the EQ VAS showed significant improvements for diabetes patients. It is important therefore, that self-management programmes measure condition specific outcomes.

Self-management skills including the three enablers:

The finding that participants across all 4 conditions were significantly more often using self-management skills and techniques, as measured by the hei-q subscale skills and technique acquisition, is important given that the primary aim of the SMP is to enhance participants' ability and capacity to self-manage their condition. In Australia Nolte et al⁷⁰ similarly reported skill and technique acquisition to be the self-management skill that improved the most among 842 participants attending self-management programmes. Depression patients showed improvements in 7 out of 8 domains, and diabetes patients showed improvements in 6 out of 8 domains. These patients were using more self-management techniques compared to COPD patients who showed improvements in 2 out of 8 domains, and pain patients who showed improvements in 2 out of 8 domains. Where improvement occurred

most of the effect sizes were small. Depression patients' self-management scores were lower at baseline compared to the other three conditions and so had more opportunity to improve. Richard Osborne in Australia has similarly shown that those who experience poorer pre-course self-management skills tend to improve the most (personal communication).

Interviews with SMP participants showed that the goal setting component of the SMP was greatly valued by participants, and in particular the benefits permitted by having weekly monitoring of progression towards achieving incremental goals by peers in the SMP course. The importance of these two techniques was emphasised by a number of participants. Having to share and feedback on their goals with other group members strengthened participants' motivation and action. Goal setting and action planning appear to be the most important and useful behaviour change technique on the SMP for mastering new skills. This is probably due to the fact that they are also the most frequently practiced on the SMP. Skills mastery is crucial for enhancing self-efficacy (confidence).⁷¹ Interview findings showed that some participants learnt to apply the knowledge and skills away from the group environment.

Anxiety and depression:

People with LTCs are prone to much higher levels of depression and anxiety than physically healthier peers, and there are numerous causal pathways between these mental health conditions and the onset and impact of different LTCs. There is evidence that functional and clinical outcomes are significantly poorer in patients with physical LTCs and co morbid anxiety and depression.^{72,73}

NICE guidance on the treatment of depression in adults with a chronic physical health problem supports the role of self-management, bibliotherapy (e.g. self-help books), Cognitive Behaviour Therapy (CBT) or antidepressants, for most patients with mild depression and a LTC.⁷² However, the reality in clinical practice is these co morbidities are seldom assessed. While primary care has been incentivised for screening for depression, there is no evidence that this has improved the management of depression or increased rates of referral to specialist mental health services or to social services. A recent survey in primary care found that rates of treatment for depression were lower for older patients and for those with co morbid physical illnesses.⁷⁴ The case for psychological interventions for people with LTCs is made in the DH Good Practice Guide for the national Improving Access to Psychological Therapy (IAPT programme).⁷³ IAPT is a Department of Health national programme providing low and high intensity cognitive behavioural therapy (CBT) to patients with anxiety, depression and other mental health problems.

The SMP is similar in content and process to well established and evidenced based interventions (e.g. CBT and group psychotherapy) for people with a range mental health problems including depression. A 5-point difference in PHQ-9 (depression measure also used in IAPT) scores is advocated as the minimal clinically important difference for individual change.⁵⁹ Depression patients on the SMP reported a mean decrease of 4.8 on the PHQ-9, which compares to a 6.9 mean decrease post treatment reported in the IAPT service,⁷⁵ thus highlighting the potential for the SMP to be considered as useful complimentary intervention for treating people with depression.

The positive psychological, emotional and social benefits reported by SMP participants confirm previous self-management research.^{33,34,45,76} Positive emotions are important intermediate outcomes of self-management programmes and have the potential to impact on self-management and health outcomes. Barbara Fredrickson's "Broaden and Build theory"⁷⁶ from the field of positive psychology, suggests that positive emotions broaden an individual's attention, thinking and action thus enabling the building of new, creative thought and action pathways (i.e. expanding an individual's coping skills), and the building of personal and social resources. The following quote from an SMP participant is consistent with Fredrickson's broaden and build theory.

"I had a great time - it was fun and has changed my life. Blood sugar down, exercise up, life better organised." (SMP completer, Diabetes site)

Interview findings presented throughout this report confirm previous research by Turner & colleagues^{33,34} that instillation of hope, universality (realising you are not alone), group cohesion, inspirational modelling and imitative learning are what Yalom⁵⁸ has described in the psychotherapy literature as "therapeutic curative factors". A key feature appreciated by many SMP participants was that of sharing with others in a hopeful, supportive, reassuring, empathic environment. Participants not only felt reassured that they were understood but they also appreciated the emotional and practical support provided by other group members including lay and clinician tutors.

Did patient outcomes improve over the three years of CCH among patients who did not attend the SMP?

When we looked at surveys of patients who had not attended the SMP, in both demonstration and comparison sites, we found little improvement in any of the patient outcomes. Where improvement did occur it was very likely to be due to different types of patients being recruited in the beginning of CCH (Year 1) and the end of CCH (Year3). For example, Arran & Ayrshire and Isle of Wight COPD patients reported more problems with breathlessness over the three year period, as might be expected due to the degenerative course of the condition. Cambridge COPD patients reported no deterioration over the same period, but the patients recruited in the last year of CCH (Year 3) were mostly a different sample from those in Year 1, and were from primary care. They were found to be younger than patients recruited in the first year of CCH (Year 1) who were primarily from secondary care. These data are presented in Q1 Technical Appendix.

In summary, CCH had no impact on those patients in the pathway of care who did not attend the SMP. Patients who did not directly experience the SMP in the demonstration sites, did not benefit from the other two programmes of CCH.

d) What was the experience of SMP participants and tutors?

Participants' experiences of attending the SMP:

A key aspect of the SMP is social exchange and social support. We found from our interviews that participants appreciated the opportunity to share information and self-

management techniques with each other, especially hearing that they were not the only ones experiencing difficulties.

"Also being able to develop your confidence by sharing your stories with others and saying, well they won't think I'm a bit odd, a bit peculiar because I'm aware so and so said within the group", and that gives a level of confidence when you're talking to your clinician because you know you're not alone." (LOCCHIT Patient Representative, Diabetes site)

"I was amazed how this group of strangers opened up and shared personal experiences in such a short period of time. This opportunity to talk about their pain story appeared to be a very significant point within the group dynamic. By the end of the Introduction meeting a tremendous sense of support had filled the room. Smaller group conversations had developed and people were looking forward to meeting again in the future." (Pain Site Reporter observation of Introduction meeting)

For one participant this realisation was the crucial factor which enabled her to become more involved with the group.

"To be honest with you, when you started the group, I actually sat at the back all by myself on the back row in the last chair. And then I slowly came to the front. First day I was there, I never opened my mouth. I just kept shut, and then as it went on, the week after, I got more involved. So that really brought me out of my shell, when I could hear other people saying that I wasn't the only one, and they were coming out, so I opened up then." (SMP completer, Pain site)

Some participants used the SMP as a catalyst for developing and extending their social networks after the SMP ended.

"It was through the co-creating lifestyle that I started socialising again" (SMP completer, Depression site)

"I'm meeting lots of different people, and having different opinions, networking and this sort of thing it has improved my skills in that area dramatically...this has certainly helped me get back into the real world" (LOCCHIT Patient Representative, Diabetes site).

Participants' evaluations of the quality of the SMP using the hei-q SMP course quality ratings:

In self-management courses some form of process feedback is often given using a locally developed "happy sheet". We chose to use a well validated method used in many published evaluation studies. SMP participants completed the hei-q course quality report during the last session of the SMP. Data can be presented two ways: as mean scores for each of the 9 items which are scored: 1 = Strongly Disagree, 2= Disagree, 3= Agree, 4= Strongly Agree (higher scores indicate more positive feedback, (See Q1 Appendix Table 7 for breakdown by condition) or as percentages of respondents indicating their agreement/disagreement with each item, (see Q1 Appendix Table 8).

Anonymised feedback from 649 participants showed the overall CCH mean ratings for all 9 items were three or above indicating that most participants rated the SMP course delivery positively (See Q1 Appendix, Table 7 for breakdown by condition). The scores range from

the highest score 3.7 “*Course leaders were very well organized*” to the lowest score 3.4. “*I thought that programme content was very relevant to my situation*”. This is the same pattern of results reported in Australia by Melbourne University who conducted a large scale national evaluation of self-management programmes. Participants with depression tended to rate the course delivery most positively and participants with musculoskeletal pain rated the course least positively (See Q1, Appendix, Table 7).

The results of the hei-q course quality report are positive and are given that they are similar to those reported by Osborne in Australia who included many established SMP programmes. The results suggest that overall participants are satisfied with the quality of the SMP and the delivery style and skill of the tutors.

We also found from the interviews that tutors also benefitted from delivering the SMP. Consistent with our other studies of tutors on other self-management programmes^{77,78} several of the lay tutors had undergone a positive experience themselves as participants on the SMP and were altruistically motivated to pass on their enthusiasm and learning to other participants. Clinical tutors used the skills that they developed while delivering the SMP to provide self-management support to their patients during consultations.

In summary, the majority of participants, irrespective of condition, rated the quality of the SMP highly thus providing some assurances that the SMP was delivered to a consistently high standard at all sites.

Participants who dropped out of the SMP

Inevitably, not all participants valued group-based self-management support. Our interviews showed that with some participants felt worse and dropped out because they found the group discussions uncomfortable.

“I found sitting in a room listening to other people’s problems excruciating and felt very jumpy. I found techniques not helpful because my depression was too deep. I dreaded going to sessions.” (SMP drop-out, Depression Site Report)

“I don’t want to have to stand up in front of people and start talking and I don’t want to talk about my illnesses in front of anybody because that labels me” (SMP dropout who did not attend any sessions, Pain site)

One of the main reasons participants reported for dropping out of the SMP was the repetitive nature of the course. This is one example.

“Well it was boring because it kept on repeating themselves.” (SMP dropout, Diabetes site)

Other participants reported dropping out as they felt alienated by the content of the course.

“I thought I was going to get a lot more from it than I did...I’m not a stupid person, I’m fairly intelligent and I felt that we were being treated to the lowest intelligence.” (SMP dropout, Pain site)

Some participants felt the course was not interactive enough.

"It didn't hold my attention enough. It wasn't anything like the other course I had done, you know, doing exercises and getting people coming and giving a talk on your illness and different things like that. That was just sitting, listening to this lady and it was just repetitive, so it didn't hold my attention at all." (Interview with SMP dropout, COPD site)

Other participants reported not being told what the SMP was by the referring clinician.

"I just went in there like I do with any course but I don't know what I'm going for if it's specific or something." (SMP dropout, COPD site)

Some participants reported not knowing why they were being invited to take part in the course.

"I have no idea, she phoned me up she just phoned up to see if I would like to take part in it. I don't know whether it was because, you know, I had emphysema, I don't know what it was, nobody ever said why." (SMP dropout, COPD site)

In summary, some participants did not complete the SMP course because of certain aspects of its perceived relevance, content and delivery.

SMP tutors' experiences

SMP tutor training:

The original target was to achieve training of 76 SMP tutors (6 clinical and 6 lay tutors per site). The programme as whole exceeded this target, with a total of 126 tutors being trained, although in practice 87 went on to deliver courses. There were 62 people trained as lay tutors of the SMP, and 36 went on to deliver training, and 43 had attended the SMP as participants. There was a high turnover at all but the two diabetes sites with around a half to two thirds of lay tutors discontinuing their tutor role by the end of CCH.

The training of clinicians and lay tutors for the SMP was organized by EPPCIC and included tutors from a mix of sites at each course. This enabled some cross site exchange of experience. The four day training comprised a mixed of different types of delivery including practice of core activities (e.g. goal setting, action planning, problem solving and "freethinks" (an activity in which participants generate solutions to pre defined questions and/or problems) introduction to different adult learning styles and developing effective group facilitation skills. Tutors were assessed according to a competency framework.

The SMP tutor accreditation process involved three stages: Stage 1 involved passing the four day tutor training. Of the 130 tutors who attended the training three did not pass this stage. The reasons for not passing were being unwilling to work with the SMP manual (clinician tutor), being unwilling to work within the bio-psychosocial model (lay tutor), and being unable to model effective self-management (lay tutor). Stage 2 involved being observed successfully delivering a first SMP, three tutors did not pass this stage. Stage 3 involved being observed successfully delivering a second SMP, two tutors did not pass this stage. All SMP assessors were experienced SMP tutors and had completed additional assessor

training. Tutor assessments were carried out according to an enhanced competency framework. Verbal and written feedback was provided.

The CCH Newsletters gave several accounts of the positive experience of SMP tutor training.

*"I came away from the course feeling invigorated, encouraged, enlightened and rearing to go and co-deliver my first course!" "An excellent but highly challenging four days that instilled in me the confidence to proceed with training." (CCH newsletter August 2009, pg 6)*⁷⁹

*"Through practice and rehearsal, co-facilitator confidence soared. Both clinicians and patients reported feeling more confident to demonstrate and explain skills and patients clarified their role as mentors to clinicians." (CCH newsletter August 2009, pg 5)*⁷⁹

However, interviews and observations showed a more mixed picture. Our interviews showed that some lay tutors were impressed with "how professional" it was, while others reported feeling unprepared to deliver the SMP because the training lacked sufficient delivery practice of many the activities.

"We were taught lots of things, how people learn and how to present the course but the actual programme itself the material in the programme – we didn't look at that once...it's seven sessions at three hours a go so it was 21 hours worth of material we didn't look at, which was a bit of a shock really." (SMP Lay Tutor, pain site)

This was confirmed by our researcher who attended and observed the SMP tutor training.

"Participants noted that there was not as much practice of presentation skills as they had expected, and tutors reiterated that the training was more about teaching the content of the course than the delivery of it." (Researcher field notes)

The SMP is a complex, multi component programme and in the absence of any dismantling studies being undertaken, where specific activities (e.g. goal setting, problem solving) are evaluated to assess their unique effect in producing positive outcomes, we can only speculate as to what are the key mechanisms of change. Previous self-management studies^{80,81} have found that participants value sharing experiences with the group and receiving help from tutors more highly than goal setting. Interviews with SMP participants also showed that they valued the positive group experience. Lambert⁸² identified the unique contribution of four factors which predict successful outcomes in psychotherapy.

- Extra therapeutic factors (e.g. clients existing strength and resources such as level of education, income, support network): 40%
- Therapeutic relationship (therapist who shows understanding, empathy, respect): 30%
- Models/techniques (e.g. cognitive restructuring, negative thought stopping): 15%
- Expectancy/placebo effects (hope, positive expectancy): 15%

The relative lack of importance of the specific therapeutic models and techniques compared to "common factors" such as the patients' social support networks, relationship with the therapist and creation of a positive, hopeful environment has implications for self-management programmes. First, it is important to help patients strengthen and/or build existing family and social networks to help consolidate the improvements that occur.

Second, it is important for tutors to be trained in using key interpersonal skills to be able to build a trusting and supportive relationship with patients.

In summary, there was a thorough competency based training and accreditation system for tutors. The training concentrated more on teaching the SMS and group facilitation but was insufficient for some tutors who felt the need for more practice and feedback to improve delivery skills specific to the SMP activities. Tutors should also develop their interpersonal skills in order to provide a supportive and “therapeutic” environment in which participants are encouraged to learn self-management skills.

SMP delivery:

The main reason SMP participants trained as lay tutors was because they benefitted immensely from their attendance and felt that they wanted to “give something back”, or heard about the role through being a member of the LOCCHIT.

... “I thought the SMP programme was brilliant, I thought it was very good. and nothing like the SMP programme had been shown to me or suggested to me previously. .a lot of what we go through on the SMP seems so obvious and so straightforward and yet a lot of people don’t really do or try some of the tools or things that we show them. (SMP Lay tutor, Pain site)

“I think because I got so much out of it, they said, well would you like to be a tutor? Well what does it entail? And I thoroughly enjoyed it, so I went through all the training and I’ve actually done my first course and giving other people ideas and listening to other people, it really, really was good.” (SMP Lay tutor, Pain site).

The experience of delivering the SMP was a positive experience for some lay tutors and helped them to gain the motivation to re establish important life goals and gain renewed meaning through helping others.

“It really changed my life and pulled me out my depression and into a life that I wanted which was accepting that I had a long term condition that meant I might not work again but looking at things that were important in my life like going back to college and improving my personal relationships.” (March_10_CCH Newsletter page 10)⁸³

“I lost who I was and also lost my job. I came on an SMP, then became a Tutor and realised I could make a difference for myself and others. I am a better self manager by helping others.” (Tutor from pain or depression site, May_10 Newsletter final pg 2)⁸⁴

Lay tutors described how their self-management skills were refreshed by delivering the SMP and how their confidence and self-esteem was improved by being part of something which they could see was of great benefit to many participants. Clinical tutors described how they applied the skills they used on the SMP such as identifying negative beliefs, goal setting and assessing patients’ confidence and motivation to improve their clinical practice.

“I think the different techniques that are offered during the SMP like the identifying negative beliefs- I’ve been able to offer those to people and give them chance to explore whether those are things that are helpful for them. And I think one of the most helpful

things I've found is being able to facilitate people to set realistic goals and to alter their goals. So I've found the confidence scaling hugely helpful in that" (*SMP Clinician Tutor, COPD site*)

"It evolved, yes it's just added on a lot more... because I have got 20 years' habit perhaps of being, not perhaps prescriptive but just knowing from experience what works and suggested. But I usually do open that out as to what you think will work best and that sort of is also the centre of this self-management group. So I have worked in my practices asking the person themselves, because it makes no sense to ask them to do something if they're not prepared to do it, and want to be committed to it themselves. So it's added on what we've already been doing" (SMP Clinician Tutor, Depression site)

Both lay and clinical tutors had diverse views about post tutor training support they received to deliver the SMP from EPPCIC and from their co-tutors. Generally, SMP lay tutors felt appropriately and adequately supported by their EPPCIC site lead tutor.

"I knew that if I had any problems I'd got my lead tutor...there's so many different people who are there ready to support you...no matter what day, no matter what time of day, they're there at the end of the telephone and I think that's really good." (SMP Lay tutor, Pain site)

There was evidence of tutors providing each other with support and encouragement.

"We have all had kind of corridor conversations about 'how did you deal with this bit in session 3, or what did you do in the 3 month review?' Just learning from each other really... So the culture itself helps." (SMP Clinical tutor, Pain site)

Some lay tutors we interviewed reported that their clinician co tutors did not adequately prepare for delivering the SMP, and they felt unsupported by the clinician co-tutor in some of the organisation and administrative tasks (e.g. preparing flipcharts, maintaining participant registers) required in delivering the SMP.

"The clinician was extremely lazy and complacent." (Lay Tutor, Depression site).

The same lay tutor also felt that the delivery was

"Under-rehearsed, under-practiced"

We describe in question 3 that many clinician tutors were ambivalent about their role in delivering the SMP, which may have contributed to their apparent lack of engagement with and support for the lay tutor.

In summary, some lay tutors benefitted from a renewed sense of purpose and meaning that the SMP gave to their lives and the professional tutors valued the skills and techniques which they could employ in a clinical setting. There was significant tutor turnover except at diabetes sites, which may be in part due to physical and psychological demands of the LTC, which were not sufficiently mitigated by support offered by what sites could offer.

e) What was the reach of the SMP, and how could this be improved?

We examine the characteristics of who were recruited, attended, dropped out or completed the SMP to establish the reach of the programme, and what may have been success factors that are relevant for future SMPs.

SMP recruitment:

Of 321 responses from the post course (final session) questionnaires, the majority (26%) heard about the SMP they had attended from their GP, followed by condition specific clinics (15%), a Health Professional (11%), Leaflet (7%), Letter (7%) and an advert in the local press (4%). The remaining 30% heard about the courses through a variety of methods, such as friends, relatives, posters or through their work in the NHS. There was recognition towards the mid-point of CCH that clinicians who had attended the ADP would be appropriately informed and perhaps more willing than other clinicians to refer and encourage their patients to sign up to the SMP.

"Because I think it appears that a lot of the referrals to the SMP have come through various sites through the clinicians, and actually if you have clinicians who are really living and breathing and modelling the techniques, and championing it, then one makes the assumption that more patients will get the opportunity to be referred." (ADP Clinician tutor, COPD site)

Both diabetes sites were more successful when they targeted whole GP practices that gained a sense of ownership of the course and perhaps also acted to encourage other practice members to refer their patients than GPs who worked with others who were not involved in CCH.

"I think we would have done it very differently, we would have approached practice by practice and we would have also wanted to have more control over the content of the course so that we could adapt it to the different practices." (Clinical Lead, Diabetes site, Year 3).

Variation in the SMP model, and in services to support self-management, to meet local needs:

The lack of support from health care providers has been identified by LTC patients as a bigger self-management barrier than lack of self-management skills training.⁸⁵ Models of self-care including the Wagner Model⁸⁶ from the USA and the Whole System Informing Self-Management Engagement (WISE)⁸⁷ in the UK emphasise the importance of providing self-management support by trained, skilled health care professionals working in a responsive and flexible healthcare to LTC patients. The WISE model, which has been used to provide self-management support to inflammatory bowel disease patients,⁸⁸ adopted a similar three pronged approach to CCH involving provision of support at the patient, clinician and service level. Fixed outpatient appointments were replaced with open access arrangements and the evaluation of the model showed that patients felt more able to cope and reduced their number of hospital visits. Two CCH sites (a COPD site and a diabetes site) undertook significant variations. The COPD site ran a part "generic" and part condition specific course to meet the needs of a remote community where there were fewer patients with COPD as the main LTC. In this there were parts of the course delivered to the whole group and parts in separate groups to those with either COPD or diabetes. A diabetes site extended the

session time by 30 minutes to allow more discussion. A depression site planned to run a shorter programme in a prison but this did not occur. Some CCH sites were recognising towards the end of the programme that the SMP delivery models and format may need to be flexibly tailored to integrate within existing services and better suit the needs of patients as this comment show.

"We need to open up other technologies whether e-based learning modules, just a booklet to read if patients wish, and also opportunistic teaching, whether at clinics or integrating into existing programmes like the pulmonary rehab programme... That was a bit of a shame that we weren't given an opportunity to try different ways of how do we deliver those, that SMP really. I think we would have had a higher take up as result" (Clinical Lead, COPD site, Year 3)

The site reporters made observations which helped their sites to adjust the way the SMP was provided.

The duration of SMP, provided over 7 weeks in 3 hour sessions, was found to be burdensome to some with work and other commitments, and a challenge for those in fluctuating or sustained ill health.

"It is a lot of commitment to attend 3hrs x 7 weekly sessions and therefore to increase accessibility, the SMP has been adapted in terms of the time of day the SMP is delivered which will help increase recruitment to the course and offer choices" (Diabetes site report)

In summary, several different approaches to recruiting patients to the SMPs were tried in each site, and some made explicit efforts to target patients whose clinicians also attended the ADP. It is not clear that patient demographics or indicators of health need were explicitly used to ensure the scarce resources were made available to those who might benefit most. It is possible that the recruitment of participants by a health care provider who was knowledgeable of and likely to endorse the SMP helped with recruitment and higher completion rates compared to modes of recruitment in other self-management programme evaluations.

The SMP completion rates, which ranged from 66% (depression patients) to 75% (diabetes patients) compare favourably against those of three UK self-management studies reported completion rates of 60%,¹¹ 56%⁵⁰ and 51%⁸⁹. Factors affecting uptake, such as being referred by a known clinician may also have contributed to the high completion rates achieved. The presence of a clinical tutor may have also added credibility to the course. Other explanations for achieving high completion rates may be related to the extremely well regarded and valued service provided by the EPPCIC helpdesk when booking patient onto the SMP. EPPCIC reported a telephone survey of 45 helpdesk users selected randomly who had enrolled on the SMP within the previous 6 months, of these 38 had attended an SMP course, and two thirds had attended the course in 2009. When asked how knowledgeable the person was about the SMP and the information they made available to them, the overwhelming response was high agreement. The CCH Newsletter in August (2010) described the CCH helpdesk and registration learning points and challenges.

"The team feel that when participants speak to an SMP tutor on the helpdesk this provides added benefit and a positive experience for participants. Further information can be given about the programme and participants feel reassured as a result."

The same newsletter reported on a depression site's experience of running its own helpdesk, and may help explain why depression sites achieved lower completion rates as some patients waited up to 30 minutes to get a response and thus their firsts encounter with SMP was a frustrating and negative experience.

"phone calls can take up to 30 minutes for people living with depression but this is the first step of building a relationship and instilling confidence in people to attend the course" (Aug_2010 newsletter, pg 17)⁹⁰

Methods of improving attendance were also tried in each site with advice from EPPCIC, including varying practical arrangements, having a tutor call up those who did not attend the first session, some variation in the length of sessions, and some attempts to call those who had dropped out to see if they might return or to learn from why they dropped out.

In summary, how participants are recruited, and whether they have a supportive discussion with a referring clinician or the help desk, was important in achieving high rates of uptake and attendance.

Limitations

Response rates at 6 months follow-up were disappointingly low and probably resulted from site, tutor and participant burden. The analyses on SMP completers (attended 5-7 sessions) are likely to present the most favourable estimation of outcomes as it focuses only those participants who received a high dose of the programme. Although there were many statistically significant improvements the effect sizes were small and clinical significance negligible. The improvements are generally consistent with other self-management programmes which did not benefit from the additional clinician and service improvement resources delivered in CCH. Despite having the potential to benefit more from attending, younger participants were less likely to complete the SMP, which suggests that they find the format less appealing than older participants.

The biggest limitation is the lack of a control group, which means that there are alternative explanations for the improvements reported by participants completing the SMP. The possibility cannot be ruled out that due to the inherent fluctuating symptoms of many LTCs that some participants' health and psychosocial wellbeing improvement would have occurred naturally. Control group participants in Hibbard et al⁵⁴ reported improvements in activation at broadly similar levels to participants who had attended a self-management programme (CDSMC). Also, we do not have information on what other type of services and support (e.g. IAPT, (Improving Access Psychological Therapy), DESMOND (Diabetes Education and Self-management for Ongoing and Newly Diagnosed) participants sought out which may have had a positive impact on their health and self-management skills. In future, the SMP should not only be evaluated against a control group, but also an alternative intervention such as DAFNE (Dose Adjustment for Normal Eating) and DESMOND for diabetes patients, and IAPT service groups for anxiety and depression patients.

Overall conclusion

In conclusion, the SMP consistently delivers evidence-based behavioural change techniques, albeit sometimes this consistency comes at the expense of flexibility in meeting participants' needs. Tailoring the programme so it better meets the needs of local clinicians and participants and tutors will improve recruitment and retentions. SMP completion rates were high suggesting that patients found the course useful and enjoyable.

SMPs achieved high levels of patient completion (attended \geq 5 sessions) and recruited patients who were less activated than patients in the pathway of care. Sites were relatively more successful in recruiting patients who do not traditionally attend SMPs (e.g. men, black and minority ethnic patients and patients from lower socio-economic status). The SMP provided participants with the knowledge, skills and confidence to become better self-managers and improvements in key outcomes were a function of the techniques learnt on the SMP and the experience of learning these techniques in a supportive group environment. Irrespective of condition, patients reported moderate to large improvements in patient activation, which is an important and valued outcome for LTC patients. Patients who were younger, more anxious, less activated and had poorer quality of life made the best gains in terms of patient activation. Improvements in other outcome variables tended to be small or moderate. Modest effects have public health significance when experienced on a population level.⁶⁷

All patients, irrespective of condition also reported using more self-management skills and techniques. Further, patients in all four conditions reported improvements in important condition specific outcomes (e.g. COPD mastery, pain symptoms and self-efficacy, diabetes quality of life and depression symptoms).

Depression patients, who at baseline, tended to be lower in activation, and experience a poorer quality of life, poorer mental health and used fewer self-management skills compared to other patients gained the most benefit from attending the SMP. Targeting and recruiting patients with greater needs, irrespective of LTC, will deliver the greatest benefits. When they occurred, reunions were valued by patients as a way of maintaining the social contact and support they experienced whilst attending the SMP.

The consistency of the findings with similar self-management programmes and the specificity with which the participants attributed their improvements to the SMP, which were also largely confirmed by our own and the site reporter observations, suggest that the SMP was probably responsible for these improvements.

Recommendations: Question 1

In order to support the implementation of future self-management programmes and improve key outcomes, we have developed a number of recommendations, outlined below:

SMP design and delivery:

- Further iterations of the SMP could include a greater focus on the application of self-management support (SMS) in the context of healthcare consultations in order to

equip patients with the skills for co-production in consultations and their ability to navigate the health care system.

- The SMP design could include a more flexible delivery style and concentrate on a smaller number of key behaviour change techniques to maximize participant engagement and impact. The SMP could contain more interactive sessions to stimulate participants' interest and improve retention. The SMP tutor training competency framework and accreditation could focus more on practice and feedback in presenting course activities alongside developing interpersonal skills required to run effective, supportive and "therapeutic" groups.
- The SMP should be designed to enhance a broad range of outcomes relevant to living with a LTC, as well as the social utility of the programme for peoples' lives.
- Adaption of the SMP to increase the involvement of family and friends in supporting participants' selfmanagement activities. For example, participants could be encouraged to involve family and friends in their weekly goal setting and other "homework" activities such as the gratitude diary.
- SMP reunions should be a planned part of SMP delivery in order to consolidate behaviour change and maximise continued social support.

SMP targeting and recruitment:

Recruitment strategies for the SMP should be based on health needs analysis so that resources are targeted on those who are younger, less activated and have a poorer quality of life who have most to gain, as well as ensuring local clinicians (particularly those trained in self-management support skills through courses like the ADP) are active recruiters to the programme.

SMP integration and adaptation:

The SMP should be integrated with existing NHS services (e.g. pain clinics, pulmonary rehabilitation, IAPT, DAFNE) and the format adapted to fit with a range of different technological delivery platforms (e.g. DVD, PC, web or phone social networking) to make it more appealing to younger patients.

SMP evaluation:

Self-management evaluations should include condition specific outcome measures to ensure greater likelihood of evidencing condition related outcomes.

Question 2: To what extent do clinicians increase the range and use of practices (including the three enablers) to support self-management as a result of Co-creating Health?

One of the goals of CCH is to transform the patient-clinician interaction through providing clinicians with a range of skills as well as implementing changes within the health service to support self-management. To find out to what extent this goal was achieved we investigated the following questions in relation to the Advanced Development Programme:

- a) Did the ADP manuals have content relevant to increasing practices (including the three enablers) to support self-management?*
- b) Did the ADP teach content relevant to increasing practices (including the three enablers) to support self-management in ways that motivated clinicians?*
- c) Did the ADP increase practices (including the three enablers) to support self-management and improve clinicians' motivation to support self-management?*
- d) What are the lessons from the use of the ADP in CCH for how the training of clinicians in SMS practices can be improved?*

This chapter begins by identifying the headline findings and goes on to examine each of the sub-questions above in more detail. We provide our discussion and conclusions at the end.

There were 665 clinicians who started an ADP course, and 465 completed the three workshops, a completion rate of 70%. There were 25 clinician ADP tutors and 19 lay ADP tutors. The data on the numbers of clinicians and tutors trained at each site are reported in the CCH Technical Appendix 1. Data related to this Chapter are in the question 2 Appendix, and additional analyses and graphs are in the Q2 Technical Appendix.

Headline findings:

Summary

The ADP manual comprises materials relevant to teaching clinicians communication skills helpful in establishing an equal and supportive clinician-patient relationship (establishing patients' priorities, empathy, defining boundaries) as well as techniques supporting patients' self-management (problem solving, assessing importance of patient's goals and confidence to change).

There are materials relevant to increasing clinicians' practices in agenda setting and goal setting. Both concepts are clearly described, and opportunities for practice are provided. The ADP manual does not clearly define follow up processes, nor does it contain sufficient information on follow up techniques to ensure positive impact on clinicians' consultation behaviours in relation to following up patients' goals.

These findings were supported by our direct observations and participants' and tutors' reflections on teaching sessions.

There is limited evidence that clinicians who attended the ADP increased their reported use of a wide range of practices in self-management support. There is strong evidence these clinicians reported improvements in the use of the three enablers, and some evidence their confidence in a wider set of self management support practices improved for those clinicians who reported increased use of the three enablers.

There is only very weak evidence that patients were aware of and responded to the practices taught on the ADP in consultations.

The largest proportion of the those who attended the ADP were doctors and the majority of these were GPs. Medical attendees had, on average, the lowest scores on self management support skills before training and also showed the greatest gains.

Among clinicians who had completed the ADP training, we found that previous training in self management support, professional group and care sector where the clinician worked all had strong impacts on practicing self management support and using the 3 enablers. ADP participants who had previously attended training similar to the ADP, or who spend more than a half of their working week in direct care and contact with patients with long term conditions, or were more confident and value self-management support, responded more positively to training by further increasing their practices in self-management after attending the ADP.

Regarding the differences in how clinicians from different professions responded to the ADP, we found that clinicians who were allied health professionals and psychologists were more likely to report practicing self management support and the use of the enablers particularly follow up after completing the ADP. We found that non medical professionals, particularly those who work across primary and secondary care or in secondary care, made greatest gains in several areas of practice. We think this reflects the role of clinical nurse and allied health professionals who have the scope in their roles to undertake these skills and who have ongoing contact with these patients. By contrast, there is evidence that their colleagues working only in primary care who may have mixed LTC caseloads and less emphasis in their job on self management, scored lowest in some areas, including personalising care. We found that doctors, who had prior training related to self management support, achieved greater gains on Clinical Self Management Skills scored, which is somewhat higher than doctors with no prior training. We also found that the use of follow skills up was least likely to be reported by secondary care doctors. This is consistent with interview data that these clinicians see themselves mainly as diagnosticians and are encouraged by the systems of care they work in to hand follow up on to others.

For all clinicians prior training was not a strong predictor of using the three enablers more, so it is likely these particular skills were not taught, or not effectively taught, in prior training.

We found no evidence of “spread” of ADP practices among clinicians who worked in CCH demonstration sites and who did not attend the ADP.

There was weak evidence from the PPIC consultation exit measures that some clinicians became more proficient at using the skills in practice. While the data showed significant improvements, the sampling strategy of clinicians selecting which patients completed it, was designed for training purposes not for evaluation.

Not until midway through CCH were attempts made by sites to target specific clinicians for the ADP, this meant that opportunities for building teamwork among those supporting self-management, and to provide opportunities for synergy ("White Light") with the SMP and SIP were not achieved.

The ADP was very dependent on a small number of clinician tutors and fewer lay tutors. Planned recruitment, skill development and retention of tutors are essential to sustain the model of training.

The ADP model was subject to much variation to meet local needs, and many innovations were found to improve uptake with no decrement on outcome.

a) Did the ADP have content relevant to increasing practices (including the three enablers) to support self-management?

Evidence:

We examined the content of ADP manuals focusing on how clinicians are taught self-management support skills in terms of both the theoretical description and the practical exercises. We particularly looked for evidence of the three enablers (agenda setting, goal setting and follow up) given the prominence of these self-management support practices in CCH. We analysed all manuals using a systematic method.³⁹

Findings

Agenda setting:

We found that agenda setting techniques are discussed during the first ADP session (See Intro Appendix Table 8 for checklist). Agenda setting is listed as one of the co creation skills that aims to establish what are patients' expectations regarding the consultation, and what are their priorities and likely limits to self-management. The assumption is that the patient and the clinician should share their agendas and collaboratively decide what information is exchanged and what skills are supported. It provides structure for both the patient and the clinician, helps the clinician to decide how to best allocate the time available during the consultation and makes sure that the patient's key reason for the visit is recognised.

Communication skills that support agenda setting are presented as well as a step by step guide on how to set an agreed agenda during the consultation including promoting openness, gathering the patient's views, introducing the clinician's agenda, and establishing the patient's priorities and boundaries and clarifying and negotiating what needs to be discussed.

During the session clinicians watch videoed consultations featuring agenda setting techniques. Attendees are given an opportunity to try out agenda setting techniques with an actor.

Goal setting:

Goal setting is introduced during the second ADP session. The material suggests using a collaborative approach to support the patient in defining their own goals rather than setting goals for them. The manual describes communications skills useful for setting goals and a step by step guide on how to collaboratively set goals:

- Understanding the patient's perspective on setting the consultation agenda, the patient's journey and activation, and assessing the importance and patient's confidence to achieve the goal.
- Clarifying the clinicians' perspective including assessing the patient's health status, taking a long term view and supporting patient's autonomy and freedom of choice.
- Customising goals, supporting choice among different options, identifying small and achievable steps, problem solving, increasing the patient's confidence, awareness and knowledge.
- We found there is little detail on defining and agreeing specific "SMART" goals, how they will be measured, reported, by when and to whom.

The session also comprises an exercise during which clinicians are asked to work in pairs to identify their own goal regarding using one of the ADP skills in future consultations, and rate its importance and their confidence to achieve it. In this way the clinicians are applying the technique to themselves.

Follow up:

Follow up techniques are discussed during the final ADP session. It is stated that explicit follow up on patient action plans is imperative, and flexibility in finding the right method is discussed.

During the last session clinicians perform a follow up exercise. The session also includes observing a video presenting different follow up options. However there is no detail on distinguishing between goal follow up, e.g. by returning a self monitoring diary, and simply arranging a further appointment with a clinician with no specified purpose.

b) Did the ADP teach the content relevant to increasing practices to support self-management in ways that motivated clinicians?***Evidence***

We analysed notes from direct non participative observations of ADP sessions, focusing on evidence of tutors presenting, discussing, explaining and practicing the three enablers with clinicians attending the workshops. We analysed site reporters' observations.

We analysed interviews with ADP clinical and lay tutors focusing on information regarding how the self-management support skills are taught during the sessions. We analysed interviews with clinicians who attended the ADP course to explore the impact of attending the ADP on the range and frequency of using self-management support skills in clinical

consultations, their confidence to support self-management and their engagement in organising services to support self-management.

Findings

Agenda setting

Site reporters who attended ADP sessions observed evidence of agenda setting being taught. The ADP tutors described agenda setting as a tool that fits well into a 10 minute consultation. The tutors consistently referred to the benefits to be gained by both the patient and clinician in using agenda setting. At some sites the lay tutor role modelled agenda setting to ADP delegates. Challenges associated with agenda setting were discussed and resolved within the group and delegates reported positive experiences;

“It allowed me to set priorities...I’m surprised how effective it was...it probably saved me time.” (ADP delegate, Pain site)

They also reported negative experiences of agenda setting:

“I’m not ready to do that yet. I need to look inside myself.” (ADP delegate, Pain site).

One of the delegates mentioned during the session that prioritising issues within agenda setting was challenging. Sharing experiences prompted tutors to provide strategies to improve agenda setting during consultations using simple questions which invite the patient to take the lead: *“What would you like to really focus on today?”* The clinician tutor summarised the main points and encouraged clinicians to keep trying the skills:

“You will become more efficient at using these skills as you try them”.

Interviews with ADP tutors and ADP delegates confirmed that agenda setting was comprehensively covered in the ADP and that there were several exercises to ensure that clinicians were prepared to use this strategy in their clinical consultations:

“(...) there’s a bit of theory about it in the {agenda} setting, there is a video where they show you a clinic consultation and the group attending the ADP course is asked to comment on the clinician’s skills of agenda setting and then they show a modified video which is better than the first one. But then the group is asked how it works and how it would be more appropriate to set agendas that way than the first way”. (ADP clinical tutor, Pain site)

“(...) with the clinicians we discuss agenda setting by allowing the patients to bring to the table exactly what they’re hoping to get out of their consultation, but also the clinician to be open about what they’re hoping to get out of the consultation, and then to collaboratively prioritise and set an agenda for each visit”. (T4T tutor, COPD site)

Goal setting

According to site reports, during the ADP sessions one of the clinician tutors introduced goal setting, communicating the ideas interactively and drew out the knowledge they already had. As a goal setting exercise, clinicians were asked to develop their personal SMART goals

in pairs and then invited each pair to the flip chart whereupon the group asked them questions about their goal to really establish the SMART criteria. This illustrated how much more understanding of the goal and possible obstacles one gets from asking questions and drilling down to the detail. In this way the clinicians were applying the technique to themselves. Also the clinical tutor set a good example in that goals were clearly set for the whole ADP programme and a clear explanation of why this is important and how that will be done was provided to participants.

In one of the sites an observer noted that goal setting was being confused with action planning by both the clinician and the lay tutor.

Interviews with ADP tutors and delegates show that goal setting was also featured in the ADP training content and taught accordingly:

"(...) we obviously discuss the importance of goals with the clinicians, we discuss with the clinicians how to set personal, more patient centred goals, and then we break down the goal setting into, you know, that they have to be specific, measurable, achievable, reliable and time based, so we have a really specific way of teaching goal setting that explores with the patient how important it is, how confident they are and the actual specific action plan that they are going to do as a small step towards achieving their goal, it's a very specific way that we teach it, but it's obviously the way that it's been proven to work in practice". (T4T trainer, COPD site)

"(...) there are some videos of goal setting so maybe drawing the base line and getting the patient to say if they can do that for that much time and that's how it is worked at". (Clinical ADP tutor, Pain site)

Follow-up

Data from site reports and interviews show there was scant coverage in course delivery of goal follow up.

"None springs to mind, only that they would do a follow up maybe or a questionnaire for the people that are participating, but I can't honestly think of any particular examples". (Lay ADP tutor, Pain site)

"(...) we talk about follow up with the patient through different forms and maybe challenging the clinicians that, you know, what is the most patient centred way of follow up?" (T4T trainer, COPD site)

c) What is the evidence that the ADP increased practices to support self-management (including three enablers) and improved motivation to support self-management? Who benefited from the ADP training?

Evidence

We analysed Year 1 and Year 3 surveys data^{VI} to examine whether the use of self-management support practices and clinicians' confidence and motivation to support self-management for long term conditions increased during the three years of the programme delivery for those who had not attended the ADP at the time of the survey. Analysis of pre and post ADP^{VII} data was undertaken to answer the question as to whether attending the ADP influenced using self-management support practices, and clinicians' confidence and motivation to support self-management. We analysed staff and patients' interviews focusing on information regarding changes in clinical practice, the approach to patients, understanding of the importance of self-management support and engagement in changing services to better support patients' self-management. We examined patient ratings of consultations with ADP trained clinicians using data from the Patient Partnership in Care survey (PPiC) consultation exit rating which formed part of ADP programme delivery.⁹¹

We analysed the senior stakeholders' interviews to find out whether senior people in the organizations (including board members) noticed any changes resulting from their organisation participating in CCH in the way care is delivered by clinicians. In site reports we looked for information regarding changes in clinicians' consultation behaviours (including using the three enablers).

Self-management support practices were assessed by the Practices in Self-management Support questionnaire (PSMS).⁹² The PSMS scale was developed for this evaluation and comprises three subscales: Clinical Self-management Support includes items such as building an equal clinician-patient relationship, using the three enablers and exploring the patient's self-management strategies. Patient Centeredness includes customizing the treatment to a patient's preferences, and Organisational Self-management Support includes clinicians' engagement in organizing services and teams to support self-management, and supporting a patient's involvement in service improvement.

^{VI} We collected 507 usable Year 1 surveys from demonstration sites, and 48 from the 4 comparator sites, and 461 and 182 respectively in Year 3. We started Year 1 data collection soon after introducing CCH in demonstration sites (March 2008) and completed it in September 2009. Response rates are unknown as sites controlled recruitment, and many surveys were returned with insufficient completion for analyses. See Technical Appendix 6, and Q 2 Appendix Table 1. Analyses of demographic variables in clinician samples are presented in Q2 Appendix Tables 2 and 3 show that there were few differences between the Pre ADP and cross sectional clinician samples, but there were differences in the Year 1 and Year 3 samples which may mean these are dissimilar samples on other variables such as practices in self management support. See CCH Evaluation Year 2 report. Year 3 data were collected between April and November 2010. At the same time we collected data from CCH comparator sites. However, due to poor initial recruitment by sites, Year 1 data collection was extended and covered the first and partially the second year of the programme hence it does not reflect the true baseline. It is likely that some changes resulting from introducing CCH were already present during the second year of the programme so presented results may not reflect the actual outcomes in relation to clinicians' engagement in self-management support.

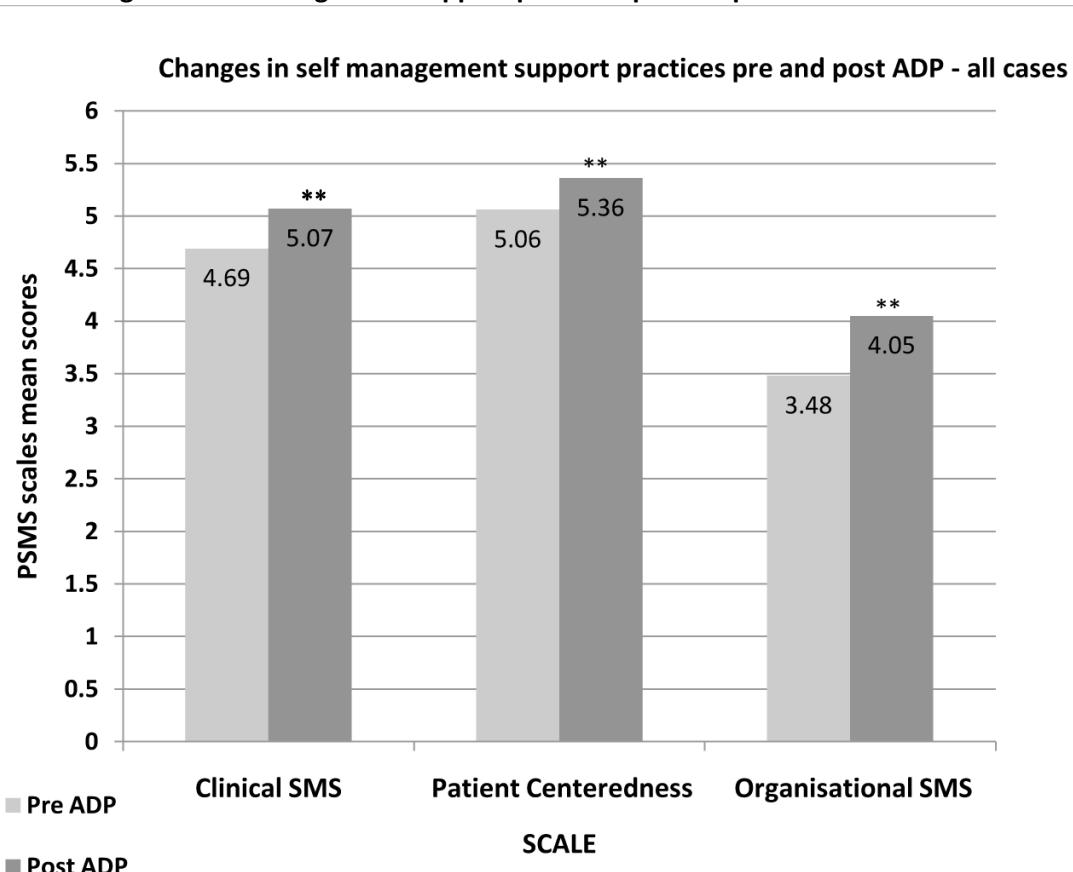
^{VII} We started collecting ADP data just before the first ADP (series A) commenced (January 2008) and completed data collection in November 2010. We surveyed clinicians (using web based and paper questionnaires depending on site's preference) three times: within 2 weeks before attending the first ADP session (T1), within 2 weeks after completing the last ADP session (T2) and 6 months after the first ADP workshop (T3). We have not used the T3 data in these analyses as the response rate was very low. We have analysed paired pre and post ADP data as well as unpaired data obtained from all ADP completers who filled in the pre or post ADP surveys or both. Throughout the life of CCH project we received 453 fully completed pre ADP surveys and 343 post ADP surveys, and 114 respondents completed both pre and post ADP questionnaires and provided sufficient information to enable data pairing, along with usable surveys. The characteristics of the Year 1, Year 3 and pre -post ADP samples were compared and results are summarised in the Q2 Technical Appendix.

Findings

1. Did the ADP increase clinicians' practices in self-management support?

Detailed analyses are contained in the Q2 Appendix. Using all the surveys of clinicians surveyed before and after the ADP, the results suggest that attending the ADP increased clinicians' self reported practices in Clinical Self-management Support, Patient Centeredness and Organisational Self-management Support (including using the three enablers in clinical consultations) although self reported confidence was not improved (See Figure 20 below and Q2 Appendix Table 4).

Figure 20: Changes in self management support practices pre and post ADP – all cases



** P<.001 (Q2 Appendix, Table 4)

Our analysis of the differences in the results on the above scales by the type of site (condition pathway the clinicians were working in) showed that there were no differences by condition in the improvements shown in all sites for the Self Management Support and Organisational Self Management Support sub scales. By contrast, the results showed that while on average across all conditions they improved on the Patient Centeredness sub scale, there was a difference in this gain according to the condition pathway the clinician was working in. The clinicians who worked in the COPD pathway gained least and those working in the pain pathway gained most, and this difference was significant. Although the dataset is too small to further test the differences, inspecting mean scores shows that one COPD site and one depression sites did not show improvements in mean scores on this subscale. However these site and condition analyses must be treated with caution as the effects were small. (See Q2 Appendix Tables 5-14).

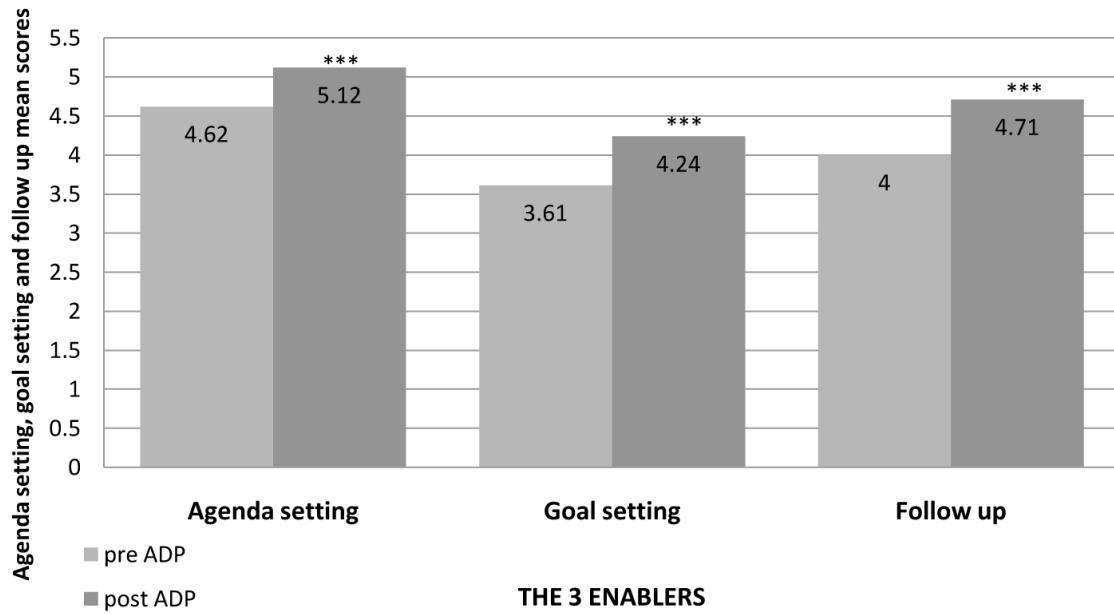
There are further reasons for caution in interpreting the findings above. With unpaired samples it is possible that those who completed the post ADP survey were more likely to be motivated to use the skills taught, to have prior training and higher skills in the areas measured before they went on the course which sustained their interest in the course and also their willingness to complete surveys. Therefore we also undertook analyses from a sub sample of clinician surveys where we could identify data paired from the same clinician before and after the ADP. The results did not reach statistical significance for any of the three sub scales in the Practices in Self Management Scale (PSMS) sub scales (Q2 Appendix, Table 15). So, while there may be an improvement in PSMS before and after the ADP, we cannot rule out that biases in the survey returns for whole samples, together with the small sample with paired data, means these are unrepresentative of all of those who completed the ADP.

2. Did the ADP increase clinicians' reported use of the three enablers?

Using both whole samples and using paired data, we had highly significant results which confirmed that clinicians used all the three enablers more often after completing the ADP training than before (Q2 Appendix Table 16 and 17). We can, therefore, be confident that attending the ADP resulted in self reported improvements in applying the three enablers. The data from Table 17 is shown in Figure 21 below.

Figure 21: Self reported changes in practicing the 3 enablers pre and post ADP

Self reported changes in practicing the 3 enables pre and post ADP - paired data



***P<.0001 (Q2 Appendix Table 17)

3. Did the ADP increase clinicians' confidence to use practices in self-management support?

We found that clinicians were more confident to use self management support after attending the ADP. This effect was shown in the smaller, paired pre and post ADP survey

sample using data from the same clinician. The effect was not shown in the larger sample of unpaired data (See Q2 Appendix Table 4 and Table 18). This suggests that confidence is improved among those who also show improvements in the three enablers but not necessarily in the wider range of practices. This may be because the ADP's most tangible focus is on the three enablers, and the impact will be greatest on those who have particularly gained the confidence to use these skills. It cannot be assumed that there will be an impact on the wider range of practices captured in the Practices in Self Management Support survey, even though many of these skills are included, albeit not strongly featured, in the ADP.

Interviews confirmed that the use of agenda setting was felt to be the most easily adopted and sustained practice.

"Since that course I've heard lots of other people talking about it and I think that there's been a stronger emphasis on, I think three things, particularly agenda setting with people" (ADP delegate, Depression site)

"(...) I think people generally seem to really like that [agenda setting] both clinicians and patients, and I think of all the skills that is the one that tends to get used. That has definitely been valuable, and that seems to be the one that...clinicians do continue with"
(Clinical Lead, ADP tutor, Diabetes site)

4. Did clinicians who did not attend the ADP show improvement in the use of practices in self management support and confidence to use these skills over the course of CCH in demonstration and comparator sites?

We analysed surveys from clinicians in CCH demonstration sites who were not directly involved in CCH activities, and clinicians in comparator sites. We found no evidence in either sample of changes in self reported practices in self-management support (See Q2 Appendix Tables 19 and 20). There were also no changes in their confidence to use self management support (See Q2 Appendix Tables 21, 22). Therefore there was no impact of CCH on clinicians who did not undertake the ADP themselves.

5. Did patients who attended consultations with ADP trained clinicians report that the three enablers were used?

We analysed pre and post ADP Patient Partnership in Care survey (PPiC) data provided by the provider of the ADP programme (CFEP UK), in the way it has been presented by CFEP UK to the programme. The training provider did not identify the patient surveys as belonging to a particular clinician; rather, they provided data to us as all returns received from clinicians who attended an ADP. This may mean the patient data does not reflect the same clinicians. Such an analysis is open to many biases, since clinicians who do not complete the course, or have negative views of the course, are unlikely to submit patient surveys. We analysed data for the first four ADP courses on each site where the PPiC was used (series A-D), which gave data as follows; pre ADP n=5420, post ADP n=1781.

We found very strong, statistically significant improvement in all areas covered by PPiC. Patients who consulted clinicians after they completed the ADP programme were significantly more satisfied with the consultation, felt well supported in their efforts to self manage their condition and confident they can carry out an agreed care plan. But the very

low response rates that clinicians achieved after they had attended the ADP workshops suggest that the returns are based on a small minority of the clinicians who completed the ADP, since using the PPiC was not possible to enforce. The data is presented in the Q2 Technical Appendix.

We also analysed data by site for series C only (the series from which there were most data). We randomly selected pre ADP PPiC survey results to match the number of post ADP returns, so we have data from the same clinician (but not necessarily the same patients) both before and after the ADP. We compared 407 pre ADP and 407 post ADP surveys. The results were very different from the previous analysis of PPiC data. An improvement was still observed on items related to the quality of the consultation, but were not observed in single items related to agenda setting and follow up (there are no items relevant to specific self management goal setting or follow up). There were also no significant improvements in patients' self confidence to manage their condition and that the clinician will follow up on plans made in the consultation (See Q2 Appendix Table 23).

There are important lessons to be learnt from these data. First that large sample sizes can give significant results for small effects which may mask important variation in response. Second, both types of analyses are open to bias from the strong possibility that clinicians who asked their patients to complete the PPiC after the clinician had attended the ADP were those most committed to the course and so more likely to administer the PPiC to their patients. We suggest, therefore, that such data is not useful for evaluating ADP course impact on patient experience of the clinician's behaviour in the consultation.

In Question 3 (Co Production Chapter) we refer to the analysis of exit questionnaires completed by both patients and ADP trained clinicians after their consultation had been video recorded which showed some discrepancies between both parties in relation to their perception of self-management support techniques being used. All patients except one reported they had experienced agenda setting, goal setting and follow up during the consultation. However, clinician reports differed from patients' reports. Clinicians reported that they used agenda setting in 30 consultations, goal setting in 13 and follow-up in only 2 consultations out of a total of 41 interactions. We suspect the differences with the patients' scores may indicate that patients do not understand agenda setting, goal setting and follow-up or that they are trying to please the clinician by rating them well on most items. This is also likely to have occurred in the patients' ratings used in the Service Improvement Programme.

We also examined interviews with patients who were part of CCH services, or attended SMPs to understand their experience of their clinician's use of specific self management support practices. We found very few examples of patients noticing specific self-management support techniques being used, and the comments made are difficult to attribute specifically to CCH. Some patients felt confident that they can obtain help and advice from their clinicians if they need it.

*"If I had a problem I'm sure I could talk to them about it and, you know, they would help me out or, and they've always not made me feel like I'm a nuisance or anything like that".
(Patient, COPD site)*

"The respiratory nurse {would} phone up and they say well you know if there's anything, we're here, you've only got to phone. I'm getting the care and attention". (Patient, COPD site).

The Bristol site reporter quoted patients who found clinicians' new consultation style incredibly helpful and in some cases life changing.

"This support has been a huge investment in my long-term well-being. Things would have been significantly worse for me without it. Thank you." (Patient, Pain site)

"Staff always kind and helpful. Appointments are focused and provide precise areas to work on and then re-visited to check progress". (Patient, Pain site)

The COPD site reporter noted that an SMP participant asserted;

"(...) their GPs now treated them differently because of self-management training. In particular, these individuals felt their GPs now provide a 'better' self-management service because they recognised the skills and knowledge {patients} now held".

Some patients noticed the clinician using specific techniques, and although this was regarded as potentially helpful to others, they did not find them useful personally

"Walk in there, set your agenda, which is sense, don't get me wrong, it's total sense, I mean I very rarely found a doctor who's strayed from the point. But there has been no need for me to go in there and set an agenda. I've never had a doctor go off the point. They're very to the point. Very accurate." (Patient, COPD site)

From both the PPiC data, clinician and patient exit measures, interviews and site reporter observations there is only very weak evidence that patients detected and responded to the practices taught on the ADP.

6. What was the experience of clinicians who attended the ADP?

Interviews with clinicians who completed the ADP showed that their attitude towards self-management changed and they became more aware of its value and meaning. For some clinicians attending the training helped them move from a traditional role of advice giving and being in control of the consultation to one of supporting patients to make decisions and take shared control.

"I once felt in discussing treatment options more openly and making sure that patients understand what's being said and allowing them more time to really explore their problems rather than, you know, me kind of saying, I've done the history, I'm going to do an exam, and this is what I give you". (T4T trainer, Pain site)

"I don't think that was a true partnership before I did ADP. I think I was still taking more of the problem solving role, and I had noticed that I had a block, and I wasn't sure how to move forward when I encountered ambivalence. Whereas now actually I feel that I have a good basic toolkit that will enable me in most settings, actually, to support the patient to self manage". (ADP clinical tutor, COPD site)

Site reporters noticed similar effects. For example, the Cambridge site report quoted a clinician who completed the ADP training.

"The first time I asked someone what they were doing to manage their health was a high point – it felt different, more relaxed, more collaborative." (ADP delegate, COPD site)

Some clinicians we interviewed indicated that attending the ADP taught them skills to make their consultations more effective.

"I had been in the NHS for ten years and I had no idea that these simple techniques existed, that it would make my practice so much more effective." (ADP tutor trainer, COPD site)

"I tried agenda setting and got the real reason from the patient why they came." (ADP delegate, COPD site)

"Agenda setting helps me focus and means that the patient feels I've listened." (ADP delegate, COPD site)

For some clinicians the ADP changed the way they feel about their practice.

"So in my sessions now, I feel that the sessions go a lot better for the patient than it used to, and I don't feel disheartened. I used to feel bad if a session didn't go well, and I used to think it was my fault, and I didn't make them change. But now I know, I have a different view on the matter. So I am generally happier in what I do, and I think my sessions are going better". (ADP delegate, Depression site)

Two site reporters mentioned clinicians being more satisfied and enjoying their consultations more after completing the ADP training. The Bristol site reporter quoted a clinician as saying:

"Speaking only about my own experience, I am very enthusiastic about this approach and have really enjoyed working in this way with my patients, so much so that after Christmas I enrolled on an 8 week module in Motivational Interviewing, which helped to further develop my understanding and (I hope!) skills". (ADP delegate, Pain site)

A depression site (SWL) site reporter quoted another ADP delegate who commented how the newly acquired skills impacted his experience of delivering care.

"The techniques {and} tools make the conversation easier. It is difficult with CMHTs as we currently do everything for clients (treatment, social care, medication etc) and that in itself is a big thing to change. In an initial assessment the ADP techniques are really useful, it allows client to be in the driving seat of their care plan". (ADP delegate, Depression site)

But some clinicians did not notice any significant changes in their practice resulting from the training.

"I don't think that's (ADP) had much effect. Or if it's had an effect, it's not an effect that actually has meant a different practice". (Dietician, ADP delegate, Diabetes site)

"I don't think my patients have benefited from me being on the ADP. I don't think they have".

(Dietician, ADP delegate, Diabetes site)

When we interviewed clinicians who had attended the ADP we found some evidence for the ADP increasing clinicians' confidence. For example, a clinician mentioned that the ADP not only had a positive impact on the way he delivered care but also enhanced his confidence to support self-management.

"I felt more confident. Asking open questions encouraged the patient to share more. You don't have to probe so much because you get more information. It kept the discussion open for longer." (ADP delegate, COPD site)

Another said: "(...) it [ADP] has taught me new skills but also allowed me to consolidate the skills and through the ADP you also learn from each other." (ADP delegate, Diabetes site)

A site reporter described an example of a practice nurse who completed the ADP together with other members of her GP team, and she noticed that the shared experience had a positive impact on her role and status within the clinical team.

"She explained how a GP would now trust her recommendations for an antibiotic for a patient, rather than repeating the home visit (as would have happened in the past). As a result, she felt there had been a flattening of the previous hierarchy that had existed in that she was now part of a cooperative 'triangle' with the GP and patient. This level of inter-professional collaboration was contrasted to those involving clinicians and patients with other long term conditions (e.g. diabetes) which she felt lacked the same degree of communication and partnership working" (Site report, COPD site).

We conclude that clinicians sampled for their opinions, via research interviews and discussions with site reporters, felt they gained from attending the ADP in both improved practices, and confidence to use them. But they often voiced concern about the lack of sustained impact on their everyday clinical practice.

7. What was the experience of ADP trained clinicians in using the 3 enablers?

We found that many clinicians found agenda setting to be the most useful and easiest to use in their consultations.

"I like the technique where you provide the patient with the agenda options that they would like to discuss and that gives them the option to say what they want to discuss, if it's not there then you give the patient the opportunity to add whatever they like to discuss, so I like that, inviting the patients to highlight what they would like to discuss. So that is something I am mindful of in my clinics". (ADP delegate, Diabetes site)

Interviews gave many examples of clinicians using goal setting.

"I say to people what are your goals for today, what would you like to get out of it. Just working with them about what their goal is, we do have a habit of setting goals for them rather than asking them what their goals are. Again it's about being very upfront with the patient saying that they have to set their own goals rather than us making suggestions and

then workings together to break down the goal to ensure the steps are achievable and realistic". (ADP delegate, Diabetes site)

"We're much more involved in trying to encourage patients to set goals". (ADP delegate, Diabetes site)

One of the site reporters quoted a clinician who completed ADP training.

"I have - on several occasions - ended up re-negotiating the goal with the patient to something they see as more achievable rather than accepting the first suggestion that they make. Prior to the training I would not have realised the need to do this. I now know that in the long term it saves time to have an achievable (if smaller) goal at the outset than to set something too challenging and renegotiate at follow-up. It is also more helpful for the patient to experience success with a small goal and build on it than to be too ambitious and fail". (ADP delegate, Pain site)

But interviews gave very few examples of clinicians using follow up techniques, and they gave no examples of SMART criteria for goal follow up.

"(...) we try to do the follow up within four weeks of having set the goals and that essentially at the moment gets done by our nursing staff over the telephone, and if in case they are not there, leave a message asking them to ring us back to just let us know how things are going". (T4T trainer, Pain site)

Similarly site reporters mentioned using the three enablers together with other communication techniques taught in the ADP. Two demonstration site's site reporters quoted clinicians who started successfully using ADP techniques during their consultations.

"It was good to consolidate and practice ideas. I use reflective listening, agenda and goal setting, ambivalence and scaling regularly. I would say it has brought about improved motivation for patients." (ADP delegate, Depression site)

"The techniques learned on the ADP are really useful in the Pain Clinic. It has helped me to formulate questions that help an individual to move forward in self-managing their condition". (ADP delegate, Pain site)

These comments also support the integration within the ADP of techniques based in motivational interviewing that may be required to support the use of the three enablers to be used effectively.

We noted that several clinicians interviewed found it difficult to apply the three enablers in their everyday practice. It is also possible these clinicians did not employ the other communication techniques taught in the ADP which are likely to make using the three enablers more effective.

"(...) but really very rarely have I felt able to goal set and goal follow-up, and I know it's an integral part of this whole initiative, but until we have the infrastructure in place to support

*that, then it's really only been a handful of times that I've set specific goals for patients".
(Clinical ADP tutor, COPD site)*

We conclude that clinicians felt they gained skills and confidence from learning to use the three enablers, but often they focussed only on agenda setting and struggled to apply the enablers in their practice. It is likely that the related communication techniques to enable productive interactions which are derived from motivational interviewing²⁹ as described in the introduction, are also required to effectively use the 3 enablers in routine consultations.

8. What was the experience of senior stakeholders of the use of the 3 enablers by clinicians?

Evidence from interviews with senior stakeholders carried out in Year 3 agreed with the findings from clinician and patient interviews and site reports. Changes in clinicians' practices as a result of the ADP were both observed and experienced in most demonstration sites.

*"(...) she's presented a number of times of how she has changed her practice. Even a simple thing like the forms she uses, she's changed all of that. So, in terms of enabling and supporting staff to make improvements in the daily practice, that's been quite significant."
(CEO, COPD site)*

"(...) for me personally it's made a massive impact, and the project has changed, continued to change the way I work with patients" (Clinical Lead, COPD site)

Overall, it seems that agenda setting was the easiest of the three enablers to implement. This finding adds to the evidence for the same finding from both clinician and patient interviews. Agenda setting was also found to be the most valuable enabler.

"(...) I think people generally seem to really like that [agenda setting] both clinicians and patients, and I think of all the skills that is the one that tends to get used. That has definitely been valuable, and that seems to be the one that...clinicians do continue with" (Clinical Lead, Diabetes site)

Goal setting and follow-up on the other hand, were thought to have more value in community settings and found to be more difficult to implement due to time constraints.

"I think that goal setting for me has been particularly valuable in the community clinic...and they actually love goal setting... but sometimes these kind of skills there is no time for them... [follow up] has possibly been valuable for maybe other members of the team...but it hasn't really changed things." (Clinical lead, Diabetes site)

Finally, there appears to be some demonstrable differences noted by senior stakeholders in clinician practices over the different sites but all of them felt there was still some way to go.

"I think we see clinicians and the services that they work in feeling much more comfortable and having a better understanding of why service user engagement, we see some evidence of them using some of their newly acquired skills via CCH to do that, but were not there yet there is still a long way to go" (Clinical Lead, Depression site)

The ADP was well received by senior stakeholders although there is also recognition that it will, on its own, have a limited impact on clinical practices.

9. What factors predict clinicians' motivation to learn about and use self-management support practices and how they have changed during the life of the CCH programme^{VIII}?

Using the same samples we used above to look at the use of practices in self management by clinicians who had not attended the ADP in demonstration sites and in comparator sites we examined job type, prior training in self management support practices, and personal motivation measures to see who is most likely to employ these practices. Answering this question may help future programmes target training more effectively.

Job related factors

We found that psychologists and counsellors, followed by nurses and professionals allied to medicine were more likely to use practices to support self management, while doctors were the least likely. We found that nurses participate in organising services to support self-management the most, perhaps because respondents were often clinical specialists in the condition in question, and had some responsibility for organising services and supporting team working. (See Q2 Appendix Table 24).

These findings were confirmed in the Year 3 samples of clinicians who did not attend the ADP at demonstration and comparator sites. This suggests that clinicians who have had training similar to the ADP will be the most motivated to use self-management support practices, even without attending an ADP. In neither of the samples was length of time working with people with LTC a predictor of using self-management support skills (See Q2 Appendix Table 25).

Psychological factors

Our analyses of surveys of clinicians in both Year 1 and Year 3 in demonstration and comparator sites found that clinicians who felt confident to provide self-management support to their patients and those who understood the value of self-management support were the most likely to engage in self-management support practices for long term conditions. Additionally, we found that clinicians are more likely to report that they currently engage in the organization of services to support self-management if they felt supported by their colleagues in their efforts to support patients' self-management and felt enabled to choose their preferred way of supporting self-management. These are psychological factors that could be enhanced in training programmes such as the ADP, i.e. by building on the pre-existing motivation and capabilities of those they offer the programme to, providing a more individually tailored programme based on the needs and motivation of the clinician. (See Q2 Appendix Tables 26 and 27).

Our analyses suggest that if resources are scarce, the ADP might best targeted on those who are least likely to be already using these practices to support self management, i.e. doctors. However, the analyses below also suggest the programme has particular benefits for some doctors, as they showed more marked gains.

^{VIII} Gender and age of clinicians were analysed as predictors of motivation and use of practices in self management support skills and found not be significant. Data was reported in the first and second annual reports.

10. Who benefits the most from attending the ADP programme?

We explored pre and post ADP surveys data to determine which clinicians are the most likely to benefit from attending the ADP programme. In these analyses we are looking for changes over time showing an “added value” of attending the ADP.

Job related factors:

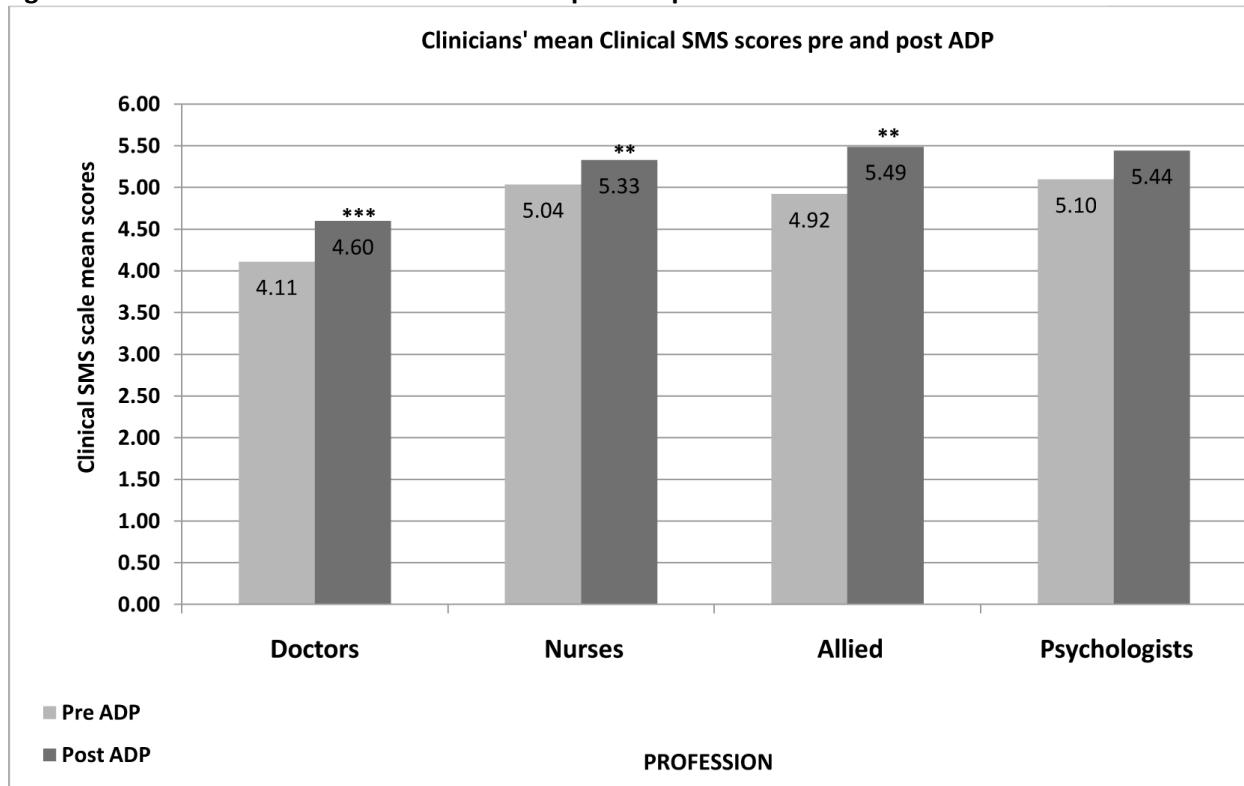
There are four job related factors we measured that may influence how people respond to the ADP. They are whether the clinician had prior experience in practices to support self management, their professional group, whether they worked in primary or secondary care or both sectors, and whether they currently spend more than half their working week in clinical roles with patients with long term conditions. Data on all four variables is presented in the appendix (See Q2 Appendix Table 28).

Because these variables may have combined effects, we present some key results by professional group only, and then look at the combined effects to identify which clinicians gained most from the ADP.

Prior training: We found that clinicians, who before starting the ADP had prior training in self management support practices, were even more likely to practice all three types of self management support after completing the ADP.

Professional Group: When examining the Clinical Self Management support sub scale data by professional group, we found significant increases for all professional groups other than psychologists. We think that that psychologists are also more likely to have had prior training in these skills may account for there being no significant increase. (See Figure 22 below).

Figure 22: Clinicians' mean Clinical SMS scores pre and post ADP

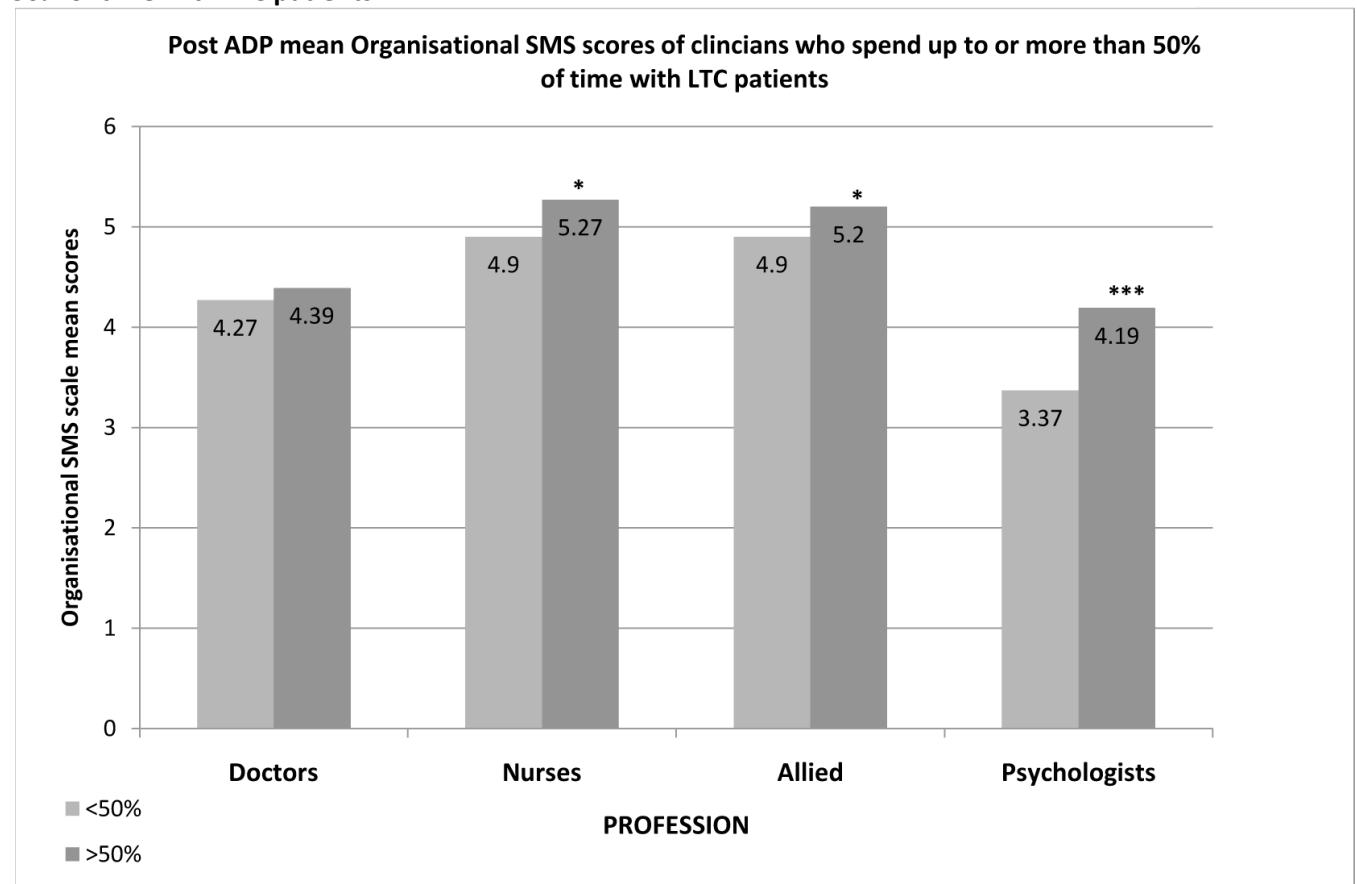


** P<.001; *** P<.0001 (Q2 Appendix Table 28)

In relation to organising services to support self management, we found all professional groups reported improving these skills.

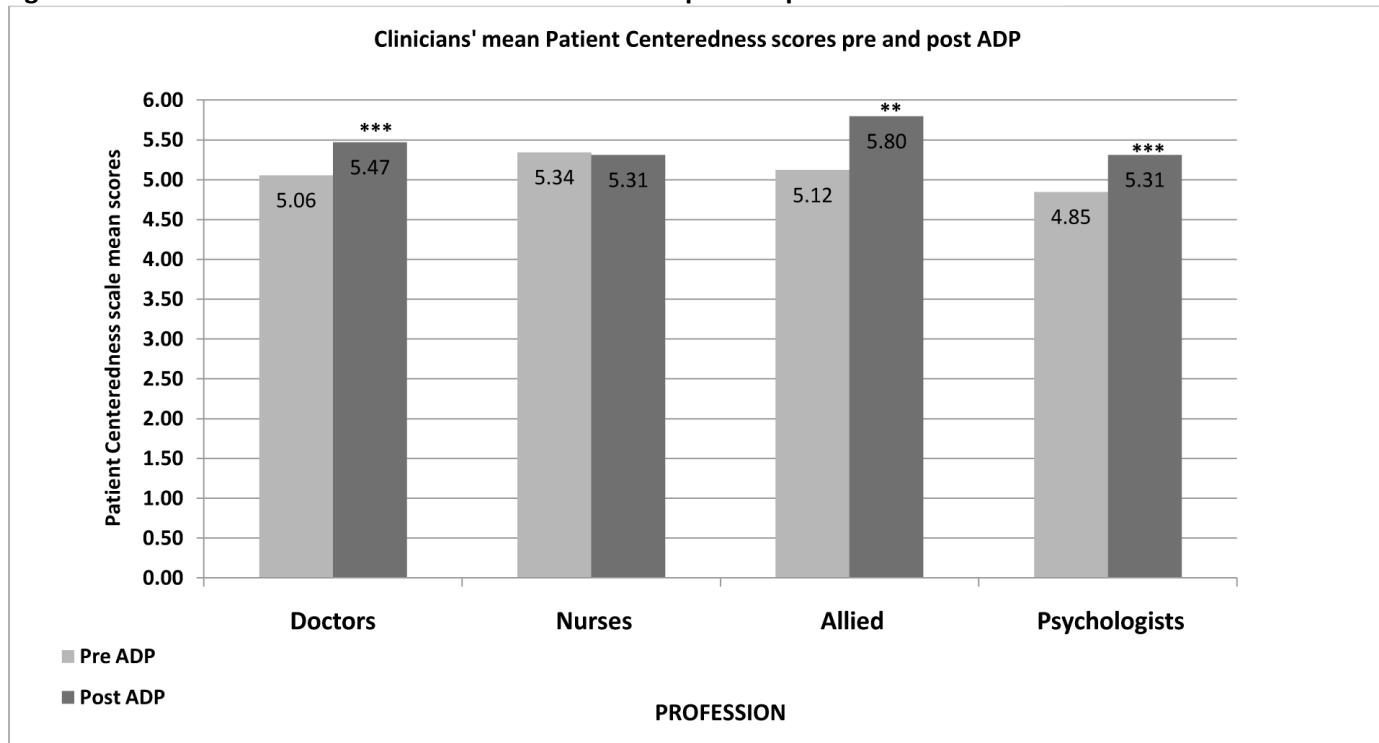
Time currently working with people with LTC: We found those clinicians who currently have more than half of their working week involved in clinical contact with people with long term conditions, more often engaged in self-management support after attending the ADP. In other words, these clinicians were even more likely to benefit from the ADP. The graph below (Figure 23) shows that where clinicians spent more than half of their working week in a clinical role supporting self management skills of patients with long term conditions, they also gained most from the training related to organising services to support self management. The importance of this finding is not apparent however, as it is likely to be linked to other variables such as lower access to prior training and professional group. (The full set of graphs is available in the Q2 Technical Appendix).

Figure 23: Post ADP mean Organisational SMS scores of clinicians who spend up to or more than 50% of time with LTC patients



We examined the scores on the Patient Centeredness sub scale which is concerned with personalising care. The results showed that, again, the doctors showed the most significant improvement, while also having the lowest pre training levels on these skills on average. For non medical professionals the gains were less, although there were larger absolute improvements for allied health professionals and small absolute improvements which were highly significant changes for psychologists. Nurses did not improve in this area; again suggesting high self reported skills already achieved before the course leave little room for improvement. (See Figure 24).

Figure 24: Clinicians' mean Patient Centeredness scores pre and post ADP



* P<.01; ** P<.001; *** P<.0001 Q2 Appendix Table 28

Care type: Looking at the place of work of the post ADP respondents, we found that clinicians who work in both primary and secondary care organizations are the most likely to engage in the organization of services to support self-management compared to their colleagues who work only in primary care or secondary care organizations. However these were most likely to be non medical practitioners and were a small proportion of the clinicians. We found there were more GPs working exclusively in primary care in the sample. Given that we have already established that doctors are most likely to have low scores on many practices to support self management, this “confounding” or double counting effect, may explain why primary care clinicians score least well on the sub scales concerning organisation of care to support self management ($\chi^2 = 51.0$, df=6, $P < .00001$).

We established that there were very strong predictive effects of pre-existing levels of use of the skills in all three subscales of the PSMS (See Q2 Appendix Tables 29, 30), and the use of the three enablers. However, we also sought to establish if there were relative gains for those who have different job and prior training characteristics prior to the ADP. This is because it is useful to know if the ADP produces similar gains for all, or whether more gains are achieved by different clinicians, and whether such variables as having had prior training would be useful in targeting resources.

In order to examine the combined effect of care type, profession, previous training, and time currently spent on direct care for LTC, we applied a General Linear Model of regression. This model tests the combined effect of all four variables on participants' pre ADP scores on the three PSMS subscales and use of the 3 enablers. We present the data in Q2 Appendix Tables 31-36.

- Using data from the Clinical Self Management Support (CSMS) scale we found that post ADP scores on the CSMS scale are strongly influenced by pre ADP CSMS scores and having had prior training. That is, those who had said they had had some previous training related to self management of LTCs prior to the ADP made greater relative gains. The non medical professionals with no previous training achieved the greatest gains from the course followed by doctors who had prior training related to self management support followed by non medical professionals with previous training and the doctors with no prior training achieved the lowest post training scores on Clinical Self Management Support. (See Q2 Appendix Table 31).
- Using data from the Patient Centeredness (PC) scale we found that post ADP PC scores are strongly influenced by baseline ADP PC score, and having had previous training, as we did on the CSMS scale above. Non medical professionals with no previous training, and working in secondary care or across the primary and secondary care sectors, showed the highest scores for patient centeredness. We think this is consistent with this group being clinical nurse or allied health specialists whose role is likely to include customising care to an individual patient's requirements. Primary care non medical professionals with previous training scored the lowest. It is possible these are mainly GP's practice nurses who often have a mixed caseload of patients, not necessarily specialising in one LTC pathway, and for whom personalising self management support is only a small part of their role (See Q2 Appendix Table 32).
- Using data from the Organisational Self Management (OSM) scale support we found post ADP outcome was only influenced by baseline scores (See Q2 Appendix Table 33). That is, those who were most involved in organising care before the ADP were also more likely to show improvements in this area of work after the ADP, perhaps because it is already within their role and skill set to do so.
- Using data from Agenda Setting (AS) scale we found baseline scores were strongly predictive of post ADP AS scores (See Q2 Appendix Table 34). We found that those who already used agenda setting were even more likely to do so after the ADP. Since there was no effect for prior training it may be that this skill was not contained in the prior training of these clinicians.
- Using data from the Goal setting (GS) scale we found a strong predictive effect for baseline ADP GS score on post course scores. Non medical professionals scored significantly higher compared to doctors (See Q2 Appendix Table 35). This is consistent with the view that training in goal setting is more prevalent in the training of non medical professionals. Again, since there was no effect for prior training it may be that this skill was not contained in the prior training of these clinicians.
- Using data from the Follow Up (FU) scale we found those healthcare professionals, particularly non medical professionals, and who had had previous training and who are working in secondary care organisations or across primary and secondary care organizations scored the highest for follow up. We suggest this effect, again, is similar to that noted on the Organisational Self Management (OSM) sub scale, as this group is likely to be clinical nurse and allied health professionals working in specialist roles in the

pathway of care, with scope to organise systems of follow up. Whereas, doctors working in secondary care organisations or across primary and secondary care organisations scored the lowest. (See Q2 Appendix Table 36).

Psychological factors

We found that among clinicians who attended the ADP, those who felt they were competent in providing self-management support before they attended the ADP were also more likely to practice self-management support before they attended the ADP. This was strongest for the Clinical Self Management Scales (which includes skills relevant to supporting behaviour change). They were also more likely to have had prior relevant training. In addition, we found that clinicians who felt supported by their colleagues and supervisors in their efforts to support patients' self-management (known as "relatedness") "and felt that they are free to chose and apply their preferred way of supporting self-management (known as "autonomy") were more likely to engage in organizational self-management support after completing the ADP training⁹³ (See Q2 Appendix Table 37). These effects are similar to those we reported above for clinicians who had not attended the ADP. Therefore the following training should be addressed by organisations seeking to enable clinicians to learn, develop and maintain these practices. Training that

- targets motivation and the factors that support motivation, such as working with colleagues who value the same skills (relatedness),
- supports the use of practices (autonomy), and
- builds a sense of competence by, for example, peer or patient feedback.

d) What are the lessons from the use of the ADP in CCH for how the training of clinicians in SMS practices be improved?

Evidence

We reviewed evidence from interviews, newsletters, and measures of patients and clinician's views at "exit" from a consultation, and site reports for evidence of how the ADP had been implemented and its suitability for application in other services as routine. (See also Themed paper 3¹⁴, and the Q2 Technical Appendix).

Findings:

Variation in the ADP to achieve sustainability

Some tutors were confident that the course had been so beneficial that it is very likely to be sustained in current or very similar form:

"(.) from the work we've done so far it has been very encouraging that our practice development unit is quite keen to work with us and perhaps look at delivering either this course or a very similar course in the future to a wider audience of clinicians". (ADP clinical tutor, COPD site)

"(...) she's [Board Member, clinician] presented a number of times of how she has changed her practice. Even a simple thing like the forms she uses, she's changed all of

that. So, in terms of enabling and supporting staff to make improvements in the daily practice, that's been quite significant." (CEO, COPD site)

While valued in all sites, there were concerns about the sustainability of the ADP courses.

"I don't know if that will be sustained, but, so I do think it is very valuable and I would like to see it continue, but again there will be issues there about how you sustain it, how you keep training tutors, how you fund it and how you recruit people onto it". (Clinical Lead, Diabetes site)

Some mentioned that too few members of clinical teams were being trained to make a significant impact on sustaining the motivation and practices of those who had been trained.

"I think as I say the difficulty for people who have done it and it's only been one or two people in the practice who have done it, they are not going to make any cultural change there, it's going to be too tough. They won't be able to sustain it, they will find it very hard themselves to sustain it". (Clinical lead, Diabetes site)

"So intuitively I think people's enthusiasm, say delivered by ADP, wanes off quite rapidly, and what we haven't got right yet is really supporting people to maintain that". (Clinical Lead, COPD site)

A comment by a COPD site project manager is typical of many comments across all sites, emphasising the need to adapt the ADP to local needs.

"You know, the flex or the inflexibility initially of the ADP was a difficult one to get around. But we've taken that on and we've worked within the scope of the project to be able to do something that's more useful and helpful for local needs more localised and will help us in the future to be able to sustain it, which it might not have been at the beginning."

Although the ADP was a manualised programme, after the first four series of workshops, sites were keen to adapt the delivery to local needs. The variations are documented in more depth in the Q2 Technical Appendix and in the Third themed paper.¹⁴

Skill maintenance and support for implementation was planned to be supported by action learning sets after the ADP. No registers of who attended were taken so it is unknown who or how many clinicians attended, and they ceased to occur after the first few series. The lack of systematic built support to maintain the skills learnt on the ADP was noted.

"That's a gap I think at the moment in our system in terms of how do we continue to support those people that have been through the training, and what we haven't done yet I don't think is set up a system for either regular updates or bringing those people together, you know, to look at results or whatever, and I think that's something we still have to work on...there will be a requirement for looking at how do we update peoples' skills and bringing people together to talk across different specialities and across

primary and secondary care to look at how they are using the Co-creating Health approach and what benefits they're having." (CEO Pain site, Year 3)

Towards the end of CCH some sites were using a form of informal personal coaching to support post ADP practice implementation, with a COPD site employing a lead tutor to conduct personal coaching as an option. This model was not documented in detail so it is unclear to whom this support was provided, and it was not employed in other sites.

"I feel now when I complete training with people, I want to go and spend four or six weeks in their practices with them and just be available as a resource for them to actually really underpin their skills and really get them confident." (Clinical Lead Tutor, COPD site, Year 3)

The ADP was designed to be delivered through three workshops of four hours each co-led by a clinician tutor and a lay tutor. Over the course of running of the CCH programme, this co-delivery model was modified to include just one clinician or one lay tutor, to a combination of two to three clinician tutors with one or two lay tutors, across the eight demonstration sites (See question 3).

Modifications in the ADP workshop structure

At some sites instead of conducting three separate, four hour long workshops, one longer session was used, or whole GP practices attended (See Technical Appendix 6: CCH Programme and Evaluation datasets). The use of actors was discontinued on some sites. An online ADP course was trialled by a COPD site just after the completion of the third year of CCH. There is good evidence that the course, with some variations, produced similar results and is therefore adaptable to the training systems of these sites. In the future use of the ADP model, capturing planned course variation and evaluating the impact of the changes could provide important learning for how to optimise training.

Each site also made some modifications of content, but these were not documented. The PPiC⁹¹ (a patient consultation exit survey developed by CFEP UK Limited), was discontinued after the first 4 courses at each site as after this point sites were required to fund this directly. Other changes included removing actors and using tutors for all role plays, including more discussion of clinicians' aims for the course and linking this to personal practice "homework" action plans.

Using measurement for improving the ADP

The data on numbers of attendees in "dashboards" was readily available to sites and used to monitor course throughput and to estimate demand for new courses (See Technical Appendix 6). Data on the characteristics of who attended or dropped out was not collected by sites nor by CFEP UK, and it is not evident that matters of drop out were actively managed, nor were there systematic methods used to find out why individuals dropped out.

Patient exit ratings (PPiC) surveys were used as part of the ADP training. They were not analysed by or for each site to give measures of improvement, although the data was presented in aggregate by CFEP UK at Forums.

The Post PPiC is key to sustaining the learning that delegates have worked so hard to accomplish throughout the series. If you are like most clinicians, you will be pleased to see that patients' experience the results of your work through improved techniques and increased patient confidence to self-manage." (Statement by CFEP UK in CCH newsletter April 2009, pg 15).⁹⁴

The use of patient exit ratings features also in the SIP and in the evaluation linked to the observation of consultations (See question 3 and Q3 Technical Appendix 3). These different measures have very different scientific properties. Drawing comparisons across the findings from the data does show that patients of ADP delegates report having positive experiences including support for self-management. However, these measures are very susceptible to bias in favour of positive ratings of clinicians given that they are administered immediately after consultations and often by members of the clinical team of the clinician themselves. We contend that the use of robust measures of patient experience, before and after a consultation, and triangulated with the clinician's ratings of the same features of a consultation, would be a very powerful measure of progress of the clinicians in learning to apply skills learnt on the ADP to consultations.

Sites did, however, make use of qualitative methods to demonstrate the value of the ADP skills, taking a "cameo" or snapshot role play approach, as a CEO from a COPD site explained

"We've actually, well I initiated a suggestion to the team, and they actually went and presented at the Board, and the way they presented it, it wasn't here's a presentation PowerPoint; it was a {Clinical Lead} and one of the patients actually acting out the conversation to actively demonstrate the very different way of approaching it." (CEO COPD site Year 3).

We suggest that in future, video tape vignettes are used in the marketing and recruitment process for future ADP courses.

Post ADP support for skills development

We describe in question 3 some of the ways that support might be provided to enhance transfer of learnt skills in the ADP to practice. Two site reports, both from pain sites, noted that some clinicians recognised the limitations of the ADP programme and planned to continue training beyond the ADP to gain further skills to support co-productive consultation skills

"Speaking only about my own experience. I am very enthusiastic about this approach and have really enjoyed working in this way with my patients, so much so that after Christmas I enrolled on an 8 week module in Motivational Interviewing, which helped to further develop my understanding and (I hope!) skills". (Written comments from ADP attendee, pain site report)

Organisational targeting of ADPs

The interviews with clinical leads showed that they did not have specific plans for the targeting of ADP recruitment; rather they sought all comers, and then moved to try to engage specific secondary care, community services or GP practices. While some achieved

whole GP practice sign up, most sites had practitioners volunteering from a number of services. A depression site undertook almost all ADP training in primary care, achieving coverage to some degree of all GP practices. Low concentrations of trained clinicians posed problems for achieving sign up to services to engage in the Service Improvement Programme (SIP), and ongoing practice of their skills as this interviewee stated:

"In the, particularly in the {Hospital} site where (Clinical Lead) is, that there's such a culture of medical paternalism, particularly amongst (his) peers, that I can't see how all the benefits of co-creation could possibly be realized or be experienced because people are only seeing one or two people who've been through the Co-creating Health programme." (Executive Sponsor, COPD site)

A further issue was the extent that clinicians felt they were unsupported by peers if they were the only person recruited from their team to the ADP, and were also not involved in SIP activities. A site report noted:

"It has clearly been difficult for (practice nurse) to sustain this within her practice, as she stated that 'sometimes the white light still needs to be switched on and the bulb changed!'

In summary, there were few attempts until midway through the programme to target specific clinicians and teams for the ADP.

Sustaining clinician tutor input to ADPs

The target of training 3 clinician tutors per site was over and under achieved across sites (See Technical Appendix 6). At times sites struggled to put on courses because of tutor drop out. Interviews with clinician tutors revealed some of the burdens placed on the few ADP tutors trained per site.

"...There's only one of her and she only does about ten hours a week so it's a bit more of a challenges. So if she gets more funding that's something we'd extend!" (Project Manager, COPD site, Year 3)

There was no accreditation of ADP training, and we comment on the possible impact of this in question 3 in relation to the quality of tutor delivery. Accreditation may also be an incentive for clinicians to become tutors. For the model to be sustained a wider pool of clinician tutors is required and processes of quality assurance of delivery put in place. The role of lay tutors in the ADP is examined in question 3, and it is notable that one site did not use lay tutors.

Overall conclusions from the question:

The ADP programme achieved the main aim of increasing the practice, motivation and confidence of a range of clinicians to support self management skills in their patients, although the evidence of these effects is greatest for the use of the three enablers.

But there was no evidence of spread to clinicians working in same pathway of care who did not attend an ADP. For programmes to achieve a widespread and habitual level of SMS, concerted efforts will be needed to get beyond those who are likely to volunteer for such training.

We also found that clinicians who had some prior training in self management support were more likely to engage in providing self-management support currently, and this effect was also shown for those attending the ADP. In a separate analysis we found that simply having had more years working with people with LTC was not a predictor of using self-management support practices, perhaps because training is required to acquire these skills if they were not part of basic professional training. It is important therefore to provide training, and to ensure training is tailored to the prior skill level of those attending the course.

We examined what job related and psychological factors are associated with clinicians being more engaged in self-management support. We found that clinicians who had previously attended training similar to the ADP are more likely to engage in providing self-management support whether they attend the ADP or not. Having already attended training would suggest they are motivated towards supporting self-management, and because they have relevant skills they are likely to feel confident that their actions will be effective. A similar relationship was found in a study by Williams and Deci⁹⁵. We were unable to collect detailed information from clinicians about the nature of prior training, to avoid response burden in completing the surveys.

We found that the sample of clinicians who attended the ADP on whose surveys we conducted paired pre and post ADP survey analyses showed both improved practices in self management, confidence to use these skills and used the three enablers more after the course. Prior training did not predict use of the enablers in the full sample. We suggest that in this more focussed sample, we are seeing a positive effect because of the combination of supportive factors. The ADP has a strong focus on the three enablers, and the impact will be greatest on those who have particularly gained the confidence to use these skills. This may be explained by these being the most motivated clinicians, and those for whom a virtuous cycle of peer support, job role, prior training and availability training on the ADP, are combined to create strong motivation for using these skills.

However, it cannot be assumed that there will be an impact of the ADP on the full range of practices captured in the Practices in Self Management Support survey in part because they are not as heavily featured in the ADP as the three enablers. Moreover, we found that psychologists and counsellors are the most likely to report before and after the training having skills to support self-management, and to use the three enablers, followed by professionals allied to medicine and nurses, particularly those working across primary and secondary care or in secondary care that are likely to be in clinical specialist role.

We are unable to distinguish the effects of prior professional training from continuing professional development. Doctors were the least likely to have CPD training to support their patients' self-management prior to attending the ADP. They are also a profession which does not feature self management support skills strongly in basic training. For psychologists, communication skills and self-management support techniques (including the

three enablers) are strongly featured in their professional training, and increasingly are a part of the skill set of nurses and professions allied to medicine when working in clinical specialist roles. Perhaps this is the reason why they report strong engagement in practicing self-management support, while doctors are more likely to have been trained to deliver care in more prescriptive ways, and their consultation times are traditionally much shorter.

Some authors suggest that successful implementation of self-management support into clinical practice is dependent on delegation of key tasks to appropriate members of clinical team.⁹⁶ Multidisciplinary teams that include nursing and AHP specialists may increasingly rely on these team members to engage in self management support tasks. This begs the question as to whether all members of the team need to attend an ADP if in practice the self management support tasks will be delegated. We would suggest that an “entry Level” course is required for all, which may be less intensive than the current three workshops of the ADP, as most successful self-management programmes rely heavily on nurses,⁹⁷ and regular team meetings where all the clinical team members get involved in planning care and setting guidelines for providing chronic care are also important.⁹⁶ Patients with long term conditions need time with their providers, regular assessments, discussion of follow up options as well as ready access to other resources to be able to effectively self manage their condition. Having specialized clinical teams where each member is responsible for providing a certain aspect of care can help to provide comprehensive care to people with long term conditions and overcome barriers associated with lack of time or lack of continuity of care.⁹⁸

We explored who benefited most from the ADP programme. Clinicians who had previously attended training similar to the ADP and who spend more than a half of their working week in direct care and contact with patients with long term conditions were even more likely to employ support self-management support practices after completing the ADP training than those who had no such prior training and less clinical work in their current role. Clinicians who are more confident and value self-management support also respond more positively to training by further increasing their practices in self-management after attending the ADP.

This begs the question of the best use of scarce training resources. Providing training such as the ADP has been shown to be most attractive to those who report already having high motivation to use the skills, already use them and have had prior training. They do, however, benefit from the training, and our analyses suggest that, taking account of their already higher skills and motivation, they gain most. But, if organisations want to increase the spread of these skills to those not already trained and using them, they will need to consider methods of recruitment, and also differentiate provision, to meet these different needs.

Analysis of interviews and demonstration site reports showed that the ADP had positive impacts on some clinicians’ awareness of the meaning and value of self-management support and changed their relationship with their patients. Many stated that attending the training gave them relevant skills to support self-management, with agenda setting being the most popular of the three enablers and considered the most effective, followed by goal setting and follow up. Some clinicians also mentioned that participating in the programme changed the way they feel about their practice and increased their satisfaction with their work. However, these interviews also showed that many clinicians found using self-

management support techniques to be difficult to apply in practice. The most commonly cited barriers were because of time constraints and lack of opportunity to refresh and consolidate new skills.

Interviews with patients showed some positive changes in the way their clinicians had delivered care, however some felt that although changes in clinicians' behaviour are probably useful to others, they did not always find they added value in their consultations, and time limits on consultations were experienced as a constraint to patients as well. The evidence from patient exit measures is very prone to numerous flaws in design and was not sufficiently robust to draw conclusions about whether patients detected and responded to the self management skills that ADP trained clinicians reported using. Senior stakeholders expressed positive views regarding the impact of CCH on clinicians' self-management support skills. However, some of them acknowledged that it is just the beginning and more work needs to be done to embed and to spread the learning from CCH to more clinicians in their sites. We explore their views in more detail in question 4.

The observation of consultations (reported in question 3) suggests that clinicians, even those most confident in using these skills, struggle to use them in practice. This also suggests that clinicians will need continued and individually tailored training to achieve confident and competent performance likely to have positive and sustained impact on their consultations with patients with long term conditions.

For the training model of ADP to be sustained, local variation in the content and format of delivery has proved successful, and further testing of models that more closely fit the training needs of clinicians and their clinical practice are key to ensuring the resource is used effectively. Building in measurement of who is recruited, their training needs, the uptake and response to course inputs, could be used to improve delivery. Building in specific support for sustaining new practices and their use in services will require the use of additional resources such as coaches, and feedback on consultation skills.

Recommendations: Question 2

We make the following recommendations for improving clinician training in self management support using the CCH ADP model.

- Training needs analyses are necessary to determine which clinicians are most likely to benefit from ADP (or similar training). This needs to target those who are suitable to attend courses similar to the ADP, taking account of prior skills already learnt in previous training, and the scope within the job role to perform the skills regularly.
- Evaluation data should be collected on who attends the ADP and with what impact to understand how to better target the ADP resource.

To build on the initial gains in competence in using SMS skills, we recommend that:

- Ongoing development for clinicians is provided, for example by coaching, to consolidate and refresh the skills developed from attending the ADP, and that the provision is based on an analysis of individual and team training needs.

- Future ADP training courses for clinicians would benefit from using well designed post consultation exit ratings by both the clinician and patient, and /or tutor facilitated feedback on videotaped consultations to enable clinicians to gain feedback on their skills.
- Provision of courses such as the ADP could test different formats of delivery e.g. including web or other e training formats, the use of audio or video feedback on consultations skills, to provide training designed to meet identified training needs and to achieve widespread uptake.
- The use of video vignettes of the co production skills applied in real consultations could be used to market the courses more effectively.
- Given the importance of team working in managing LTCs, and the boost to motivation that working with peers who are trained and motivated to also use SMS practices, it is recommended that training in SMS is targeted on whole teams and whole GP practices. However, where clinicians' roles are likely to differ in the extent of using the SMS skill in practice, as in multidisciplinary secondary care teams spanning hospital and community services, we further recommend that training is differentiated to reflect that not all clinicians need the same level of training.
- Planned recruitment, skill development and retention of lay and clinician tutors is essential to sustain the model of training.
- Enhancing the credibility of training, maintaining the quality of training delivery, including attention to fidelity of content and delivery, is increasingly managed by formal accreditation systems, which was absent in the ADP provision. We recommend that formal accreditation of ADP courses and related further SMS training is provided in future.

Question 3: Does Co-creating Health use co-productive methods of delivery? Does Co-creating Health support more co-productive interactions between patients and clinicians?

In this chapter we review the extent to which CCH supports co-production - a co-productive model being a key feature in the delivery of the programme. In addition we explore the extent to which CCH supported more co-productive interactions between patients and clinicians in the programme. We define co productive interactions to be an equal collaboration between patients and clinicians that uses the patient's experience of living with a LTC in ways that the patient is encouraged to engage in the decision making process about their own illness with technical support from their clinicians. We begin by examining the main elements of co-production within CCH, these being site delivery of the SMP and ADP courses, observations of clinical consultations and observations at national learning events known as National Forums. The chapter explores the following questions^{IX}:

- a) What is the evidence that the CCH initiative was delivered in ways that maximise co-production?*
- b) What is the evidence that the programme delivery was experienced as co-productive?*
- c) Is there evidence that the ADP and SMP courses in the CCH initiative were designed to support co productive interactions between patients and clinicians? Was co-production built in to other CCH activities?*
- d) Is there evidence that the programme resulted in observable changes in co productive consultation practices, and how might programmes support co productive consultations in future?*

This chapter begins by identifying the headline findings and goes on to examine each of the sub-questions above in more detail. We provide our discussion and conclusions at the end. See Q3 Technical Appendix for additional data.

Headline Findings

The SMP and ADP clinician and lay tutors were able to co-deliver in a style that supports adult learning by providing structure and encouraging engagement, but they were less strong at supporting autonomous decision making, and some, by sticking rigidly to the manual, delivered in prescriptive style. The lay tutors were mainly limited to being an assistant to the clinician tutor during ADP course sessions, and one site chose not to use lay ADP tutors.

Manualised delivery protocol of SMP courses, in particular, was felt to constrain the scope of clinician and lay tutor's contributions. While almost all involved in CCH endorsed the

^{IX} Service improvement activity is excluded from this analysis. See Technical Appendix 5 –Service Improvement Programme

value of the co-tutor delivery model of courses, some clinician tutors, particularly in the ADP, felt lay tutors were not credible co tutors.

The course design of the SMP focussed on self management skills with a minor part of one session with material focused on co productive consultations. The ADP course had a major focus on materials to support skills in co productive consultations. Lay and clinician co design was an increasing feature of local site activities and national forums as the programme matured.

Exit ratings from consultations tended to show patients felt valued and supported by clinicians but these measures are open to many biases. Video analysis of consultations of experienced ADP trained clinicians and tutors showed evidence of a range of co productive skills by this small sub set of champions for the ADP, although use of the three enablers was not widely evident in these consultations.

Introduction

CCH aims to transform the traditional interaction between clinicians and patients into a more productive relationship, in order to facilitate more reliable SMS. This is known as the co-production model.⁹⁹ See our Third Themed paper for a discussion of the origins of co-production and how it may apply in the context of self-management of LTCs¹⁴.

The co-production model describes an equal collaboration between patients and providers in a way that uses the patient's experience of living with a LTC in the design and delivery of services.¹⁰⁰ Co-production emphasises an equal partnership between service providers and patients in a way that patients are encouraged to engage in the decision making process about their own illness with technical support from the clinician. This is expected to enable effective knowledge transfer and shared decision making resulting in better health outcomes.^{101,102} This model requires a shift in clinician consultation style and skills from the traditional approach whereby clinicians dictate the course of treatment to a shared partnership between patients and clinicians.¹⁵ One of the aims of both the ADP and SMP courses was to teach specific skills required to practice a co-production model in consultations between clinicians and patients.

The SMP and ADP were each co-led by a clinician tutor and a lay tutor. The programme theory of CCH proposes that co-delivery may have some advantages over delivery by either clinicians or lay tutors alone. For example, it may afford new opportunities for both clinicians and patients to learn from the way the tutors can co produce the training and can readily relate the course material to their own respective roles and experiences, not least the transfer of learning to enable both parties to have productive interactions during consultations. The co-delivery model is innovative in the UK and may challenge traditional expectations of clinician-patient authority and knowledge.

The theory for ADP and SMP training is that positive comments made by the tutor about a person's ability to manage a task leads to an increase in self-efficacy beliefs in the learner. People who have higher self efficacy are more confident in carrying out their intended actions.¹³ The pedagogic theory underpinning this part of the evaluation is the Self Determination Theory (SDT)⁴² which states that the likelihood of an individual learning and

practising new behaviours depends on the type of motivation required for that action: internal or external. Internal motivation is considered to be spontaneous, autonomous and self-satisfying, whereas external motivation is usually driven by external rules, rewards or punishment or internal factors such as a person's own values and needs.

In the context of the ADP and SMP, it is important to discover if the structure and delivery style of the training are designed to support the development of internal motivation, which is fostered by learning which encourages independent thinking, provides social recognition for learning and builds a sense of competence to undertake the self-management activities by patients and supportive activities by their clinicians. These behaviours and attitudes include the SMS tools that patients and clinicians need to have "co-productive interactions" within clinical consultations as well as SMP and ADP delivery, within the LOCCHIT, clinical practice and at CCH learning events.

a) What is the evidence that the CCH initiative was delivered in ways that maximise co-production?

Evidence

We used direct non participant observation using a proven rating scale for delivery style and field notes to record the reasons for ratings and to give examples of how content was delivered (Q3 Appendix Tables 1-6). The numbers of sessions and tutors are described in the Technical Appendix 1 Table 9.

We assessed four dimensions of delivery style: *Trainers' autonomy support* is a dimension which assesses the extent to which tutors are able to encourage independent yet supported decision making within the course. *Structure* is a dimension which assesses the extent to which a tutor ensures that all aspects of the session are clear and structured and that participants' learning is supported. *Involvement skills* is a dimension which assesses the extent to which a tutor respects their participants and demonstrates understanding of their needs. *Participants' engagement* assesses the extent to which participants get involved with the session and actively engage with the exercises.

Findings

Results from observation rating scale and field notes

As can be seen in Figures 25 and 26, motivational styles of delivery by clinician and lay tutors were similar on both the ADP and the SMP programmes (See Q3 Appendix Tables 1 and 2). It was found that both types of tutors were more skilled at providing structure (example from observation notes: "*tutors kept them focused on the topic*") and encouraging engagement: ("*tutors were successful in engaging quieter participants*"). Tutors less often demonstrated encouraging autonomy ("*tutors took negative feedback on board*") and using interpersonal skills ("*tutors were pleasant, welcoming and encouraged participants to join in*").

Figure 25 Motivational styles of co-delivering ADP courses by lay and clinician tutors

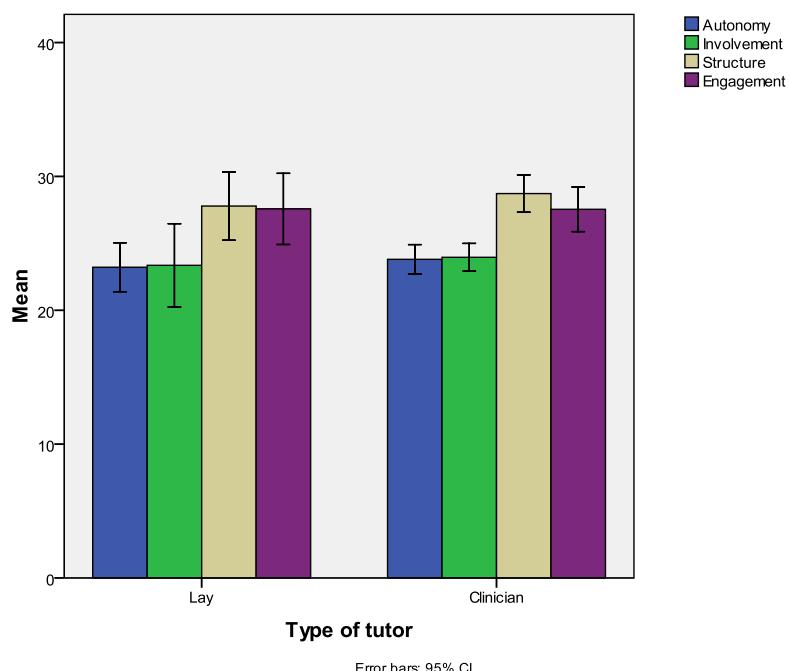
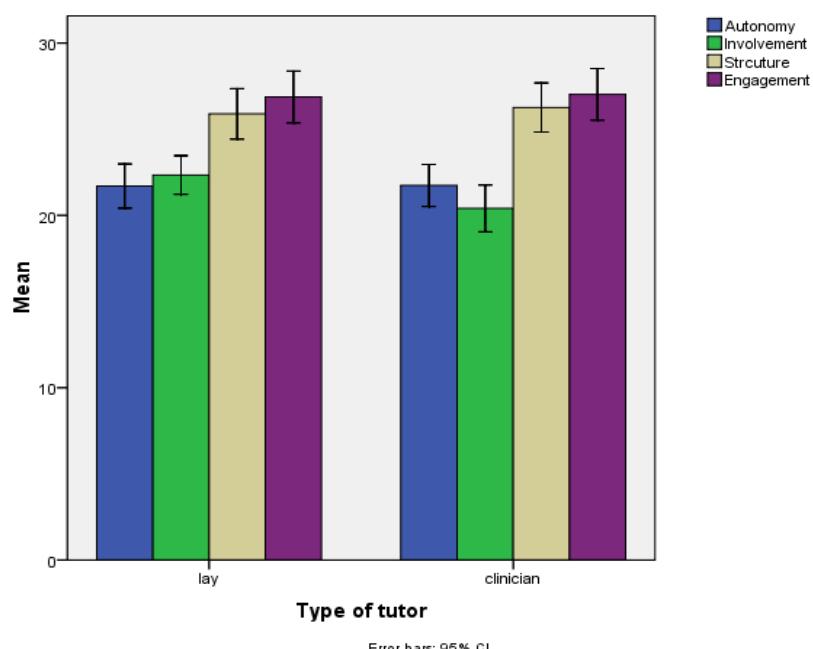


Figure 26 Motivational styles of co-delivering SMP courses by lay and clinician tutors



Considering the results across both the ADP and the SMP courses, we found both types of tutor were more skilled at providing structure to the session by laying down clear instructions and engaging participants than they were at encouraging independent decision making and recognising the needs of participants (Q3 Appendix Tables 3-6). These skills are also important in co-productive consultations, which suggest that tutors were not as strong role models in this respect as they were for the more directive aspects of providing structure and engagement in the session.

Results from observation notes

Observation notes were also recorded to reflect on the extent of the sharing of power and responsibilities while co-delivering the SMP and ADP courses. At most sites, it was observed that the lay and clinician tutors undertook shared and different roles which seemed to work well:

"The lay and clinician tutors worked really well together, their delivery style was well rehearsed and structured, {and} they also knew their roles very well." (Observation notes, ADP course, Depression site)

"Most of the session was led by lay tutor however the medical bits which was about what diabetes is etc. were led by clinician tutor, who also answered all the medical related questions that were asked however the lay tutor discussed lifestyle changes and adjusting to life with diabetes. The dynamic between the two tutors worked really well." (Observation notes, SMP course, COPD site)

However, at some other sites, it was observed that the lay tutor's contribution seemed to be mainly confined to briefly sharing of their personal experience of living with a LTC while the clinician tutor lead most of the sessions.

"The lay tutor helped with collecting some thoughts on the paperboard and was around for questions but she did not have a visible role in delivering the workshop. It appears to me there was an understanding she would help with administration tasks and talked about her experience briefly. As from her role in the training, my impression was that the lay tutor could or could not have been there." (Observation notes, ADP course, Depression site, Year 2)

Tutor reflections on their delivery style

The SMP and ADP tutors were trained, and in the case of SMP, underwent accreditation, during which they had feedback on their delivery of course material. Both processes were commented upon in interviews with tutors and tutor trainers.

"Some of the feedback that we've had when we first delivered the programme...it wasn't keeping with the ethos that we're trying to get over. So for example it was very much, you know, us standing up there giving lectures and slides and presentations which...which was foreign to the audience who were being taught approaches to be much more collaborative, but we weren't actually being collaborative in the way we were delivering the programme" (Interview ADP tutor and trainer COPD site)

"I think the only thing that I liked is it would have been useful to see a course before I had delivered it" (Interview ADP and SMP clinical tutor, Diabetes site)

We concluded that opportunity to observe other tutors deliver courses, and to be given explicit feedback on delivery style was not formalised in either course.

Summary

The SMP and ADP clinician and lay tutors were able to co-deliver in a style that supports adult learning by providing structure and encouraging engagement. They were not as strong

at encouraging autonomous decision making and nor were they as strong at encouraging involvement by respecting and responding to participants' needs. Some tutors seemed to adopt a directive and prescriptive delivery style by strictly following the course manual that lacked enthusiasm, responsiveness and clarity.

The lay tutor's role was observed to be mainly limited to being an assistant to the clinician tutor during ADP course sessions. Tutors had little opportunity to reflect on their delivery style, except when being accredited for the SMP, and some felt this focussed too much on fidelity of delivery not on the co-productive style of tutor delivery.

Manualized delivery protocol of SMP courses is perceived by some clinicians and patients to limit the scope of their respective contributions (See question 1). All tutors, attendees, senior management staff and patient members of LOCCHITs endorsed the value of the co-delivery model in principle, with exception of one site.

b) What is the evidence that the programme delivery was experienced as co-productive?

Evidence

We conducted interviews with the tutors of the SMP and the ADP courses, attendees, senior management staff and patient members of the LOCCHIT at eight demonstration sites to elicit perceptions and experiences of the co-delivery model in SMP and ADP courses and more broadly to enquire about the extent of additional patient engagement at sites such as LOCHHIT and national forums during the course of the CCH initiative. We also present extracts from site reporters' (SRs) reports that provides another perspective of co-production in action.

Findings

Co tutor delivery of the SMP

We found that many SMP tutors valued the presence of lay tutors who provided insight into the patients' side of the story and served as a good role model for an expert patient in the SMP courses.

"It was demonstrating the role-modelling of how as a patient you can work with a health professional." (SMP lay tutor, Diabetes site)

"Well I think they're like a role model really. So I think if they are enthusiastic about self-management and about how it has benefited them then that can be a real inspiration." (SMP clinician tutor, Pain site)

"A health professional explained how they value the experience, the time volunteered and the unique contributions from the lay tutors" (Site Report, COPD site)

Similarly, the presence of a clinician tutor was also viewed as an invaluable and trustworthy source of clinical information by both the SMP lay tutors and SMP attendees.

"If I wasn't co-delivering with a clinician tutor, I will question the course content and worry whether recommended practices in the course are medically accurate. I mean I was more confident in learning and teaching new ways of managing my condition, since a clinician agreed with them too." (SMP lay tutor, Pain site)

Clinician and lay tutors, SMP patient attendees, LOCCHIT patient members and site reporters expressed many more positive than negative views about the co-delivery model for the SMP, indicating that they believed that it created a balance between tutors in SMP course.

"I mean you have two parts of the equation, which is the lay tutors are bringing to the table living and experiences, their lives with the long term condition. Then you have the health professionals bringing the know-how and their medical knowledge, it was perfect fit." (SMP lay tutor, Diabetes site)

"Well, one is the health care professional she could do the mechanics and the bones of the thing, and the other one had it, so it worked perfectly well." (SMP attendee, COPD site)

"I think it's (co-delivery model) very; very important to show that actually there isn't a barrier between the health professional and the patient that they can communicate with each other well. So role modelling that I think is really important." (LOCCHIT Patient representative, Depression site)

"Co-working of SMP Tutors was viewed as a positive experience with an equal power basis. There was a sharing of roles, decided by who was the best person to do the job and deliver the required information." (Site Report, Pain site)

We found evidence in the responses of the SMP lay tutors for appreciation about the concept of co-delivery model and challenges that clinicians might face.

"I can see the other side of situation better now, clinicians are also humans and since they have so many years of training, it is difficult for them to change" (SMP lay tutor, COPD site)

Lay tutors of the SMP courses were initially hesitant about sharing power with a clinician, but felt at ease gradually with the benefit of positive experience.

"I'm sure there were discomfort in the early days about how things were going for them personally – I think that's normal, it's a big thing to do. Both of them coped well I think and I think all of the lay tutors now are a lot more confident than they were when they started." (SMP Tutor, COPD site)

Although highly valued, learning to work as equal partners was perceived as challenging by some SMP clinician tutors.

"I've found that challenging at times to let things go and to, yeah, just let it go and accept that that's part of working in partnership as it were." (SMP clinician tutor, COPD site)

"It did feel a bit unnerving, as you start to question, what is my actual work role here? I am used to more autonomy and having my judgements respected by others." (SMP Clinician tutor, Pain site)

We heard that SMP clinician tutors found the SMP course delivery to be too dependent on following the manual and that there was little scope for any specialist input as a clinician. At one site the SMP clinician tutor, the SMP lay tutor and the SMP participants also felt that a clinician's clinical expertise was not made relevant to the course content.

"I'm not convinced that actually I've really contributed a huge amount that couldn't have been contributed by somebody who personal experience of COPD, as SMP manual had told you everything." (SMP Clinician tutor, COPD site)

Co-tutor delivery of the ADP

Clinician tutors were positive about the role of clinician tutors in the ADP, since this is the traditional mode of clinician training delivery. Broadly, we found that ADP Clinician tutors also valued the presence of lay tutors who provided insight into the patients' side of the story and served as a good role model for an expert patient.

"I'm aware that the patient co-facilitators have an important role I think in these courses, I think they add credibility and they add an experience that clinicians themselves can't add because they're giving the other side of the picture" (ADP Clinician tutor, COPD site)

We heard that some clinician attendees and tutors of the ADP asserted the need for better training of lay tutors, as they believed that lay tutors lacked presentation skills and confidence of the standard an ADP tutor should have.

"I suppose the other thing that would improve the experience is any improvement in the co-facilitators, so if, you know, the better the quality of the co-facilitators the better the quality of the presentation, and the better the quality of the whole ADP experience." (ADP Clinician Tutor Diabetes site)

"The observation that I have made is that the lay tutors that are there don't have the experience to do that (co-deliver in ADP), they are out of their depth and it affirms the health professional's views so I think that it has a reverse effect." (ADP Clinician Tutors, Pain site)

Lay tutors of the ADP courses were initially hesitant about having a co delivery role with a clinician, but felt at ease gradually with the benefit of positive experience.

"Well I'm more comfortable with clinicians now, in the initial stages, you know, a doctor and such like were people, well in the old fashioned type, you looked up, but then working with them." (ADP Lay Tutor, COPD site)

"I felt, apprehensive is the word, all those clinicians and GPs sitting there and what threw me the first time was when I went round the room to see if you can help and I was asked "what are you doing here, we can manage this ourselves" and that kind of threw me a little bit. Well I spoke to Dr [name removed] and I said to her "look, I don't understand why I'm here because I've just been told..." and they said "look, the patient has a powerful voice, you have to be here". Now I've actually been one, two, three, four, this is series four we're doing, I feel

great now. The clinicians I'm working with. They accept me as a colleague, and they're asking me to do part of the programme." (LOCCHIT Patient Representative and ADP lay tutor, Pain site)

One site chose not to train lay ADP tutors. The first three series (A-C) was co delivered by an experienced EEP tutor. Our non participant observation, site report and interview data showed that her input was mainly to tell about her journey from a patient's perspective, and to facilitate an exercise about agenda setting exercise with actors. Clinician tutors understood and appreciated the benefits associated with co delivery model, however they did not consider it necessary to successfully deliver the ADP.

"I mean it's absolutely true that the patient's perspective is necessary in understanding the benefits of these approaches, but a lot of the time clinicians bring the stories that really bring the patient's perspective. I wouldn't say it's necessary, but I would imagine it's, I would anticipate it's beneficial" (ADP clinician tutor, COPD site)

They were convinced that due to the nature of skills taught on the ADP a lay person's input was not vital.

"I've seen the impact it can have to have patients or lay individuals in a room, and it's generally very positive. But in the end we are here teaching a skill set, and that's what it's about, and I would anticipate that ADP tutors with or without a lay tutor can deliver that". (ADP clinician tutor, COPD site)

"I don't anticipate we would find a lay tutor who'd be able to bring the same skills. So I do not expect it to be equivalent input from both". (ADP clinician tutor, COPD site)

There is very little research to support the comparative value of co tutoring in clinician training in SMS in LTC, so future programmes could usefully contribute evidence by systematically evaluating new models of delivery.

Summary

Clinician tutors found lay tutor delivery added credibility to the course content of both the ADP and SMP by sharing real life coping experiences and lay tutors and patient attendees valued the clinician tutor as a source of medical knowledge. However, some clinician attendees and clinician tutors felt a limit should be defined for the patients' role in consultations, which underpinned their reservations about co tutor delivery. Similarly, some patients found it uncomfortable to share the tutor role with clinicians, possibly reflecting their views of the unequal power relationship traditionally experienced with clinicians.

We found clinician tutors valued co tutoring the SMP but also questioned if their contribution was value for money. Given there is no evidence from research worldwide supporting the greater effectiveness of the clinical, lay co tutor role in the SMP, or that clinicians achieve better outcomes than lay tutors¹⁰³⁻¹⁰⁵ and the concern raised by some clinician tutors as to the value for money of their role, alternative models could be explored that harness both sets of perspectives but without co tutoring by clinicians at every session.¹²

We found that lay tutors varied considerably in their confidence and delivery skills, and many were uncomfortable in this role initially. Some experienced negative comments from clinician tutors about their contribution in both programmes. This suggests they would benefit from more tailored support and development, and possibly direct payment to reinforce perceptions of the value of their role.

Clinicians assumed that they alone would be tutors on the ADP, and they had some difficulties adjusting to co tutoring with a lay tutor, in part because of perceptions that lay tutors do not have the relevant skill set and knowledge to speak beyond their own experience- hence the lay tutors were constrained in this role. Some clinician tutors also voiced their discomfort with sharing clinician's experiences of their work with their patients with the lay person. These views were reported in more depth in our themed papers.^{41,106}

c) Is there evidence that the ADP and SMP courses in the CCH initiative were designed to support productive interactions between patients and clinicians? Was co-production built in to other CCH activities?

Evidence

We systematically coded ADP and SMP manuals to identify the content relating to encouragement of a more active and involved role of patients in decision-making about management of their LTC. We undertook interviews and observed LOCHITs and national forums.

Findings

Co production in SMP and ADP course content

It was found that all three sessions of the ADP course explicitly and consistently emphasised the need for a shift from a directive approach to a more equal partnership between patients and clinicians. This is also evident in the extracts from the manual below:

"Traditional vs. collaborative interactions – Information and skills are taught based on the clinician's agenda vs. patient and clinicians share their agendas and collaboratively decide what information and skills are taught". (ADP session 1)

"Traditional vs. collaborative interactions – decisions are made by the clinician vs. decisions are made as a patient-clinician partnership". (ADP, session 1)

"Skills taught: support independence and choice in patients, explore ambivalence, i.e. negative affect, perceived barriers/challenges to a healthy and active lifestyle, try and elicit reasons for change, reasons not to change, use empathy and reflection to help patients feel accepted and respected." (ADP session 2)

"Ask before advise, problem-solving, ask about plan". (ADP session 3)

The SMP course is primarily concerned with general self-management behaviours and techniques. As described in question 1, 20 minutes of two role plays in Week 6 had discussion about an equal, honest and open relationship with the clinician and demonstrating how patients could be pro-active and initiate discussion about making self-management decisions.

"Any consultation with a health professional is a two-way process. The health professional brings their clinical expertise and the patient brings their personal experience of living with their condition and how it affects their life." (SMP session 6)

Co production in site and national programme activities:

We found that patients participated with varying degrees of activity in co-delivery of the SMP and ADP courses but patients often took on multiple roles in CCH, from being SMP attendees, to lay tutors, to being the patient members of the LOCCHIT and part of the site team at national Forums. Therefore there were opportunities for co-production.

Many patients reported feeling uncomfortable and unsure about their precise role in formal meetings and at the Forums. They also found understanding of jargon, which was prevalent, to be socially exclusive.

"Yes, locally I am involved with the sustainability of CCH within the {site} and I'm getting involved with the committee meetings who are talking about marketing and sustainability and moving CCH forward when we finish up at the end of this year. I also did the National forum in 2009 and I'm booked in on the 2010 one. I also went for sister site visit to look at how they are getting on, what they're doing so I feel I am quite involved with it in actual fact. I feel it's not only being the tutor I think I am contributing to the whole thing." (Site Reporter, Pain site)

"When I first came onto the LOCCHIT I felt a little bit overwhelmed as there were a lot of acronyms being thrown around and it was going over my head, and I was beginning to wonder whether I would actually be of any value on the LOCCHIT but that was very much in the initial stages, once the LOCCHIT actually got going, I found that actually my opinions were highly valued and, responded to and in fact my opinion was sought on a number of different issues." LOCCHIT Patient Representative, Diabetes site)

The five national forums were planned from the outset to include patients from sites as well as patient/ lay experts as guest presenters. The extent of lay involvement in planning and in the events themselves was greater in each subsequent forum as the design team learnt from observations and evaluation feedback from each event.

Summary

All three sessions of the ADP course have content support co productive consultation. By contrast, we reviewed the whole SMP manual and found in only one session (Week 6) there to be material explicitly designed to teach the skills and knowledge necessary for increasing equal and productive relationships between patients and clinicians. The site level LOCCHIT and the National Forums all had patient involvement built into the design, and patient involvement increased throughout the course of CCH in programme design and delivery at site and national level. Patient representative at all eight sites felt welcomed and valued at LOCCHIT meetings and CCH national forums. However, in the initial stages they were sometimes perceived as uncomfortable and too clinician focussed and led.

d) Is there evidence that the programme resulted in observable changes in co-productive consultation practices, and how might programmes support co productive consultations in future?

Evidence

Patients' experiences of consultations with clinicians were assessed through exit measures, and there was an evaluation team measure of co-production used which applied in our analysis of videotaped consultations using published questionnaires.^{107,108} The PPiC was used by the ADP as an exit questionnaire and reports were provided to ADP attendees before and after a clinician completed the ADP course, which assessed the degree to which a clinician employs skills for co-creation during the consultations⁹¹ (See question 2).

The post ADP PPiC returns can be said to reflect consultations experienced by patients with ADP trained clinicians. The evaluation team measure compared patients' perspectives on perceived empathy, enablement and the presence of the three enablers during a consultation as experienced by the patient. The evaluation team measure was completed by the clinician after the same consultation and all but five consultations were with ADP trained clinicians or clinician trainers of the ADP.

We video-taped 44 consultations of ADP trained clinicians and tutors with their patients, some of whom had attended an SMP, to investigate the extent to which clinicians' consultation style had changed towards a more equal partnership with their patients. Using a coding system for verbal content, we looked for evidence of clinicians and patients using the self-management support techniques.

Findings

Results from PPiC and exit questionnaire data

In Q2 Appendix Table 23 we present PPiC data, and Q3 Appendix Tables 7-9, we show the evaluation team's exit data, and in Q3 Appendix Table 9 we compare the two as they relate to the three enablers. PPiC data shows patients who consulted clinicians after they completed the ADP programme were significantly more satisfied with the consultation, felt well supported in their efforts to self manage their condition and confident they can carry out agreed care plan. The ADP used the PPiC as a measure of patient experience of co-productive consultations. However, the items do not closely link to the three enablers. (See Q3 Appendix Table 9). There are two items which appear to measure agenda setting but none are closely related to goal setting and action planning by the patient or goal follow up, rather, there are items that are more general such as "*follow up on your health care from your last visit*"- which is not specific to self-management goals. The confidence ratings do include reference to confidence to carry out "*what you and your doctor/health professional planned today*", but this may or may not relate to self-management goals. It could include agreeing to go to see another clinician for further diagnostic tests.

We conclude that the PPiC data is not suitable for measuring whether the ADP resulted in more co-productive consultations as experienced by patients.

The exit measure used by the evaluation team included items designed to capture the patient's experience of the three enablers. In these "expert" consultations, the patients rated the three enablers to be present in almost all consultations, but clinicians reported an agreed action plan, goal setting and follow up being present in about three quarters of the same consultations (agenda setting and goal setting), i.e. less frequently, and their ratings of the quality of the consultation and impact on the patient was lower than the patient's assessments (Q3 Appendix Tables 7 and 8). It is possible there is a bias towards agreement by patients in all such data, which are compared in Q3 Appendix Table 9. We discussed in Question 2 the problem of positive bias in patient self report exit measures, which also applies to the SIP measures.

A more objective method of assessing the nature of co-productive consultations can be obtained from systematic ratings of video tapes of consultations. We present selected sections to illustrate the use of co productive skills, across a range of consultations with patients with differing, and sometimes co-morbid conditions.

Observation of the use of the 3 enablers in consultations

We found evidence for clinicians eliciting the agenda for the current consultation. After the initial greeting and the patient's description of symptoms, in one example the clinician asks:

"Alright. Let's think this through then. And what do you want to get out of today? Have you kind of come in thinking, well I want to talk about this, I want to talk about that or are you thinking, well I'm a bit unsure about where to go?" (Pain management consultant, National support team)

We also observed evidence of clinicians exploring the patient's priority:

"Alright, then, what do you want to start with? The hypo? The sugar climbing higher" (Specialised diabetes nurse, Diabetes site)

We observed clinicians exploring the importance of the change the patient wants to implement (using a confidence rating scale):

"When you actually think about coming along to the class on a Thursday, how confident do you think you will be able get there and be part of the group, if there was a scale, where zero is, there's no way I'll manage it, and 10 as, oh no, I think I can definitely come along and take part. What number would you give me?" (Physiotherapist, COPD site)

The same clinician, during the same consultation, using the scale, explored the confidence the person had of implementing the change successfully

"How confident are you that you could do that? If you think about confidence on a scale of 0 to 10, where 0 is not confident at all and 10 is super confident?" (Physiotherapist, COPD site)

He also facilitated creation of SMART goals and supported the patient's problem solving by asking about their own ideas.

We observed an example of the clinician suggesting using methods to follow up an action plan that was created collaboratively

"Good, so I'll look forward to seeing you at the class, and we could just take things from there. If there are any problems in the meantime, you know where I am, just give me, my phone number is on the back, just give me a shout". (Physiotherapist, COPD site).

Observation of the use of additional co productive skills in consultations

We examined the video tapes to look for other skills that support co productive consultations commonly taught in communications and motivational interviewing courses.

Specifically, we found that clinicians attempted to encourage patients to express their preferences and perceived barriers to self-management of their LTC.

Video extract of consultation between ADP trained clinician and patient with diabetes

C: What is the biggest commitment for you?

P: Well, I would obviously want to lose weight and I want to control my diabetes better, so...

C: You want to do both?

P: Yeah.

We found evidence for clinicians directing the patient's attention towards positive achievements in their self-care of their condition.

Video extract of consultation between SMP clinician tutor and patient living with COPD

P: I watch my two grandchildren on a Tuesday, where before I used to run about and play with them, I try to look after a three year old and a six year old and I can't run about anyway. I'm trying to play board games and things to keep [unclear].

C: What I'm hearing from that is there're two things. One is that maybe your exercise tolerance has dropped a little, but the other really good thing is that you've modified your activities, which is a really good.

We found evidence for patients engaging in open, confident and pro-active conversations with their clinicians about future self-management of their LTC. We give three examples below.

Video extract of consultation between SMP clinician tutor (and ADP trained) and patient with COPD

P: (laughs) I can't think, I always like baking, which I used to be able to be, I would say I couldn't do anything physical, because anything like that (P makes rotating movements with her hands) I've got to, you know, mix up, anything's a bit more strenuous, I feel this is such a drawback

C: yeah yeah

P: whether you can help me with this side of it it'd be great, something that you can tell me what to do so I can get in that, you know

Video extract of consultation between ADP trained specialised diabetes dietitian and patient with Diabetes

P: I really, no, no. I really don't. The way I am, is, basically, whatever is there, is there. You live with it, kind of thing. That's the other person. I don't think about what's going to happen this afternoon. What I do is to live now. Why worry about tomorrow?

C: Do what you're interested in this minute and that's it.

P: That's it, yeah. That's the way I am, whereas she thinks long-term, so.

Video extract of consultation between ADP trained specialised diabetes dietitian and patient with diabetes

P: Because indoors I have Shredded Weetabix and Shredded Wheat indoors so or Special Ks now that it's cheap. I do have them cereals indoors, in fact, all the time. I haven't got the milk to, because I don't buy the milk so much now. I'm just wondering if I have the cereal, does it mean I'm going to have more milk. Am I going to start, be tempted to start the milk again? Nah, I wouldn't like, we'll see. I won't do that. I love my herbal tea. I really do.

C: Okay, alright then. Should the change be then that you're going to have cereal instead of bread in the morning?

P: Bread in the morning, right. And I'm confident; I'll be an 8 on that. I'm definitely confident I'm going to do that.

It was found that clinicians used skills of empathy in a friendly manner to help support the self-confidence of patients to use their preferred ways of managing their LTC.

Video extract of consultation between SMP clinician tutor (and ADP trained) and a patient living with COPD

P: I always feel better [after napping], but I'm afraid it is not like I sit there doing nothing

C: and then you don't want

P: I don't want to do that [nap in the afternoons and doing nothing]

C: so maybe have some power naps is a way you can manage as well, and I wouldn't feel guilty about that, a lot of patients come out and when they do have a nap in the afternoon, they feel really bad about it, don't feel bad

P: I know (laughs)

Clinicians adopted an open approach characterised by unconditional acceptance of and respect for the patient, carefully directing the patient's attention towards sources of ambivalence about the behaviour including the potential harmful consequences for their health.

Video extract of consultation between SMP clinician tutor and a patient living with COPD

C: That's one of the benefits you're getting from smoking, is there any other benefits that you get from smoking?

P: I think it kind of calms me down a bit.

C: So you use it for stress as well?

P: Aye, probably, uh huh.

C: What are the downsides for you, smoking?

P: Obviously, it's normally on my chest, I know it's not going to get any better, I'm going to get worse as I get older, but obviously this making it happen quicker than it should happen obviously.

C: So it sounds like you're in a difficult situation then doesn't it, that on one hand you know the benefits of stopping, but the other hand you're using the cigarettes to help with stress, and you also feel that it can help even get the phlegm up, yeah?

P: Uh huh, it is because it puts you into a fit of coughing, so that brings it, I know it sounds silly and I'm stupid, but that's me.

C: No, I don't think you're stupid, I just think you've got in a difficult place just now. But maybe, where some chest techniques, we can show you alternative ways.

We also found that clinicians encouraged patients to join in with decision-making about care of their LTC by inviting suggestions from their past experience. We give two examples below.

Video extract of consultation between ADP trained specialised diabetes nurse and patient with diabetes

C: Is there anything that you would use in that sort of situation?

P: Sometimes I just use that, have a slice of bread and that seems to be okay when I've had sort of semi dodgy one before. Or even eat cereal because I've always got cereal. I might have eaten cereal.

C: Yeah, yeah. I mean, those are good things. We usually advise that you start off, though, with something a bit quicker, a bit quicker absorbed, to bump your sugar up quickly and then to have something like bread or cereal.

Video extract of consultation between SMP clinician tutor (and ADP trained) and a patient living with COPD

C: well what have you found it helps?

P: very little when it starts, just oxygen

C: just oxygen?

P: Hmm

C: yeah, I think oxygen but also stopping the activity that's made you breathless, and is there any position you've found better than others in terms of when you get?

P: Sitting up, standing straight

Organisational support for co-productive consultations

Interviews showed that some clinicians found the skills to be a useful extension of their current skills, particularly if it fitted with their philosophy of care.

"I had been in the NHS for ten years and I had no idea that these simple techniques existed, that it would make my practice so much more effective." (ADP tutor trainer, COPD site)

"I really enjoyed the course and the three days that I was there, and it did teach me new skills. I was never a clinician that would tell other patients to do this, do that, I always knew that wasn't the right way to do it. So again, because I was aware of self-management previously, but I never had practiced it myself or was confident to do it, do going on the ADP course helped a lot" (ADP delegate, Diabetes site)

"(...) my philosophy, my approach has not changed, but the way that, but the techniques that I've learnt have definitely helped, really helped". (ADP delegate, Pain site)

More fundamentally, some felt they not only learnt skills but also changed their approach.

"It used to be, this is what I prescribe for you and this is what you're taking. I mean now I have started actually setting the agenda with patients, really trying to find out what is it that's important for them and in first place, you know, they don't all necessary just come for the pain and often that leads to completely different avenue, you know, which has got nothing to do with pain". (ADP clinical tutor, Pain site)

But some clinicians felt there had been no impact of attending the ADP on their consultation practice.

"I don't think that's (ADP) had much effect. Or if it's had an effect, it's not an effect that actually has meant a different practice". (ADP delegate, Diabetes site)

"I don't think my patients have benefited from me being on the ADP. I don't think they have". (ADP delegate, Diabetes site)

Some tutors stressed that the ADP is only the beginning of change process and to achieve sustainable results the learning has to be continued.

"I also learnt that it isn't that easy to change. I think it's very important to understand that you can't expect people to go and change their years of practice. Also the learning that came with it is that it can't be done in three half days. It's a whole different style. But in these three half days if you could motivate people enough to change and to find out and pursue with it then that's a start". (ADP clinical tutor, Pain site)

Finally some clinicians, even towards the end of CCH, stated that the way services are designed hampered their ability to provide self-management support on regular basis.

"(...) but really very rarely have I felt able to goal set and goal follow-up, and I know it's an integral part of this whole initiative, but until we have the infrastructure in place to support that, then it's really only been a handful of times that I've set specific goals for patients". (Clinical ADP tutor, COPD site)

Summary

We found that the PPiC data was not suitable for evaluating the experience of patients' views of consultations. Evidence from the evaluation teams' clinician and patient exit measures also showed a positive bias by patients to rate the presence of the three enablers when neither the clinician's rating nor direct observation showed they were present. Patients were highly likely to report that they were supported to manage their condition, however all patient reported measures in these contexts are likely to be biased towards showing such favourable results. Experienced clinicians (ADP tutor trainers) provided more conservative ratings of the impact on patients of their co-productive skills, which suggests caution is needed in interpreting exit measures as an outcome of programme activities in CCH.

Consistent with findings from PPiC and exit questionnaire data, videos of consultations of experienced ADP trained clinicians and tutors have also shown an open, friendly, warm and honest relationship between clinicians and patients. Patient's views and preferences were valued, welcomed and encouraged by these experienced clinicians, but use of the three enablers was not widely evident across the 44 consultations analysed. We found several examples of ADP trained clinicians using self-management support techniques during the videotaped consultations for patients with long term conditions. Agenda setting and goal setting were used by these clinicians; however we found only one example of agreeing follow up.

The three enablers and co-productive consultation skills are attractive to some clinicians, but are a challenge to existing skill sets and organisation of services.

Overall conclusion

There was good evidence that co production was designed into course delivery and programme design. The respective contributions of clinicians and lay tutors were valued, but co equal contributions to delivery were not always achieved. There remains a lack of evidence for the impact of co tutor models on outcomes in patient and in clinician programmes. Therefore future programmes might test the comparative value of variations in tutor delivery.

The extent that co production, and the use of the three enablers was practiced in consultations relies on weak evidence from patient exit measures which have very strong positive biases. In question 2 we found that patients, when interviewed tended not to have detected the use of the three enablers by their clinicians, and perhaps reflecting low course content in the SMP, were seldom able to instance using the enablers themselves in consultations. The experienced clinicians whose consultations were videotaped used a range of co productive skills, but they also tended to overestimate the extent of use of the three enablers. There was much more evidence for agenda setting, some goal setting and only one instance of goal follow up. Feedback of videotaped recordings would be a useful training aide. The evidence suggests that building competent practice in co productive consultation skills by clinicians requires more than a short clinician development training programme.

Recommendations: Question 3

We make the following recommendations for improving programmes to support self management and co productive clinician- patient interactions.

- To attain and maintain high standards of delivery of the ADP and SMP, the initial training, accreditation and ongoing development of tutors could be improved by using direct observation of other tutors and feedback on delivery style as well as coverage of course content.
- Support, development and recompense should be provided for lay members of site and inter site activities.
- The SMP co tutor model could be amended to revert to 2 lay tutors as core but with clinician input for sessions requiring their clinical expertise and modelling of their role in co-production and health service navigation.
- If lay tutors are to fully contribute as co tutors in clinician training in the ADP, their role needs to be defined, provided with additional training and feedback in delivery techniques and recompense given to enhance their contribution in the eyes of clinician tutors and participants.
- Building competent practice into co productive consultation skills for clinicians requires organisational support and a planned approach to skill development, which is likely to include using direct observation of clinical consultations and coaching from clinician tutors.

Question 4: What lessons are there for integrating CCH into the wider organisation?

As part of the evaluation, we looked into the main factors that help and hinder the delivery of CCH. We present below the main findings for implementation at an organisational level, both within the existing pathway of care of one LTC, and into new pathways. The comprehensive findings around “what works”, and the theoretical underpinning of the evaluation on models from implementation science, are contained in the Technical Appendix Number 4 Programme Evaluation, at the request of the Health Foundation. The perspectives of senior stakeholders is presented in detail in our Fourth Themed paper.¹⁰⁹

This chapter reviews overall programme fit, approach to sustainability and key lessons by looking at three broad questions:

- a. *Were there clear and communicated aims and measures of progress, and success available to site leaders? How can systems of measurement assist implementation in other services?*
- b. *Was there a “fit” with the strategic aims and culture, as well as national policies, local strategies and commissioners’ priorities in the sites? How can the model of service support these priorities and policies?*
- c. *Did the trusts have the policies and procedures to support the model to become integrated across the wider organisation? How can this be achieved in future?*

We begin the chapter by outlining the key messages, outline the organisational context to CCH and then move on to explore each of the questions above. We also end the chapter with our conclusions.

Key Findings

The aims and expectations of impact were many and quite similar across sites. There was good evidence of leadership by CEOs in communicating success and progress. Sites made good use of qualitative data (personal stories). However, the expectations for achieving demonstrable impact on clinical outcomes and healthcare use were not met. Some of the expectations were unlikely to be achieved by the programme as constructed (such as reduced emergency admissions). The aims of the programme were not specific in this respect, and therefore expectations of senior leaders remained uninformed and unchallenged by evidence collected in their site by those delivering CCH and by the evaluation. There was no agreed model for each condition pathway that would enable measures of healthcare use to be linked to CCH activities. Second, there was no agreed model for how in each condition to identify and collect measures of outcome used in routine clinical practice, so that the only such measures were those collected in surveys by the evaluation team, i.e. not those which are used typically to measure the value of new service models. CCH as designed, did not build in an agreed dataset of process and impact measures that could be collected from routine data sources available in each site that linked to the aims of CCH. Such datasets are required to justify future investment decisions.

There were impacts on the ethos of trusts in their engagement of patients as partners at a strategic level. CCH was seen in most trusts to be synergistic with a direction of travel, not a driver of change. The lack of direct link to key policies, e.g. self-management of LTC, mutuality and personalisation, will be a barrier to normalisation of CCH. This could be addressed by making more explicit links to the QIPP programme, personalisation and other key policies. There were also impacts on the ethos of trusts in their engagement of patients as partners at a strategic level more widely within the healthcare economy. This could be a platform for taking forward engagement of other services in the use of the CCH model.

There were some aspirations to support the normalization of CCH through human resources policies and training procedures, and governance procedures but no evidence these were in place at the end of this phase of CCH. CCH achieved much through the efforts and skills of champions, and their access to those in key roles to give leadership and resources. CCH is not yet normalized via local policies and procedures, and so is vulnerable to competing pressures for resources.

Organisational context to CCH

Considerable evidence exists on the challenges of "top down" programmes of organizational change in healthcare.¹¹⁰⁻¹¹² CCH has some features of top down change, for example application to be a demonstration site required evidence of senior clinician and executive engagement. The Health Foundation also put in place contractual expectations of sites and technical providers, and required regular reporting against milestones by monthly monitoring of activity in "dashboards", and less frequent milestones for release of funding. By contrast, there was also an element of co creation by sites and providers, which allowed for some variation in approach by sites. CCH was managed at site level via a Strategic or Executive sponsor and a local CCH implementation team (LOCCHIT) which was required to have clinician, project manager and user members.

The importance of engagement of system leaders, such as Chief Executive Officers (CEOs), who have power, access to resources, credibility and expertise are invaluable in achieving success. The Health Foundation recognised this by explicitly undertaking numerous activities such as visible leadership in the competitive application process to become involved in CCH, through to specific activities at national learning events, and interviews and formal "VIP" visits to test the views of CEOs on the progress and prospects for CCH being sustained beyond the period of investment by the Health Foundation.

Evaluation data sources

To answer the question of "what worked" in CCH at the programme level, and what were the barriers to and drivers of success at programme level, we draw on the full range of evaluation data sources.

Our theoretical framework draws on theories current within implementation science. The first body of knowledge concerns organisational readiness, sustainability and spread.¹¹³ We also draw on an established practitioner framework for quality improvement of services, the UK's NHS Institute for Innovation and Improvement's Sustainability Guide.¹¹⁴ Finally we draw upon a perspective from sociology called Normalisation Process Theory concerning the extent that the programme fits with existing systems of work and values.¹¹⁵

Organisational readiness for change is the product of the collective perceptions of motivational readiness of people in the organisation to undertake the changes required of them, the institutional resources such as the capacity and skills of staff, and organizational climate or shared sense of values and rules about "the way we do things here". Following this approach, we sought the perspectives of Chief Executives, Executive Directors of Commissioning and Executive sponsors and Clinical Leads for CCH, as they are leaders who are identified by their role as controllers of resources as well as their agreed role within the programme of change. Their perspectives give potentially important insight into the resources at their disposal, their experience of the climate of change for the programme, and their understanding of the organisational levers of change necessary for any large scale change programme to be successful. In addition we have drawn on all sources of data available to the evaluation referred to in previous sections, and have undertaken further analysis of these sources to answer this question.

a) Were there clear and communicated aims and measures of progress, and success available to site leaders? How can systems of measurement assist implementation in other services?

Evidence

We draw on the interviews with the CEOs, Executive Directors and Clinical Leads, and our report on the use of NHS datasets (Technical Appendix Number 7).

Evidencing impact

Learning from within the site and sharing this with key stakeholders was seen by most CEOs and Clinical Leads to be important to making CCH a success. Finding the right evidence to present was a challenge. There were many examples of CEOs having witnessed the impact of patient stories and demonstrations of the changed clinician-patient dynamic as influential on them and their Boards. This type of demonstration was used in the absence of "hard" data, as a health board CEO said in year 2.

"we do not have any data that we collect that demonstrates what clinical benefits there might be, for those clinical resisters and sceptics, until they see clinical benefits its giving them an excuse to not participate. We have shown [the Board] the new interaction between patient and clinician. We let them actually observe the feedback in action so the Board was very very excited."

A few CEOs were less tolerant of the lack of standard metrics and aims. For example a PCT CEO in year 2 stated.

"It was the latest flavour of the month eighteen months ago – we were keen that we were going to be part of the programme because it was part of our underlying philosophy –but really I have heard nothing since. (What would convince your Board?) Two things. Some hard data around patients being repatriated and some soft data about how it feels for the patient. if it is just not viable .Then I would really like us to be open and honest about that".

The aspirations for service level change are described in detail in the Fourth Themed paper¹¹⁶, and are summarized here. These were possible to group into larger themes. The first is *doing what we already do but better-* reducing emergency admissions and making better

use of resources, tailoring services to patients' views, improving the service reputation and market share. The second large theme *is doing things differently* concerned with mutuality of responsibilities between patient and clinician, whole pathway services from anticipatory care to participatory care, and embedding CCH across services for other LTC.

The breadth of expected and experienced outcomes and impacts by these system leaders, from those for patients, to clinicians and to services, is described in the Fourth Themed paper. The problems of measuring these impacts are many. From the perspective of CEOs and Directors of Commissioning, there were expectations of tangible benefits for patients, clinicians and the system of care. There are real challenges in evidencing these benefits since the main outcomes are "soft" psychosocial benefits for patients and perceptions of improved consultations by clinicians.

Other outcomes the leaders wanted to evidence, such as reduction in mental ill health associated with a long term physical condition, would be difficult to evidence in the timescales of this programme. Also, they would have impact on services beyond the immediate condition pathway in the case of diabetes, COPD and pain. These impacts are then difficult for commissioners to evidence as they are part of separate commissioning programmes.

Use of routine NHS healthcare data

The evaluation produced an interim report on the use of NHS datasets (Technical Report- Number 7). This was made available to CCH sites in the early part of Year 3. Such data has the potential to show impact on avoidance of emergency or elective secondary care. Given the emphasis of CEOs and system leads in Year 1 on potential impacts on both primary and secondary care use, such data were felt to be important to the evaluation and to enable sites to see impact on outcomes important to the future business case for supporting self-management of LTC. There are unavoidable problems in the use of such data, including known error rates in coding.

There were also several avoidable problems. Sites were unable to facilitate access by the evaluation team to primary care data, (although this was possible in comparison sites). Demonstration sites did not routinely use such data in the monitoring of the more narrowly defined condition groups included in CCH, mainly because the pathways are not commissioned across primary, community and secondary/ or tertiary care, and these metrics are related to how patients move between providers. In relation to measuring the specific impact of CCH activities, sites struggled to define a "dose" of CCH as it might affect a patient, apart from having attended an SMP in the previous year of data collection. This meant that sites could only identify tens not hundreds of patients usually used in such analyses.

The sites were unable, therefore, to evidence healthcare use impacts. While many senior executives were content to rely on patient reported outcomes, largely of a psychosocial rather than clinical nature, it may be a hindrance to justifying the continued investment in CCH, given the current QIPP emphasis on justification of healthcare resources for productivity as well as quality and prevention.

Here we focus on the extent that CEOs, Executives and Clinical Leads felt able to articulate clear and communicated aims and measures of progress, and success. There was often good use made of patient stories and demonstrations to show how CCH is intended to work and how participants have benefited personally. But they often referred to the lack of site level programme impact measures. In the main, sites had no regularly available measures, other than evaluation data reports, to report on the quantitative impacts of CCH. The views of two Clinical Leads are typical of many others.

"Without having the regular feedback, and I think that's where the overall system is not configured to prompt people." (Clinical Lead, COPD site, Year 3)

"But frankly, you know, what I think has been missing is a local audit of impact. Local measurements around the specific condition that we're working with.. [...] to demonstrate the quality change that you see in the lives of the people that have taken part, other than personal accounts." (Clinical Lead, Pain site, Year 3)

In summary, the aims and expectations of impact were many. There was commitment to leadership by CEOs and to communicating success and progress. Sites made good use of qualitative data. The lack of quantitative data used to monitor the impact of CCH and the evaluation data was only a partial answer to the needs of sites for evidence of impact during the programme. The programme was hindered by the misalignment between the programme aims and the measures of impact at site level. However, this can be addressed in plans to roll out the CCH model to other services by establishing clear aims and metrics at the outset.

For CCH to be implemented into healthcare trusts as routine, it is important to have measures that are part of routine service administration capable of measuring the intended targets such as uptake by key patients and clinicians, and impact on patients, clinicians and the efficiency, cost and effectiveness of services. With the emphasis on programmes to influence early intervention and effective use of non emergency services for the smaller number of "frequent fliers" (those who consume disproportionately higher healthcare resources through unplanned care), there is real scope to build the case for spread and sustainability by focussing on (a) measures for healthcare use and outcomes of a small group of patients, and (b) to prospectively plan to track healthcare use by LTC cohorts of patients likely to be affected by the spread of the CCH model to their services.

b) Is there a "fit" with the strategic aims and culture, as well as national policies, local strategies and commissioners' priorities? How can the model of service support of these priorities and policies?

Evidence

There were four themes which emerged across the interviews with the CEOs, commissioning leads and Clinical Leads as healthcare economy leaders. These were *strategies for self-management for long term conditions, mutuality, and the psychological health of people with LTC*. The newest theme to emerge during Year 2 and Year 3 was *fit with policies of Choice and Personalization*. (See Fourth Themed Paper¹¹⁶). We provide a resume of key points here:

Strategy for self-management for long term conditions

A specific strategy for self-management of long term conditions did not exist in any site throughout the course of CCH, but there were emergent strategies.

Strategies for long term conditions

The responsibility for strategy was consistently seen by CEOs of provider and commissioner trusts to be a PCT function.

Strategy for conditions

PCTs did not have condition specific strategies, although some saw CCH as fitting somewhat with their general strategic intent. An example is the interest in care of the elderly cited by a PCT Director of Commissioning

"So our strategy probably doesn't have a really strong alignment to this in that {it is} largely focused around older people.{it is} something that we need to [do something about]."

Strategies for self-management

CEOs were clear that their trusts had not developed specific strategies for self-management in the course of CCH. Rather, they had seen the need for self-management and interpreted the possible benefits of CCH as taking forward aspects of self-management they were already resourcing. For example, a PCT CEO saw CCH as fitting with the need to improve "self help" and care closer to home, along with intent to work in closer partnership with the council. Others acknowledged that they have an aspiration to create strategies for long term conditions. One trust that specifically cited CCH as being behind the principles of the new service also acknowledged that the self-management aspect of the strategy was weak. A provider trust CEO in year 3 stated

"we've managed to persuade our commissioners locally to commission a pain pathway which is based on Co-creating Health principles."

Strategy as place of care

PCTs cited links with their attempts to provide better community and primary care services and to reduce secondary care admissions. For example, a health board CEO in year 3 stated.

"I think this links in with 'Your Health' the primary care strategy, because it is about shifting the balance of care in the sense that where is the right place."

This theme of "place" was common across PCTs and provider trusts, whereby CCH was seen as an opportunity to resource services more appropriately provided outside hospitals. But from the provider side the interest is in managing part of this business, from both large tertiary and small secondary care trusts. A provider trust CEO stated in year 3

"We are going to come together with community based service to form an integrated care organisation. So that fits exactly with the co-creating health project."

Strategy for pathways of care for conditions:

The opportunity for CCH 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 CCH was not developed at any site. For example a PCT CEO in year 2 stated:

"We've got better integration with secondary care service and particularly around rheumatology.....and its allowed the PCT to develop strategic plans and pathways of care for {musculoskeletal pain} services overall.{but} . We've missed a trick about integrating this with primary care and in particular our long term conditions work. We've got to move into pathways of whole systems - clinical pathways delivery and development and engagement and ownership of patients and re-negotiating this relationship between patients and clinicians particularly around this .long term condition type work. So I think it kind of has been a bit of a disappointment to us."

A PCT CEO from a diabetes site stated it had not helped change the shape of services.

"What it probably hasn't helped is, actually shifting significant numbers of diabetic patients into the community and GPs taking on more of the diabetic ongoing monitoring function.

Personalisation and choice:

During years 2 and 3 of CCH the potential links for CCH to policies encompassing personalisation of care and choice of provider were discussed by PCT CEOs. A care trust CEO stated

"The Co-creating Health Project is so aligned with the values and objectives of personalisation in terms of getting people into positions where they can operate for themselves, exercise choice, that it's not different from personalisation at all."

A PCT CEO stated in year 2:

"We have done some service redesign on the {pain} pathway and some of the principles that the Co-Creating Health has been included. We may have missed a trick. It could have influenced us much more. It's limited. There is potential for us to harness it to do more."

However, as a Director of commissioning in the comparison site for depression and diabetes said, the amount of budget that can be freed up for people to use to buy services in reality was very constrained.

Mutuality

CEOs on a few sites were keen to stress the potential fit of CCH with policies that emerged during CCH. In Scotland, a health board CEO was clear in all three years of the fit with "mutuality" which is "*the relation between the clinician and the patient. In terms of 'Better Health, Better Care', one of the proposals is that people work together; better to help each other. This approach is very much at the heart of this. We should see whether improving and developing the respect between the clinician and the patient - rather than just telling – works".*

In England there has not been an explicit policy fostering mutuality. However some leaders have seen the links, which stretch back to the Wanless report¹¹⁷ which foresaw the benefits of the “fully engaged scenario”, and in Year 3 these leaders could see a fit with policies that foster a more empowered service user as part of public health strategies.

The interviews suggest that the sites could see possible ways in which the “ethos” of CCH resonates with policies encouraging personal control over aspects of services by users, and mutuality in Scotland. However, no concrete evidence emerged of sites making commissioning decisions that took this forward in relation to services that were part of CCH.

Strategy gaps – mental health and physical long term conditions

The depression sites were consistent in highlighting the links between mental health and physical long term conditions. A mental health provider trust CEO said in year 1:

“That people with long-term physical health conditions have a greater risk of mental health, particularly clinical depression. So we felt strongly that some learning between long-term physical health conditions and mental health was important.”

This was echoed by a care trust CEO year 1:

“And if this programme ultimately captures the benefits to people who have got psychosomatic illness, which is a real physical manifestation but is a result of low self-esteem or depression or whatever, it’d be a massive breakthrough.”

By year 3, there were continued aspirations from the mental health providers to see links with physical long term conditions:

“We’re looking at how we better link the self-management depression programmes with wider self-management, because of the broad correlations between depression and physical ill-health.”

However, the reality of commissioning even by the PCTs in depression sites did not embrace the links. In a care trust the director of mental health commissioning stated in year 3:

“We do have a long term condition strategy. Depression obviously doesn’t sit under that”

The sites with diabetes, COPD and pain seldom made these links at the level of CEOs and system leaders. The PCT leads in depression sites explained that they commission services separately for mental health and physical health primarily because they are provided by different trusts. These barriers were not influenced by CCH.

CCH “ethos” as an influence on policies and practice in patient engagement

A theme that emerged across CCH was the generalised impact of the active, partnership approach to involving patients in service improvement and strategy, rather than the tokenistic and episodic approaches they described as typical.

"our philosophy is service users, people with long term conditions, they are continually working with us in terms of developing the strategy, in terms of understanding what we are delivering, is it effective, is it helping us, so it's not something that we suddenly have to do and say we have to go out and find some service users you know, they were involved in developing the, I think the original bid, so they have been involved all the way along the line"
(CEO, Pain site, Year 3)

CCH became shorthand in some organisations for this new approach to patient engagement.

"We've got the engagement and the organisational structure through the fact that there's organisational objectives {for} self care, self-management, it kind of runs through that. We've got the Patient Focus Public Involvement people about getting more people involved...So it fits so much with everything else that, and Co-creating Health has had a fairly high profile an organisation that it wouldn't just disappear, it would live on, I'm hoping somewhere, yes." (Project Manager, COPD site, Year 3)

But trust leaders could cite examples elsewhere in their trusts where services were being redesigned to better engage patients, so they were not identifying CCH as the main impetus.

"Well if you asked me is anything else like CCH happening here, and I would say yes- the rheumatology services here have pioneered partnership working and patient engagement. We wanted CCH to bring a new model to a service that was not a leading light." (CEO of a Diabetes site, Year 3).

Similarly, other leaders saw CCH as being useful in bringing the philosophy of patient partnership to bear that had been well established in other services already.

"We have excellent mental health services locally which really have a partnership approach with those with enduring conditions. And HIV services have embraced new models as their service users are quite vocal and assertive about their demands on us. We hoped CCH might help bring the same values into the general hospital services, though I am not sure how successful that has been." (Diabetes CEO site Year 3).

We conclude that CCH was seen in most trusts to be synergistic with a direction of travel, or in some cases a way of improving services that were found to be less in line with the desired direction of travel than others that existed already within the trust, so CCH was not seen to be the main driver of change. The lack of direct link to key policies, e.g. self-management of LTC, mutuality and personalization, will be a barrier to normalization of CCH. Indeed, an enthusiast of CCH from a large tertiary provider cautioned that self-management of long term conditions is

"one of those areas at the minute that falls in to the hobby category of policy. With areas like that you are never quite certain how it's going to be supported over time as other pressures get tight."

There were also impacts on the ethos of trusts in their engagement of patients as partners at a strategic level more widely within the healthcare economy.

c) Did trusts have the policies and procedures to support the model become integrated across the wider organisation? How can this be achieved in future?

Evidence

In the interviews with senior stakeholders (CEOs, Executive Commissioners, Clinical Leads and other healthcare leaders, and patient members of the LOCCHIT) we asked questions about the local policies, procedures and documents such as job descriptions and training plans, appraisal mechanisms that could be used to make CCH a part of everyday reality for clinicians and healthcare managers. Where feasible, we also asked for documents referred to in these interviews.

Policies and procedures

The Clinical Leads and Executive Directors acknowledged that their trust strategies and policies referred to the need to support self-management, in line with local and national policies. Some said that CCH had influenced the translation of these policies into practice, by instilling a "culture" of self-management, and of patient engagement as described above in the Fourth Themed paper.¹⁰⁹

When asked more specifically about how trust or departmental level operational policies and procedures supported CCH, particularly around the embedding of the three enablers in clinic organization, and the on sustaining of clinician skills in SMS, almost all respondents acknowledged that there had been little thought given to this.

"So I'm trying to think what a policy might look like which says this is the way we're going to do it" (Executive Director COPD site, Year 3)

I don't think we've made any conscious... again, it'd be helpful to get the project manager's view on that, my view from the bridge would be that we've not done a great deal on that. (CEO, Mental Health Trust, Depression site, Year 3)

In four sites there was mention from at least one executive level respondent who described the possibility of embedding the ADP programme via regulatory and development processes, i.e. induction and the workforce development plans, and two referred to trust based appraisal systems and the re accreditation systems for GPs as future possibilities. There was preference for some form of formal accreditation of the training if it was to be used in this way:

Interviewer: "So the ADP part needs to be within workforce development?"

"Yes. linked to...the establishment of some more formal recognition for a qualification or level of competence, I think would be helpful both for the professionals and for supporting the case for its permanent establishment." (CEO commissioner, depression site, Year 3)

A similar idea was expressed in relation to secondary care clinicians, and to ways of integrating approaches with clinical governance processes involving primary care feedback.

"We are looking at how we would integrate this into job planning, into appraisal of clinicians as being part of the way that we embed this in the Trust. We're looking at the possibility of

integrating it into our current clinical governance days that a lot of our clinicians have where they can bring in GP colleagues to actually review their results. The issue with us is how do we integrate it with the processes we have in place already with supporting clinicians rather than setting something up that's completely (new)." (CEO, Pain site, Year 3)

One respondent referred to the ways it might be built into capability assessment systems relevant to job pay and promotion.

"Some of work that we've done – this is relation to the ADP – has looked initially at, well linking it to the KSFs{knowledge and Skills Framework-Agenda for Change}, so knowledge and skills training people, and that's a way through PDR {Performance and Development Review} that will be continuing to support people". (Project Manager, COPD site, Year 3)

Another respondent indicated that ADP content was being built into training contracts.

"So what we're looking to do is through our local education provider is actually have them work with us to provide the courses, and they've committed to join us in that, and the PCT have indicated support for including this in the training contract between themselves and the University, which I think is important as well. So I think what's important is that we're putting measures in place to make sure that we can continue with this once the Co-creating Health project finishes." (CEO, Pain site, Year 3)

A project manager reported aspirations, but no concrete plans for CCH content in training provision locally.

"it would come as part of our Trust induction, whether it comes as part of personal development, part of supervision, this becomes embedded for all clinicians; everyone that comes through as a new member of staff will have some sort of training around self-management built into their programme, their Trust induction." (Project Manager, Depression site Year 3)

However, no trusts were able to evidence these statements with documentation that described the CCH approach. In exploring why embedding CCH had not been built into operational policies and procedures, there were many examples where this simply had not been discussed. Two executive level respondents gave examples that suggested they would not feel ready to do so until there was more tangible evidence of uptake and of impact, and with confidence in the evidence base being built of data from the local provider site. Two provider trust executives defended the lack of procedures to embed CCH by the lack of evidence for its effectiveness.

"I guess if I was a clinician, I'd say so you want me structurally to do something where you have no evidence to show that what you've just asked me to do works in any way, shape or form." (Executive Lead, COPD site, Year 3)

"Actually we are still proving concepts and we are more confident in the last six months in terms of clinical outcome but until we've got to that point we are not there yet." (Executive Lead, Diabetes site, Year 3)

In relation to the PCT, there had been aspirations to include evidence of how a service would support SMS for LTC, but the provider trust respondent felt it was not being acted upon.

"The PCT they wanted to in their business case proforma to include a section on how does this support self-management and partnership working. They also wanted a section in the staff appraisal system about the same thing. But they haven't actually implemented it." (Project Manager, Pain site, Year 3)

We also asked patients if they were aware of any discussions on these matters at the LOCCHIT and any procedures which affected them as patient members, such as systems of remuneration for their contribution. No patient representatives on the LOCCHIT reported any discussion of these matters except in relation to reimbursement for particular tasks such as travel to sites to be a co tutor on a course.

Champions

There was also recognition that CCH had been throughout its life heavily reliant on a small number of key peoples' energy and skills, who could access support of people in key roles.

"I think having key individuals to keep the purpose of that and the understanding of that at high profile, at a level that continues to sustain is quite important. I think that they do need to be local champions otherwise it will get lost in all the pressure the commissioners are going to be under". (Project Manager, Pain site, Year 3)

"I'd say it's fairly dependent on key people. I would say that there is probably four or five of us that if we stopped doing what we were doing then everybody would revert to type without doubt. So I think based on that, it's something that people know about, it's something that people talk about, but I wouldn't say it's wholly embedded in the systems yet." (Project Manager, COPD site, Year 3)

I think that's where the clinical leadership, where managers, directors have to also work side by side with all our clinicians to just keep bashing that through." (CEO, COPD site, Year 3)

The following three quotations are taken from leaders within the same site in Year 3 and illustrate the role of key people in pivotal job roles in the process of embedding and sustaining CCH.

"I have had incredible support {Clinical Lead}, amazing, amazing support in many, many ways and she has been very (...) at recruiting clinicians onto the course and also into doing surveys, I mean, you know, without her getting any of the clinicians to fill out a survey would have been diabolical, even though it was still hard, you know, we didn't do great, certainly did well when she was about, and again she has been the main driver into getting people onto SMP, and she has obviously got the clinicians involved, incredibly helpful, and I think initially the fact that she's gone out there on her own and done some evaluation stuff which wasn't supported by the programme or the Health Foundation." (Project Manager, Diabetes site, Year 3)

"Well it is yes it is pretty dependent on key people and if you were to ask me, you know, what is, you know, what's one of the big risks to building on this success is all around people and management capacity. So if key people move on then there's a problem but just in terms of

what we're able to cope with as a management team and, you know, more widely as a team within the hospital. So there are limits clearly and we need to think about how we resource this hospital and, you know, more generally to drive for these sorts of changes." (CEO, Diabetes site, Year 3)

Interview question: Beyond you who else knows about CCH and would feel identified with it apart from you? "I think my exec committee would, my chief exec would, even though he's new I have brain washed him already...my medical director speaks very eloquently about CCH. My board know about it...I think my medical director would without a doubt and (Name) would. The chief exec now... PCT is very on board and has been championing it in the community. They are quite good at that and also GPs." (Executive Lead, Diabetes site, Year 3)

In summary, there were some aspirations to support the normalization of CCH through human resources policies, training procedures and governance procedures but no evidence these were in place. There was reliance throughout CCH on the efforts and skills of champions, and their access to those in key roles to give leadership and resources. This is a positive impact of CCH but it also suggests it was not yet normalized by the end of CCH, and so is vulnerable to competing pressures for resources. Plans for spread of the model of CCH should include links to operational policies including systems of workforce planning, job plans, appraisal, staff remuneration, re-accreditation and governance.

Conclusions

CCH in its first phase was a very ambitious and complex multi level programme. There were many ambitions for its achievements, and some of these were fulfilled such as the engagement of clinicians in self management, the linking of self management support across trusts and throughout pathways, and the personal learning for clinicians and patients. However, the programme aims and expectations of achievements could have been more clearly articulated at programme level. This would have lead to greater clarity for site leaders enabling them to more effectively plan the systems of measurement to inform performance monitoring and communication within the organisation. The expectations of impact on healthcare use were not linked to the use of available data. The lack of clear aims linked to plans for how health and health outcomes (beyond self report research survey measures) would be captured for each condition pathway by sites, as well as by the evaluation team, has meant that the sites do not have the type of data they would usually use to make a case for investment in new service model.

There was evidence of increasing awareness in the later part of this first phase of CCH, within sites and at programme level, of the need to integrate measurement for performance and for evaluation, and to use a mix of current data sources and rich qualitative data from key informants such as tutors and participants in programmes. Frustrations with the mismatch between available NHS data and the need to show evidence of clinical and healthcare use impact, has made sites consider more carefully how they seek to evidence the impact of CCH as they plan its integration into other services.

While CCH is broadly in line with national policies promoting self care, in this phase it was not linked well with QIPP, personalisation and mutuality at programme or site level. Local policies and procedures to embed the support practices were not being used in a coherent way to normalise the new model. However, there were some examples where sites were

beginning to use systems such as appraisal and revalidation to support clinician commitment to learning and using these new practices. There was also some evidence of sites planning to achieve more integrated approaches to planning and delivering self care for LTC across trust boundaries. In trusts, such as one of the diabetes sites that is taking on community service provision, there may be more opportunities for combined community and hospital provision to support self management within LTC pathways.

Senior level leadership of CCH was established as a key success factor for CCH at the outset by the Health Foundation. Several processes, such as VIP visits and feedback via national forums involving CEOs, were very effective in securing this commitment. At site level there was over reliance on a small number of champions, who often took on many roles. Awareness of the need to translate Executive “buy in” into securing the resources within organisations to support site level leaders, was an important learning point for all sites.

If trusts have clear aims for CCH, can articulate them, and measure some of them in a meaningful way to track progress and measure achievements, it is more likely the Executive level commitment will translate into resourcing local staff to develop the CCH model as routine in existing services and out the CCH model into other services.

Recommendations: Question 4

We make the following recommendations to improve the application of the CCH model in services beyond the demonstration site pathways in this first phase of CCH.

- **Making the business case with the right data:** A complex multilevel programme requires agreed aims along with means of measuring and communicating the progress of the programme and its impact. Where possible the measures include those already in use in the healthcare system to promote comparison with other initiatives, and to enable comparison between services as the new model of service is rolled out to new pathways. Such data is essential to support business cases for investment.
- **Fit with local policy and care pathways:** Future self-management programmes should be designed to readily fit with policies that transcend specific condition pathways, but which can also be readily evidenced at local level as contributing to these policies via the implementation of the programme in the pathways as they are described and measured by commissioners.
- **Normalisation within existing procedures:** Future self-management programmes should be planned to integrate with and be supported by policies and procedures that enshrine the intervention into the way the organisation habitually operates including systems of workforce planning, job plans, appraisal, staff remuneration, re-accreditation and governance.
- **Informed and active senior leadership:** CCH achieved strong engagement of senior leaders particularly CEOs at a personal level, this resource can only influence the success of CCH in the sites if fully informed of performance and impact. CEOs should be involved in defining the programme aims, outcomes and measures to they are able to make decisions about future investment.

Report Conclusions

Co creating Health, in its first phase, has achieved some but not all of the five stated aims presented in the introduction.

Patient experience and outcomes

CCH aimed to demonstrate “*improvement in the health and well being for patients; improved patient activation, (knowledge, skills and confidence to manage); improved quality of life (QoL) and improved condition specific health indicators*”.

These outcomes were achieved, in varying degrees across the four LTCs, for those who attended five or more sessions of a SMP. Patients from all four LTCs made significant improvements in patient activation and improved their self-management skills. Condition specific outcomes were improved in all four LTCs. For example, depression patients reported improvements in depression and anxiety, as well as improvements in health status and quality of life. Pain patients reported improvements in pain symptoms and confidence to manage their pain as well as improvements in health status, anxiety and depression. COPD patients had more mastery over their condition. Diabetes patients improved their diabetes quality of life.

Some 846 patients, have completed the programmes. It is likely the survey returns reflect the views of patients who have benefited most from CCH, as is often the case in evaluations of programmes in use in real world contexts rather than in controlled studies. There was no evidence of benefit that we could detect for patients who did not attend SMPs. Of note is the high uptake, and completion rates compared to other SMPs, as well as the reach to patient groups less often attracted to generic SMPs, and the good outcomes across arrange of outcome measures for all four conditions. Given that SMPs are relatively new in mental health, the achievement of SMPs at depression sites suggests the approach has an important place in the range of services for people with depression.

The SMP is a well designed programme, using tried and tested change processes, although there is room for improvement particularly to support co productive healthcare navigation and consultations. There is scope to reduce the reliance of clinician co tutors at each session, given their high cost, and evidence that their tutor style was not reliably co-productive and supportive of the lay tutor. Some success factors for the high uptake and completion rates, despite the limitations of delivery, are suggested from our analyses. These factors include active recruitment by clinicians, provision of a supportive SMP help desk at the time of the referral, follow up from tutors for patients who either do not attend or drop out of the SMP, and reunions after the SMP course has finished. Together these factors suggest that course attendance may need to be supplemented by other social interactions to be optimised. In future, more personalised delivery, including social networking forums, and telephone contact with tutors may be a cost effective approach to maximising reach, engagement and retention.

Clinician practices to support self-management.

CCH aimed to ensure that “*clinicians adopt self-management support (SMS) practices and routinely use the three enablers*.”

The ADP was a well designed course which proved to be popular and credible with a wide range of clinicians from many different professions and working in a range of clinical contexts. The approach to targeting ADP in sites was not linked or planned in the first half of this phase of CCH to build synergies across the programmes of CCH. For clinicians, this meant they sometimes felt isolated among colleagues who were not yet adopting the new approaches. A more systematic and holistic approach is required to fully incorporate the principles of co-production and SMS into the existing skill sets of the workforce and the current organization of care.

The ADP taught consultation communication skills and focussed on a limited set of practices to support self management known as the three enablers. Attendees, on average, achieved improvements in confidence and self reported use of the enablers. Again, the low response rates to surveys will mean results may be biased towards those who most favoured the programme. The evaluation found only limited evidence of the impact of the learning on routine clinical practice. Building more skilled and confident clinician consultation styles after clinicians attended the ADP could be supported by facilitated feedback from videotaped consultations by a skilled trainer or mentor, as it is increasingly used in postgraduate medical training in this way. This could be included in an e learning approach to enable clinicians to access valuable skilled support remotely and when required, rather than by traditional group workshops and learning sets.

Those clinicians who gained most tended to be in professions and job roles with prior training in these skills, and with more than half their current work in direct clinical practice. While GPs were the largest clinical group, medical clinicians in primary and secondary care had the lowest use of these skills before and after attending the ADP. Consultations for LTC are often in the context of teams and with clinicians over several consultations, and in some cases, in-patient admissions. Future programmes might profitably look at targeting training and team organisation to ensure patients with LTC are enabled to contact the clinician (by traditional consultation and e methods) most suited to providing sustained and skilled services to support behaviour and motivation for self management.

A few clinicians trialled through the SIP activities some methods of distributing self management support within the clinical team, such as having a lay person or a nurse discuss their self-management agenda before the patient had the medical consultation, or afterwards to more fully plan the action plan and goal follow up. The extent that this division of duties and skills is effective for the patient has not been evaluated to our knowledge, and could be evaluated in future programmes.

The Service Improvement Programme in the first phase of CCH focussed on clinician lead experiments in methods of using the three enablers in consultations. Future service improvement could productively focus on designing pathways to support more personalised and co productive services, including the use of e health technologies to enable sharing of co produced self management plans with key clinicians across the pathway of care, and with family or carers. Similarly, e technologies could be used, including patient accessed health records, to support self management.

Co-productive consultations

CCH aimed to “*change the relationship between patient and clinician to a collaborative partnership in which patients and clinicians identify a shared agenda, set goals and agree a plan for goal follow-up (three enablers), and patient satisfaction with services.*”

A key assumption of CCH was that clinical consultations provide a huge opportunity for co producing decisions and plans to self manage the LTC. Taking the evidence presented in this report, there is evidence of a gap between intentions and practice in supporting self management by co productive consultations. The results showed, even for the clinician ADP tutors, that co production was not confidently and competently applied as routine.

The reasons why clinicians do not always achieve the results they seek during consultations are complex, including the challenge to their traditional style, and the perception that it requires longer consultations. While many clinicians could incorporate agenda setting in their consultations, the task of incorporating the interactive “package” of the three enablers of agenda setting, goal setting and action planning, and follow up on goals in their consultations were considered to be time consuming and impractical for many clinicians, particularly secondary care doctors. Aspects of patient centred care, where the emphasis is on communication skills rather than on behaviour change skills, appears to be less challenging.

In evidence presented in answer to evaluation questions 2, 3 and 4, we draw on all sources of data, from the surveys, interviews, service improvement measures, and observations of ADP tutors with their patients. These data showed that of the three enablers, the easiest and most often used by clinicians was agenda setting, with less goal setting and action planning and very little goal follow up. Part of the explanation may lie in the sequential nature of the processes in a consultation- i.e. that all consultations have a beginning, over which the clinician has the most control. The remainder of the consultation may not be so controlled by the clinician. A related explanation includes the fact that many secondary care clinicians tend not to follow up patients, so have found that discussion of follow up is problematic in their consultations.

A second explanation may lie in the congruence of goal setting, action planning and goal follow up with the current practices and philosophy of the clinician. The ADP survey results show that practitioners from allied health professions, counselling and psychology had high levels of these skills at the outset and tended also to report improved practice of the skills after the ADP. Our interviews with system leaders clearly saw it as essential that clinicians themselves would experience benefits in their working lives from applying these new practices in order for the changes in their practice to be embraced and embedded. Clinicians tended to comment on the immediate effect of using the enablers within the consultation, while in reality, the impact is likely to occur outside the consultation and may not be evident to the clinician for some time, which means the feedback loop is not established. It is not evident that clinicians could readily judge how the effort of applying new skills was sufficiently rewarded by seeing obvious immediate benefits to patients and to the smooth conduct of their consultations.

A third explanation arises from the "fit" between the clinician and patient, as it was a common comment in the ADP and SIP that clinicians found it difficult to use the SMS skills with less activated patients, and this could influence their confidence to make future attempts with subsequent patients .

A fourth explanation arises from the fit with the skills of a clinical team. In the ADP, the model taught focussed on the role of a clinician in a one to one consultation, yet clinical teams are often required to address the complex needs of a patient with a LTC. CCH did not address how patients can engage with teams, nor how teams, particularly those that integrate services across hospital, community health and social care services, can more co productively include patients and their families as active participants in their care.

We conclude that the three enablers and co-productive consultation skills are attractive to clinicians but that for many the skills are not congruent with their existing skill sets and the organisation of services.

Sustaining CCH

CCH aimed to "*introduce changes which are sustainable through building capacity and capability.*"

The programme as whole, with a minority of sites being the exception, under performed on the planned numbers of patients and clinicians completing programmes, and the numbers of teams engaged in the SIP. So far, CCH has not been trialled at sufficient scale to have a service wide impact, since for example on average only around 40 patients completed an SMP per year per site (based on 805 completions in 2.5 years), and 23 clinicians per year completed the ADP (based on 465 completions in 2.5 years). Site tutors were established in this phase and the means for ongoing tutor recruitment and training, although at the end of the first phase of CCH some sites were heavily reliant on small numbers of clinicians and patients to undertake tutoring and other CCH activities.

The aims for a second phase of CCH explicitly address the aspiration of creating a wider cadre of those capable and willing to champion and support the model in future. The lesson for sites yet to engage with CCH must be to plan and resource the manpower required, to consider less costly skill mix of those involved in tutoring and to improve motivation to continue to be a tutor. However, to achieve much greater access by significant numbers of people with LTC, the model of group based programmes is unlikely to meet the needs of all patients, and has obvious barriers to scalability. Partnership with external providers, e.g. those providing telephone health coaching, e based self management may be options that commissioners would find attractive, and may also overcome some of the evident limitations of reliance on those willing to undertake tutoring roles alongside other duties. Similar restrictions existed in resourcing the ADP, and models including partnership with external providers, and more flexible models of delivery, will be required to achieve widespread implementation.

More appropriate healthcare use

Finally, CCH aimed to achieve “better, more appropriate utilisation of resources. No increase in consultation time overall, reduction in numbers of follow-up appointments and emergency visits to A&E. Patients accessing other non-NHS resources.”

It was clear from the interviews with senior stakeholders that there were strong aspirations to achieve demonstrable benefit to patients on measures the NHS is used to using, that is, clinical outcomes and healthcare use. For reasons detailed in the Technical Report number 7 –Health care use and NHS datasets , the design of CCH precluded this type of evidence being suitable for the conditions selected, and where suitable, was not available from the sites’ NHS databases in sufficient quantity and quality for evaluation. It is unclear therefore, how commissioners can judge the utility of CCH against other interventions to improve LTC outcomes, and their respective costs and payback on investment. This is a challenge for the second phase of CCH, and for services for people with complex LTCs worldwide.

Overall conclusion

We conclude that CCH in its first phase has demonstrated that self management support can be provided in the services of four long term conditions, with at least as good outcomes as other models of group based programmes in the UK and elsewhere. The programme engaged clinicians and taught them to use some key self management support techniques, but is not evident these are then employed as routine, nor is it evident that services have been changed to support the new practices. The CCH demonstration sites now have the experience of clinicians and people with LTC to draw upon, as well as evidence from what works elsewhere, to continue to experiment with testing approaches which could be introduced at scale to impact on far larger numbers of people with LTC who could benefit from self management support.

The view of a site champion as applied to one site, perhaps also reflects the achievement of CCH in its first phase more widely.

“Actually we are still proving concepts, and we are more confident in the last six months in terms of clinical outcome, but until we’ve got to that point we are not there yet.” (Executive Lead, Diabetes site, Year 3)

Report Recommendations

Question 1

In order to support the implementation of future self-management programmes similar to the SMP and improve key outcomes we make the following recommendations.

SMP design/delivery

- Given the importance of the three enablers in all aspects of CCH programme delivery, further iterations of the SMP should include a greater focus on the application of self-management support (SMS) in the context of healthcare consultations in order to equip patients with the skills for co-production in consultations and their ability to navigate the health care system.
- The SMP design could include a more flexible delivery style and concentrate on a smaller number of key behaviour change techniques to maximize participant engagement and impact. The SMP could contain more interactive sessions to stimulate participants' interest and improve retention. The SMP tutor training competency framework and accreditation could focus more on practice and feedback in presenting course activities alongside developing interpersonal skills required to run effective, supportive and "therapeutic" groups.
- The SMP should be designed to enhance a broad range of outcomes relevant to living with a LTC, as well as the social utility of the programme for peoples' lives. Sites could consider adapting the delivery of SMP to increase the involvement of family and friends in supporting participants'-selfmanagement activities. For example, participants could be encouraged to involve family and friends in their weekly goal setting and other "homework" activities such as the gratitude diary. SMP reunions should be a planned part of SMP delivery in order to consolidate behaviour change and maximise continued social support.

SMP targeting and recruitment

- Recruitment strategies for the SMP should be based on health needs analysis so that resources are targeted on those who are younger, less activated and have a poorer quality of life who have most to gain, as well as ensuring local clinicians (particularly those trained in self-management support skills through courses like the ADP) are active recruiters to the programme.

SMP integration and adaptation

- The SMP should be integrated with existing NHS services (e.g. pain clinics, pulmonary rehabilitation, IAPT, DAFNE) and the format adapted to fit with a range of different technological delivery platforms (e.g. DVD, PC, web or phone social networking) to make it more appealing to younger patients.

SMP evaluation

- Self-management programme evaluations should include condition specific outcome measures to ensure greater likelihood of evidencing condition related outcomes.

Question 2

In order to support the implementation of future self-management support programmes for clinicians similar to the ADP and support the implementation of the practices into routine consultations, we make the following recommendations.

- Understanding which clinicians are most likely to benefit is possible to determine with training needs analyses to target those who are suitable to attend courses similar to the ADP, taking account of prior skills already learnt in previous training, and the scope within the job role to perform the skills regularly. Evaluation data should be collected on who attends the ADP and with what impact to understand how to better target the ADP resource.
- To build on the initial gains in competence in using SMS skills developed from attending courses such as the ADP, we recommend that ongoing development for clinicians is provided, for example by coaching, to consolidate and refresh these skills, and that the provision is based on an analysis of individual and team training needs.
- Future training courses for clinicians using the ADP model would benefit from using well designed post consultation exit ratings by both the clinician and patient, and/or tutor facilitated feedback on videotaped consultations to enable clinicians to gain feedback on their skills.
- Provision of courses such as the ADP could test different formats of delivery e.g. including web or other e training formats, the use of audio or video feedback on consultations skills, to provide training designed to meet identified training needs and to achieve widespread uptake.
- The use of video vignettes of the co production skills applied in real consultations could be used to market the courses more effectively.
- Given the importance of team working in managing LTCs, and the boost to motivation that working with peers who are trained and motivated to also use SMS practices, it is recommended that training in SMS is targeted on whole teams and whole GP practices. However, where clinicians' roles are likely to differ in the extent of using the SMS skill in practice, as in multidisciplinary secondary care teams spanning hospital and community services, we further recommend that training is differentiated to reflect that not all clinicians need the same level of training.
- Planned recruitment, skill development and retention of lay and clinician tutors are all essential to sustain the model of training.
- Enhancing the credibility of training, maintaining the quality of training delivery, including attention to fidelity of content and delivery, is increasingly managed by formal accreditation systems, which was absent in the ADP provision. We

recommend that formal accreditation of ADP courses and related further SMS training is provided in future.

Question 3

In order to support the implementation of programmes that include co production of their delivery, and which seek to support co productive consultation practices, we make the following recommendations.

- To attain and maintain high standards of delivery of the ADP and SMP, the initial training, accreditation and ongoing development of tutors could be improved by using direct observation of other tutors and feedback on delivery style as well as coverage of course content.
- Support, development and recompense should be provided for lay members of site and inter site activities.
- The SMP co tutor model could be amended to revert to 2 lay tutors as core but with clinician input for sessions requiring their clinical expertise and modelling of their role in co-production and health service navigation.
- If lay tutors are to fully contribute as co tutors in clinician training, their role needs to be defined, provided with additional training and feedback in delivery techniques and recompense given to enhance their contribution in the eyes of clinician tutors and participants.
- Building competent practice into co productive consultation skills for clinicians requires organisational support and a planned approach to skill development, which is likely to include using direct observation of clinical consultations and coaching from clinician tutors.

Question 4

We make the following recommendations to improve the application of the CCH model in services beyond the demonstration site pathways in this first phase of CCH.

- *Making the business case with the right data:* A complex multilevel programme requires agreed aims along with means of measuring and communicating the progress of the programme and its impact. Where possible the measures include those already in use in the care system to promote comparison with other initiatives, and to enable comparison between services as the new model of service is rolled out to new pathways. Such data is essential to support business cases for investment.
- *Fit with local policy and care pathways:* Future self-management programmes should be designed to readily fit with policies that transcend specific condition pathways, but which can also be readily evidenced at local level as contributing to these policies via the implementation of the programme in the pathways as they are described and measured by commissioners.

- *Normalisation within existing procedures:* Future self-management programmes should be planned to integrate with and be supported by policies and procedures that enshrine the intervention into the way the organisation habitually operates including systems of workforce planning, job plans, appraisal, staff remuneration, re-accreditation and governance.
- *Executive Leadership:* Senior leaders such as CEOs should be involved targeting the resources of a new SMS programme where they believe there will be most gain. It follows that they have a key role to play in defining the programme aims, outcomes and measures to they are able to make decisions about future investment and disinvestment.

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Glossary	
Term used in CCH	Definition
Action Planning	A method of breaking an identified goal down into smaller, more achievable steps, the purpose of which is to increase self-efficacy.
Action Learning Sets	In the ADP this referred to a group of between 4 and 7 clinicians and tutor(s) who met regularly to support one another in their ADP learning in order to take purposeful action.
ADP	Advanced clinician Development Programme: A programme designed to develop clinicians' skills in co-creating health and supporting patients to self-manage their condition.
Agenda setting TOOL	One of three enablers: A physical prompt, such as a checklist, to help people with long-term conditions to define their agenda for consultations before or during the consultation.
Amotivation	Lack of motivation to engage in a certain activity and a person can be prompted to do so even by an external rewards or pressure.
Autonomy support	Taking the perspective of others' into account, acknowledging their feelings, providing them with pertinent information, opportunities for choice and a meaningful rationale. Minimizing the use of pressure and demands.
Bibliotherapy	Bibliotherapy is an expressive therapy that uses an individual's relationship to the content of books and poetry and other written words as therapy.
CBT	Cognitive Behavioural Therapy is a way of talking about how you think about yourself, the world and other people; and how what you do affects your thoughts and feelings.
CCH	Co-creating health initiative: designed to produce better health outcomes and quality of life for people with long-term conditions by addressing the relationship between people with long-term conditions and clinicians and the health system in which they receive care.
CFEP	Client Focused Evaluations Programme- UK Surveys Limited- The Technical Provider for the Advanced clinician Development Programme.
CDSMC	The Chronic Disease Self-Management Course is a generic led self-management programme developed by Professor Kate Lorig at Stanford University. The CDSMC is known as the Expert Patient Programme in the UK.
Clinician SMP tutors	An accredited clinician tutor for delivery of the CCH Self-Management Programme for patients with long-term conditions
Clinician	Clinician: A nurse, doctor or other registered healthcare professional.
CLRN	Comprehensive Local research Network: locally based Department of Health NIHR funded Research Networks that coordinate and facilitate the conduct of clinical research and provide a wide range of support to the local research

	community.
Co-tutoring	A trained patient and a trained clinician tutor co-delivering either the SMP or ADP.
Co-creating Health National SUPPORT Team	The Co-creating Health National Support Team is made up of the Health Foundation working in partnership with CFEP, Expert Patient Programme Community Interest Company (EPPCiC), Finnamore Management Consultancy, the Programme Office and the Evaluation Team.
Co-creation	Co-creation as defined by The Health Foundation: Describes a philosophy of approach to health care, where the relationship between health professionals and people living with long term conditions is one of shared management In this relationship, the knowledge, the decisions about intervention or management of care and the responsibilities for managing health and health care is shared.
Collaborative Agenda setting	A collaborative way for people with long-term conditions and their clinician to clarify how they will use the consultation time.
Collaborative decision-making	A process whereby a health professional and the patient consider the available information about a condition-related problem and the clinical and behavioural options which are available to address the problem, taking into account the patient's preferences and motivation.
Co-morbidity	The presence of one or more disorders/diseases in addition to a primary disease or disorder.
COPD	Chronic Obstructive Pulmonary Disease
Cross-sectional	Data collection which takes a slice of data across all sites to compare the demonstration and comparator sites at a particular point in time.
ET	Evaluation Team
Drop outs from SMP	Patients who enrol but who attend less than 5 sessions of an SMP course
EPPCIC	Expert Patient Programme Community Interest Company
EuroQol index	The EuroQol index (EQ 5D index) and the EuroQol Visual
EuroQol Visual Analogue Scale (EQ VAS)	Analogue Scale (EQ VAS) are widely used measures of health status and health-related quality of life respectively
VAS	
Evaluation Team	The Evaluation Team are based at Coventry University in the Applied Research Centre for Health & Lifestyle Interventions and carried out the evaluation of CCH
EPPCIC	Expert Patient Programme Community interest Company: A Technical Provider which developed the SMP.
External motivation	Motivation which is externally driven and occurs when a person is compelled to do something or act a certain way because of coercion, or external rewards such as money. ¹¹⁸
FMC	Finnamore Management Consultants- A Technical Provider which supported the Service Improvement Programme (SIP).
Follow up	One of three enablers: a systematic way of following up people living with long-term conditions in order to discuss the progress they have made towards achieving the goals that they have set.

Formative evaluation	The measurement of the extent of ongoing learning as a result of the programme.
Goal setting	One of three enablers: Goal setting is a systematic way of helping people with a long-term condition identify goals, which are important to them as individuals.
Hei-Q	Health Education Impact Questionnaire is a measure to assess outcomes in patients with long term conditions attending self-management programmes.
Healthcare professional	This term includes clinicians or managerial staff in a healthcare organisation.
HES	Hospital Episode Statistics: The national statistical data warehouse for England of the care provided by NHS hospitals and for NHS hospital patients treated elsewhere.
Implementation Science	Encompasses all aspects of research relevant to the scientific study of methods to promote the uptake of research findings into routine settings in clinical, community and policy contexts.
Improving health outcome	A positive change in health related behaviours, level and frequency of self-reported symptoms, clinical measures and self-efficacy encompassing biological, psychological and social domains.
Internal motivation	Refers to motivation that is driven by an interest or enjoyment in the task itself, and it occurs when people are internally motivated to do something because it either brings them pleasure, they think it is important, or they feel that what they are learning is significant.
Interpersonal involvement	The dedication of psychological resources, such as time, energy, and affection.
IOW	Isle of Wight
Knowledge management	<i>"Knowledge management is a conscious strategy for moving the right knowledge to the right people at the right time to assist sharing and enabling the information to be translated into action to improve the organizational performance.</i>
Lay tutor	A trained patient tutor co delivering either the SMP or ADP
LOCCHIT	<i>LOCA CO-CREATING HEALTH IMPLEMENTATION TEAM:</i> The project team within participating demonstration sites responsible for managing the implementation of the Co-creating Health initiative locally.
Logic model	Sets out how the CCH intervention programme is planned, understood and produces intended health outcomes.
Longitudinal	Data collection where samples of data were taken from the same participants over time.
LTC	A long-term condition is one that cannot be cured but can be managed through medication and/or therapy.
Navigating the healthcare system	Patients' knowledge of obtaining healthcare services and treatments.
Non-attenders	Patients or clinicians who register but do not attend for any session of an SMP or ADP course.
Outcome evaluation	An assessment of whether the intervention achieved the programme goals.
Paired condition	Comparing sites which are working on the same LTC, for the

	purpose of evaluation, data collection and analysis.
Pathway of care	An explicit statement of the goals and key elements of care based on evidence, best practice, and patient expectations used to systematically plan and follow up a patient focused care programme.
Patient	The preferred term is ‘a person living with a long-term condition’. However, patient or service user can be used instead where appropriate.
Patient experience	Receiving treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way. Having information to make choices, to feel confident and to feel in control.
PAM	Patient Activation Measure is a measure which assesses the extent to which patients feel able to manage their own health condition.
PAS	Patient Administration System: A computerised system for storing, analysing and recording patient information.
PDSA	The four stages of the PDSA cycle: Plan - the change to be tested or implemented Do - carry out the test or change Study - data before and after the change and reflect on what was learned Act - plan the next change cycle or full implementation
Process evaluation	Assesses how the initiative produced a certain outcome.
Programme	The Co-creating Health initiative is made up of three programmes: Advanced Clinician Development Programme (ADP) Self-management Programme for patients / people living with long-term conditions (SMP) Service Improvement Programme (SIP)
Programme Team	There are three programme teams from each of the partner organisations. These teams are responsible for managing the delivery of each programme. The teams are made up of staff from the technical provider organisations. Client Focussed Evaluations Programme - CFEP– Expert Patient Programme Community Interest Company - EPP (CIC) Finnamore Management Consultants - FMC
Quality Improvement (QI) data	Data which are collated and then fed back to staff and services so that it may inform and improve performance.
QI measures	Quality Improvement measures
QoF	Quality and Outcomes Framework: The annual reward and financial incentive programme detailing GP practice achievement results.
Reliability	Repeatability or consistency of results if measured again at a different time, under same conditions with the same participants.
Run Chart	A run chart, also known as a run-sequence plot is a graph that displays observed data in a time sequence. Data are displayed represent some aspect of the output or performance of a manufacturing or other business process. Time is generally

	represented on the horizontal (x) axis and the property under observation on the vertical (y) axis. Often, some measure of central tendency (mean or median) of the data is indicated by a horizontal reference line.
SDT	Self Determination Theory (SDT) which states that the likelihood of an individual learning and practising new behaviours depends on the type of motivation required for that action, essentially internal or external, or amotivation.
Self-care	Individuals taking responsibility for their own health and well-being which includes, staying fit and healthy, both physically and mentally, taking action to prevent illness and accidents, and better use of medicines and treatment of minor ailments.
Self-efficacy	Beliefs in one's capabilities to organise and execute the course of action required to produce given attainments.
Self-management	'The individual's ability to manage the symptoms, treatment and physical and psychological consequences and lifestyle changes inherent in living with a long-term condition.
Self-management support	Self-management support is a concept that facilitates self-management and results from a person with a long-term condition working in partnership with their clinician. Self-management support in CCH also consists of self-management courses for people with long-term conditions.
Series A-I	ADP courses, each alphabet corresponds to one ADP course and each course consists of 3, four-hour long workshops.
SIP	Service Improvement Programme includes a collaborative learning community within sites by supporting the implementation of rapid, small tests of change and by using measurement for quality improvement.
Sites	The healthcare organisations who are taking part in the Co-creating Health Initiative. These consist of at least one primary care/ commissioning organisation and a secondary/tertiary care provider.
SMART goals	S- Specific, Simple M- Measurable, Motivational A- Attainable R- Realistic T- Timely
SMP	Self-Management Programme for patients: A programme designed to educate patients in how to overcome the challenges involved in living with a long-term health condition.
Structure (in COURSE delivery)	Provide consistent guidelines and rules for behaviour, give clear expectations, provides optimal challenge, offer timely and informative feedback; all of which should be delivered in an autonomy supportive manner.
Summative evaluation	An overall assessment of the success of the programme.
Technical provider	An organisation that provides a programme for patients (SMP EPPCIC), or clinicians (ADP, CFEP) or services (service improvement, FMC).
Theory-driven evaluation	An evaluation of why the programme results in the observed outcomes.
Three enablers	Evidence-based strategies shown to be effective in supporting

	self-management: agenda setting, goal setting and follow-up.
T4T	Train the trainer: Training for tutors
Validity	Validity of an outcome measure measurement tool is considered to be the degree to which the tool measures what it claims to measure.
White light	The major impacts of the CCH initiative are expected in the “white light” area, where the three approaches of patient self-management, clinician support for self-management and service support for self-management are integrated.

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