

**Evaluating the Delivery and Impact of the
'Year of Care for Diabetes' Project
Interim Report
November 2009**

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Executive summary

Introduction

Diabetes UK commissioned Tribal to undertake an evaluation of the delivery and impact of the Year of Care Project to run alongside the two year delivery phase that began in autumn 2008. This builds upon the initial evaluation of the preparation phase, continuing to capture and share formative lessons and also assess the impact and outcomes of the project on patients, NHS stakeholders and organisations, commissioning and costs.

One year of the delivery phase is now complete and it is important to assess not only the successes of Year of Care but also the failings, the weaknesses and the limitations so that they may be addressed over the coming year.

Key Messages

Year of Care is making a difference to the way some patients are now engaging in their own diabetes care. In some places patients are thinking about their blood results when they receive them, attending clinics more frequently, feeling less anxious about clinic appointments, being involved in discussing goals and targets and changing the way they diet and exercise.

There are differences in the way Year of Care is being delivered in the three pilot sites. These differences are a result of community culture, demographics, history of diabetes care in the area and personalities. However, they also relate to levels of understanding and commitment in the sites. There is no one right way to implement Year of Care but it is essential that understanding and commitment are such that they enable care planning to occur.

Appropriate training is critical to the successful understanding and implementation of Year of Care. Currently, pilot practices have used the national training programme, 'Successful Diabetes' and other courses in psychology and behavioural change. The latter has not made an impact on promoting an understanding of care planning. The national training programme in particular is extremely effective and many have spoken of the inspirational effect of participating in the programme. However, the issue of capacity to deliver the national programme is a major challenge to the roll out and sustainability of Year of Care.

Year of Care can potentially induce a major cultural change in an organisation. Those who state they have been 'doing Year of Care for years' demonstrate a lack of understanding of what Year of Care entails. It is not simply a set of component activities but rather an attitudinal shift affecting the power relationship of a clinician and patient. It helps to replace a paternalistic and benevolent approach with an empowered and equal partnership.

Senior buy in at local and PCT level ensures that care planning is explored, encouraged, facilitated, and supported at both levels. It enables appropriate resources to be made available and effective monitoring of standards and quality to take place.

Methods

Ongoing formative evaluation is taking place across the three pilot sites using both quantitative and qualitative data. The quantitative data is being collected using the agreed measures and all the baseline data for the first wave has now been collected and analysed. The second wave of data collection began at the end of September. Case studies have been undertaken at all three pilot sites. Formative evaluation continues to be undertaken through the visits to pilot sites.

Findings

Quantitative Data

The Diabetes Year of Care evaluation has collected a vast amount of data for the participants across two pilot sites; North of Tyne and Calderdale and Kirklees. There have been over 1,900 patient responses to two different surveys and 51 GP practice returns.

Five different surveys have been used to collect data. These are: Health Care Commission (HCC, Consultation Quality Index (CQI), Diabetes Treatment Satisfaction questionnaire (DTSQ), World Health Organisation Quality of Life (EQ-5D), Primary Care Resources and Supports for Chronic Disease Self Management (PCRS). The Client Service Receipt Inventory (CSRI) is being conducted as telephone interviews with Year of Care patients.

The HCC survey compares responses from the pilot sites to national available data of the specific PCTs in 2006. Although there is little difference in diabetes care in Year of Care practices and others, it is not anticipated that changes will be obvious this early in the programme. Other surveys have indicated overall satisfaction with the services given.

It is important to triangulate both the quantitative and qualitative findings to create a rich picture and understanding of the underlying context of diabetes care in the pilot sites.

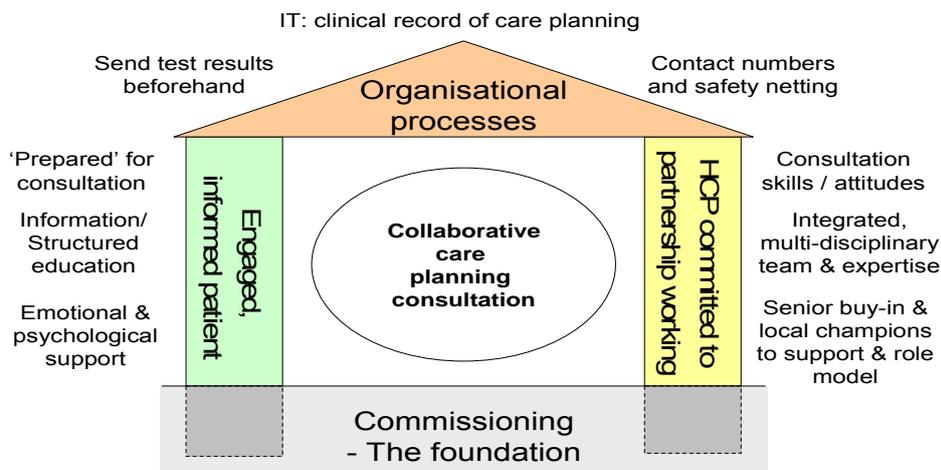
Qualitative Case Studies

Three case studies were conducted during September and October where two researchers attended for a week at each site and interviewed patients and healthcare professionals to get their views on Year of Care.

Discussion

Care planning is a multifaceted, complex intervention. It demands enormous changes into the way people behave, both for clinicians and patients, which inevitably lead to huge cultural changes and attitudinal shifts. Inevitably, the process of change is not always recognised by those in the midst of it. The format for the discussion is based on the House and Windmill models.

Figure 1: The Year of Care House model



The Consultation

Collaborative Care Planning Consultation: The Year of Care consultation uses the skills drawn from three different consultation theories; ‘empowerment’, ‘motivational interviewing’ and ‘counselling’. Empowerment focuses on making people feel good and strong whilst having a pleasant chat with them. Motivational interviewing develops specific skills to elicit actions and counselling allows the person to talk and work things out themselves. The Year of Care consultation uses all three methods to listen for the patient’s perspective, understand and value that, and find out what their health beliefs are. At the same time the clinician’s story must be evident and their perspective at hand to provide information and negotiation to help the patient arrive at their own conclusion and action plan.

Goal Setting: In the action or care plan, if only advice is given or the clinician says themselves what should be achieved in the long term, the chance of the patient visioning the next steps, working out how those immediate changes can be brought about and what the barriers are to achieving them, has been lost. The clinician needs to engage in a problem solving process with the patient so that they work out themselves what immediate steps can be taken. These are big changes in core behaviours.



Organisational Processes

Test Results Beforehand: Receiving test results before an appointment enables a patient to be prepared for a consultation. It gives them time to assess their feelings and emotions and the implications of the results. It enables them to begin to assess what they need to know and do for their own care. Many patients receive their results one week prior to their appointments but in some cases this may be just a few minutes. In a few cases patients receive them during the consultation.

IT Clinical Record of Care Planning: The aim of having effective IT systems is to support the care planning process and not to drive it. The system provides a useful aide memoir with appropriate prompts, though more experienced clinicians find they are able to consult with their patients without recourse to the systems. They tend to complete the record after the consultation so that it does not get in the way of communication with the patient. Although many clinicians who use the computer during the consultation do not feel that it gets in the way of the consultation, patients have commented negatively on clinicians’ focus on a computer screen during a consultation.

Contact Numbers and Safety Netting: Year of Care relies on a robust system of administrative and managerial procedures to be effectively in place. All patients are called for blood tests to be made, and then recalled for appointments. Many practices invite patients for appointments at least twice a year, and on some occasions such as in Tower Hamlets they are given appointments for checks 3 or 4 times per year. Strict processes are the safety nets which exist to ensure no patient is forgotten or missed.

Engaged Informed Patients

Prepared for Consultation: The engaged patient is one who understands their results and the significance of those results. They take a leadership role in the consultation and come to it with an agenda that they have identified themselves and which enables them to engage in discussion and conversation with the clinician.

Structured Education/Information: Patients will not be engaged in the process of care planning without an understanding of what it constitutes. The basic message with change management is to communicate and communicate effectively. Most patients do not evidence much knowledge of what Year of Care or care planning entails. They understand what processes they go through but are not able to contextualise it within a care planning framework. This is an omission that smacks of paternalism in that it implies we know what is best for you, we want you to be a true partner in it, but we are not really going to tell you what it is. The folder or pack that is given to all patients in Tower Hamlets is an example of what could be done.

Emotional and Psychological Support: Emotional and psychological support is essential for patients going through the upheaval of coping with diabetes. This support is provided via a number of mechanisms; having access to information, having access to people to contact either professionals or diabetes support groups, and having structured education so they feel empowered to deal with the daily constraints and requirements from a position of knowledge and therefore strength.

Consultation Skills and Attitudes: Having the right consultation skills and attitudes is reliant on receiving appropriate training. Training is key to lighting the spark of change, both in knowledge and behaviour. The culture of the organisation, including team work and collegial support must help maintain the momentum of this changed behaviour.

Multi-disciplinary Team and Expertise: The successful implementation of Year of Care is reliant on many factors and one key factor is the identification and integration of tasks. We have examples from the pilot sites which show how disintegration occurs where these tasks are not clearly delineated. In one practice, a nurse took on the administrative or support role of assisting patients with their evaluation questionnaires, which proved a task too great and the proverbial last straw, finally leading to the withdrawal of the practice from the project. In another site, the specialist unit ran care planning but did not have an HCA to take bloods, or do basic checks and measurements. The infrastructure of a large Trust did not allow for such a task profile and it therefore became part of the nurse's duties. This again resulted in an imbalance of tasks and the curtailment of care planning, at that stage, in the unit.

Senior Buy-in and Local Champions to Support and Role Model: The spark of new knowledge and changed behaviour can be easily extinguished in a culture that is not supportive of care planning. No matter how enthused a clinician, once they return to a culture that does not welcome or nurture those beliefs and methods, previous behaviours could soon re-emerge. After all, sending out results and producing action or care plans involves an additional workload, and maintaining consultation skills where the clinician does not give advice upfront is often counter-intuitive and requires a certain amount of restraint. It is necessary to have effective support within the organisation, from senior buy-in to supportive infrastructural and administrative mechanisms for these behaviours to be maintained.

HCP Committed to Partnership Working

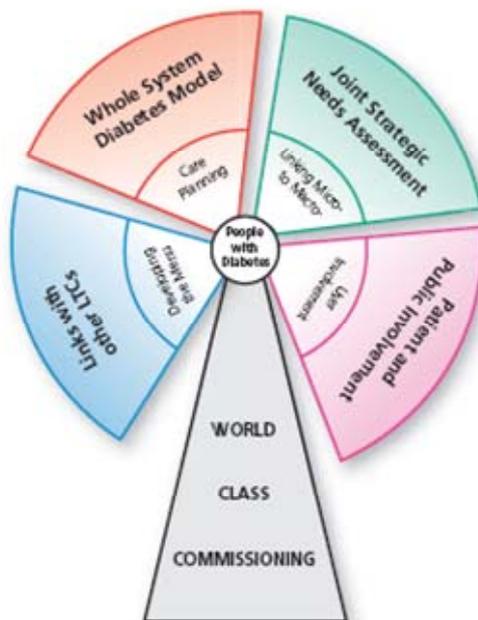
Commissioning -the foundation

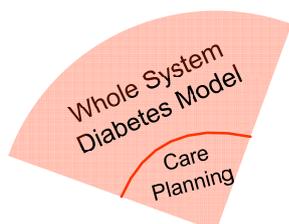
Identify and Fulfil Needs: Patients arrive at consultations, discuss their goals and identify what would help them to achieve those goals. This process leads to an important step in allowing the patients themselves or with the aid of the clinician, to identify their needs. These needs relate to a variety of services that can be procured, such as seeing a dietician, a chiroprapist, having an exercise programme, cookery classes or structured education, or to issues that are more personal and specific such as loneliness, depression or anxiety. Options are then identified which may help to meet those needs or alleviate those conditions.

Procure Time for Consultations, Training and IT: The commitment to provide adequate support in terms of project management, training and IT is recognised across the sites but delivered to different standards. This must be seen in conjunction with cultural and other factors. In terms of IT, system inadequacies either become stumbling blocks that prevent advancement or inconveniences that are overcome using creative devices. Therefore, procurement must be seen within a wider context of the whole system, rather than a specific piece of soft and hardware.

Quality Assure and Measure: Quality assurance and measurement takes place at both national and local levels. The evaluation process conducted by Tribal, the use of both quantitative measures collected at three points in time, and qualitative case studies undertaken twice, are means of assessing the quality of activities and perceptions of experiences. In Tower Hamlets, the quantitative measures are met by the use of the Picker survey.

Figure 2: The Year of Care Windmill model





Care Planning: Care planning is the model of care promoted by Year of Care. It is essentially an approach that relies on screening and collecting of biomedical components as the first stage in enabling an informed and empowered 'conversation' to take place which is central to the consultation and self management.

One Stop Shops: Two practices in Calderdale and Kirklees have introduced One Stop Shop practices. This is a restructuring of processes whereby a variety of healthcare professionals are available in one place at one time to screen, offer advice, and consult with patients. While these practices see this way of working as the optimum, and it is indeed popular with patients, it has focused more on restructuring than recognising and implementing the core components of Year of Care.

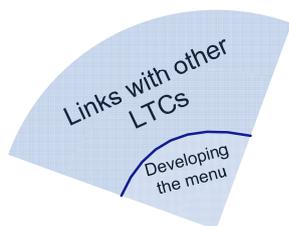
Local Specialist Services: Calderdale and Kirklees and North of Tyne are both two tier systems, though North of Tyne has a Diabetes Resource Centre with specialist clinicians. Tower Hamlets has a tier between primary and hospital based care, the intermediate team with a consultant lead in the community.

Resources: Additional resources were made available to all practices in the pilot sites during the first year to assist setting up the project though this is not available for the second year.

Monitoring and Consistency: There is little in the way of monitoring at this stage. Some pockets of practice do this such as audits of care plans in Tower Hamlets, though currently this is more to do with education and skill development than quality assurance. Project managers attempt to monitor by providing support and recently the project manager in Calderdale and Kirklees is undertaking a 'walk through' of all the practices in the area.

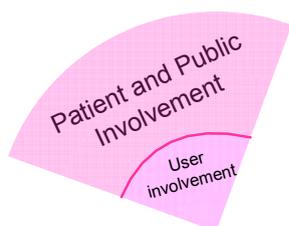


Linking Micro to Macro: It is not yet feasible to link micro to macro for commissioning purposes. Information is not yet being recorded or collated and practices are not doing this manually. Other methods suggested could be vouchers that patients are given and are then returned to the practice or PCT to monitor usage. Another possibility is for networked practices (in Tower Hamlets) to meet at specific time periods to work out precisely what facilities or resources have been used. The limitations are clearly linked to inadequacies in information technology. Once a template is available, accessible and used, it will be possible to achieve this aim.



Links with other LTCs: Some practices are beginning to introduce care planning into other LTCs while some are using Year of Care appointments to look at a patient’s other LTCs. This linkage of co-morbidities is regarded by many as the sensible and obvious way forward in managing a patient and promoting self-care.

Developing the Menu: Tower Hamlets has a booklet, ‘Supporting Self Care’ with options available for patients to read. However this booklet is now out of print and not being republished though it is available on line and easily accessible to clinicians. Many of the population in this area are not obviously computer literate and it seems a shame that they now have to rely on being told what is on the menu. However, often health trainers are available to discuss options. It is important to take into account local idiosyncrasies such as not wishing to travel away from the local vicinity in Tower Hamlets or wishing to have all women swimming sessions.



Patient and Public Involvement: Patient and public involvement has been taken very seriously in Tower Hamlets. The commitment to this element is seen by having an Assistant Director for Patient Involvement as part of the Programme Board as well as the Commissioning Manager for Self Care, who has a wealth of experience in this area. Many events have been organised where local people have been invited to provide suggestions, comments and responses to questions or proposals.

Risks

The identified risks are:

- The lack of full time project management at Calderdale and Kirklees and North of Tyne.
- Training is not yet meeting the needs of pilot practices (let alone other practices) in terms of quantity.
- Momentum is losing ground.
- The differentiation amongst Year of Care and non Year of Care patients in one practice in Calderdale and Kirklees presents a barrier to making care planning part of routine care.
- Structured patient education is not taking place in sufficiently large numbers.
- Patients are not being prepared for care planning.

- Year of Care is taking much longer than anticipated to become embedded in practices in Calderdale and Kirklees with the resultant and expected change in culture.
- Clinicians in practices in Calderdale and Kirklees are putting too much emphasis on IT.
- The evaluation questionnaires are seen as burdensome and one practice has used that as the reason for withdrawing from Year of Care.
- Unmet needs are not being captured and therefore not feeding into the commissioning cycle.
- Patients are not being adequately involved in the Year of Care project in Calderdale and Kirklees and North of Tyne.

Conclusions

It is important to consider how sites can support change in attitudes and behaviours and to recognise the impact of culture on an organisation.

The national training programme is a huge asset to Year of Care but it does not have sufficient capacity for rolling out in a timely fashion.

The practices have all shown different ways of implementing Year of Care and a key lesson from this is that there is no one right way. Local conditions, idiosyncrasies, histories and personalities must all be taken into account when deciding what Year of Care will look like in a particular setting.

Year of Care is an enormous challenge. It requires senior buy in and clinical leaders and where this is not in place it risks failure.

Year of Care can engender a sense of aspiration and commitment amongst healthcare professionals.

Recommendations

The recommendations are that:

- Greater support is provided in the form of funding for full time project managers, and systems for advice and assistance.
- A plan is introduced to consider capacity issues with the national training programme.
- Year of Care templates are introduced with effective IT support to all practices.
- Unmet needs are captured in Year of Care IT templates.
- Pressure is put on increasing capacity for structured education for patients.

1 Introduction

1.1 Background

Current figures indicate that 2.3m people in the UK have been diagnosed as having diabetes with further estimated 0.5m people whose diabetes is undiagnosed. By 2010 the number of people with diabetes is expected to be around 4m, making it one of the major burdens on an individual's health and on NHS resources.

The Diabetes National Service Framework (NSF) sets out 12 standards to be achieved by 2013 and emphasised the importance of care planning in achieving these standards. *Choosing Health: Making healthy choices easier* (DH 2004)¹ sets out a national strategy to improve health and prevent disease, and introduced a commitment to *Year of Care*.

A *Year of Care* describes the on-going care a person with a long term condition should expect to receive in a year, including support for self-management, which can be costed and commissioned. A commitment to develop and test the *Year of Care* approach was reaffirmed in *Our Health, Our Care, Our Say* (Department of Health 2006)².

More recently, the NHS Next Stage Review (Department of Health 2008)³ sets out its vision for a modern NHS. This includes a commitment to personal care plans for all people with long term conditions. The *Year of Care* approach offers a potential framework through which these commitments can be realised.

Against this backdrop the joint Department of Health and Diabetes UK Care Planning Working Group (2006)⁴ published a report that described a partnership approach to care between health professionals and people with diabetes, and offered guidance on incorporating care planning into diabetes services.

The *Year of Care* programme arose as a response to the commitment laid out in *Choosing Health* and builds upon the approach outlined in the Department of Health and Diabetes UK Care Planning Working Group report.

The 'Year of Care' programme is a partnership between Diabetes UK, the Department of Health, The Health Foundation and NHS Diabetes. It is about making the annual review process genuinely collaborative through care planning and ensuring that services needed to support this approach are identified and available through commissioning.

The Year of Care programme successfully completed its preparatory phase (June 2007 – August 2008) during which three pilot sites worked with the Year of Care programme team to develop tools, put in place structure and processes and engage local stakeholders for the two year delivery phase.

¹ DH (2004) *Choosing Health: Making healthy choices easier*. London: DH

² DH (2006) *Our Health, Our Care, Our Say: a new direction for community services*. London: DH

³ *High Quality Care for All: NHS Next Stage Review Final Report (2008)* Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

⁴ *Care Planning in Diabetes: Report from the joint Department of Health and Diabetes UK Care Planning Working Group(2006)*. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063081

Diabetes UK commissioned Tribal to undertake an evaluation of the delivery and impact of the Year of Care programme to run alongside the two year delivery phase that began in autumn 2008. This builds upon the initial evaluation of the preparation phase, continuing to capture and share formative lessons and also assess the impact and outcomes of the project on people with long term conditions, the Department of Health, academics, NHS stakeholders and organisations, commissioning and costs

One year of the delivery phase is now complete and it is important to assess not only the successes of Year of Care but also the challenges, weaknesses and limitations so that they may be addressed over the coming year.

1.2 Aims and Objectives of the Evaluation

The overarching aim of the evaluation is to test the feasibility of implementing a Year of Care across the NHS. In addition to providing valuable knowledge about what is required to deliver a Year of Care successfully and best practice guidance, it will also inform wider policy making which seeks to encourage self care and empowerment for the full range of people with long term conditions.

The key objectives of the evaluation are to understand:

- How the Year of Care has been implemented, in terms of care planning approaches, tools, pilot structures and processes, staff and skills and resources.
- The key lessons and learning, including barriers, incentives and best practice guidelines.
- The impact of the Year of Care on patients, NHS staff, local organisations, service delivery, commissioning, and culture.
- How different components of the Year of Care 'house' model affect process indicators and patient outcomes.
- An economic analysis of the costs of delivery and potential savings from the Year of Care approach.

The evaluation also seeks to explore how differences in local pilot implementations influence the outcomes of the project, identifying key factors which have a positive or negative impact.

1.3 Overview of the Evaluation

Overall the evaluation can be viewed as having three main workstreams, which operate in parallel and collect a range of qualitative and quantitative data:

- Ongoing site visits across the three pilot sites.
- Quantitative data collection.
- Case studies which provide an in-depth qualitative understanding of issues.

1.4 Anticipated Audience for this Report

This report is written principally for the Year of Care Project Team and Steering Committee. It is part of the evaluation programme and aims to assess at this stage of the project what the successes and barriers to success are. It includes some background for contextual purposes. The executive summary has been written to allow it to be a separate document with key messages and a full discussion, as well as risks, conclusions and recommendations.

1.5 About this Document

This document describes evaluation activities and progress for the period November 2008 to November 2009. It contains the following sections:

- Descriptions of the methods and progress against the methodology.
- The findings from both quantitative and qualitative methods of data collection.
- A discussion of the findings structured according to the house and windmill models.
- A discussion of challenges and risks to the project.
- Conclusions and recommendations for the further development of the project.

2 Methods

2.1 Evaluation Activities

Ongoing formative evaluation is taking place across the three pilot sites using both quantitative and qualitative data. The quantitative data is being collected using the agreed measures and all the baseline data for the first wave has now been collected and analysed. The second wave of data collection began at the end of September.

The timing of the collection of data is different at the sites. North of Tyne allocated three months to hand out and collect baseline data for the HCC survey in North Tyneside. From September to December 2009 they will hand out and collect the 12 month questionnaires using the same patients, and 12 months later they will be able to collect the 24 month data. In West Northumberland, the packs were sent out from July to September 2009 for baseline data.

At Calderdale and Kirklees, most practices have stopped recruiting patients to evaluate Year of Care and will begin again from this point in time. They are attempting to ensure they pass questionnaires on and receive them from patients who completed the first wave of questionnaires so that patient data is able to be compared. Where this is not possible data will be generalised by practice.

Tower Hamlets are using the Picker Institute questionnaire in their pilot practices for their quantitative measures.

Formative evaluation continues to be undertaken through the visits to pilot sites. These are to project board meetings, steering group meetings or meeting which have been set up to discuss particular issues and concerns.

2.2 Assessment of Evaluation Methods

Much of the discussion is based on evidence gleaned from the qualitative analysis with some supporting evidence from the quantitative methods. The quantitative methods that have been used in this project are able to give us some useful information, such as that diabetes patients in Year of Care practices are not different to other practices. We know that they do not do worse than other practices but at this stage it is not possible to say that they do better on the basis of the questionnaire data alone. This is not surprising for several reasons:

- It will take some time for the impact of care planning to be recognised by patients.
- The questionnaires are used in only two of the three practices, one of which is not demonstrating that Year of Care is being used to its optimum.
- It is difficult for the methodology to demonstrate specificity given that they assess general characteristics such as satisfaction, which are influenced by personal circumstances and attitudes, differences in local delivery and wider environmental factors such as the recession.
- The use of case studies has enabled an enormous amount of rich and valuable data to be collected. Qualitative data provides insight into the opinions, perceptions, thoughts and values of individuals who are at the receiving end of the care. Their views, together with those of healthcare professionals' enable us to challenge prior theories about the impact of care planning and to consider issues and aspects that had not previously been identified.

3 Findings

3.1 Quantitative Data Analysis

Introduction

The Diabetes Year of Care evaluation has collected a vast amount of data for the participants in the pilot across two pilot sites; North of Tyne and Calderdale and Kirklees. There have been over 1,900 patient responses to two different surveys and 51 GP practice returns⁵. See Table 1 below for the numbers of data returns.

Table 1: Returns

Measurement category	North of Tyne	Calderdale and Kirklees	Northumberland	Processing	Total
Patient Survey 1 – Health Care Commission Survey	457	259	128	28	872
Patient Survey 2 – Other (CQI, DTSQ, EQ5D)	767	221	42	62	1,092
Ad-hoc Patient Feedback	-	-			0
Staff PCRS Survey	37	10	4	7	58
Bio-metric data	-	-			0
Client Service Receipt Inventory Interviews	25	20			45
Total returns and interviews	1,286	510	174	97	2,067

Initially we suggested that between 50 and 100 patients will need to be recruited to be able to detect differences in outcomes. ‘As a guide following Cohen and assuming a medium effect size, between 50 and 100 patients will need to be recruited at each practice to detect differences in outcomes at the 5% level of significance.’⁶ We have recruited sufficient to detect a 5% difference.

⁵ This is the data collected and entered into our systems October 2009.

⁶ Year of Care Response to Questions June 24, 2008

The responses have been monitored throughout the project and we have provided regular summaries and commentary on the overall results. In parallel to this we have established reports and procedures to send GP level results to the sites for distribution.

Health Care Commission Survey

This survey is distributed to patients in advance of their appointment. The majority of respondents are over 50 (89%), with a slightly older response profile from North of Tyne. The ethnicity profile across the two sites differs, with 99.8% of responses from North of Tyne white, and 86% of responses from Calderdale and Kirklees being white.⁷ While we cannot say that ethnicity has had an impact on the results, we can say that differences may be practice specific rather than ethnicity specific.

The majority go to their doctors' surgery for their check up, with a small proportion visiting the hospital clinic. The majority (71%) find it very convenient, 76% find the clinician has the most up to date information, 76% have enough time for discussion, 88% have confidence in the clinician, and 83% feel the clinician knows enough about their condition. These majority of respondents were answering "very ..", "always or almost always" or "yes, definitely" to the questions several others also answered positively but not choosing the most positive response. For example 71% found their appointments very convenient but 25% also found them fairly convenient and only 4% found it not convenient, Similarly only 3% find the clinician rarely or never has the most up to date information, 3% responded no they did not have enough time for discussion, 1% responded no they did not have confidence in the clinician, and less than 1% responded no their clinician knows enough about their condition.

A high proportion feel they know enough about their medication and when to take and how much; 93% and 96% respectively. They also tend to know enough about food and exercise, 77% and 75% respectively, but few report being very good at these aspects, with the majority being 'fairly good.' The majority (74%) do not have a number they can contact out of hours.

There are statistical differences in the responses from the two sites.

- North of Tyne respondents are more likely to find the appointment convenient, more likely to have had more than one check up in the last year, feel they have enough time to discuss, that the nurse or doctor knows enough and get answers they can understand. They are also more likely to have had their bare feet examined, been weighed and seen a dietician.
- Calderdale and Kirklees respondents are more likely to feel they are good at keeping physically active and have confidence and trust in who they saw. They are more likely to both want and get their test results in writing, receive a written copy of their care plan and arrange their next visit. It is difficult to draw any conclusions about the sites or their work based on these findings.

Comparison to the response to the Health Care Commission survey

We have compared our HCC results with HCC results for each PCT collected in 2006⁸. For North of Tyne we compared with North Tyneside and for Calderdale and Kirklees we combined the results from Calderdale PCT and Kirklees PCT. The survey was undertaken before the recent restructuring. Key differences that are seen in our results compared with the PCT results are:

⁷ Note Northumberland data was not included due to their different stage of evaluation.

⁸ The responses from North of Tyne were compared to responses from patients in North Tyneside PCT to the 2006 Health Care Commission survey. The responses from Calderdale and Kirklees PCT were compared to combined patients responses from Calderdale PCT and Kirklees PCT to the 2006 Health Care Commission survey. (This was prior to the merger of the two PCTs).

- Those involved in Year of Care are more likely to have Type 2 diabetes.
- There are more males.
- They are less likely to have other health problems affecting their day-to-day lives.
- Ethnicity is similar.
- They are more likely to go to their GP for their diabetes check up.
- They are more likely to have had check and tests and get results in writing
- More of them knew their HbA1C value.
- Fewer needed emotional support.
- They were less likely to have a number for a doctor or nurse to call out of hours.
- They were less likely to test their own blood glucose levels.

The site specific differences in responses are:

- In North of Tyne those on the Year of Care were more likely to find it convenient to those surveyed in 2006. It is not possible to state that these changes are attributable to Year of Care.
- In Calderdale and Kirklees those on Year of Care were more likely to find they discussed their goals and their ideas on the best way to manage their Diabetes. It is important to remember here that these results are compared with the PCT survey in 2006 and not comparing differences between the two pilot sites. It indicates that those people who completed questionnaires are more likely to have discussed their goals than the population who responded in 2006. It may well be that this is due to the changes that have come about through Year of Care.

CQI, DTSQ and EQ5D

The second survey given to patients after their consultation has three instruments in it: the Consultation Quality Index (CQI), the Diabetes Treatment Satisfaction questionnaire (DTSQ) and the World Health Organisation Quality of Life (EQ-5D). The respondents to this, as with the HCC, are generally aged over 50 (87%), with a slightly older response profile from North of Tyne. The ethnicity profile across the two sites differs with 98% of response from North of Tyne being white and 85% of responses from Calderdale and Kirklees being white.

- **CQI** – The CQI is designed to assess empathy and enablement through a series of questions and two scores; the PEI (Patient Enablement Instrument) score and the CARE score. There is a positive relationship between these two scores; the higher the empathy score, the higher the enablement score. The respondents tend to feel better around the self management categories after their consultation. A minimum of 60% selecting better for all categories. There was a high level rating of excellent for the different elements of the consultation. They tended to feel they knew who they saw well with 37% stating they knew them very well. 92% felt the skills and attitudes rated were very important.
- **DTSQ** – This suggested a high level of satisfaction with their current treatment, the convenience and the flexibility of it and their level of understanding. 72% are very satisfied to continue and 68% would definitively recommend this treatment to others. These questions used a 0 – 6 scale, for example for satisfaction where is

6=very satisfied to 0= very dissatisfied, 4-6 being satisfied and 3 neither satisfied nor dissatisfied and 2-0 dissatisfied. Using this scale 94% are satisfied to continue to some degree, 4% are neither satisfied nor dissatisfied and only 2% are dissatisfied to continue. Similarly 92% would recommend this treatment to others, 4% are unsure and 4% would not.

- **EQ-5D** – For this the majority selected no issue with the different categories, except pain, where only 48% report no issue with pain or discomfort. The highest aspect with no issue is self-care; 87% report no problems with self care.

There are statistical differences in the responses from the two sites. The North of Tyne respondents are more likely to know the person they saw in the clinic and, possibly as a result, are more positive about elements of their appointment such as making them feel at ease and being able to tell their story. They are also more likely to feel that, as a result of their appointment, they are more able to cope with their diabetes. This may well be due to changes that have resulted in the way consultations are run as a result of Year of Care.

Primary Care Resources and Supports for Chronic Disease Self Management

The Primary Care Resources and Supports for Chronic Disease Self Management is a survey for staff at the GP practices. It is completed at a practice level or by different members of staff in the practice; with between none and five returns for each practice. The PCRS has two dimensions - patient and organisational support each made up of eight elements.

The average scores are above 5.2 for all aspects of patient support and organisational support. Aspects scoring highest are Continuity of care, 7.7, Patient involvement, 7.0, and Patient care team, 7.0. The aspects scoring lowest are Integration of SMS into primary care, 5.2, and Problem-solving skills, 5.3.

There are no statistically significant differences in the responses from North of Tyne and Calderdale and Kirklees. This is not a surprising result as healthcare professionals believe they are doing a good job and that they are doing care planning. This does not take into account the extent to which they really are care planning to its optimum, it simply reflects their understanding of what they are doing.

This tool helps provide an overview of sites positions and the difference between the highest and lowest scoring practices which allow areas for improvement to be identified.

Biometric Data

It is possible to obtain data for BMI, BP and HbA1c at GP practice level at North of Tyne. This is being actioned currently. Calderdale and Kirklees are only able to provide QoF data and Tower Hamlets is not able to provide any data without going through ethics and governance procedures.

Client Service Receipt Inventory Interviews

The Client Service Receipt Inventory (CSRI) is being conducted as a telephone interview with Year of Care patients. The interview includes the CSRI instrument which focuses on patients' use of services across the acute and community setting. The patients are also asked additional questions to understand how services and support can be improved locally.

What are the data telling us?

This is a key point in the pilot and a time at which to reflect on what the data are telling us and what the key messages are. To do this we have conducted a thorough statistical analysis of the instruments and looked at the results. There are many potential relationships in the data we could explore but we have focused our analysis at this stage.

We have conducted analysis of the patient surveys at the response level and the staff surveys at average GP practice response level. Table 2 below describes our approach to the analysis and what we were looking to explore.

Table 2: Overview of approach

CQI, DTSQ and EQ5D	For the collection of CQI, DTSQ and EQ5D surveys we have explored whether how well respondents know the person they saw affects their responses, what factors contribute to their satisfaction, and whether they would recommend Year of Care.
HCC	For the HCC survey we have considered the respondents' convenience rating to understand what drives their opinion on convenience. We have also explored how many times they have had a check-up in the last 12 months to see whether this affects their appointments, opinions and ratings.
PCRS	For the PCRS we have considered the scores and also the correlation between the different elements to explore what factors are related.

After the survey level analysis we built a GP practice level dataset to explore whether there were any relationships across the surveys for these aspects.

The key results from the data are:

- There are more positive responses from people who 'know who they saw very well' and 'know who they saw not at all'.
- Satisfaction ratings and whether people would recommend Diabetes Year of Care are driven by both aspects of the consultation e.g. really listening and aspects relating to their health and management of diabetes.
- The higher the empathy score, the higher the enablement score.
- The number of visits in the last 12 months increases the tests and examinations that people have had access to e.g. seeing a dietician.
- Convenience could be driven by whether it is considered to be worthwhile and a good use of their time.
- The PCRS dimensions⁹ e.g. patient self management education and goal setting action planning tend to be correlated, that is practices performing well on some

⁹ The PCRS dimensions are the different aspects that the practices are scoring in the questionnaire on their resources and support.

aspects also perform well on the other correlated aspects. Although there are aspects such as ongoing quality improvements which are seen to have less association with the other aspects and to be more of a stand-alone issue for practices.

- We found no statistically significant correlations across the instruments.

This section goes through the results for each aspect in turn and the following section makes recommendations as to what should be explored to improve the programme.

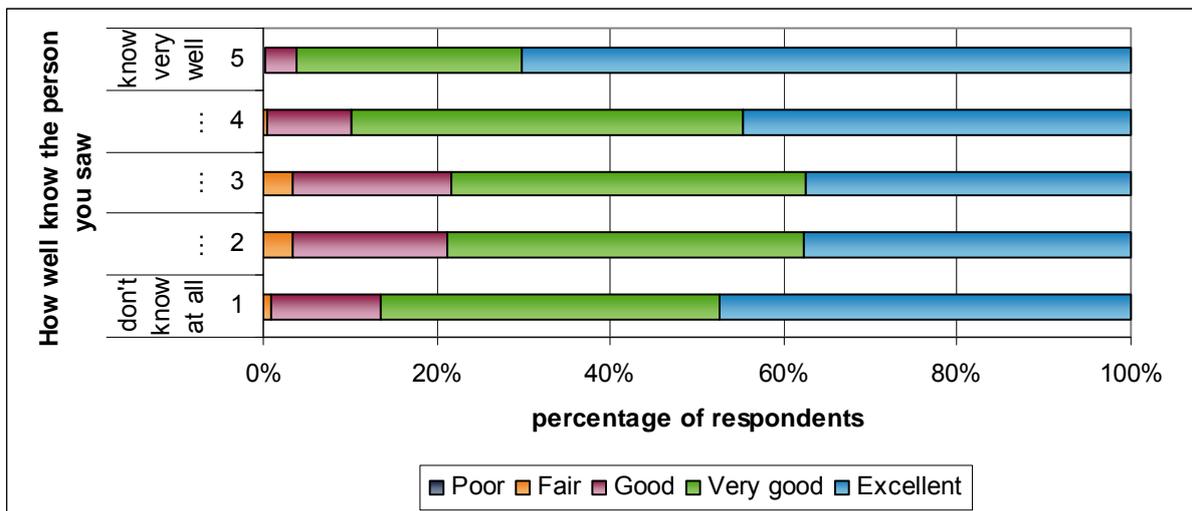
How well they know the person they saw

There are some interesting findings from respondents’ rating of how well they knew the person they saw, where 37% knew them very well and 14% did not know them at all. There is a difference in the responses depending on how well people know the person they saw. Across the survey often the more positive results were obtained from these two groups, where they knew the person very well or not at all.

How well they know the person is associated with aspects such as how they view their outcomes from the consultation, how they view aspects of the consultation, how they rate convenience, flexibility, satisfaction with their understanding, whether they would recommend it and whether they are satisfied to continue.

For example, Figure 3 shows how people responded to how good the person they saw today was at being interested in them as a whole person. This is broken down by how well they knew the person they saw. This shows that respondents who don’t know them at all are more likely to respond ‘excellent’ than those who know them ‘a little’ to ‘well’.

Figure 3: Being interested in you as a whole person by how well known the person was who was seen



Satisfaction and whether recommend

There are similarities in what drives satisfaction with treatment, whether they are satisfied to continue and whether they would recommend the treatment, all of which have at least 68% giving the highest rating. They are driven by two key types of factors: firstly aspects of the consultation and secondly aspects relating to their health and management of diabetes.

The more people view the aspects of their consultation positively, the more satisfied and likely to recommend they are. These include how they view their outcomes from the consultation, how they view aspects of the consultation, how well they know the person they saw, how they rate convenience, flexibility and satisfaction with their understanding.

Their satisfaction and whether they would recommend is also driven by their health and management of their diabetes. These are factors such as how their diabetes affects their day-to-day activities, whether they have problems with their usual activities, pain or discomfort, anxiety or depression, how they rate their health and how often their blood sugars are unacceptably high. For example, those who are very satisfied are likely to show signs of being in control of their diabetes, responding 'never' to 'Have your blood sugars been unacceptably high?', rating their health good, and have no pain, anxiety or are affected in their day-to-day life with diabetes.

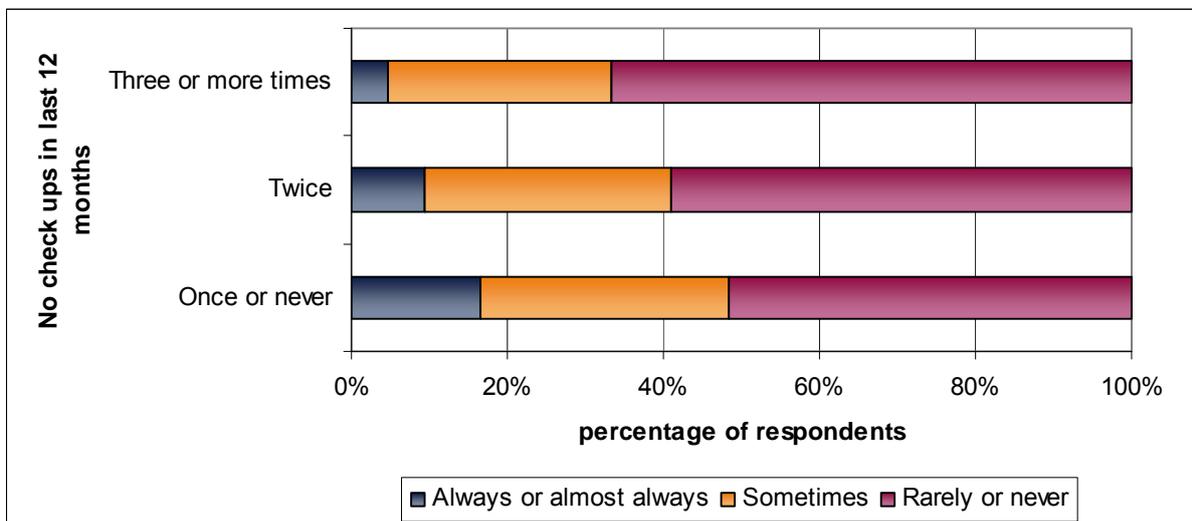
Number of visits in last 12 months

The number of check-ups that a respondent has had in the last 12 months affects their responses to the HCC questionnaire. Those who attended more frequently tend to have more opportunity for all of the tests and examinations listed in the questionnaire. However, they also were more likely to respond 'rarely' or 'never' to aspects of their consultation listed in the survey. For example, the opportunity to discuss their ideas about the best way to manage their diabetes, see Figure 4. This could be related to the fact that 'always' is different for someone who has attended once to someone who has attended several times. However there were also some aspects which are more positively responded to by those who more regularly attend:

- Has the care plan helped you to manage your diabetes?
- Did you have enough time to discuss your condition?
- Did the doctor or nurse know enough about your condition?

It is worth noting that we believe that if the person has had three appointments over the last 12 months their care plan may have been referred to but it would seem unlikely that the whole process would be undertaken at each appointment. From the fieldwork it was apparent that those with more frequent appointments tended to be those with more complex health problems and those needing the most support to manage their diabetes so it would be expected for this group to have higher needs and need more input.

Figure 4: Discuss your ideas by the number of check up in last 12 months



Convenience

How convenient respondents felt their appointments were, is affected by the number of check ups they have had; those with more finding it more convenient. Those who found the appointment more convenient were more likely to respond 'rarely' or 'never' to aspects of their consultation listed in the survey. They also were more positive to similar aspects such as enough time for discussion, the care plan helped them manage their diabetes, the doctor or nurse know enough about their condition, they had confidence and trust in them and got answers they could understand.

Those who find the appointments more convenient are more likely to have had tests and examinations and possibly the key components of the consultation in their opinion. For example it could be that respondents find it more important to have time for discussion than to discuss specific aspects e.g. medication or their views on management. This suggests that convenience rating could be viewed as rating of both the convenience and whether it is a good use of people's time.

There was evidence that people who found it more convenient were in better health and management of their health. Those who found it convenient were more likely to rate their health as excellent, very good or good and not feel their diabetes affects their day-to-day life. There is also an indication that they are better at healthier eating and taking physical exercise. This is not necessarily a Year of Care specific finding.

Perceptions of convenience can however be driven by a wide range of variables, it could be about opening hours, availability of clinic slots or GP slots, location of the practice, transport routes to the practice, need for access through community transport etc. The difficulty is that looking at one variable against another is often too simplistic as it does not give the whole story. For example those who find their appointment convenient are more likely to have seen the dietician and are more likely to be eating healthy food. The fact they are more likely to be eating more healthy food is likely to be because they have seen a dietician rather than because they find their appointment convenient.

PCRS

The PCRS has two dimensions - patient and organisational support, each made up of eight elements. There is high correlation between most of the factors. Those which are highly correlated and correlated with more than 10 other aspects, include:

- Individualized assessment
- Goal setting/ action planning
- Patient involvement
- Problem-solving skills
- Integration of SMS into primary care
- Systems for documentation of SMS

These aspects could be considered key drivers for organisation and patient scores. There are some aspects which are less correlated, most notably ongoing quality improvements (QI), which is only correlated with one factor other than the scoring. Where the practice sits on the scale of ongoing QI 'does not exist' through to 'uses a system to routinely track key indicators of measurable outcomes' does not relate to the other organisational and patient care factors.

Across instruments

We looked at whether there are any relationships across the different instruments for these aspects. For example, questions include if there is a relationship between the staff rated patient or

organisational scores and the patient rated CARE measure score, the Patient Enablement Instrument score, the satisfaction rating etc.

We found correlations in the data within the instruments and also correlations between instruments used in the same survey e.g. the CARE measure and whether they are satisfied. However we found no statistically significant correlations across the instruments. Hence although the PCSR assesses the resource and support available for self management of chronic disease there is no evidence of a link with patient satisfaction instruments.

What are the key messages?

There are two key messages to be explored further:

- There is a benefit from knowing someone very well and feeling comfortable in a consultation and also not knowing the person a patient sees at all, to have a consultation focused on the patient and their needs. There is a need to explore ways to increase the process measures for people who don't know their clinician very well.
- The more positive responses are received from people in a better state of health. There is potentially a need to explore how Diabetes Year of Care meets the needs of those who may have more challenging health needs and how their satisfaction and convenience can be improved.

It is important to consider the impact that the inverse care law in this context may have on some of these findings. This law states that '*The availability of good medical care tends to vary inversely with the need for it in the population served*'¹⁰

Over the next year we will continue to collect data and hope to be able to identify any changes in responses from individual participants over time.

¹⁰ Hart JT *The Lancet*, Volume 297, Issue 7696, Pages 405-412

3.2 Focus on the Client Service Receipt Inventory

The client service receipt inventory (CSRI) is being conducted as a telephone interview with Year of Care patients. The interview includes the CSRI instrument which focuses on use of services and also additional questions to understand how services and support can be improved locally.

This data we now have will act as a baseline. The second wave of interviews will take place over late summer of 2010 and will provide data which will be compared to the baseline data to assess additional resource usage. This will help answer questions relating to the costs of Year of Care.

Overview

As of 6th November 2009, 45 telephone interviews have been undertaken using the Client Service Receipt inventory.

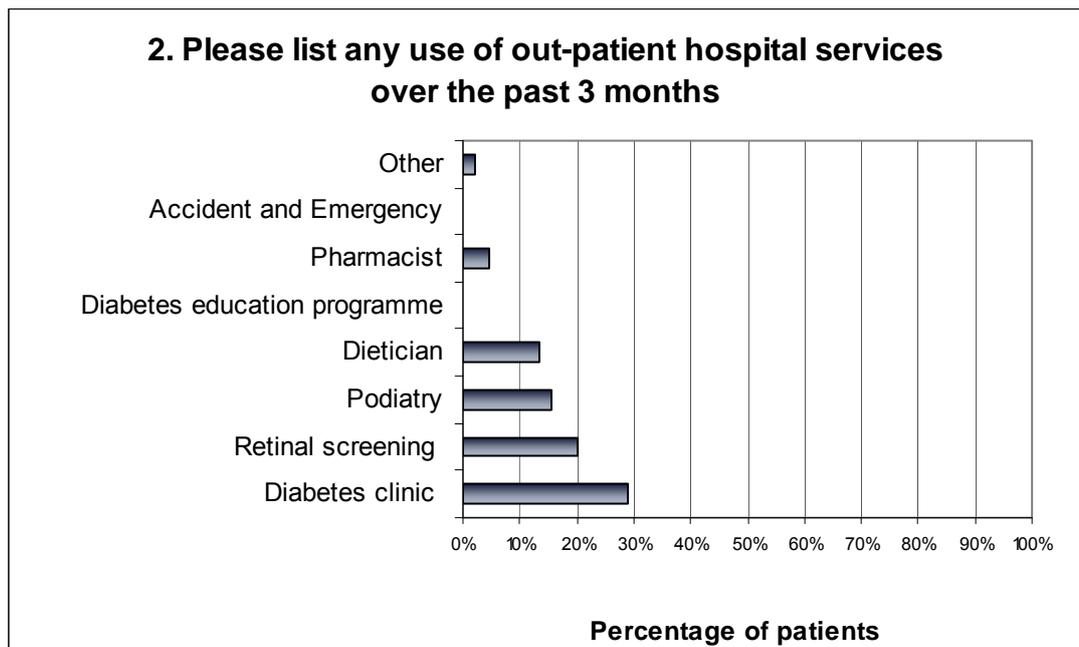
There have been 25 telephone interviews with patients from North of Tyne and 20 interviews with patients from Calderdale and Kirklees. These interviews were with people at the beginning of their Year of Care experience and are baseline interviews for their use of services prior to Year of Care. We will be conducting further interviews with this cohort during the second year of the project.

Quantitative results

The first question asks them about their in-patient hospital services over the last 12 months. Only five of the patients had used in-patient services in the last year: two had used the emergency centre for their diabetic care and the other three had used other services (urology, oncology, and for ulcerative colitis).

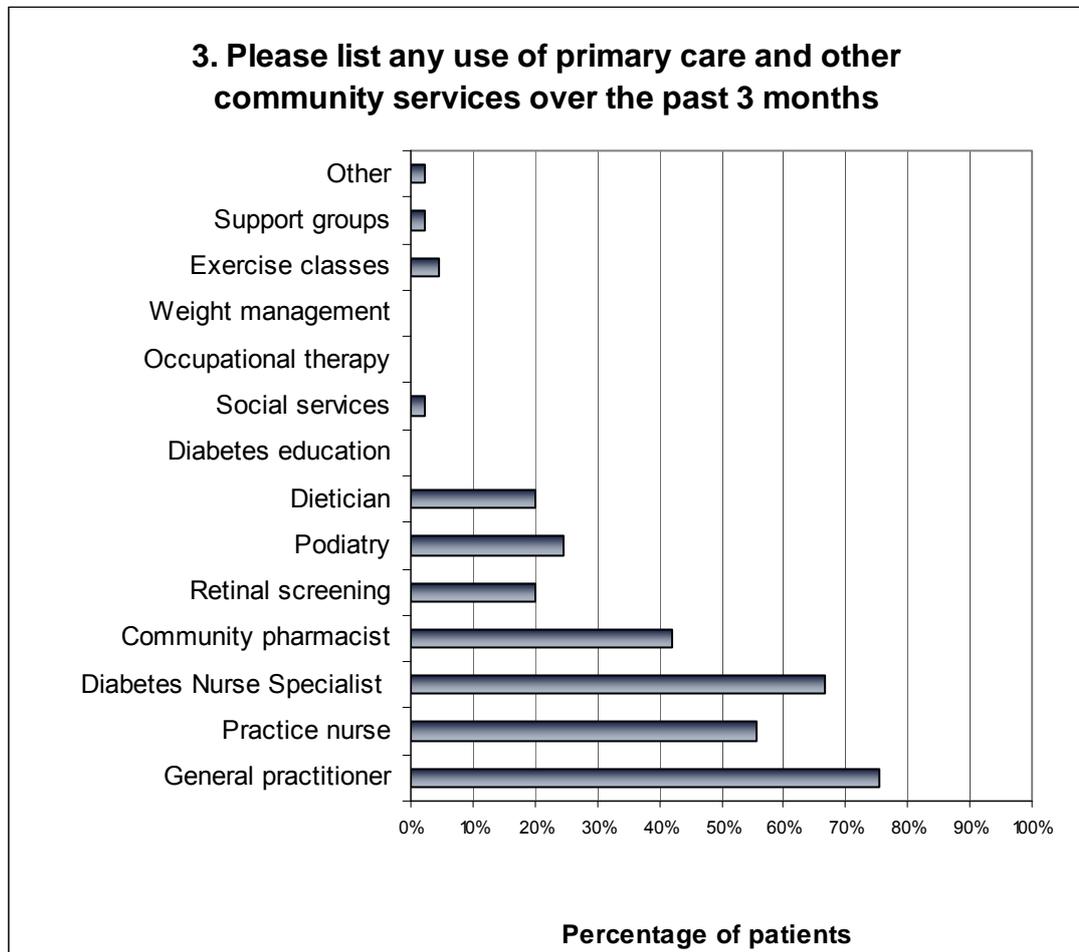
The second question asks about their use of out-patient hospital services over the past three months. 16 of the 45 have received out-patient treatment, with the highest proportion going for diabetes clinic or retinal screening appointments. The responses are presented in the following figure.

Figure 5: Use of out-patient services



The third question asks about use of community services over the past three months. 38 of 45 have used community services; the highest proportion see their GP, practice nurse or the diabetes nurse specialist.

Figure 6: Use of out-patient services



Qualitative feedback

The telephone interview also gave the patients opportunity to provide comments and explanation to their responses. They were also asked

- What do you think of the range of diabetes services in your area?
- Do these services have an impact on how you manage your diabetes?
- What in your area will help support people living with diabetes?

The majority of patients interviewed think highly of the range of local diabetes services on offer. Illustrative comments include:

‘To say they’re adequate is not enough-they are keeping track of me. I know I can ring the practice nurse without difficulty if I need to.’

“I find them excellent. My GP was one of the first to start a diabetes clinic. My diabetes checks and scan also led to diagnosis of a non-diabetes related tumour, so a very positive effect.”

Of the patients who commented, almost all felt that the services have a positive impact on how they manage their diabetes. Illustrative examples of this include:

‘Have made me realise how I needed to change my diet, and I have done so. Emphasising how essential weight loss is important but equally as important is explaining what overweight actually is. It wasn’t until my MOT at 60 that I realised I was actually overweight.’

“They monitor me and I know they are there when I need to talk to someone about it or any problems that come up.”

Just three patients interviewed so far have felt that the services did not have an impact on their diabetes management. These three patients stated:

‘Not particularly-I have always had a healthy diet anyway- lots of fruit, bread, veg, no red meat.’

“No, I would do the same anyway.”

“Not really, I suppose I would manage my diabetes the same at another place if I had to.”

There have been a number of suggestions on what would help support people living with diabetes locally. These include:

- Setting up a local support group for people with diabetes and family members.
- Being signposted to books on diet, healthy eating and healthy living.
- More emphasis and information on portion control and what constitutes a health portion size.
- Use of a PDA (Personal Digital Assistant) for individuals to monitor food intake and exercise regimes.
- The DESMOND course, or a similar programme, running on a continual week to week basis rather than being in the current format of a one off course.
- More emphasis on detailed and/or personalised leaflets and information sheets as patients can forget some of what they have been told by the diabetes nurse.

Summary

This interview tool has provided useful insight into the use of services by this cohort of patients and their views. We intend to follow up, where possible, with each of these patients a year after their initial interview. This would help us identify any possible shift in service use which will help inform questions on costs of the Year of Care programme.

3.3 Focus on the Consultation Quality Index (CQI)

The Consultation Quality Index (CQI) is designed to assess empathy and enablement through series of questions and two scores:

- the PEI (Patient Enablement Instrument) score
- the CARE score

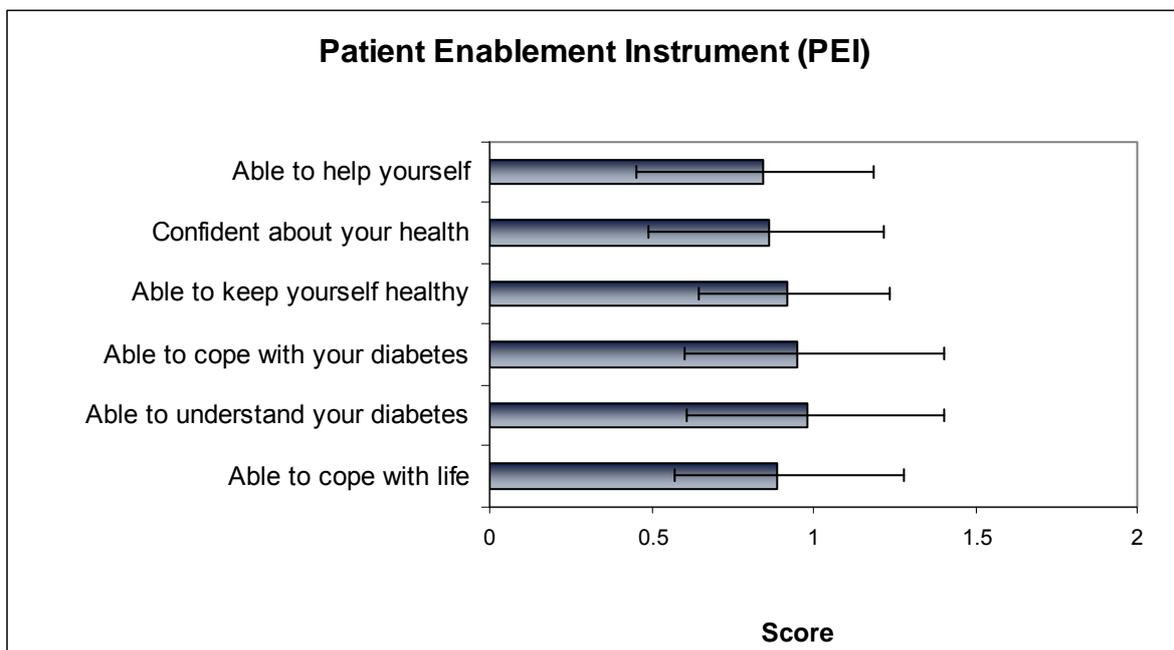
To explore the CQI at a practitioner level we have explored those practitioners who have at least 15 patient responses.

Patient Enablement Instrument (PEI) Score

For the PEI a score of 2 represents a response of "Much better/More" a score of 1 a response of "Better/More" and a score of 0 represents "Same/Less".

The six dimensions for enablement are shown in the following graph. The graph shows the average for all responses which is between 0.8 and 1.0 and also the range of responses using the black error bar. The highest scores are for able to understand your diabetes and the lowest for able to help yourself.

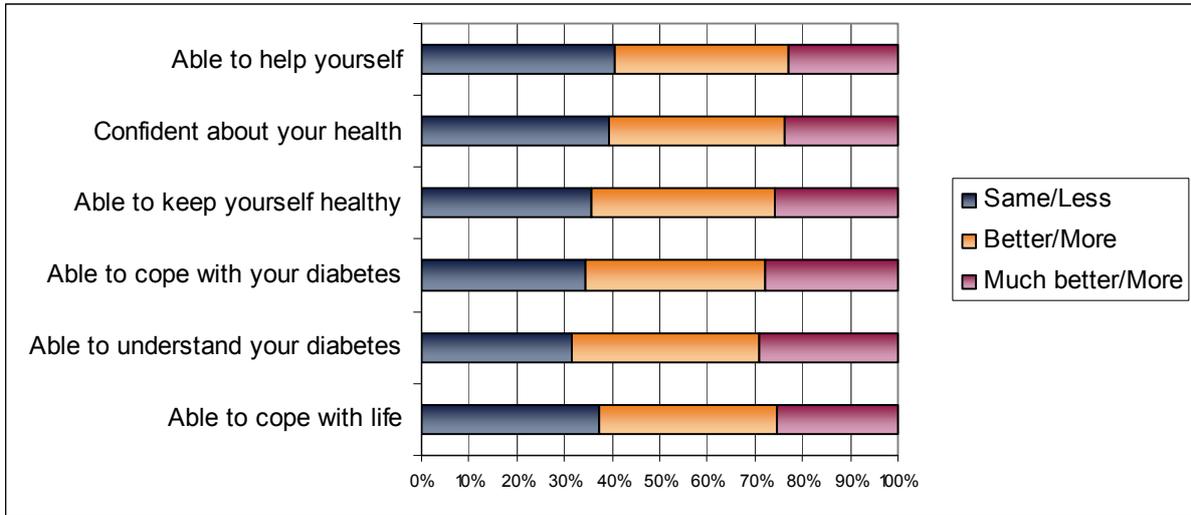
Figure 7: PEI scores



As well as exploring the actual scores we can consider the profile of scores given. The following graph shows the frequencies of scores for each element. From this we can see:

- Able to understand your diabetes has the most responses saying better or much better
- Able to help yourself and confident about your health have the highest proportions saying same or less.

Figure 8: Profile of responses for PEI scores



The following section provides some quotes from the case studies to illustrate the quantitative data that has been collected and to make some triangulated sense and coherence of all the data available. The quotes either support or challenge the statements.

PEI

Able to help yourself

‘It was just a general chat with the nurse. I asked her questions and it took about 20 minutes which was fine. It was good – I liked the way she explained the results. She said there was a number of ways of doing things. She listened to me. She respects that I have my own way of doing things. She presented things to me as “this is what you could do” rather than telling me what to do.’ (P12 Tower Hamlets)

‘I have a problem with smoking and the doctor has offered options for help with this... there are programmes I could go on and I am aware of local services as the doctor has told me about them. I’m a grown up and its up to me to access them.’ (P8 Tower Hamlets)

‘Care planning is about keeping up motivation. It’s about owning the care plan – how can I do this day to day. 3 hours a year are spent with the HCP on diabetes. Over 8000 are down to self-management..... For people with diabetes to be self managing, they have to be empowered. How do you get empowerment without patronisation? Healthcare professionals have to take a step back but not let go of the reigns.’ (P5 Tower Hamlets)

Confident about your health

‘I would be a lot worse off healthwise if I didn’t have these sessions.’ (C&K)

‘If everything seems fine I don’t go to the doctors. I do see the nurse but we haven’t set any goals in the session. I do ask questions if I have aches and pains.’ (P1 NoT)

'It turns my blood pressure sky high. I feel patronised. This is what happens and there can't be a deviation. There is no acceptance that my blood sugars fluctuate more. I feel I know more than she does. And so it doesn't achieve anything.' (P6 NoT)

'More knowledge. I know that I am doing ok.' (P18 Tower Hamlets)

Able to keep yourself healthy

'I know more about my condition. It's up to me to put it right. They're only advising, not telling me.' (C&K)

'I haven't been given the option of blood strips on prescription. By testing bloods regularly, I'm checking and if I check every day it helps to keep me on track and helps the NHS by me not deteriorating. The nurse said you shouldn't be checking the bloods, we do it. But only every 4 months.' (P6 NoT)

Able to cope with your diabetes

'I don't find it helpful. I don't understand what they're trying to achieve. They tend to pick on one thing. For example, someone of my age should have a blood pressure of 140/80 but because I have diabetes I have been told it should be 120/80. I don't understand why this has to be lower. A cholesterol level of 5 is for 'normal people' which implies that we are not normal as we have to get ours down to 4. I feel terrible when I take cholesterol tablets. When I mentioned the side effects to a doctor a few years ago, he went mad. I don't find it helpful if I am not treated as an individual. Therefore getting the results beforehand wouldn't help because of other health problems. If I understood the results, I would be able to prepare what to talk about – I would know what to ask the doctor or nurse but it does not make any difference if I don't understand.' (P19 Tower Hamlets)

'I saw the nurse. It was good. She understood the position and explained that my BMI has improved. She gave me plenty of time and we talked about lots of things – swimming, diet, exercise etc. It was good – I felt informed about where I am with controlling my diabetes.... I was given examples of exercises that would suit me and also given a diet sheet.' (P15 Tower Hamlets)

Able to understand your diabetes

'I am given enough time for the session – it takes as long as it takes – at least half an hour. The nurse asks me if I understand the results. She goes through them with me one by one and if there are problems she tells me what I should do. She explains lots of things and then lets me ask questions. She asks me questions too. She makes suggestions. She makes me aware and gives me advice. We do set targets and she explains how I can control my diabetes. Last time I didn't need to set any goals because I am going fine.' (P11 Tower Hamlets)

Able to cope with life

'I feel lonely and want more contact. I asked if I could go to a day centre and the GP referred me but I don't get enough days. I have lots of other health conditions and want to be around people as it helps to reduce my anxiety. I am keen to go to exercise classes – the classes my doctor referred me to had very good instruction

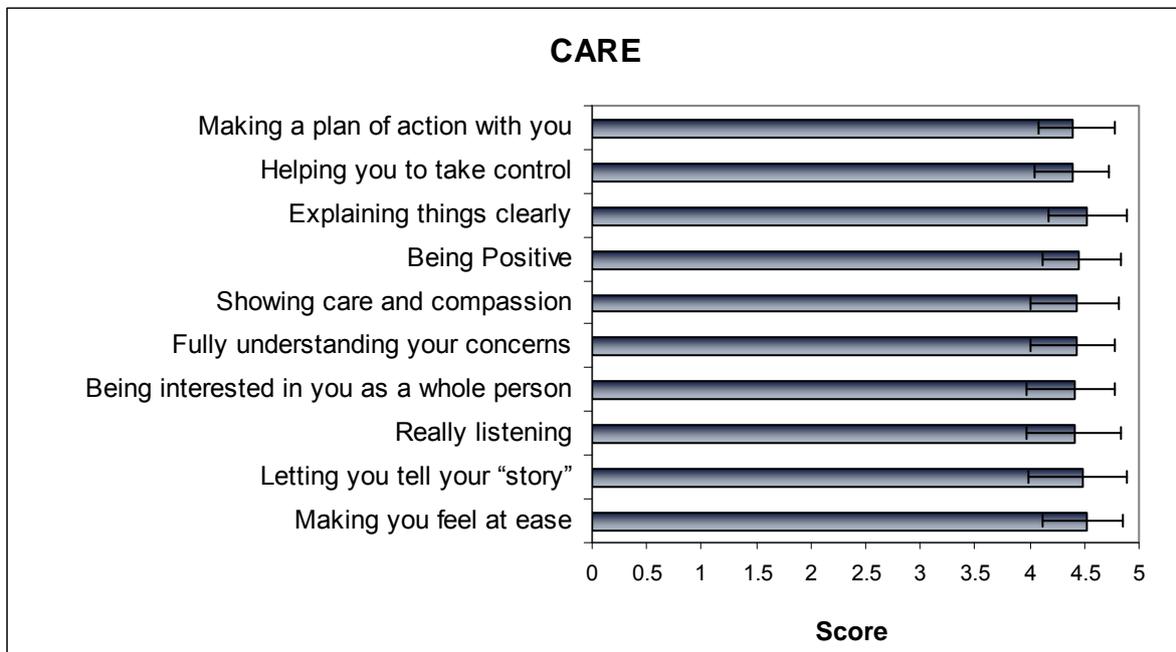
and where culturally sensitive. They made a programme to suit me.’ (P15 Tower Hamlets)

CARE Score

For the CARE, a score of 5 represents a response of "Excellent", 4 a response of "Very good", 3 a response of "Good", 2 a response of "Fair" and 1 represents "Poor".

The 10 dimensions for enablement are shown in the following graph. The graph shows the average for all responses which is between 4.4 and 4.5 and also the range of responses using the black error bar. This shows an average between the “Very good” and “Excellent” point. The highest scores are for Making you feel at ease and Explaining things clearly, although there is little variation between the average scores.

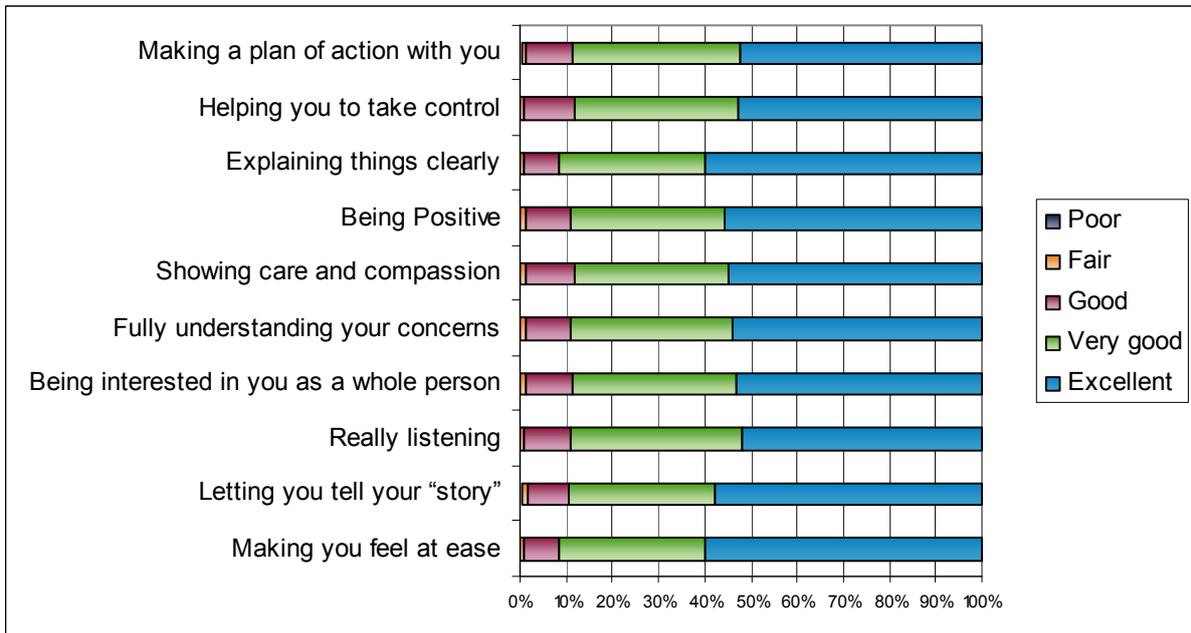
Figure 9: CARE scores



As well as exploring the actual scores we can consider the profile of scores given. The following graph shows the frequencies of scores for each element. From this we can see:

- Making you feel at ease and Explaining things clearly have the highest excellent rating

Figure 10: Profile of responses for CARE scores



Care

Making a plan of action with you

'I have to keep on dieting and this is something that I agreed jointly with the nurse. The nurse suggested that I should do more exercise and told me about groups that might suit me.' (C&K)

'They want me to lose half a stone in six months. Me and the nurse decided on the amount. It is hard for me to exercise but I agreed to do a bit every day. I got my results before the appointment and there was a care plan saying what I was going to do now.' (FG1,1 NoT)

In this practice patients are not given a written care plan. When asked if the patient would find it helpful, the response was 'no. I'd find it irritating and patronising. There are lots of issues with setting goals. The principle is great but it takes a lot of time.' There was a strong sense of ownership of the care plan. 'Clinicians have got to get off their high horse. They're not going to be sitting behind the patient for 6 months. The ownership has to come from the patient with diabetes.' (P3 Tower Hamlets)

Helping you to take control

'The pharmacist proposed a change to my medication but he talked to me about options and let me choose what would be the best way of doing things for me.' (C&K)

'The professionals make suggestions but I don't feel as if anyone is telling me what to do.' (C&K)

'I had a number of visits to the hospital and each time they take BP and I make a note of it in my diary. I am pleased to get the information. I had an argument with Dr.. as a result of getting the information. My Hb1Ac was 6.9 and I like to keep it

below 7. Dr.. wanted me to keep up with my meds, he said it should be 6.5. He's moving the goal posts. I don't like taking tablets..... I'm due to go for a 6 month check up at the beginning of October. At the last check up (March or April) I was sent a letter telling me what Dr.. had told me, not what the results of the test were..' (P7 NoT)

'I have talked about options in relation to my diet. The doctor plants seeds of suggestions – he is very good at doing this without getting your back up. He says "have you thought about..." (P10 Tower Hamlets)

Explaining things clearly

One patient was not clear as to the point of the consultation. 'I wasn't aware that was the point of it. I thought it was about how my diabetes was progressing and to talk of problems. I didn't realise I was setting goals. They did ask goals but I didn't realise this was important.' (C&K)

'I have the results before my appointment. It helps me understand if there are any improvements from previous year. Helps me keep track of things like diet... The document was very clear and if I didn't understand I would ask at the appointment.' (FG2, 2 NoT)

'They do go through everything which is brilliant.' (FG4,1 NoT)

'They didn't even tell me the tablets should be taken 12 hours apart. I only found that out at a different pharmacy. I've never been offered what else to do because I can't walk. They know I'm under stress but I haven't been offered advice. They look at my diabetes and cholesterol and that's it. No offer of alternatives' (FG4,1 NoT)

'The first one was done in the clinic. Then when I went I looked at it, juggled it about. Then she sent a new plan out a few days later. .. It's written plainly so I can understand it. It has objectives of what to achieve and how they can help achieve them. How to get bloods down. Laid out simply. Your views are added in.' (P5 NoT)

'The review is good. The nurse tells you everything you should and shouldn't do. She explains everything perfectly. Other nurses that I have seen in the past don't have the experience to explain things so well. You get plenty of time here – she covers everything and gives me a good check up. She is brilliant. She explained about the folder to me.' (P4 Tower Hamlets)

Being positive

'It's better now. There is more chance to see things and judge for yourself. My family can look at the information – it's helpful for them to understand. Things are better. ... It is a lot better for me to understand these things. The nurse has a better chance to explain things and she takes time to check things' (P11 Tower Hamlets)

Showing care and compassion

This patient is blind and unable to read anything. 'I have my bloods taken and they ring me to tell me I'm alright so I don't need to go in and see them. If I'm not right I go and see them.' (P8 NoT)

Fully understanding your concerns

'The difficulty I have is that I feel she has set and rigid information. It's not individualised, it's very generalised. I'm not on medication. The information given is go on the diabetes website, look at the diet. Carbs don't work for me. I found the carb diet doesn't work. The information she has is that you can't veer from that. It's rigid national information. No leeway. That hasn't changed... ..She would respond to queries, but if I didn't ask anything she wasn't forthcoming.' (P6 NoT)

'The doctor is very good and knows what he is talking about. If you need to start insulin you can do it from this practice you don't have to go to Mile End Hospital. I feel as if my doctor takes my views into account but we do sometime disagree about things and discuss them. He wants me to go on insulin but I don't because of the driving. I will go on it if I have to but the doctor will have to make a good job of persuading me.' (P5 Tower Hamlets)

Being interested in you as a whole person

'I have the test done before my review and then see the chiroprapist and the doctor. They talk about my personal life - it's friendly and they ask about any problems. ' (FG2,4 NoT)

'She involves me in the conversation and asks me how I fee about things when we are going through the results to compare with how things were 6 months ago. She is always available for advice if needed. I am limited to the exercise I can do as I have arthritis.' (FG3,2 NoT)

Really listening

'I'm happy. I trust them. It's easy to contact them. Nothing phases them. I've got confidence. Two nurses are lovely. If I have a problem they sit and listen and try best to help... Same with Dr.. but I don't often see him. I'm listened to. From the receptionist, seem to want to listen to you. Even when I had my feet checked.... They seem to explain, if Hb1Ac are up, this will happen, that will happen. They're open about the results and what they mean.... I nearly lost my sight at the GP. Then I went to the hospital.' (P5 NoT) This patient has her diabetic care at Diabetes Resource Centre.

'He was prepared to listen. He took my comments which could be critical. He wasn't pleased when I said 'you're moving the goal posts.' (P7 NoT)

'He has a very consultative manner as opposed to prescriptive. He doesn't say, you've got to take those pills or else. He does listen. It's not formalised goal setting and it's not written down. He's good at explaining.' (P3 Tower Hamlets)

'It was ok – she knows everything and used an interpreter. Did listen to all my views. I can't remember if I always see the same nurse.' (P15 Tower Hamlets)

Letting you tell your story

'There was enough time to go through everything. The doctor asked about my priorities. He does focus on my agenda but he won't let you get away with stuff. It was great, really good. A good mixture of professionalism and time. Sometimes doctors can make you feel as if they are too busy. I always see the same doctor – I really like that. Consistency is very important to me. He knows me and can look at changes and trends going on for me and he also know what is going on for me and my family. Things are clear and well laid out.' (P8 Tower Hamlets)

Making you feel at ease

'I came out thinking that was good, I enjoyed it, it was useful, but after a couple of days I'd forgotten it. It wasn't something that would change my life which it should have. It wasn't scary enough. I need someone to say, if you don't do this you could lose your sight, your legs. I'm blasé because my partner is. I need someone to tell me how bad it can get.' (C&K)

'I was worried when I got here but I relaxed after a while because they were so friendly – this makes it easier for me to go back next time. It is important to go for regular check ups.' (C&K)

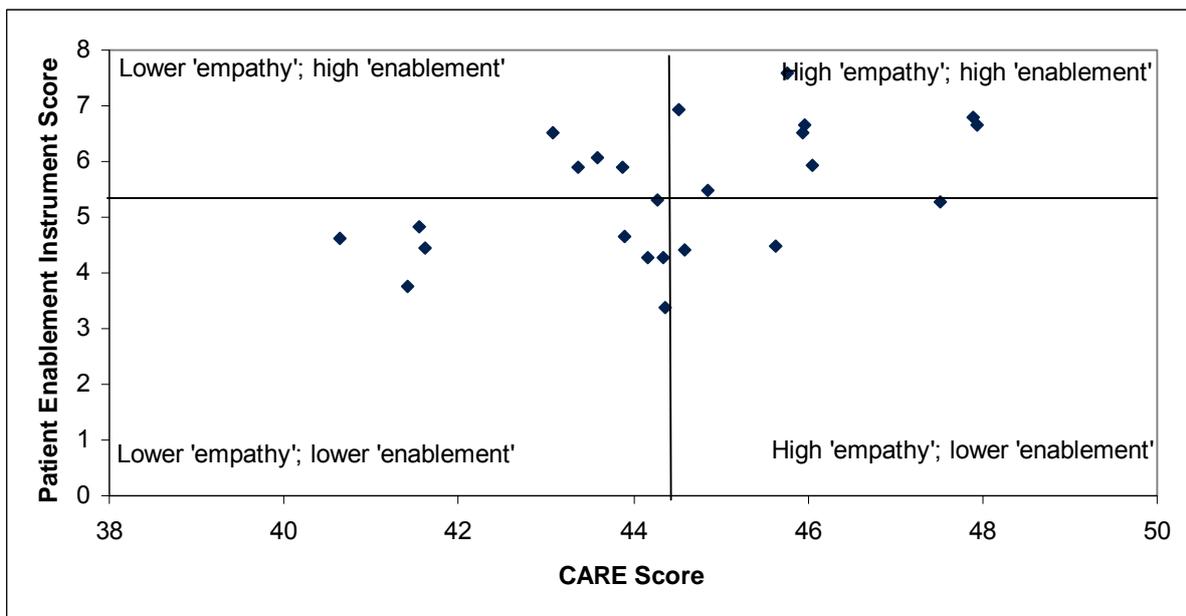
'They asked me questions about how I am feeling and were very nice to me. Sometimes I get nervous when I have appointments but they helped me to feel relaxed. They were very good at what they do.' (C&K)

'The two nurses here are great – I am very satisfied. They do listen and take my views into account. They explain things to me. They put you at your ease and don't hassle me about doing exercise on days when it is raining. They just explain "if you were to do this..." Their main emphasis is on me managing my diabetes.' (P16 Tower Hamlets)

Overall scores

There is a correlation between the enablement and empathy scores. The following chart shows the two scores split across four quadrants, where those in the top right having scored high in both aspects and bottom left low in both.

Figure 11: Overall CQI scores



3.4 Focus on Primary Care Resources and Supports for Chronic Disease Self Management (PCRS)

The Primary Care Resources and Supports for Chronic Disease Self Management (PCRS) tool:

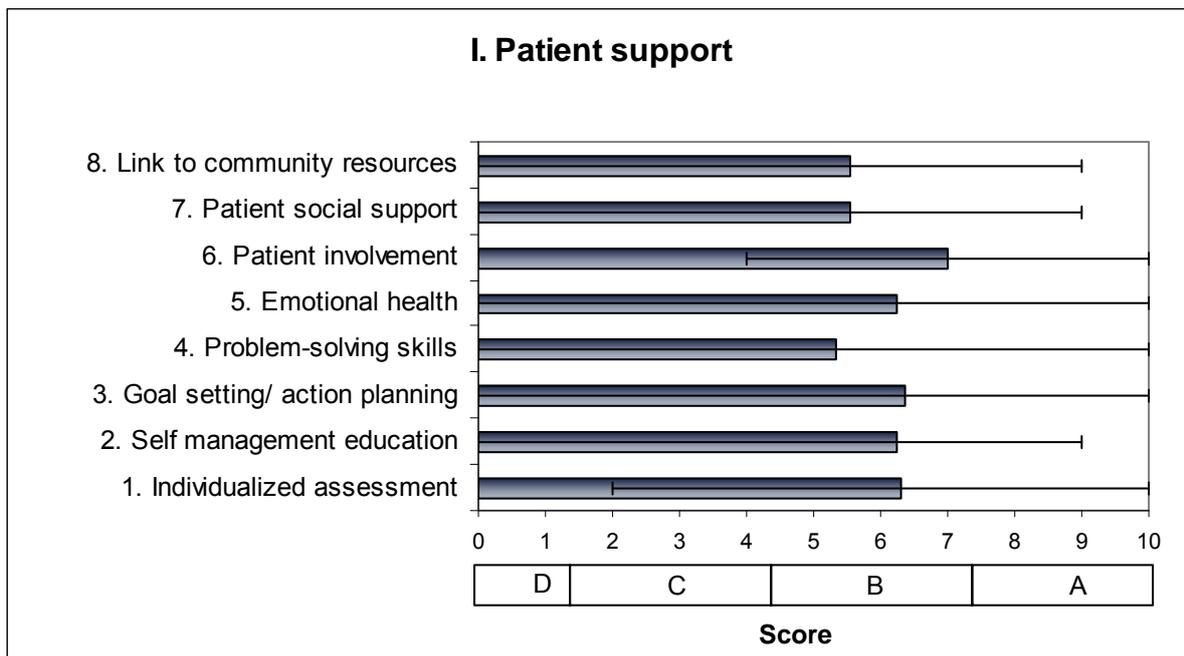
- Functions as a self-assessment, feedback and quality improvement tool to help build consensus for change.
- Identifies optimal performance of providers and systems as well as gaps in resources, services and supports.
- Helps teams integrate changes into their system by identifying areas where self management support is needed.

It is a survey for staff at the GP practices completed at practice level or by different members of staff.

Patient support

The eight dimensions for patient support are shown in the following graph. The graph shows the average for all responses which is between 5.6 and 6.7 and also the range of responses using the black error bar.

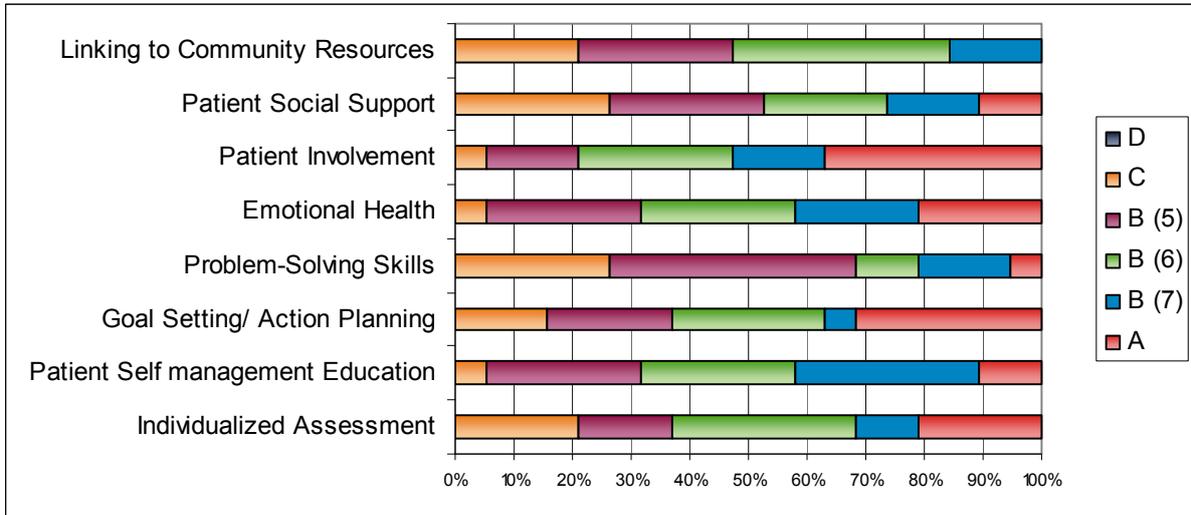
Figure 12: Patient support scores



As well as exploring the actual scores we can consider the profile of scores given. The following graph shows the frequencies of scores for each element. From this we can see:

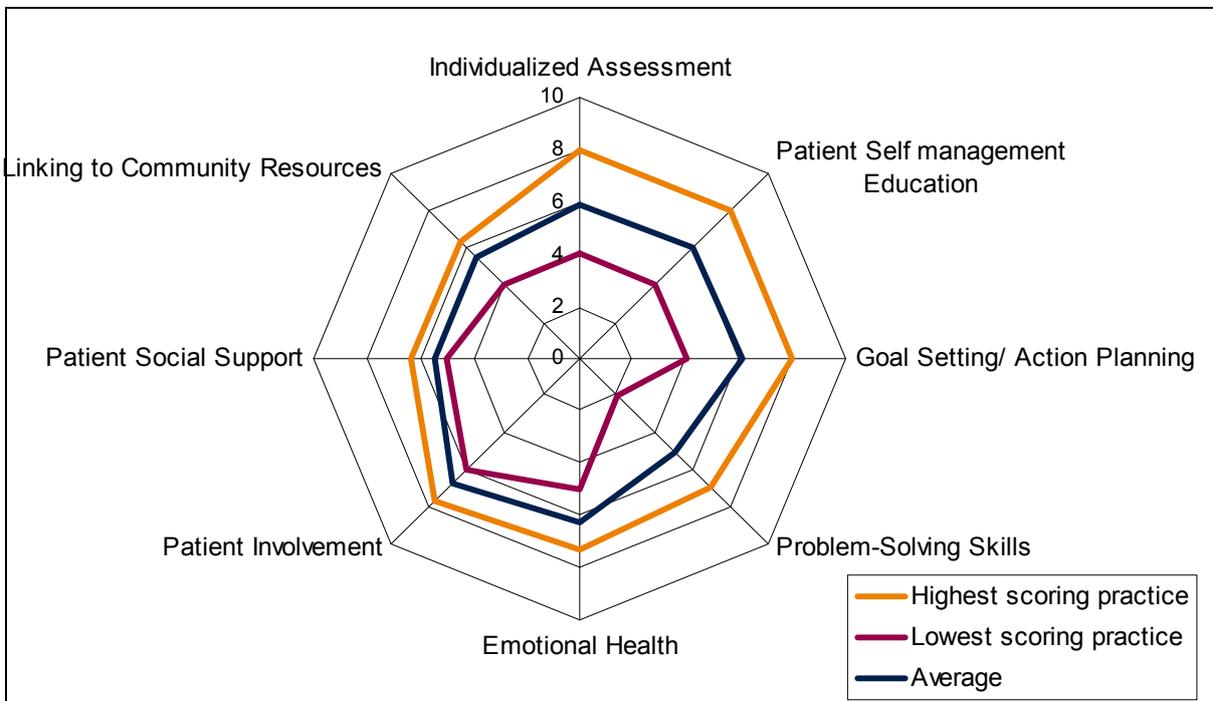
- Patient involvement scores the most at eight or more.
- Problem solving skills has the highest proportion scoring 5 or less, linking to community resources and patient social support also relatively low.

Figure 13: Profile of responses for patient support scores



A spider diagram is suggested for future use and feedback to sites, where the larger the area covered by the shape the better the performance. The following chart shows the average score profile and the performance of the practices with the lowest and highest overall scores for illustration of the variability. However it should be noted that these are the highest and lowest overall scores. For any one element there may be practices with a higher score for the individual element but they have a lower overall average score and likewise for the lowest score.

Figure 14: Spider diagram for patient support scores



The following section uses some illustrative quotes to add richness to the quantitative measures above. It will use the 8 elements within this section of patient support one by one to draw some depth though these are examples of statements made and are not representative of whole cohorts of patients or site typical.

Individualised Assessment

'We ask them if they've had a chance to look at the results we sent them. We threw it straight in the bin, we didn't realise. Some looked.' (Practice Nurse C&K)

'It's a lot of extra work. I have no solid conviction that getting bloods to them before is useful to them re getting more out of the consultation. I'm sure for some it will make a difference. Some are highly motivated people and will take the opportunity to analyse the results. Some will over-analyse them. Some will be empowered in that the doctor is taking it seriously, maybe I should. I'm not sure that enough people get benefit.' (GP C&K)

'Talk me through your results. What does that mean to you? Any concerns? ... Well I have this exercise thing on prescription. Is that something you'd like? You said you're interested in exercise. What would that look like for you?' (GP NoT)

'We show them their test results graphically.' (GP1 Tower Hamlets)

If they remember they bring it in. If not I print it off and go through it with them. I can spend 30 minutes going through the results letter.' (N5 Tower Hamlets)

Patient Self Management in Education

'DESMOND should be available for everyone.' (GP C&K)

'Why are patients more open to looking at what they should do if a health trainer says do it than if a GP says it.' (Pain Doctor C&K)

'HAMLET is very successful here. All those we sent went and came back to say how much they enjoyed it.' (Nurse Practitioner Tower Hamlets)

Goal Setting / Action Planning

'I write the goals on the paper.' When explored further it appeared that the words were his with agreement by the patients, rather than their words specifically. (GP C&K)

One GP in a one stop shop practice, when asked who makes the final decision said, 'clinician.' (C&K)

'If their target is different to mine, I would put theirs first. It would have to be something major that I would add on.' (PN NoT)

'We've had the discussion, so let's put some structure. Which do you want to circle today? Which is most important?' (GP NoT)

'You set goals with patients but two months later goals change because life changes. You're not making plans for a year ahead. It's your present care plan.' (GP NoT)

'As they talk we write down what they say – I would like to... It was different because we used to say, the patient says. But now we say I'. (N1 Tower Hamlets)

When asked if they get patients to write the goals themselves, the nurse said, 'They don't think of concerns themselves.' (N6 Tower Hamlets)

Problem Solving Skills

'Previously I was never, you must do this, you must do that. I always had a conversation and listened to their views. Now it's more structured. I'm thinking more from the patient's point of view, rather than the professional's. It focuses your mind on their motivations to make changes.' (PN NoT)

'..tailoring it to the patient. If you did some exercises, 'what would it look like?' What helps to motivate people to get them to think about things themselves.' (GP NoT)

'Until you had a try, you don't appreciate what you can achieve re the language you use with patients. It takes a lot to get that attitudinal shift. How many people can really consult?' (GP NoT)

Emotional Health

'If they don't do it, they think they fail you as a GP.' (GP NoT)

'People used to get worried that sending out results would make them anxious, concerned or not understand. Provided they know they're coming in to a supported consultation. ..Tailor the consultation to who's coming in. Value the patient's intelligence.' (GP NoT)

Patient Involvement in Decision Making

'Our role is to go through all the results – we have a lot to get through with them including alcohol consumption, depression, PALS, training, diet, impotence. At the end we ask them if there is anything they want to achieve but is often like pulling teeth to get anything out of them. You often find that you have set the goal for them.' (Practice Nurse C&K)

'We suggest goal setting and patients look blankly. The ideal world is designed around patients making all the decisions. In real clinical practice most patients don't want that choice. They want to be told by me.' (GP C&K)

'We give them the information to make their own choices... Everybody knows red is danger and green is good.. They are more aware (because of the colours in the folder) and therefore more keen to take the healthy options and book appointments to see if there is an improvement.' (Practice Nurse Tower Hamlets)

'We explore, anything you'd like to ask, anything you're concerned about? No it's ok pet. I don't really know. You tell me what to do.' (Nurse NoT)

'They come in knowing what they're going to talk about....I wouldn't have expected that before Year of Care.' (GP NoT)

Patient Social Support

'It's actually more rewarding. We don't spend so much time doing heights, weights etc. We spend more time engaging with patients and finding out about their problems at home rather than ticking boxes.' (Nurse Practitioner Tower Hamlets)

'What other LTC has 45 minute consultations? We're not providing an equitable service for FGM, contraception, menopause, sex abuse, domestic violence. It's not equitable care.' (Practice Nurse Tower Hamlets)

'I think its blown up out of all proportion. People who think that GPs need this amount of training for care planning don't have an understanding of the range of things GPs need to keep up to date with. There are so many more things - like child protection - that I need to be up to date with in order to be able to practice. Its not a good use of my time.' (GP Tower Hamlets)

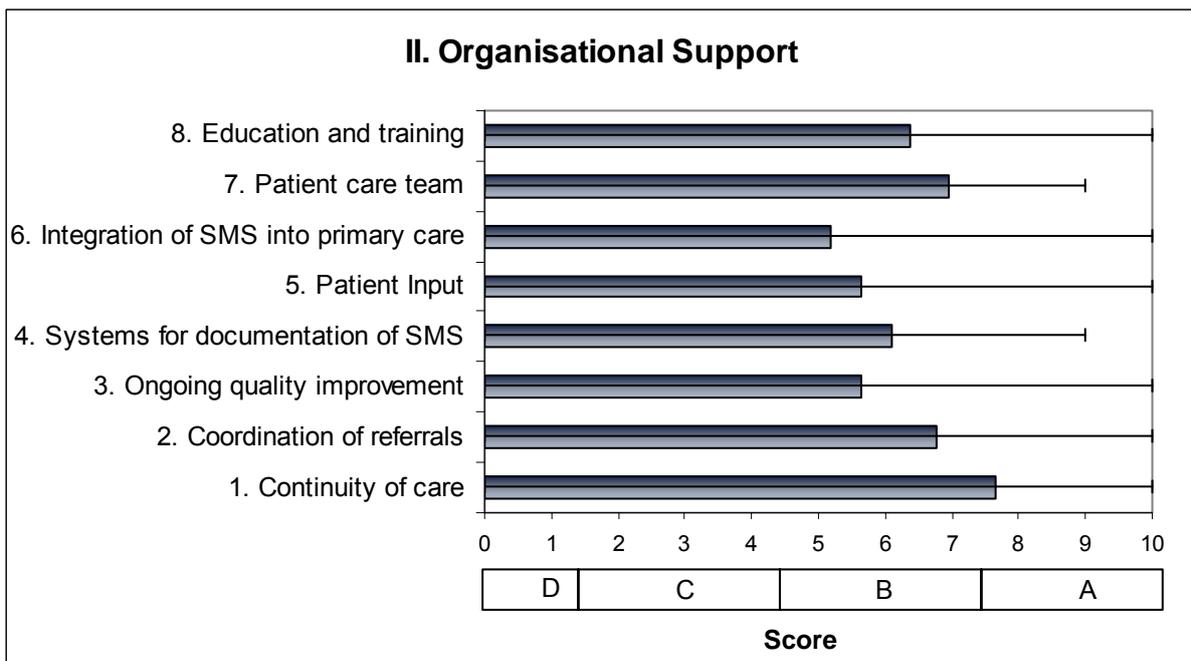
Links to Community Resources

Tower Hamlets has 'Supporting Self Care' booklet which is now on-line.

Organisational Support

The eight dimensions for organisational support are shown in the following graph. The graph shows the average for all responses which is between 5.0 and 7.4 and also the range of responses using the black error bar.

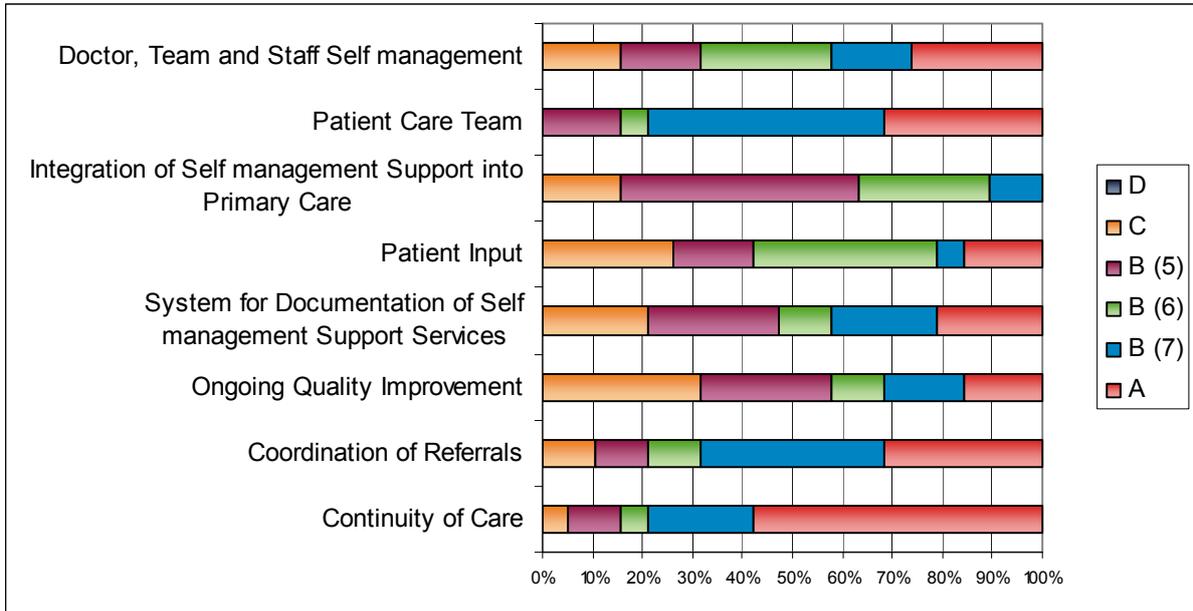
Figure 15: Organisational support scores



As well as exploring the actual scores we can consider the profile of scores given. The following graph shows the frequencies of scores for each element. From this we can see:

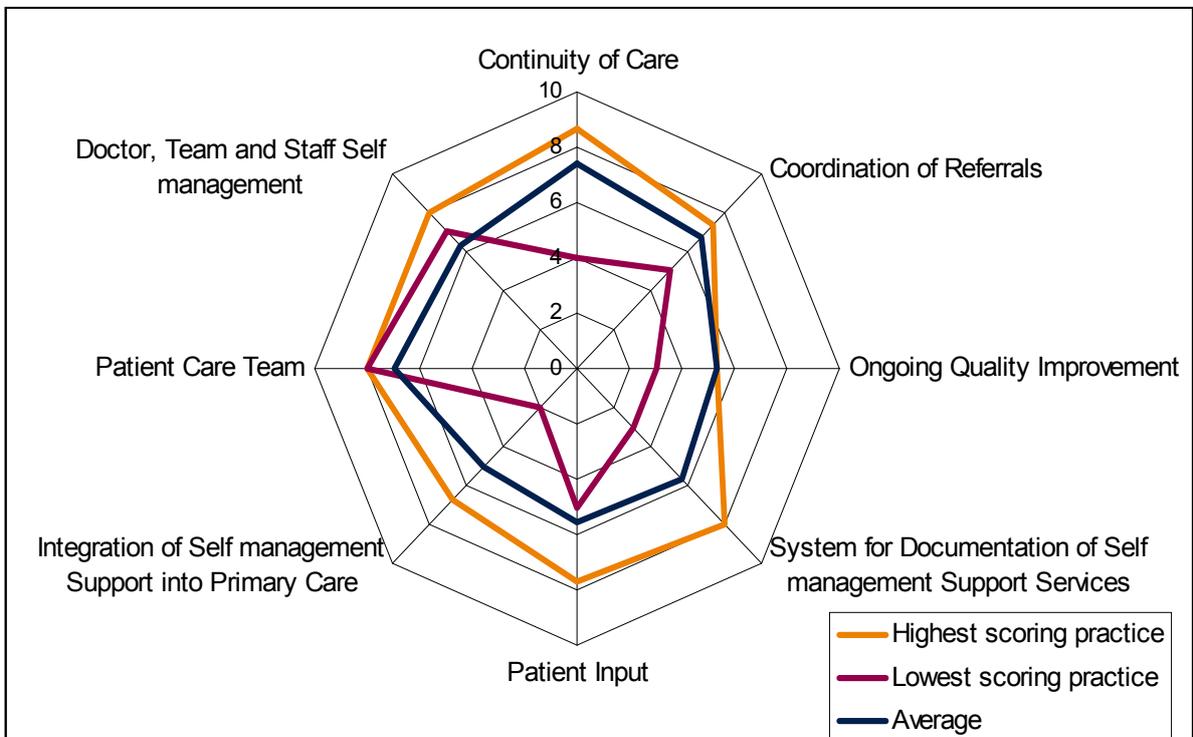
- Continuity of care is the most scoring eight or more.
- Integration of self management support into primary care is the highest scoring 5 or less, ongoing quality improvement is also high.

Figure 16: Profile of responses for organisational support scores



A spider diagram below gives the average across the dimensions which is shown in blue. The larger the area covered by the shape the better the performance. The highest and lowest scoring practices are also shown.

Figure 15. Spider diagram for organisational support scores



The following section provides some quotes from the case studies to illustrate these data.

Continuity of Care

‘Before formalising the clinic this way, patients saw the nurse ad hoc. They had their annual review when they wanted it. There was no robust recall.’ (GP C&K)

‘Very little has changed. The structure is the same in the clinics.’ (GP C&K)

‘Why aren’t they doing Year of Care at the hospital? DSNs aren’t doing it. Their job is to support us in practice... People on the ground are pulling their hair out.’ (PN Tower Hamlets)

Co-ordination of Referrals

‘After care planning, a lot of referrals are made to retinal screening, dietician, education. It gets put on a database. I do that.’ (Administrator Tower Hamlets)

On-going Quality Improvement

‘We had a meeting with all staff to change attitudes. We assume they (patients) just want to be told what to do, but that’s how the meet and greet came about. Let them come and tell us. It will be a slow change. ..It’s no good for people to complain. We need to get them to tell us what they want. We’ve asked them to choose their best receptionist. Now the receptionists are on their best behaviour. I’m going to do it for the clinicians. We’re supposed to be appraising ourselves. Who says if we’re working well – it’s the patients. They’re going to send me to a loony bin!’ (Nurse Practitioner Tower Hamlets)

System for Self-management of Documentation Support Services

‘Pretty much useless. We’re still waiting for the template. These top down services don’t work in general practice because they promise to deliver and never do. We’ve been waiting 18 months from when they told us it’s available. I’ve not seen it. Pope came round 4-5 months ago with the system but I’ve not heard. I’m not too concerned. It might be cumbersome.’ (GP using SystmOne C&K)

‘It’s great. A stable system.’ When asked about the inability to put in goals, she said, ‘there are ways round it. They can physically type but in consultations it is quicker to hand write.’ (PM, EMIS LV C&K)

‘IT is really difficult. We have a difficult programme – EMIS PCS. We always have problems, we’re the last to have anything... They think we’ve all got EMIS Web, are fluent and using it. No-one is taking responsibility about it. They say ‘if you can use a mouse you can use EMIS Web’ – it’s condescending and not helpful.’ (PN Tower Hamlets)

‘EMIS is great. It works well.’ (PN, EMIS LV NoT)

‘GPs don’t want SystmOne. We like EMIS.’ (GP NoT)

Patient Input

‘It’s been easy to engage them but what do we do as a result? We’ve had 120 patients between 2 practices at events. Success isn’t getting them to the meeting but to come back and provide something that their involvement has had an impact.’ (Patient and Community Involvement Tower Hamlets)

'Diabetes Support Groups - large groups won't work. Small, locality based and practice based.' (Patient and Community Involvement Tower Hamlets)

Integration of Self-management Support into Primary Care

'We must have backfill. The PCT agreed the need to backfill but the money never came.' (PN Tower Hamlets)

'I can see the value. I'm not against the model or the idea. But there needed to be a lot more support on the ground level. Hold my hand, show me how it works. I've lost the plot. I still feel in melted phase and haven't refrozen. This isn't an established change in our practice at all. It's not as if there isn't the will.' (PN Tower Hamlets)

'It hasn't had any great impact on the rest of the organisation.' (PN NoT)

Patient Care Team

'For us, it's made us be a team, be more supportive to each other.' (Practice Nurse Tower Hamlets)

'There's more meetings between staff and HCPs. More communication, emails, word of mouth, constantly we have to communicate.' (Administrator Tower Hamlets)

Doctor, Team, Staff Self-management Education and Training

'One GP discussed attending the psychology training. He said, 'although in theory the training brought up ideas on ways of running consultations which could reveal and form important ideas that patients had, this is very difficult to put into practice in a consistent format. ...we couldn't engage the whole model. There are time constraints. I enjoyed the training, it was interesting but not directly applicable.' (C&K)

'This has been fairly useful – I have been to a psychological session and the sharing and learning events. We were reluctant to send results ahead of the consultation before these events but we were convinced by other pilot sites that it would be Ok – I didn't attend this session but the doctor and practice nurses did and shared their learning with us.' (Pharmacist C&K)

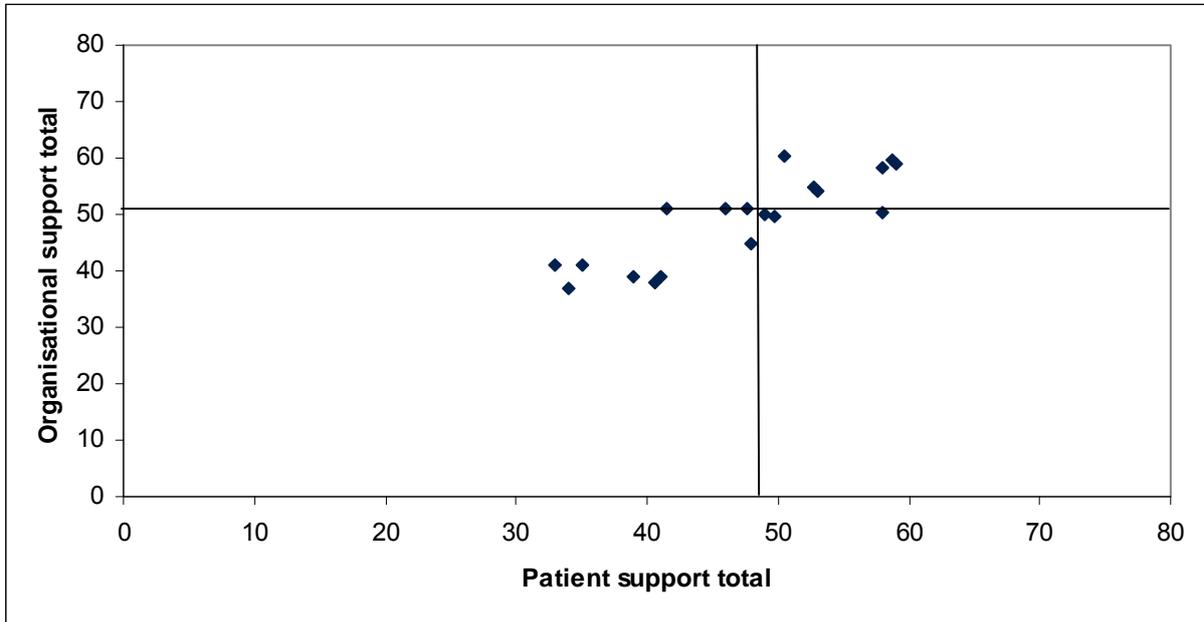
'We had some good meetings in York with the other pilot sites – we got lots of information about what they were doing at the other sites. What would be most useful is more of these sessions with other pilots or to go a visit the other pilots to see what they are doing.' (PN C&K)

'Role playing – cringe making but it served its purpose... follow up days were good. Had just 1. Maybe one more would be good about a year after starting'. (PN NoT)

Overall scores

There is a positive correlation between the two scores in that those performing better in the organisational support tend also to score better in the patient support score.

Figure 16: Overall PCRS scores



3.5 Qualitative data

Three case studies were undertaken by two researchers from Tribal’s Research and Evaluation Team (Gail Louw and Janet Clark). A week was set aside for each case study and a total of 9 days was spent at Calderdale and Kirklees, 8 at North of Tyne and 10 at Tower Hamlets. The healthcare professional to be interviewed were identified by the Project Manager at each site, and the patients were invited to attend by the practices themselves. The interview schedule is found in A.

The numbers we were able to interview in all three practices were good; there were 50 in total in Calderdale and Kirklees, 41 in North of Tyne and 49 in Tower Hamlets. We were able to visit all the practices in Calderdale and Kirklees and Tower Hamlets and interview staff whilst there. At Tower Hamlets we interviewed patients in 6 of the 8 practices.

We were able to visit only one practice in North of Tyne though interviewees attended for interview at a central point. Most of the interviews with patients at North of Tyne were conducted in focus groups or by telephone. It was particularly useful to spend almost 4 hours talking at different times to the three key clinicians at the Diabetes Resource Centre.

Full and detailed reports have been written for all three pilot sites and the key highlights will be presented in this section. Quotes and learning from the three sites are included throughout this report.

Report of the Calderdale and Kirklees Case Study

The case study took place from 14-18 September 2009. Interviews took place in 5 practices. There were two focus groups; one with a Diabetes Support Group, none of whom were in Year of Care practices, and the other was held at a practice. Some interviews were held on the telephone but most were face-to-face.

Interviews were held with the following groups:

Table 3: Interviews in Calderdale and Kirklees

Patients	GPs and other Doctors	Practice Nurses / HCA	Dieticians/ Podiatrists / Opticians	Administrators/ Practice Managers	Commissioners	Project Team	Total
26	5	5	4	7	0	3	50

C&K currently have a practice manager who works on a number of different projects and is able to commit only a part of her time to Year of Care. Although the project manager is highly dedicated and effectual, her inability to devote a significant and necessary amount of time to the project is problematic and a principal reason for the project not progressing as effectively as it might.

Two of the practices run One Stop Shop clinics. These are seen in the practice as an optimum approach with Year of Care as a means to achieving this end. One GP from a one stop shop practice said, *'Year of Care has helped a great deal. We've used it to allow us to set up one stop shop. The PCT wouldn't have funded a podiatrist, dietician, pharmacist. So it's been invaluable.'* In one of these practices patients are identified as Year of Care or non Year of Care patients, as having opted in or out of the project and the practice treats patients differently accordingly. The basis for their status is whether they have agreed to complete the evaluation questionnaires. The treatment differs in that only Year of Care patients receive their blood results prior to their appointment.

Since the case study took place, one of the practices has withdrawn from the project. The practice was not keen to be interviewed but agreed to a short 10 minute interview which extended to 45 minutes. During this time three healthcare professionals were able to explain why they felt disgruntled with the project. It became clear that the additional burden of explaining, coercing and organising the evaluation questionnaires was the breaking point, particularly as no support for this activity was available from administrative staff and it rested on the shoulders of an already over-committed nurse. However, the principles of care planning are implemented with results sent before the consultation, a patient centred consultation is conducted (though this was not observed and is based on comments made by the participants) and a written care plan, albeit rather complicated, is produced.

There is a lack of recognition of the term Year of Care, and also of what it means. This was apparent not only amongst patients but those in practice who see themselves as peripheral to care planning, such as the podiatric assistant, eye scanner and some administrators. The lack of clarity of Year of Care is mostly endemic throughout the organisations apart from key and senior clinicians. People are confusing it with *'regular MOT checks'*. They do not identify changes that have take place as relating to Year of Care.

The national training was not provided to the original pilot practices, although the course has since run in the area. Participants at the national training were from other practices and included district nurses. The unsystematic nature of recruitment to the course resulted in people attending for CPD purposes rather than to take the learning back to practices to inform and influence practice.

The training for healthcare professionals covered only psychology and behavioural change. Some felt the need for more training that was appropriate to care planning and specific to Year of Care. There was no training for administrators, receptionists, healthcare assistants, podiatric assistants or eye scanners and none felt that they had had any training cascaded down by those who had attended courses.

There is insufficient training for patients. Few of the interviewees had attended DESMOND training and even fewer had any awareness of Year of Care.

All practices send out blood results, apart from one which sends them out to a selected group of patients. However, many patients do not register that they have received them. All practices have said they sent out information about Year of Care, but few patients registered receiving this either. Most patients agreed it is good to get results beforehand even one patient who had received a mistake in her results.

The practices do not appear to explain or include all staff in organisational changes.

The lack of a usable Year of Care template for IT systems is considered by many as a major problem in the project. They do not feel they are able to undertake care planning as effectively as possible without the template. It is causing a great deal of frustration and bad will towards the project.

Most people do not recognise a major difference in the culture of the organisation but a second year may have a greater impact on people's perceptions.

There appears to be a commitment to the notion of partnership working but less of a consensus as to what it actually means.

We wanted to get a sense of the difference in diabetes care since Year of Care. One GP stated, *'Diabetes patients get a much more comprehensive service. Before it was fragmented. Most of the blood results would go, not have results in time. It's a more structured approach.'* It was useful to speak to professions allied to health such as podiatrists, dieticians and eye scanners. These professionals run clinics in non Year of Care practices and are in a good position to see how different the care experience is for patients from different practices. On the whole these professionals were not able to see a great deal of difference in the patients they saw, other than the obvious benefits they felt patients got from being part of a one stop shop approach. They did not feel that patients were more engaged in Year of Care practices, though it is important to stress the small sample and the newness of the approach. It takes time for cultural changes to have a perceived and perceptible impact.

One pharmacist appeared to wish to be extremely positive about Year of Care but managed only to be equivocal. *'In the second year of Year of Care some patients have reduced their medication. Its hard to know if this can be attributed to Year of Care - it could be down to the individuals or our recall procedures.'* Another point for consideration by him was; *'The Year of Care can have the effect of slowing down processes because it focuses on patient priorities and they may only want to tackle one thing at a time.'*

Two practice nurses expressed their view about whether Year of Care works or not. *'There has been no change – I have been here for eleven years and the Year of Care has made no difference. The only thing that may have changed is that patients may be slightly more willing to tell the truth and may be able to get people to talk about their priorities but I think this is more to do with knowing them a long time than the Year of Care approach. The Year of Care has brought about a fantastic one stop shop clinic but beyond that it is just a box we tick at the end of our session. Patients don't know what their goals are when they come back for their next session.'*

The practice manager in a Year of Care clinic in a one stop shop practice that has Year of Care and non Year of Care patients *'doesn't look different to a normal diabetic clinic other than people have a piece of paper with care record plan for the next 12 months.'*

Report of the North of Tyne Case Study

This case study took place from 21-25 September, 2009. Interviews were held with the following groups.

Table 4: Interviews in North of Tyne

Patients	GPs and other Doctors	Practice Nurses / HCA	Dieticians/ Podiatrists / Opticians	Administrators/ Practice Managers	Commissioners	Project Team	Total
26	5	3	1	1	2	3	41

North of Tyne is a well established centre for care planning. The originators of the philosophy behind Year of Care come from Northumbria and many still work in this area.

The original project team working on Year of Care was, by all accounts, extremely dynamic and able to invest many with a strong commitment and passion for the ethos and principles engendered by Year of Care. The original project manager had a clinical psychology education and worked full-time on the project for 14 months. The current project manager has 4 other projects on which she works, leaving far less time to devote to the Year of Care project.

The project team has the benefit of strong leadership and commitment from clinicians in both specialist and primary care. In addition the team has a member who spanned all sectors as a GP in a local practice and a Medical Director of a Trust. The project team are active in running structured events to engage practices in care planning development. One project member has a link role spanning primary and secondary care. The project team debate issues of development, momentum and sustainability.

There are 23 Year of Care practices in North of Tyne (out of a total of 29) and 15 in West Northumberland. The decision to open the project up to as many practices as possible was explicit at the outset of the project. The evaluation was not a pre-requisite for practices entering the project and they did not commit to participating in the completion of questionnaires. 3 or 4 practices have never completed any questionnaires.

As West Northumberland has only recently begun its involvement with Year of Care, the case studies did not include any interviews with patients or healthcare staff from those practices.

Insufficient interviews were conducted to get a real sense of what is happening in practices in this area. Only one practice was visited and a small selection of healthcare professionals from only 5 centres were interviewed.

In this site, few patients were able to evidence an understanding of the term Year of Care and clearly insufficient information is provided to them about the project and its philosophy.

IT systems seem to work well. Although there are problems in terms of not having appropriate templates and lack of support, it appears that people manage and IT does not get in the way of delivering care planning.

Cultural change appears to be subtle and not always obvious, but there have clearly been changes that have been recognised by patients and healthcare professionals alike. Comments made by patients reflecting positive change included: *'Its better now... They tell me to walk but I have cellulites so walking is difficult'*. (FG1,1) *'I am taking lots of tablets – they don't talk to me about this at the review.'* (FG1,2) *'He's communicating more information than he did a couple of years ago. Last two occasions Dr.. has been more open and able to communicate. Before he was more severe.'* (P7) *'I used to ask for results, but it is better to have it written down.'* (P7)

However, some patients have also not noticed any changes: *'Its just the same – nothing has changed.'* (P1) *'Not noticed a difference.'* (P2) *'I've been going to the hospital since 2000. It's more or less the same. Same nurses.'* (P5).

Healthcare professionals expressed their views on changes: *'Year of Care has made me look at my role as a practitioner – to take a step back and look at the way I deal with patients. It has legitimised me saying to patients – its all about you and your diabetes – you can use me as a resource.'* (N1) *'Before followed a format with a checklist. Now consultations are more individual.'* (N3) *'Prior to Year of Care we were doing a diabetes clinic and following the model but not as strictly. Year of Care gives some discipline and structure to it. ..Year of Care allows me to sit down and give the pen to the patient to write down. I'm so used to writing it. But some patients give it back to me – oh no, I don't want to care plan.'* (GP1) *'Year of Care emphasises the patient centred care approach.'* (GP2)

Commissioning has strong leadership in this area and much has been achieved. *'We have clinical champions from specialist care and from primary care.'* (Comm 2) The biggest limitation is the inability to identify unmet needs. It is recognised that the mechanism to solve this problem is through information technology.

Although DESMOND is recognised as essential by HCPs, it is still not providing total cover of all newly diagnosed patients.

There is powerful understanding of consultation principles from a number of sources in this area.

Although we were not able to get an enormous amount of data from this case study, what we did get was useful. Although much of it is positive, there are clearly some negative comments which have referred to above and are expressed more fully in the case study write up.

There were two quotes which reflect the overall positive and strong state of Year of Care within this area. In response to a question as to whether Year of Care has made a difference, one patient said, *'it stops me from being so frightened about it. They explain all the side effects. I'm really happy.'* (P5) *'If I were a patient I would want to have a care planning system in place. I think it respects people more as individuals. It gives people more rights.'* (N3)

Report of the Tower Hamlets Case Study

The case study was undertaken from 5-9 October 2009. All 8 practices in the site were visited and staff and patients were interviewed by both researchers. Practices identified up to 3 patients to interview in each site but not all of them turned up for interview. Two interviews were held by telephone and the rest took place face to face. Two focus groups were scheduled; 2 turned up to one but none to the second.

Interviews were held with the following groups:

Table 5: Interviews in Tower Hamlets

Patients	GPs and other Doctors	Practice Nurses / HCA	Dieticians/ Podiatrists / Opticians	Administrators/ Practice Managers	Commissioners	Project Team	Total
19	8	10	3	4	1	3	49

Tower Hamlets benefits from having a full time project manager and a strong project team with senior leadership and buy in. This enables support and censure to be in place to ensure effective care planning occurs.

In all of the practices HCAs are part of the care planning team and undertake appropriate activities thus freeing practice nurses to concentrate on the consultation and goal setting.

All patients in Tower Hamlets are given a folder that has clear and precise information in colour which is comprehensible to all. This is used as the basis of all information given to patients and is an effective means of providing information to which patients can relate. A nurse commented on this aspect: *'Because we go through the blood results, they are more aware (because of the different colours) and therefore more keen to take the healthy options and book appointments to see if there is an improvement. Colours are an incentive. Everybody knows red is danger and green is good. Patients are more willing to come. They say – I'm coming back in 3 months.'* (N3)

Year of Care has had a significant impact on many practices making sure that patients are called and recalled for annual reviews and follow-ups. This was not happening systematically in many practices prior to Year of Care.

There is a high level of satisfaction amongst patients with the consultation that is provided by practices. Patients tend to value receiving their blood results even when they receive them immediately prior to their appointment. *'It's better now. There is more chance to see things and judge for yourself. My family can look at the information – it's helpful for them to understand. Things are better. ... It is a lot better for me to understand these things.'* (P11)

There are many challenges within the Bengali community specifically wanting direction from clinicians (and in particular doctors), making repeated and emergency appointments, travelling away from their home for long periods, feeling isolated in many cases and relying on members of their family for interpretation, support and correct diet.

There is a reasonably good awareness of care planning amongst patients in Tower Hamlets. There were many comments by patients expressing their views on receiving blood results prior to appointments, how consultations are run, and about setting goals. Many comments appreciated the amount of time available for the consultation. *'There was enough time to go through everything. The doctor asked about my priorities. He does focus on my agenda but he won't let you get away with stuff. It was great, really good. A good mixture of professionalism and time.'* (P8) *'The nurse did the review – it took about half an hour to 45 minutes which was enough time. We covered what I needed to cover – I like the way it is done and I think it is good the way they take you through the results. It is a two way thing – they go through the results, compare with last years and then ask what is important to me.'* (P18)

The need for structured education has been strongly recognised in Tower Hamlets. The first Picker Survey identified this as a serious limitation and much has been done to attempt to rectify this by providing a range of different approaches to engaging patients in education. A Project Board member spoke about the findings from the Picker Survey on patient education. *'Patients hadn't been offered anything they recognised as education. They didn't understand what blood tests were for even when they were told, they didn't understand the implications of care, they were ignorant of risks, they were ignorant of what the medication was for and they were thirsty for more knowledge.'* (PB 6) Patients value the education that is provided. One patient commented: *'I did the HAMLET course – it was very good and opened my eyes. It scared me – some of the people on the course were very heavy. For me the course turned things around. I changed my food habits a lot. The course explained how to look after your body it explained about the importance of eye tests and I get mine tested every year now.'* (P12)

It is recognised amongst the project team that insufficient training is made available to HCAs and this is being addressed by providing courses and encouraging them to attend.

Tower Hamlets has been particularly effective in involving users and patients in discussing and exploring issues around diabetes care, partly due to the key role that has been played by practice administrative staff in arranging meetings and focus groups. There is a particularly vociferous and committed patient member of the project board. There are some support groups that run on an ad hoc basis but more would be useful. *'Perhaps there should be more of these. I was referred to the sports*

centre but this was only for 6 weeks. I was offered these two years after being diagnosed but this doesn't seem to be available now. I would find it helpful.' (P19)

Networks are being introduced into Tower Hamlets. These are similar to polyclinics in size and comprise anything from 3 to 5 practices in localities. There are diverse and strong opinions about networks with some feeling optimistic and enthusiastic and others feeling concerned and angry.

Practices tend to be reasonably satisfied with the IT systems they have. *'We have EMIS LV – it didn't work well at the beginning but now its much better. The care planning document has been updated. We send out standard letters on the system and record goals which can be coded. If patients are referred to a programme that is recorded on the system. The care plan is saved into the patients records.'* (N7)

The value of strong leadership and senior buy-in is recognised; *'We have strong clinical leads ..The medical director is very involved. We also have a lead GP who is very involved. This gives us more confidence that we have the right people round the table. The medical director attends patient events and goes out to the practices – this gives YoC a high profile at the practices.'* (PB 1)

Year of Care certainly seems to have made a difference to the lives of patients with diabetes in Tower Hamlets. Some examples of comments made by patients are; *'I know what is going on now which is a relief. I know what I need to do and what will happen if I don't. I do feel more in charge both during the consultation and in managing my condition. The training really helped me to understand things as well as the reviews. You have to do your own thing – they {clinicians} don't necessarily know what is right for me as well as I do. You have to do what you have to do – not what they tell you to.'* (P12) *'I am more in control. I have my results and information so I am not so reliant on the system. I can share the information with my own family and use it to encourage them to be more healthy.'* (P18)

3.6 Key Summary from the Three Sites

Understanding of Year of Care

As a term, Year of Care has not penetrated the consciousness of patients. However, there is some understanding of care planning, not in so many words, but in terms of the practical concepts of receiving blood results prior to appointments and being involved in setting goals.

Changes to Roles

There is greater recognition on the part of HCPs to the change in roles of GPs, nurses and HCAs in Tower Hamlets than in North of Tyne and Calderdale and Kirklees. HCPs seem to regard their roles as being more structured and clearer in terms of what they are required to do. They talk of greater responsibility (HCAs), of giving advice, options and choices (GPs), and of less time doing heights and weights, and more time engaging with patients and allowing patients to take the lead (nurses).

Organisational Changes

More robust systems have been put in place across all sites to ensure that there is an effective system of calling and recalling patients for appointments. Administrative systems are in place in all sites to support the changes brought about by Year of Care. This includes returning blood results prior to appointments and additional duties relating to the evaluation of the project.

In most practices more time is allocated for appointments in line with longer consultations.

Receiving Blood Results

This activity tends to be the single biggest change that has been introduced through Year of Care across all three sites. There is some variance in the way this is done, from one end of the continuum where patients in one practice who are deemed not to be Year of Care patients do not receive their

blood results prior to their appointment while others do, to the other end where a site-wide procedure exists of sending out colour folders with clear and precise information about blood results to all patients with diabetes.

Receiving blood results is met with a mixed response. Although many people value receiving the results prior to their appointments, others have made ambivalent or negative comments about it. Quite a few patients have said they do not receive their results although the systems are in place and the administrators confirm that the results are sent out. In some practices in Tower Hamlets, results are given a short while prior to the appointment so that patients did not forget to bring them in and there was little time to get anxious. We were not able to get much evidence that patients did get anxious, but this is a perception in some practices.

The purpose of sending results beforehand is to 'prepare' patients for their consultation. Whilst clearly this works as anticipated with some, others take little notice of them, either ignoring, forgetting, or dismissing them. However, it is deemed feasible that this is part of the change process and the impact and value will be acknowledged as time progresses.

Consultations

Without observing consultation practices it is difficult to be certain that a patient centred, non-patronising, enabling and empowering consultation takes place. Patients tend to state that they are happy with their consultations, that they find them useful, enlightening, that they have sufficient time, they go away in a better state than they came and that they understand what they must do. The word 'understanding' is a key one that is often mentioned by patients in all sites. Some still feel patronised and others simply want to be told what to do. This was seen particularly in Tower Hamlets where the cultural inclination amongst many in the population to be told by the doctor is something clinicians are fighting against.

Many patients have stated how they like having a consultation with nurses as they don't want to 'bother' the doctors. But nurses are valued for their own sake, for their knowledge and skills and ability to make patients feel comfortable.

The importance of tailoring a consultation to the individual was cited by one GP, and many GPs and nurses imply this is what is done. However, it was not possible to assess the extent to which this is done in the sites.

Setting Goals

There is variety in the extent to which goal setting is undertaken by patients or by clinicians. In some cases, clinicians write the goals, while in a few practices these are done by the patients themselves. Sometimes the patients state the goals and the clinician writes them or types them in.

Some goals were vague while others were more precise and specific.

The collaborative nature of goal setting has been mentioned by many but collaboration is a moving feast. Amongst some, collaboration means suggesting targets and goals and the patient agreeing them, while others allow the patient to envision the goal and how this is achievable by asking helpful, probing and sometimes difficult questions.

Written Care Plans

Patients' attitudes to written care plans are similar to that of blood results. Some value them, use them, refer to them and keep them. Some bring them to consultations ringed with coffee stains, showing at least that they are looked at. Others don't remember receiving them or have no idea where they are. In between is a diversity of responses reflecting some point on the continuum.

Care plans may be handwritten, typed in a word document, printed off and given to the patient while they wait, or sent to them later by post. In some cases, patients themselves write their care or action plan.

Staff Training

Appropriate, sufficient and timely training is considered essential for the success of Year of Care. The national training programme is universally admired and valued. Healthcare professionals have spoken of complete turnarounds in attitude after attending these programmes. However, not all staff have received the training and the issue of capacity is regarded as a serious challenge to the project. One important approach to address the problem of capacity is to train local staff as trainers. This is beginning to happen though rather slowly.

The training that has developed in North of Tyne is being rolled out nationally and over 150 people have so far received this training. The format of the national training is well regarded including the timing of a single day and a later half day.

Staff have spoken of other training received either via 'Successful Diabetes' or university delivered courses. Whilst much of these have been considered useful by participants, some of the training did not address key issues of care planning and concentrated on psychology and change behaviour.

The problem of finding time to undertake training was recognised by many, as was the need to update and meet at intervals to consolidate learning and maintain momentum. Other needs identified were to ensure administrators and HCAs received adequate training.

Professional Skills and Knowledge

To a large extent, comments by patients were extremely positive about the skills and knowledge of their healthcare professionals. Where they were less than positive, comments related to people being inflexible or too generic.

Health Trainers

Health trainers are employed in some practices in Calderdale and Kirklees and seem to be valued both by HCPs and patients. Something along similar lines exist in a practice in Tower Hamlets where people who 'meet and greet' are employed to answer basic questions and discuss problem areas.

Patient Education

DESMOND, DAFNE and HAMLET are regarded as excellent courses for people with diabetes both by patients and HCPs. However, there is insufficient capacity for demand and not even all newly diagnosed patients are offered the opportunity of attending the courses. Those patients who have had diabetes for some while and had not attended a course were not offered any structured education.

Patient Involvement

Whilst all sites have some patient representation, involvement tends to vary from tokenistic to genuine. Tower Hamlets has a strong patient and user involvement tradition and events are run to garner ideas and attitudes and to pass on information as widely as possible.

Information

There are some excellent pockets of good practice regarding information. In Tower Hamlets patients have enthused about a pack they receive with information entitled 'You and Your Diabetes' which comes with a DVD. This is information that is given with the purpose of aiding understanding of diabetes. On the whole there is a general call for more information by patients about diabetes care generally and diet, and information about Year of Care.

Information Technology

There are inadequacies in the use and capability of information technology across all sites. The difference, however, is in the response to these problems. Calderdale and Kirklees seem to use this as an excuse for not undertaking care planning to its optimum and not rolling it out extensively in a practice. In North of Tyne and Tower Hamlets they recognise the issues but appear to work within the problems. Whilst SytmOne is regarded by some as the system with greatest potential and the one for which templates are being designed, others swear by EMIS and express complete loyalty to that system.

Some clinicians still focus their attention on the computer while undertaking consultations rather than on the patients. This is a problem with some people though it is certainly not an issue raised universally.

There appears to be insufficient support available for practices that have IT problems or are not able to maximise its functionality or capability.

Culture

There was little sharing of definition about culture and some interviewees understood cultural change as changes that have taken place within the organisation without demonstrating much of an understanding of the changes in attitude, approach and relationships that cultural change encompasses.

Although many people spoke of little or no change, some in Tower Hamlets spoke of real changes that had resulted in themselves or their practice. They spoke of being more of a team, of introducing changes into other LTCs, of having more meetings and communicating more and of greater satisfaction by patients with the attendant positivity that emanates from that. But some also spoke of more bureaucracy and lack of flexibility.

Working in Partnership

Interviewees were asked how they would describe their relationship with their patients. They spoke of equality, being a firm but friendly advisor, being cooperative, being a facilitator, having an open and genuine relationship, being consistent, and not being authoritarian or paternalistic. Some even spoke of it being a partnership.

Engaged Patient

We were able to get a sense in the interviews with patients that they were becoming more engaged with their own diabetes care by going through care planning. This is also seen in greater attendances at clinics, responses within the consultation and goal setting, and actual changes in patients' behaviours.

Commissioning

There is little yet in the way of data feeds into commissioning and micro to macro influences. Unmet needs too are not being identified and it is recognised that much of this can only change once the appropriate mechanisms are available. Although IT systems would be the most efficient method to retrieve such data, it is possible to do this via a manual trawl. Referrals appear to be taking place on a more significant scale currently.

Leadership

It is important to have senior buy-in and leadership to ensure momentum and consistency and to provide appropriate incentives and censures. This is certainly the case in at least two of the sites.

Impact of Year of Care

It is clear that Year of Care has had a definite and dramatic impact on the lives of people with diabetes in Tower Hamlets. Whilst it appears that this is the case in North of Tyne, we have less evidence to demonstrate it. There is little evidence that it is making much of an impact in Calderdale and Kirklees.

3.7 Factors Influencing Progress at the Three Sites

The three sites were chosen using a rigorous approach for specific reasons.

Tribal's Phase 1 Report clearly stated the key underlying factors that enabled each site to offer a unique contribution.

- Calderdale and Kirklees PCT were already developing *Year of Care* services for diabetes, heart failure and chronic obstructive pulmonary disease (COPD). Commissioning activities had included work to stratify local populations according to service needs and interventions to mobilise local health and social care markets, particularly those that promoted self-care.
- NHS North of Tyne had taken a lead role in developing the national care planning model. Together with local practices they had developed and piloted care planning both as a concept and a service delivery model. *Year of Care* provided opportunity to capitalise on this expertise and in particular to develop a training programme for primary care staff.
- Tower Hamlets was starting from a different position amidst the deprivation, health inequalities and diversity of an inner city community. There had been a more recent transfer of level one patients with diabetes into primary care and there was an ongoing need to bring all primary care providers up to an appropriate standard. Tower Hamlets brought experience of dedicated projects for specific groups within their community e.g. the 'Ocean Estate Diabetes Project', which aimed to empower people to manage their own diabetes more effectively. This and other projects also emphasised their experience of successful partnership working with a range of organisations across different sectors.¹¹

The sites have been able to demonstrate different approaches based on differences in personalities, training, and cultural demographics. The sites have a good range of socio and ethnic mix. Calderdale and Kirklees may have less of an ethnic range but practices have a good social spread. North of Tyne has some ethnic diversity and Tower Hamlets has excellent BME representation. This in itself offers interesting challenges.

It is difficult to state how Calderdale and Kirkless or North of Tyne may have dealt with the problems associated with health inequalities as seen in the population in Tower Hamlets. Tower Hamlets PCT have a great deal of experience and knowledge which has helped them identify methods and approaches to implementing care planning in such a community.

Calderdale and Kirklees was the only site which did not use either the national training programme or 'Successful Diabetes' training. This has had an impact on the levels of understanding and consequent commitment to care planning.

¹¹ Tribal. Evaluating pilot sites as they prepare for the 'Year of Care': Final Project Report Diabetes UK August 2008

There is some inequity in the amount of resources that the three sites have directed at the project. Tower Hamlets have been able to devote considerably more resources to the project than the other two sites. This has had an impact on the project in a number of ways:

- There is a full time project manager at the Tower Hamlets site but not at either of the other two sites.
- Tower Hamlets have undertaken a number of patient and user involvement activities which incur expenses.
- Tower Hamlets have provided colour printers to all of their practices based on feedback from patients and users. Although this has been successful, it may not be feasible for other sites to implement should they agree this is a useful addition.

4 Discussion

4.1 Introduction

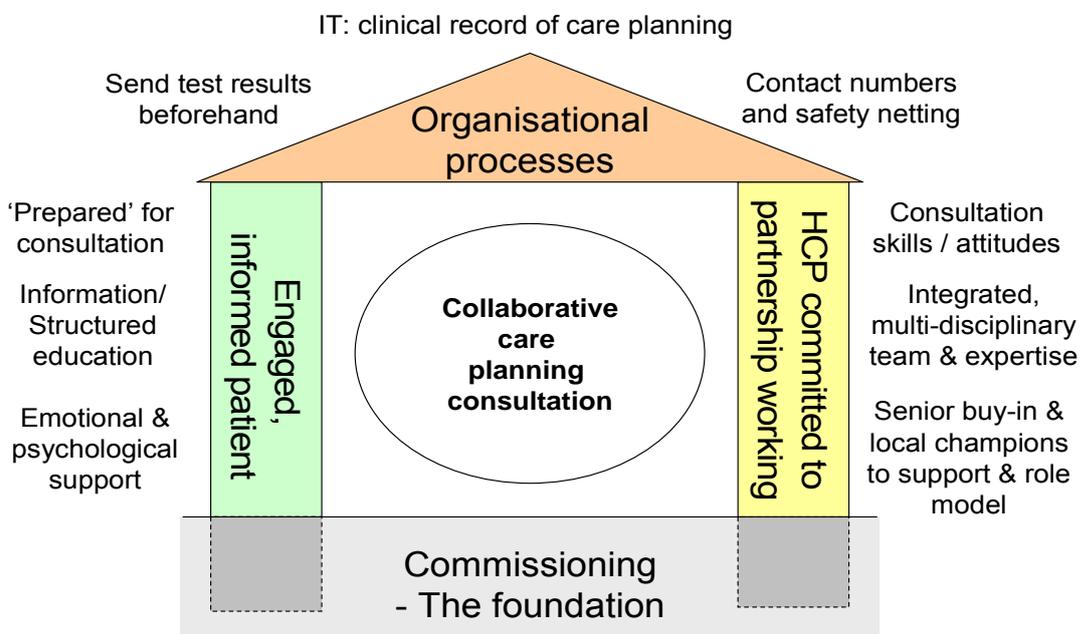
Care planning is a multifaceted, complex intervention. It introduces enormous changes into the way people behave, both for clinicians and patients, which inevitably leads to huge cultural changes and attitudinal shifts. Inevitably, the process of change is not always recognised by those in the midst of it.

The format for this discussion is based on the House and Windmill models.

4.2 The House Model

The House model is shown in Figure 17.

Figure 17: Year of Care the House model



The Consultation

Collaborative Care Planning Consultation

The Year of Care consultation uses the skills drawn from three different consultation theories; 'empowerment', 'motivational interviewing' and 'counselling'. Empowerment focuses on making people feel good and strong whilst having a pleasant chat with them. Motivational interviewing develops specific skills to elicit actions and counselling allows the person to talk and work things out themselves. The Year of Care consultation uses all three methods to listen for the patient's perspective, understand and value that, and find out what their health beliefs are. At the same time the clinician's story must be evident and their perspective at hand to provide information and negotiation to help the patient arrive at their own conclusion and action plan.

Where patients do not wish to engage in the consultation (*I didn't bother to open up the envelope with my results in it, or, I didn't understand anything*), it is important for the clinician to work hard at understanding what the problems are and explaining and teaching in such a way that the patient is engaged and involved. The clinician in a consultation has an important part equal to that of the patient's. They need to enable the patient to reflect what the patients themselves want and help them to problem solve. Final responsibility rests with the patient, but the professional has a commitment to provide other perspectives, information and knowledge during the consultation.

In the consultation, if the clinician continues to speak over the patient, telling them how well/badly they've done or what they should do without allowing the patient to reach those conclusions for themselves, they are perpetuating the adult/child relationship and preventing the patient from assuming power and responsibility.

It is difficult to be clear about the extent to which consultations reflect the Year of Care theory. To a large extent, excellent consultations are counter intuitive to GPs and other HCPs in some respects. For example, they would wish to congratulate or warn patients on behaviours, while Year of Care suggests this should be done with reticence and only after the patient identify for themselves the pleasure or concern of their actions. All GPs and Practice Nurses we spoke to suggested their consultations were conducted in a way that reflects the Year of Care ethos. They spoke of partnership, respect, understanding, trust. But it was only one GP in North of Tyne who was able to indicate a real understanding of the challenges of the Year of Care consultation. The Year of Care consultation clearly is not a binary state of excellent or useless, and must be seen as a continuum. However, improving and developing these consultation skills requires ongoing thought, discussion, training and support.

Goal Setting

At least one patient we spoke to found the concept of goal setting to be patronising. There is the danger clearly that working out what an adult has to do to change or maintain behaviour can be deemed as such, but it suggests that the patient concerned did not experience goal setting at its optimum, as goal setting should not be an activity that induces child/adult responses. Goal setting should be about enabling the patient to identify what is realistically feasible and achievable and working out how this can actually be done.

In the action or care plan, if only advice is given or the clinician says themselves what should be achieved in the long term, the chance of the patient visioning the next steps, working out how those immediate changes can be brought about and what the barriers are to achieving them, has been lost. The clinician needs to engage in a problem solving process with the patient so that they work out themselves what immediate steps can be taken. These are big changes in core behaviours.

Organisational Processes

Test Results Beforehand

Receiving test results before an appointment enables a patient to be prepared for a consultation. It gives them time to assess their feelings and emotions and the implications of the results. It enables them to begin to assess what they need to know and do for their own care. Many patients receive their results one week prior to their appointments but in some cases this may be just a few minutes. In a few cases patients receive them during the consultation.

Interviewees stated that receiving results may be perceived by the patient as something that is not necessary, they are uninterested in or they simply don't understand what the results mean. If that attitude is relayed to the clinician who dismisses it and does not address the root causes of it, i.e. lack of understanding and knowledge, fear or any other reason specific to the person, the opportunity of involving that person and of them taking responsibility for their own care may be lost.

IT Clinical Record of Care Planning

The aim of having effective IT systems is to support the care planning process and not to drive it. The system provides a useful aide memoir with appropriate prompts, though more experienced clinicians find they are able to consult with their patients without recourse to the systems. They tend to complete the record after the consultation so that it does not get in the way of communication with the patient. However, many clinicians who use the computer during the consultation do not feel that it gets in the way of the consultation.

Although many practices complained about their systems in Calderdale and Kirklees, this did not appear to be an issue in North of Tyne, (albeit the discussions took place with only a small sample of practices) or in Tower Hamlets. The lack of appropriate templates was the most common problem identified in Calderdale and Kirklees. The fact that the system was not able to generate a care plan, that it had to be photocopied, scanned and handwritten, were all cause for concern. Although care plans were handwritten and scanned in North of Tyne and Tower Hamlets, this did not seem to be bothersome.

The few practices we spoke to in North of Tyne all had EMIS systems and were pleased with them. In Tower Hamlets all the practices had either EMIS LV or EMIS PCS. In Calderdale and Kirklees, two practices had SystmOne and three EMIS and there was a strong sense of dissatisfaction with the IT systems (apart from one EMIS practice). Much of the blame for perceived inadequacies in the way Year of Care was working was put down to IT. There was no sense in Tower Hamlets or North of Tyne that they wished to change to a different system, only that there were a few minor problems that could be solved. However, some of these 'minor problems' in North of Tyne had been identified many months before, but nothing had yet been done to amend them. Those practices which did not have in-house support for IT seemed at a loss as to how to improve matters. EMIS Web is a system that is being piloted in Tower Hamlets with apparent potential.

Contact Numbers and Safety Netting

Year of Care relies on a robust system of administrative and managerial procedures to be effectively in place. All patients are called for blood tests to be made, and then recalled for appointments. Many practices invite patients for appointments at least twice a year, and on some occasions such as in Tower Hamlets they are given appointments for checks 3 or 4 times per year. Different practices have procedures on when to invite for appointment; most do so on birth months and some others during the

first half of a year. Strict processes are the safety nets which exist to ensure no patient is forgotten or missed.

Prepared for Consultation

It is interesting to note how many healthcare professionals take 'engaged' to mean that patients were more knowledgeable about diabetes, they'd used the internet to look into the condition and found out more about specific diets and other interventions.

The engaged patient is one who understands their results and the significance of those results. They take a leadership role in the consultation and come to it with an agenda that they have identified themselves and which enables them to engage in discussion and conversation with the clinician.

Clinicians are presented with a challenge when patients simply say in the consultation, 'You tell me. You're the expert.' Many patients say they wish to be told, particularly elderly patients who are suddenly presented with a different, and uncomfortable, position of having to reflect deeply on their own behaviour, wishes, barriers, problems, and attitudes. Another situation is that of the patient who wants to be 'scared' into changing behaviours. Fear may be effective in the short term but only motivation, comprehension and knowledge is effective at longer term change.

Structured Education/Information

Patients will not be engaged in the process of care planning without an understanding of what it constitutes. The basic message with change management is to communicate and communicate effectively. Most patients do not evidence much knowledge of what Year of Care or care planning entails. They understand what processes they go through but are not able to contextualise it within a care planning framework. This is an omission that smacks of paternalism in that it implies we know what is best for you, we want you to be a true partner in it, but we are not really going to tell you what it is.

The folder or pack that is given to all patients in Tower Hamlets is an example of what could be done. It was developed in consultation with patients at large scale events where the voice of patients was listened to when asked what they wanted to see and how they wanted to see it. They stated they wanted colour, and the folders were produced in colour. Indeed, every practice was given a colour printer to ensure that colour was included in any letters sent to them relating to their results or care plans.

People with diabetes are thrown into a quagmire of conflicting and confusing misinformation or lack of information. Bad news obliterates sense making of information and even after a period of time it is often difficult to assimilate and act upon information, particularly spoken information at the time of a consultation. It is therefore essential, and seen as essential by healthcare professionals and patients alike, to have structured education for all patients. DESMOND, DAFNE and HAMLET are all examples of these programmes which exist and have met the needs of thousands of patients with diabetes throughout the land. Unfortunately there are thousands more who require attendance but who are unable to do so as sufficient capacity simply does not exist.

Emotional and Psychological Support

Emotional and psychological support is essential for patients going through the upheaval of coping with diabetes. This support is provided via a number of mechanisms; having access to information, having access to people to contact either professionals or diabetes support groups, and having structured education so they feel empowered to deal with the daily constraints and requirements from a position of knowledge and therefore strength.

Diabetes peer support groups are an under-utilised resource. Several patients spoke of their wish for groups or social opportunities where they could speak to people in similar situations. There are a number of reasons for people not joining organised groups including; time constraints when working or looking after a family or being a carer, not wishing to be part of a formal group, insecurity and shyness, and not knowing about the groups. There is not a great deal that can be done about the first three, other than to be welcoming to the shy, but there is something that could be done about the last point. Facilities and resources could be made available to advertise and market the groups. This does rely on at least one champion to take the group forward and provide impetus and enthusiasm. From our experiences in the sites there is no lack of such champions around. The PCT has taken a proactive role in trying to encourage and lead such groups in Tower Hamlets, and this is useful as long as it is clear at what point they take a backward step and allow the group to assume independence.

Consultation Skills and Attitudes

Having the right consultation skills and attitudes is reliant on receiving appropriate training. Training is key to lighting the spark of change, both in knowledge and behaviour. The culture of the organisation, including team work and collegial support must help maintain the momentum of this changed behaviour.

The key issue with effective training is ensuring that the organisation is prepared for Year of Care prior to training taking place. If they are not prepared there is the danger that training is simply seen as CPD for clinicians with nothing changing in the practice as a result of it. The infrastructure and levers must be in place within the organisation to ensure that the messages and learning that trainees bring back is rolled out within the practice and implemented in the organisation. As much of this is dependent on a cultural change, it is important that those doing the training are the right people and are able to influence change within the workplace.

To ensure that there is sufficient training, it is necessary to have appropriate funding levels and streams. It is therefore important to have a commitment for training from the SHA and commissioners. Funding must be available to secure sufficient core trainers in a locality to take on the training function. Training cannot be an add-on to an already demanding job or left to those who may not be adequately skilled or quality assured. Organising trainers is complex. It takes time and effort to identify people who have the right skills and are interested in becoming trainers, to allow at least six weeks to release them for training and for the organisation to be prepared and ready for change.

Training is resource heavy, particularly in the first instance until all training is complete and only a 'mopping up' of new staff is required. It is therefore impractical to employ sufficient trainers up front. However, the need for training is immense, not only in the pilot practices but throughout the pilot sites and further afield in due course. Although the experience so far of using universities has not been successful, it seems an opportunity may be missed of developing a relationship with an organisation which has the infrastructure and resources to undertake this work. There are universities who have the flexibility, commitment and interest to work collaboratively with the team to develop a suitable module. Currently the thinking is that accreditation is less important than quality assurance and the present co-delivery arrangement is working well to support new trainers. In the current system, an additional feature that works well is the instantaneous feedback that is given rather than course work with later commentary.

Another possibility in terms of spreading the load is to involve commercial organisations in the delivery of training. 'Successful Diabetes' has trained two thirds of the practices in Tower Hamlets. (The national training programme has trained one third of them.) More evaluation of the training of this organisation should take place.

As a private provider 'Successful Diabetes' can change its delivery to meet the clients' needs. The national training programme, on the other hand, will strictly enforce those criteria that will lead to clinical behaviour changes recognised as being key to Year of Care.

It is also important that healthcare assistants and managers who do supporting work undergo training.

Multi-disciplinary Team and Expertise

The successful implementation of Year of Care is reliant on many factors and one key factor is the identification and integration of tasks. We have examples from the pilot

sites which show how disintegration occurs where these tasks are not clearly delineated. In one practice in Calderdale and Kirklees, the nurse took on the administrative or support role of assisting patients with their evaluation questionnaires, which proved a task too great and the proverbial last straw, finally leading to the withdrawal of the practice from the project. In North of Tyne the specialist unit ran care planning but did not have an HCA to take bloods, or do basic checks and measurements. The infrastructure of a large Trust did not allow for such a task profile and it therefore became part of the nurse's duties. This again resulted in an imbalance of tasks and the curtailment of care planning, at that stage, in the unit.

Senior Buy-in and Local Champions to Support and Role Model

The spark of new knowledge and changed behaviour can be easily extinguished in a culture that is not supportive of care planning. No matter how enthused a clinician, once they return to a culture that does not welcome or nurture those beliefs and methods, previous behaviours could soon re-emerge. After all, sending out results and producing action or care plans involves an additional workload, and maintaining consultation skills where the clinician does not give advice upfront is often counter-intuitive and requires a certain amount of restraint. It is necessary to have effective support within the organisation, from senior buy-in to supportive infrastructural and administrative mechanisms for these behaviours to be maintained.

It is a fine line for a local champion to tread. They take the risk of being labelled intrusive, meddling or pushy. Or indeed they may take a position that is too laissez faire in which case they may be accused of being uninvolved or unsupportive. However the value of having a local champion is to have someone who has great clarity of the key principles and philosophies of Year of Care but who also understands the local challenges, the constraints and barriers to successful implementation and who can call on their own experience and knowledge to shed light and offer solutions. In addition, they have the ear of those in power and can present effectively arguments for whatever is needed be it funding, personnel, or resources, but also explanations for things that might have gone wrong.

Having senior buy-in to the project provides that additional impetus and force to enable activities to take place, pressure to be put where it is needed, and funding to be made available to meet the demands of the project.

Commissioning -the foundation

Identify and Fulfil Needs

Patients arrive at consultations, discuss their goals and identify what would help them to achieve those goals. This process leads to an important step in allowing the patients themselves or with the aid of the clinician, to identify their needs. These needs relate to a variety of services that can be procured, such as seeing a dietician, a chiropodist, having an exercise programme, cookery classes or structured education, or to issues that are more personal and specific such as loneliness, depression or anxiety. Options are then identified which may help to meet those needs or alleviate those conditions.

There are facilities for seeing dieticians, chiropodists, having exercise programmes and attending structured education (albeit with the limitations discussed earlier). There are also referrals to assist patients suffering depression or other mental health illnesses. Loneliness is a less easy condition for referral, but support groups may provide some measure of assistance.

Although services are available they are not necessarily offered to the extent that might be required. An exercise programme is packaged in 6 sessions and patients often wish to attend longer. This is currently not feasible. Additionally, what is available may not suit a patient. This is often seen in places such as Tower Hamlets where patients do not wish to travel and even a distance of one mile may be seen as too great. It is also sometimes unclear to the referring clinician whether the patient will have to pay for a service.

At least two patients spoke of their wish to have blood sticks on prescription. They feel they would like to take control of measuring their glucose levels on a daily basis and to control their diet accordingly. However, the sticks are not available on prescription which has resulted on one occasion in angry letters being sent accusing the practice of all manner of pernicious and neglectful behaviour. Clearly the well worn argument around resource allocations and management are still in evidence and some wishes may never be realised.

Procure Time for Consultations, Training and IT

The commitment to provide adequate support in terms of project management, training and IT is recognised across the sites but delivered to different standards. This must be seen in conjunction with cultural and other factors. In terms of IT, system inadequacies either become stumbling blocks that prevent advancement or inconveniences that are overcome using creative devices. Therefore, procurement must be seen within a wider context of the whole system, rather than a specific piece of soft and hardware.

Training must be identified in terms of the specific needs of a practice taking into account the potential for cascading knowledge, and ensuring the right people in the practice attend the training. Training needs to be ongoing to reflect the need to upskill new appointments.

Training also needs to be commissioned to ensure HCPs' unmet needs are fulfilled.

Quality Assure and Measure

Quality assurance and measurement takes place at both national and local levels. The evaluation process conducted by Tribal, the use of both quantitative measures collected at three points in time, and qualitative case studies undertaken twice, are means of assessing the quality of activities and

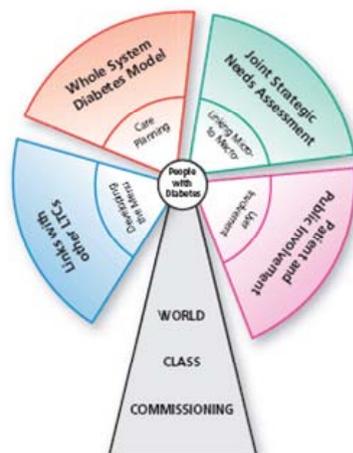
perceptions of experiences. In Tower Hamlets, the quantitative measures are met by the use of the Picker survey.

On a local level, quality of care plans is assured at Tower Hamlets by sampling anonymised care plans and measuring them against agreed criteria and standards, though one board member at that site expressed concern that *'we're going down the road of collecting data rather than caring for patients.'*(PB7) This again is an area with fuzzy boundaries; ensuring that measurement is not undertaken for its own sake but helps inform and therefore lead to higher levels of quality.

4.3 The Windmill

The Windmill model is shown in Figure 18.

Figure 18: Year of Care the Windmill model





Local Models of Care

There are a number of different models of care. Care planning is the model of care propagated by Year of Care and this section will discuss the impact of different models across the three sites.

One Stop Shops

The one stop shop issue muddies the Year of Care waters. While the one stop shop practices see this model as the optimum, and that Year of Care is a means to the end, they often mistakenly believe that one stop shop is equivalent to Year of Care. Thus in one of these practices, they differentiate between patients they see as Year of Care patients and non Year of Care patients. The Year of Care patients are all sent blood results prior to their consultation and goals are set and written with them. This is not true of what they call 'non Year of Care patients' who do not have blood results sent out or goals written down. Clearly the principles of care planning are not embedded throughout this practice.

From a commissioning point of view, one stop shop is seen as appropriate for a segment of the population who require specialist input. However those people with Type 2 diabetes who have no serious complications do not need to see specialist clinicians such as podiatrists, for example, if healthcare assistants have relevant training in finding foot pulses. It is more cost effective as part of the annual review, to have all biometrics undertaken by an appropriately trained healthcare professionals rather than a multitude of different ones.

It is important for the one stop shop practices to reflect on whether that approach goes anywhere towards implementing changes in self management behaviours. It is interesting to note that changes in structures such as implementing a one stop shop is more straightforward and has more tangible and visible effects than changes that take place in relationships that occur as a result of different consultation methods.

Local Specialist Services

The models of care are different in North of Tyne compared to other areas such as Calderdale and Kirklees, and Tower Hamlets. In the former, there is a strong three tier system with the middle tier being a specialist clinic, the Diabetes Resource Centre. In Tower Hamlets, the middle tier between primary and hospital based care is intermediate team with a consultant lead in the community.

The specialist clinic in North of Tyne is populated by clinical champions of Year of Care. These are Diabetologists, nursing staff and a dietician who have been engaged in the earliest stages of formulating the principles and ideology round Year of Care. They are drivers of Year of Care in the area and provide strong leadership nationally, not only in the philosophy but also in the provision of a training programme.

It is useful to consider if Year of Care will work in specialist care given that patients are referred to it for specific interventions and consultations. Care planning clinics did run in the specialist clinic three years ago and, anecdotally, they were appreciated by patients. However, organisational barriers such as attempting to change the administrator function is harder in specialist care as the service often doesn't manage the administrative function. They were therefore not able to employ a health care assistant to collect the necessary biometric data to feedback to patients prior to their consultation. The latest information, however, is that a HCA is now due to be employed and care planning will be re-

introduced into 2 clinics.

One of the questions that arise in this model of care is who does the annual review; is it by the person who mostly provides care or always by primary care with specialist services undertaking problem solving. Hand held records provide a useful mechanism to enable clinicians in both primary and specialist care to contribute to action or care plans.

Another issue that must be considered is who leads the process. Once the lead is outside the primary sector, QoF points are affected. QoF provides an importance incentive in facilitating change in practices and this would be affected by information being collected in the specialist clinic rather than in primary care.

Changing care in the secondary and tertiary tiers is more cumbersome than in primary care. If the PCT wants care planning embedded, they are able to reorganise skill sets for greater efficiency or cost effectiveness. However, it is not easy to reorganise services in specialist care to suit one department. The specialist and secondary care sectors do not have LES agreements or any other sweeteners to facilitate change.

Resources

Additional resources were made available to all practices in the pilot sites during the first year though this is not available for the second year. PCTs have resourced their practices differently based on their identification of priorities.

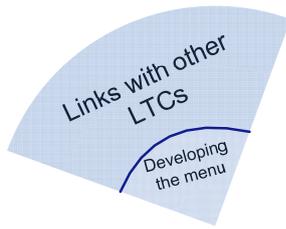
Monitoring and Consistency

There is little in the way of monitoring at this stage. Some pockets of practice do this such as audits of care plans in Tower Hamlets though this is more to do with ongoing support and skill development than quality assurance at this stage. Project managers attempt to monitor by providing support and recently the project manager in Calderdale and Kirklees is undertaking a ‘walk through’ of all the practices in the area.



Linking Micro to Macro

It is not yet feasible to link micro to macro for commissioning purposes. Information is not yet being recorded or collated and practices are not doing this manually. Other methods suggested could be vouchers that patients are given and are then returned to the practice or PCT to monitor usage. Another possibility is for networked practices (in Tower Hamlets) to meet at specific time periods to work out precisely what facilities or resources have been used. The limitations are clearly linked to inadequacies in information technology. Once a template is available, accessible and used, it will be possible to achieve this aim.

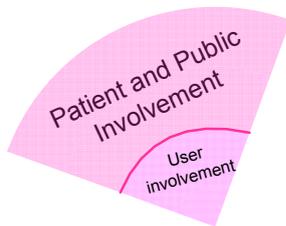


Links with other LTCs

Some practices are beginning to introduce care planning into other LTCs while some are using Year of Care appointments to look at a patient’s other LTCs. This linkage of co-morbidities is regarded by many as the sensible and obvious way forward in managing a patient and promoting self-care.

Developing the Menu

Tower Hamlets has a booklet, ‘Supporting Self Care’ with options available for patients to read. However this booklet is now out of print and not being republished though it is available on line and easily accessible to clinicians. Many of the population in this area are not obviously computer literate and it seems a shame that they now have to rely on being told what is on the menu. However, often health trainers are available to discuss options. It is important to take into account local idiosyncrasies such as not wishing to travel away from the local vicinity in Tower Hamlets or wishing to have all women swimming sessions.



Patient and Public Involvement

Patient and public involvement has been taken very seriously in Tower Hamlets. The commitment to this element is seen by having an Assistant Director for Patient Involvement as part of the Project Board. Many events have been organised where local people have been invited to provide suggestions, comments and responses to questions or proposals.

Both North of Tyne and Calderdale and Kirklees have users on their Programme Boards.

The test as to whether user involvement is tokenistic, paying lip service or genuine is in the impact of that involvement. Tower Hamlets is able to demonstrate that they are taking genuine notice of what is being said by incorporating change and modifying practices based on the comments received. Two examples demonstrate how asking, listening and acting has resulted in changed action; a coloured folder (discussed above in more detail) has been introduced to much acclaim, and issues such as all women swimming classes have been initiated for Bengali women who require them.

4.4 Answering the Big Questions

Who and what is involved in delivering a Year of Care?

Year of Care is a complex and multi-faceted model of delivering care. It incorporates far more in the way of change to behaviour than is recognised or appreciated. At its most basic it sends out blood results prior to an appointment, discusses goals with patients during a consultation, and makes referrals to help patients reach those goals. At its most sophisticated it changes the basis of the entire clinician/patient consultation. It empowers the patient to envision how they can take control of their diabetes using problem solving skills. It has integrated, technologically driven mechanisms to link individual needs into more population specific needs (the micro to macro shift), and it introduces subtle yet powerful cultural change within organisations to make them more genuinely patient and team centred.

Everyone who delivers diabetes care is involved in Year of Care. The changes that take place in an organisation in terms of different tasks and skill requirements, (such as HCAs and administrative staff undertaking a different range of activities), the different methods and techniques used by clinicians in consultations and the cultural shifts that impact on all staff and patients, make it clear that this is not something that can be compartmentalised or take place in a discrete section within an organisation.

Currently Year of Care is seen as a model of care in primary care, yet it is shown that it is feasible in different situations such as specialist care centres.

What has been the impact of a Year of Care?

Thus far, the impact has been mixed. However it is clear that Year of Care has made a difference to the lives of many patients. In Tower Hamlets particularly we were able to get a strong sense of the changes that patients have introduced into their lives by attending clinics at Year of Care practices. They spoke of not missing appointments now, of understanding what their results mean, of being encouraged to change diets and undertake more exercise. They mentioned that things are different now from the way they used to be.

In Calderdale and Kirklees we also got a sense from some patients that things had improved. Many patients who commented positively in this site spoke of the value of the one stop shop but also of the benefits from receiving blood results early, making sense of them and having a more patient centred consultation.

In North of Tyne, the benefit of a centre with a highly developed philosophy of care planning is evident. There is evidence too in this site of care planning being practiced at its optimum, particularly in a practice where the GP is part of the Programme Board and her consultation skills are used as part of the training materials. The excellent training programme that emanates from this site is available nationally and this training forms the core of ensuring current and future impact.

Is it feasible to implement a Year of Care more widely?

There is currently insufficient capacity in terms of delivery of the national training programme to roll out the Year of Care on a wide, national scale. The importance of having a training programme that is tried and tested and fit for purpose is crucial. Calderdale and Kirklees have demonstrated the dangers of implementing Year of Care where appropriate training has not taken place, and thereby not enabled understanding of the concepts of care planning to be attained. Currently, the national training programme has been spoken of by those who have undergone the training as excellent and inspiring. However, there is insufficient capacity to deliver this on a large scale. Training trainers locally is recognised as a move to address this need, though the numbers that are needed to be trained and who can be trained properly (more than simply adequately) are small relative to the number of practices that exist in the country.

Perhaps the question needs to include a time element. If Year of Care is to be implemented on a wide scale in the short term, it is not feasible without a dramatic sea-change in training capacity. This would entail incorporating other methods of disseminating the training, perhaps by having controlled centres with quality assured training. It is also important to establish how effective 'Successful Diabetes' is as a course.

There is no one right way to implement Year of Care and different practices must consider what is appropriate for them, taking into account issues such as their histories, personalities, commitments, idiosyncrasies as well as population and cultural factors.

How can a Year of Care approach be quality assured?

It is certainly a great deal easier to quality assure a project with a defined and contained number of practices and a project manager to participate in doing so. Once it becomes conventional practice it becomes far more difficult. It is at this point that the PCT needs to take an active position in introducing quality assurance processes. Tower Hamlets have undertaken an audit of care plans. Whilst this is still a process that is being developed and is currently educational formative process, it is a good basis on which to grow a robust and sustainable methodology. However, this is not proposed as a sole means of assuring quality but just as one mechanism within a larger set to do so. Ways of assuring quality once the project assumes independence are areas to be considered further.

What are the transferable lessons?

Care planning may be appropriate for many long term conditions and in some places, such as individual practices in Tower Hamlets, the principles of care planning are being introduced in stroke and COPD.

There are three key interwoven transferable lessons; appropriate training to ensure effective understanding and commitment to care planning, monitoring of quality to ensure practice does not slip and standards are maintained, and senior buy in and commitment at both PCT and practice levels.

Effective training with follow-ups at specific determinable intervals are important to introduce care planning, to engender commitment to its principles and methods, to identify bad practice or failings and correct them, and to sustain good practice.

Monitoring can take place at PCT, local or peer level. Practices themselves might introduce discussions of care planning at team meetings. Clinical supervision could focus on individual HCPs' performances and challenges in practicing care planning optimally, and systems of peer support can exist where issues are discussed and debated. In Tower Hamlets the networks of practices might enable senior clinicians to meet and talk about issues in an open and non threatening way.

Senior buy in at local and PCT level ensures that care planning is explored, encouraged, facilitated, and supported at both levels. It also enables appropriate resources to be made available.

A further transferable lesson is to ensure, as far as possible, that structured education is made available to patients to enable them to benefit from thorough understanding and knowledge of their condition so they may assume a true partnership in their care and self-management.

5 Challenges

5.1 Maintaining momentum

In two of the pilot sites we visited (Calderdale and Kirklees and North of Tyne), we were able to ascertain that the initial verve and fervour of the first year was less evident, not for want of enthusiasm but for the inevitable dampening as a result of daily workload for all those involved in the programme. This is exacerbated by the lack of a full time worker on the project to manage the project comprehensively on a day to day basis. Both Calderdale and Kirklees, and North of Tyne do not have full time project managers working on Year of Care. In fact, the project is just one of a number of other projects on which they work. Neither was able to say what proportion of the time is spent on Year of Care. The difference in previous full time project management support is stark.

The need to maintain momentum is a recognised challenge in North of Tyne and a meeting of the steering committee was held to develop a work plan. Within this work plan, colleagues are asked to identify priorities and steps to achieve the priorities over the next 18 months. They are also asked to identify who will undertake them, the support that is needed and how they will make sure they are done.

5.2 Patient involvement

Although this is working well in Tower Hamlets, it is seen as an area that has not been fully developed in the other two sites. Although a patient is represented on all three steering groups, there is little more that is done to develop patients' input into the training and roll out of the project.

It is important to undertake awareness raising with patients at an early stage of the implementation of care planning.

5.3 Training the right people

In Calderdale and Kirklees, training from the national team was delivered to a group of 40 clinicians. However, the invitation to training was sent out widely and many of the people who attended came out of general interest or for CPD purposes. This was clearly a missed opportunity to target key clinicians in practices who would be able to take the learning and vision back to the practices and disseminate the principles, create a learning environment and implement care planning processes. Some of the attendees were district nurses and although it is important to have care planning inculcated into this group of nurses who deliver care to patients who are housebound, they need to be part of an organisation that is prepared for care planning. A tipping point needs to be reached in an organisation. Training just one person in a large organisation is unlikely to create sufficient impetus to change and instead of contributing towards the tipping point, it is more likely simply to diffuse into past practices.

Training without organisational and senior clinician sign up is potentially of little value and wasteful in terms of opportunity costs.

5.4 Commissioning

Involving and feeding into commissioning is seen as key to the future development of Year of Care.

Currently data is not fed into the commissioning process in any of the three sites. Menus of care or options do not tend to feature in care planning and the 'micro' does not yet extend to the 'macro'. One of the ways of achieving this is to have a system in place to identify unmet needs. This was an issue that is being discussed in North of Tyne and it is suggested that a field is inserted into a record which would be able to identify all unmet needs, and collate these into a report which would be fed into the commissioning process. The Year of Care template is central to the effective workings of such a system.

Block contracts do not allow the flexibility that a Year of Care model requires in order to be able to identify unmet needs and to cater for them. Different contracts will be drawn once different providers are identified for a variety of alternative options. This is currently being discussed as part of service reviews being undertaken at North of Tyne.

5.5 Rolling out

Getting the next group of people and practices to take on board the Year of Care approach is a major new challenge. In North of Tyne they have already engaged 39 of the practices in North Tyneside and West Northumberland. In Calderdale and Kirklees, there are now only 4 practices as one has recently withdrawn from the project and another from the original 6 had done so a while ago. Instead of developing and expanding, the project is stagnating and, in two places, focusing on aspects which do not incorporate the principles of care planning. However, this is recognised and steps are currently being taken to identify more practices. In Tower Hamlets, the Year of Care was introduced in a further 14 practices from September 2009, using tools and resources developed within the pilot.

The national commitment is to introduce care planning across the country and the political agenda is a strong lever for rolling out the programme. Key to the effective roll out is a strong training programme. The national training programme is a well developed and effective course that has been shown to be well received and valuable at introducing clinicians to the principles of care planning. However, two important questions remain: is it able to reach all the people it needs to, and where is the follow-up and continued support. The latter point relates to follow-up sessions which can take place annually, or peer support in the form of periodic meetings or action learning sets.

5.6 The Year of Care term

Few patients have heard of the term Year of Care. Where they have heard of it, the understanding is varied. Many people, both patients and healthcare professionals, have expressed the view that Year of Care, as a term, does not aid understanding or association with care planning.

6 Risks to the Project

6.1 Risks

The lack of full time project management at Calderdale and Kirklees and North of Tyne is serious. Year of Care is a fundamental change to culture and practice and needs support to ensure training and ongoing development is available. Project Managers are key to ensuring these are organised and advertised.

Training is not yet meeting the needs of pilot practices (let alone other practices) in terms of quantity. Whilst the quality appears to be excellent, insufficient people are being trained and turnover of staff exacerbate this problem. Training is fundamental to enabling a cultural change to emerge and be sustained.

Appropriate people need to be trained, i.e. two clinicians from each practice. Unless appropriate people are trained and updated at a later stage, they will be unable to cascade the learning within the organisation. Once structures are put in place in the organisation, continued learning and discussion needs to take place to renew aspects that might slip, such as consultation skills.

Momentum is losing ground. This is recognised in both Calderdale and Kirklees and North of Tyne though in North of Tyne the steering group is reacting with appropriate impetus and energy to stop the danger of a slide and to ensure they forge ahead. There is the risk that in Calderdale and Kirklees, Year of Care will coalesce into a small and narrow function of sending out blood results and writing down goals, without necessarily applying adequately the underlying principles of greater responsibility and partnership.

Structured patient education is not taking place in sufficiently large numbers. DESMOND and HAMLET cater only for newly diagnosed patients and those who have been diagnosed some while ago and have not attended any courses are slipping through the net.

Patients are not being prepared for care planning. However, going through a Year of Care consultation once should make them more prepared for it a second time, and understand the processes, if not the principles.

Year of Care is not becoming adequately embedded in practices in Calderdale and Kirklees with the resultant and expected change in culture. Support staff is seldom aware of what Year of Care means or the reasons for the changes.

Clinicians in practices in Calderdale and Kirklees are putting too much emphasis on IT. IT is the scapegoat for care planning not being adequately implemented. Care planning is feasible without precise Year of Care templates in place, though admittedly this would make it easier. However, not having Year of Care templates is not perceived to be a burden in North of Tyne and Tower Hamlets and alternative practices are evident such as writing action plans, scanning them and photocopying them.

The evaluation questionnaires are seen as burdensome and one practice has used that as the reason for withdrawing from Year of Care. They did not have an administrator to help with the process and queries went to the overloaded practice nurse instead. It is unclear whether this is a genuine reason or simply an excuse.

Unmet needs are not being captured and therefore not feeding into the commissioning cycle. This will not enable information to be obtained as to options, take up of these, and concomitant costs.

Patients are not being adequately involved in the Year of Care project in Calderdale and Kirklees and NoT. Diabetes peer support groups are useful vehicles for engaging in learning and discussion and for representation and dissemination. More of these groups could be set up in all three sites and help and support given to make them self running and sufficient.

Year of Care is not recognised as a term by patients and many practice staff are not able to explain what it entails. It is less important that the term is understood than that patients can relate to the principles of care planning.

6.2 Risks to the Project

Table 6 presents a number of risks and contingencies for the evaluation and for the delivery of Year of Care services.

Table 6 – Risks, Mitigations and Contingencies to the Project

Risk	Likelihood	Mitigation	Contingency
Full time project management not being in place in 2 sites.	H		Although it is not possible to provide funding centrally for reasons of equity, it could be feasible for sites to fund this locally, or to free up sufficient resources to achieve each discreet function that they identify as being crucial to the project's success
Training not given to sufficient numbers.	H	The training programme is excellent.	Consider alternative partners to roll out the specific and unadulterated programme. Identify local trainers and roll out a training the trainers programme. Provide more administrative support to the training team. Provide financial and locum support to focus their efforts more on training.
Appropriate people not being trained.	M	The lessons from training in C&K have been taken on board,	Ensure only appropriate people are trained in the short and medium term. These people are two key clinicians from practices. Provide on-going support to the teams on a local basis by having local learning/discussion events and update training.
Loss of project momentum among practice staff.	H	This is recognised in NoT and a work plan is being completed by key individuals who are	Regular face to face events to pull stakeholders together in each site. Regular feedback of data to practices with two monthly updates of evaluation progress across the field.

		identifying priorities.	
Differentiation of YoC and non YoC patients.	H	This is happening in one practice in C&K.	Discussions, attendance at learning events, invitation to training sessions.
Structured patient education not being made available.	H	DESMOND and HAMLET are recognised as excellent programmes.	Encourage Diabetes Support Groups to be formed. Provide education to them and encourage dissemination of the knowledge amongst members. Attend their meetings to provide input on care planning.
Cultural change not embedding in practices.	H	This is happening in some practices.	Encourage training, attending learning events, engaging in discussion, perhaps action learning sets (though this is improbable).
Scapegoating IT.	M	This is not an issue in NoT or Tower Hamlets. YoC templates are close to development.	Encourage people to be creative about action plans. Provide support by project manager for practices that need IT support and do not have in-house help.
Unmet needs not being captured.	H		A field for unmet needs should be included in the template. This will enable data to be captured and reported on at the commissioning level.
Patients not being involved.	H	All sites have a patient representative.	Explore additional methods of incorporating patient perspectives into the programme given their reported willingness.
Year of Care is not recognised as a brand name.	H		Consider rebranding.

It is also important to assess what the risks are to the evaluation itself.

Table 7: Risks, Mitigations and Contingencies to Evaluation

Risk	Likelihood	Mitigation	Contingency
Questionnaires being found burdensome.	M	This is not too much of a problem in some	Encourage administrative staff to help with questionnaires.

		practices.	
Small volume of survey data sent back.	L	Staff appear to know what is expected far more now.	Continue to provide support and feedback to practices.
Insufficient staff time to engage with the evaluation.	M	This is a big problem in one practice in C&K.	Project Manager is working with the practice to encourage them to use the administrators to help with the tasks.
Lack of access to people in case studies.	L	This has not been too serious a problem. Some relationships have been formed with staff at practices in C&K and direct contact is possible.	Contact practices directly if necessary. Ensure sufficient time is available to set up case studies and interviews. Keep pushing to ensure interviews are set up.

7 Conclusions

It is important for Calderdale and Kirklees to consider how they can support change in attitudes and behaviours. The project manager has recognised the complexity and stated; *'It's not failing, but it is more difficult than people have anticipated.'* Much work still is needed in embedding Year of Care into the culture of the organisation. Training and on-going support is crucial to achieving this.

North of Tyne benefits from an influential and hugely sophisticated understanding of the principles of care planning, as well as the base for the national training programme. It is widely spread throughout the area as well as into West Northumberland and has clearly made great inroads into the area. Quantitative data show successful implementation and to some extent the qualitative data supported it though we were not able to get a definitive sense of activity there.

Year of Care is working well in Tower Hamlets. It has clearly made a change to the lives of many patients. There has been a great deal of self reflection and debate as to what works well and what does not. There is great commitment evident not only from the senior staff at the PCT, a highly active and involved Project Board, a project manager who is proactive and supportive to the practices, but also, and crucially, the staff at all levels in the eight practices.

The practices have all shown different ways of implementing Year of Care and a key lesson from this is that there is no one right way and local conditions, idiosyncrasies, histories and personalities must all be taken into account when deciding what Year of Care will look like in a particular setting.

Year of Care is an enormous challenge. It requires senior buy in and clinical leaders and where this is not in place it risks failure. Appropriate management and infrastructural support must be in place.

Year of Care can engender a sense of aspiration and commitment. This is evident in a comment made by a nurse in NoT. *'If I were a patient I would want to have a care planning system in place. I think it respects people more as individuals. It gives people more rights.'* (N3 NoT)

8 Recommendations

Greater support is provided to Calderdale and Kirklees in the form of funding for a full time project manager, and systems for advice and assistance in improving the site.

A plan is introduced to consider capacity issues with the national training programme.

Year of Care templates are introduced with effective IT support to all practices.

Unmet needs are captured.

All sites look at the Tower Hamlets folder with coloured information and consider whether its introduction may be helpful.

Pressure is put on increasing capacity for structured education for patients.

Within this next year focus is put on considering ways of monitoring and quality assuring care planning.