This report was produced by Guy’s & St Thomas’ Hospital NHS Foundation Trust and Whittington Health as a joint local evaluation of the Health Foundation’s Co-creating Health improvement programme.

In their local evaluations, participating sites aimed to assess the impact of Co-creating Health on service use, costs and patient experience in their local health economies.

The report was initially produced for internal use and to inform the independent evaluation of the programme. However, Guy’s & St Thomas’ Hospital NHS Foundation Trust and Whittington Health have kindly agreed for it to be made more widely available so that others can learn from their experience.

The full independent evaluation of phase 2 of Co-creating Health is available at: www.health.org.uk/publications/sustaining-and-spreading-self-management-support
Co-creating Health Phase 2
Joint Local Evaluation – January 2013

Guy’s & St Thomas’ Hospital NHS Foundation Trust
with Lambeth and Southwark

&

Whittington Health with Islington and Haringey
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Executive summary

Background

The Co-creating Health project, funded by the Health Foundation, included two sites in type 2 diabetes, Guy’s and St Thomas’ NHS Foundation Trust (GSTT) and Whittington Health (WH). For the project’s second phase (2010–12), we have conducted a joint local evaluation of the programme, as a supplement to the Health Foundation’s other evaluation work. Co-creating Health consists of three key elements: the Advanced Development Programme (ADP) for healthcare staff, the Self Management Programme (SMP) for patients and the Service Improvement Programme (SIP).

Method

The project has been running since 2008 at both sites. We collected data retrospectively of patients’ clinical outcomes (before and after attending the SMP) and staff members’ application of learning (after attending the ADP). Over the second phase, we then prospectively followed the programme as it was used in 5 local general practitioner (GP) surgeries, conducting interviews with staff and patients.

Results

Among patients with an initially elevated HbA1c (the key marker of long-term outcomes in diabetes), attending the SMP was associated with a mean reduction of 0.6%, comparable to some drug treatments. (For example, Sitagliptin also gives a mean reduction of 0.6% at a cost of £434 per annum.) Patients and staff in our research mostly liked the programme and reported achieving certain learning objectives. However, recruitment was a major challenge and response bias a possible threat to the research method. A key question remains as to whether improvements are maintained long term. Engaging clinicians and patients and achieving whole systems change is difficult in the face of structural barriers in the organisation of healthcare systems.

Conclusion

The Co-creating Health project was associated with statistically significant and clinically important improvements in HbA1c and most of those who went through the programme supported it. However, challenges remain in engaging local populations of both NHS staff and patients.
Background

Co-creating Health is a national project, funded by the Health Foundation, over a total of five years, with the second phase taking part in 7 demonstration sites from September 2010 to the end of 2012. It seeks to enable patients to become equal partners with clinicians in managing their long-term condition, helping them to contribute equally to decisions about their treatment. This collaboration promotes self-management and care planning to improve health outcomes, providing an integrated package of support and development.

In the first three-year phase, with feedback from patients and health professionals, the two Co-creating Health diabetes sites, Guy’s and St Thomas’ Hospital Trust and Whittington Health, redesigned support programmes to meet their local needs. In the second two-year phase and beyond, we are implementing the programmes while continuing to adapt to individual group needs, with participation from entire GP practices and departments at both sites as well as standalone training programmes.

At both sites, we have focused on people with type 2 diabetes, who are also involved in the planning and delivery of the project. Co-creating Health has been implemented in the diabetes departments of GSTT and the WH and a number of primary care sites, GP surgeries and diabetes intermediate care clinics.

There are three key elements to the project:

- A generic training programme in consultation skills concentrating on care planning and self-management support for health professionals, run over 2 to 3 sessions, known generically across all seven sites as the Advanced Development Programme (ADP).
- A Self Management Programme (SMP) for people with type 2 diabetes consisting of a weekly 3-hour session over 5 to 7 weeks.
- A Service Improvement Programme (SIP) to promote changes to healthcare services that support people to self-manage.

The programmes for clinicians and patients focus on processes, called ‘enablers’ that are central to success. These enablers consist of:

- agenda setting: helps the patient to consider and explain what they would like to achieve during the consultation
- collaborative goal setting: uses a patient-centred approach facilitated by the clinician to elicit and agree on specific, achievable and realistic behavioural goals that the patient wants to achieve
• goal follow up: using systems to ensure that there is continual regular contact between the patient and an agreed healthcare provider, ensuring support, motivation and advice in relation to their goal.
Diabetes – what is it and why is it important?

Diabetes is a common long-term condition in which the amount of glucose (sugar) in the blood is too high because the body is unable to use it properly. Normally, the pancreas produces insulin, which controls the levels of glucose in the blood. Diabetes occurs when the body does not produce enough or any insulin, because insulin producing cells in the pancreas have been destroyed (type 1 diabetes), or when the pancreas does produce insulin, but it cannot be used properly, often referred to as insulin resistance (type 2 diabetes). As people with type 1 diabetes across GSTT and WH predominantly attend secondary care services and the Co-creating Health project spanned, primary, intermediate and secondary care areas, the project focused on people with type 2 diabetes.

Type 2 diabetes usually appears in the white population in people over the age of 40 and in the black and Asian communities, in those over 25 years old. It is also becoming more common in children, adolescents and young people of all ethnicities. Type 2 diabetes accounts for between 85 and 95 per cent of all people with diabetes.¹

In the UK, the diagnosed population is 2.9 million, a prevalence of 4.5%.² It is a serious and complex condition that can have a devastating impact on individuals and their families. It leads to an increased cardiovascular risk and complications including retinopathy, one of the leading causes of blindness in working age people, potentially serious foot problems being the most common cause of non-traumatic limb amputation,³ and renal failure. The National Audit Office estimated that the total cost of diabetes to the NHS in 2009–10 was at least £3.9 billion.⁴

Type 2 diabetes is a progressive condition, it frequently requires an increase in medication over time to improve glycaemic (blood glucose) control and reduce the risk of complications. People with diabetes have to make choices that impact on their diabetes several times each day, involving diet, exercise, and medication adherence / use. Education and support, which facilitates successful self-management can improve health and wellbeing, and maintain independence and quality of life by improving glycaemic control and reducing the risk of the tragic consequences of diabetes complications it has been recognised as a vital part of diabetes care.⁵,⁶

¹ All About Diabetes, Diabetes UK reviewed January 2012: www.diabetes.org.uk
⁵ Diabetes National Service Framework: Standards, Department of Health, 2001
⁶ Quality Standards for Diabetes in Adults, National Institute for Health and Clinical Excellence, Quality Standards Programme, March 2011
**Diabetes in the local context**

The GSTT and WH Diabetes Teams serve multi-ethnic, urban populations, with significant health needs, in South (GSTT) and North Central (WH) London. The co-existence of deprivation, social inequality, ethnic diversity, mobile populations and poor health literacy locally not only increases the prevalence of diabetes directly, but also means that many of those most affected benefit least from traditional models of healthcare. Furthermore, it is increasingly recognised that people living with diabetes are also managing an array of other long-term conditions. It is estimated that people with diabetes aged under 65 years have, on average, another 3 long-term conditions. People with diabetes aged over 65 years have, on average, another 7 long-term conditions. This multi-morbidity brings a further significant challenge to healthcare providers and the large number of patients living locally with diabetes.

**Lambeth and Southwark**

There are about 22,000 people with diabetes in Lambeth and Southwark (served by GSTT). It is estimated that 4 in 6,000 people have undiagnosed diabetes and are therefore at high risk of developing complications before the condition is diagnosed. By 2015, it is estimated that between 30,000 and 35,000 people will have diabetes in Lambeth and Southwark. Most alarming is the sharp increase in diabetes in local young people, adolescents and people in their 20s and 30s, driven in part by local childhood obesity rates of 25% and 10–15% of children being overweight.

There are major health inequalities in diabetes care and outcomes across London and the UK, with Lambeth having the 8th highest diabetes-attributable mortality in England (across 152 boroughs) and Southwark having the 12th highest.

**Islington and Haringey**

There are about 20,200 people diagnosed with diabetes in Islington and Haringey (served by WH). It is estimated that a further 3,200 people locally have undiagnosed diabetes and are therefore at high risk of developing complications before the condition is diagnosed. There is a hugely significant projected increase in numbers of people with diabetes in the near future in Islington and Haringey: in 2015, 25,000 people will have diabetes; in 2020, 27,000 people with have diabetes; in 2030, 33,000 people will have diabetes. This increase in diabetes prevalence is partly driven by increasing rates of obesity and also reflects the social deprivation and ethnic diversity across the local populations.

Currently, there are major health inequalities in diabetes care and outcomes across London and the UK, with Haringey having the 18th highest diabetes-attributable mortality in England (across 152 boroughs in England) and Islington having the 21st highest.
The Co-creating Health project – with its emphasis on training for health professionals and patients in shared decision making, agenda and goal setting, promoting equal responsibility and collaboration between patients and health professionals – is a model of care that provides a structure which has the potential to break down traditional barriers in health care, strengthening partnerships with our local populations not just in diabetes care but in all long-term conditions.
Evaluation overview and specifications

The aim of the local phase 2 evaluation was to assess the benefits of the Co-creating Health programme in the two sites focusing on type 2 diabetes. By carrying out a joint evaluation, we are able to increase the value of the research, in exploring the effects of the Co-creating Health model in different localities. Our local evaluation reflects the overall programme evaluation themes to:

- achieve local sustainability – our main intention has been to develop knowledge to inform local commissioning and promote expansion of the programme
- create a cadre of clinical and non-clinical leaders who effectively champion the Co-creating Health – by identifying factors that contribute to successful implementation of the programme; this will enable us to present the programme in a way that is meaningful to local professionals with examples of good practice and participant success (including the voices of the participants)
- encourage adoption of the Co-creating Health model within the original long-term condition and to a wider population – we have studied the uptake of the current programme to understand the barriers that might exist and how these can be overcome. In addition, we are able to emphasise the transferability of the programme to other long-term conditions (LTCs)

The evaluation identifies the specific clinical benefits that patients experience through Co-creating Health and explores perceptions of self-management changes. We have also studied the experiences of health professionals taking part in the programme and their perceptions of impact on their consultation approaches. We have focused the prospective element of our evaluation on primary care to identify specific benefits when both patient and practice clinicians participate in the relevant Co-creating Health training programmes. This knowledge will be important for the wider diabetes community as the development of effective self-management models is a national priority. For example, the National Institute for Health and Care Excellence (NICE) standards for diabetes (2011) include a recommendation that patients should have at least an annual opportunity to set health goals and formulate an action plan. This evaluation provides evidence of the clinical impact on diabetes control, specifically on HbA₁₀, and reports on patient’s perceptions of their health behaviours following the self-management course and health professionals’ perceptions and reported ability to adopt changes into their consultations.

The two fundamental research questions we have addressed in this evaluation are:

1. Do patients who participate in the Co-creating Health programme have improved clinical outcomes (weight, glycaemic control (HbA₁₀))?
2. To what extent do different primary care health professionals implement the ADP approach in their practice, what factors enable or inhibit adoption, and does this impact on how well they support patients?
Our shared local evaluation embraced two approaches, a retrospective component and a prospective component. Retrospectively, we sought to analyse before and after clinical data for all patients who had been through the SMP, principally HbA1c. Additionally, we surveyed all health care professionals who had been through the ADP at one site (WH).

Prospectively, we sought to recruit two or three primary care practices at each site to the Co-creating Health second phase (SMP and ADP were only included in the evaluation period) and follow their experiences. We planned to do this using both interviews and questionnaires, before and after, with patients and health care professionals. Given small numbers and some logistical difficulties with collecting the data, we are not reporting the questionnaire data.

The evaluation team included both healthcare professionals involved in running and delivering the programmes (MB, AR, HM) and academic staff who had an evaluation focus (LN, HP, HM). We also acknowledge and thank Katja Stramer (UCL) who carried out the interviews and assisted with the qualitative analysis, and Linia Patel (WH) and Wenda Aitchison (GSTT), who were the local administrators for the project and who supported the evaluation.

**Recruitment challenges**

Over the course of recruiting a total of 5 practices, delivering the Co-creating Health programme and carrying out the evaluation, challenges with recruitment and engagement became apparent. This impacted on the research and numbers recruited, but also highlights a challenge for the Co-creating Health programme.

As discussed further in the qualitative evaluation below, the 5 practices reported a total of 1,424 patients with type 2 diabetes, but the number who were invited and expressed interest in the SMP course was 83, just 6%. Out of those, just 53 started a course (64% of those who expressed interest; 4% of the total), and just 39 completed a course (74% of those who started; 47% of those who expressed interest; 3% of the total). This represented both resources available to recruit patients, patient suitability for the course, patient interest in the course and a
variety of practical barriers. Common problems included language difficulties, patients in full-time employment being unavailable, and patient’s additional health problems. We were unable to determine the total number of clinicians (GPs and practice nurses) at the 5 practices. Forty-two attended the ADP from the five practices, but just 18 completed the full course (43%).

Various approaches were used in the different practices to promote recruitment and engagement. Targeting patient invitations and how patients were invited seemed to improve patient recruitment. With healthcare professionals, local champions had driven the selection of the 5 practices, but this did not always translate to broader staff enthusiasm.

We thus recognise that there is a self-selection bias in our evaluation and we also propose further research needs to consider how to (cost-effectively) improve engagement and roll out the SMP on a much wider scale.
Quantitative analysis of Self-Management Programme participants

Introduction

In undertaking this part of the evaluation we wished to look at key diabetes markers used globally, to examine changes in diabetes control for those that have attended the Self-Management Programme (SMP). This is a retrospective analysis of all patients who have attended over the 5 years of Co-creating Health. As this is a ‘real life’ review of test results, which have been carried out in the everyday care of patients with diabetes in general practice and secondary care, we did not expect to have complete results for all patients who attended the SMP. Presented here is an analysis of HbA1c and weight for those where data were available, which shows a clinically significant reduction in HbA1c for people with HbA1c of >7.5%.

Background

People with type 2 diabetes were invited to attend the SMP, which takes place over 5 weeks at GSTT and over 7 weeks at WH. Retrospective data for patients who attended the SMP were collected for those who had attended the SMP from the first and second phases of Co-creating Health. For the GSTT site, data were collected using fax back forms that were completed by the surgery staff. Some data were also collected by the study coordinator who visited the practices specifically to collect the data. At the WH site, the data were collected from the hospital database system for all those who had attended the SMP. At the GSTT site 2,250 people were invited by letter or at consultation to attend. Of those 273 registered an interest to attend, 222 commenced the SMP and 177 completed it. At the WH site, 377 individuals completed the SMP.

The primary outcome measure is improvement in HbA1c as a key predictor of long-term health in patients with diabetes, we also collected data on patients weight. To be included in the analysis subjects needed to have data on HbA1c prior to and after their SMP. We therefore included people who had an HbA1c within a year prior to the start date of their SMP course and who also had a reading more than eight weeks after, but within one year from the start date of their SMP. Of the 177 who attended in Lambeth and Southwark, so from the GSTT site, there were 87 with pre- and post-data. From the WH site, there were 79 with pre- and post-data, therefore the analysis will consist of data from these 166 people.
Statistical analyses

Variables were summarised using mean, standard deviation (SD), ranges and counts using SPSS for Windows (version 20). The data were assessed for normal distribution and paired t-tests used to assess statistical significance at the 5% level. Non-parametric testing using the Wilcoxon test was considered, but not required. Regression to the mean was also considered.

Results

Of the 166 people with results 76 were men (46%) and 90 women (54%). The average age was 65-years (range 38 to 88, SD 11.1). The mean diabetes duration was 12.5 years (range 1 to 33 years, SD 7.6). Mean body mass index (BMI) was 31.8Kg/m² (range 20.4 to 50.88Kg/m², SD 6.6).

The mean pre SMP HbA₁c was 8.02%, ranging from 4.0 to 16% (SD 1.83). Figure 1 shows the individual HbA₁c readings at baseline. There was a statistically significant drop in HbA₁c of 0.22% (95% confidence interval (CI) 0.01 to 0.433) p=0.049 to a post-SMP mean HbA₁c of 7.81% (SD 1.81) across the group. However the individual changes in HbA₁c shows how some individuals increased and some decreased their HbA₁c post the SMP (Figure 2). Figure 3 shows this in more detail with individuals grouped by baseline HbA₁c and also shows the mean change in HbA₁c for each group.

There was a non-significant drop in weight of 0.6Kg across the group. Figure 4 shows the individual changes with some increasing and some reducing weight, and Figure 5 shows the mean weight changes by baseline HbA₁c.

Those with good control at baseline (HbA₁c <7%) had a small increase in weight and HbA₁c while those with suboptimal control above 7% improved both diabetes control and lost weight (Figures 3 and 5).

In a sub group analysis of all those with baseline HbA₁c of >7.5% (n=88), Figure 6, there was a statistically and clinically significant drop in HbA₁c of 0.58% (95% CI 0.24 to 0.92) p=0.001 and a weight loss of 0.83Kg (95% CI –0.36 to 2.027) p=0.170 that remained not statistically significant with those with the poorest control HbA₁c >9% having the greatest drop in HbA₁c and weight.
Individual Baseline HbA1c Readings n = 166

Figure 1

Individual changes in HbA1c from baseline to post course n = 166

Paired t-test 0.23% drop p=0.049

Figure 2
Mean change in HbA1c by baseline HbA1c group

Figure 3

Mean change in HbA1c %

HbA1c groups at baseline

Individual changes in weight from baseline to post course n = 141

Weight change in Kg

Figure 4

Paired t-test 0.60Kg drop p=0.132
Mean change in weight by baseline HbA1c group

![Bar chart showing mean change in weight Kg for different baseline HbA1c groups at baseline.]

Figure 5

Analysis by baseline HbA1c above 7.5% at baseline (paired t-test)

![Graph showing analysis results with legend and statistical significance.]

<7.5% n = 78  
≥7.5% n = 88  
HbA1c mean change 0.58% drop p0.001  
Weight mean change 0.83Kg loss p0.170

Figure 6
Discussion

The data show an improvement in glycaemic control without weight gain for those with above ideal diabetes control (HbA1c >7%). This combination of improved diabetes control and weight loss is important, as often when medication is increased to improve diabetes control with no corresponding change in an individual’s diet, the improvement in diabetes control is gained at the cost of weight increase, an ongoing dilemma when considering best treatment options for both patients and health professionals.

Of significance is that this improvement has been achieved in a group of people with an average duration of diabetes over 10 years. The United Kingdom Prospective Diabetes Study (UKPDS) demonstrated that type 2 diabetes is a progressive disease and that people steadily increase their weight and HbA1c with time (1). However, this analysis indicates the people with a relatively long duration of diabetes, with less than ideal diabetes control, were able to achieve weight loss and a drop in HbA1c after attending the SMP; despite being a group in whom we would usually expect to see a deterioration – not improvement – in these parameters.

The considerable variation in HbA1c at baseline needs discussion (see Figure 1). Almost half (47%) of the participants had good glycaemic control with an HbA1c of less than 7.5% at baseline. A small number of subjects had extremely elevated levels of above 10% (ideal range 6.5 to 7.5%), and a small number were low at baseline (<6%). This may have diluted the overall group result, as we would not expect those with HbA1c of less than 6% to decrease their HbA1c. In some situations, where hypoglycaemia is occurring, we would expect an increase to a safer level. As we can see in Figure 3, showing changes in HbA1c from baseline, in the group with HbA1c of less than 7% there was a small increase in HbA1c.

We would hope that those with an HbA1c above 7.5% could improve their control after the SMP as this is the target for treatment for many individuals and the level at which treatment is escalated and patients encouraged to make behaviour changes.

The subset analysis of those with an HbA1c >7.5% demonstrates a greater change in HbA1c (0.58% drop p0.001 (95% CI 0.24 to 0.92)), which is clinically significant and reduces risk.

Figure 3 shows the mean HbA1c changes when split by baseline HbA1c group. This shows how those with poor control (HbA1c >9%) at baseline reduced their HbA1c significantly, while those with moderate control (HbA1c 7 to 9%) at baseline had less of a drop and those who’s baseline HbA1c was already <7%, had a slight increase in their HbA1c. The changes in weight (Figure 4) were similar to a large drop in the baseline group above 9%, less of a drop in those with

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moderate control and then a slight increase in weight in the group with a baseline HbA1c of <7%. This is the effect that we would have anticipated in an *apriori* hypothesis and suggests that the results are reliable.

These results show a positive effect in a group who we would expect to be deteriorating, and prove that an SMP can help people with long duration diabetes to improve their HbA1c control. This could have a large impact on the potential healthcare costs for these people if they are able to maintain better control for longer and reduce their risks of complications.
Survey analysis of the Advance Development Programme

Application of learning evaluation

Introduction and methodology

In Co-creating Health Phase 2, we continued to use the Advanced Development Programme (ADP) to teach clinicians communication skills to support patient behaviour change. Both GSTT and WH sites took ownership of this training, which was adapted by lead ADP tutors to meet local needs and to spread learning to other LTCs. However, the focus of training continued to be giving clinicians the skills to support self-management, using three enabling strategies: agenda setting, goal setting and action planning.

Each ADP consists of 2 to 3 sessions, each lasting 3 hours, in a group setting of up to about 16 clinicians. A Clinical Tutor and Lay Tutor deliver the course in an equitable teaching partnership. The course uses collaborative, interactive, discursive teaching methods. It includes training in joint agenda setting, exploring importance and confidence and supporting behaviour change. Local adaptations related to the length and timing of the course, for example providing a 2-session course, each lasting 2 hours, for delivery within a GP practice. Adaptations also related to the course content, for example providing a greater focus on the experience of the individual living with a LTC and promoting SIPs in the course member’s place of work.

When we were first setting up the ADP in Co-creating Health Phase 1, we concentrated on inviting local opinion leaders to attend the course, focusing on diabetes management. We needed to advertise the ADP and generate interest and enthusiasm among clinicians. During Co-creating Health Phase 1 and into Phase 2, we have spread the ADP training to clinicians managing a range of other LTCs. We continue to provide ADP using a combination of Clinical Tutors and Lay Tutors. We run 5 to 6 courses per year.

Methods

To evaluate the ADP, we assessed the impact of learning on clinical practice using an online questionnaire (hosted on SurveyMonkey). This was designed by one of the team (MB) and was based on a questionnaire she had initially designed and successfully applied in Co-creating Health Phase 1. The questionnaire specifically aimed to measure whether the ADP had led to a change in daily professional clinical practice and focused on whether the ADP skills were being used in the learner’s environment. The questionnaire combined open and closed questions to allow quantitative analysis and a qualitative assessment of professionals’ stories and opinions. Written statements were used, which respondents agreed with on a 5-point Likert scale, from Strongly Agree to Strongly Disagree. If low scores were given, clinicians were asked to say why they felt there had been little learning.
The questionnaire was sent to ADP graduates who had completed the course at least 3 months previously. The ADP graduates were contacted by email. Between September 2008 and November 2012, 252 health care professionals attended the ADP at the WH site. Of these, 13 graduates finished the course too recently and were not included in the survey. This left a potential sample of 239.

Results

Out of the 239 professionals, the questionnaire was undeliverable to 44 because: the email address was inaccurate; the clinician had moved post; the clinician had retired; the clinician was on sabbatical leave; the clinician was on maternity leave; or the clinician was the author of the questionnaire.

The questionnaire was sent to 195 professionals. Those sent this questionnaire included: consultant doctors, GPs, specialist nurses, community nurses, practice nurses, psychologists, dietitians, pharmacists, podiatrists, physiotherapists, occupational therapists, smoking cessation advisers, sexual health advisers, speech and language therapists, mental health workers and practice managers. The ADP was provided to clinicians working in diabetes, respiratory medicine (chronic obstructive pulmonary disease (COPD)), musculoskeletal pain, sickle cell disease, HIV medicine, sexual health and mental health, across primary, community and secondary care settings.

Ninety-two individuals responded, a response rate of 47%. Unfortunately one replied that they were unable to complete due to personal circumstances, leaving 91 usable responses.

The respondents had completed the ADP: within one year (2012) in 22 responses; 1 to 2 years previously (2011) in 21 responses; 2 to 3 years previously (2010) in 11 responses; 3 to 4 years previously (2009) in 14 responses; 4 to 5 years previously (2008) in 15 responses. There were no dates given on 8 responses.

The first seven questions were answered on a 5-point Likert scale. We have summarised the results with the percentage who agreed or strongly agreed to each question, out of those who gave applicable responses, in the table below.
<table>
<thead>
<tr>
<th>Question</th>
<th>Agree (%)</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>N/A†</th>
</tr>
</thead>
<tbody>
<tr>
<td>The ADP has significantly improved my knowledge and understanding of how to support patient self-management.</td>
<td>87% (78/90)</td>
<td>20</td>
<td>58</td>
<td>11</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>95% CI*: 79% to 93%</td>
<td></td>
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<tr>
<td>The ADP has provided me with new skills that I could use in my professional practice.</td>
<td>87% (78/90)</td>
<td>24</td>
<td>54</td>
<td>10</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>95% CI: 79% to 93%</td>
<td></td>
<td></td>
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<tr>
<td>The ADP has had a positive impact on my daily professional practice.</td>
<td>77% (69/90)</td>
<td>16</td>
<td>53</td>
<td>19</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>95% CI: 67% to 85%</td>
<td></td>
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<tr>
<td>I have implemented parts of the ADP course into my daily professional practice.</td>
<td>87% (77/89)</td>
<td>14</td>
<td>63</td>
<td>9</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>95% CI: 78% to 93%</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>The ADP skills have improved my professional relationship with patients.</td>
<td>74% (66/89)</td>
<td>9</td>
<td>57</td>
<td>19</td>
<td>4</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>95% CI: 65% to 82%</td>
<td></td>
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<tr>
<td>The ADP skills have led to improved health in my patients.</td>
<td>46% (39/85)</td>
<td>4</td>
<td>35</td>
<td>39</td>
<td>6</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>95% CI: 36% to 56%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I would recommend the ADP to others.</td>
<td>94% (85/90)</td>
<td>41</td>
<td>44</td>
<td>4</td>
<td>0</td>
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95% CI* – 95% confidence interval  
N/A† - Not Applicable
Respondents were then asked to rate on a 10 point scale (1 to 10) their answers to two questions, “How confident do you feel about your ability to use what you have learnt on the ADP?” (anchored 10 is "very confident" and 1 is "not confident at all") and “How much has your practice changed as a result of the ADP?” (anchored 10 is "a lot" and 1 is "not at all").

The median response for how confident respondents felt was 8 (95% bootstrapped CI: 7 to 8). 84% (76/90; 95% CI: 76% to 90%) rated their confidence as between 7-10.

The median response for how much respondents felt their practice had changed was 7 (95% bootstrapped CI: 7 to 8). 64% (56/88; 95% CI: 53% to 73%) rated their practice had changed between 7 and 10.

Feedback from ADP graduates

Various common themes have been reported by the ADP graduates as a result of them doing the ADP course and applying the skills learnt.

1 Increased job satisfaction:

The ADP graduates reported changed ways of working that improved their job satisfaction. They described providing consultations that are more focused and which achieved more for the patient.

“I have a better understanding of patient’s desire to change/confidence to change and thus am better able to provide a targeted approach. Better communication with patients. Better time management, through better understanding of the hidden agenda within a consultation, from the start.”

“Helped me to become last paternalistic generally and therefore have more productive consultations.”

“I learned that I can have a focused efficient consultation while remaining empathic.”

“This has enabled me to steer my consultations in the right direction when there may be multiple issues to discuss.”

“I think I better meet patients’ needs and expectations.”

“I make patients my main focus, and not about myself and my feelings of personal failure if/when a patient does not accept a treatment option. I now see myself as information provider and support system and, despite clear explanations, if the patient still decides not to accept it then I make it clear to them that that is also their choice. I initially found this hard to implement especially with the knowledge of possible health deterioration thus rendering further treatments ineffective if patients do not seek treatment early.”
2 Partnership working with patients:

The ADP graduates described working in partnership with their patients and how this approach can improve outcome, change patient behaviour, improve adherence and improve patient health.

“I have changed the way I approach and think of the way I treat people (as individuals rather than 'patients'), and have realised the importance of people being involved and having a say in the way they are treated. This also leads to an improvement in their condition, as they are more likely to comply with what agrees with them.”

“By discussing and including patients in their own care, I have found that the compliance rate of treatment amongst patients has increased.”

“I now feel more confident during consultations because the ADP sessions equipped me with some key phrases or methods of questioning that I can use when I come across a particularly difficult patient or situation. I let patients tell me what they need from me or find troublesome about their medical condition or medicines; I try to avoid talking to them all through the appointment. This increases patient satisfaction as well as the productivity of the consultation. As a result I feel more satisfied with my work.”

“I feel that I can achieve more in the 20 minutes with agenda setting and I think patients feel more involved as they make the decisions and so their motivation improves. The relationship is more even and this makes for a better consultation and better outcomes in terms of patient health.”

“I feel confident asking the patients what their agenda is and what would they like to address during our appointment. If a patient responds with 'I have no agenda, I am here because the doctor told me I should come' I use a few ‘powerful questions’ which will often bring about a response from them which leads on to agenda setting, problem solving and action planning.”

“I learnt to take a step back from the usual 'giving advice' to probing what the patient thought the problems might be and how she thinks she can change her lifestyle, but also to trying to discover what she thinks we as HCP can do to help, what she feels she needs from us and trying to meet these needs. Also – if her expectations are unrealistic as to what can be achieved trying to address this without making her feel a failure.”

“I think it is all about a mind shift in the way that you deal with patients, a partnership, as opposed to the old style paternalistic approach.”

3 Pressure of time in the consultation:

The ADP graduates described the time pressures they face in their day-to-day clinical jobs. For some, this can limit their ability to use the ADP communication skills. Others described how the ADP allowed them to have more focused consultations within the given timeframe.
“Time restraints often limit the ability to use techniques learnt in ADP and is not appropriate for a lot of patients I see in general practice due to language barriers.”

“The skills taught in the ADP are crucial tools for patient-centred consultations. The hard part is remembering to apply them in time limited high pressure environments. When applied they create consultations that are more rewarding for both parties and more motivating for patients.”

“I think unless you give yourself time to practice the skills they are not used when they can be most helpful. Time pressures seem to have increased and as the skills are not second nature I revert back to a more didactic approach to survive – this is short termism though!”

4 Need for ongoing learning and support from other clinicians:

The ADP graduates have learnt skills that they are applying in their clinical practice, but they describe a need for support and learning, to sustain and develop those skills.

“I think the reason is that this sort of skill requires regular practice, feedback and reflection which I have found hard to do on my own.”

“Would probably have more impact if incorporated within monthly supervision to ensure better practice, reflection and re-application, unfortunately this has been sidelined due to other work commitments.”

“Knowing that my colleagues have undergone this training allows us to have a 'shared language' regarding the patients' experiences.”

5 Need for more information and data on outcome:

The ADP graduates recognise that the skills they have learnt are valuable in a consultation but also want more information about whether this approach to supporting self-management has a measurable impact on improving health outcomes.

“I believe that better understanding and goal setting helps to improve outcomes for the patient as the behaviour changes are owned and more likely to be carried through. I do not have quantifiable evidence of this from my daily practice however.”

“I am unsure, as this is a difficult thing to measure. However it seems obvious to me that if you engage better with a patient that they will engage better with treatment - it is just what happens in the medical world – you have pleasure in seeing a GP who you get on well with and you are much less likely to DNA [not attend] an appointment where you feel that the HCP [healthcare professional] is doing everything he can to help you. So yes, in that sense I believe it does improve health outcomes – indirectly speaking.”

“I am able to highlight instances where patients have outlined how they intend to manage their smoking cessation or illnesses, and patients are more likely to stick to these interventions which therefore improve their health”.
“I think it (ADP) has improved satisfaction more than health. Although it probably increases adherence to treatment and exercise prescription.”

“Have not audited this (whether ADP skill improved health in respondents patients) but would be interesting.”

“I have rated this as neutral (whether ADP skills improved health in respondents patients) because I am not sure that applies to all my patients. It may apply to only some of them.”

“Cannot say one way or the other (whether ADP skills improved health in respondent’s patients). Useful piece of research I think.”

“Excellent training, I recommend it to all my colleagues – even if the evidence proves to not be strong enough (which I hope not be the case) I still think this is an essential training as one could see it from the angle of a customer service training. Absence of evidence is not evidence of absence! It is about choosing the right outcomes to measure the impact - perhaps self management is only one aspect but there are wider benefits I believe. Patient satisfaction, quality, competition, tendering is high on the agenda etc and the more you increase patient satisfaction, engagement, less DNA, increased completion of treatment, the more likely you are to keep your service up and running and potentially expand. There are so many benefits for this training! Great training, I will continue to recommend it to everyone dealing with clients in our case – patients. Thank you again!”

6 Applying new skills in the consultation:

The ADP graduates described how they are using new consultation skills that they learnt on the ADP. They highlighted new techniques that they have learnt, including agenda setting, exploring ambivalence, action planning, goal setting and adopting a motivational interviewing style of consultation. They are teaching others in these techniques and described how these skills are changing their clinician–patient relationship and are improving health outcomes.

“I am now a GP registrar and am using this method very often with my diabetic patients. Not everyone is receptive to it and some are expert avoiders at answering but I find it very helpful for identifying and creating realistic goals with patients for lifestyle modification.”

“I learnt a new approach to communication, a further development of those skills I use and teach to GP registrars. This was especially around how to best understand patient motivation to achieve behaviour change and to use this to jointly develop management plans. I have found this especially important to help patients take ownership of what they are going to take away from the consultation. I have used this learning to improve my consultation style, especially around gauging change around key health promotion discussions such as smoking cessation, harm minimisation in alcohol, management of weight and exercise as key elements of long-term condition management. I also use this new learning to support my teaching of communication skills to future GPs.”
“[I have] learnt how to improve my communication/empathy with pts [patients] – using techniques such as motivational interviewing etc. Really learnt the gravity of what a patient has to face when they are diagnosed with a long-term condition and what that it means in terms of their ability/motivation to make change and improve their health outcomes.”

“Introduction to some useful and simple tools to focus the sessions….. Agenda setting ideas, communication tools, Confidence rulers, how service improvements can support clinical and patient activation.”

“I have used these skills when seeing patients including helping patients to set their own agenda at the beginning of an appointment. This means we can focus on their concerns and issues as well as addressing my agenda re their diabetes control. […] I have used the ‘importance ruler’ to explore how important making changes are to the patient and also how confident they feel about doing this. I think ADP has helped me concentrate on specific issues in a consultation, without trying to cover ‘everything’ in one appointment. Setting an agreed action plan at the end of an appointment, means that the patient has a focus on changes they will try to make before a follow-up appt [appointment] and can share this plan with other HCPs.”

“I have been using regularly couple of skills that I have learnt to motivate patient to make lifestyle changes. e.g. problem solving, smart goal setting, confidence and importance scale, double sided reflection, agenda setting, exploring ambivalence etc.”

“I leant how to support and encourage patients to make decisions, and in fact take the lead role in their management. I am no longer afraid, or take it as personal failure, if a patient does not accept a treatment option. I found that when patients are faced with the decision, and therefore the consequence, of choosing, or not choosing as the case may be, a treatment they feel involved in deciding what happens to them which is very important to them. Patients often feel not in control when diagnosed with a long-term condition, and giving some of this control back is essential.”

Summary – ADP application of learning evaluation

Our experienced clinicians highly valued the ADP. The focus on consultation skills to promote patient behaviour change was novel. Clinicians have implemented skills into their daily practice. We are spreading learning to other LTCs, including COPD. The ADP has stimulated teams to undertake service improvement and fundamentally change their approach to self-management support.

Respondents rated their confidence to use ADP skills as between 8 and 10. We need structured ongoing training but this continues to be difficult. We have provided action learning sets and update sessions, both of which had limited attendance. It is particularly challenging for clinicians to find the time to commit to further training opportunities. We have found that learning has been most sustained when a whole team attends the ADP, which can allow team members to support
each other in applying and learning the ADP skills. In addition, it is likely that this effect also reflects the underlying philosophy of a team in supporting patient self-management.

Some have found their own solutions for ongoing learning. For example, some clinicians have worked with an “expert” in ADP skills, who they invite to observe their work and to feed back on their communication skills. This may be an expert ADP practitioner or a psychologist who is particularly trained in motivational interviewing techniques. It would be valuable to gather together these innovative approaches.

Our experienced clinicians highly valued the ADP. The focus on consultation skills to promote patient behaviour change was novel. Clinicians have implemented skills into their daily practice. We are spreading learning to other LTCs, including COPD and musculoskeletal pain. The ADP has stimulated teams to undertake service improvement and fundamentally change their approach to self-management support.
Qualitative evaluation – interviews of patients and clinicians

Aims of the qualitative evaluation

The aim of this part of the evaluation was to establish whether patients and clinicians who had attended the courses showed increased support for an approach where the patient takes a more active role in their own healthcare and feels empowered to take responsibility for their own health and self-management.

Specifically, the aim was to explore whether, as a result of attending the SMP or ADP course respectively:

**Patients**

- reported taking a more active role in their own healthcare
- felt empowered to take responsibility for their own health
- reported improved confidence and skills in self-management
- were using specific techniques demonstrated on the course, such as agenda setting, goal setting, and goal follow-up
- had made behavioural changes in order to improve their health and self-management of diabetes.

**Clinicians**

- supported the concept of patient empowerment and an approach where patients take more responsibility for their own health
- had changed their consultation style or service specifically to support patients in taking a more active role in their healthcare
- were using specific techniques demonstrated on the course to support patient self-management of their diabetes.

Method

The aim was to recruit 4 to 6 general practice surgeries who were undergoing ADP and SMP training within the study period (2 to 3 in north London and 2 to 3 in south London), and to interview a sample of clinicians (3 per practice: 2 GPs and 1 nurse) and patients (5 to 6 per practice), including interviews before the course and 1 to 2 months after the end of the course.

The Co-creating Health teams at both sites recruited practices according to Co-creating Health guidance, by inviting interested practices to participate, identifying a local champion at each practice, organising ADP courses at a time and location convenient to the practice, and inviting whole teams to the course. The Co-creating Health teams collaborated with practices to establish the preferred approach to identify and recruit patients to the SMP courses.
Clinicians were invited to take part in the interviews by the local champion and patients who had registered to attend the SMP course were invited by Co-creating Health administration. Contact details of clinicians and patients who had agreed to take part were passed on to the evaluation team.

Telephone interviews were conducted by a researcher independent of the Co-creating Health team and recorded with participants’ consent. A semi-structured schedule of questions was used to explore participants’ perception of diabetes care and current needs, the impact of the course on self-care and consultations between patients and health professionals, and perceptions of the course (see Appendix).

Interviews were transcribed and independently analysed for themes by two academic researchers from the evaluation group.

**Results**

**Participants**

Five general practice surgeries held ADP and SMP courses within the study period (3 in North London, 2 in South London).

**Patients**

The practices reported a total of 1,424 eligible patients with type 2 diabetes (range 189 to 472 patients per practice). The number of patients invited to the SMP ranged from 40 to 300 per practice, with the number not known for one practice. Strategies to recruit patients to the SMP varied across sites and by practice: for example, one practice provided the entire list of 472 eligible patients to the Co-creating Health team, whereas at another, the practice nurse selected patients and provided a list of 14 patients to invite to the SMP.

A total of 82 patients expressed an interest in the SMP. The courses were (in total) 15 hours in south London and 21 hours in north London, provided in weekly 3-hour sessions for 5 or 7 weeks respectively. Fifty-three patients started a course and 39 completed (74%), where completion was defined as attending all 5 sessions in south London or 5 of the 7 sessions in north London.

Contact details were provided for 30 patients, of whom 19 were interviewed. The main reason for patients not being interviewed was inability to contact the patient after several attempts. One patient who had agreed to be interviewed, but could not conduct a telephone interview due to hearing problems.

Of the 19 patients who were interviewed, 5 were interviewed pre-course and 18 post-course. It proved difficult to contact patients for pre-course interviews due to a difficulty in establishing a list of patients who would attend the course in advance. One patient who had provided a pre-course interview died during the study period.
The patients interviewed were 9 men and 10 women, with a mean age of 64 years (range 48 to 77), and the most common ethnic groups being White British (N=8) and Black Caribbean (N=6), with the remaining patients being Black Other (N=2), White Other (N=1), Asian Indian (N=1) and Other European (N=1). One patient was working part-time, 6 were not in work, and 12 were of retirement age. The range of former occupations was varied, including skilled, unskilled and professional posts. Time since diagnosis of diabetes ranged from 1 year to over 30 years (mean 10 years).

The mean duration of interviews was 21 minutes (range 12 to 47 minutes).

**Clinicians**

A total of 42 clinicians (31 GPs and 11 practice nurses) attended the ADP from the 5 practices. The courses were 6 hours, normally provided in 3 2-hour sessions, booked 1 month apart, although one practice requested their course as 2 3-hour sessions.

Eighteen of the 42 clinicians (43%) attended the full course, defined as attending all sessions for the full duration. Proportionally fewer GPs than nurses attended fully (12/31 GPs and 6/11 nurses), although this is not a statistically significant difference: Fisher exact p=0.5.

Twenty-one clinicians were approached for interview (15 GPs and 6 practice nurses), of whom 8 were interviewed (7 GPs and 1 practice nurse). The main reasons for clinicians not being interviewed were inability to contact the clinician after several attempts, inability to arrange a convenient time with a clinician who was contacted, or the clinician reporting that they were too busy to be interviewed. The clinicians provided 3 pre-course and 8 post-course interviews.

The clinicians interviewed were predominantly female GPs (N=6), with one female nurse and one male GP. The mean age was 46 years (range 35 to 60) and mean time since qualification 24 years (range 13 to 40 years). Five of the clinicians (4 female GPs and 1 female nurse) were the lead contacts (Co-creating Health ‘champions’) for the practices. The clinicians who were interviewed had higher attendance on the course than average: 5/8 attended the whole course, compared to 18/42 clinicians from the whole sample. However, this is not statistically significant: Fisher exact p=0.3. Nurses and male GPs were under-represented in the interviews, compared to whole sample (comprised of 46% female GPs, 27% male GPs and 27% nurses). The mean duration of interviews was 16 minutes (range 10 to 27 minutes).

**Summary findings from the patient interviews**

In the semi-structured interviews, patients were asked some general questions about their health, diabetes and current diabetes care, followed by more detailed questions about perceptions of their current care and relationship with health professionals, perceptions of the SMP course, and perceived impact of the course, including any changes in their approach to self-management.
Experience of current care

All patients were attending routine diabetic check-ups, which varied in frequency (from several times a month, 3- or 6-monthly, or annually), location (GP surgery, community clinic, hospital, or a combination), and regular clinician at the practice (nurse, GP, or a combination). Some patients were receiving additional check-ups (e.g. for eye or foot care). Some patients were taking medication for diabetes (metformin, insulin, or both). Patients reported a variety of other medical conditions, most commonly high blood pressure, high cholesterol and heart conditions. Medication use varied from none to 13 or 14 tablets a day. Several patients mentioned or were taking medication for depression.

The majority of patients (16/19) reported that they were satisfied with their current care at the practice, that they had a good relationship with clinicians, and that they felt they had the opportunity to ask questions or express concerns as required. For one patient it was unclear what she felt about her current care, and one patient gave a lukewarm response (neither positive nor negative), although he reported that he didn’t ask many questions. One patient reported dissatisfaction with current care: he was disparaging and sarcastic about both primary and secondary care (Patient 18). One patient had been dissatisfied with her previous general practice at the time of diagnosis, but had since moved practice (Patient 13).

In terms of sources of information about diabetes, leaflets provided by the GP or hospital were most commonly mentioned (9 patients), followed by the internet (6 patients). No patients reported using support groups, such as online support forums.

Four patients reported unmet needs in care, which included the two patients who had reported dissatisfaction. These were: help to motivate himself (Patient 18), more help with reducing her HbA1c (Patient 13), more emotional support from the nurse and more consultation time with the GP, and visits by a district nurse to help administer insulin.

Two patients made suggestions for improvement in the approach to diabetic care: one that the GPs at the practice should change less frequently, and another that information should be given to school-age children about healthy eating and exercise to prevent diabetes.

Pre-course expectations

The 5 patients interviewed pre-course expressed mainly information needs. The topics which they hoped the course would cover were: information about diet (2 patients), blood sugar, -erm prognosis, medication and new treatments, and whether current symptoms were a sign of nerve damage. Two patients had no expectations, intending to find out what the course was about on arrival, although one of these patients expressed a worry that the course might involve experimental ‘tests’, resulting in her being ‘made into a cripple’ (Patient 10). This patient reported that she had been sent a leaflet about the course, although she hadn’t read it.
**Post-course: perceptions of the course**

Seventeen of the 19 patients reported that they liked the course.

Of the 2 who didn’t, one patient felt it was ‘boring’ and ‘for beginners’ and attended only 2 sessions. However, he had subsequently cut down on his smoking:

“I wanted to anyway and this course came along and I said, okay, you know, I'll help myself and reduce the cigarettes.” (Patient 12)

The second patient who did not find the course helpful had also been critical about his current care. He felt that he already knew all the information, and that he was unlikely to change. He had refused to take part in the goal-setting activities on the course.

“Well, I didn’t… they just told me things I already knew, you know, a lot of things are very obvious, you know, and when they… I just sat there laughing a lot of the time, and they’d say, ‘What are you laughing at?’ And I’d say, ‘Well, this and this’, and then they said, ‘You’re right.’ I said, ‘Well, there you go!’ [laughs]. And even at the end the woman said, ‘Did you learn anything?’ I said, ‘No.’ ‘Did we tell anything you didn’t know?’ ‘No.’ … We know about it, but it doesn’t mean we’re going to do it … What’s the point, you know?” (Patient 18)

**Aspects of the course which were liked**

Knowledge was the most commonly mentioned aspect of the course, mentioned by the majority of participants (17 patients), particularly information about diet. This included basic information about which foods to eat more or less of, which foods promote more stable blood sugar levels, and how to order a diabetic-friendly meal in a restaurant. Other frequently mentioned topics were: hypos and how to avoid them, long-term health consequences of diabetes, symptoms to look out for, medication, self-monitoring, exercise and good foot care. Some patients had not previously attended a structured education course for their type 2 diabetes and much of the information was new, for example, the information that the dizzy spells they were experiencing were related to their blood sugar, and strategies to manage this. Other patients were aware of much of the information, but valued its reinforcement as a motivator, or the tips about applying the information in practice.

Several patients reported that they made gains on an emotional level, for example, a sense of confidence that their current approach to self-care was along the right lines, to be less hard on themselves, or not to be disheartened if they don’t immediately achieve their goals.

“What I learnt from it was that it’s not an impossible situation, and so long as I look after myself, I can have a full life, within reason.” (Patient 19)

“Understanding that if you don't manage to reach all your goals in any particular week, it's ok, repeat the goal for the following week… it doesn’t mean you’re a failure.” (Patient 4)
More than half of the patients specifically mentioned social aspects of the course: spending time with others who are coping with the same problems, and sharing tips about how to cope.

Several patients reported the value in seeing others who were coping worse than themselves and learning about what not to do from others’ examples. Patients reported that this provided a confidence boost.

“Listening to other people, how they went about things, you know. One guy could walk for miles, another person tried to control their diet, you know, I mean, different things like that. But there was this woman, and listening to her, she was letting everything go in front of her, you know, her kids would get it first, then her husband’s dinner to get made first, never looked after herself, and she got worse and worse, you know. They told her, you’ve got to try and make time for yourself, so just listening to other people’s problems kind of helped.” (Patient 16)

Several patients mentioned that they liked the presenters, either in terms of their general style, or their expertise – the fact that the nurse could answer specific questions about diabetes, or the personal experience of the lay presenter in coping with the condition.

**Patients reporting changes as a result of the course**

Six patients reported specific behaviour change as a result of what they had learnt on the course.

Of these, three reported a sea change in their perspective about diabetes as well as behavioural changes:

1. Patient 17, a retired school assistant, reported that she hadn’t taken her diabetes seriously prior to the course, due to a lack of information:

   *Pt* When the doctor told me I’ve got diabetic, I thought, oh yes, all right; just don’t eat so many cakes. But when I had the class there was, like, good food, exercise, you’ve got to monitor it more, the cuts and... Well, there was a lot. They... It was quite interesting. I got a lot from it.

   *IV* And these were things that you didn’t know before, about diabetes?

   *Pt* No.

   *IV* No; you didn’t know about the possible complications and...?

   *Pt* No, I didn’t know you can go low, high. You can... well, you could die if you don’t keep your weight and that. You know what I mean?

   *IV* Yes.

   *Pt* There was more into it than I realised. It wasn’t just diabetes; it’s my life, diabetes.

She had started to self-monitor more regularly (blood and urine) and exercise (walking locally), and expressed the intention to ask more questions of her GP:

   *IV* But, do they answer your questions and explain things, so you can understand them?

   *Pt* Yes, yes, but I’ve never asked about diabetic that much, but with the depression or the...I, with the liver and that, yes. And when I ask questions and that, yes.

   *IV* Right, but not specifically about diabetes; you haven’t asked, right?
Pt No, but I will now, because it’s more important than I thought it was, so yes.

IV Right, okay, so can I ask you, since you went on the course, is there anything that you do differently now that... from before the course, before attending.

Pt Look, as I said, look after myself better and check the blood more. Like, I never bothered with the urine samples, very much. I do that more regular and I do try and go out every day, because I didn’t go out, just for fresh air and walk around. Because, to get more exercise. I do that more now.

IV You do that more now?

Pt Yes. So... because before, well it’s only that she... they were sort of saying; it doesn’t matter how much you do, as long as you do – you could do something. You haven’t got to run the marathon, like, sort of thing. You know what I mean?

(2) Patient 19, a retired steel worker, had felt invigorated by the course, as a reminder to look after himself and to take responsibility for his own health:

Pt Right, for somebody like myself, that was the first course I’d had for many, many, years, and you tend to forget things. But when you go there you’re reminded of things. You’re reminded how to look after yourself, and you listen to other people’s problems, and they handle the situations, and what have you. I thought it was fantastic. …

I met a few people with diabetes who, perhaps, they are not looking after themselves, are you with me? And I see how they decline very, very quickly, and it’s rather frightening sometimes. For myself, I am again reminded that I have to look after me, and can’t leave it to the doctors all the time. I have to do my share of being responsible for me, like, you know? …

It gives me confidence that I am responsible for my diabetes. I can’t blame the doctor, and expect them to do everything for me. But, the course I was on, again, initiated the responsibility I have by doing the right things at the right times, and getting on with it, and keeping in touch with my doctors.

In terms of self-management, the patient reported that he was ‘more conscientious’ about what he was doing since the course:

Pt Well, before I got into the habit of eating and eating, I mean, I love… I love ice cream, for example, are you with me? I mean, I could eat… I could eat ice cream out of a bucket, but the point is, I can’t do that. And I was reminded again, you can have a little bit of ice cream, there’s no harm, I can have a little piece of chocolate, so long as I’m not gorging myself with it.

IV Right, so, now you can… you watch your diet a bit more than before?

Pt Absolutely.

IV Since you went on the course? Right.

Pt In fact I’ve lost a wee bit of weight, which is good. I mean, I’ve never been overweight, but I’ve lost a bit of weight anyway.

Since the course he hadn’t felt he had set specific goals for himself, but he had made other small changes to his normal routine:

Pt Just a bit more attention about myself, bit more attention to how I live, and the way I live, that’s all. Regular rests. I can’t keep going 12 hours a day, so, I try and get to bed before 11 o’clock at night.
(3) Patient 13, a part-time health care assistant, had attended only 4 sessions of the course, due to her shifts at work, but felt it had had an immense impact:

Pt  Yes, it was what I expected, it was fantastic, the few lectures that I attended actually helped me to control my diabetes.

I mean to make a plan to say, all right, like walking. I’m very lazy, I’m working and when I get up in the morning on Saturdays, the days I’m not working, I will just take a long walk. I don’t run! But I will take a long walk and I will say, all right, this is what I’m going to do this week.

IV  I see, so it helped you make plans for the week.

Pt  Yes, for me to make plans and say...because sometimes the metformin I take makes me go to the toilet, then I will have to control myself, this is what I’m going to do, and it actually helped me to set goals and to try to conquer those goals.

It has helped me and made a lot of difference. I look at things objectively, I don’t sit down and start getting angry with myself or start blaming this, blaming this. I look at it objectively: I have diabetes, diabetes is not going to control my life, I will try to control diabetes. I do things that will improve it, I do a lot of walking, control my diet, and just take things as they come. I don’t sit and get depressed as I used to do, this course has helped me.

The few days that I attended actually gave me...motivated me to do something like my exercise, my eating, my drinking. So I look at life differently from being a sufferer of diabetes, I plan to do something and I will do it. If I plan to go walking I will do it. If I plan to do, to hoover my house, I will do it. I don’t just sit as I used to sit and start brooding about diabetes. That course has actually motivated me to take control of my life.

Three patients reported using specific strategies from the course:

(1) Patient 5, a retired commercial driver, reported success using several strategies: goal setting, problem solving, writing down what he wanted to discuss with the GP, and ordering a diabetic-friendly meal in a restaurant. The patient had applied strategies both to his diabetes self-management and everyday problems, and felt that this had helped his overall efficiency, mood, and consequently his confidence:

IV  Can you say a little bit more about the self-management?

Pt  Well, that’s learning what’s-name, learning to set your day out, right, with your tablets and everything and using your day more to… fully than what I was doing before. So, you’re actually, erm, sort of, working your day that you’re in, instead of trying to do too much, just do a little, right, if you follow what I mean. And make sure you take your tablets at certain times, you know, within your day that you’re up.

Goal setting had helped with his organisation:

Pt  Well, I was going out every day and sort of buying the shopping, but forgetting half of the things that I had to get, so then I went out the next day and I was going back into the same shop to go and get things. Now, I’m actually working a system where, before I leave the house, I write out a list, right, and then go to the shop. And I’ve got a list of everything I’ve got to do during that day, right, and then come home.

IV  Right, and has it improved your confidence in communicating with your healthcare providers? Have you noticed any difference?
Pt  Yes. Well, I've noticed that the surgery... I took the piece of paper with what you want to talk about, gave it to the doctor, she looked at it and she burst out laughing, you know. And she sat there and she listened to me, what I had to say and that was one change, right, because normally, I'm in and out. They, you know...

IV  I see. So you prepared a list ahead of time as to what you wanted to discuss?

Pt  Yes. That's right. I took it when... as soon... the minute I went into her room, right, I slapped that down in front of her, right, and she looked at it, she burst out laughing, like, you know. So, then that was [name of clinician], like.

IV  Right, but then, after she finished laughing, did she then respond to everything?

Pt  Oh, yes. No, she talked to me. She explained it. Yes, it was a good response actually.

In a similar vein, the patient had used problem solving to deal with a problem with his mobile phone, which he felt had helped with his emotions:

Well, it got me frustrated, right, and, well, I don't know if my blood pressure went up but I really got annoyed over it. But then I threw the phone on the table and then I sat down and sort of worked through it, right, so, you know... and I solved the problem and I was... you know, well, today I'm completely better.

The patient also reported increased confidence as a result of successfully eating out in a restaurant:

Pt  And it felt... you know, because of the course, I was told on the course that... not to take out because I'm diabetic, just eat what you fancied, right. So, you know, I had, what was it? Steak, and the chef took all the fat off around it so it's a lean piece of steak, and instead of having chips with it, I had a salad.

IV  Right, and this you learnt on the course then, how you can eat healthily?

Pt  That's right, yes. I learnt at the course was, if you ask, you'll get [laughs], instead of denying yourself.

IV  Right. That's important, right.

Pt  Because, that's the first time I've eaten outside.

IV  Really? And did you stop eating out because of the diabetes?

Pt  Yes, totally. I wouldn't eat anything out.

IV  Were you afraid of eating the wrong things?

Pt  That's right, yes, you know. But, what I was told was that, you eat what you fancy, right. If it's meat and it's got fat on it, take all the fat off, right, so you've got a lean piece of meat, not overcook it and, instead of having chips or potatoes, have a salad with it. And that's what I did, and I did enjoy it, you know.

(2) Patient 6, a former after-school club manager, felt she had learnt useful strategies which had improved her confidence and led to a more manageable approach to her self-care. She felt the dietary advice from the course was more practical than she had previously been given:

Pt  On the DESMOND course, they, sort of, 'Cut out everything'. On your course, on the course that we're talking about, they said that I could have little treats if I wanted to, and it wasn't... it wasn't going to harm me, and things like that. Whereas when I first found out, I just thought, strict diet, vegetables, you know?... I got really fed up with eating food.... but when I went on this course, I learnt that I can eat what... you know, in reasonable amounts, I can eat what... really what I want, you know.
She also valued the strategies to help with her emotional equilibrium:

\[\text{Pt} \quad \text{In the course they had a scale, you know, that you can dip down, and then you can come up again, and how to bring yourself back up again and get on that even keel. That's what I learnt there, and, like I said, I learnt that you don't... you don't have to rush around, you know, you can take things easy, you know.}\]

And goal setting:

\[\text{IV} \quad \text{Right, and do you remember anything that you learned about the goal setting? Do you use that?}\]

\[\text{Pt} \quad \text{Yes, I do. I set myself, say, like, on such and such a day, I say, oh, well, I'm going to do this, and then I go and do it.}\]

In addition, the combination of increased knowledge about diabetes and the strategy of writing down what to discuss with the doctor had improved her confidence in communicating with her GP:

\[\text{Pt} \quad \text{At first, when I first was diagnosed, everything was gobbledegook, but since I've been on this thing, this course, I can understand what he's saying now.}\]

\[\text{IV} \quad \text{Right, okay, so, and you find that helpful, of course, right?}\]

\[\text{Pt} \quad \text{I do, yes, and I find helpful you know the little leaflets that they gave you that you can write down what to say to the doctor before you go there. Because you get there, you get panicked, and then you forget what you're saying. So, they're helpful as well.}\]

\[\text{IV} \quad \text{Right, so, are you doing that, writing it down before you see him?}\]

\[\text{Pt} \quad \text{Yes, I write down... I write it down now, so, I don't forget what I want to ask him.}\]

The third patient, Patient 15, a retired social worker, reported that she was using action planning, although due to a technical failure, details were not recorded.

In terms of other reported behavioural changes, one patient said that he was eating more healthily and watching his intake of salt and sugar as a result of the course (Patient 1), and one patient reported that she intended to write down information prior to her next appointment with her GP (Patient 9), whom she hadn’t yet had an appointment with since the course.

From the remaining 9 patients (i.e. excluding the 2 patients who had felt they had learnt nothing from the course), it wasn’t clear whether the course had prompted any behavioural change. These patients said that they liked the course and that they had learnt from it, and in response to questioning, would describe an information topic or a self-management strategy that they were using (such as eating healthily, taking exercise or action planning). However, on further questioning it would become apparent either that the patient was describing an existing behaviour that pre-dated the course, or that they were describing activities undertaken during the course (such as goal setting), which they hadn’t used since the end of the course.
Perceived barriers to change

Patients who reported that they anticipated difficulties putting their learning into practice mentioned willpower, motivation, comfort eating, difficulty in resisting sweet food, difficulty eating healthily on a low budget, and doctors being rushed (1 patient each).

Two patients reported that they had experienced reluctance from their GP surgery to support active patient involvement in their own care. One patient had visited her surgery to request her regular 6-monthly appointment which was due, but had been told that the nurse would send the appointments out by post. She was disappointed that by the time of the interview, she was still waiting for the appointment (Patient 9). Another patient had reported reluctance on the part of her surgery to supply a blood sugar monitor (Patient 11).

Suggestions for course improvements and future developments

There was a mixed bag of suggestions from 9 patients. Two patients had wanted the course to be longer, as they had missed some sessions for a variety of reasons. Three comments were requests about content: more information on diet, practice in preparing and cooking a healthy meal, and less information on insulin. Two patients commented that the discussions sometimes got side-tracked. One patient wanted presentations to use computers not a blackboard, and one patient commented that some fellow patients on the course lacked basic information about diabetes.

Four patients spontaneously requested a follow-up course, either as regular fixture, an occasional refresher, or simply being able to attend the whole course again every couple of years.

Patients’ spontaneous reference to blood sugar levels and HbA1c

Patient knowledge of actual and target disease management outcomes (e.g. HbA1c test results) is hypothesised to be an important pre-requisite of effective patient ‘activation’.8

Patients were not asked specifically to report their blood glucose levels or HbA1c test results as part of the interview, however, spontaneous references to these were noted. The descriptions identified from 8 patients indicated various levels of understanding and perceived importance of these markers, as well as confidence in discussing them with clinicians and collaborating with clinicians to effect improvements.

To give some examples:

One participant (Patient 10) showed lack of confidence in understanding her blood sugar levels:

**IV** Do you have any concerns about your diabetes? Do you have any specific concerns?

**Pt** No, only when I go there to take my sugar. Then they might tell me it’s gone up one, or gone up, or it’s lovely, or something, you know.

**IV** Right. But do they explain things in a way that you understand?

**Pt** Well, it’s not... My diabetes is... My diabetes, it’s not my diabetes. It’s not bad to that extent. They only tell me if sometimes... if it’s six, it might go up to seven, or... um, six it might... at five, or something like that.

**IV** But do you understand what it means when they tell you the number six or five or...? Whether it’s gone up or down, do you understand what it means?

**Pt** That would be... If it’s... if it was five and it had gone up to six, or it was six and it’s gone up to seven, that means that it’s gone up.

**IV** Right. But do they explain to you what it means?

**Pt** I don’t remember if they... Maybe. Maybe. I just can’t remember.

**IV** Right. And do you ask them questions about it?

**Pt** No, not directly.

In the post-course interview, this patient mentioned blood sugar while describing her current health and a recent blood test, and again, showed little sense of ownership or control over her own blood sugar levels or the test results:

“My condition. My condition. Because I not only have sugar, they said that I have sugar, not only that alone, my pressure is very top and I had two big operations. … Well, it’s the first… Remember I told you that I went to see the doctor and took the blood test. It’s the first I’ve seen my doctor. I haven’t seen him again after that. So you can’t say nothing much about that so far because you haven’t seen him. It was just one time and it was… there wasn’t enough time to say, you understand?”

One patient expressed a concern about her HbA1c, but was aware that she was struggling to articulate this (Patient 13, post-course):

“The last time I went she told me my, is it HB, is it H, HABC, is a bit high so the doctor wrote for me to come and he has referred me to a diabetic clinic… No matter how I try I do control my sugar level but it’s just HABC that is actually giving me concern, it doesn’t seem to be going down. And I, you know what I’m talking about.”

Another patient reported her own approach to responding to her blood sugar levels (Patient 8, post-course):

**Pt** Well, when I go they give the good encouragement and they tell me what is what and increase my medication, and things like that, and then check up again, you know. And they give me booklets, they write down...[to] test my sugar levels three times a day, which I don’t even bother do no more because for me don’t make no sense. If it’s high and I take my medication, it go down a little bit. It still go high, then it do down, then maybe drop to three point this, then I bring it back up, and it is up and down, they know that, so.

**IV** So you don’t bother checking it yourself, then?

**Pt** I check it sometime. I do check it sometime.

**IV** Sometimes.

**Pt** It depends on how I feel. If I feel funny, I check it.
One patient was concerned about his blood sugar levels and had wanted to continue self-monitoring (Patient 5, pre-course):

“I was taking... doing the tracking of it myself, but the last one I did was 5.8 and my doctor told me not to bother anymore.... The only thing that I would like to find out is whether I've got too much sugar or not enough, you know, because when I asked that question before they turned around and said, if you go giddy, take... that's [unclear] for you, right, and then if you go giddy and you find you get hot and clammy, your sugar's low and just suck on a sugar sweet. That's all I was told.”

This patient did not mention blood sugar in the post-course interview.

One patient had successfully persuaded clinicians to provide a machine for self-testing, although she remained concerned about her blood sugar in comparison to target levels (Patient 11, pre-course):

IV Right, and which aspect of the condition worries you the most then?
Pt I think about it getting worse and me not being able to cope with it. I mean I would like to stabilise. I don't know if I'm stable.
IV You don't know if you're stable, right.
Pt No, I don't. I know that the government changed the guidelines not long after I was initially diagnosed, and I know that I've never been able to achieve what is apparently the optimum on the government's guidelines.
IV All right, and do you know how to keep track of your blood sugar yourself?
Pt I do, because I asked for a machine, which was not... They didn't originally want to give it to me because, I think they thought I would become a neurotic self-watcher, but I look at that on an irregular basis. But if, for example, I'm on holiday then I will look at it probably every day, because I'm out of my normal routine.
IV Right, and within your normal routine how often would you look at that?
IE Maybe once a week, maybe once a fortnight.
IV Right, okay, and then when you see a difference, right, in the levels, what do you do next then?
IE I stop drinking tea and coffee, and tend to drink a lot more water.
IV Right, okay.
IE Because I don't like tea or coffee without sugar [laughs].

Post-course, the patient mentioned blood sugar only in the context of informing the interviewer about recently scheduled blood tests.

Summary findings from the clinician interviews

Clinicians were asked about their role in diabetes care, previous relevant training, perceptions of current care and unmet needs, perceptions of the ADP course, changes in consultation style or practice as a result of attending the course, and suggestions for course improvement.
Overall, the interviews highlighted a mix of views across all interview topics. New points were made by all interviewees, and there was no evidence of saturation of themes across the topics.

All clinicians were involved regularly in the care of patients with diabetes, although their role varied across practices. All clinicians felt that they had previously received some relevant training, either from their basic medical or nursing training, postgraduate training or other courses attended (e.g. in motivational interviewing), although their perceptions of how well this had prepared them for consultation with patients with LTCs and type 2 diabetes varied.

**Perceptions of current care**

Clinicians held a variety of views about the effectiveness of current care provided by the health service for patients with type 2 diabetes. Five clinicians gave an overall positive evaluation, with descriptions ranging from ‘pretty good’ to ‘brilliant’. These clinicians highlighted the range of services, the evidence base for treatments, NICE guidelines, and the DESMOND structured education programme. Three of the clinicians mentioned the role of the QOF (NHS Quality Outcomes Framework) GP incentive scheme as a means of improving and/or monitoring the quality of care. The three clinicians who gave less positive evaluations used descriptions ranging from ‘variable’ to ‘poorly’, noting problems with lack of time, lack of emphasis on promoting lifestyle change, too much emphasis on medication and medicalising the problem, lack of focus on the patient, lack of a systematic approach and poor continuity of care.

When asked about barriers to effective care, clinicians mainly focused on patient factors: lack of understanding of diabetes and its long-term implications, failure to understand that being symptom-free does not indicate good health, denial, lack confidence or motivation, failure to appreciate the importance of making lifestyle change or taking medication, depression and other life issues, lack of ownership of the problem, and failure to attend. A few clinicians also mentioned factors involving both doctors and patients, such as a conflict of agendas in the consultation, lack of support for patients to take control, and the need for both doctors and patients to change the traditional mind-set that it is the doctor’s role to ‘sort out’ illnesses. One clinician noted that doctors often find it easier simply to give instructions due to a shortage of time.

Clinicians had a range of suggestions for improving current care. The most frequently mentioned was the need for more time, for example, to allow clinicians to get a more detailed picture of the patient’s individual circumstances in order to tailor advice, or to ensure that patient education isn’t fitted in only when time permits. One clinician suggested a change in the appointment system, to give patients much greater input at the time of diagnosis. This clinician suggested that if time was invested to embed self-management skills at the outset, the standard 10-minute consultation would be sufficient for routine care in the long term. Another clinician suggested better use of time, so that the right people could deliver ‘the right messages in the
right place when the patients are receptive’. Several clinicians mentioned improved communication among health professionals and continuity of care across different parts of the service. Other suggestions were to support patients to self-care and be in control, and to improve accessibility by making it easier for patients to have appointments.

**Pre-course expectations**

The 3 clinicians who provided pre-course interviews had different hopes for the course:

- Clinician 3 hoped to learn how to make consultations more effective within the time, to personalise care and to achieve more meaningful management, rather than ‘simply ticked boxes, and see them again in six months’.

- Clinician 4 wanted the whole practice ‘to understand what patient-orientated medicine, expert patient, means’ and to find a way around the problem of time constraints.

- Clinician 8 wanted to learn techniques to help engage patients in changing their lifestyle and improving compliance with medication. He described his frustration at giving the same advice time and time again, making him feel like a ‘bully’ and a ‘failure’.

**Post-course: perceptions of the course**

The clinicians showed a mixed response to the course.

Three clinicians were very positive:

“I now feel much more confident in helping patients to identify how they can help themselves, and how they can take control of their own care.” (Clinician 2)

“I really enjoyed it. I thought it was very well delivered. It was really nice to do it in a house with our team, because it felt very relevant to, kind of, embed it into the way things, the way we work in the practice, and it was a nice, sort of, team building session as well. And I thought it was useful and relevant, and nice to focus on”. (Clinician 3)

“I think the programme was very good. I think it was well run and organised, as a practice we like learning with each other… fun to do it as a practice…I think it’s made me more aware of the, you know, importance of self-management, or more acutely aware of that.” (Clinician 7)

Three clinicians felt the course was fair, or met expectations:

“I think it is really helpful in primary care, but I don’t think the focus should be on this is a new way of managing patients or… because I think that absolutely isn’t the case, but it’s more here are some tools that you may find helpful in your sort of goal of sharing management with patients, and, you know, this is how we’re going to help patients get on board, as well. I mean, I think… I think it has definitely raised awareness in our practice about… and made us think about… how we can sort of move this agenda forward for all our patients with long-term conditions and sort of, you know, having care plans together. So it’s definitely sort of raised it in
our minds, but I'm not sure it has actually made us take a very practical step forward yet.”
(Clinician 1)

“It was, I think it’s very useful, I think it’s got potential, but I think that people have got a long way to go before they change their – and I mean patients and practitioners – before they change their habits. So, I can see that it’s not an instant win”. (Clinician 4)

“I’m just not convinced about the, kind of, actual Co-creating Health thing in the general practice sector... I’m not so convinced about it that they have to, in terms of people that are coming with multiple unsorted problems in general practice and trying to work through that and, or you decide to deal with it or not.” (Clinician 8)

Two clinicians were more negative:

“I was a bit disappointed, and I’ll tell you why. It was because there was very little background into what motivational interviewing is, and what I have found really helpful from my reading… the one thing that I most remember is the sentence that says, you know, it is human nature that, when you are criticised, you automatically put up a front and you refuse to do anything, and I think it would have been interesting to have a bit of psychology and to explain to the staff why they have to do it in the first place.” (Clinician 5)

“It was much too long and boring, and it repeated a lot of stuff which, certainly all the younger doctors, know already. They’ve all been trained in it… It was a complete waste of time and they only did it because I think there was some financial incentive… I didn’t really know [what to expect] because it had some stupid title that you couldn’t guess from the title what it was going to be at all. I can’t remember, what was it called? Co-creating Health or rubbish, which completely doesn’t tell you what it’s about; it’s supposed to be about communicating risk and stuff with diabetic patients. It was written by people who had no experience of general practice and who weren’t very bright.” (Clinician 6)

**Clinicians reporting changes as a result of the course**

The specific skills were very popular, particularly the ruler for patients to rate the importance of a particular aspect and their confidence in addressing it (reported by 5 clinicians), the strategy to explore patients’ ambivalence by reflecting back to the patient the pros and cons of a possible course of action (3 clinicians) and goal setting (3 clinicians). For goal setting, however, clinicians reported that they felt the need to manage patients in order for this to be practical: one clinician said she needed to ensure that patients suggested goals that were small and manageable, another felt it was particularly important to document the goals to ensure they were followed up, and a third clinician had developed a leaflet to use with patients to record their targets specifically with regard to improving their biomedical markers. A few further strategies were mentioned by individual clinicians, such as asking patients what they have done to improve their
health (rather than starting off by nagging them), and making a simple statement to a patient that if they don’t want to follow the recommendations, then it is up to them:

“One question that the nurse said was quite good, I think it was the thing about, okay well if you don’t want to do any of the things I’ve suggested, that’s up to you, if you don’t want to take tablets or lose weight, that’s up to you. That’s quite a useful thing to say. Normally I just say, well as you know if you don’t get your diabetes under control, you risk going blind and having your legs chopped off.” (Clinician 6)

A few clinicians noted that the course had highlighted the importance of involving the patient more in their own care, as an overall approach, although their descriptions of translating this into practice generally took the form of involving patients more in the beginning of the consultation when setting the agenda or remembering to ask the patient what was important to them.

Only 1 clinician (a female GP) appeared to experience a transformation of approach, where she felt that her previous consulting style, although she had tried to be ‘patient-centred’, simply hadn’t put the patient in centre stage of their own health:

“I think it was quite a paternalistic… even though I tried to be patient centred, it tends to be like very much, sort of, paternalistic, focusing on how we can get down the HBA1C with medication maybe, rather than sort of actually, sort of, people leading their own way… Well I think in medical school, and also as a GP particularly, we’re taught how to consult in a very patient centred manner. But we’re not taught the whole concept of motivational interviewing which is what this training is very much based around. And it’s also about recognising that it’s about co-creating health, it’s about working in conjunction with your patients, so that they can take greater responsibility. And I just don’t think that... it certainly wasn’t taught when I was a medical student, and even a GP. And I think this takes training one step further, this is about learning a very new technique which certainly wasn’t taught to me as a medical student. And so I feel that this needs to go right back to the communications training, and how to carry out an effective consultation in medical school.” (Clinician 2)

**Perceived barriers to change**

Time proved the most frequent response to this line of questioning. Clinicians mentioned the difficulty of embedding the skills in practice – remembering to look at the list of strategies, for example, in a busy clinic; having time to practise the skills so that they can be used effectively; using the skills for every patient rather than only when there are difficulties with the consultation; it is often quicker to tell the patient than to ask or listen; and the need for clinicians to establish the approach in routine care before time drifts by and you ‘just revert to normal’. One clinician who reported using ‘all of the skills’ had noticed a significant impact on consultation time:
“I use it all the time, it’s doing my head in because my consultations are so much longer now, that I’m running horribly late most days… I’m hoping that in time that people will make those changes and that will in turn mean that the consultations are much shorter, because everyone is kind of singing from the same hymn sheet, and actually patients are self caring more effectively and not needing to see me so often… So it’s about, sort of like, investing to save - I’m hoping.”
(Clinician 2)

Suggestions for improving the course and future developments

The clinicians didn’t mince their words when giving feedback about the course. Several clinicians reported that it was too long, with a lot of repetition, and that there was a need for ‘a more challenging level’ of content, and trainers who were more suited to teaching GPs.

Other suggestions included spending proportionally more time practising the skills with the actors and less time ‘selling’ the approach that patients should be more involved in their own care. However, clinicians did note that there was considerable variability within their own practices about their colleagues’ ‘buy-in’ to this approach and likely normal consulting style. In particular, some clinicians noted that their GP colleagues felt that they had already been trained in consultation skills and knew all of this already, but it was not known how they actually consulted in practice.

Several clinicians were quite concerned about the possibility of the learning being lost over time, as pressures of the reality of general practice pushed the ideas and strategies to the background. Some suggested that their practice needed a refresher session or simply a whole practice meeting specifically to make plans for embedding the approach into routine care. One clinician reported that the practice had already held a follow-up session, which she had found to be a useful motivator to remind her to use the strategies. Another practice was considering how to incorporate the approach into a LES (NHS Local Enhanced Service) GP incentive contract.
Conclusions – qualitative evaluation – interviews of patients and clinicians

Attendance and participation as a marker of interest in this initiative

Basing the courses in the general practice setting proved disappointing in terms of involving patients and clinicians in the initiative. The proportion of patients who expressed an interest in attending the SMP course was low, compared to numbers in the apparently eligible population. A quarter of patients who started the SMP did not complete it, and the 39 patients who completed the SMP represented only 2.7% of the eligible population of 1,424 patients from the 5 practices.

The clinician response was similarly disappointing. Out of the 42 clinicians who attended, less than half attended for the whole course, despite the length of the course (2 or 3 sessions) and the courses being booked at a time convenient to the practice, in the practice, as part of a whole practice initiative. Of the 8 clinicians who provided interviews, 5 were the Co-creating Health champions for the practices, so the views obtained are likely to be much more positive than is representative of the clinicians from these practices. The views of nurses and male GPs were also under-represented, due to low levels of participation in the interviews.

The role of the patient in their own diabetic care

Although patients were generally satisfied with their current care and their relationships with their regular clinicians in the practice, generally patients seemed to be in a passive role with regard their routine care. Patients were sent appointments (whether in general practice or at the hospital) at a frequency determined by others, rather than being involved in setting their own schedule. As a result, they were often vague about the frequency with which they had routine appointments and details of their own condition, including test results.

Clinicians didn’t particularly report that they felt in charge either – pressure of time dictating what could be covered in a consultation was a persistent theme. Clinicians felt constantly frustrated that patients appeared to lack understanding of their condition and motivation to change, while acknowledging that there was little time to address these when juggling competing priorities at a patient’s appointment.

Patients’ responses to the SMP

Patients were generally very positive about the course. Patients liked the format and the content, and particularly appreciated the focus on knowledge, regardless of whether or not the information was new to them. About a third of the patients had made specific behavioural changes to their self-management, and three of the 19 patients had reported a transformation in
their perspective of their diabetes, where the course had highlighted not only the importance of the condition but their own role in managing it.

Although there were only two patients who were adamant that they hadn’t learnt from the course, there was little evidence of change in behaviour in the remaining majority of patients. It wasn’t clear whether some of these patients were likely to apply their learning in due course, or whether patients had enjoyed the course but subsequently had no intention of changing their routine. To be fair, as the interviews took place shortly after the course (on average, within 1 to 2 months), there was little time for changes to be embedded, and there was no follow-up of biomedical health markers which might have picked up more subtle changes that patients may not have reported.

However, the results showed that while some patients had gained a great deal from the course, the majority had shown no obvious change. This raises the question of whether some patients may need additional support in advance of a course, or a course to be provided in a different format, in order to help patients to prepare for the course, and to get the best out of it.

As an aside to the questions about the impact of the course, it was decided to look at patients’ references to biological markers of diabetic control in the interviews. For patients to be empowered to address their type 2 diabetes, an understanding of the key biological markers of diabetic control (HbA1c and blood glucose levels) would be expected, as well as a sense of confidence in discussing these with their regular health professionals. However, these outcomes were mentioned infrequently by patients in the interviews, and the descriptions indicated that patients generally did not feel that they understood, or had ownership of, this aspect of their health. There was no indication that patients who had attended the course felt more confident in having discussions about blood glucose levels or HbA1c with health professionals, or that they felt that they had a greater sense of control over how to manage these themselves.

Clinicians’ responses to the ADP

The difficulty in recruiting interviewees and the poor attendance at the courses – despite following the Co-creating Health model promoting a whole practice approach – is the key message from this study. The clinicians who were interviewed gave a mixed response, some very positive, some less positive, some more negative, which was not at all as positive as would be expected from a small sample of clinicians who were mainly comprised of the Co-creating Health champions of the practices.

Several of the clinicians reported using the strategies from the course, with some positive results, but the interviews indicated that only one clinician felt that her approach had genuinely transformed – that she felt that all her previous training and experience had essentially been based on a doctor-centred perspective of a ‘patient-centred’ approach. Similarly to the patients,
the results suggest that some clinicians are more ready for this initiative than others, and that a ‘one size fits all’ approach is not necessarily most effective. Training a whole practice at a time proved less successful than expected, suggesting that alternative approaches might be worth considering.
Overall discussion and conclusions

The Co-creating Health project has been a challenging, exciting and inspirational initiative, which has drawn together clinicians, patients and managers, across primary, secondary and community care, to work together to improve healthcare and self-management support. At the GSTT and WH sites, we concentrated on developing and providing this new approach for patients with type 2 diabetes and the clinicians caring for them.

We were able to show a clinically significant improvement in diabetes control in patients who attended the Self-Management Programme (SMP) with a poor starting HbA1c. The reduction in HbA1c of 0.6% (in those with a starting HbA1c of over 7.5%) if sustained will have a significant impact on reducing the risk of diabetic complications. This is of particular importance given that diabetic complications are the major cause of patient morbidity and the chief source of great cost to the NHS in diabetes management. It is further important to note that this degree of HbA1c improvement is similar to that reported with the newer antidiabetic drugs being developed and launched. For example, there has been a huge growth in the use of DPP-4 inhibitors (Dipeptidylpeptidase-4) over the last 2 years. The most used agent, Sitagliptin, gives a mean reduction in HbA1c of 0.61% at the usual treatment dose of 100 mg daily.9 A year of treatment with Sitagliptin will cost the NHS £434 per patient.10 In comparison, the SMP will give a similar reduction in HbA1c, but will also give the patient the skills to manage the other multiple co-morbidities and long-term conditions they are struggling with.

There are undoubted challenges to providing the SMP to all patients with type 2 diabetes. Virtually all patients really enjoyed the SMP and particularly noted improvements in their diabetes-specific knowledge. They want the SMP to continue in some format. However, there are issues relating to limited recruitment of patients onto the programme. Some recruitment strategies work much better, especially direct and personal invitation from a clinician known to the patient. With the very large numbers of patients with type 2 diabetes locally and nationally, if recruitment was optimised, there would also be a significant problem with provision of SMP places available for patients. Different strategies would need to be considered, including trying to identify the characteristics of patients who respond best to the SMP, which might perhaps include the starting level of HbA1c, level of patient activation and level of patient knowledge.

The Advanced Development Programme (ADP) communication skills training was highly valued by some clinicians, who described increased job satisfaction, partnership working with patients and new skills learnt and used. However, this was not a universal opinion and there appears to

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be a very different response relating to the setting of the training and the profession of the clinician. In Co-creating Health Phase 2, for the prospective evaluation work, at both sites we concentrated on providing the SMP and ADP to whole GP practices, including GPs and Practice Nurses. The ADP training was therefore provided to a range of clinicians, from the most passionate advocates of self-management support and champions of diabetes care through to the notably less enthusiastic. It was difficult to access feedback from these clinicians and when achieved, was not so positive.

In contrast, the Application of Learning Questionnaire was sent to a diverse range of clinicians who had done the ADP, across primary, community and secondary care, including many different professionals managing many different conditions. Their strongly positive feedback described a highly valued course that gave them new skills to apply in their clinical work. This may reflect their volunteering to take part in the ADP and perhaps a more flexible attitude to learning new skills. In the future, different recruitment and ADP provision strategies would need to be considered, including identifying which components of the course are particularly valued by different clinicians and perhaps, patients and clinicians doing training together.

We did not achieve a whole scale transformation of patient health or clinician ways of working in the GP practices involved in this evaluation. There are various barriers to this whole systems change that we need to review and we would suggest that this is a focus for the Health Foundation in the future. The patient journey from passive recipient of healthcare to an active self-manager, directing their own medical management, is long and arduous, both in terms of time scale and workload involved in changing entrenched patterns of behaviour. This is unlikely to happen in a sustained manner after a single course. The clinician transformation from didactic, paternalist to a supportive clinician working in partnership with the patient is similarly demanding and clinicians described going back to the comfort of the “old ways of working” under the pressure of time and the ongoing stress of the clinical environment.

Unfortunately, the GP practices involved in this evaluation did not undertake any known work in service improvement, despite this being discussed as part of the final training session on the ADP. For the Islington practices, this may have been because there is a Diabetes Locally Enhanced Service (LES) being launched, which focuses on self-management and they may have put change on hold until this starts. In Lambeth and Southwark, a modernisation initiative, launched after the Co-creating Health project, may be having the same effect. Currently healthcare services do not significantly support patient self-management. The consultation between clinician and patient is at the heart of healthcare. If healthcare systems are not changed, sustained self-management support will not happen. The ADP communication skills need to be embedded into practice and routinely used at all patient consultations around long-term conditions. Healthcare systems need to change so that embracing agenda setting, action
planning and goal follow-up becomes routine in the consultation and patients are continually supported to improve their health, change behaviour and actively self-manage.

While we continue to strive for this ideal of the Wagner Chronic Care Model (3), we have shown that the SMP and ADP bring improved healthcare outcomes and improved quality of care in the consultation. The improvement in HbA1c and glycaemic control after attending the SMP is of particular note and will convert to a significant reduction in diabetes complications and improved outcomes for patients. Supporting self-management is a key feature of care planning and all of these approaches are now a fundamental part of high-quality care, as defined and expected by the NHS (4) and the National Institute for Health and Care Excellence (5). With the work we have so far undertaken, we are prepared to face the challenge of sustaining and spreading the Co-creating Health approach to supporting self-management in the future.


13 NICE. Diabetes in Adults. NICE Quality Standards, QS6, March 2011. Available at: http://guidance.nice.org.uk/QS6
Appendix – Qualitative evaluation – interview schedules

Semi-structured interview schedules for the patient and clinician interviews

(1) Patients’ pre- and post-SMP interviews

Note: Questions are indicative of areas to explore. Actual wording, questions asked, etc, are dependent on responses/responsiveness of the interviewee.

Demographic information
Could I begin by asking you a few questions about yourself:
1. Age/Gender/Marital status/Children/Education level/Work status/Ethnicity?
2. How long ago were you diagnosed with diabetes/told you have diabetes? (Probe for an account of how did you find out you had diabetes, and could you tell me how you felt about it at the time?)
3. Are there any other long-term conditions you’re being treated for?
4. Could you tell me which medications you’re currently on (specifically for diabetes or any?)

Current healthcare utilisation
1. How long have you been with (particular) practice?
   Thinking specifically about your diabetes:
2. What tests/GP visits/hospital appointments specifically for diabetes: frequency (within the past year?)
3. Relationships with doctors and other health professionals – are needs being met?
4. Could you tell me about your experience when you go for routine check up? (Probe: Who do you see? GP/Hospital Specialist/Nurse?).
5. Continuity of care: Do you usually see the same person? Does it matter to you whether you see the same person or not? (Probe: If yes, why?)
6. Do you feel you are able to tell them about your concerns? Do you feel they understand what you’re talking about?
7. Do they answer your questions and explain things in a way you can easily understand? (If not: please explain why) Can you give any examples?
   Probe: Do you feel they understand your concerns? Given sufficient time to express your concerns? Are you listened to? Do you feel you have enough time to ask questions? Is there anything lacking in your routine check ups?

Support
1. Do your family or friends get involved in the day-to-day management of your condition? (How, in what way?)
2. Has it affected your relationships, family, friends in any way? (If yes, in what way?)
3. How supportive do you feel your family/friends/healthcare providers are? Which, if any, do you rely on most for support? (Practical or emotional or both?)
4. Where do you get most of your information about your condition from? (Probe: Membership of any national or local groups? Do you belong to any diabetic support group? Use the internet (Diabetes UK), social networking sites etc?)

**Patients' beliefs about illness, current concerns/difficulties**

I’d like to ask you a few questions about the impact diabetes has on your quality of life/emotional health/physical health/family/day-to-day tasks:

1. How difficult have you found it dealing with your condition? What’s been the most difficult for you? (Probe: Why?)
2. Which aspect of your condition worries you the most?

**Perceptions of the SMP course**

1. General Impressions/Expectations
2. Specific likes/dislikes
3. Perceived learning/Development
4. Usefulness-effects of the intervention
5. Suggestions for follow-up
6. Do differently?
7. Any other factors contributing to participants' experience?

1. Impressions of the programme as a whole – Did it meet your expectations? Was it what you expected? In what way?
2. Which aspects did you find best/most helpful/least helpful? Why?
3. As a result of participating in the course, do you feel you are able to understand your illness/cope with you illness/keep yourself health/confident about your health?
4. Do you feel more equipped to improve things about your own health? In what way?
5. Has it increased your understanding of potential complications and how to prevent them? (Probe for specific examples)
6. Do you feel you have learnt any skills to enable you to cope better with your symptoms or issues you might have? (Probe which ones, what would you now do differently? If not, elaborate) (Note any spontaneous mention of goal setting/action planning/confidence level/communicating with healthcare professionals)
7. Has attending the course made any real difference, given you something practical you can use? (*Probe for specific examples*)

8. Do you feel any clearer about what you can do to self-manage your condition/look after yourself/your diabetes? (*How? In what way?*)

9. Overall, do you feel that you are able to manage your condition/diabetes better than before attending the course? (*Probe why, in what way, why not, what gets in your way/obstacles to self-management*)

10. Have you been to see your GP/nurse since attending the course? Was communicating with your GP/nurse any easier/different than before the course? (*How, in what way?*)

11. Do you feel more confident about getting what you need out of your consultations?

12. If you have to choose one thing/main/essential thing you’ve got from attending the course, what would that be?

13. Are there any issues, things not covered/or not explored enough that you would like to follow-up on?

14. Any aspects of the programme that you think could be improved? Would do differently/make improvements/that would be more helpful?

15. And finally, is there anything else you’d like to add, either about the course itself, or your own experience with managing your diabetes?

*(2) Clinician pre- and post-ADP interviews*

**Demographic and general information**

*Age/Gender/Role in GP practice*

*Year of professional qualification/How long in particular practice*

1. Role in relation to patients with diabetes – how many patients with type 2 on average would you see in a month?

2. Has your role, in relation to diabetic consultations, changed over the years? (*Probe: If yes, how?*)

3. Average length of time you would normally spend with these patients per visit?

**Previous Training**

1. Have you had any previous training specifically in consultations with patients with long-term conditions like diabetes? (*Probe: Can you recall what was the main emphasis/skills taught?*)

2. Has your general training as in communication/consulting skills proved adequate for these consultations? (*Why/why not? What’s lacking?*)

3. What to you are the key difficulties in consultations with patients with diabetes?
4. What do you think are the main obstacles/barriers which prevent patients from improving self-management of their condition?

**Awareness of issues**
1. What’s your opinion about how patients with type 2 diabetes are looked after overall by the health service (not specifically by you, or your GP practice).
2. What, if anything, do you feel needs to be improved? *(If more than one thing mentioned, probe: if you could change just one thing what would that be?)*

**Impressions of the ADP course as a whole – expectations**
1. Impressions of the programme as a whole – which aspects did you find best/most helpful/least helpful? *(Probe Why/how?)*
2. Did it meet your expectations? In what way?

**Ability to apply concepts taught/effectiveness of skills taught**
1. Has attending the course made any practical difference in your consultations with type 2 diabetic patients? How/In what way/examples?
2. Are there any specific skills you’ve picked up or improved upon since attending the course in order to help patients improve their self-management of their condition? *(Reflective listening/Goal setting/Understanding patients’ concerns/Action planning/Follow-up?)*
3. If you have to choose one thing/main/essential thing you’ve learnt in order to increase your effectiveness in supporting your patients, what would that be?
4. How confident do you feel that you will be able to put the skills taught into practice?
5. How confident are you that the skills covered/taught such as reflective listening/goal setting etc will make a real difference in your patient’s abilities to self-manage their condition?
6. Do you feel that your consultations are different/have changed from before the course? In what way? *(Probe: If not, why not?)*
7. Do you feel better equipped in dealing with patients who are not managing their condition?

*(If SMP course has already taken place for the practice)*
1. Have you had a consultation with a patient that has attended the self-management course? If Yes:
2. Have you noticed any change in the consultation on the part of patients who have attended the self-management course?
3. Since attending the programme, has talking/communicating with your patients been any easier/different? How, in what way?
4. Have you found any difference, age, gender, ethnicity social background, in terms of what works/what doesn’t work in these consultations?

**Final thoughts on programme**

1. Any aspects of management of diabetes that wasn’t covered/left out/need more thinking about – for future improvement to the programme? Anything more that could have been achieved? Anything missing?

2. And finally, since attending the course, has your view as to what constitutes a good consultation changed or not? If yes, how?

3. Is there anything you would like to add?

4. Has there been any feedback from other members of your team about their thoughts on the course?