

**Year of Care
Tower Hamlets Case Study
5 – 9 October 2009**

Services for life

Document control sheet

Client	Diabetes UK
Document Title	Year of Care: Tower Hamlets Case Study
Version	1
Status	Draft
Reference	
Author	Gail Louw
Date	12 October 2009
Further copies from	email: documents@tribalgroup.co.uk quoting reference and author

Quality assurance by:	Heather Heathfield and Janet Clark
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Document history			
Version	Date	Author	Comments
1	26 Oct 2009	Gail Louw	

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1 Year of Care at Tower Hamlets

1.1 Introduction

1.1.1 A qualitative case study was undertaken in Tower Hamlets from 5 – 9 October 2009. Two researchers (Gail Louw and Janet Clark) spent a total of 10 days in the area and interviewed 49 people including patients, healthcare professionals and members of the Project Board. The interview schedule that was used is in Appendix 1.

1.1.2 All 8 practices in the site were visited 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.

1.1.3 To maintain the maximum anonymity, but to enable the reader to have a sense of which quotes are from the same person, we have assigned a random number to the group; GP1 may be from the same practice as GP6 or GP2 but this is arbitrary, and Patients have numbers that are not associated with the practices that they are from. Nurses (N) are not differentiated between Practice Nurses and Nurse Practitioners in order to protect anonymity. Administrators are (A) and Practice Managers (PM). All Commissioners, Providers and Project Team will be assigned a PB for Project Board.

1.1.4 Interviews were held with the following groups:

Table 1: Interviews according to Groups

	Patients	GPs and other Doctors	Practice Nurses/ Nurse Practitioners/ HCA	Administrators/ Practice Managers	Commissioners	Providers	Project Team	Total
East One	3	1	1					6
Wapping			2					2
Stepney	4	2	4	1				10
Jubilee St	3	1	1	1				6
Whitechapel		1	1	1				3
Tower	2	1						3
Brayford Sq	3	1	1					5
St Katherine's Dock	4	1						5
Project Board					4	1	4	9

TRIBAL

Members*								
TOTAL	19	8	10	3	4	1	3	49

Some on the project team have joint positions as commissioners or providers as well. They have not been double counted.

1.2 Patient Profile

1.2.1 Table 2 below provides a brief profile of the patients who were interviewed. Their practices are not included so as to preserve anonymity.

Table 2: Patient Profile

Number	Medium	Gender	Ethnicity
1	Telephone	Female	?
2	Telephone	Female	White British
3	Face-to-face	Female	White British
4	Face-to-face	Male	BME
5	Face-to-face	Female	White British
7	Face-to-face	Male	BME
8	Face-to-face	Male	White British
9	Face-to-face	Female	BME
10	Face-to-face	Male	White British
11	Face-to-face	Male	BME
12	Face-to-face	Male	White British
13	Face-to-face with wife and advocate	Male	BME
14	Face-to-face with advocate	Male	BME
15	Face-to-face with advocate	Female	BME
16	Face-to-face	Male	White British
17	Face-to-face	Female	White British
18	Face-to-face	Female	BME
19	Focus Group	Female	BME
20	Focus Group	Female	BME

*P6 was a duplication and has been removed.

1.3 Recruiting Patients for Interviews/Focus Groups

1.3.1 We were not always successful in actually meeting up with interviewees who had agreed to be interviewed, or attracting patients to focus groups. In at least two practices, no interviewees turned up and no patients arrived at the second focus group.

1.3.2 One staff member said that *‘they won’t commit to coming and talking to strangers.’* It was also said that they would have been happier to come and speak to us if they had been

accompanied by the Diabetes Nurse or the GP, which would have compromised the object and certainly defeated the confidentiality necessary for the interview.

1.4 Year of Care at the Eight Practices

Tower

1.4.1 Patients are invited by letter for their blood tests which are taken by the HCA. They return later to the nurse to have their feet checked and a urine sample. The nurse fills in the YoC template. Results are then sent to the patients and they are invited for a 20-30 minute appointment with a doctor. They are given a letter with their agreed goals.

1.4.2 There are three full time GPs at this practice (plus a part time trainee). Two of the three doctors care plan for diabetes.

Stepney

1.4.3 Patients are recalled initially for blood tests. At that point, the HCA gives them a date for the first check up which may be 10 days or 2 weeks later. Results are not sent out because *'they say they never receive it, they don't read it or bring it in.'* The patients are given a print-off of the blood results when they return to see the HCA. Most patients return for a third time to the clinic for their review appointment though some, who may not return for their next appointment on a separate day, are seen after their appointment with the HCA.

1.4.4 The nurses do most of the consultations and refer to the GP in cases of complications. The colour coding on the blood results that the patients are given are considered very effective, particularly with those patients who are illiterate or cannot read English.

1.4.5 Patients come for check ups every 3-6 months, preferably 6 months where their bloods, medications and lifestyles are reviewed.

1.4.6 Stepney has a 'meet and greet' system whereby patients are spoken to in the waiting room to see if any queries or questions can be answered.

St Katherine's Dock

1.4.7 This is a single GP practice. *'We've been doing YoC for 15 years'*. A letter with blood results has been sent to patients for the past 15 years. Patients are given 6 appointments per annum; 2 with GP, 2 with Practice Nurse and 2 with HCA. They have 30 minutes with the GP and 45 with the Nurse. The GP handwrites notes on the blood results letter that gets sent to patients.

Jubilee Street

1.4.8 This practice has been doing YoC for 1.5 years. The patients are called in to see the HCA for bloods, to check feet and blood pressure. This is a 20 minute appointment. 2 weeks later they see a DSN of which there are two in the practice. They attend for a 40 minute appointment. On arrival at the appointment they are handed their results. They tried sending out results to patients before the appointment but they found that patients *'didn't receive it, forgot to bring it with them, didn't read it or couldn't understand it.'* This decision was made after a lot of discussion amongst the team which comprises 2 GPs, 1HCA, the Administrator, 2 Practice Nurses. They all meet once per month and discuss issues of concern for the diabetes team.. The patients are told in the letter that is sent to them before the appointment to come in 10-15 minutes early to read their pack.

- 1.4.9 The receptionists are told what is in the pack as they may need to speak about it to patients. Nurses spend a *'a long time going through the pack'*. Patients are given a page to write down anything they would like to discuss. They are told they may hand the paper in at any time at the receptionist during the week prior to their appointment or bring it in to their appointment. However, none has ever been received. After care planning, a lot of referrals are made to retinal screening, dieticians, and education via the administrator.

Whitechapel

- 1.4.10 Patients are called in for a blood test which then generates another appointment for them to collect their results. When they come to collect their results the next appointment is explained and they are asked to think about goals before this appointment. A nurse does care planning with the most straightforward cases and a doctor picks up the more complex cases. There was a diabetes specialist nurse but she is on long term sick leave. Her focus was working with patients on insulin. A diabetes dietician comes to the surgery once a month. The 2 HCAs do all the tests and checks.
- 1.4.11 In this practice, blood results are not sent out to all patients. The doctors and nurses make a clinical decision as to what goes out or not. Very often there is an influx of worried calls when results have been sent out. Patients see a HCA and then a nurse or a GP if there are complications or if they are insulin dependent.
- 1.4.12 An interesting aspect of this practice is that it attracts people to sit in the waiting room and treat it almost like a social centre. *'We want to move more towards being a centre of excellence than a coffee shop. Patients said, are you going to get a coffee machine here?'* They are planning to make it more clinical looking so that it is *'safe and friendly but fit for purpose'*.
- 1.4.13 A large number of their patients come in around 20 times per year. *'We're trying to reduce demand. It has a huge impact on access. A patient advisor is starting. They will be the first port of call, to identify needs and education.'*
- 1.4.14 Appointment times are: 10 minutes for bloods, 30 minutes for HCA, 30 minutes for care planning and 20 minutes follow up review after 6 months.

Wapping

- 1.4.15 All the annual reviews are undertaken in the first 6 months of the year and the second half of year deals with follow-ups. Blood results are sent out prior to the appointment. The patient population in Wapping tends to be literate and English speaking. The GP tends to see the patient after the Practice Nurse.

Brayford Square

- 1.4.16 They used to do bloods in hospital and patients received the results at the start of the consultation. Results are now available for patients to pick up two weeks before their appointment. Appointments are half an hour per patient and they are carried out by the nurse. The patients are seen by the doctor if their medication needs changing. If the GP sees them they will go through their care plan.
- 1.4.17 Patients come for follow up after 6 months. Everything is done through phone calls rather than letters in this practice.
- 1.4.18 90% of patients are Bengali and information is written for them about the appointment. They are asked to get help from their families or a health advocate to explain the processes. They are trying hard to reduce the problem of DNAs.

East One

1.4.19 Results are planned to be given before the consultation but may be given only during the appointment. Patients are asked to pick their results up prior to the appointment but some do not do this. This practice has moved from being salaried GPs to a partnership and they have to increase access hours. Care planning is done by the nurse and GPs as there are insufficient nurses to undertake it. A care plan is given to the patients at the end of the session.

Table 3: Summary of Year of Care at the Eight Practices

Step/Activity	East One	Wapping	Stepney	Jubilee St	Whitechapel	Tower	Brayford Sq	St Katherine's Dock
Results sent before appointment	no	yes	no	no	collect results	yes	collect results	yes
Consultation - goal setting	yes	yes	yes	yes	Yes	yes	yes	yes
- written care plan	yes	yes	yes	yes	Yes	yes	yes	verbal
- partnership working	yes	yes	yes	yes	Yes	yes	yes	yes
- engagement	yes	yes	yes	yes	Yes		yes	yes
IT	PCS		LV		LV	PCS	LV	LV
Additional comments			Meet and greet					Single practice

2 Networks

- 2.1.1 The big change in Tower Hamlets is the introduction of networks which will be similar to polyclinics in size and comprise anything from 3 to 5 practices in localities. Commissioning will take place across the network rather than individual practices. Funding will be undertaken through the introduction of 'care packages' which will be based on the typical package of care needed for the area. The networks will not require new buildings, they just need *'infrastructure and capacity.'* (PB 6) It works on the principle of *'cooptition – competition and co-operation.'*
- 2.1.2 Responsibility for the efficient and effective running of diabetes care delivery in the locality will lie at the network level. *'..total responsibility not only for how they perform but also how the practice down the road performs.... Money goes to practices, but if the network fails, money gets taken back.'* (PB 6) The principles derive from the belief that money and peer pressure have an inordinate impact on clinical change behaviour.
- 2.1.3 Networks are able to employ or buy in specialist input. *'To maximise money for the network, they need to buy in only what is needed.'* (PB 6)
- 2.1.4 All networks have to adopt care planning through the YoC approach and the same documentation will be used. The first wave of networks went live on 1 September 2009; the second will do so in December 2009 and the third in April 2010. The networks were devised through a McKinsey consultation and there is a suggestion that the networks are considered to be insufficiently patient focused.
- 2.1.5 *'We want to get funding from the DH to pilot one of the networks in creating a culture that enables patients to self care.'* (PB 1)

2.2 Responses to Networks by Healthcare Professionals: Positive

- 2.2.1 There is a diversion of opinion concerning networks in the area, with some enthusiastic and positive and others dubious or antagonistic. One nurse was very positive; *'It's a good thing. We can speak to other surgeries and find out what good things they're doing that we can incorporate. We can share ideas and information.'* (N3).
- 2.2.2 *'Year of Care has brought diabetes out as something we have to tackle. With the new networks that are forming I want to be a GP with special interest in diabetes. The networks will allow a group of practices to work together and look at their short comings – we may for example decide to employ a diabetic nurse across the practices. This approach will give us a chance to share learning across practices and to compare how we do things.'* (GP1)
- 2.2.3 *'It would work if we had a hub and spoke model with secondary care at the hub.'* (GP4)
- 2.2.4 *'It will enable us to share financial rewards, and to share standardisation.'* (PM1)
- 2.2.5 *'It would be useful to get retinopathy in the area. But we don't need a network to do that.'* (N5)
- 2.2.6 *'I understand that with the networks care will be more centralised. There may be extra staff – for example there may be a diabetic nurse for care planning and management. There is a lot of admin with YoC. With YoC within the networks we have types of diabetic patient and we have criteria relating to appointment for each type of patient. We will use the YoC template in the network package. With year of care there is one route for all patients – they have their tests, get their results and have their care planning appointment. With the network YoC is slightly different. There are different routes for different types of patient. The main difference is the frequency of the review depending on*

the patient type. We will still do care planning in the same way and use the same documentation.' (GP5)

2.2.7 *'We are a small practice and our patients don't like going to new places and seeing different people. The networks look to streamline services, to share education and information and to influence commissioning.'* (GP8)

2.3 Responses to Networks by Healthcare Professionals: Negative or Concerned

2.3.1 *'It's just another layer of bureaucracy. We have a practice manager. Why have a super practice manager. It's a waste of £120,000.'* (GP4)

2.3.2 *'There is a suggestion to do a care plan. I don't do it, it's more verbal. But it will have to be implemented for the network. Our HbA1cs are proof that we're working well. What we're doing is fine. 95% are under 9. I can't see anymore to be achieved by the networks.... We have the best results. We'll be in a group with practices who don't have good results.'* (GP4)

2.3.3 *'Useful if it's implemented in an agreeable manner. My concern is that it's sucking lots of time away from people and the problem is the amount of time people are dragged away from activities.'* (GP3)

2.3.4 *'My patients may be told by the Network Manager to go to a different practice. It totally destroys continuity of care.'* (GP4)

2.3.5 *'There is a problem with practices working together. There's a worry about practices with poorly controlled diabetes patients pulling the network down.'* (N4)

2.3.6 *'We all want to maintain our own patients in our own practices.'* (N5)

2.3.7 *'I don't see the point of networks other than money for GPs.'* (N5)

2.3.8 *'How will it work for the hospital? Will the network become a cottage hospital that they got rid of?'* (N5)

2.3.9 *'There will be a diabetes nurse for each network so taking diabetes care away from the practice nurse. That's the main thing I devote myself to, giving really good care. ..They won't be able to recruit 8 diabetes nurses. It's a backward step for practice nurses because they're going to take it away. Where does it leave the practice nurses?'* (N6)

2.3.10 *'Not all networks are getting on. You have to build trust.'* (PM1)

2.4 Challenges: Scrutiny

2.4.1 *'The potential is that you could end up with a different care service in each network. .. There is no way of consistency checking or competency checking.... Need on-going patient feedback, audit of what people say they're doing they are doing, competency assess staff, review of consultation process. Need examples of care plans and quality check them. We need a mechanism for checking. Also the patient's experience, the patient's outcome, whether the staff still have competencies and they have not fallen into bad habits. We don't have robust mechanisms – only if there is serious error or a serious incident.'* (PB 7)

2.5 Patients' Perspectives on Networks

- 2.5.1 Only two patients made comments about the networks, both of whom were from the same practice.
- 2.5.2 *'I am worried about the networks. I don't want to be traipsing off to other practices to get results. This would be awkward for the patients here – not so convenient so more like a reduction in service than an improvement. I thought this practice would work out expensive because of only having one GP but when I looked at the figures they showed that it isn't. I won't be happy if we have to go to other practices for things. We have always had our blood checks done here. There may be some good things with the networks. Things like access to dieticians, local podiatry and the opportunity for group work could all be terrific advantages. At the moment there are very long waiting lists for podiatry unless you have a serious problem.'* (P5)
- 2.5.3 *'I am aware of the proposals for the networks and I am worried about the lack of consistency that they would bring. I would not necessarily see a doctor who knows me. With a long term condition I think it is important that the doctor has personal knowledge of the individual and can see them as a whole person. For example my doctor takes account of other things that are going on for me – such as a bereavement and problems with my son. He is aware of these things and we have amended my targets accordingly. He sees my family members too so has a holistic approach to the whole family.'* (P8)
- 2.5.4 *'What happens when records aren't collated? Something might get missed.... One HCP must have an overview of everything.'* (P5)

3 Understanding of Year of Care

3.1.1 Comments reflecting healthcare professionals understanding of Year of Care are shown in Table 4 below.

Table 4: Comments Reflecting Understanding of Year of Care according to Disciplines

Discipline	Comment
GP	<ul style="list-style-type: none"> • It's about having all the checks done within the year. It is also about involving the patient. • It's the whole package, not just diabetes itself, it's everything. • Programme with the purpose to improve healthcare awareness and general awareness of diabetes patients. • Improve patient's self management of diabetes. Help them be more aware of what they can do to improve. • It's about trying to empower them and get them to think of ways of managing their condition. • It's about diabetes care and involving patients more with their illness. • Its about improving diabetic care and about the patient taking ownership. Care planning is about looking at the whole picture, how the patient understands things and how they can help themselves. • Improving clinical care through a multi disciplinary team. Help and educate the patient to manage their own condition and improve their clinical outcomes
Practice Nurse / Nurse Practitioner	<ul style="list-style-type: none"> • The whole person is looked after rather than the disease.. They may bring in housing, financial situation. Worries may affect diabetes. • To see how we can empower the patients to look after themselves and manage their diabetes as much as they can. • It's giving information to those who are diabetic to encourage them to care for themselves, be up to date and improve their care and may be take control of their diabetes. • It's a way to get diabetic patients involved in their own care so they have ownership. In theory the patient makes the decision but normally this is something you get to together. • Empowering patients to manage their own condition. Helping support them looking at their results and then finding a way in

	<p>which they think they can improve the control of their diabetes.</p> <ul style="list-style-type: none"> • Instead of haphazard hit and miss, care planning takes place in a particular way and tries to look ahead for the whole year and think proactively. • Its about care planning and getting the patient more and more involved
Healthcare Assistant	<ul style="list-style-type: none"> • Giving the best care to patients with diabetes. • First part of the diabetes annual review to check bloods, bp, BMI. • The patient is involved in their own care and makes choices about what they want to focus on. Its about self management and patients having more involvement in the process.
Practice Manager	<ul style="list-style-type: none"> • Change the way we manage patients with diabetes, to empower them to take ownership and responsibility but ultimately to understand what diabetes is about and how they can help themselves.
Administrator	<ul style="list-style-type: none"> • Better care planning for patients. More consistency in appointments for patients. More personalised approach.
Commissioner	<ul style="list-style-type: none"> • A benchmarking exercise looking at where you are now and where you want to be. • Planning care for patients for the following year. Putting them in the driving seat. Working in partnership. Setting goals and targets for the following year. Self managing. Patient agenda more than practitioner agenda.

3.2 Patients’ Understanding of Year of Care: Have heard of it

3.2.1 The comments below reflect the understanding that patients have of Year of Care.

- *‘It’s a scheme changing the way diabetes care is delivered. The main aspect is a patient education programme leading to empowerment to take greater day to day control. It is a cost saving activity for patients to take greater responsibility but it is for patients’ benefits as well.’ (P3)*
- *‘It’s about having a more structured approach – to ensure that all the things that should be done are done to optimize the health of patients with diabetes. Important aspects are involving patients much more and care planning.’ (P5)*
- *‘I have heard of it. It’s good that they listen to you and I am more aware of things. I am able to check on myself and see how I am doing. It’s good to be able to compare results with the previous year’s results.’ (P11)*
- *‘It about the check up I have every six months’. (P12)*
- *‘It’s about you managing your diabetes – I have had a booklet.’ (P14)*

- *'I have heard about it. Its about monitoring my progress and about controlling my medication.'* (P18)

3.3 Patients' Understanding of Year of Care: Unsure

3.3.1 These comments show an uncertainty of the term.

- *'I have heard of it. I think it's a diabetes initiative but I'm not really sure.'* (P8)
- *'I think it was mentioned but not explained.'* (P10)
- *'I have heard of YOC – not sure what about. Something about what to do year to year.'* (P19)

3.4 Patients' Understanding of Year of Care: Haven't heard of it

3.4.1 These patients are not familiar with the term.

- *'Not heard of it. I go to the hospital as well as my GP for managing my diabetes but I haven't heard this term used.'* (P1)
- *'I haven't heard of it but I do have a folder.'* (P4)
- *'I haven't heard of it but I do have a pack.'* (P6)
- *'Not heard of it'* (P9, P16, P17)
- *'I have an annual check but I have not heard of Year of care.'* (P13)
- *'I am not familiar with the term but I do know about the review.'* (P15)
- Changed Roles

4 Changes to Roles

4.1 Changes to GPs' Roles

- 4.1.1 *'It has given a more structured, planned approach to diabetes. Year of Care enables us to present the approach to patients as something we do and I think this has enabled us to reach more patients. We now see them in a structured way and call them back – to patients it looks like we know what we are doing.'* (GP1)
- 4.1.2 *'I give more advice which is good. Prevention is better than cure.'* (GP2)
- 4.1.3 *'The workload has massively increased but we have absorbed it by staff morale.'* (GP3)
- 4.1.4 *'We have used the YoC as a template for other care packages.'* (GP5)
- 4.1.5 *'Working in this way has resulted in a shift with other patients. We are more focused on what they want to do and give them options and choices.'* (GP5)
- 4.1.6 *'No dramatic change for me – the changes are more for the nurses – things for them have changed clearly and significantly. I have always tried to involve the patient as much as possible so the approach is not a big shift for me and I am not doing the care planning directly.'* (GP6)

4.2 Changes to Nurses' Roles

- 4.2.1 *'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.'* (N1)
- 4.2.2 *A nurse was dismissive of the effect it has had on doctors' roles. 'In this surgery it is just nurses who do it. It would be good to get doctors involved. Nurses have embraced it.'* (N1)
- 4.2.3 *'I'm having to spend more time with patients, having to look at them more holistically. When you deal with patients you begin to understand them more. Before, bah bah bah you've finished. Now sitting a long time with them, talking through lots of issues, goals, objectives, what they can do for themselves.'* (N2)
- 4.2.4 *'My role is supposed to be nurse practitioner and nurse lead, but it has become that of a DSN. I've always done it but maybe not in a formulated way. I've always shared and said how do you think you can affect your HbA1c. Is all that time spent writing it down anymore valuable than the oral conversation we've had?'* (N5)
- 4.2.5 *'Before the GP was doing the review. Now I do the review. But the GPs think they should see them after me. If I see them and then they see the GP, I'm not doing care planning.'* (N6)
- 4.2.6 *'Care planning has made me look at patients differently. I focus less on the disease and take a more holistic perspective. For example if someone has arthritis there is no point referring them for more exercise. It's a lot more for me. I have to invest more time with the patients but it will get easier with time as people get more used to it.'* (N7)

4.3 Changes to Other Healthcare Professionals' Roles

- 4.3.1 *'Before my job was simpler. Now I have more responsibilities. It's ok but I am afraid at times in case I miss something about the feet... We have more to do. We've taken over*

lots of the nursing work. I like it but it's a shame that the wages don't go up. I've taken on more responsibility but the wages stay the same.' (HCA1)

4.3.2 *'Much more focus on making sure all patients come in for tests and checks than before.'* (HCA3)

5 Patient Involvement in Year of Care

- 5.1.1 This is an aspect that is rather advanced in Tower Hamlets. An Associate Director for Patient Involvement is a member of the Project Steering Group. A large number of events have taken place and much thought is put in to improving and making events more accessible and meaningful.
- 5.1.2 *'We have done a lot of patient events – YoC has been a good opportunity to speak to patients. – asking people what they need to stay healthy. Bengali women said that they wanted swimming – they wouldn't go to the women only session because the lifeguards were male – we have had to change this. We have learnt more about how to convey culturally sensitive messages about portion control.'* (PB 1)
- 5.1.3 *'We have had useful patient engagement .. and very useful material from those events. We had specific events looking at documentation. We pulled in a group of patients to work on documentation, particularly care planning outputs. We're still learning about techniques. We have a lot more to learn. We're better at doing patient events.'* (PB 3)
- 5.1.4 *'It's been easy to involve them but what do we do as a result?'* (PB 4)
- 5.1.5 *'We've had several events... The hook is, come in and tell us what your diabetes care is about. What can we do to change things? How shall we organise patient education? What extra help do you want to manage your diabetes? How would you like to have your diabetes tests fed back to you? These were in 2008 and it led to the folder and training for staff. The result of the events is the folder, colours,, training for staff on how to administer work round YoC, investment in practices round staff training. It led to a catalyst of change.'* (PB 4)
- 5.1.6 *'I went to a conference – the PCT paid for me to go – it was run by Diabetes UK I think and/or maybe the Department of Health.'* (P3)
- 5.1.7 *'I came to a meeting at the surgery to talk about diabetes. I found it hard to understand. They gave out some paper and talked – I was not clear why I was there.'* (P14)

6 Organisational Changes since Year of Care

- 6.1.1 There has been an impact on the organisational arrangements in practices since Year of Care began.
- 6.1.2 *'The recall system forcers or encourages them a bit. If they think I don't want to go, (the Administrator) will offer another appointment. If there's a patient I'm worried about, I'll phone them up myself.'* (N4)
- 6.1.3 *'Initially it was isolated, just one doctor. I was surprised it wasn't shared amongst more people. They weren't involved but everyone needed to know. What would happen if the one person who does it leaves.'* (PM1)
- 6.1.4 *'Getting systems to change is difficult. Just getting admin to do what you want.. I'm not in control of them and being new is not easy. ...Here I haven't got the influence. It's very frustrating.'* (N6)
- 6.1.5 *'When people come for the review and I then send them to the HCA for bloods and he says, no, it's not necessary.'* (N6)

7 Care Planning: Results

7.1 Results Forms

- 7.1.1 This section presents the views of healthcare professionals on results forms. Tower Hamlets makes use of folders with clear representations of different results, colour coded according to the traffic light system.
- 7.1.2 *'We show them their test results graphically.'* (GP1)
- 7.1.3 *'We use a different care plan here which is simplified and has pictures. The documents that have come through from the PCT don't work well with our patient population (mainly BME). The PCT want us to use their care plan template but we don't think it will work well with our patients and we are not happy about this. We want to continue with our version which uses simpler language.'* (HCA3)
- 7.1.4 *'We're not providing a detailed letter. But there is a folder with diabetes information in it.'* (GP4)
- 7.1.5 *'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)
- 7.1.6 *'If they have a letter saying please see the practice nurse, they think, I must go see the GP. Sending letters isn't helpful. They do like it in the end. It's a transition.'* (N6)

7.2 Patients' Positive Views on Receiving Results

- 7.2.1 *'I got my results before the appointment but this practice has done this for the last six or seven years. I do find it helpful to have them before the appointment – it helps me make an agenda. I think now it tends to be more focused on my agenda than it used to be. I find that having the results before means that I don't waste time absorbing the results in the doctor's appointment.'* (P5)
- 7.2.2 *'I did get the pack and I got my results before the appointment. It gives you the opportunity to discuss things in more detail. The doctor gave me pointers and I had last year's results to make comparisons which was very helpful.'* (P8)
- 7.2.3 *'You do get your results but after your appointment. It's helpful and keeps you informed about your condition. They are easy to understand. It tells you how your results rate and what you should be aiming for. It could be a good thing to get your results beforehand but it could be daunting for certain people. I might start looking things up before the appointment – for me this would be a good thing as I think I would have more questions. For some people it might be frightening.'* (P10)
- 7.2.4 *'I come in for tests and then results – for the last two years I have been called in twice a year. I am called in to pick up my results and after than I get an appointment. It's good to have the results before the appointment so that I can think about things. The results are easy to understand. My wife is English and helps with the results and also sometimes comes to appointments with me. I am not sure that I was given a menu of services.'* (P11)

7.3 Patients' Ambivalent Views on Receiving Results

- 7.3.1 *'In the past I hated getting blood results in advance. It was the wording on the letter (not YoC letter). The attitude was, things have got to change. They still use the same letter. They haven't changed the wording. They should use colour but they don't.'* (P3)

7.3.2 *'I had a review a month ago. I had the pack before my appointment but I didn't read it. I get worried easily and I don't like to be left worrying about things. The nurse discussed it all at the appointment – she went through the results and explained everything.'* (P9)

7.3.3 *'I had my review about 5 months ago and I did have some results before the appointment. Some came through before and I got some on the day of the appointment. I did get my own copy of the results. I used the interpretation service here and my daughter to help me understand them. It would be helpful to have it translated.'* (P15)

7.3.4 *'Don't find it helpful. 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)

7.4 Patients' Views: Results Received Immediately Before Appointment

7.4.1 *'The folder had information about my weight and other results. They gave it to me when I came for my annual review. It would be better to get the results before the appointment so that I could think about what to ask.'* (P4)

7.4.2 *'I had a pack. I got it on the day of my appointment. They asked me to come in 10 minutes before my appointment to pick it up and look through it. It's better than having to phone up for the results. The results were clear and easy to understand.'* (P12)

7.4.3 *'I get information before my annual review. It helps me to understand what is going on. I get the results immediately before my review it would be better if they could be sent home before the review so that I could look at it with my family.'* (P14)

7.4.4 *'I had a pack before my annual review – I think I was given it on the day when I turned up. It had a record of my readings. It would have been handy to have this sent before the appointment but the nurse went through it with me so it was ok. I don't remember getting a menu of options. The pack is good – the results are easy to read and understand.'* (P16)

7.4.5 *'I got a folder when I came in for my review. It had last year's test results so that I could compare with this year's results. I wouldn't want the results before the appointment – if they were ok I think that I wouldn't come in! I would come in if they weren't ok though. I find the results a bit confusing and would struggle to understand them if they were sent through the post before.'* (P18)

7.4.6 *'I did get the results but sometimes it is difficult to understand them. I was given the results when I went for the appointment.'* (P20)

7.5 Patients' Views: No Results Received

7.5.1 *'I've not had any information. I haven't received a folder or any information with my results or leaflets. I do remember filling a questionnaire out after my consultation but I haven't been sent any information. When I have tests taken I go to the hospital to get my results and they try to explain what they mean. I haven't been sent my results before an appointment.'* (P1) This is an example of a patient's response to the issue of receiving information and blood results in a practice where this is routinely undertaken.

- 7.5.2 *'I wouldn't want the results ahead of my appointment.'* (P7)
- 7.5.3 *'I think I have a pack but I have not looked at it that closely so I'm not sure what is in it. I don't think I had the results before my appointment. The nurse seemed to think they should have given it to me at reception when I came in but I used the touch screen rather than going to the desk. The nurse explained why I was supposed to get the results before the appointment when I saw her. It seems like a lot of extra work and bureaucracy both for me and for the practice. It is not necessary to get the results first.'* (P17)
- 7.5.4 In discussion with one of the Project Board on the reasons why some patients do not recognise or remember that they have received their blood results, the interviewee said; *'it depends on the personality, an elderly Type 2 might be confused. It needs to be less confusing by talking in simple language and by being upfront... Giving blood results has to be in context. It is part of the educational package... It needs to be personal to them.'* (PB 5)

8 Care Planning: Consultation

8.1 Healthcare Professionals' Perspectives

- 8.1.1 We tried to get a sense of how the consultation was run. This section presents views from healthcare professionals.
- 8.1.2 *'The emphasis in consultation has shifted from "should" to "could".. I bring up issues in the care planning and say what would happen if their weight went down or if their blood sugar came down.'* (GP1)
- 8.1.3 *'We give them the choice of what they'd like to do. This is where you are with weight, how will you be able to move it. If they want exercise, we will refer clients . They say, you are the nurse, you tell me. If we tell them, they won't. So we have to get them to say what they will do. To get them to take ownership. One of the training was good, how to get people to capitalise on what they say – they give a timeline. How long to get to where they want. Before we said we'll send them to exercise but now if they say they will go to exercise, they do go.'* (N1)
- 8.1.4 *'Time has made a big difference... Makes me feel I'm doing a lot more'. (N2)*
- 8.1.5 *'We keep badgering, eventually it sinks in. We give the same message over and over again.'* (GP4)
- 8.1.6 *'You have to be careful how you phrase things. I have a patient. The first time I met him to do part 2 he was very angry because the first thing was about his weight.. I'm sorry it upset you. .. Now he's fantastic, he comes in to all his appointments.'* (N4)
- 8.1.7 *'I've always tried to empower patient and always led them to believe it's their diabetes not mine and I'm here to support you. My consultations weren't hugely different.'* (N5)
- 8.1.8 *'I start off telling them what YoC is and why they've received a letter. Why they saw one person and now me. I say it's now your chance to say what you'd like and opt to improve your diabetes and health. Some do, others don't look at results. I ask what are their concerns and things to improve. Mostly it draws a blank. Most don't have goals. They say, you tell me, you should know.'* (N6)
- 8.1.9 *'I go through their results with them. I look at the changes over the last year. I ask them how they feel about this and what they think they should be doing. I have a rapport with them and ask them they would like to do. They do understand and this year it has been easier because we are comparing this year's results with last year's results. They are able to tell me what they feel they need to do. In the first year it was much harder going.'* (N7)
- 8.1.10 *'It is important to make patients understand the implications of their decisions and choices. The older generation often struggle with the process. They may find it hard to walk and be in pain – it can be difficult for them to exercise but there are things they can do with their diet.'* (GP7)
- 8.1.11 *'When I work with patients in these cases I ask them what they understand, if they have any concerns about their medication or any other pressing issues. I try and sort out the things that are important to them and then explain the results. I draw diagrams to help with this. I use the charts to illustrate where they are and what would be optimal for them. I ask them about their concerns and what they want.'* (GP8)

8.2 Patients' Views on Consultations: Positive Responses

- 8.2.1 Many of the comments focused on the amount of time, specifically that they felt they weren't rushed and they had enough time for their consultation.
- 8.2.2 *'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)
- 8.2.3 *'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)
- 8.2.4 *'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 dame 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)
- 8.2.5 *'There was plenty of time to talk and I can ask questions. I am happy with it. She changes my medication if necessary. It would be good to be invited to a review every six months rather than once a year. We talk about the food that I am eating and she talked to me about vitamin supplements. I put my trust in her. We have not really set targets.'* (P9)
- 8.2.6 *'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)
- 8.2.7 *'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)
- 8.2.8 *'We look at last year's results compared to this year. There is enough time – I don't have an interpreter but it is ok. It is good to see the results and to see how things are going. The nurse advises me and I do the best to control my own diabetes.'* (P14)
- 8.2.9 *'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)
- 8.2.10 *'I wrote down my own feelings at the end of the session. There was plenty of time – about 45 minutes – we were able to cover everything that I wanted to. She asked how I was feeling but she was in control. We discussed diet and control.'* (P16)

8.2.11 *'There was plenty of time and I didn't feel hurried. The session was alright. We just talked and I can't really remember who steered things. It felt like the nurse was driving things but I can't really remember. I don't always see the same nurse when I come in but it's not a problem. The nurses are all very nice. I have not really asked them much but I think they would explain things if I asked them to – I would know where to go' (P17)*

8.2.12 *'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)

8.2.13 When asked if the patient feels they own the condition, the patient said, *'I prefer to manage it. The PN supports it. I am always 'fighting' with the doctor. the young lady doctor senses if I have a problem and is intuitive. 'Men cannot communicate'. He makes recommendations without discussing it and tells me what to do. The PN and lady doctor discuss and I prefer that approach'.* (P19)

8.3 Patients' Views on Consultations: Ambivalent Responses

8.3.1 *'The sessions are pretty good. Sometimes I want to ask questions but I don't like to bother the doctor. Sometimes I do ask him things but he is a very busy man. I know that you should try and help yourself. We do talk about a target to lose weight – but not a specific amount'.* (P10)

8.3.2 *'I have had diabetes for 5 years but only lived in the area for 2 years. I haven't noticed any difference to the way things are done with my annual review – only that my medication has changed. The review took 20 minutes and that was enough time to get through everything I needed to talk about. I didn't have an interpreter – it would have been good to have some language support. It went ok and I was asked about my health – I discussed what I wanted to do and what was important to me. It was a two way thing and I was able to raise my problems. We talked about exercise and diet and agreed some changes to my diet.'* (P13)

8.3.3 *'I am trying to do what I am told, which is not always easy. The nurse explains more and more but sometimes it is difficult to understand.'* (P20)

8.4 Patients' Views on Consultations: Negative Responses

8.4.1 *'I find the idea to be a nightmare. The things I want to achieve are impossible – I want my blood sugar to be lower than it is. I suppose I could try and lose weight through weight watchers. I am a former nurse – I have a real anxiety that if I find it hard other people won't be able to cope. Some people want the doctor to tell them what to do and it is a huge leap. I worry that people will fall between stools – the doctor will think that they are doing things for themselves when they are not and there could be a lack of clarity.'* (P5)

8.5 What was Achieved

8.5.1 *'I feel a bit more informed and get some comfort from the session. I know that if I had a problem they would be there for me. It's very hard to control diabetes yourself.'* (P 1)

8.5.2 *'I am able to have a full discussion about all my health needs. Allows me to think about what I need to do.'* (P5)

8.5.3 *'I achieve a lot – I have become very conscious of what I eat and do more exercise. I started going to the gym to lose weight'* (P7)

8.5.4 *'Each time I get a greater understanding of my condition and understand more about how I can go about maintaining and improving it'.* (P8)

- 8.5.5 *'I talked to her – asked questions and she answered them. I am better informed.'* (P9)
- 8.5.6 *'I get a view on what has happened and what has changed since last year. It helps me think about what needs to be done. Some people don't think for themselves and want to be led but I am not like that.'* (P10)
- 8.5.7 *'I pick up points and think about things. It helps me think about different ways of doing things.'* (P12)
- 8.5.8 *'I have a better understanding of diabetes and how to care for it. I am able to discuss everything with the nurse in one go.'* (P14)
- 8.5.9 *'As a result of the information I was given I walk more and have lost weight. I have also changed my diet. The nurse has encouraged me to do these things.'* (P15)
- 8.5.10 *'Reduced readings. I understand more about my diabetes. It has helped me to help my brother in law who has been diagnosed.'* (P16)
- 8.5.11 *'More knowledge. I know that I am doing ok.'* (P18)

8.6 Identifying Needs

- 8.6.1 We tried to get a sense of whether the patients' needs are being identified during the consultations. Apart from one GP who said, *'There are only 3 dieticians in TH. They are understaffed.'* (GP4) the other comments are all from patients.
- 8.6.2 When asked if the needs were met, the patient said, *'Yes. I got what I wanted, a referral to the dietician. I had confirmation that all else was ok.'* (P3)
- 8.6.3 *'Absolutely – referral to chiropody has been helpful. I feel as if services are for other people not me – it has really helped that the doctor referred me. He has also referred me for retinal eye screening.'* (P8)
- 8.6.4 *'I saw a dietician – she was a very skinny girl who told me what I shouldn't eat. This didn't really work for me but since then the doctor has talked to me about diet and about colour coding of food and this has been helpful'* (P8)
- 8.6.5 *'Not really. I think this might apply more to younger people. Older people just want to focus on keeping well. I think that young people have different needs to older people in terms of diabetes.'* (P10)
- 8.6.6 *'It has offered me things that could help me such as exercise, information about food and diet. They asked me if I want to see a dietician but I don't want to go.'* (P11)
- 8.6.7 *'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 were culturally sensitive. They made a programme to suit me.'* (P15)
- 8.6.8 *'They have given me leaflets – mostly about services that could help and information about the condition. I have seen a dietician and a diabetes nurse specialist.'* (P16)
- 8.6.9 *'Yes. When I saw my sugar level I understood how it affects different things – this made me realise that I need to do things like keep active.'* (P18)

8.7 Identifying Needs: Ambivalent Responses

8.7.1 *'I used to talk to a diabetic nurse about what to eat. We don't cover this any more and it would be useful. We don't really talk about needs. I was feeling a bit depressed and she gave me a number to ring but I don't bother.'* (P9)

8.8 Options Offered

8.8.1 *'I'm not always offered options.The doctor recommended me for an exercise class.'* (P5)

8.8.2 *'I have linked up to Diabetes UK and get the magazine. The nurse suggested going to the gym which I did for a while but now I have a treadmill indoors. She also suggested walking - I have some information on walking groups but I haven't followed it up.'* (P7)

8.8.3 *'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)

8.8.4 *'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)

8.8.5 *'I access day care but this was not set up through my GP. I pick up information and they do discuss things with me. I went to a session on diabetic advice at the Jubilee practice –it was good.'* (P11)

8.8.6 *'We talked about services that I could take up but I don't want to use any of them.'* (P12)

8.8.7 *'We talked about exercise and diet. I was not offered any programmes but I am going back in 3 months for another review. If things get worse I will have to go on insulin – I don't think I have many options really.'* (P13)

8.8.8 *'I have been given options about my food to contain my diabetes – I have been given options of ways to control my condition and then I had to choose what would work for me'* (P14)

8.8.9 *'I was offered exercise classes and diabetes classes – I went to a female only group at the mosque and another at my day centre. It was useful and I learnt about what calories are in food and how much sugar is in food.'* (P15)

8.8.10 *'They offer services – the gym. I have been to a women's support group in the past – this was here at the surgery. This was very good and we went to the gym and swimming - would like these to start again.'* (P18)

8.9 Options Offered: Ambivalent Responses

8.9.1 *'They would have given me if there were options to be had. They've cut delivery of dietician services to the practice. The dietician is at Mile End hospital. I've opted to go to the foot clinic at Mile End hospital, but they don't feed back information to the practice.'* (P3)

8.9.2 *'Not really other than being offered support for depression. She hasn't really talked to me about things like exercise.'* (P9)

8.9.3 *"The hospital recommended statins which give Afro-Caribbean people problems. The hospital gave me a new one to try out (only 5 micro grams a day). I felt it wasn't enough.*

I was referred back to the diabetes nurse. The diabetes nurse suggested Benecol and we talked about different options. My experience with the doctor was not collaborative but it was with the nurse.’ (P19)

8.10 Things that could have been different

8.10.1 *‘Everything was clear but it would have been easier with an interpreter. I am not normally offered this at the doctors but it does help.’ (P13)*

8.11 Motivation and Empowerment

8.11.1 *‘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.’ (P5)*

8.11.2 *‘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)*

9 Care Planning: Goal Setting

9.1 Healthcare Professionals' Perspectives

- 9.1.1 *'I try to set specific goals and things that they can achieve rather than big broad goals that are unrealistic. It is important to identify goals that the patient finds acceptable. The goal setting mainly comes from us – patients have a very hazy idea of how diabetes works. If you ask them about goals they generally say they want to lose weight and come off their tablets..... .Care plan is a shared task. It is a cooperative task. We show them that it is within their power to make changes. However some things are harder for them to control than others.'* (GP1)
- 9.1.2 *'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)
- 9.1.3 *'Getting the patient to plan taught us how to deal with other problems, not just diabetes.'* (N1)
- 9.1.4 *'Sometimes it's really difficult. You can spend 15 minutes waiting for them to say what they are going to do. With interpreters it's very difficult.'* (N2)
- 9.1.5 *'I ask them, what you think you'll be able to do from what we've discussed'.* (N3)
- 9.1.6 *'I get a feeling early on. A patient doesn't want to change. It's his choice.'* (N4)
- 9.1.7 *'If someone's well controlled it's hard to get goals... I try not to put things in their mouth. Have you thought about losing weight? Or, it's well controlled, good, keep it that way.'* (N6)
- 9.1.8 When asked if they get patients to write the goals themselves, the nurse said, *'They don't think of concerns themselves.'* (N6)
- 9.1.9 *'With the goal setting I gauge it to see what is realistic in both the short and long term. It tends to be driven by them – there is not point in setting goals that they don't think they can achieve. Its about what is important to them.'* (GP8)

9.2 Patients' Perspectives: Positive Reactions

- 9.2.1 *'She asks me what I think of the results and we set goals. Mine was to lose weight. She did suggest that I might want to lose weight. I also had a target to keep my blood sugar down and to keep my eye appointment. I do a lot to manage my own condition – the hospital is the hardest place to manage it because there are often long waits.'* (P4)
- 9.2.2 *'The nurse gave me a target that I have to lose weight. She is very good, Very caring. I would rather see the nurse than the doctor. I spent plenty of time with her in my annual review. She tests my blood and goes on the computer. She tells me to stop smoking and drinking. I decided I needed to do this but she helps me by giving me lots of information. I set a goal to reduce the size of my waist.'* (P7)
- 9.2.3 *'He is very good. He uses the term care planning in the session. I do have goals especially around fitness, exercise and diet. They have been effective. The doctor realises the need to negotiate with me when we are setting goals. Goals are about improvement – such as bringing down cholesterol. He makes the goals realistic. He is aware of my lifestyle and helps to set goals that will fit around my lifestyle.'* (P8)

- 9.2.4 *'I am already doing what I need to so there is nothing I need to change so we didn't set any goals in the session. I did set some goals on a course that I went on but that was about two years ago.'* (P12)
- 9.2.5 *'We discuss my priorities in the session. We did talk about goals and targets. We set a goal to bring my blood sugar level down – it felt like a joint goal between me and the nurse – she advised me and I felt that I needed to do it. She is ok – she explains thing in a way that I can understand.'* (P14)
- 9.2.6 *'We did set goals about weight loss, increase in exercise and to consume less rice. The goals are my goals – I want to be well.'* (P15)
- 9.2.7 *'We did set goals and it was a joint thing – she told me what goal I should aim for. I felt some I couldn't achieve and some would be hard for me. They all went down on the list but that was OK as it has given me something to aim for. In the last couple of years I have got better control of my diabetes – my diet has improved.'* (P16)
- 9.2.8 *'I did set goals to reduce my weight and to control my diabetes. I consider them to be my goals – the nurse asked me what I want to achieve and by when – I chose the goals and have lost some weight already.'* (P18)

9.3 Patients' Perspectives: Ambivalent Responses

- 9.3.1 *'We didn't talk about goals – they just tell me how I am progressing. They tell me what I should be doing to control my diet. I do take my blood regularly and keep a record of the results.'* (P1) The lack of a shared perspective on what goal setting looks like is stark in this response which varies from that of a HCP in the same practice.
- 9.3.2 *'I used to go to hospital before surgery opened a clinic. I went on a course. I had an annual review at the hospital. The Nurse gave me books and a care plan with goals and what I want to achieved. I haven't had anything similar at the GP surgery – there doesn't seem to be time. Perhaps I haven't had one as I have fought hard to achieve my goals.'* (P19)

9.4 Patients' Perspectives: Negative Reactions to the Concept of Goal Setting

- 9.4.1 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)
- 9.4.2 *'I can't remember if I set any targets – I'm not really a target sort of a person. It would annoy me. I wouldn't want to hear that [that targets were going to be set] to be honest.'* (P17)

9.5 Confidence Rates

- 9.5.1 Patients are asked to rate how confident they are in achieving their goals.
- 9.5.2 *'When you put people on the spot they will say what they will do. But I'm not sure this happens.'* (N1)
- 9.5.3 *'Confidence rating is quite difficult. If you ask me to do one I wouldn't be able to. I need something visual. I sometimes draw a ladder. Where are you on the ladder.'* (N5)

9.6 Written Care Plans: Received

- 9.6.1 We wanted to get a sense of what patients do with their written care plans.
- 9.6.2 *'They bring it back with coffee stains so they are reading it.'* (N1)
- 9.6.3 *'Yes – it was very helpful. I have kept it in the folder and I do look at it.'* (P7)
- 9.6.4 *'I do have a written plan and I do find it helpful. It is useful to guilt trip yourself and to help you remember. I also find that it is good to show my wife as it affects both of our lifestyles.'* (P8)
- 9.6.5 *'Yes – it's good to look back at it. I do use it.'* (P11)
- 9.6.6 *'Yes I did get a plan and a diet sheet. It was helpful and I have used the diet sheet – it's the kind of thing that you can pick up and choose things from.'* (P12)
- 9.6.7 *'I did get a plan and it was helpful. I refer back to it as I work towards my goals. My readings are coming down and I feel as if I am achieving something. I reduced my insulin at the last review.'* (P16)
- 9.6.8 *'Yes it was helpful. I have something in writing that I can go back to. I do look at it from time to time.'* (P18)

9.7 Written Care Plans: Unsure

- 9.7.1 *'I think it may be in my pack – I don't know because I haven't looked at it.'* (P9)
- 9.7.2 *'I don't know – I wouldn't keep anything with goals and targets because it would annoy me. I might have had a letter in the pack but I have not really looked at it.'* (P17)

9.8 Written Care Plans: Not Received

- 9.8.1 When asked if the patient had received a care plan – *'Don't think so'* (P4)
- 9.8.2 *'Don't get a written plan at the moment but I do make my own notes.'* (P5)
- 9.8.3 *'No but I don't think it would help me although I wouldn't dismiss it. It's not a bad idea for some people.'* (P10)
- 9.8.4 *'No but did get other information like the diet sheet.'* (P15)

10 Staff Training

10.1 Training Received

- 10.1.1 *'I went to the training run by Rosie. I went to two sessions and the health care assistant and nurse from this practice also went. The training explained the principles of Year of Care and also covered coordinating care, involving patients, organising appointments. It explained how everyone benefits from a better understanding of diabetes.'* (GP1)
- 10.1.2 *'I've been to a lunch time meeting. By the time I finish my session, I finish at 1 or 1.30. I try to join. They're very good. If only I could finish in time and go there regularly. I'd like to get to more.'* (GP2)
- 10.1.3 *'I've had two lots of training, both times with the national team. The first time I didn't know anything. I was very negative, I was a disbeliever. I didn't think it would work with my patients. We embraced it. HCAs also trained. I was negative about HCAs doing foot work. But I was wrong and we really embraced it. We did all our patients, over 500!'* (N6)
- 10.1.4 *'I have had training to do the foot checks. I have been on a one day training on care planning – the concept was a bit new to me but made sense – the training was fun and sufficient for my needs before I starting delivering things to patients. I have also been involved in delivering the HAMLET training – I did this on secondment for a while.'* (HCA3)

10.2 Responses to Training

- 10.2.1 *'The first lot was just knowing about the need to look at the person and not the diabetes. We thought we were doing it but then realised we're missing all the social aspects of the patient... We met other groups and heard how they're managing. We were struggling with how to bring patients back so we could learn from them.'* (N1)
- 10.2.2 *'I liked the training. It was good to meet other people and I learnt a lot. I felt I had a better understanding of Year of Care at the end of the training.'* (GP1)
- 10.2.3 *'We've had lots of training. We had a very good overview of what's happening in a study group with doctors and nurses organised by Anne. First training was foot check at Mile End. It was very good. Had practical training.'* (HCA2)
- 10.2.4 *'I went on the Rosie Walker training. I think it would have been better to have a bit of an introduction then get us started and then have more training. It would have been more meaningful that way. The PCT has organised further training on care planning which was useful – they also run share and learn events every three months for the pilot practices. I am going on a care planning update – more information is useful. I'm not sure if what we are doing is right – no-one tells us if there is a right or a wrong way of doing things.'* (N7)
- 10.2.5 A Project Board member cautioned to be aware of the different needs and requirements of staff. He said, *'Must be careful that one size doesn't fit all.'* (PB 5)

10.3 Challenges

- 10.3.1 *'Finding time is a problem.'* (GP2)
- 10.3.2 *'I attended the first initial training (Rosie Walker) and the follow up. I've attended training and meetings associated with YoC. Generally they're on a Thursday afternoon which is mostly practice nurses' afternoons off, and GPs. There has been the expectation that we all attend them. There's a lot of resentment that we must go on a Thursday afternoon. How can we take that time back and pay for it? No one's thought of remuneration for us. Everyone's fed up. Oh, this is the YoC project. Everyone must give their life to YoC! You*

get a certificate and it's meant to make your life better. I'd rather go shopping! Everybody's really fed up.' (N5)

10.3.3 *'Rosie was very good but very biased to articulate whites – didn't relate to most of our population. There are difficulties with communication. It's nice to build a house and talk of care planning if you speak English.'* (N5)

10.3.4 *'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. It's not a good use of my time. The concept is great and suits my approach to medicine but as a GP I don't actually do that much on year of care. I think the training was good for the nurses.'* (GP6)

10.3.5 *'I have attended some YoC workshops and talked to our practice nurse a lot. I have also looked at general information on sharepoint. The workshops that I have been on have covered the house model and care planning. They have been with other practices. The problem with the workshops is that they take up away from clinical work – it feels like a chore going. Sometimes they are quite useful and sometimes they are not.'* (GP8)

10.3.6 *'It's difficult to get away when you're single handed.'* (GP4)

10.4 Those Who Have Not Had Training

10.4.1 A GP who was new to the practice and had not had any YoC training was asked if he would like to have some. *'Depends what it entails. I would need a half hour chat, not the whole day. Oh God no, please. If it's relevant, in case there's minutiae I'm unaware of.'* (GP3)

10.4.2 *'I've just had one day's training on feet. It would be good to understand what YoC is all about.'* (HCA1)

10.4.3 *'I haven't been on the care planning training yet and will start care planning once I have been.'* (GP7)

10.5 Training Needs

10.5.1 *'There is a high turnover of practice nurses. We need new training sessions every 6 months.'* (N5)

10.5.2 *'We need more training on how we can get patients' diabetes more under control.'* (N1)

10.5.3 *'More training? No. Maybe just a get together to see how everyone is doing. Once in 6 months or once a year.'* (N3)

10.5.4 *'How to deal with non attenders and patients that don't want to participate. Patients who aren't initiated about YoC we send a leaflet but that doesn't help that much. On the phone I spend 10 minutes to explain'* (A1)

10.5.5 *'I would have liked the training to be less arguing about you, I, he, me in setting objectives, but just get computer up, sit there, do scenarios and consultations, see how it works. Do play acting, pick up consultation skills. Have it in Bengali via an advocate. Be very practical and evaluate that, rather than education theory. We do need things that would happen, a deaf or blind patient.'* (N5)

10.5.6 *'It would be good to know more in depth on YoC, what's happening.'* (HCA2)

10.5.7 *'What worried me is that when you do care planning you are supposed to have proper goals but there seems to be a bit of confusion across the practices. I think we need more clarity of what is a goal and what isn't.'* (GP5)

10.6 Training for Healthcare Assistants

10.6.1 *'At the beginning they did training with HCAs. I would like to see it as a rolling programme because HCAs move on.'* (N4)

11 Professionals' Skills and Knowledge

11.1 Patients' Perspectives – General

11.1.1 *'They are very approachable and very helpful. I know that if I had any questions I could always go there and they would be there for me. I think they are knowledgeable.'* (P1)

11.2 Patients' Perspectives on Nurses

11.2.1 *'She is very good. It is a good examination and lots of explanation. She listens to me and takes my views into account. Sometimes I disagree with the doctors and I talk to the nurse about it. I tend not to disagree with her as she is so good. .. I feel less clear if I see a doctor. The doctor tells me different things to the hospital which is confusing'* (P4)

11.2.2 *'She is knowledgeable – she won some award. She is very good at listening. I used to go to another surgery – she was there and when she moved here I moved too because of her.'* (P7)

11.2.3 *'She had a good knowledge and explained things well. They are all good here. I always see one of two nurses and they give you the time you need to talk to them.'* (P12)

11.2.4 *'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)

11.2.5 *'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)

11.2.6 *'She is very knowledgeable. She listened to my views. The nurses vary a lot but that is fine – if I want to see a specific nurse they will arrange it for me. I prefer to see the nurse rather than the doctor.'* (P18)

11.3 Patients' Perspectives on Doctors

11.3.1 *'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)

11.3.2 *'Doctor is fully aware of diabetes but I think patients with diabetes should also see specialists from time to time. We do focus on my needs in the sessions and the doctor will ask questions.'* (P10)

11.3.3 *'I always see the same doctor. Its alright. He listened and explained things and gave me information on things I needed to know about.'* (P13)

11.3.4 *'I'm happy to talk to a nurse to do my care planning process. But I want to see my GP every six months.'* (P5)

12 Patient Education

12.1 Available Education

- 12.1.1 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)
- 12.1.2 *'We have specific diabetes classes, HAMLET – we have made some changes we have developed a longer HAMLET course that is more in depth and also developed a Diabetes day to day course which in a few hours and aims to get key messages across. This change came about after social marketing where people said they didn't know why they were attending HAMLET.'* (PB 1)
- 12.1.3 *'People can also go on the training. They have made the course shorter as people were dropping off the longer course. There is also a booklet and CD which has started going to everyone.'* (N7)

12.2 Healthcare Professionals' and Staff's Perspectives

- 12.2.1 *'We have had very poor take up onto structured training. People won't leave the E1 area and some don't even want to travel to the other side of E1 to access services. There was a modified version of the HAMLET course developed but there was still poor take up. One of my patients went on an expert patient course and was very enthusiastic but he was probably the exception.'* (GP1)
- 12.2.2 *'HAMLET is very successful here. All those we sent went and came back to say how much they enjoyed it. We encourage everyone to go. We send names so if people don't go, they phone up to see and will arrange transport. We have a local centre.'* (N1) Clearly the local aspect is essential to encourage take-up of the facility.
- 12.2.3 *'There's been a big push but not everybody wants it. They don't want a group but they will go and see a dietician. Where you provide education is big. The HAMLET course runs here.'* I(N4)
- 12.2.4 *'About 30-45 minutes patient education is needed about YoC. Or focus groups on a monthly basis.'* (A1)
- 12.2.5 *'The training for patients had a low take up when it was being run from the hospital but the take up has increased since the session started running in the community.'* (HCA3)
- 12.2.6 *'HAMLET has been very good as a diabetes education project but there is very poor uptake from patients within the community. People aren't willing to take time out and find out how to look after their diabetes.'* (PB 4)

12.3 Patients' Perspectives

- 12.3.1 *'I went on a course – it was a few hours long.....I think I was referred there by my GP but was a fair while ago now. There was a session on how diabetes works and another session on cooking and diet. It was interesting and the people running the session were very good. They gave me a CD which I still have.'* (P1)

- 12.3.2 *'I have been on a one day training session at the hospital – it was about food mainly. I did know a lot already because they had told me things when I was at the hospital.'* (P4)
- 12.3.3 *'They run a lot of HAMLET courses. I went on one early on and thought it was wonderful. Lots of patients in the past never got anything and I think that is why they are running so many to catch up. I thought the original course was great although not everyone did. There was a good cross section of people on my course and a good ethnic mix. It was very motivational. People on the course lost a lot of weight over the six months between the initial course and the follow up. I worry about the generic expert patient courses – I think courses should be condition specific.'* (P5)
- 12.3.4 *'I went on training at the hospital – I have been on two half day sessions. It was very good. It covered what to eat and exercise.'* (P7)
- 12.3.5 *'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)
- 12.3.6 *'I did go on a course at Mile End hospital – it gave me lots of information about diet. The course was three days and very good and explained everything about diabetes – why it happens, how to control it, food types, portions to eat. The nurse referred me to the course and it was in English and Bengali.'* (P13)
- 12.3.7 *'I went on a HAMLET course for 4 weeks – it was very helpful – I got a lot of advice including information on portion control. It was good for other people too.'* (P14)
- 12.3.8 *'I have been on a self management course – I'm not sure who referred me I think I just asked for a pack and enrolled. It was for 3 or 5 weeks and I found it very helpful. Learnt about goals, food and what would happen if I don't control my diabetes. Because it is run in a group there are lots of people asking questions. The information on cooking was very helpful and they gave us a booklet at the end of the course.'* (P16)
- 12.3.9 *'She (the nurse) did ask if I wanted training – I have had it in the past – 2 years ago. It was a couple of hours on diets and portion control at Mile End hospital. It was good - everything was made clear.'* (P18)
- 12.3.10 *'I have been on the training programme which was nice. I have not been referred to anything else. At the training programme, I learned how to look after my life. It involved diet and exercise.'* (P20)

12.4 Patients' Ambivalent Responses to Education

- 12.4.1 *'The nurse has talked about training but I am not really interested.'* (P17)

12.5 Commissioners' Perspectives

- 12.5.1 *'At the moment we send patients on courses but the GP doesn't get information fed back to them on whether that person has attended the course so can't proactively talk to them about the course. This is because most of our programmes are provided through community organisations so data on individuals cannot be shared. It would be helpful to have this information available to GPs. This is one of the biggest questions for us in commissioning. We analyse activity data but we don't have the intelligence behind it to give context. For example we may know that people are dropping out of programmes but we don't know why.'* (PB 1)

- 12.5.2 One member of the Project Board expressed scepticism at the figure expressed of 7,000 patients having gone through structured education in the borough. (PB 3) It was also stated that there are 11,000 people with diabetes in Tower Hamlets.

12.6 Alternatives

- 12.6.1 The idea of running small groups to explain results and goals is being thought of at different practice. *'Does YoC need to be done differently in a group education way? Do we need someone spending 2 hours with an advocate to explain what the results letter is. Do it to 20 patients once a month. Have a rolling programme. The first Monday afternoon of every month, every new patient is invited to a meeting to discuss this is what the letter is about.'* (N5)
- 12.6.2 *'We are thinking about running some groups here at the surgery to help patients understand the concept – maybe have about 10-15 patients come in at a time and give them examples of goals and explain care planning.'* (HCA3)
- 12.6.3 *'We are trying to reduce the stigma amongst the Bengali community through a local health education programme and use a local TV channel to reinforce messages.'* (GP8)
- 12.6.4 In response to a question on motivating patients, an interviewee spoke about; *'sending texts on mobile phones, how you're getting on with exercise and eating. It might work first time round but then its nagging and you become resistant and they'll look for a process of disowning... Patients need supporting and coaching at how to manage these goals. You need to get them to realise what's in it for them.'* (P5)
- 12.6.5 *'We need to put it on in local mosques, communities or GP practices. It must be local. We've learnt that lesson.'* (PB 4)

12.7 Challenges and Constraints

- 12.7.1 *'Before the classes were done in the community. Now it's in Mile End. Some find it difficult going all the way to Mile End. The elderly need someone to go with them.'* (N3)
- 12.7.2 *'We have had a few patient events. The first was an introduction event and lots of patients attended – about 20. Patients are expecting a higher standard.'* (A1)
- 12.7.3 *'Why don't patients take up education? Is it fear of why they're going to nag me again... A lot more emphasis could be given to patients. What do patients need to know about it and how do they prepare themselves.'* (P5)

12.8 Coloured Printers

- 12.8.1 *'Not all of us have a coloured printer.'* (N2)
- 12.8.2 *'The colour printers have been extraordinarily expensive.'* (GP6)

12.9 Health Advocates

Positive Experiences

- 12.9.1 *'We use health advocates on certain set days of the week and will always make appointments for people who do not speak English at a time when an advocate is available. They may bring their son or daughter with them – we don't encourage this but we don't discourage it either. Because of confidentiality we will always check who people are that have come with them. It can make it easier if they bring their child with them as*

the children are often brighter and have a better understanding so I can make it easier explaining things.' (GP1)

- 12.9.2 *'For us, we have the same advocates all the time. They have cultural awareness. They break down the thing of exercise. Lots of Bengali ladies don't exercise. They feel they're busy enough running a home and we're asking additional things. The advocate brings a massive dimension. They have their own relationship with them. They may suggest they do something.'* (N4)

Challenges

- 12.9.3 *'A couple will interpret exactly. Others .. go into a long conversation and the interpreter gives us 1 or 2 lines. We may be losing things. But she says, they're just repeating themselves. But we don't understand what's so important that she's repeating.'* (N1)

- 12.9.4 *'How can we expect people to set objectives if the advocates don't understand. The advocates should be trained from the beginning. Setting confidence rating through an interpreter who doesn't understand..'* (N5)

- 12.9.5 *'We have an advocate around almost every day to help but communicating through an advocate can be hard. It can also be hard communicating through relatives as they don't always say what you want them to say. If the relative is involved with the care plan it is important that they come along to the appointment but it also important that the patient has the control.'* (GP6)

- 12.9.6 *'Only a very small percentage of our patients speak English. We have interpreters at the practice (2 in the morning and one in the afternoon) but we have a number of doctors and nurses here (five or six) and when we are doing six clinics a week we can't resource it. We don't like to rely on family members for interpretation and so we can struggle with this. Both the HCAs speak Bengali and we help out where we can but we can't always help if we have our own clinics.'* (HCA3)

- 12.9.7 *'Some health advocates are heavily involved in care, they interpret and assist the patient in health care. We must not only train diabetes workers but also advocates. Anne's been looking at getting our advocacy and interpreting teams more involved.'* (PB 4)

12.10 Meet and Greet/Health Trainers

- 12.10.1 *'We have meet and greet. They sit in the waiting room and chat to people. They take bp, weight and bring them to different rooms. At the same time, they get a relationship going.'* (N1)

12.11 Diabetes Support Groups

Need

- 12.11.1 *'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)

- 12.11.2 *'They've been trying to get a patient support group and it's not been successful. The planning wasn't brilliant. The invitations were late and the practices didn't send people along. There were 9 patients and 8 PCT reps. Anne and Abbas should come along but no one else should.Patronising PCT vs. patients, uninformed, uneducated and don't know what's good for them.'* (P5)

- 12.11.3 *'Diabetes Support Groups must link into SureStart. No-one wants to take responsibility. We need to have HCPs involved until they are confident they will run it themselves.'* (PB 4)

Lack of Need

- 12.11.4 *'I don't really need things. I look after myself so I am a good patient. The nurse has talked to me about support groups but I don't really need them.'* (P4)

Size

- 12.11.5 *'I went to a diabetes patient meeting – it was very large and we didn't get much of a chance to talk to each other. I think that setting up patient groups is a good thing – this seems to be linked to Year of Care. We need more time to speak to each other at these meetings – not just a speaker speaking to us. The food available was all curry and some people don't like that. One woman told me she wouldn't come again because of that. These meetings need to be structured and have opportunity for people to talk to each other. Some people won't speak if there are 20 people in a room. They could get us to work in small groups.'* (P5)

- 12.11.6 *'I went to a meeting at the surgery to talk about diabetes. I found it hard to understand. They gave out some paper and talked – I was not clear why I was there. I think it was about how to test your blood sugar but I'm not really sure.'* (P9)

- 12.11.7 *'Large groups won't work. Small locality based or practice based.'* (PB 4)

Other Needs

- 12.11.8 *'I have been to a couple of meetings and they were well attended. There should be more information for people with diabetes. Information about what benefits you can claim.'* (P10)

- 12.11.9 *'The last diabetes support meeting (which was not well attended) was in a place that wasn't used before and was held during prayer time. All patient events must be done within one hour.'* (PB 4)

13 Information to Patients

13.1 Useful Information

- 13.1.1 *'I was given the pack when I came for my review. The pack is good. I have had information about controlling my diabetes and what to eat.'* (P7)
- 13.1.2 *'I have had other information - the You and Your Diabetes DVD was very helpful. I find it useful to know that other people have the same issues and that how you feel is ok. It was be very difficult.'* (P8)
- 13.1.3 *'I got some information through the post about training for the year of care and what to expect. I got a DVD about how to control my diet.'* (P18)

13.2 Negative or Ambivalent Responses to Information

- 13.2.1 *'I got very little. I received 'Day to Day with Diabetes' which is general and issued to the whole Borough. I was given a folder and told this is for you to keep, we may need to come back to it but don't worry. I may have thrown it away. I don't know where it is. It wasn't explained what it was for. I never heard anything about 'This is YoC.'* (P3)
- 13.2.2 *'Information in other languages would be helpful for some – some of the elderly can't read and write so it wouldn't help them.'* (GP8)

13.3 Information Needs

- 13.3.1 *'It would have been nice having a covering letter from the practice saying, we're part of YoC and this is what it is about.'* (P5)
- 13.3.2 *'I have had a folder with my test results but I have not really looked at it. The information was in English but it would be good if it was in Bengali. My 16 year old child tried to explain it to me. I did get my test results but they didn't really make a difference because I didn't really understand them. They would need to be in Bengali for me to understand properly. I didn't notice the text on the back of the pack offering translation but would have taken the offer up if I had known.'* (P13)

14 Information Technology

14.1 Satisfaction

- 14.1.1 *'At the beginning it was cumbersome but we've got used to it.'* (N3)
- 14.1.2 *'I'm happy with EMIS LV. It does everything.'* (GP4)
- 14.1.3 *'I can do a flow chart correlation on the computer which is really good to show them. We can go back however long they've had diabetes.... I point to the screen.'* (N4)
- 14.1.4 *'LV works ok for care planning. We have templates. We adjusted the templates. There are no problems.'* (PM1)
- 14.1.5 *'We use EMIS PCS. We have to manually look at foot checks and retinal screening and enter them. Its not been that bad really – issues have been raised in meetings. The new template that we have is much better.'* (GP5)
- 14.1.6 *'The way that the system flags patients is good. If someone has not attended their care planning session and comes to see me about something else they are flagged on the system so I know to talk to them about this.'* (GP7)
- 14.1.7 *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)

14.2 Dissatisfaction

- 14.2.1 *'We use EMIS PCS which is dreadful. It is very poor for searches. Last week I did a search for people who had had a diabetes review – this search highlighted that the system is very unreliable. We are going to have EMIS Web which will have much better reporting but this is not going to happen very quickly. Details of the care plan is copied into the medical records on the system so we do have access to this information'.* (GP1)
- 14.2.2 *'EMIS is a dinosaur. Vision is a different system. It's much better. It's windows based.'* (GP3)
- 14.2.3 *'I get frustrated when it doesn't work properly. IT always lets us down. We had an update put on in preparation for the networks which made everything awful. I'm a nurse, I'm not an IT person. No one can log in, access anything. It's just irritating.'* (N4)
- 14.2.4 *'IT is really difficult. We have EMIS PCS. We always have problems, we're the last to have anything. If you're doing YoC, you have to have 2 screens open. .. It's really time consuming.'* (N5)
- 14.2.5 *There are several different pressures when doing the annual review which is a template entry. We do all the stuff on template. When we've gone through the template then we need the document for care planning and goal setting and we go through that. It's repetitive. The more literate patients wonder why we're going through it all again. Patients say, I don't know why you're telling me all this again. They're the ones who have taken the trouble to read it. It confuses patients.'* (N6)
- 14.2.6 *A member of the Project Board stated that 'LV is outdated and PCS is a disaster.'* (PB 3)
The member also stated that Emis which would enable patient access to their electronic record *'which would complement the YoC.'*

14.3 YoC Templates

- 14.3.1 *'I try to use the templates as much as possible. It's helpful but if the computer goes down.. It's always packing up.'* (GP2)
- 14.3.2 *'We have EMIS LV. Care planning is not linked to the template. It's completely separate. We have to go out and attach it to the patient's file.'* (N1)
- 14.3.3 *'I've stuck to the first care plan that was introduced. I haven't looked at the new one.'* (N3)
- 14.3.4 *'We use EMIS LV – we have a template for what we do on our system. The PCT wanted us to merge their template into our system. Our recall system works well from an IT perspective. I don't see why we couldn't add our own care planning template to the system.'* (HCA3)

14.4 Printing the Care Plan

- 14.4.1 *'We write and print it for the patients. We don't do it later because we have to give it to them.'* (N1)

14.5 Focus on the Computer

Healthcare Professionals' Perspectives

- 14.5.1 *'The patient tries to tell you something – I'm old fashioned. If you can manage both, but I can't.. In the olden days you paid all your attention to them. But you only have 7 or 10 minutes – most patients come for 2 or 3 complaints.'* (GP2)
- 14.5.2 *'It gets in the way. What we need is a voice recorder that can print as we go.'* (N1)
- 14.5.3 *'If you want to get patients interested, you deal with them first and IT later.'* (N2)
- 14.5.4 *'I usually do it at the end. It flows.'* (N3)
- 14.5.5 *'The computer does get in the way. It's 15 pages long. It's gone from a good doctor/patient relationship to me tapping away when the patient speaks. It does interfere. Before I entered stuff into the computer after the patient left. But there's too much. I won't remember.'* (GP4)
- 14.5.6 *'I do the data entry when they leave.'* (N4)
- 14.5.7 *'If you don't fill it in at the time, when would you get time to do it later? Plus you have to write notes. I do scribble some for referrals. Can't see how else it can be done.'* (N6)

Patients' Perspectives

- 14.5.8 *One patient was vociferous in this point concerning the computer. Indeed, the entire interview revolved round this point which was revisited with every question. 'When I go to see the nurse, she's on the computer. You sit there waiting to see what she says. That's all..... I can't say much because me being partially deaf. She's on the computer and when she talks she doesn't face me so I have to stretch my neck to see what she's saying.'* (P2)

14.6 IT Training

- 14.6.1 *'They haven't given us any training. Someone has to take responsibility. There's a presumption we can all access EMIS Web. Can you train us on it. 'If you can use a mouse you can use EMIS Web'. That's condescending and not helpful.'* (N5)
- 14.6.2 *'I'm not good at IT, getting into different templates. Some practices send care plan off afterwards but I print it out and give it to them. I've had no training at filling in templates. What I put on I assume is ok. Training was more hypothetical. I need practical training of filling it in.'* (N6)

15 Culture

15.1 Healthcare Professionals' Views on Patients in Tower Hamlets

- 15.1.1 Tower Hamlets is a borough with very specific challenges. Many of them are to do with the cultural backgrounds of the population. This section presents the comments made about these issues.
- 15.1.2 *'Lots of Bengali patients are accepting of their lot whereas others often view their diabetes as a burden.'* (GP1)
- 15.1.3 *'Their attitude is – you are the doctor, give me the tablets and I'll be better. Their lifestyle is chaotic. Most are laid back. They're not keen to do things... If a child sneezes, they come in as an emergency. If we can train them... They have such a strong faith that they'll do things at the risk of their health, such as fasting on Ramadan.....I tell them something and they think because they are getting the same message from other HCPs. People now realise tablets are not the answer. The more they can do to control, the better. In the last 17 years so much has changed in East London, people's perception of illness, particularly diabetes.... Patients used to say, don't tell me what to do, give me a tablet. Now they're saying, you're right. It's difficult to shake their beliefs but now they're beginning to make changes.'* (GP2)
- 15.1.4 *'In diabetes we are way out of control. There's a lack of education, lack of interest, lack of awareness. They're blasé. Unless you ram it down their throats, they're not interested. Keep on banging on the door. Year of Care is part of that.'* (GP3)
- 15.1.5 *'Literacy in TH is low. In UK it is 11 years but in TH it is probably 9 or 10. Plus language and understanding of English is very poor. We need interpreters. We don't want to talk like a child but we have to check and review and get them to repeat it.'* (PM1)
- 15.1.6 *'Some are in Bangladesh for 4 or 5 months of the year. .. The stereotype of a Bengali patient is one who does what they are told but some are more ignorant of their health condition than others. ...Bengali patients tend not to be keen on insulin which can be a big barrier for them.'* (GP6)
- 15.1.7 *'Asian patients often like to be told what to do by the clinician – it's a cultural thing.'* (N7)
- 15.1.8 *'With the Bengali patients you can't push too hard or you won't achieve anything – for example it is often good just to set one goal. If you set lots it often doesn't seem to work. I find it helps getting the family involved. I use pictorial resources when I talk about diet with Bengali patients – they make a big difference.'* (N7)
- 15.1.9 *'Our Bengal patients tend to be passive and think that if they are sick it is the doctor's job to sort it out. Some are fantastic and some are in denial in which case the process frustrates and irritates them.... With the Bengali community elderly people can be hard to engage in care planning. They can get anxious and be daunted by self care. Some see it as an obstacle and it can cause more stress'* (GP8)
- 15.1.10 *'If you have a LTC and you're told you must get your weight down, they will say, Only Allah can tell us.'* (PB 4)
- 15.1.11 *'Need to break the dependency culture. It's a vicious circle, where do you start? Education in schools and communities .. The biggest challenge is getting them to understand what diabetes is, also what a HCP does for you. They think they must see the GP.'* (PB 4)

15.2 Cultural Change: Positive Responses

- 15.2.1 These comments are included here as positive responses to questions around cultural change. It may be argued that some of these comments reflect process or infrastructural changes rather than changes to culture, but as changes in an organisation have an implicit impact on culture, they are included here.
- 15.2.2 *'There has been a good take up which makes those involved pleased. People here are cheered up by the fact that we are getting people involved and that diabetes is becoming seen as a manageable problem.'* (GP1)
- 15.2.3 *'We try to be patient centred – relating to how the patient feels and what would be good for them. The actual interaction we have with the patients and the goal setting feels authentic. The bit where we talk with patients feels good.'* (GP1)
- 15.2.4 *'With nurses we see patients for stroke or COPD and we try and encourage them to say how they will do things.'* (N1)
- 15.2.5 *'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!'* (N1)
- 15.2.6 *'It's been very positive. It's made us more of a team. For us, it's made us be a team, be more supportive to each other. We work very closely with (Administrator).'* (N4)
- 15.2.7 *'Definitely. Nurses are more involved. There are more meetings between staff and HCPs. More communication, emails, word of mouth, constantly we have to communicate.'* (A1)
- 15.2.8 *'It has drummed into everyone the importance of patient empowerment and focusing on the patient.'* (GP5)
- 15.2.9 *'I am sure that there have been some changes between the nurses and the patients. I think the patients understand their results better and know their numbers. I think they have a better understanding of diabetes.'* (GP6)
- 15.2.10 *'Staff are very happy with the concept despite it being extra work.'*
- 15.2.11 *'The patient satisfaction level has gone up. It used to be that patients came in when they felt like it or felt unwell. Some patients got lost in the system. Now we don't have that problem (although we do have staffing issues at the moment). Our recall system is working well – it is fantastic. There was some resistance from staff at the beginning as it was lots of work. We had to allow longer appointments for the nurses but now the HCAs have taken tasks away from the nurses – we have looked at our skills mix and used people accordingly to make things more streamlined. I spend half a day a week working on admin things for year of care.'* (HCA3)

15.3 Change: Equivocal Responses

- 15.3.1 *'For change to happen, you need to be informed all of the way; it's going to have a positive outcome, these are the tools for change. From the start it wasn't a choice, not a group decision. It was enforced change (though I do believe in it). The outcome, the transitional unfreezing and refreezing process hasn't happened. I can see the value. I'm not against the model or the idea. 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'. (N5)

15.3.2 *'That's what I'm concerned about here, there's been no change here. It's a doctor dominated set up. Doctors are in charge here, nurses fit in. Cultural change needs to recognise where nurses fit in. But it's complicated by the network idea. Some practices won't embrace YoC as they'll get a diabetes nurse from the network. She'll do it.'* (N6)

15.4 Negative Change

15.4.1 *'It's more bureaucratic now. There's no flexibility. Everyone is budget driven. You're not getting a holistic picture. You're just focusing on the targets. .. You have to give a reasonably short burst of information. Patients won't want to sit for 45 minutes going through a care plan. My feeling is they'll DNA if they have to sit for 45 minutes.'* (GP4)

15.4.2 *'The culture shock is the length of the appointment.'* (PM1)

15.5 Working in Partnership

15.5.1 We wanted to get a sense from the healthcare professionals of how they perceived their relationship with patients. We started by asking them what word they would use to describe it and then tried to develop their ideas around partnership.

15.5.2 *'The word I would use is cooperative.'* (GP1)

15.5.3 *'I'd like to be told that I respect them. I take them as a person, not someone who has a disease. I treat people how I would like to be treated.'* (N1)

15.5.4 *'Yes, because we give information and they tell us what they can do. We encourage them and they take on board what we say. It's a mutual partnership.'* (N3)

15.5.5 *'I do see a partnership. With care planning they get my name on it. If they have a problem they come back to me.'* (N6)

15.5.6 *'Interactive. I think this approach is nicer for patients. We do work in partnership with them but sometimes the patient doesn't seem to care. It is hard to get goals out of some patients. Sometimes – especially with the Bengali patients you have to push them to get a goal. Younger people tend to be more confident and want to do more and older people tend to be more passive'. (GP5)*

15.5.7 *'Friendly but a firm adviser. I don't believe in authoritarian doctors – I try and bring over my patients and understand their issues. I definitely work in partnership. Some patients are prepared for this approach. We have a lot of Bengali patients – many have an old fashioned expectation about doctors – they prefer the doctor to tell them what to do. We do try and forewarn them and understand their fears and problems.'* (GP6)

15.5.8 *'Equal. It's not about being authoritative. We listen to them more and understand their point of view. We have had to work at it and are still learning. I have been a nurse for 30 years.'* (N7)

15.5.9 *'Facilitator. – helping them to manage their disease. We work in partnership by having a two way discussion. With some patients this is not always possible. We ask them if they have ideas and why they think things aren't going well. The nurse prepares people to speak to their family and a significant proportion of our patients bring their family members with them to their appointment.'* (GP8)

15.5.10 *'Open and genuine. I think that it is good that I am from the same cultural background. They open up and trust me. I am very comfortable working with them and there is lots of respect between me and my patients. We do work in partnership with our patients – it's very much a team effort. I try and get them to open up with me before I give them their results. The approach doesn't feel tokenistic.'* (HCA3)

15.5.11 *'If we don't have a consistent approach, how does a patient learn the skills of a partner... In order to develop those skills, the patient needs those skills right from the start and reinforce them in multiple contexts.'* (PB 7)

15.6 Engaged Patients

15.6.1 We also wanted to understand if healthcare professionals believed their patients were now more engaged and if so, how they felt about it.

15.6.2 *'The engaged patients tend not to be Bengali – they tend to be white or Maltese. Some are very engaged and enthusiastic – they are good at keeping records when their insulin dose is adjusted. One of my patients argued for an insulin pump – he was very determined. Another was very engaged but not doing very well. He had poor control and asked to change his medication. When I suggest medication options he goes away and reads up about them on the internet and makes choices. He is the sort of patient that suits the Year of Care very well. For those that are really engaged YoC has given them a structure to hang their interest on.'* (GP1)

15.6.3 *'Up to 10% of patients are very engaged with the process.'* (GP1)

15.6.4 *'Certain groups of patients you feel it is a waste of time and resources. Someone sits in front of you and they're interested. Some, you talk to them and it makes no sense. Certain groups it's difficult to get through to. Some are keen and with it to take on board what we're trying to do.'* (N2)

15.6.5 *'Patients are a lot happier. They seem to understand more. Patients confide in us more.'* (HCA1)

15.6.6 *'They're telling me, I've lost weight or my HbA1c has gone down or they feel they're eating well. When I see you in 3 months, I'll do this etc. It's coming from them.'* (N3)

15.6.7 *'90% of our patients wouldn't know what you were talking about if you said Year of Care. But say several reviews this year where we looked at what you need to work on. They come to appointments which is a sign they're engaged. Whether they fully understand the process doesn't matter.'* (N4)

15.6.8 *'I feel they are. From what I see, they're attending. I'm getting messages from reception – if they DNA, they want to make an appointment very soon. They're becoming much better at keeping us informed.'* (A1)

15.6.9 *'From feedback from clinical staff, we seem to have better control, constant reminders, constant education.'* (PM1)

15.6.10 *'There is more patient involvement – they can see where they are at and what they need to do. It's not just about us doing blood tests – they need to make changes and they are starting to realise that. This is a big difference to how things were before.'* (GP7)

15.6.11 *'Young people generally tend to be the most engaged. They are much easier to work with and I enjoy working with them. They are much more clued up about their results and what they need to do. It is harder with the older people – it can be easier to make their children understand.'* (N7)

- 15.6.12 *'Some patients are engaged. It's really good when they do engage. It's nice to get away from the previous way of working with patients. Patients are much more aware – they understand their illness much more than we do so it is a learning process for us. When patients do engage we can use them as a resource to talk to other patients.'* (GP8)
- 15.6.13 *'Quite a lot of our patients are really engaged. Some don't get the goal setting and find it hard to carry on with it when they get home. They do however seem engaged when they are at the surgery.'* (HCA3)
- 15.6.14 *This year it is a bit easier because patients know what we are talking about because they have been through the process once. In the past we have lost track of some of our diabetic patients but this doesn't happen now.*
- 15.6.15 *'It will take a while for them to see how good it is for them.'* (N6)

15.7 Incentives

- 15.7.1 *'It has to be worth while for them so it's not a chore. We can reward them with something. We did healthy lifestyle for people to go on walks or swimming. They met here and we took them. We gave them a bag of vegetables. They were happy to do things to get the bag of vegetables.'* When asked who funded the project, the nurse said, *'We had money from prescribing...The PCT wanted to put out the project throughout TH, but it collapsed in a heap because the PCT is slow to do things.'* (N1)

15.8 Patients with Mental Health Problems

- 15.8.1 *'Care planning doesn't work for everyone. Patients with mental health issues can struggle – I just give them the basic information and refer them on as necessary. We would still send their results out before the appointment and try again to care plan when we see them next time.'* (N7)
- 15.8.2 *'Where patients have mental health issues we still try and do as much care planning as is possible for the individual patient'* (HCA3)

16 Commissioning

16.1 Menu of Care

- 16.1.1 *'At the beginning patients were given a spiral bound book with all the options to read in the waiting room. It was too much for them to take in. We have devised a leaflet for our area with information about services local to this practice which is much easier for patients. Now health trainers are available and we can refer patients on to the health trainers and they go through the options with them. Many of the Bengali women want free swimming – it can be hard to get them to engage with exercise as many of them don't go out much.'* (GP1)
- 16.1.2 *'We realised that it would be useful to put the directory on EMIS so that the information is easily accessible to GPs but the feedback from GPs was that patients won't travel to use services so they want information about local services. As a result of this we have developed a website with printable local information – we have made sure that YoC and diabetes are at the forefront of this but it covers all aspects of self care.'* (PB 1)
- 16.1.3 *'Supporting Self Care. We're not planning to republish the paper version.'* (PB 3)

16.2 Referrals: Implications for Commissioning

- 16.2.1 *'Referral on to weight loss and exercise programmes can feel inspirational....I do think there are more things to refer people on to but it may be that the Year of care has just made us more aware of the services that are available.'* (GP1)
- 16.2.2 *'There are plenty of services to support people here but they won't necessarily take them up. Patients want very local referrals. There is quite a long waiting list for exercise referral – we also refer to the dietician.'* (GP7)
- 16.2.3 *'We are using the new template which has exercise on prescription, diabetic education, dietician, psychological and pain clinic referrals. We don't know if the person has attended the session generally although we would find out if it was a referral to the HAMLET course'.* (N7)
- 16.2.4 *'Nurses make more referrals now – they refer patients on for exercise, dietician, sharps bin referrals, smoking cessation and beetle nut chewing (either to the practice or to the local pharmacy).'* (HCA3)
- 16.2.5 *'Goals are put on the system. We don't monitor where we refer people on to – we would have to code everything and then we would need to get information back from the services (and there are a lot of them) and we would need to patients' consent for them to report this back to us.'* (GP5)
- 16.2.6 *'Some of the referral options on our system for other services are unclear. For example I don't know if I refer someone for specialist exercise whether they are going to have to pay for that or not as it isn't clear on our system. This means we cannot be clear with the patients when we are referring them. Our care plan isn't on the system but I don't think this should be a problem but I suppose it can't feed into commissioning. We could cumulate information from our system on referrals to inform commissioning but we don't have any information about whether patients actually attend services when we refer them on. We would know with the dietician but not others.'* (GP7)
- 16.2.7 *'There are still not many resources to refer people on to. Women want women only swimming sessions and they want it to be free. Nobody took time to find this out before Year of Care. I think this is going to be commissioned. They also want classes in cooking. There are quite a lot of services which cater culturally for our patients. I refer people on*

to health trainers (for help with smoking, diet and exercise) and to exercise on prescription. I refer people to the dietician who comes into the surgery.’ (N7)

16.2.8 *‘I went to the Mile End Stadium with my husband but it cost £21 every month. One lady said I would have to go back to the GP. I saw a nurse and was referred to the centre. I like swimming but thinking about what to wear is a problem – I feel shy.’ (P20)*

16.3 Available Services

16.3.1 *‘We have specific diabetes classes, HAMLET,... weight loss and exercise cookery classes. Healthy Moves, an exercise programme to increase activity for diabetes patients..... The electronic version will have some other things included and we also will be signposting people to where they may be able to get information about local classes e.g. Tai chi in the local church hall.’ (PB 1)*

16.3.2 *‘If they say we want to go swimming, they’ll be given 3 or 5 sessions at the gym but afterwards they have to pay. With swimming they need female only lifeguards. Health and well being, we do a lot here. But what they want and what is available needs to be addressed.’ (PB 4)*

16.4 Secondary Care

16.4.1 *‘Year of Care should not be secondary care. In Type 1, they get care in the hospital setting. If they’re overseeing the patient while they’re here, they should take on that approach. The principles could and should be applied to every LTCs. But staff don’t have the skills to run consultative approach with patients.’ (PB 7)*

16.5 Identifying Unmet Needs

16.5.1 *‘We know that if needs are not met within the first couple of weeks after they are identified people are much less likely to take them up.... We do have some waiting lists for our programmes.’ (PB 1)*

16.5.2 *‘There’s a problem getting information collated from the patients as to what patients are opting to choose. It’s put on a word document and each care plan has to be opened individually.’ (PB 2)*

16.6 Transferring Micro to Macro

16.6.1 *‘We cannot transfer information from the care plans at the moment because the care plans are confidential. As yet we have not been able to overcome this.’ (PB 1)*

16.6.2 *‘It can happen if the information can be recorded and collated. Unless a practice manually records what services people want to go to or are referred to because the care plan is a word document, you have to open one per patient. ... it could work with a voucher that gets sent back by a service. .. You can count the number of referrals. But there is an attrition rate – if patients don’t go to all six sessions.’ (PB 2)*

16.6.3 *‘There are big ongoing gaps. There is no effective infrastructure for that. It needs to be built into the routine structure of work and we can’t do that now. A model for this would require networked practices to meet as a team once a month. In those conversations there should be the beginning of an understanding of micro to macro – bring problematic cases. What this person needs is x, and I’ve got someone.. .. through clinical networking and story telling.’ (PB 3)*

16.7 Population Needs Assessments

- 16.7.1 *'Public health do and they do share it with us – they have for example the number of people with diabetes and the number who are not managing their condition well..... As we develop the networks we need to get them to understand the importance of collecting local data. We need to get better at this to support commissioning. It needs to be accurate. Sometime there are too many codes in the system to allow for accurate recording at a practice level. This can result in vagueness.'* (PB 1)
- 16.7.2 *'We had a big push 2 years ago with PH. ...EMIS Web is amazing. ..Now we can query data. Provided practices are coding we can do custom searches. But it is just in its infancy. We haven't collected biometric measures formally but through EMIS web we can do that.'* (PB 3)
- 16.7.3 *'The PCT invests a lot in self care and understand the importance of it but doesn't have a good understanding of our population and its self care needs. We are trying to address this now. We need to also understand more about the return on our investment.'* (PB 1)

16.8 Developing Markets to Meet Current and Future Needs

- 16.8.1 *'We have identified what is needed through patient events. I have been to about 4. We are doing some participatory budgeting although we haven't done this with diabetes. The local authority is good at this and we are learning lessons from them.'* (PB 1)
- 16.8.2 *'We regularly have external reviews of services. Public Health does needs assessments and work with social care to bridge gaps'* (PB 2)
- 16.8.3 *'The PCT has done work on that with social marketing, advertising and awareness events.'* (PB 3)

16.9 Quality Assurance

- 16.9.1 *'We have the Picker survey, care planning training from the national team and PPI events.'* (PB 2)
- 16.9.2 *'We had a sample of anonymised care plans. We will ask people again for anonymised copies.'* (PB 3)
- 16.9.3 *'I'm anxious that we're going down the road of collecting data rather than caring for patients.'* (PB 7)

16.10 Recording Options and Service Use

- 16.10.1 *'At the moment we know how many people are referred to programmes and how many attend but we don't know how many from each practice because we can't share personal data at the moment. Because lots of services are commissioned from the third sector we can't share the data. We are considering getting people to sign consent forms to allow data sharing. We do get demographic information about who attends each programme.'* (PB 1)
- 16.10.2 *'The assumption is that practitioners are but we can't collate it. It is very generic; we can't say where or who. They can only record if Read code exists; e.g. dietetic referral but not weightwatchers.'* (PB 2)
- 16.10.3 *'We try to do this. We put as many codes into the template as exist for service options. It's a long template. Many people haven't been coding. There are loads of services that don't have a Read code. ..People's quality of doing it is poor. ..The billing system will capture onward referrals in the health service.'* (PB 3)

16.10.4 *'Some of the options we offer are not very flexible for patients who are working.'* (N7)

16.10.5 *'Not sure about informing commissioning – they already know what people want – patients want local services. They just don't have the resources to fund it.'* (GP8)

16.11 Secondary Care

16.11.1 *'It has been a good process. It has caused us to look at hospital patients and try and get some of them back from hospital and treat them here. Hospital can only see people so often whereas we can see them more regularly.'* (GP1)

16.11.2 *'Why aren't they doing YoC at the hospital? The DSNs aren't doing it. Their job is to support us in practice.'* (N5)

16.12 Leadership

16.12.1 *'We have strong clinical leads – could probably benefit from more leadership from secondary care. We also have strong patient representation 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. He is probably more influential at practices than with patients as they tend to consider their GP as the most important person not the medical director!'* (PB 1)

16.12.2 *'The medical director has high visibility and credibility'.* (PB 2)

17 Comparisons before Year of Care

17.1 Healthcare Professionals' Perspectives

Positive Change and Responsibility

- 17.1.1 *'YoC is making them aware and to take responsibility for their health'. (GP2)*
- 17.1.2 *'Before the Year of Care it was only the patients that presented themselves that got checked – it was possible for people to lie low and not get seen – care was very patchy' (GP1)*

Positive Change and Culture

- 17.1.3 *'With Bengalis it is more frustrating because they keep saying, you're the doctor, you tell us. The 2nd generation, English speaking ones have embraced it and are more involved.' (N1)*
- 17.1.4 *'Now we say, bring in your sister-in-law (who does the cooking), They didn't think they could do it before.' (N1)*
- 17.1.5 *'There's a change of attitude on recalling patients. In the past they will have a laissez-faire attitude.' (N2)*
- 17.1.6 *'I put a lot in and they realise that. I'm doing something they weren't getting before.' (N6)*
- 17.1.7 *Some are getting really good HbA1c control – year of care has definitely made a difference. Patients were not satisfied before but we are not getting any complaints now. They used to complain that they couldn't get an appointment.' (HCA3)*

Positive Change and Care Planning

- 17.1.8 *'We've improved on the management and care of patients. We're looking at them holistically.' (N2)*
- 17.1.9 *'There's more partnership since YoC'. (N2)*
- 17.1.10 *'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)*
- 17.1.11 *'Before they haven't felt the need to be in control. Now it's more open about what's impeding them from being in control.' (N3)*
- 17.1.12 *'Now that we have a proper system where patients come in twice, we have a more systematic approach on how to handle patients. We're working towards better results. We look at current targets and review protocols. We're doing that a lot more since YoC. Our QoF results are much better after the first year of YoC. Retinal screening went up by 20%. The annual reviews, we met all targets. Now we are trying to improve clinical by having the interim review. (A1)*
- 17.1.13 *'Before patients weren't involved in their care. Now people want to know more. Why are they repeating it every 6 months? Why isn't it working? People are asking more about their results.' (HCA2)*

Positive Change and Processes

- 17.1.14 The HCA obtains a whole range of biometric data that frees up the nurse to engage in more active care planning with the patients. *'I ask all the information; waist, BMI, smoking, exercise, check urine, send off to lab if there's a problem, ask if they've had retinal screening, refer them if not.'* (HCA1)
- 17.1.15 *'Our results have improved – it may be because we are putting more admin input into reviews than before.'* (GP6)
- 17.1.16 *'Since year of care started there has been a significant improvement in the uniformity of management of diabetic patients – all their tests and checks are done, their retinal screening is done and all the boxes are ticked. By the time they get to see the doctor the doctor can focus on any complications rather than information gathering. People don't go missing from our system anymore.'* (GP7)
- 17.1.17 *'The way we work is a bit different. Now we have a YoC team (an admin person a nurse and a GP). We work together on YOC to reinforce messages. Care planning has shifted the way we approach patients. We are much more holistic. We have improved our diabetes care – there has been a massive improvement within the practice. We are the most improved practice on YoC in Tower Hamlets. We were doing annual reviews before YoC but YoC has offered more resources.'* (N7)

Positive Change and Knowledge

- 17.1.18 *'The Year of Care has caused things to change – many patients know what to eat and what they should not eat and this has made a significant difference.'* (GP7)
- 17.1.19 *'The YoC – its lots more paper and more time with patients. Some patients don't need the full 30-40 minutes. Others need more time to educate them about it the results. We tell them to go away and read information but they often don't. I think it is getting easier now we have been doing it for a while.'* (GP8)

Positive Change and Communication

- 17.1.20 *'It's changed how I communicate. I've a good communication with patients anyway but it's made me ask more open questions.'* (N4)
- 17.1.21 *'We used to give some visual information before YoC we would print off results for some patients – this has been happening for a few years but with YoC all patients get this.'* (GP5)

Lack of Change

- 17.1.22 In one practice the nurse was voluble in her anger at some features of the way YoC was run and the limitations they were obliged to work within. *'The start off was shaky. The project was rolled out and there was no choice. Staffing levels weren't taken into account. There's a huge amount of work and no additional nursing. 50% of the time I've been 2 nurses down. We must have backfill but the money never came. We're low on admin staff. They're expecting me to do admin, recall and with articulate English speaking patients it can take 40-45 minutes. ... People on the ground are pulling their hair out.'* (N5)
- 17.1.23 *'In the previous one I was at, it was going like clock work. Here, nobody was completely committed. They weren't doing it and didn't believe in it. This is what we have to do, so we'll do it. Now, we can't get patients here in the numbers we need. We're not seeing enough diabetes patients every week. They all need an annual and 6 months.'* (N6)

Over-emphasis on Diabetes

- 17.1.24 *'25% of my time is spent on diabetes'. (N4)*
- 17.1.25 *'Patients with diabetes are contacted more often, seen more frequently. They have to because they are linked to QoF. If they are not seen, diabetes patients have 12 alerts.' (A1)*
- 17.1.26 *'Diabetes is not the only disease. Look at COPD, cancers, asthma, obesity....What other LTC has a 45 minute consultation? We're not providing an equitable service for FGM, contraception, menopause, sex abuse, domestic violence. Not equitable care.' (N5)*

17.2 Patients' Perspectives

Positive Change

- 17.2.1 *'Not really but I was well informed before it started. I think the formal care planning may be beneficial if I get a grip of it. I think there is more structure to dietetics, podiatry and exercise which can only be a good thing. I think the care planning will make people think that they will be examined in six months so they better do things.' (P5)*
- 17.2.2 *'I think there has been an increased level of information over the last couple of years. This has made me feel more a part of things. I have more ownership of my condition and understand more about how I can manage it and slow it down. The consultation feels more inclusive now – more like a discussion... I know more. I understand more about why it is important to take my medication at the right time and understand more generally about health and fitness.' (P8)*
- 17.2.3 *'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)*
- 17.2.4 *'It's got better. It's much more easy to understand. It's good to have a copy of your results so you can compare how things are going with the previous year. The nurse is more knowledgeable and there is chance to ask more questions. There is also access to training that didn't seem to be there before.' (P12)*
- 17.2.5 *'It has improved a lot. There is a lot more advice and a lot more involvement. It's much better. They give you advice on how to maintain a healthy life and you are encouraged to pass this advice on to others through informal routes.' (P14)*
- 17.2.6 *'I think the checks are more frequent now. The nurse takes more time in the appointment and talks about more things.' (P15)*
- 17.2.7 *'I feel that they care for me more now. I get more information and I don't feel so isolated. I used to just take the tablets and nobody bothered but now I talk more to the doctors and nurses... Before I just used to watch what I was eating but I didn't come in.' (P16)*
- 17.2.8 *'It has changed for the better. Reviewing progress and comparing the results is good. I get more information now too.' (P18)*

Little Change

- 17.2.9 *'I haven't noticed that anything has changed.' (P1)*
- 17.2.10 *'Nothing has changed.' (P4)*

- 17.2.11 *'There has not been much change in this practice – the new way of doing things is like how things have always been done. I think it may be making more difference in other practices though.'* (P5)
- 17.2.12 *'Nothing is different.'* (P7)
- 17.2.13 *'It's just the same.'* (P9)
- 17.2.14 *'Reviews are fairly routine. Nothing has really changed but the doctor seems very thorough.'* (P10)
- 17.2.15 *'No different.'* (P13)
- 17.2.16 *'I used to be called in once a year and now I am called in more frequently. Once a year suited me better. They are always very nice here. I haven't noticed any other changes. I preferred it when it was once a year and everything was done in one session'* (P17)

Difference Made to Them

- 17.2.17 *'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)
- 17.2.18 *'It encouraged me to help myself. I realise that I can make improvements myself – its not just about medication there are other things I can do.'* (P14)
- 17.2.19 *'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)

18 General

18.1 Miscellaneous

18.1.1 *'I think diabetes is dealt with fine. But, do I feel that the doctors are under pressure and they have to do too much. I think the PCT is cutting corners. Its no good just sending leaflets out to people – lots of people don't read them.'* (P11)

18.1.2 *We've missed a trick. If it works for one long term condition, we need it for all. Why do a hypertension annual review. We need YoC for all your health needs.'* (PB 7)

18.1.3 *'Care provision is unequal for Types 1 and 2. If offering care planning to one group and not to the other, how do we know it's not valid for both groups and why would we provide different care? If patient involvement works for one group, why not others?'* (PB 7)

18.2 Bottom Line

18.2.1 *'From what patients say, they have more time to talk about issues, not just about diabetes. Attendance has gone up. We've noticed, those that weren't coming are coming now because they're not coming to be told off.'* (N1)

18.2.2 *'Things are better than they were but there is still a lot more to be done.'* (N7)

18.3 Key Headlines

18.3.1 There is value in a HCA doing a range of activities that frees the nurse to care plan.

18.3.2 The folder that is given to patients appears to be extremely helpful. It provides clear, precise information that all can understand and use as a measure.

18.3.3 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 YoC.

18.3.4 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.

18.3.5 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.

18.3.6 There is a reasonably good awareness of care planning amongst patients in Tower Hamlets.

18.3.7 Patients value the training that is provided.

18.3.8 More YoC training should be provided to HCAs.

18.3.9 Small local support groups could be useful.

18.3.10 There are diverse and strong opinions about networks with some feeling optimistic and enthusiastic and others feeling concerned and angry.

18.3.11 Practices tend to be reasonably satisfied with the IT systems they have.

18.3.12 Year of Care does seem to have made a difference to the lives of patients with diabetes in Tower Hamlets.

Appendix 1: Interview Schedules

Year of Care Case Study - Questions for Patient Interviews

Introduction to include:

How we will use the data

Anonymity

Confidentiality within the group

Informed consent

Length of group/interview

1. What is your understanding of the Year of Care? What does it mean to for you as a patient?
2. What information, if any, have you received about what to expect from the Year of Care? What do you think about this information? (Probes: Was it presented to you in a way you could understand? What did you think about the format? What did you think about the content? What was good about it? What could have been improved?)
3. What did you think about your care planning approach? (Probes: Did it cover the right things? Was there enough time? What was good about it? How could it be improved?)
4. What did you think of the skills and knowledge of the professional who carried out your care planning session? (Probes: Did they listen to you? Did they explain things to you? Did they seem to have the right information? Did you feel your views were taken into account?) Is there consistency of staff?
5. At the end of the session/s have you been clear about:
 - What you have decided to do?
 - What the professional is going to do?
 - What would happen next?
6. Is there anything that could have been done differently to make things clearer?
7. Were you given a written plan? If so did you find this helpful?
8. What, if anything, to you feel you achieved in this/these session/s?
9. Did you find the process helped to identify your needs? If so has it helped to meet your needs?
10. Do you feel you were offered options in the process? If so how? Could this have been improved on?
11. How do you think this process compares to how things happened before you started on the Year of Care programme?
12. Has your involvement in the Year of Care made a difference to you? If so can you say how?

Year of Care Case Study – Staff Interviews

Introduction to include:

How we will use the data

Anonymity

Informed consent

Length of interview

1. What is your understanding of Year of Care?
2. What has your involvement been? (Length of time, roles)
3. How is Year of Care run here? (What does it look like? Do they involve the patients in setting the goals? How are they implemented in practice? How are they recorded in practice? Do the patients have options? What is offered? Is it outside of normal offering? How far are they going down that route? Are they given options in the care planning approach? Do they send test results beforehand?)
4. How has your role changed since being involved with Year of Care? (What do you do that is different? How have your attitudes changed to your work, to the patients, to colleagues?)
5. How has patient recruitment worked? (Have there been difficulties recruiting? How do patients respond? Are patients able to say no? What would the difficulties be in them saying no?)
6. What are your views on training – the training you have received? (How effective, in what way? How did it support or prepare you? What was lacking or deficient? Has the learning helped? In what way? Was the timing right? Should there be more? If so when and to cover what?)
7. What are your views on IT? (What should the systems do and do they do it? Is there an IT clinical record of care planning? What systems do they use? What is the history of their use? Do they support it? Can the systems feed data into commissioning? Are there IT templates? Do they get in the way of the consultation – the computer being the focus rather than the patient? What happens when things go wrong with it? How has it made things easier/more difficult?)
8. Do you think there has been a change in culture in the organisation since Year of Care? (How would they describe the culture of their organisation? What are the changes – how was it before and now? How can you infer that it is because of YoC or that it would have happened anyway? In what ways are these better/worse? How have they coped with organisational change? What are the staff's attitudes to workload? What are the staff's attitudes to YoC? Is there senior buy in to support culture change? Is there a resourced local champion to support / enthuse / role model?)
9. What word would you use for your relationship with patients? Do you feel that you work in partnership? (With whom and how? Is this something that comes naturally or have you had to work at it? What has it been like for you? Is it sufficient, or tokenistic, or could it be more collaborative? How? What is preventing it? Is the patient 'prepared' for consultation? Have

they received Information/ structured education? Do they receive motivational psychological support? Are they aware of process and options? Can they access their own records? Have they received pre-consultation results? Do they feel they have personally relevant information?)

10. What is your experience of dealing with patients who are more engaged? (Is it comfortable for you? Why/why not? How different is it now from the beginning of YoC? What happened? Stories, narratives).

Year of Care Case Study – Questions for Commissioners

(THIS IS AN UPDATED VERSION AFTER COMMENTS FROM A COMMISSIONER AT TOWER HAMLETS)

Introduction to include:

How we will use the data

Anonymity

Informed consent

Length of interview

1. What is your understanding of Year of Care?
2. What is your role with this project? (get a sense of their relationships with the project – professional, how well they work or don't).
3. Are you working with the project teams to understand what people want? (How? How far do they take it – do they accept what they are told? What are the processes?)
4. Are you able to identify and fulfil the needs of patients? (what do they mean by this? How is this achieved?)
5. How is a menu of care established and publicised? (What do they understand by this? How do they do it?)
6. How is micro to the macro commissioning undertaken? (How is this done?)
7. How is population needs assessments undertaken? (What do they understand by this in relation to YoC? How do they relate the individual to the population should needs not match assessments?)
8. How are current and future needs assessed?
9. What external consultant are commissioned to support YoC and its implementation, e.g. training, IT consultancy?
10. How is the effectiveness of YoC quality assured and measured?
11. How is diabetes management commissioned in this area?
12. How has leadership/cross section engagement been established?
13. How has a local champion been established and how effective is this?

Year of Care Case Study – Focus Group Questions with Patients

Introduction to include:

How we will use the data

Anonymity

Informed consent

Length of interview

Areas to cover:

1. What is your understanding of Year of Care? What does it mean to you as a patient?
2. What changes in practice have you noticed? What differences has it made for you? (if any). (Particularly, receiving test results, greater collaboration during the consultation and what that means, menu of options. Managing their diabetes now compared to previously.)
3. Are there new services available to support you that weren't available before? (What are they? Are there any they would like but aren't available.)
4. How has the training and education been in the past year? (Useful, what was helpful, what could be better, lacking.)

Year of Care Case Study – Questions for Focus Group Interviews with Staff

Introduction to include:

How we will use the data

Anonymity

Informed consent

Length of interview

1. What have been the changes that you've noticed since Year of Care began, if any.
2. Do you think there has been a change in culture in the organisation? (How, what, why.)
3. What has been the impact of partnership working and the engaged/informed patient?
4. How effective is the training for staff? What are your views on the training and education programme for patients? Do you see the results of this training? How?
5. What do you see are the barriers and constraints to effective implementation of Year of Care?
6. What works well?