

# Co-creating Health

## Supporting Self Management

### For people with long term conditions



#### **Self Management Programme Reunion March 2009**

Co-Creating Health takes a whole systems approach to transform the patient-clinician interaction into a collaborative partnership.

A partnership between The Whittington Hospital NHS Trust, NHS Islington, NHS Haringey was selected in July 2008 by The Health Foundation to be one of the 8 UK demonstration sites.

The programme is an innovative collaboration between primary and secondary care and between clinicians and patients. The focus locally of the Co-Creating Health initiative is type 2 diabetes.



# The Whittington Hospital Diabetes Outpatient Clinic Philosophy

We will work in partnership to support you in managing your diabetes.

We will be welcoming and listen to your concerns in a confidential and professional manner.

We value your opinion about our service and will often ask for it, using either surveys or questionnaires.

We actively support our staff in professional development.

We provide training for our patients through self-management programmes.

Together we aim to co-create high quality care.

*Developed at a service improvement workshop in December 2009 by clinicians and a patient who has completed the self management programme*





# Key Achievements



- ❖ Statistically significant reductions in HbA1C and LDL cholesterol in patients participating in the Self Management Programme
- ❖ Feedback from patients on the Self Management Programme is overwhelmingly positive:
  - 100% would advise other patients to attend the Self Management Programme
  - Patients score the programme 9.5 out of 10
- ❖ Regular quarterly self management programme reunions involving question and answer sessions with diabetes specialist clinicians.
- ❖ 96% of clinicians who have attended the Advanced Development Programme said the ADP provided them with new skills to use and 89% would recommend the ADP to others
- ❖ Monthly process and outcome measures are demonstrating consistent improvements in consultations. Care planning consultation is taking place with increases of recorded collaborative agenda setting, goal setting and follow up on goals. 70% of consultations set an agenda, 62% set a goal, 70% set an action plan and 73% set a goal follow-up.
- ❖ The Consultation Quality Index (CQI-2) was used in the diabetes clinic, to measure patient-centred care and clinician performance in 2008 and again in 2009. Clinic scores increased across all elements, including patient enablement (6.3 to 7.0) and clinician empathy (43 to 46)
- ❖ A Core Group of patients formed to inform service improvement
- ❖ NHS Islington Pilot self-management LES
- ❖ Service Improvements – confidence ruler; agenda/goal setting sheet; templates (on electronic patient management system and in notes) prompting care planning
- ❖ A LEAN diabetes clinic
- ❖ Work presented at Diabetes UK national conference (2009) and IHI International Forum (2010)
- ❖ Featuring in a British Medical Association news article
- ❖ Presentations at national vascular & IMPRESS conferences

## Key achievements we heard about in our Strategic workshop:

- ❖ Primary and secondary care collaboration
- ❖ Hearing ADP participants changing their practice
- ❖ Developing measures that have been adopted by CCH
- ❖ Using the three enablers knowingly in consultations
- ❖ Making small changes and watching them work



# Key Challenges

- ❖ Recruitment of patients onto the Self Management Programme (SMP)
- ❖ Recruitment of clinicians onto the Advanced Development Programme (ADP)
- ❖ Communication of where the Self Management Programme fits in the patient education pathway
- ❖ Getting enough capacity in the programme to reach the 'White Light'
- ❖ Involving patients more, now and in the future
- ❖ How ADP and SMP are marketed
- ❖ Selling the programme to others
- ❖ Evaluation, capturing clinical impact and health service use
- ❖ Time, staff, funding, sustaining keenness and energy

# Key Lessons Learnt

- ❖ Clinical and executive leadership important to the success and spread of this initiative
- ❖ Importance of partnership between patient and health care professional tutors in delivery of both the Self Management Programme and the Advanced Development Programme
- ❖ Whole practice/team approach to all three aspects of Co-creating Health approach (Advanced Development Programme, Self Management Programme and Service Improvement)
- ❖ Condition-specific Self Management Programme – peer support and shared experience
- ❖ Building on personal relationships between primary and secondary care and between patients and clinicians

# With thanks to our local CoCH team:



## **Steering Group**

Siobhan Harrington, Executive Lead  
Dr Maria Barnard, Lead Clinician  
Trish Turner, Project Manager  
Cathy Jenkins, Whittington DSN  
Dr Nick Brand, Islington GP  
Dr Jonathan Riddell, Haringey GP  
Wendy Harper-Tarr, Haringey Practice Nurse  
Mary Price, NHS Islington  
Fiona Yung, NHS Haringey  
Joni Inniss, Patient Representative  
Jonathan Townley-Smith, Patient Representative

## **Self Management Programme Tutors**

Joni Inniss, Lay Tutor  
Gloria Bujan, Lay Tutor  
Bindie Wood, Lay Tutor  
Pat Barber, Lay Tutor  
Shabi Choudhri, Lay Tutor  
Sandra Braithwaite, Lay Tutor  
Trish Turner, Lay Tutor  
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## **Advanced Development Programme Tutors**

Dr Maria Barnard, Lead Clinician  
Cathy Jenkins, Whittington DSN  
Dr Dow Smith, Islington GP Trainer  
Dr Nick Brand, Islington GP  
Shantell Naidu, Haringey DSN  
Janice Mavroskoufis, Whittington Dietitian  
Joni Inniss, Lay Tutor  
Claire Davidson, Lay Tutor  
Bindie Wood, Lay Tutor



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# Background

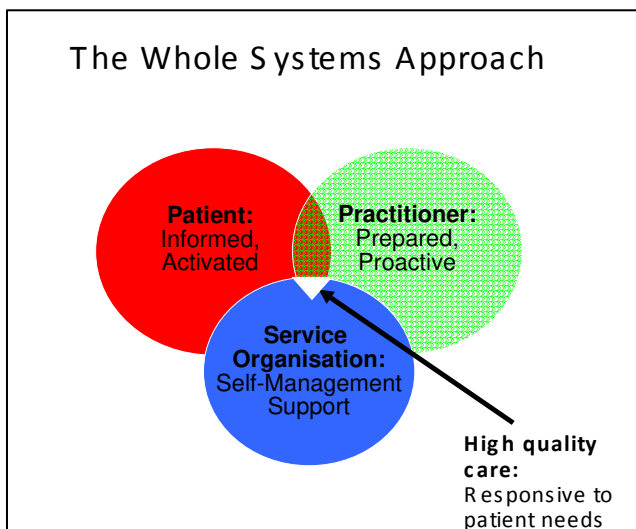
Over 400 studies worldwide have shown that supporting self-management can lead to dramatically improved outcomes for patients. Despite this, it remains at the periphery of most health services.

The Co-creating Health initiative aims to transform healthcare for people with long-term conditions. Through this initiative, The Health Foundation is supporting 8 ambitious healthcare organisations from across the UK, to create new models of healthcare that embed self-management within mainstream health services.

Providing responsive, effective services for people with long-term conditions creates enormous challenges for health services. Healthcare professionals cannot address these challenges alone. Many people are ready to take a more active role in their own care, but they need to work in partnership with their clinicians to achieve lasting improvements in their health. This is what we mean by 'co-creating health'.

Co-creating Health is unique in taking a whole systems approach to transform the patient-clinician interaction into a collaborative partnership. The three elements to the programme reflect Wagner's Chronic Care model of what needs to be in place across health and social care systems to support self management. These three elements encompass:

- ❖ engaged, informed patients - patients are participating in a Self-Management Programme (SMP) to build their self-management skills
- ❖ clinicians committed to partnership working - clinicians are undertaking an Advanced Development Programme (ADP) to develop their consultation/communication skills
- ❖ supportive organisational processes - local services in primary, community and acute settings are being redesigned to support self-management.



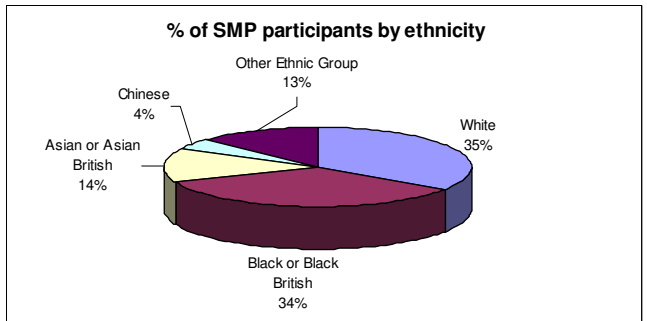
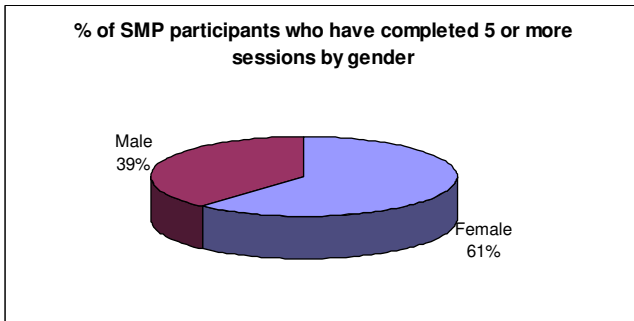
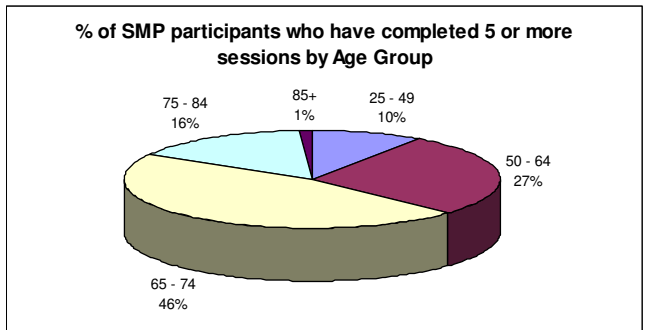
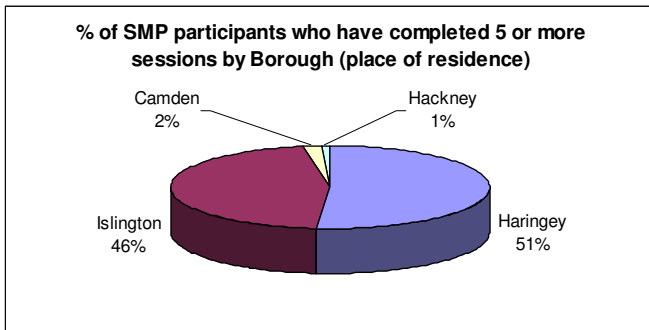
Each of these 3 elements incorporate the three “enablers”:

- ❖ Collaboratively setting an agenda
- ❖ Goal setting and action planning
- ❖ Follow up on goals

# Self Management Programme

Since April 2008 we have run 15 Self Management Programmes (SMP), with 130 patients completing 5 or more sessions. 70% of patients who started, completed the programme

## SMP: Evaluation



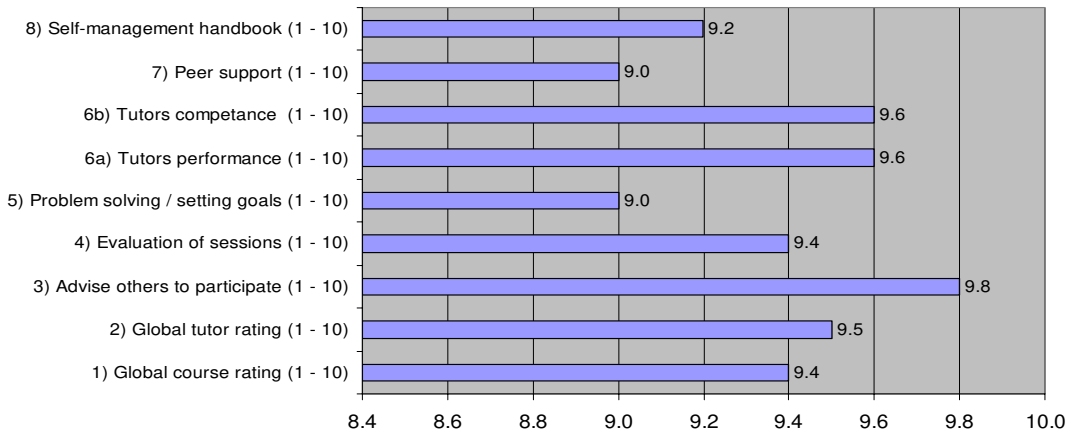
## SMP Assessment Results

❖ We are currently running an in house assessment of the SMP – focusing on biomedical and biochemical outcomes, behaviour change (diet, exercise), self management skills and self efficacy.

❖ We have performed an audit which showed that after the SMP, there was a significant improvement in HbA1c (-0.7% [ $\pm$ 1.7] at 5-8 months,  $p < 0.05$ ; -0.3% [ $\pm$ 0.7] at 9-12 months,  $p < 0.05$ ) and in LDL cholesterol (-0.6 mmol/l [ $\pm$ 0.8] at 9-12 months,  $p < 0.05$ ) in participants.

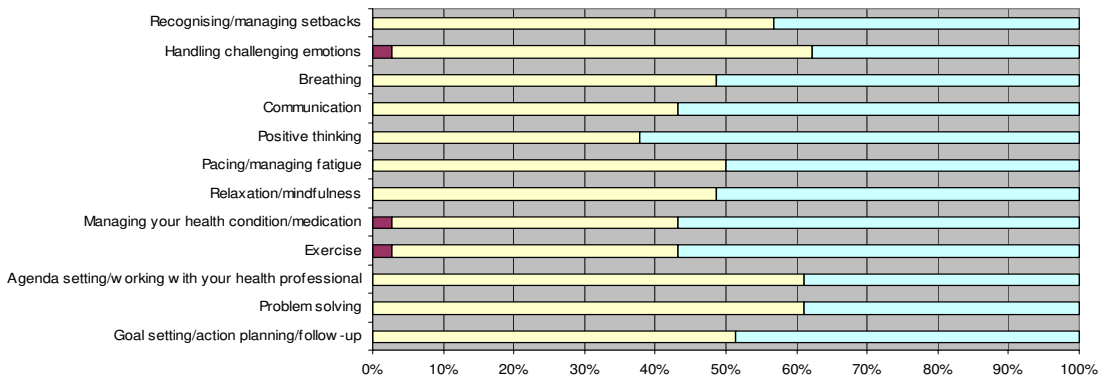
# Programme Evaluation Results

## Overall SMP Evaluation (Series 2 - 13, n = 96)



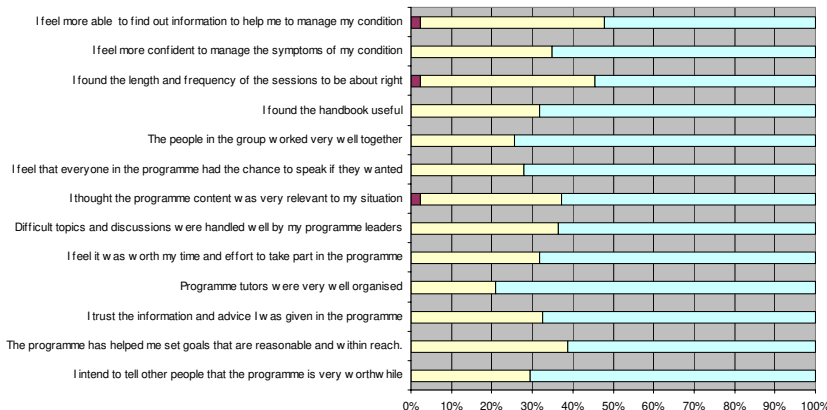
## Overall HEI-Q SMP Content Score (Series 6 - 11, n = 44)

■ Strongly disagree ■ Disagree  
■ Agree ■ Strongly agree



## Overall HEI-Q scores (Series 6 - 11, n = 44)

■ Strongly disagree ■ Disagree  
■ Agree ■ Strongly agree



# SMP: What patients have to say

- ❖ “Everything was useful and relevant to my condition”
- ❖ “It is an eye-opener and makes me feel more confident about looking at my problem right in the face as it were”
- ❖ “Have felt very uncomfortable going to this at first, but grew in confidence with the tutors”
- ❖ “Most knowledgeable, informative, realistic, understandable”
- ❖ “[What I liked about the course was] ... meeting other diabetics with different problems, and lots of solutions”

## SMP: Reunions



We have held seven reunions for participants of the self management programme. These ongoing course reunions, held every quarter, continue to provide peer support and occasions for personal goal setting, potentially sustaining improvements found in participant's health.

At the March 2009 reunion, participants had decided it would be valuable to be able to have some of their diabetes questions answered by a Diabetes consultant at the next reunion. Participants had many questions and Dr Barnard used the self-management tools of exploring the problems and using the experience of the group to find answers. In the first session she covered kidney problems in Diabetes, how to interpret test results, and why people are prescribed statins. We ran out of time and not all the questions were addressed, so the group invited Dr Barnard to come back and continue answering questions at the next reunion.

Evaluation results from the reunion held in September 2009, where over half of the attendees completed the short questionnaire, showed that 100% strongly agreed that the session with Dr Barnard was helpful and 100% of participants felt that the reunion was worthwhile attending.

Comments about the reunion included,  
“Attending it was great. I take more care of my blood sugar and tell my friend.”  
“Dr Barnard was very good and informative and I found her helpful”  
“Invite other specialists to lecture and answer questions e.g. dietician, cardiologist, nephrologist - all relating to diabetes.”  
“I enjoy goal setting/action planning/follow up”

# SMP: Patient Stories

## Peter's story

On diagnosis Peter experienced confusion, combined with a lack of robust information and education whilst being offered well meaning but incorrect information from friends and relatives.

Peter and his partner felt that it was not until they attended the SMP that Peter started feeling more confident about how they were able to manage his diabetes together.

Gradual progression of achieving his goal during SMP increased his level of confidence. He now feels more confident to communicate his thoughts and feelings about his diabetes more effectively and knowledgeable with his clinicians when attending appointments.

On a scale of 0 – 10 in terms of confidence in managing his long term condition, Peter gives a resounding score of 9.

## Core Patient Group

Some of the SMP graduates have formed a 'Core Group' and meet bi-monthly. The purpose is to increase patient involvement in the CCH initiative and to inform service development. This is an extremely valuable resource for future service improvement projects.

To date three meetings have been held. The group are keen to ensure that there are opportunities for SMP participants to follow-up with each



## Daphne's story

Daphne Johnson who participated in the SMP in June last year recently shared the benefits of attending this programme. "The best thing for me has been that I feel more confident in asking my GP for the support I want and need.

I am now more aware of the things I didn't know, such as the importance of keeping an eye on my HbA1c and requesting that it is measured regularly by my doctor or nurse. It has helped me to be pro-active in enquiring about what is available and to be assertive in my requests to improve my health outcomes. To know that I have choices in managing my condition, when there is fuller disclosure by my doctor."

**Above: Joni Inniss and Daphne Johnson at Islington Diabetes Day**

Other, to offer support and encouragement with working towards their goals. The participants are setting up a walking group and a newsletter with local information on clubs and groups to attend.

# SMP: Presentation to International Forum

Abstract for presentation accepted for the International Forum of Quality and Safety in Healthcare 2010

**Title: A collaborative approach to support self-care: implementing the Co-creating Health Diabetes Self-Management Programme**

**1) Context: Where was this improvement work done? What sort of unit/department? What staff/client groups were involved?**

The Whittington Hospital NHS Trust, NHS Islington and NHS Haringey are located in North Central London, serving an urban population of diverse social and economic status. We were selected as a diabetes test site for The Health Foundation's Co-creating Health (CCH) Initiative, a national demonstration programme aiming to make self-management an integral part of care for people with long-term conditions. To achieve this, we formed a partnership between primary and secondary care and between patients and clinicians.

**2) Problem: What was the problem that you set out to tackle? How was it affecting patient/client care?**

London performs significantly worse in most diabetes performance indicators than the rest of the UK. We serve a multi-ethnic population with a significant prevalence of diabetes and health needs. We aimed to provide self-management training for patients, to improve diabetes care and to provide an opportunity to develop collaborative working and involve patients in service improvement.

**3) Assessment of problem and analysis of its causes: How did you quantify the problem? Did you involve your staff at this stage? How did you assess the causes of the problem? What solutions/changes were needed to make improvements?**

The national survey of people with diabetes had shown that only 15.7% of local people with diabetes had participated in an education and training course on how to help manage their diabetes. After being selected by The Health Foundation, we were involved in developing the CCH Self-Management Programme (SMP) for people with type 2 diabetes. This aims to build patient skills to self-manage, combining diabetes content with techniques such as action planning.

**4) Strategy for change: How did you implement the proposed change? What staff or other groups were involved? How did you disseminate the results of your analysis and your plans for change to the groups involved with/affected by the planned change? What was the timetable for change?**

We set up a Steering Group of primary and secondary care staff and patients to direct the project. We identified patients (6) and clinicians (6) to train as SMP tutors from a variety of backgrounds, including Dietitians, Diabetes Specialist Nurses, Practice Nurses. They deliver the SMP in an equitable teaching partnership that mirrors the therapeutic relationship. Each SMP consists of 3-hour weekly sessions, over 7 weeks in a group setting (16 patients). We ran 10 courses over 12 months and will run another 10 in the next year.



### **5) Measurement of improvement: How did you measure the effects of your planned changes?**

Patient perceptions of the SMP were elicited by written statements, which the patients agreed with on a 5 point-scale, from (1) 'not at all' to (5) 'very much'. Improvement in diabetes control was measured by audit of blood tests on the laboratory results system. This compared overall glucose control (HbA1c), lipids and renal function before and over one year after attending SMP. Results are expressed as mean [ $\pm$ SD]. Paired t-test assessed significance of change.

### **6) Effects of changes: What were the effects of your changes? How far did these changes resolve the problem that triggered your work? How did this improve patient/client care? What problems were encountered with the process of changes or with the changes?**

To date, 90 patients have completed 10 SMP courses. They highly valued the SMP (global course rating 9.5/10). High scores were given for problem solving / goal setting activities (4.5/5) and peer support (4.5/5). All would advise other patients to attend. After the SMP, there was a significant improvement in HbA1c (-0.7% [ $\pm$ 1.7] at 5-8 months,  $p < 0.05$ ; -0.3% [ $\pm$ 0.7] at 9-12 months,  $p < 0.05$ ) and in LDL cholesterol (-0.6 mmol/l [ $\pm$ 0.8] at 9-12 months,  $p < 0.05$ ).

### **7) Lessons learnt: What lessons have you learnt from this work? What would you do differently next time?**

The rate of attrition has been very low but recruiting patients onto the SMP has been a challenge. The most successful method has been a personal letter of invitation from the Diabetes Consultant (39% of participants). Continually raising awareness of the SMP in primary care (e.g. at meetings) and amongst patients (e.g. posters, coffee mornings) has been important. In future, we may concentrate on individual GP practices, running the SMP in house for their patients.

### **8) Message for others: What is the main message based on the experience that you describe here that you would like to convey to others?**

This innovative, collaborative model provides an effective approach to support diabetes self-management. Ongoing course reunions continue to provide peer support and occasions for personal goal setting, potentially sustaining improvements found in patient's health. This project has been an opportunity for greater working with our patients: some SMP graduates have trained as lay tutors and others have formed a 'Core Group' to inform service development. This is an extremely valuable resource for future service improvement projects.

# SMP: Tutor's story

## I'm an Self Management Programme Tutor.

I'm now starting to teach my third SMP group. I heard about it in a Diabetes UK support group. They had a guest speaker and they said that there was this program that was about Co-Creating Health and they were looking for people with certain long term conditions who were looking to be part of a team, a joint team with clinicians.

It really sparked my interest. I was still coming out of illness, not working, hadn't been working for quite some time and I thought this would be something that's really interesting and that I could feel would be right up my street. I had an interview a few months later and then in January/ February of this year I had my tutor training for the Self Management Programme - I was really nervous about it. I was so worried, I thought, I haven't done anything like this for a long time, I'm going to be useless and I felt completely lacking in confidence.

**BUT THE TRAINING ITSELF WAS BRILLIANT**

I waited maybe three or four months before I then had my first SMP group and in the meantime I had attended the course myself. It was a bit topsy-turvy so I had done the training and I was waiting to then to go on and deliver the training.

The SMP course was brilliant,

**I GAINED SO MUCH FROM IT.**

All the agenda setting and the goal setting was very useful and I felt really motivated and it was really good once a week to go with a group of people who were in a similar situation and with the same condition sharing their experiences, trying different things out and it was absolutely fantastic.

It was really good for me in terms of gaining self management skills. I'm just about to start teaching my third SMP course and I think what I would say about the SMP, the role of being a tutor is that

**IT WAS REALLY POSITIVE**

It's really amazing to see people transform who come along from week one and they have their stories to tell and they want to share their experience and some things they're coping well with and some things they're still finding difficult and through the course the group really gels and people seem to really flourish and blossom and help each other and that's fantastic.

Very recently I completed the training to become an Advanced Development Programme tutor which was again fantastic. It was absolutely brilliant. I just loved it and again I was really nervous. But it was such a good experience and again it was part of being a joint approach with clinicians and with other SMP tutors. So meeting other people who had got different long term conditions was just wonderful, in a really beautiful setting, but we worked so hard. People really do listen to you, which really surprised me. My role was to do some presenting which is something that I'm familiar with prior to becoming ill, prior to my diagnosis. But then I was there to represent the patient voice and to try to give a face to the experience - if you like and give a story. I had prepared something because I like to be organised, and I thought that was it - I'd finished. So I got up off my chair to go, and then they said would you mind if we asked you a few questions? And I was just really surprised because I didn't think that



they would have any extra questions for me after what I said, but they did. There was all the different clinicians or healthcare professionals from different backgrounds, and they all had different experiences and I enjoyed answering their questions and it made me think a lot about how since my early stages, I'm actually getting back on track now to who I was, and how I was, and where I want to be going.

I think being involved with both aspects of the program is again really good, to take back to the SMP groups and to say yes you're learning these skills and then the clinicians that you work with they're also learning the same kind of language, the same tools.

The SMP program I would say it's a friendly, informal environment so everyone feels really comfortable and it's small groups, it's manageable. And there is role play and people get to feed back their thoughts or comments and there is lots of discussion. And you do the problem solving exercises, and I think that's good because people get to share the value of their experience with this group of strangers, and people say that's a really good idea and I'm going to try that for me.

There's one person who in one of the groups attended the first one and was really keen, but he hasn't been able to make it to two because the community transport has been cancelled. So it's things like you know that people are going to be unwell because they are. So how can you support people to get the travel, if that's what they need to come. What happens if they miss sessions?

I think initially when I was first diagnosed I was so shocked that I felt that I was always at the doctors. I think it's a good thing that now self management for me means that

### I REALLY DO LOOK AFTER MYSELF

and I know how to do that and I know what to look out for. I think that has made a huge difference in confidence levels. Being able to weigh up the pros and cons of do I take this tablet - which makes me feel awful but lowers my blood sugar level? Or do I come off that, and have to do the work myself? I talked to my doctor about it quite a lot



and I just felt that I would rather do the hard work myself than have something that made me feel so ill even if it was convenient. And things like the self management, setting goals for exercising, increasing your exercise and eating healthily and monitoring things like your HbA1c, understanding the importance of that and thinking yes you can be proactive yourself.

It has given me much

### BETTER RELATIONSHIPS *certainly with my GP.*

Although now I see all my health care professionals including my GP a heck of a lot less. Most of my friends and family would say is that there was a period where I was lacking in confidence and quite withdrawn and very worried and unwell and now they've seen me go through that and return to who I am and my personality and my sense of humour I think has come back.

I treat it almost as a return to work experience because I'm able to monitor what my energy levels are like now as compared to how they used to be. So it's like a barometer and I find that is brilliant, because now I'm at a stage where I'm thinking if I can manage this commitment I could probably manage something part time and that has been really valuable for me to think slow steps, gradual steps towards returning to work.



# Advanced Development Programme

Since January 2008 we have run 6 Advanced Development Programmes (ADP), with 68 clinicians completing all 3 sessions (40 Islington, 10 Haringey, 18 Whittington). A shortened ADP was held in Islington Central Medical Centre and St John's Way Medical Centre in Islington over summer and currently two series are running in Highgate Group Practice in Haringey. 10 Action Learning Sets to support clinicians learning and practice of their ADP skills have been held. Six clinical and three lay tutors have completed the ADP Train the Trainer course and are now trained to provide the ADP.



## ADP: Evaluation

- ❖ 89% of clinicians who have attended the ADP agree that they have significantly improved their knowledge of how to support patient self-management
- ❖ 96% said that ADP provided them with new skills to use
- ❖ 93% said they had implemented parts of the ADP into their daily professional practice
- ❖ 88% said the ADP had a positive impact on their daily professional life
- ❖ 89% would recommend the ADP to others.
- ❖ Respondents rated their confidence to use ADP skills as 7.3/10

# ADP: What clinicians have to say

“It has been really brilliant at helping me to manage those patients who I previously found most difficult to manage ... it really ... offers practical ways of engaging patients actively in their own care.”

“I have to say that I found the tools to be used extremely useful. I had no idea how a few changes in a phrase that a health care professional uses, can have such an impact on a session.”

‘It allows you to get an agenda on the table right at the beginning of the consultation and find out what you are dealing with that day. You can avoid that situation where somebody presents another problem just as they are about to go out of the room.’

‘I’m a doctor who patients probably become a bit dependent on, and that wasn’t doing them any favours. That was quite an eye-opener. I realised that by getting them to think about what they were doing, they would end up being much better off.’

## ADP: Action Learning Sets

Action Learning Sets are designed to provide support to clinicians who are trying to embed the skills and tools learnt in ADP into practice. A group of 6 – 8 clinicians meet and work through issues that participants have come up against during consultations.

Here is one participants reflection on a positive experience at an Action Learning Set.

“I was wondering how easy it would be to agree to a ‘shared agenda’ if my patient has a massive list of issues to discuss, especially, if they were not diabetes related.

When I put my concern to the group, someone from the group asked me, “Imagine if you were going on a holiday with a friend. Imagine that you had met up in a coffee shop to discuss which sights to see when away. What would you do?”

I thought that was a brilliant analogy!

I answered, “We would draw up our lists separately and see if we have any similar interests. If we had found places that we both wanted to see, we’d plan our trip around those. If our lists were poles apart and showed completely different sights., then we would have to compromise – of course we can always cancel the holiday!”

# Let the patient decide

Polly Newton learns about a course that encourages doctors to give patients more control over the management of long-term conditions such as diabetes, COPD and depression. The hope is that the project will embed self-management support in mainstream health services, thereby increasing patient engagement and improving clinical outcomes

**G**ILLIAN GREENHOUGH used to begin each consultation by asking her patient: 'How are you today?' Now she is more likely to enquire: 'What are we doing today?'

A small step for one London GP, perhaps, but — if Dr Greenhough and others are to be believed — a giant potential leap for the medical profession.

'It allows you to get an agenda on the table right at the beginning of the consultation and find out what you are dealing with that day,' says Dr Greenhough.

'You can avoid that situation where somebody presents another problem just as they are about to go out of the room.'

Her change in approach stems from a project called the ADP (advanced development programme) for clinicians, which is designed to enhance doctors' skills in helping patients manage their long-term conditions.

The ADP is part of Co-Creating Health, a three-year initiative funded by independent charitable organisation The Health Foundation, which also encompasses a self-management improvement programme for patients with long-term conditions and a service improvement programme.

The aim of Co-Creating Health, says The Health Foundation, is 'to embed self-management support within mainstream health services'.

Doctors attending the ADP use role play and other learning tools to help them build more collaborative relationships with patients who have long-term conditions such as diabetes, COPD and depression.

In particular, clinicians are encouraged to support such patients in setting their own realistic goals (to take a short walk three times a week, for example, or to play a game with their children each weekend). Success is measured partly by the achievement of those goals.

## Benefits of expanded patient control

Handing the patient more control should (the theory goes) create a virtuous circle of goals being met, greater patient confidence in managing long-term conditions, increased patient engagement and improved outcomes.

Dr Greenhough, chair of Islington PCT professional executive committee, admits she was initially sceptical about attending the course at the Whittington Hospital NHS Trust, which is hosting the ADP in partnership with Islington and Haringey PCTs. (Of the eight UK 'demonstration sites' for Co-Creating Health, seven are joint hospital trust/PCT ventures in England, and one involves Scottish health board NHS Ayrshire and Arran.)

She was reluctant partly because the course takes three half-days, and partly because the Whittington programme focuses on diabetes — not a condition in which she specialises within her practice.

Her misgivings were short-lived.

Among the most helpful skills she learned on the course, she says, was a new willingness to seek a 'joint agenda' with patients at the beginning of consultations — no matter what their conditions.

Once the patient and the clinician have listed the issues they want to discuss, they can reach agreement about which should be prioritised and which might have to be addressed on another occasion.

With an agreed agenda from the outset, says

Dr Greenhough, the doctor is much less likely to spend all the allotted time dealing with the first problem presented by the patient, only then to be confronted with an issue that is clearly more significant and which cannot be deferred until the next appointment.



**GREENHOUGH:** new approach helps avoid the situation where patients reveal their 'real' problem at the end of a consultation

'The aim is to see whether ultimately you have healthier patients who are more actively self-managing and need less of your time'

She does not claim her consultations no longer overrun ('everyone would laugh me off the planet,' she says candidly), but she certainly finds them more satisfying.

And the ADP had another profound effect.

'It really made me think about the way I do things,' Dr Greenhough says. 'I'm a doctor who patients probably become a bit dependent on, and that wasn't doing them any favours. That was quite an eye-opener.'

'I realised that by getting them to think about what they were doing, they would end up being much better off.'

Maria Bamard, clinical lead for the Whittington Hospital, NHS Islington and NHS Haringey Co-Creating Health site, says clinicians have a key role to play in encouraging and sustaining self-management by patients with long-term conditions.

She says: 'I don't think you can have patients self-managing in an isolated way. I think there is a whole ethos

and culture change that needs to happen in the health service to help them, both from clinicians and in the way the service is run.'

Dr Barnard — lead consultant in diabetes at the Whittington — points out there is little in the way of consultation skills training for hospital clinicians, so the ADP is 'a very new experience' for them.

But she says even for GPs the programme differs significantly from standard training in consultation skills.

'What people go away with are some specific techniques to use to support self-management and to encourage behaviour change,' she says.

Dr Barnard says some doctors who have attended the course now send out test results to patients before planned consultations so there can be some thought beforehand about the issues on the agenda.

She acknowledges that allowing time to set an agenda and goals may make for longer consultations initially.

'It is time-consuming,' she says. 'But the aim is to see whether ultimately you have healthier patients who are more actively self-managing and need less of your time.'

Whittington Hospital lead diabetes specialist nurse and ADP tutor-in-training Cathy Jenkins says follow-up is crucial in the process of supporting self-management.

She says: 'If the patient just goes away and there is nobody to check back in with, they are less likely to maintain their goals. I have patients who tell me: "It's because I'm coming back to see you that I know I can cope with this".'

Another key factor is to agree on objectives that the patient feels confident about achieving, says Ms Jenkins.

For example, patients might readily acknowledge the importance of taking their medication regularly, but think that they have only a 50 per cent chance of meeting that goal.

'We know that you need to [think you have a 70 or 80 per cent chance of success] to be able to carry out that behaviour,' says Ms Jenkins. 'So I might say to that patient: "OK, what might make you more confident? What's stopping you being more confident?" You explore the barriers with them, and they start to try to come up with action plans themselves. You never say: "I suggest you do this." You say: "What can you do?"'

## Evaluating the results

Co-Creating Health is due to end in 2010 and its impact — already being scrutinised internally by the organisations taking part — will be formally evaluated by researchers at Coventry University.

They will assess (among other things) the benefits to patients, healthcare professionals, organisations and the healthcare system. But it is expected that the ADP will continue in some form — either under the auspices of The Health Foundation or otherwise.

Alf Collins, national clinical lead for Co-Creating Health and consultant in pain management at Taunton and Somerset NHS Foundation Trust, admits to being uncertain about whether the course will lead to demonstrable benefits in terms of clinical outcomes. But in terms of its impact in other ways, he is less equivocal.

He says: 'Is it helping in terms of quality of life for people with long-term conditions? I am pretty sure it is.'

'Is it helping in terms of people with long-term conditions feeling confident in going about their daily lives? I am very sure it is.'

● See [www.health.org.uk/current\\_work/demonstration\\_projects/cocreating\\_health.html](http://www.health.org.uk/current_work/demonstration_projects/cocreating_health.html) for more information. Doctors may also be interested in the Expert Patient Programme, which is a self-management programme for people living with long-term conditions. See [www.expertpatients.co.uk](http://www.expertpatients.co.uk)

# ADP: Presentation to International Forum

Abstract for presentation accepted for the International Forum of Quality and Safety in Healthcare 2010

**Title: Clinician skills training to support patient self-management: implementing the Co-creating Health Advanced Development Programme in a Diabetes Team**

**1) Context: Where was this improvement work done? What sort of unit/department? What staff/client groups were involved?**

The Whittington Hospital NHS Trust, NHS Islington and NHS Haringey serve an urban, multi-ethnic population, with significant health needs, in North Central London. We were selected as a diabetes test site for The Health Foundation's Co-creating Health (CCH) Initiative, a national demonstration programme making self-management integral to the care of people with long-term conditions. We wanted to work across organisational and professional boundaries and formed a partnership between primary and secondary care and between patients and clinicians.

**2) Problem: What was the problem that you set out to tackle? How was it affecting patient/client care?**

The quality of local diabetes care is variable, as measured against national targets. Diabetes care is dependent on patients effectively self-managing. Clinicians must be skilled in supporting them. The diabetes team was involved in self-management programmes, but expertise was focused on individuals rather than the whole team. We aimed to teach clinicians communication skills to enable patient behaviour change, and to take ownership of this training and adapt for local requirements.

**3) Assessment of problem and analysis of its causes: How did you quantify the problem? Did you involve your staff at this stage? How did you assess the causes of the problem? What solutions/changes were needed to make improvements?**

Primary care clinicians may focus on consultation skills during training, but have limited opportunity to reflect on them once practising. Secondary care clinicians may have no formal training. After being selected by The Health Foundation, we participated in the Advanced Development Programme (ADP) for clinicians. This aims to give clinicians the skills to support self-management, using three enabling strategies: agenda setting, goal setting and action planning.

**4) Strategy for change: How did you implement the proposed change? What staff or other groups were involved? How did you disseminate the results of your analysis and your plans for change to the groups involved with/affected by the planned change? What was the timetable for change?**

We set up a Steering Group of primary/secondary care staff and patients to direct the project. We initially invited local opinion leaders to attend the ADP. Each ADP consists of three 3-hour monthly sessions, in a group setting (16 participants). We allocated places equally between primary and secondary care and mixed participants across professions. We identified 5 clinicians and 3 patients to train as ADP tutors. They now provide the course in an equitable teaching partnership. We will run 5 courses over 5 years.



**5) Measurement of improvement: How did you measure the effects of your planned changes?**

The impact of learning on clinical practice was measured by online questionnaire, sent to all clinicians who completed the ADP (sent 3-17 months after ADP). This focused on whether ADP skills were being used in the environment of the learner. Written statements were used, which clinicians agreed with on a 5 point-scale, from (1) 'strongly disagree' to (5) 'strongly agree'. If low scores were given, clinicians were asked to say why they feel there has been little learning.

**6) Effects of changes: What were the effects of your changes? How far did these changes resolve the problem that triggered your work? How did this improve patient/client care? What problems were encountered with the process of changes or with the changes?**

To date, 48 local clinicians have completed the ADP, 61% responded to the questionnaire. 89% agreed that the ADP significantly improved their knowledge of how to support patient self-management. 96% said the ADP provided them with new skills to use. 93% said they had implemented parts of the ADP into their daily professional practice. 88% said the ADP had a positive impact on their daily professional life and 89% would recommend the ADP to others.

**7) Lessons learnt: What lessons have you learnt from this work? What would you do differently next time?**

Respondents rated their confidence to use ADP skills as 7.3/10. We need structured on-going training. Learning has been most sustained when the whole team attended the ADP (e.g. Diabetes Specialist Nurse Team). Sharing knowledge is valuable. We invited GPs with their Practice Nurse, but in future will test training the whole practice team. We are adapting the course locally, focusing on content, the patient voice and time requirements.

**8) Message for others: What is the main message based on the experience that you describe here that you would like to convey to others?**

Our experienced clinicians highly valued the ADP training. The focus on consultation skills to promote patient behaviour change was novel. Clinicians have implemented skills learnt into their daily practice. We started with diabetes but are spreading learning to local teams working in other long-term conditions, including COPD. We adapted the ADP to run a 'beginners' course and envisage providing 'intermediate' and 'advanced' courses. The ADP has stimulated teams to undertake service improvement and fundamentally change their approach to self-management support. 23

# ADP: Clinician's Story

## I've been interested in self-management in diabetes for many years.

I was a practice nurse before I was a specialist nurse – I'm a diabetes specialist nurse – and had been involved in running self-management groups for people with diabetes as part of a research project. So, when I came to work in secondary care, I was aware that the ethos surrounding the sort of service that we, as diabetes nurses, provide was very much conducive to self-management ... but we weren't encouraging people to self-manage in quite the way that I had been doing when I'd been running groups.

In diabetes, we're perhaps a bit further along that road because to manage diabetes is just

**SO DIFFICULT**

Often – if you're taking insulin several times a day, for instance and you're having to watch your diet and do blood tests – it's very intensive. So, when Co-Creating Health came and it was a real opportunity to mainstream this approach into our practice, I was really pleased.

I wanted to be an Advanced Development Programme tutor as soon as I found out what that was. And all my colleagues have been through the ADP now and we're all singing from the same hymn sheet.

I think that there's quite a lot of ambivalence for clinicians around changing the way that they behave. I think that we have to recognise that our patients are ambivalent about change and we have to learn skills – techniques – to help them weigh up the pros and cons of behaviour change and, hopefully,

**MOVE TOWARDS** *changing*  
**HEALTH RELATED BEHAVIOURS**

and it's just the same with clinicians. We're comfortable in the way that we consult; we think we're good at it and, if somebody comes and suggests we might do it a different way, then we're a little bit suspicious – maybe sceptical

So, what we're doing in the ADP is quite challenging, and there are those who will go through the whole process and then not change at all and there will be people who I think change somewhat and then there'll be the people who are full on for it and who are going to take these techniques away and

*Use them, STRAIGHT AWAY*

That's one of the things that I've learnt, actually – is that you can't make people do this. As a participant,

at first, I felt quite muddled about it. I wasn't sure where these different skills were coming from. I felt I needed to know more about the research behind it. I went away and had a look at some of that and I think that it takes a long time to practice and to feel confident in using some of these techniques. So it wasn't something that came easily – even though I was really keen.

It's been great being able to direct people towards the Self-Management Programme which comes as part of the Co-Creating Health because I know that, on that programme, they'll have the peer support of the other people and, also, that they'll be doing exactly the same as what we're doing in the ADP. So they'll be learning about how to action plan: how to decide what their goals are, how to come up with action plans to take

**STEP TOWARDS** *those goals.*

So you're trying to explore with them how important it is to change and, if it isn't important, to begin to perhaps move people along into finding it more important – so getting them to talk 'change talk', if you like, asking them 'What would be the good things about changing as opposed to staying the same?'

If a patient – she feels okay; she feels healthy; she thinks that everything's going okay but, clearly, her blood sugar results are bad. But she has told me that she thinks things are going well. So my agenda is that her blood sugar's bad; hers is, 'I've only come to see you because I've got to come for a routine check-up and I feel fine.' So trying to help her weigh up – find some importance in addressing the blood sugar – is very hard. But, anyway, for her, I think that, in the end, I just had to go with empathy. I'd



never met her before; I had to go with developing the relationship. So I had to stand back from thinking, 'We must make a change now' – I had to stand back from that and think, 'Okay, what can I achieve today?' and suggesting that she comes back and we have another conversation. If she brings the blood test that she's been doing at home that we could continue our conversation. And I don't think I would necessarily have played it that way.

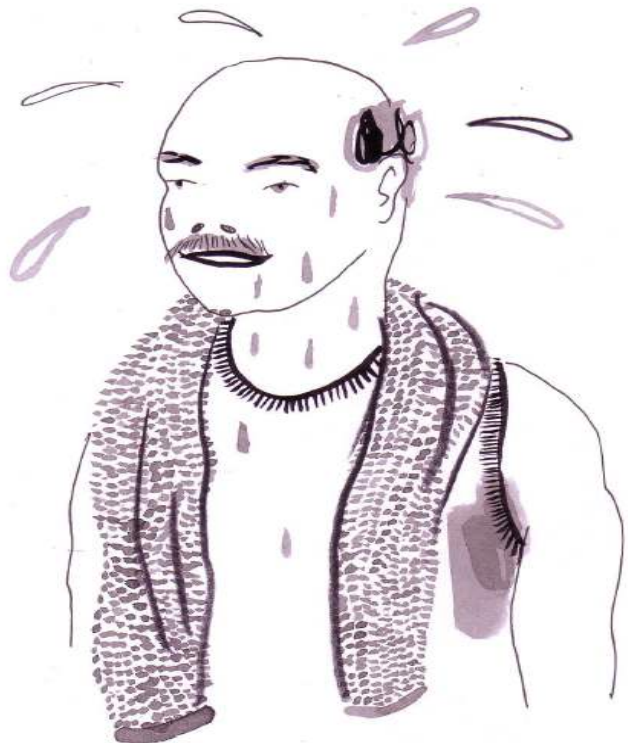
And, yesterday, I had several people who were very, very, very overweight and had seen lots of healthcare professionals. Every time they'd said, 'By next time I'm going to lose some weight' and hadn't lost any. And there, I really felt that they were people who could have done with the peer support of the self-management programme. So I gave them the leaflet and they were all quite keen to ring up and make an appointment to go on that.

So, for instance, there was a chap who, during the conversation, he told me that he knew he wasn't active enough but he was on his feet all day at work and his feet ached by the time he got home. He couldn't afford to join a gym but he would like to be more active. And so I was able to say to him, 'Well, if you are interested in that type of stuff – gym work – I can find out for you – locally, I know that you can get very reduced rates and go to our local gym down here where they'll give you tuition free and then you can have a programme with them. I will phone him in two weeks. We agreed that I will phone him to see whether he's joined because so often you go away with the best of intentions and you don't actually follow up on it

We should go in and do the ADP within a GP practice so you have all the doctors and all the nurses learning together. And, that way, they can support each other afterwards. And I think that's probably going to be the way forward.

People say, 'Well, we just don't have time.' And I think, 'Okay, you say you can't do this because you haven't got time ... So, once you've got skilled at using these skills, it doesn't take as long as you think it's going to take but, then, if you haven't got time, then what are you hoping to accomplish then anyway?

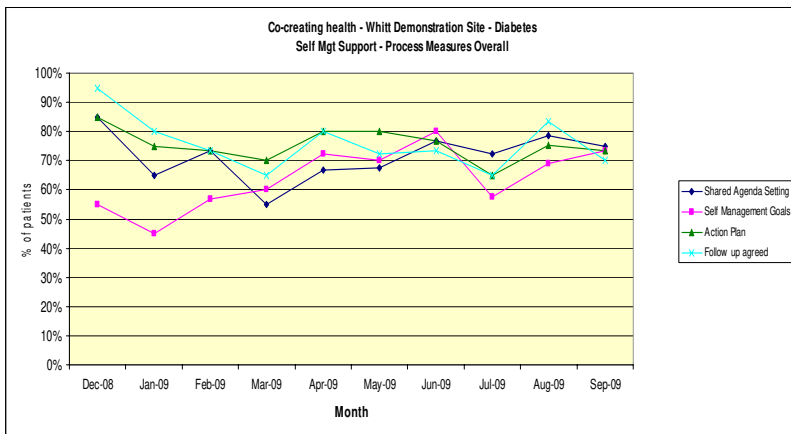
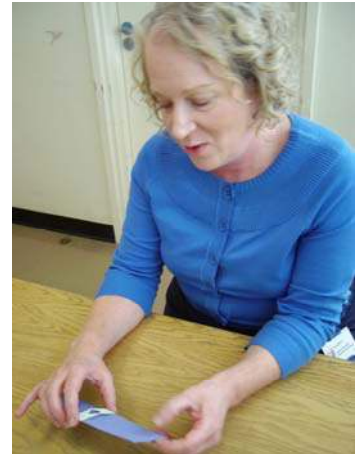
I found the service improvement tools really interesting and applicable to all other areas – not just around the Co-Creating ideas but others. The idea that you can try small changes, try them out quickly, get your information quickly and decide whether to go forward with that one or whether to try it slightly differently or whether to just not do it at all. I found that quite liberating actually.



# Service Improvement Programme

We started our service improvement programme with a workshop involving 50 patients, clinicians and managers. We identified the changes needed to local health services to support self-management using shared agenda setting, action planning and proactive follow-up of agreed goals.

We now have fourteen teams involved in quality improvement activities which include: development of an agenda/goal setting tool and a confidence ruler; adapting the diabetes template on the electronic patient record; blood test results prior to appointments; patient group meetings with clinical input; email follow-up; terminal/kiosk to record outcome measures.



## Confidence Ruler

A confidence ruler designed and developed by a doctor at the Whittington is ready to be produced and distributed to health professionals.

## Email Follow-up

Highgate Group Practice are providing email support and advice for non-urgent issues

## Consultation Quality in the Diabetes Clinic

The Consultation Quality Index (CQI-2) is a measure of patient-centred care and clinician performance. This tool has been used to evaluate consultations at the Whittington Hospital in September/October 2008 and was repeated this year. This has shown an improvement in scores since all the team completed ADP training.

## Self-Management Prompts in EMIS template

Highgate Group Practice have incorporated prompts into the practice patient management system (EMIS) to ensure that agenda setting, goal setting, action planning and follow-up is discussed during the patient consultation. An instruction sheet has been produced for other practices to follow the simple steps to set this up on their own system.

## Applying LEAN

The Diabetes team has held two workshops to apply the "LEAN" methodology to improve the processes and patient flow through the outpatient clinic. Improvements have already occurred and small groups are working on specific projects.

**My Diabetes Plan**

How are you doing with your diabetes?  
 Excellent  Good  Not Good  Not sure

I am doing well with:	I want to do better with:
<input type="checkbox"/> Exercising	<input type="checkbox"/> Exercising
<input type="checkbox"/> Eating better foods	<input type="checkbox"/> Eating better foods
<input type="checkbox"/> Taking my medicine	<input type="checkbox"/> Taking my medicine
<input type="checkbox"/> Checking my blood sugar	<input type="checkbox"/> Checking my blood sugar
<input type="checkbox"/> Managing my weight	<input type="checkbox"/> Managing my weight
<input type="checkbox"/> Reducing my salt intake	<input type="checkbox"/> Reducing my salt intake
<input type="checkbox"/> Cutting down on smoking	<input type="checkbox"/> Setting a quit smoking date
<input type="checkbox"/> Checking my feet	<input type="checkbox"/> Checking my feet
<input type="checkbox"/> Drinking less alcohol	<input type="checkbox"/> Drinking less alcohol
<input type="checkbox"/> Other	<input type="checkbox"/> Other

To improve my health, I will work on one of my chosen activities.  
 This is what I am going to do: \_\_\_\_\_  
 How much: \_\_\_\_\_  
 When: \_\_\_\_\_  
 How often: \_\_\_\_\_  
 How important is this activity to me? (circle a number):  
 Not 1 2 3 4 5 6 7 8 9 10 Very  
 How confident am I that I will be able to do this activity? (circle a number):  
 Not 1 2 3 4 5 6 7 8 9 10 Very

## Agenda/Goal Setting Sheet

At follow-up of initial PDSA cycle for the agenda/goal setting sheet, 6 out of 9 patients achieved their goal

# SIP: Consultation Quality

Presentation to Diabetes UK Annual Professional Conference 2009

The Whittington Hospital   
NHS Trust

## Consultation Quality in the Diabetes Clinic

Patricia Turner<sup>1</sup>, Maria L Barnard<sup>2</sup>, Siobhan Harrington<sup>3</sup>

<sup>1</sup>Co-Creating Health Project Manager, <sup>2</sup>Lead Consultant in Diabetes, <sup>3</sup>Director of Primary Care  
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### Introduction & Aims

- Consultation skills that support patient self-management are essential in managing long-term conditions, but can be difficult to evaluate.
- The Consultation Quality Index (CQI-2) has been proposed as a measure of interpersonal care.
- The CQI-2 was used in a diabetes clinic, to measure patient-centred care and clinician performance.

### Methods

- CQI-2 adapted for diabetes was kindly provided by Dr Simon Eaton<sup>1</sup> (Lead Clinician for Care Planning, Year of Care).
- CQI-2 measures four components: enablement (Patient Enablement Index [PEI]); continuity of care; consultation length; empathy (Consultation and Relational Empathy [CARE]).
- Patients completed a confidential questionnaire rating their clinician immediately after review.
- Results are given as mean and range.

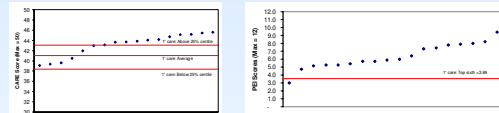
### Results

- Patients completing the questionnaire were aged between 21-86 years.
- 24% had Type 1 diabetes and 48% were of white ethnic group.
- 217 questionnaires were returned, evaluating 8 doctors, 6 specialist nurses and 2 dietitians.
- Overall clinic CQI-2 score was high (19/24, range 15-22).
- Clinic scores for PEI (6.5, range 3.0-9.4), consultation length (29 minutes, range 19-37) and CARE (43.0, range 39.1-45.9) were high compared to normative general practice data (top sextile scores: PEI > 3.7, consultation length > 10.1 minutes, CARE > 43.5).
- CQI-2 scores were similar for doctors (19, range 15-22), nurses (18, range 15-22), and dietitians (20, range 20-21).
- Senior doctors scored higher than junior doctors.
- The two top performing clinicians have received advanced training in consultation skills.

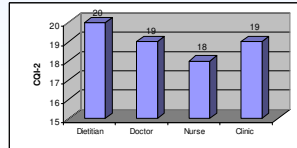
### Summary

- The CQI-2 was straightforward to administer.
- It can differentiate between clinicians and reflects experience and training.
- Changes in the clinic CQI-2 score will be used to monitor future service improvements.

### CQI-2 Results

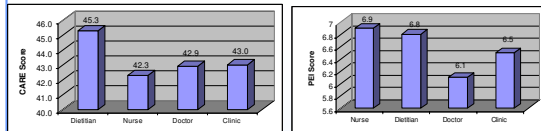


The figures above show the CARE and PEI scores for each participant, and demonstrates the difference from the published normative data for General Practice (not diabetes clinics).<sup>2,3</sup>

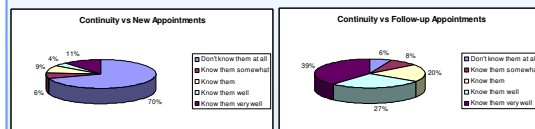


Note that the length of consultations for all specialties were over 10 minutes

The Consultation Quality Index (CQI-2) Score is the overall total of Consultation Length, Empathy, Enablement and Continuity scores. The figure above shows the CQI-2 score by clinical group and overall clinic.



The figures above show the Empathy (CARE) and Patient Enablement Index (PEI) scores by clinical group and overall clinic.



The figures above show that of the patients who attended new appointments, 24% of patients said that they felt they knew the clinician very well, well or knew them, compared to 86% for follow-up appointments.

### References

- <sup>1</sup>Al-Ozairi E, Eaton S. How was it for you? A simple patient questionnaire to measure consultation quality. *Diabetic Medicine* 2008;25 (Suppl 1); 59
- <sup>2</sup>Mercer SW, Howie JGR. CQI-2 – a new measure of holistic interpersonal care in primary care consultations. *BJGP* 2006; 56: 262-68
- <sup>3</sup>Mercer SW, McConnachie A, Maxwell M, Heaney D and Watt GCM. Relevance and practical use of the Consultation and Relational Empathy (CARE) Measure in general practice. *Family Practice* 2005; 22: 328–334



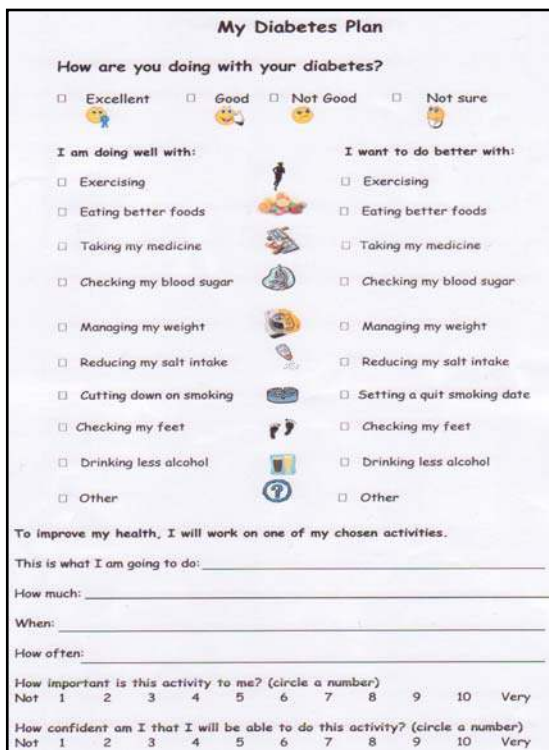
## Developing an agenda and goal setting tool for clinical use

Cathy Jenkins, Trish Turner

**Aim:** Two of the processes that enable effective self-management are agenda setting, where clinicians and patients agree what they would like to achieve from the consultation, and goal setting, where patients set their own realistic behavioural goals. Our aim was to produce a tool that would aid these processes within the diabetes consultation.

**Methods:**

We are taking part in The Health Foundation's Co-creating Health Initiative, which aims to embed self-management within health services. As part of this initiative, we used the Plan-Do-Study-Act rapid cycle testing methodology for this work. An agenda/goal setting sheet was identified and adapted for local use. The sheet was tested in clinical consultations with eleven patients with diabetes who were asked for verbal feedback about layout, acceptability and ease of understanding. Clinicians were asked for feedback. The template was changed accordingly



**Results:**

- The tool was designed to include content on lifestyle, medication and blood glucose testing.
- The layout included attractive graphics and a simple scoring system to identify areas patients wanted to address.
- Patients and clinicians enjoyed using the tool.
- Both groups thought that it helped to focus on important issues.
- Patients were keen to work on specific goals and of those that have returned for follow up so far, six out of nine have achieved their goals.

**Conclusion:** Health related behaviour change is the cornerstone of effective self-management. This agenda/goal setting tool is an acceptable and effective way of facilitating this. The next phase will be to test the tool within the busy general diabetes outpatient clinic.

“I came here today expecting you to tell me off about my weight. Instead I found myself 28 having a conversation where I took the lead and told you what I was going to do about it”

# SIP: Confidence Ruler



Following completion of the ADP, Dr Nicole Braham, our Associate Specialist, was using importance and confidence scoring techniques in her clinic. She observed that patients sometimes struggled to answer these questions. This led her to test whether a visual prompt would help patients in responding to the questions: *'How important is it to you to achieve this goal?'* and *'How confident are you in achieving this goal?'* She has put this through several PDSA cycles, to produce a usable product.

Nicole initially produced a piece of cardboard (with the help of her children!) with a scale on it, in different colours, running from 0 – 10. She tried this out with patients, who told her that having a physical prompt was helpful but they would prefer the scale to be horizontal rather than vertical. They thought this would feel less threatening. Nicole then went to a local art shop and got coloured card, which she asked her children to fashion into a simple card version of a sliding ruler. She again tested this in clinic. This enabled the patient to hold the ruler and move a sliding part to the number that corresponded with how important a goal was to them and how confident they were in achieving that goal. Feedback indicated that the patients preferred to have something like this that they could physically interact with. She observed that patients tended to move the scale back and forwards before deciding on their final score. This indicated that patients were really concentrating and were focused on thinking about the goal and all the issues that would prevent that change in behaviour from happening.

Nicole then started working with Cathy Jenkins, our Lead Diabetes Specialist Nurse (DSN) and Lead ADP Tutor. They carried out various tests, using different colours on the sliding scale to indicate a low score and an increasing score (for example, going from red at zero to green at a score of 10). However, they discovered that people from different cultures and different ethnic groups associate colours with different emotions. They concluded that it was potentially confusing to associate numbers with strong colours. They sought advice from a patient who is experienced in design and learnt that large numbers in black font on a grey background was best for patients who may be visually impaired, as may be the case in people with diabetes. Cathy then asked her daughter-in-law to produce a confidence ruler based on these design principles (above photograph). This design has so far proved very successful and we have recently applied to NHS Innovations to fund development of this ruler for the whole UK. We are anxiously awaiting their decision!

# SIP: Improving the Whittington Hospital Diabetes Outpatient Clinic



Members of the Whittington Diabetes Team came together in October 2009 to look at improving the diabetes outpatient clinic for both patients and staff. Administrative, managerial and laboratory colleagues attended with clinicians, to look at the patient journey through clinic. This was the first in a series of workshops which aim to reduce wasted time and effort in the clinic (using “LEAN” principles). These are part of our CCH service improvement national programme. Dr Maria Barnard, the local Clinical Lead for Co-creating Health, said: “There were a lot of positive suggestions from everyone about how we can make things better. We’ve got 4 quick win projects that we’re working on. Then when we come back together, we’ll start looking at the more difficult issues – that will be the real challenge!”

# SIP: Presentation to International Forum

**Abstract for presentation accepted for the International Forum of Quality and Safety in Healthcare 2010**

**Title: Improving Diabetes services in North Central London to support patient self-management**

**1) Context: Where was this improvement work done? What sort of unit/department? What staff/client groups were involved?**

The Whittington Hospital NHS Trust, NHS Islington, NHS Haringey in North Central London were selected as a diabetes site for The Health Foundation's Co-creating Health national initiative. We are working in a collaboration between primary and secondary care and between patients and clinicians. We serve a deprived, ethnically diverse local population where the impact of poor diabetes management is significant.

**2) Problem: What was the problem that you set out to tackle? How was it affecting patient/client care?**

London's diverse, mobile population makes delivering diabetes care challenging. There is a higher proportion of at-risk communities in London than nationally. There is not enough support to help people manage their own condition through self-care. Organisational boundaries significantly affect diabetes care provision and access to services. This particularly disadvantages patients with more complex needs and/or lower health literacy.

**3) Assessment of problem and analysis of its causes: How did you quantify the problem? Did you involve your staff at this stage? How did you assess the causes of the problem? What solutions/changes were needed to make improvements?**

Fifty patients, clinicians and managers met to identify the changes needed to the local health system to support self-management using shared agenda setting, action planning and proactive follow-up of agreed goals.

Fourteen teams are currently involved in quality improvement activities which include: development of an agenda/goal setting tool and a confidence ruler; adapting the diabetes template on the electronic patient record; blood test results prior to appointments; patient group meetings with clinical input; email follow-up; terminal/kiosk to record outcome measures.

**4) Strategy for change: How did you implement the proposed change? What staff or other groups were involved? How did you disseminate the results of your analysis and your plans for change to the groups involved with/affected by the planned change? What was the timetable for change?**

Programmes training clinicians and patients in self-management skills were used to promote the idea of service improvement. A series of workshops involving patients and clinicians were held to identify, develop and share ideas and nurture innovation. Training was provided to clinicians in the Improvement Model using PDSA to redesign and improve the quality of their services. Implementation and spread of successful changes are to be completed by June 2010.

## **5) Measurement of improvement: How did you measure the effects of your planned changes?**

We developed, designed and agreed definitions for process and outcome measures. Four process measures around agenda setting, goal setting, action planning and goal follow-up are sampled monthly from ten patient records per site. The outcome measures include patient enablement questions adapted from the Consultation Quality Index and patients measuring their confidence to manage their condition (scale of 0–10). A patient survey is used for the outcome measures, with some captured on an electronic terminal/kiosk. The monthly results are plotted on a run chart and shared with 5 participating teams (primary/secondary).

## **6) Effects of changes: What were the effects of your changes? How far did these changes resolve the problem that triggered your work? How did this improve patient/client care? What problems were encountered with the process of changes or with the changes?**

Process measures have improved over nine months from December 2008. At first these measures decreased due to definitions not being specific. Since February, there has been a steady improvement. Having a shared agenda has increased from 43% to 70% (against project target of 60%). Goal setting has increased from 40% to 62% (project target of 60%). Action planning has remained relatively constant at 70% (project target of 60%). Goal follow-up has increased from 65% to 73% (project target of 70%). Overall the patient enablement scores showed a steady improvement of 10% to 15%. The patient confidence score for managing their diabetes remained relatively constant at 8.5 out of 10.

## **7) Lessons learnt: What lessons have you learnt from this work? What would you do differently next time?**

A 'Core Group' of patients who have completed the Self Management Programme provide the essential patient voice, informing service improvement work. Training clinicians in communication skills and service improvement methods proved essential to inspire and continue the impetus of improvements. In the future we would carefully define our measures from the very beginning of the work, so that there is clarity amongst teams about what the measures are.

## **8) Message for others: What is the main message based on the experience that you describe here that you would like to convey to others?**

Working with patients, carers, local health professionals and national and international experts, changes are being identified and tested locally to support self-management. Service improvement projects are essential to transform diabetes care locally and are spreading into other long-term conditions. Integrating the different elements of Co-creating Health, including patient and clinician training has been fundamentally important to stimulate service improvement and optimise diabetes care.



# Concentrating efforts in primary care – NHS Islington Pilot Local Enhanced Service (LES)

In a move to increase Co-creating Health activity in primary care, NHS Islington developed a pilot “Supporting Self Management” Local Enhanced Service (LES) running from August until March 2010. The 2 practices involved are St John’s Way and Islington Central. Most clinicians from these practices received training in a shortened version of the Advanced Development Programme in August.

The experience of delivering this training has enriched the Co-Creating Health team’s learning about how the programme will be further developed for primary care.

Here are some comments from course participants from the two practices:

“I was quite sceptical about the whole ADP course; however I can see now where these skills fit into my working practice.”

“Before this course I never really thought about how I can help patients to help themselves other than using a didactic method.”

“We all have patients with chronic conditions and it can be frustrating not being able to help them make changes – so some good techniques here to help them to help themselves.”

The practices are also encouraging their patients to attend the Self Management Programme and will undertake monthly service improvement initiatives with the aim of embedding the principles of self management into their core practice. They are taking monthly measures in the same way as other teams involved with CCH to see whether the changes being made are increasing the proportion of consultations with a collaboratively set agenda, agreed achievable goals and a record of what follow-up arrangements on those goals are. They will also be measuring patient’s ability to cope with their diabetes, to keep themselves healthy, to help themselves and assess their confidence level on a scale of 1 to 10 in managing their diabetes.

The impact of the pilot LES will be reviewed in April 2010.

For any queries about the LES, contact [mary.price@islingtonpct.nhs.uk](mailto:mary.price@islingtonpct.nhs.uk)

# Co-creating Health beyond June 2010 through a diabetes lens - a briefing paper

Presented to NHS Islington Diabetes Local Implementation Team, 2009

## 1) Purpose of this briefing

This briefing is intended to inform commissioners - primary, practice based, community, and acute – on how the whole systems Co-Creating Health programme contributes to the commissioning of services for diabetes outlined in the Health care for London Diabetes Guide for London.

The NHS Islington Diabetes Local Implementation Team (LIT) meeting of 19.10.09 asked for an outline of how CCH links to local and London wide strategic frameworks, specifically:

- How CCH could be embedded in and supports the context of the Diabetes Guide for London, particularly tiers 1 & 2
- The impact of CCH to date in terms of outcomes and effectiveness, including drawing care into primary and community care settings and improvements on biomedical markers such as HbA1C levels
- The strengths of CCH in delivery of the Care Planning agenda

## 2) Summary

Co-Creating Health takes a whole systems approach to transform the patient-clinician interaction into a collaborative partnership.

Headline results to date are:

- statistically significant reductions in HbA1C and LDL cholesterol in patients participating in the Self Management Programme
- 89% of clinicians who have attended the Advanced Development Programme agree that they have significantly improved their knowledge of how to support patient self-management
- monthly process and outcome measures are demonstrating improvements in the percentages of consultations where a care planning consultation is taking place with increases of recorded collaborative agenda setting, goal setting and follow up on goals

Support from The Health Foundation for the activity of the programme in its current form is due to run until June 2010, with the evaluation completing in August 2010. The Health Foundation will be making a decision in March 2010 whether or not they will continue to fund the programme in some form beyond June 2010.

In order therefore to sustain the current good work and to spread to more pockets of the local health care community, both within diabetes care and other conditions, the CCH Steering Group want to flag up to commissioners how CCH helps to deliver on the Healthcare for London Diabetes model and to flag up the resources that will be needed beyond June 2010 to sustain and further develop the programme.

The Co-Creating Health programme is applicable and transferable to all long term conditions - elements of the programme have already been adopted by clinicians working with people with COPD, kidney disease, sickle cell disease and by generalist practitioners (GPs and Practice Nurses) in primary care.

The model embraces key elements of a care planning consultation and so there is rich local knowledge and activity when it comes to developing local responses to Care Planning.

Because patients are integral to the model and providing rich information on views and wishes in relation to local services, CCH also contributes to World Class Commissioning (competencies 1,3,4,7) and has huge **34**

potential to contribute to improving patient involvement and satisfaction levels with local services and the Quality improvement agenda.

In relation to the development of polysystems, the ethos and outcomes of the Co-Creating Health model have the potential to contribute centrally to both supporting patients to become more powerful in managing their own conditions and in increasing public expectation of being supported to increase their capacity to self manage.

## **1) Background information on Co-Creating Health**

The aim of Co-Creating Health is to examine how we can embed self-management support for people with long-term conditions within mainstream health services. It is a 3 year demonstration programme funded to August 2010 by The Health Foundation.

A partnership between The Whittington Hospital NHS Trust, NHS Islington, NHS Haringey was selected in July 2008 by The Health Foundation to be one of the 8 UK demonstration sites. The programme is an innovative collaboration between primary and secondary care and between clinicians and patients. The focus locally of the Co-Creating Health initiative is on type 2 diabetes.

Co-Creating Health is unique in taking a whole systems approach to transform the patient-clinician interaction into a collaborative partnership. The three elements to the programme reflect Wagner's Chronic Care model of what needs to be in place across health and social care systems to support self management. These three elements encompass:

- engaged, informed patients - patients are participating in a Self-Management Programme, (SMP) to build their self-management skills.
- clinicians committed to partnership working - clinicians are undertaking an Advanced Development Programme to develop their consultation/ communication skills
- supportive organisational processes - local services in primary, community and acute settings, are being redesigned to support self-management.

Each of these 3 elements incorporate the three "enablers":

- Collaboratively setting an agenda
- Goal setting and action planning
- Follow up on goals

Monthly Process measures are made on these 3 enablers from 7 teams across the site. In each of the teams 10 sets of notes are audited for evidence of a recorded collaborative agenda set, goals and action plan and how the goals are to be followed up.

Outcome measures (see appendix 2) are taken of patients' self reported ability to:

- Cope with their diabetes
- Keep themselves healthy
- Help themselves

And confidence (on scale 1 – 10) they feel to manage their diabetes

The programme is led locally by a Steering group made up of patients, clinicians and managers from the partner organisations, with support from a dedicated Project Manager. Patients and service users are integral to the delivery of all aspects of the programme, including the delivery of training programmes both to clinicians and to people with diabetes.

The vision for both the Self Management Programme for people with diabetes and the Advanced Development Programme for clinicians is to build local capacity and capability and both courses are co-delivered in partnership between a lay person and a health care professional. To date 7 lay tutors and 6 Health Care Professional tutors have been trained for the Self Management Programme and 6 local Health Care Professionals and 3 lay people have been trained to deliver the Advanced Development Programme.

In order to increase the concentration of the CCH effect in primary care, a pilot "Supporting Self Management" Local Enhanced Service was launched with 2 Islington practices in August 09 to run until March 2010 with an evaluation report expected in April 2010.

### **1) Impact and effectiveness of Co-Creating Health**

Results of the national evaluation being conducted by Coventry University will not be available until August 2010, so some local ongoing evaluation is being conducted which shows the following:

#### **• The Self Management Programme (SMP)**

To date (Jan 2010), 130 patients have completed the Self Management Programme (SMP). The feedback from patients is overwhelmingly positive - 100% would advise other patients to attend Self Management Programme (SMP). Participants highly valued the SMP (global course rating 9.5/10). High scores were given for problem solving / goal setting activities (4.5/5) and peer support (4.5/5).

After the SMP, there was a statistically significant improvement in HbA1c (-0.7% [ $\pm$ 1.7] at 5-8 months,  $p < 0.05$ ; -0.3% [ $\pm$ 0.7] at 9-12 months,  $p < 0.05$ ) and in LDL cholesterol (-0.6 mmol/l [ $\pm$ 0.8] at 9-12 months,  $p < 0.05$ ).

#### **• Training for clinicians in skills to support self management and the care planning consultation.**

To date, 68 local clinicians have completed the Advanced Development Programme (ADP). 61% responded to a local questionnaire. 89% agreed that the ADP significantly improved their knowledge of how to support patient self-management. 96% said the ADP provided them with new skills to use. 93% said they had implemented parts of the ADP into their daily professional practice. 88% said the ADP had a positive impact on their daily professional life and 89% would recommend the ADP to others.

Clinicians find that ongoing support is needed to fully embed skills into practice. This is an area that we are working on along with the other 7 sites nationally.

#### **• Service Improvement Programme**

Patients, clinicians and managers from the Whittington, and primary and community care services in Islington and Haringey met to identify the changes needed to the local health system to support self-management using shared agenda setting, action planning and proactive follow-up of agreed goals.

In addition, session 6 of the Self Management Programme asks "What in your local health service gets in the way of you being able to self manage?" and "If you used agenda setting, goal setting, and goal follow up with you health professional, what do you think may happen?"

Further, patient Self Management Programme reunions and a patient Core Group meet regularly with further service improvement ideas. To date 7 reunions have been held. This is providing rich information on patients' views and useful starting points for service improvement.

Fourteen teams are currently involved in quality improvement activities which include: development of an agenda/goal setting tool and a confidence ruler; adapting the diabetes template on the electronic patient record (EMIS); blood test results to patient and clinician prior to appointments; patient group meetings with clinical input; email follow-up; terminal/kiosk to record outcome measures.

We developed, designed and agreed definitions for process and outcome measures. Four process measures around agenda setting, goal setting, action planning and goal follow-up are sampled monthly from ten patient records per site. The outcome measures include patient enablement questions adapted from the Consultation Quality Index and patients measuring their confidence to manage their condition (scale of 0–10). A patient survey is used for the outcome measures, (see appendix 2) with some at the Whittington captured on an electronic terminal/kiosk. The monthly results are plotted on a run chart and shared with participating teams (primary/community/secondary).

Process measures have improved since December 2008. At first these measures decreased due to definitions not being specific. Since February, there has been a steady improvement. Having a shared agenda has increased from 43% to 70% (against project target of 60%). Goal setting has increased from 40% to 62% (project target of 60%). Action planning has remained relatively constant at 70% (project target of 60%). Goal follow-up has increased from 65% to 73% (project target of 70%). Overall the patient enablement scores showed a steady improvement of 10% to 15%. The patient confidence score for managing their diabetes remained relatively constant at 8.5 out of 10.

- **Shift of care away from hospital and into primary and community**

Whilst this has not been a focus of the programme to date, there is no reason why it shouldn't be so in the next phase. If, as is appearing to be the case, whole systems support for self management results in improved HbA1C levels, this will reduce complications and necessity for specialist care over time.

## **1) Issues**

Support from The Health Foundation for the activity of the programme in its current form is due to run until June 2010, with the evaluation completing in August 2010.

The Health Foundation are currently considering whether there may be a further phase of CCHi beyond August 2010, but their Board will not make a decision on what this might look like until March 2010.

In order therefore to sustain the current good work and to spread to more pockets of the local health care community, both within diabetes care and other conditions, the CCH Steering Group want to flag up to commissioners how CCH helps to deliver on the Healthcare for London Diabetes model and to flag up the resources that will be needed beyond June 2010 to sustain and further develop the programme.

## **2) How does Co-Creating Health support the Healthcare for London diabetes Model?**

Co-Creating Health provides an exemplar model in contributing to delivery on 2 of the 6 principles underlying the London Diabetes model, notably:

- Individual with diabetes at the centre of their care
- Care planning and self management

The following table outlines further detail of how CCH supports the London model:

<b>section reference / page</b>	<b>London Diabetes Model</b>	<b>How Co-Creating Health supports the model</b>
4.1 p20	There needs to be more collaboration between healthcare professionals across primary and secondary care, and across PCT and provider structures	This collaboration is exemplified in CCH with a steering group made up of clinicians, managers and patients from primary, secondary and community settings
5.2 p22	Individual with diabetes at the centre of their care – A shift towards a more collaborative relationship between clinicians and patients. This will require clinicians and patients to develop new skills and approaches, as well as changes to healthcare systems and cultural change	CCH takes a whole systems approach to transform the patient-clinician interaction into a collaborative partnership through training for both patients and clinicians and the service improvement programme
5.3 p24	Care planning – The diabetes model should: <ul style="list-style-type: none"> <li>• Support people with diabetes to self-manage their condition by providing education and information resources</li> <li>• Involve patients in the system and designing their care pathway</li> <li>• Provide healthcare professionals with training and information resources</li> </ul>	CCH is fundamentally a care planning process and provides each of these elements
6. pp 30 - 33	Tier one, two, three and four All care settings should enable collaborative care planning and this should be measured	The measures in the CCH programme include monthly measures in participating teams of <ul style="list-style-type: none"> <li>• Agenda setting</li> <li>• Goal setting</li> <li>• Goal follow up</li> </ul>
6. p30	Tier two – enhanced care- Structured education programmes for patients and carers	The self management programme of CCH offers structured education in a 7 week x 2.5 hr course based on the Stanford model of chronic Disease Self Management Programme – similar to the Expert Patients Programme, but with some condition specific content. Currently targeting those with type 2 diabetes who have had their diabetes for 1 year or longer.
8.5 p 53	Training and support – primary care – Staff caring for people with diabetes must have training and resources in collaborative care planning	The Advanced Development Programme of CCH provides clinicians with training in skills to deliver a care planning consultation

11.1 p60	<p>Priorities for commissioners – key elements – nos 2, 4, 6,</p> <p>2: Local service development is informed by user involvement</p> <p>4: People with diabetes receive effective education to self-manage their condition, and there is a focus in collaborative care planning</p> <p>6: Primary care professionals providing diabetes care receive training, development and support, including training on care planning</p>	<p>User involvement is integral to CCH. The Service Improvement Programme of CCH (SIP) bases new tests of change for improvement on suggestions made by service users</p> <p>The SMP is producing results of statistically significant reductions in HbA1C and cholesterol. The focus on all elements of CCH is on collaborative agenda setting, goal setting and goal follow up</p> <p>The ADP offers training in the core skills required for care planning</p>
14.1	<p>Workforce and education group The Pan London Diabetes Board will take responsibility for London-based courses, these will include care planning as a foundation skill throughout 2009/10</p>	<p>The CCH Advanced Development Programme (ADP) provides training in care planning skills, and should inform sector level workforce development plans</p>

**1) Timeframes and considerations**

Planning for the Self Management Programme beyond June 2010 will need to begin in January 2010

Planning for the Advanced Development Programme for clinicians needs to consider:

Adaptations of the ADP for primary care, using learning from the courses delivered to date, including the shortened course delivered to the 2 practices on the Supporting Self Management LES.