Year of Care
North of Tyne Case Study
21 - 25 September 2009

Services for life

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1 Year of Care at North of Tyne

1.1 Introduction

- 1.1.1 A qualitative case study was undertaken in North of Tyne from 21 25 September 2009. Two researchers (Gail Louw and Janet Clark) spent a total of 8 days in the area and interviewed 39 people including patients and healthcare professionals. The interview schedule that was used is in Appendix 1.
- 1.1.2 Interviews and focus groups took place mainly at the Windsor Hotel, Whitely Bay. There were four focus groups with patients and carers. One practice and the Diabetes Resource Centre were visited. Interviews were either by telephone or face-to-face.
- 1.1.3 For the sake of anonymity, interviewees have been assigned numbers that bear no relation to when they were interviewed or where they are from. Focus group participants are represented by FG, the number of the focus group and the number they have been assigned within the group. Thus (FG1,1) is the first focus group and patient assigned number 1. P1 is a patient, GP1 is a GP, A is Administrator, D is Dietician and Comm is Commissioners.
- 1.1.4 Interviews were held with the following groups:

Table 1: Interviews according to Groups

	Patients and Carers	GPs and other Doctors	Practice Nurses/ Nurses	Dieticians	Administr ators	Commis sioners	Project Team	Total
Focus Group 1	3							3
Focus Group 2	6							6
Focus Group 3	2							2
Focus Group 4	6							6
Other Patients	8							8
Swarlan d Ave		1	1					2
Appleb y			1					1
Beaum ont Park		1						1
Lane		1			1			2

End								
DRC		2	1	1				4
Commi ssioner s & PT						2	2	4
Total	25	5	3	1	1	2	2	39

One member of staff is a project team member and a commissioner but she has not been double counted and is counted here as a commissioner.

- 1.1.5 North of Tyne is a well established centre for care planning. The originators of the philosophy behind Year of Care come from Northumbria and many still work in this area.
- 1.1.6 The original project team working on Year of Care was, by all accounts, extremely dynamic and able to invest many with a strong commitment and passion for the ethos and principles engendered by Year of Care. The original project manager had a clinical psychology education and worked full-time on the project for 14 months. The current project manager has 4 other projects on which she works, leaving far less time to devote to the Year of Care project.
- 1.1.7 The project team had the benefit of strong leadership and commitment from clinicians in both specialist and primary care. In addition the team had a member who spanned all sectors as a GP in a local practice and a Medical Director of a Trust. The project team were active in running structured events to engage practices in care planning development. One project member had a link role spanning primary and secondary care.
- 1.1.8 There are 23 Year of Care practices in North of Tyne (out of a total of 29) and 15 in West Northumberland. The decision to open the project up to as many practices as possible was explicit at the outset of the project. The evaluation was not a pre-requisite for practices entering the project and they did not commit to participating in the completion of questionnaires. 3 or 4 practices have never completed any questionnaires.
- 1.1.9 As West Northumberland has only recently begun its involvement with Year of Care, the case studies did not include any interviews with patients or healthcare staff from those practices.
- 1.1.10 Interviews with the doctors from the Diabetes Resource Centre were used to inform the background to Year of Care and to explore philosophical and methodological issues. The learning from these interviews have been used more substantially in reports that have emerged from this case study rather than within this write up.

1.2 Lessons from First Project Team

- 1.2.1 There are a number of lessons that the first project team were able to learn and to pass on. They are:
 - Ensure there is a clinical champion from primary care on the team.
 - Have a strong project team with good relationships within it.
 - Have committed people in the project team who believe in the project and its approach.
 - Project teams should be in place to support the implementation of the project.

- Be aware of cultural shift.
- Late afternoon sessions are the best way of involving patients in focus groups.
- Encourage attendance at focus and other groups through practices.
- Communication and continuing communication is essential.
- Feedback mechanisms must be in place.
- Understand what the next steps are and what expectations are.
- Training and awareness sessions must be made available for HCAs and Administrators. They need contextual knowledge.

2 Understanding of Year of Care

2.1 Healthcare Professionals' Understanding

2.1.1 Comments reflecting healthcare professionals understanding of Year of Care are shown in Table 2 below.

Table 2: Comments Reflecting Understanding of Year of Care according to Disciplines

Discipline	Comment
GP*	 Programme to try and improve care for Type 2 diabetes in general practice. Focuses on patient empowerment. It is a model where we can consult diabetes patients using a tool, involving them in decision making and giving them a care plan and approach diabetes differently. Trial of which NoT PCT are one of the pilots and looking at the effect of patient centred care and care planning on a patient's diabetes.
Nurse	 It's a collaborative approach – its about involving people in the long term in the management of their condition. It is also about supporting their requirements. Pilot study looking at care planning in diabetes. Centres around a change in the relationship between a person with diabetes and clinicians. It's a way in which the balance of power changes – not just paying lip service to empowerment. Patients have more information which leads into them having more say.
Dietician	Giving ownership of diabetes and results to people with diabetes so they have equality with HCPs. What they think is as important as the HCP. Levelling things up from the patient's point of view, allowing them to set their own goals and plans an dhow to achieve them. Results beforehand is a big lever.
Administrator	More onto control of patients to manage their own diabetes in a way they can up to a point with the assistance of the healthcare professionals.
Commissioner	Provided opportunity for individual patients and clinician to have a more meaningful dialogue on choices, care and interventions needed for delivering package of care for diabetes.

2.2 Patients' Understanding

Heard of it

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

- 'Yes they are making a special effort to look after people who are ill, to be more aware of what individual's need.' (FG1,2)
- 'Yes. A special effort from you and the doctor.' (FG1,3)
- 'Have heard about it. Means looking after patients' care'. (FG2,1)
- 'Educating people a bit more to inform them and increase knowledge that is readily available.' (FG3, 2)
- 'Yes I have heard of it. It's about information and knowledge for patients.' (FG3, 1)
- 'Bring the treatment and help with diabetes up to date on the patient side.' (FG4.5)
- 'Intended to get patients more involved in their own care.' (P6)
- 'intended to put the patient more in the picture of what's been done to care for them in the community.' (P7)

Not Heard of it

- ' No.' (FG1,1; P4, P5)
- 'I get a form from my doctor to go to the chemist and then get prescription directly from the chemist. Don't know if this is the same thing?' (FG2, 3)
- 'Not heard of it.' (P1, P3)
- 'I've only heard about it in conjunction with this interview. I had not heard about it before I was asked to take part in this interview.' (P2)
- Only one patient in FG4 had heard of YoC.
- 'No. But I don't think I have diabetes. They said my blood count was 13 but I said never, cos I'm as right as rain.' (P8)

2.3 Self Care

2.3.1 'Patients need to take decisions themselves, manage their illness themselves, rather than us telling them this is right for you. Take control and responsibility. They make changes, we advise.' (GP1)

2.4 Year of Care at Selected Practices

2.4.1 This section provides some insight into how YoC is run at a number of selected sites. These are based on the comments made by interviewees and a visit to one practice. It does not enable a rich picture to emerge of how YoC is run in North of Tyne.

Swarland Avenue

2.4.2 Diabetes clinic is run once per week. 85% of the Type 2 patients are looked after in the practice. The weekly clinic is run by the Dietician, Practice Nurse and GP. They maintain a register, call and recall and review. Patients have a half hour appointment annually with each HCP.

- 2.4.3 Newly diagnosed patients see the nurse or the GP and are referred to DESMOND training. All patients attend the diabetes clinic once a year. The practice has a dedicated receptionist.
- 2.4.4 Two weeks before an appointment, patients attend for biomedical tests. Information is entered onto the computer and a letter goes to the patient before their clinic appointment with the results. The can attach areas of concern and bring them in with them. Patients are given a care plan with their goals, an action plan and a page for their notes. They return for a review after six months and their plan and goals are revisited.

Appleby Surgery North Shields

- 2.4.5 Patients are invited for their annual review in the month of their birthday. They receive a phone call or letter to attend the surgery to see the HCA who does the weights and measures. A letter is sent to patients a week before their appointment with their blood results. There is space on the letter for them to write down their ideas and plans though they do not have to do this.
- 2.4.6 Diabetic clinics are nurse led. The GP is in the practice and available should a problem arise. The consultation lasts for 30 minutes. Templates are filled in during the consultation.

Specialist Centre

2.4.7 Year of Care is not run at this centre. They are planning to bring care planning into 2 clinics. Three years ago there was a care planning clinic which ran as a pilot. There were various obstacles including not having an HCA to do pre-clinic appointments.

Beaumont Park, Whitley Bay

2.4.8 The nurse runs a weekly diabetic clinic. The GP is available if there are any problems. They are not involved in the Tribal evaluation and do not hand out questionnaires. *The whole package isn't happening.'*

Lane End

- 2.4.9 This practice has been running a YoC approach for over 3 years. A clear agenda is set with patients with a timeframe. The consultation is tailored to the individual patient and psychosocial issues are identified in the course of the consultation. The GP is the GP Lead in the pilot site of North of Tyne.
- A search is run every quarter to identify all diabetes patients to see if they are seen at primary, or specialist care of if they are housebound. Each patient has a diary date determined by their birth month. Full annual review includes a double appointment with the HCA. Once blood results are back, the GP looks at all results individually to decide if a full annual review will be with the GP or the dietician. The PN only does 6 monthly reviews. Patients receive 3 invitations to attend, an initial letter and up to 2 reminders.

3 Changed Roles

3.1 Changes to a GP Role

3.1.1 'Nothing, no extra work. The consultation is different but we were moving to it already. It hasn't changed the way we run the diabetes clinic. No extra sessions, not longer. 30 minute appointment every 6 months or more frequently if there are problems.' (GP2)

3.2 Changes to Practice Nurses' Roles

- 3.2.1 'My consultation technique has changed. The patient takes the lead. I always thought this was the best way of doing things but this has formalised the approach.' (N1)
- 3.2.2 'Looking back to being involved in care planning clinics in surgery, the dynamics of the consultation were different with the vast majority. More like equal conversation between 2 people. It felt a lot better, more healthy.' (N3) This nurse used to work in a GP practice and introduced care planning into it.

4 Organisational Changes since Year of Care

4.1 Appointments

- 4.1.1 'I go for a blood test every three months. I get a letter for an appointment every 6 months. I can get an appointment within 2-3 days.' (FG4,4)
- 4.1.2 'I was diagnosed in October and they sent for me in January. There was no more till September. I had to ask for it.' (P4)
- 4.1.3 'It's more time consuming fitting in appointments with the doctor rather than them making appointments with the practice nurse.' (A1)

4.2 Impact on Organisation

4.2.1 'It hasn't had any great impact on the rest of the organisation. It has had a little on admin as it's changed the way she works. It's challenging at the start. Get people in, arrange both appointments, timescale was tight.' (N2)

4.3 Specialist Care

4.3.1 'Will it work in specialist care given that patients are referred to for specific things. ..Goals have been set in primary care. In that case do we need to do full care planning or just the bit patients have focused on. Then just action planning with them... Changing the administrator function is harder in specialist care. It's tied up to departments you don't manage. In primary care, the GP manages the admin function. There are organisational barriers.... We have run care planning clinics in specialist care and they mean well and were appreciated by patients. It's tricky to roll out. .. Travel in rural areas is significant. There are different challenges to face. ..Seeing people with complex problems. Different groups such as young adults.' (D1)

5 Care Planning: Results

5.1 Received Prior to Appointment

- 5.1.1 'I had my tests taken the week before my appointment and they did send a document before the appointment to help me think about questions for the appointment. It was helpful.... I do get a sheet with readings before I go.' (FG1, 2)
- 5.1.2 'Now we get documents before it helps up to think more about it. Before I just used to forget about it.' (FG1, 1)
- 5.1.3 'I get my results before my appointment. It's good to get them before. I did get a care plan. I think I kept it but I have a very bad memory.' (FG1,3)
- 5.1.4 'I have the results before my appointment. It helps me understand if there are any improvements from previous year. Helps me keep track of things like diet... The document was very clear and if I didn't understand I would ask at the appointment.' (FG2, 2)
- 5.1.5 'But they did send my results to me at home. I think this is good so that I know what is happening.' (P1)
- 5.1.6 'Making out a plan by which you get all the tests done before the clinic appointment. Everything is detailed out on the report and sent out before the appointment so you have all the information and you can discuss it with the doctors.' (FG4,2)
- 5.1.7 When asked if it was helpful to receive the results early, one participant said, 'No, not really. It's just medical jargon and figures. Just baffled us. I looked at the previous one, not much different. I didn't know what was good or bad.' (FG4,5) When asked if there was an explanation, she said, 'no, the nurse is always rushed, stretched.'
- 5.1.8 'I had a number of visits to the hospital and each time they take bp and I make a note of it in my diary. I am pleased to get the information. I had an argument with Dr.. as a result of getting the information. My Hb1Ac was 6.9 and I like to keep it below 7. Dr.. wanted me to keep up with my meds, he said it should be 6.5. He's moving the goal posts. I don't like taking tablets..... I'm due to go for a 6 month check up at the beginning of October. At the last check up (March or April) I was sent a letter telling me what Dr.. had told me, not what the results of the test were..' (P7)
- 5.1.9 This patient is blind and unable to read anything. 'I have my bloods taken and they ring me to tell me I'm alright so I don't need to go in and see them. If I'm not right I go and see them.' (P8)

5.2 Not Received

- 5.2.1 'I got my results at the surgery.' (FG3,1)
- 5.2.2 3 out of 4 in FG2 did not have results before their appointment.
- 5.2.3 'I had the tests done before my appointment but only the eyes tests results were sent to my home before the annual review appointment. I have been having my blood tests done quite regularly and seeing the doctor and the nurse quite regularly but results have not at any point been sent to my home address and not the point of annual review.' (P2)

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- We go a week before. We see a doctor once a year. At 6 months it will be just the nurse then we see the doctor. Nobody said anything about getting the results before the appointment.' (FG4,1)
- 5.2.5 'I don't get postal results.' (FG4,4)
- 5.2.6 'At the hospital I used to have bloods taken a week before but now I get bloods on the same day.' (P5) This patient goes to the DRC.
- 5.2.7 'I didn't receive blood results before this time. I was having difficulty with timing with clinics because I work. Once I got a letter beforehand. Last October. It was fine, didn't make a difference but it is good to have it in front of me. Having it in front of me wouldn't help me prepare for the consultation. Maybe I'd look for excuses or reasons..... They (work) wouldn't let me go early to get the bloods taken. I made a fuss so they agreed to be done in the morning (of the appointment)' (P6)

5.3 Patients' Attitudes to Receiving Results

- 5.3.1 'Good idea because you can prepare questions and think about how you could improve in certain areas or may need to change medication.' (FG2,1)
- 5.3.2 'I think it would be a good idea because it would give you longer at the appointment to discuss other things.' (FG2,3)
- One participant in a focus group was asked what she thought of getting results before an appointment. 'Doesn't bother me. If I got it at home, I would worry about it. If I had it before and looked at the last one and it was more, I'd get more worked up and my blood pressure would be sky high. I prefer to get it from the doctor.' (FG4.3

5.4 Healthcare Professionals' Perspectives

- 5.4.1 'They have a print out of all the results so they can see what is happening. They can decide what is most important.' (N1)
- 5.4.2 'Blood results are sent out 2 weeks before. 5% are latched on, 5% will bring their care plan. 5-10 will bring the letter. 10-15 won't bring the results letter even though it was written on it to bring it back. It's a big cultural change. Some patients say, thanks for sending it but I don't understand it. Some, why did you send them. We reinforce each visit we've changed the way the clinics are run. Results are there to bring... Need constant reinforcement.' (GP1)
- 5.4.3 'Patients can say they don't want results. We've had some. A lot have refused care plans. Why? Because they're elderly. Some have carers, patients are too frail or have dementia or are excluded.' (GP1)
- 5.4.4 'I don't know why people get het up. None of my patients need preparation. People used to get worried that sending out results would make them anxious, concerned or not understand. Provided they know they're coming in to a supported consultation. Train patients in care planning! Phh!' (GP3)

6 Care Planning: Consultation

6.1 Patients' Perspectives: How things work

- 6.1.1 'I see the nurse every 6 and 12 months. I have blood and urine tests and my feet are checked. When the results are back I see a nurse and she goes though the results. I also see a dietician.' (FG3,2)
- 6.1.2 'I saw a nurse and dietician after my initial diagnosis and had my feet checked.' (FG3,1)
- 6.1.3 'If everything seems fine I don't go to the doctors. I do see the nurse but we haven't set any goals in the session. I do ask questions if I have aches and pains.' (P1)
- 6.1.4 'The nurse has been rotten in the past. The nurse went through a load of things. Reeled them off like a tape recorder. Only have 10 minutes, statins, weight.' (FG4,5)

6.2 Patients' Perspectives: Positive Responses

- 6.2.1 'I have the test done before my review and then see the chiropodist and the doctor. They talk about my personal life it's friendly and they ask about any problems. '(FG2,4)
- 6.2.2 'She involves me in the conversation and asks me how I fee about things when we are going through the results to compare with how things were 6 months ago. She is always available for advice if needed. I am limited to the exercise I can do as I have arthritis.' (FG3,2)
- 6.2.3 'They do go through everything which is brilliant.' (FG4,1)
- 6.2.4 'Sessions have always been fine but I haven't noticed that they have changed at all. It has not been different recently in the approach they use but it had all felt as if it is part of a continual process.' (P2)
- 6.2.5 'I'm happy. I trust them. It's easy to contact them. Nothing phases them. I've got confidence. 2 nurses are lovely. If I have a problem they sit and listen and try best to help... Same with Dr.. but I don't often see him. I'm listened to. From the receptionist, seem to want to listen to you. Even when I had my feet checked.... They seem to explain, if Hb1Ac are up, this will happen, that will happen. They're open about the results and what they mean.... I nearly lost my sight at the GP. Then I went to the hospital.' (P5) This patient has her diabetic care at Diabetes Resource Centre.
- 6.2.6 'The Practice Nurse was a little more friendly and less dictatorial than she had been in the past. I felt she felt her behaviour was being monitored. She was under scrutiny. With YoC, it's supposed to give more ownership of care to the patient which wasn't the case in the past. But she said now, it's up to you. In the past she said, this is what happens. Now, is that what you want? It felt very positive.' (P6)
- 6.2.7 'He was prepared to listen. He took my comments which could be critical. He wasn't pleased when I said 'you're moving the goal posts." (P7)

6.3 Patients' Perspectives: Neutral Responses

6.3.1 When asked if their consultation was different now, both participants in FG3 said it was the same.

6.4 Patients' Perspectives: Negative or Ambivalent Responses

- 6.4.1 'They didn't even tell me the tablets should be taken 12 hours apart. I only found that out at a different pharmacy. I've never been offered what else to do because I can't walk. They know I'm under stress but I haven't been offered advice. They look at my diabetes and cholesterol and that's it. No offer of alternatives' (FG4,1)
- 6.4.2 'Alright with nurses, not so sure with GPs.' (P4)
- 6.4.3 'They take my weight and blood. Ask if my feet are swollen. That's it.' (P8)

6.5 Healthcare Professionals' Perspectives

- 6.5.1 'YoC has formalised this approach. The patient is in control. Patients are better prepared now. YoC has helped to reaffirm the message and give context. Things are a bit clearer. The care plan is attached to the consultant screen but faces the patient so they can look at it. I sit back a bit in appointments and make it more patient-centred. Let them look at the results and then go through the risks with them..' (N1)
- 6.5.2 'I work through the template and the care plan. They and I both identify. [when asked what proportion] I'd like to say 50:50 but it could be 25:75 either way. Elderly patients are happy for me to do most of the talking. ... Previously I was never, you must do this, you must do that. I always had a conversation and listened to their views. Now it is more structured. The thinking is more from the patient's point of view rather than the professional point of view. It focuses your mind on their motivations to make changes. ...I'm more aware if patients come in with knowledge, we can have a discussion. I'm in line with their thoughts It's more a partnership to achieve their goals. Much more of a two way street.' (N2)
- 6.5.3 'I say, so what do you think has gone wrong? We've had this discussion so let's put some structure. Which do you want to circle today? Which is the most important?' (GP1)
- 6.5.4 'Motivational interviewing; until you had a try you don't appreciate what you can achieve re the language you use with patients. It takes a lot to get that attitudinal shift. How many people can really consult?' (GP3)
- 6.5.5 'In some areas it could be a challenge for patients with lower intellect .. <u>Tailor</u> the consultation to who's coming in. Value patients' intelligence. Most people know bp and once discussed, Hb1Ac. Walk them through it.' (GP3)

6.6 Healthcare Professionals' Perspectives on Patients Responses

6.6.1 'How the approach is received varies from individual to individual. Some are very clued up and some find it very foreign. Some are hard to manage through the process – you can't force them to do it. Very few don't want a goal. Quite a few have written on their plan when they come back. Some get enthusiastic about their goals and they become part of their daily life. Most do take some ownership.' (N1)

6.7 What was Achieved: Patients' Views

- 6.7.1 'I go for tests and everything is ok If I don't have any problems and I find this out.' (P1)
- 6.7.2 'Somebody to talk to who understands. Silly little questions I feel I can't ask the GP. I'm not bothered about going there. I'm not nervous at all, no qualm at talking to them. Look this isn't working, let's see what else. Before there was one male GP who has the prescription wrote before you go in. One hardly speaks to you.' (P5)

6.7.3 'I suppose it's only keeping a check. Because you know you have to be monitored on a regular basis. It helps to keep in line with diet and exercise. It helps to give you the willpower and not fall off the regime.' (P6)

6.8 Identifying Needs

- 6.8.1 I'l don't go in asking questions. I could if I wanted to, if I wrote them down before I went in.' (P4)
- 6.8.2 'Identified asthma questions and needs.' (P5)
- 6.8.3 'Not really. I can know my own needs.' (P6)

6.9 Options Offered

- 6.9.1 'Yes, options on tablets, which would be best. Also DAPHNE.' (P5)
- 6.9.2 'Not really. I've been told what they thought I should look after; diet, lose weight, bp. What options are there? I'd be insulted if I was offered an exercise referral. She doesn't know me very well. It's up to me to decide what exercise I do. She tells me to go to the chiropodist. But I was told by a chiropodist that I was entitled to it. But the practice didn't tell me that.' (P6)
- 6.9.3 'No way. Definitely not.' (P8)

7 Care Planning: Goal Setting

7.1 Patients' Perspectives

- 7.1.1 'They want me to lose half a stone in six months. Me and the nurse decided on the amount. It is hard for me to exercise but I agreed to do a bit every day. I got my results before the appointment and there was a care plan saying what I was going to do now.' (FG1,1)
- 7.1.2 'I see the nurse and have my blood results two weeks before. They are sent out before the appointment so we can talk about goals. The goals we agree are written down for example weight reduction and keeping cholesterol down.' (FG2,2)
- 7.1.3 'The goal setting is done together we talked about losing weight as this will reduce my blood pressure. They are my goals. I get the care plan with my results at the appointment. I find this very helpful and we refer to the previous year's tests. At my last appointment they tweaked my blood pressure tablets and we agreed I need to lose weight.' (FG2,4)
- 7.1.4 'The GP praises the fact that I have lost weight and asks what I would like to achieve. My goal is to get off medication which is not possible at the moment.' (FG3,1)
- 7.1.5 'The doctor has made suggestions for goals but not things with specific targets we talked about reducing my weight but did not set a target we also talked about bringing down my blood sugar.' (P2)
- 7.1.6 'He gave me a ruled page. He wrote down on there the things I said I would continue to do. He asked me what I thought I could do to improve things. These were things we discussed. I thought 2009 is the year I did something.' (P7)

7.2 Patients' Perspectives: Negative Responses

- 7.2.1 'Yes. The nurse talks through your results and then talks about goals. I don't get a care plan though. I have had problems with one of the nurses at the surgery not listening to me and she has a poor attitude.' (FG2,1)
- 7.2.2 'It turns my blood pressure sky high. I feel patronised. This is what happens and there can't be a deviation. There is no acceptance that my blood sugars fluctuate more. I feel I know more than she does. And so it doesn't achieve anything.' (P6)
- 7.2.3 'The nurse says, you need to lose weight. She says you got to do it. Like a headmistress.' (FG4,5)

7.3 Healthcare Professionals' Perspectives

- 7.3.1 'I help them define goals. We talk about barriers they have to achieving goals and focus on their agenda. We need to empower patients to make this work.' (N1)
- 7.3.2 'I encourage them to bring the A4 paper. The information is in front of them with results with explanation, previous target, previous result, what would be good if down or up, risk reduction information. On the back there is this place you can write down items to discuss. At the bottom is agreed targets... If they don't bring it I print another one off. The action plan is the result of discussions of what's important to the patient. If their target is different to mine, I would put theirs first. It would have to be something major that I would add on.' (N2)

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- 7.3.3 'We don't have formal templates or formally recorded. But we use the principles and goals to work towards. It's not recorded in a specific way.' (GP2)
- 7.3.4 'Patients say it's helpful to have things written down. We set goals with patients but 2 months later goals change, because life changes. They're not making plans for a year ahead. It's your <u>present</u> care plan. Year of Care terminology worries people. They think everything has to go on for a whole year. It may hinder people. It's about tailoring it to patients. If you do some exercises 'what would it look like? What helps to motivate people to them to think about things themselves. If they don't do it, they think they fail you as their GP.' (GP3)
- 7.3.5 'Have you got your results? What do you think? Talk me through your results. What does that mean to you? Any concerns? So what we discussed is.. you'd like to do this. Well, I have this exercise thing on prescription, is that something you'd like? You said you're interested in exercise, what would that look like for you? Not interrupting!' (GP3)

7.4 Written Care Plans: Patients' Perspectives

- 7.4.1 'It's a verbal discussion but no care plan.' (FG1,2)
- 7.4.2 'It's a good idea. I see the nurse to get my results and then get a care plan and print out when I see the doctor.' (FG2,4)
- 7.4.3 'I don't have a written plan.' (FG2,3; P4)
- 7.4.4 In FG3, *n*either of the participants had a written care plan. Both thought it would be useful and that it would be important for it to be written in English and not clinical jargon.
- 7.4.5 'In hospital every time I get a check up I get results, like a care plan. It gets sent to me with every detail we discussed with the doctor or nurse.' (FG4,2) When asked if she takes it back with her, she said, 'sometimes, because they've got it on the computer.'
- 7.4.6 One participant who did not get written care plans said, 'it would be good, something to keep in touch, a link back to the surgery.' (FG4,3). Another agreed and said, 'sometimes the mind wonders and I don't remember. It would be good to go back and check.' (FG4,5)
- 7.4.7 'The first one was done in the clinic. Then when I went I looked at it, juggled it about. Then she sent a new plan out a few days later. .. It's written plainly so I can understand it. It has objectives of what to achieve and how they can help achieve them. How to get bloods down. Laid out simply. Your views are added in.' (P5)
- 7.4.8 'This time she typed on the computer what we agreed. It was a bit of her words and mine.' P6)

7.5 Written Plans: Healthcare Professionals' Perspectives

- 7.5.1 'I would like to give patients something in their hands when they leave ... Could type in while the patient is there. You need a printer in the room and print it off and give it to the patient. Or it could be handwritten by the patient or clinician. Ideally by the patient.' (N3)
- 7.5.2 'I say, so what are you going to do? The elderly say, you write.' (GP1)

7.6 Options

7.6.1 'I have been encouraged to go to a gym. I did start the sessions but I had less time and gave up. I have been ill myself and I am self employed. I don't have much time.' (FG1, 2)

- 7.6.2 'We talked about what would be good for me for example what would be the benefits of regular exercise. We did not talk about any options, groups or services that my have been able to help me with this. We also discussed depression as this is something I have been struggling with but again we didn't talk about options. I am aware of local services and would go back to my doctor if I felt I needed help in this area.' (P2)
- 7.6.3 'I haven't been given the option of blood strips on prescription. By testing bloods regularly, I'm checking and if I check every day it helps to keep me on track and helps the NHS by me not deteriorating. The nurse said you shouldn't be checking the bloods, we do it. But only every 4 months.' (P6)

7.7 Services Required

- 7.7.1 'It would be useful to have a list of local exercise options.' (FG3,1)
- 7.7.2 'It would be nice if there was somewhere to go at the clinic for exercise. Specially with winter coming on.' (FG4,3)

8 Staff Training

8.1 Training Received

- 8.1.1 'I had half a day of training last year. It covered what YoC is about and why it is being piloted. It was helpful it did get goal setting across well and made you think. The best thing about it was the session with other practices to share what we are doing. It is good to hear how everyone is getting along with it. Our admin team has received training from the GP explaining what they need to do and why. They are on board and are tend to be more pushy with patients about their appointment because they understand why it is important for them to come in.' (N1)
- 8.1.2 'I did the training. It was interesting, I learnt a lot, all about the different parts of putting together the YoC package. Everyone was doing it differently, and we could iron out problems. It gave a clear view of what we were meant to do. There was group work, a mix of nurses and doctors, primary and secondary care. The consultants were very upbeat and keen. The role play was cringe making but it served its purpose. The video was a bit stage managed. Would all of it happen in real life? It was ok. The follow up days were good. Had just 1.'(N2)
- 8.1.3 'I had 2 sessions, half days with consultant dietician and YoC leads. It was helpful, timely. I'm very pleased.' (GP1) When asked if he wanted more, he said, 'no, quite content.'
- 8.1.4 'The training was really good. It was useful, timely. It was done with lots of interaction and role play. It was not threatening..' (GP2)

8.2 Identifying Training Needs

- 8.2.1 'Maybe one more [follow up day] would be good about a year after starting Would be nice to see if someone had sorted out a IT glitch.' I(N2)
- 8.2.2 'I would like more, yes, review of that. It's nice to meet up yearly, see how everyone's doing, get new ideas.' (GP2)
- 8.2.3 'Practice Nurses don't have much opportunity for training. Recognising and valuing training is important. What price tag and who pays for it?' (GP3)

8.3 Training for Administrators

8.3.1 'There is in house training on the admin side. There is a letter to patients which explains what YoC is about. I have a good grip for what I need. I'm happy that I can find out if I need to.' (A1)

8.4 Challenges

8.4.1 'Specialist services is difficult for them to be involved in day to day training of primary care staff because of lack of resources. ... I would have liked to see a regular meeting every couple of months of interested clinicians. We need someone to facilitate it. We need a central person to pick up all the pieces. Without it, it loses impetus. Someone to rally the troops... There are too many chiefs and not enough Indians.. We need people on the ground to co-ordinate needs and to be a voice for staff. We need a training co-ordinator.' (GP3)

8.5 Professionals' Skills and Knowledge: Positive Responses

- 8.5.1 'I see the nurse when I come for my measurements and discuss things with the doctor when I come in. I see the doctor annually. The doctor covers all the points. It's a friendly discussion and advice session and not particularly medical.' (FG1,2)
- 8.5.2 'I very seldom go to the doctors I don't think I have seen a doctor in three years but I do see the nurse twice a year for appointments. That's ok.' (P1)
- 8.5.3 'This has all been fine they have been very flexible in arranging my appointments as I work away a lot. I felt that I was taken seriously and they have been able to answer all my questions. I have felt very comfortable with the way they dealt with me.' (P2)
- 8.5.4 'My nurses are brilliant. The dietician is great.' (FG4,4)
- 8.5.5 'The Practice Nurse is knowledgeable.' (P4)
- 8.5.6 'I'm not in a position to judge that but he seemed to know.' (P7)

8.6 Professionals' Skills and Knowledge: Negative or Ambivalent Responses

- 8.6.1 'I feel I can't rely on the nurse I feel I want to speak to the doctor. I have more faith in the doctor especially the old doctor that I used to have. I don't feel that Dr X is putting as much into it.' (FG1,3)
- *The difficulty I have is that I feel she has set and rigid information. It's not individualised, it's very generalised. I'm not on medication. The information given is go on the diabetes website, look at the diet. Carbs don't work for me. I found the carb diet doesn't work. The information she has is that you can't veer from that. It's rigid national information. No leeway. That hasn't changed... ...She would respond to queries, but if I didn't ask anything she wasn't forthcoming.' (P6)
- 8.6.3 'It's not the personal touch a doctor used to have. These young ones haven't known any different.... I had to fight to get the tablet changed. They couldn't understand it, looking at the computer to see if there's anything with the tablet that affects people. But it affected me and that's a dead cert. They changed my tablet.' (P8)

8.7 Training Philosophy

8.7.1 'Not empowerment or motivational interviewing, not counselling. It's using skills drawn from those to do things differently. Empowerment is a loose phrase and people mean different things. So we're not doing empowerment training, having a nice chat. Motivational interviewing is a specific skill. Listening to patients' perspectives. Find out what their health beliefs are. Understanding their perspectives and valuing that. You have information you need to share with them. You can't do anything for them but need to make them aware of their risks.. Counselling is just listening. But here we also need to thin of cholesterol- putting the professional's story in there as being equally important. But the person is responsible for themselves, knows what they want out of life. .. Making sure all things concerned are put in the melting pot.... Getting people to reflect what they want. It's not superficial, easy stuff. Some find it uncomfortable. It's about helping people problem solve.' (D1)

9	Patient Education
9.1	Training Received
9.1.1	'I had some 18 years ago. I can't remember much about it.' (FG1, 1)
9.1.2	'I went on a one day course were we were told what to eat and what not to eat.' (FG2, 1)
9.1.3	'They decided to put us on insulin. They said they were running a course, will I put you down. Yes. They were great. They weren't criticising, didn't say bad person if you have that. I felt weren't the only one with the problem.' (FG4,5)
9.1.4	One participant in FG4 had attended DAPHNE and one DESMOND.
9.1.5	'DAPHNE was really interesting.' (P5)
9.2	Training Not Received
9.2.1	2 out of 3 participants in FG1 had not received any training.
9.2.2	'It wouldn't do any harm but I would have to bring my wife as she is the one that could make changes to my diet.' (FG1, 2)
9.2.3	In FG 3, neither had been offered any training. 'I couldn't do it if it involved a lot of time.' (FG3, 2). 'I think I am doing ok so wouldn't need it.' (FG3,1)
9.3	Support Required
9.3.1	'When I was given my finger pricking box it was just handed to me by the nurse with no explanation. I was reliant on a friend to show me what to do. I would have liked some support with this.' (FG3,1)
9.4	Healthcare Professionals' Perspectives
9.4.1	'We've got DESMOND. All newly diagnosed are offered, occasionally they say no. I would like to have DESMOND all the time.' (GP1)
9.4.2	'All of our newly diagnosed patients are told about DESMOND. Most are offered it. That's been the case for 2-3 years. It's not a new thing.' (GP2)
9.4.3	'We need a rolling programme for people who never received DESMOND. All are offered at initial diagnosis. Some clinicians are anti it. They're not into the habit of referring. There's not enough on going education.' (GP3)
9.5	Patient Support Groups
9.5.1	In FG 2 all agreed that support groups would be good and that it would be beneficial to

- 9.5.1 In FG 2 all agreed that support groups would be good and that it would be beneficial to get other people's perspectives. In FG3 neither of the participants had been offered anything and one would have liked to be offered emotional support. Both agreed that support groups would be helpful.
- 9.5.2 'I was told that the DRC has a help group that I could attend. When I went it was more like a business meeting than a support group.' (FG3,1)
- 9.5.3 *'They work.'* (GP1)

10	Information to Patients
10.1	Information Received: YoC
10.1.1	'When I went for my 6 month check up, the practice nurse spoke of it and I filled in a questionnaire. I saw something in the Local Authority magazine.' (P6)
10.1.2	'Initially all Type 2 received a letter explaining YoC and then did it at the clinic.' (GP1)
10.2	Information Received: Diabetes Care
10.2.1	'I got leaflets about diabetes made into a book. I look at that when I think what shall I be doing.' (FG4,3)
10.2.2	'I received lots of information about diabetes.' (P5)
10.2.3	'I give information depending on their needs.' (GP3)
10.3	Information Required
10.3.1	'I see the nurse for my tests and then the dietician two weeks later. She encourages exercise and housework to lose weight. I would like more information on what to eat. I get a monthly newsletter called Balance to help. I heard about this from the doctor and filled a form in. I want more information about fat content and sugar content. They do encourage weight loss and exercise but not on a personal basis.' (FG2,3)
10.3.2	Some in FG2 felt that information on sugar content in food would be helpful.
10.3.3	'When I saw the dietician they didn't specify on a personal basis they just gave general information. I was not told what level my blood sugars should be.' (FG3,1)
10.3.4	'They haven't told me what to do if a hypo is coming on. Nothing was explained other than I was advised to take a sweet if I feel unwell. When it happens to me I sweat profusely and my eyes feel like they have tunnel vision. They didn't tell me about how diabetes affects the eyes, kidneys, limbs and feet I would like to have a way of identifying me as diabetic if something happens to me whilst I am out. A card that I could show people to explain what is happening to me.' (FG3,2)
10.3.5	'I might have liked more input from a dietician but I have seen one in the past and I can look things up on the internet.' (P2)
10.4	Information Not Received
10.4.1	'Didn't get any that I remember.' (P1)
10.4.2	'I don't remember having any information about care planning or forms to fill in.' (P2)
10.5	Conflicting Information
10.5.1	'I have had conflicting advice about blood ratings and what is too high.' (FG3.2)

11 Information Technology

11.1 Systems and Support

- 11.1.1 'We are on EMIS we are an EMIS pilot so our system is different. We do have a dedicated IT member of staff. If we want things adding to our template or IT person does it. Not really sure if the information we have on the system could be cumulated to inform commissioning. It used to be a big job for our admin sending out the results but we have streamlined the system so it is more manageable.' (N1)
- We have EMIS LV. EMIS is great. It works well. The care plan is on a word document and it merges onto the medical record. Anything we write on plans isn't scanned. We write after the patient's been in. If they want it they can get it. It's not major, it's up to them if they want to write it down. It works, not a problem that care plan isn't on the computer. It's only a word document that prints off and hand write in. We have a glitch with cholesterol readings. It won't transfer from the medical record to the word document.' (N2)
- 11.1.3 'In the pilot we used word documents and the results were put in the document by the HCA. The action plan we dictated the action plan and the secretary typed it onto a template.' (N3)
- 11.1.4 'We have EMIS PCS. It's been fine. We modify it and make short cuts. We get used to it and it's more and more useful. I start doing care plan on computer and it prints one out. I don't type in the results, it's done automatically. Have incorporated CP into EMIS by the IT technician. We don't get out of EMIS, we create a word document with EMIS. We have our own IT manager. It isn't difficult.' (GP1)
- 11.1.5 'The handwritten care plan gets scanned and sent to the patient. It's not a big issue.' (GP3)
- 11.1.6 'I don't like SystmOne. The PCT says it's preferred. GPs don't want it. We like EMIS. EMIS is easy to use. People who've transferred to it [SystmOne] only 3 in North Tyneside, when they transfer you can lose data.' (GP3)
- 11.1.7 'We need to add a box to the care plan to look at unmet needs.' (GP3)

11.2 Problems with Systems

11.2.1 'We have EMIS PCS. We have problems with integrated letters. We had problems with choose and book. We've been trying since we started to find someone to help. I will arrange it with Nicola.' I(GP2)

11.3 YoC Template

- 11.3.1 'We now code care planning.' (GP1)
- 11.3.2 'There will be templates somewhere. There is a LV one but it doesn't work on our system. Nobody in our practice can do it. We can see the benefits and are keen to do it.' (GP2)
- 11.3.3 'We can't write the care plan on the screen. We merge documents from other files, e.g. DESMOND referral. The form is not produced but the plan is that it will be a merge document.' (GP3)

11.4 Focus on the Computer

11.4.1 'They're on the computer all the time. They're just on the computer.' (P8)

11.5 General

11.5.1 'My concern is that IT drives the care planning process when it should be the other way. IT should support, not drive it. If an IT template isn't right, the staff will become confused, language and terminology and structure. The way they train for care planning fits in with IT – support rather than hinder. If it's cumbersome, people get waylaid with which box and it is distracting rather than helpful.' (D1)

12 Culture

12.1 Positive Change

- 12.1.1 'We have always prided ourselves on our diabetic care. We have become more confident at passing ownership to the patient. It is an increased workload but we do have pretty good IT support. Our biggest problem is if patients cancel appointments. I think that YoC may reduce patients cancelling because they are more engaged.' (N1)
- 12.1.2 'Yes, subtle, not wow, wow, wow. It makes us think about rolling it out to other chronic diseases. Others will be easier. We're doing COPD at the moment. If my patients are diabetic and vascular, they get a combined appointment and it's very similar. It's easy to roll out.' (N2)
- 12.1.3 'Basically, it just makes you more aware of sitting in the patient's shoes, what they feel is important and be able to converse with patients. A two way conversation.' (N2)
- 12.1.4 'Patients are better informed. They come in knowing results.' (GP3)

12.2 Uncertain

12.2.1 'Little, not massive. We haven't had staff changes. The staff doing the diabetes clinic 5 years ago are still doing it. We were advising patients before but not in a structured form. The QoF figures are the same. Bit of a change for admin staff. Not that big a culture change.' (GP1)

12.3 No Change

- 12.3.1 'It hasn't happened yet. Are people aware, e.g. admin staff I don't know. In the surgery [where she worked 3 years ago and introduced care planning into it] only staff directly involved in the diabetes clinic knew about care planning.' (N3)
- 12.3.2 'The diabetes clinic feels separate. It hasn't altered the organisation at all. There's no difference. The partners are aware of it and supportive, but it's your baby. They're supportive of time off for training.' (GP2)

12.4 Working in Partnership

- 12.4.1 'Equal. I might not have used this before YoC. I think I would have described myself as a guide in the past. It feels real not tokenistic. It would be too much work to do if there were not real benefits. We wouldn't do it unless it benefited the patients. I think that patients used to say things to keep us happy but this is slowly going.' (N1)
- 12.4.2 'In the main it's dependent on the patients themselves and their personality. .. I'm a professional partner. Friendly, working partnership.' (N2)
- 12.4.3 'We haven't totally devolved all responsibility to patients, but patients are more interactive in choosing their care. They are more responsible it's their illness. .. It can go both ways, some patients I'm happy to give total responsibility. Others, I will not. 50/50. It depends.' (GP1)
- 12.4.4 'I work together rather than me being paternalistic. That's always how I've worked.' (GP2)
- 12.4.5 'Working together, working collaboratively, valuing patients, listen to them but also be honest.' (D1)

12.5 Engaged Patients

- 12.5.1 'I think that patients are more engaged. They know that it is down to them. This tend to keep them more grounded.' (N1) This HCP gave an example of a patient who wanted to come in to be weighed regularly. He was a social worker and the nurse asked him if he would prefer to take his clients to the post office every week or support them to be able to go on their own. 'He did come round and see that it was up to him in the end.'
- 12.5.2 'It's lovely when patients really know what they want. Their involvement levels are high and it's easier to set obtainable targets and frequent follow up if necessary.' (N2)
- 12.5.3 'Not everyone [is engaged]. With some you explore, anything you'd like to ask, concerned about. No, it's ok pet. I don't really know. You tell me what to do. Some were very clear and had put thought into it.' (N3)
- 12.5.4 'Usually they are more well informed and ask more focused questions. They come in knowing what they're going to talk about. They do most of the talking. They've done some research. They'll have quite rigid and strict views on elements of their care and you must respect that. I wouldn't have expected that before YoC.'(GP1)
- 12.5.5 'Some are more engaged, some aren't. It's a middle class area. Most are fairly intelligent, they want to know information and be involved in choices. Some aren't interested. They want to be told. It's nothing to do with YoC.' (GP2)
- 12.5.6 'Engaged patients believe they have diabetes, understand their results and significance and would like to debate more. They take leadership in the consultation and have an agenda. They have things to consider and ask about. .. You've got to challenge them if patients say, you tell me.' (D1)

12.6 General

12.6.1 'If there's support and genuine will to do it all and sign up... going through a consultation in rote, just ticking boxes rather than being signed up.... Things don't just change without levers spontaneously. Diabetes care is complicated.' (D1)

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13 Commissioning

13.1 Services

- 13.1.1 'The dietician is there all the time. They used to have a chiropodist but not now. You have to go through the hospital to see a chiropodist now.' (FG1, 1)
- None had been referred in FG2. They stated they would like exercise classes and one commented that she would like the chance to go to a women only swimming session.
- 13.1.3 'the only service the surgery offers is a dietician.' (FG2,1)
- 13.1.4 'I was offered chiropody but that is all I have been offered.' (P1)
- 13.1.5 'I've never yet seen the dietician. I've never been offered to see a podiatrist. I do go, but I had to do it myself. The doctor said, just phone up.' (FG4,1)
- 13.1.6 'We focus on traditional DESMOND, exercise on referral, walking clubs, cookery courses.' (Comm 2)

13.2 Identifying Needs of Patients

- 13.2.1 'YoC is about innovation. That's why the PBC bought into the concept. They saw the benefit to patients and to them.' (Comm 1)
- 13.2.2 "The dilemma for us running projects is the systematic collection of information from IT templates. Looking through paper is unfeasible. We need an IT solution for unmet needs." (Comm 2)

13.3 Referrals

13.3.1 'With QoF and freedom of information, anyone can find our QoF targets and figures. We have MIDAS to look at all referral data with secondary care. It's available to everyone. The PCT uses MIDAS to monitor referral figures and QoF to monitor quality and outcome and standards achieved.' (GP1)

13.4 Secondary Care

- 13.4.1 'The doctors don't treat my diabetes. The hospital does because I'm Type 1 and have complications. I had the choice, doctor or hospital, I had a lot of stress and went to the hospital. It's really good. I see the same person. She came to the GP surgery. Everything is absolutely marvellous. I'm on good terms with the consultant at the hospital. I run the diabetic support group. No problems.' (FG4,2)
- 13.4.2 'I don't go to my own practice for diabetes care. The practice won't take you because of insulin. I get seen at North Tyneside hospital.' (P5)

13.5 Micro to Macro

- 13.5.1 'The fear is raising expectations. How do you commission choices. How do we know what is needed to commission.' (Comm 1)
- 13.5.2 'Not yet. It's all linked to the IT template. The focus has been on embedding care planning. Now we need to focus on commission intentions.' (Comm 2)

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13.6 Population Needs Assessment

13.6.1 'We do because of a big piece of work of service review. There is a map of services available at the moment, with an assumption around population needs. Part of YoC is around understanding why services aren't appropriate, what service users are saying.' (Comm 2)

13.7 Quality Assurance and Measurement

- 13.7.1 'We have to have a range of indicators to measure. How do you know what you measure in the first place is right. ... You've got to make sure you have an IT infrastructure. (Comm 1)
- 13.7.2 'Service providers do, to a degree. Not to the detail we ought to. It is highlighted in our service review.' (Comm 2)

13.8 Options/Service Use

13.8.1 'We have focus groups feeding views in. We have a PPI strategy with road shows where we ask people for issues. We have a patient panel.' (Comm 2)

13.9 Money Contracts

13.9.1 'Not at the moment. We have a two tier model, enhanced model in primary care and block contracts. If we develop more providers for markets we will have different contracts.' (Comm 2)

13.10 Leadership

13.10.1 'There is a North Tyneside network working. There is the Diabetes Resource Centre. We have clinical champions from specialist care and from primary care. And we have Derek Thompson.' (Comm 2)

14 Comparisons before Year of Care

14.1 Patients' Perspectives: Positive Change

- 14.1.1 'Its better now... They tell me to walk but I have cellulites so walking is difficult'. (FG1,1)
- 14.1.2 'I am taking lots of tablets they don't talk to me about this at the review.' (FG1,2)
- 14.1.3 In FG 2 the comments were:
 - Treat patients better
 - Nicer manners
 - Easier to get appointments
- 14.1.4 'He's communicating more information than he did a couple of years ago. Last 2 occasions Dr.. has been more open and able to communicate. Before he was more severe.' (P7)
- 14.1.5 'I used to ask for results, but it is better to have it written down.' (P7)
- 14.1.6 'Having bloods taken and then being called up. They're seeing into it. I swear I haven't got diabetes!' (P8)

14.2 Patients' Perspectives: No Change

- 14.2.1 In Focus Group 2, all said it was just the same although one commented that he had moved to the area three years ago and it was a big change from the way they do things in the area in which he used to live.
- 14.2.2 'Its just the same nothing has changed.' (P1)
- 14.2.3 'Not noticed a difference.' (P2) The patient wanted to know how to find information about YoC.
- 14.2.4 'I've been going to the hospital since 2000. It's more or less the same. Same nurses.' (P5)

14.3 Healthcare Professionals' Perspectives

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

14.4 Difference Made to Patients

14.4.1 'I don't think it has, but I feel a bit less patronised.' (P6)

Version 1 - Draft

15 Patient Recruitment

15.1 Mechanisms

- 15.1.1 'It has been offered to every patient. We have 234 diabetic patients and there is a low percentage of patients choosing not to engage. I have one Cantonese patient and she comes in with her daughter. We have a few patients with lower literacy I try and use a format that they will understand and ask them what works for them. Lots of patients tell me if they don't understand and I will draw pictures for them.' (N1)
- 15.1.2 'Everybody has opted in. Some opted out in that they don't bring their letter and they're not interested in formulating plans or targets. I respect that because it's their decision. They say, can't be bothered with that now. I come here because you're the professional. I want you to tell me what to do. It's too much like hard work.' (N2)
- 15.1.3 'Those who came for the annual review between November and February. We didn't give them a choice, we were persuasive. Nobody minded.' (GP3)

16 Questionnaires

16.1 Patients' Perspectives: Received

16.1.1 'I got a questionnaire when I went for my appointment but I didn't get a leaflet about YoC.' (FG1, 2)

16.2 Patients' Perspectives: Not Received

16.2.1 FG1 – 2 out of the 3 participants didn't remember the questionnaire – they said they might have filled one in at the surgery.

16.3 Healthcare Professionals' Perspectives

- 16.3.1 'There's been a mixed response to questionnaires. Lots of refusals, a quarter to a third. Receptionists get them back.... Excuses are: hadn't got reading glasses, sick of doing questionnaires. ... No problems with the questionnaires and admin. It's not very onerous. Sorted out, give to admin staff, she knew what it was about, mark numbers on it and give it to us to send out.' (N2)
- 16.3.2 'The questionnaires are too many especially to fill them in before leaving. Sometimes we'll give them to take away but we don't know if they return.' (GP1)
- 16.3.3 'I didn't know about the second wave!' (GP1)

17 General

17.1 Miscellaneous

17.1.1 'Since I was diagnosed, you're in denial at first. It irritates me that it takes so much time of my life, my job. I'd rather personally have a one stop shop. Pop in at lunch time, easier to get to the session if you work full time. There is no consideration made if you can't get to the surgery during the day.' (P6)

17.2 Bottom Line

- 17.2.1 In response to a question as to whether YoC has made a difference, one patient said, 'it stops me from being so frightened about it. They explain all the side effects. I'm really happy.' (P5)
- 17.2.2 'If I were a patient I would want to have a care planning system in place. I think it respects people more as individuals. It gives people more rights.' (N3)

17.3 Key Headlines

- 17.3.1 There is a very strong philosophical base in North of Tyne which provides leadership and debate, and ensures an eye is kept on issues of development, momentum and sustainability.
- 17.3.2 Insufficient interviews were conducted to get a real sense of what is happening in this area. Only one practice was visited and a small selection of healthcare professionals from only 5 centres were interviewed.
- 17.3.3 Insufficient information is provided to patients about Year of Care.
- 17.3.4 IT systems seem to work well. Although there are problems in terms of not having appropriate templates and lack of support, it appears that people manage and IT does not get in the way of delivering care planning.
- 17.3.5 Cultural change appears to be subtle and not always obvious, but there have clearly been changes that have been recognised by patients and healthcare professionals alike.
- 17.3.6 Commissioning has strong leadership in this area and much has been achieved. The biggest limitation is the inability to identify unmet needs. It is recognised that the mechanism to solve this problem is through information technology.
- 17.3.7 Although DESMOND is recognised as essential by HCPs, it is still not providing total cover of all newly diagnosed patients.
- 17.3.8 There is powerful understanding of consultation principles from a number of sources in this area.



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).



Introduction to include:

Year of Care Case Study – Questions for Commissioners

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.	Do you establish and publicise menu of care? (What do they understand by this? How do they do it?)
6.	Can you transfer the micro to the macro? (How is this done?)
7.	Do you undertake population needs assessments? (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.	Do you develop markets to meet current and future needs? (How do they assess current and future needs)
9.	Do you procure time for consultation, training and IT?
10.	Do you quality assure and measure? (How?)
11.	Do you record options / service use? (When? What happens to this? How is it then used?)
12.	Do you produce money contracts?
13.	Is there leadership/ cross section buy in? (How do they define buy in? What is the effect of buy in?)
14.	Is there senior buy in / local champions? (What is the effect of 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 notices 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?