

STAKEHOLDER VIEWS ON PHASE I OF THE YEAR OF CARE PROGRAMME AND ITS LOCAL AND NATIONAL ACHIEVEMENTS TO DATE

BACKGROUND

The Year of Care programme sets out to learn how routine care can be redesigned and commissioned to provide a personalised approach, including support for self management, for people with long term conditions. It is firstly about making routine consultations between clinicians and people with diabetes truly collaborative, through care planning, and then about ensuring that the local services people need to support this are identified and available, through commissioning.

The Year of Care is a partnership initiative between the Department of Health, Diabetes UK, NHS Diabetes (formerly the National Diabetes support Team) and The Health Foundation. It is a three year programme and is being piloted in Calderdale & Kirklees PCTs, NHS North of Tyne and Tower Hamlets PCT. The pilot sites aim to:

- Establish care planning in routine practice;
- Identify sections of the local diabetes population by potential need for services and support for self care;
- Develop new and existing providers to support self care;
- Systematically link individuals' needs and goals into population level commissioning; and,
- Explore the costs and benefits of providing these services and support.

The Year of Care programme has been divided into two phases: a feasibility study which took place between November 2007 and August 2008; and a 24-month implementation and impact evaluation phase that commenced in November 2008. An external evaluation team (Tribal Consulting) were appointed by a process of competitive tender to evaluate the process of preparing for and delivering a Year of Care, as well as laying the ground work to assess the impact of the intervention.

Alongside, but separate to, this external evaluation, a series of 16 interviews were conducted between May and October 2008 with a sample of the key stakeholders involved in the preparatory phase of the Year of Care programme. These gave a wider perspective on the work of the programme overall and also provided insight into the specific approach and role of the national team. Interviews were conducted with a purposive sample of individuals from each of the following groups:

- Year of Care Board
- Year of Care Reference Board
- Year of Care Evaluation Steering Group

- NHS North of Tyne pilot site
- Calderdale & Kirklees PCT pilot site
- Tower Hamlets PCT pilot site
- Tribal Group evaluation team
- Co-creating Health project diabetes sites

The aims of the interviews were:

1. To review the process of the Year of Care for Diabetes programme at three pre-determined times over the 24 months of the study and provide key stakeholders with an opportunity to debrief after each of three stages of the programme;
2. To capture the reflections and lessons of key stakeholders within the Year of Care programme in a timely fashion and share these reflections in an appropriate and well-timed manner with all the stakeholders involved or interested in the Year of Care programme.

The interviews were relatively unstructured, enabling interviewees to discuss and reflect on the issues that were important to them and their experience of the Year of Care programme. However each interview was guided by the following questions:

1. Tell me how you became involved in Year of Care and what your role is; what has been the catalyst for you?
2. Can you remember what your expectations were?
3. What are/were your responsibilities and how have you worked to achieve them?
4. Did you encounter any difficulties/challenges?
4. What skills and expertise were available to you; was anything missing?
5. What levers/incentives were you able to use?
6. Tell me what has been achieved so far and what needs to be done?
7. What's worked well?
8. What's not working so well?
9. Is there anything you'd do differently?
10. What has been the most significant thing to impact on this programme?
11. What are the main challenges and risks facing this programme?

Interviews were conducted in private and anonymity was guaranteed; interviews were recorded and transcribed in full and lasted between 1 hour and 1 hour 45 minutes. After the transcript had been returned to the researchers, all names, place names and personal identifiers were removed from the transcript and it was sent to the interviewee to be checked and validated. Two earlier iterations of this report have also been sent to participants.

It is our intention that further waves of interviews will be conducted at 10 months and 20 months, but the same interviewees will not necessarily be interviewed at each of the three waves, as sampling will be guided by the themes and issues to emerge at different stages in the programme. Key themes will be tested and refined through each wave of data collection. A list of participants in this baseline wave of interviews can be found in the Appendix.

This study will run alongside the external evaluation of the Year of Care pilot sites, and data over the three waves of data collection will help us to reflect on the following issues:

- What have we learnt about the concept and practice of Year of Care? Which parts of the concept seem robust and which part less so? Does the concept need adapting? Has Year of Care delivered on its objectives?
- What are the key themes for stakeholders?
- How well have we supported the three pilot sites as they prepare for and then deliver Year of Care?
- How well have we supported or encouraged Year of Care in other geographical areas?
- How well have we linked into appropriate areas of policy?
- How can we move forward with the next stage of the Year of Care programme?
- How can we support or encourage Year of Care for other long term conditions?

KEY THEMES

Six themes emerged during a detailed thematic analysis of the 16 interviews and these were:

1. National and local drivers
2. Achievements
3. What worked well?
4. What didn't work so well?
5. Skills, knowledge and support: available & missing
6. Potential risks and future challenges

Each of these themes will now be addressed in turn.

National drivers

Interviewees felt that the Year of Care programme **aligned well with current policy**, including the choice agenda, the long-term conditions agenda; the policy of personalisation; System Reform in terms of new ways of working; the Diabetes NSF, and of course obesity and prevalence. The trend started with these policy positions was confirmed in the Prime Minister's speech in January 2008, in Lord Darzi's review, and in the Patient Prospectus, in its emphasis on supported self-care. Over the period of developing the programme and during the feasibility study, little emerged that has been counter to the ethos of the programme. Crucially, the way that stakeholders have been implementing the NSF for Diabetes lined up with Year of Care; one interviewee noting *'fundamentally, we truly believe in the values around Year of Care and what it means'*. Because Year of Care is so well *'linked with all the big health reform policy issues that needed to be cracked'*, testing and development of the concept may well produce transferable lessons to other areas of policy and other long term conditions.

'How could we use the reform agenda to demonstrate how personalised care could be delivered in what is the most complex of conditions, diabetes?'

'I think that there has been a paradigm shift within the diabetes culture, the whole diabetes community about the importance of self-management, personalized care and as something that really needs to be addressed as part of the care package. Now I don't think that that is solely about Year of Care. That preceded it and is one of the contextual things that have enabled Year of Care to be a success'.

'In a way, an argument for doing it now, would be the timing of wider policy development, so the things like the Darzi Review and stuff like that. This fits really well with it. So one of the benefits that we pushed it forward was that we are in a position to inform things like the personalization agenda and stuff like that'.

'Commissioning potentially is a lever, but I don't think we have used it really....I don't think intellectually we have made that jump'.

The Year of Care programme was driven by the then National Clinical Director for Diabetes who assumed the role of Senior Responsible Owner (SRO) for the programme. There was unanimous agreement from interview participants that this national leadership role was critical to the success of the programme; that the SRO had the skills and attributes to enthuse stakeholders about the programme and help to make complicated issues and concepts systematic, manageable, understandable and accessible, without '*watering down*' the concept. The SRO's role was to drive the programme; to shape and to enthuse others to shape the concept and implementation; and to form key political links and allies. This important role is often overlooked in the NHS but is nonetheless critical for the success of complex programmes such as a Year of Care.

'She is very clear about what she thinks is needed and has the confidence and the experience and the kudos to stand back and articulate that quite clearly.'

'X has an ability to think strategically and then apply it to nitty gritty, which... and there were lots of kind of intellectual challenges and difficulties which were also linked to the process in terms of how we handled and explained things say to pilot sites or whoever.... - she is a good leader in that she always... she brings belief, and she is willing to go into any situation and say "this is a fantastic initiative, it has got the power to like make a massive difference" and that is quite a powerful thing. She is quite kind of inspirational figurehead for it. I think her position gives her some legitimacy, but beyond that is her personal, and I would almost say it was more personal to do with – it is just that because of the position that she is in, I suppose people are predisposed to listen to her'.

'I think that it has been important that there has been a vision for it, for the concept, and I think that the leadership with the vision has been important, I think that it would have struggled to deliver without that. So there is the leadership skills, there are the engagement skills with all the key parties.....I think that the leadership has been key to its success so far; clearly the links into policy levels and other organisations are key from the National Clinical Director.'

Local drivers

A number of key drivers at the pilot sites were identified as:

- Organisational commitment and back up at the pilot sites;
- Diabetes commissioning intentions; the need for the programme to be owned at the top of the organisation, and recognised in corporate directives, so that it becomes a high level strategic objective;
- Good well established relationship between primary care and specialist team locally;
- Key personnel leading at each site have been instrumental and historical relationships between key local people has really driven the process;
- A common inspirational vision about developing progressive health services;

- Well connected, well respected local staff leading or championing the programme;
- Good specialist services;
- Public Health agendas linking into Year of Care;
- Funding from central team for a local resource;
- Year of Care helping to bottom out issues relating to commissioning, finances, tariffs and so on.
- Local organisations seeing Year of Care as something they want to be involved in: a new way of working;
- Service user involvement, including social marketing;
- Practice population engagement events with interpreters and translators;

‘...the downside is that people don’t carry on doing anything if there is no more extra money. A lever in the NHS, even if it is a relatively small amount of money...is that things get prioritised if money comes in. Without money there is no influence or limited influence and then you are just relying on the passion of people doing it, and it becomes hard as other priorities get in the way and I think that is difficult for sustainability of the project, but then maybe the project does not need to sustain in its current form, maybe that is where the thinking comes in’.

Achievements

Interviewees noted one of the key achievements of the programme to be the **theoretical development of the concept** of a year of Care. It was felt that the process of theoretical development was very clear, inclusive and transparent. The process included developing a theoretical framework and a data-driven model as part of the work of the learning events. Throughout the preparatory phase of the programme, the Year of Care ‘central team’ and pilot sites developed a methodology for theory development and testing.

‘The exploration that has been going on, the chewing and mulling over concepts, the getting really messy and very dirty with a lot of stuff that ultimately we are not going to use, but wading through that and arriving at points of clarity. I mean that process from where I have been sitting I think has been very clear’.

‘From the point of view of a theoretically driven evaluation, we are not having control groups. We are not methodologically driving this, so we have to be able to articulate what we are doing and why we are measuring things according to some theoretical framework’.

‘A major piece of learning has been the intellectual struggle that we have been through as a collective enterprise to handle every single difficult idea that came up. So where we identified an issue as fundamental, we didn’t fudge anything about – but in the interests of having to prioritise things, there were some things we delayed thinking about; and that we’ve got taken all these immensely difficult concepts and developed them into often visual sound bytes...’.

As part of the theory development and testing that occurred at the pilot sites and throughout the learning sets, **a shared language** emerged by which key stakeholders could:

- Put a framework around the concept, developing a common understanding;
- Identifying the outcome of a Year of Care;
- Reiterate the centrality of supported self-management
- Put support for self-management firmly on the diabetes agenda;
- Get the three pilot sites up and running;
- Developing a local commissioning model which embraces care planning; and
- Raise the profile of care planning with associated attitudes, behaviours and training.

‘The key achievements have been obviously engaging the pilot sites and developing those despite their differences really. And managing those, and facilitating their way through it. Keeping all the key influences on board, managing really complex expectations from clinicians and commissioners at pilot sites.....So managing that complexity in a systematic way...’

‘Getting some framework around what Year of Care looks like, getting the house, getting the menu, you know just... even just getting a presentation that any of us can get up and deliver on the Year of Care and having that common understanding of the key group, I think has been a great achievement and of course it is changing as well, it evolves over time’.

‘It does put people with diabetes right at the heart of the health service and just coming up with the whole concept of how to pitch that and get that going and to promote that is a real achievement.’

‘I don’t think there is one person that I come in to touch with the Year of Care project from its start, that has not been completely enthused and motivated about it. And I think it is because the project actually makes sense to people and it puts people with diabetes at the centre of what is going on. And if that could be a massive change agent for getting the balance of partnership working truly embedded’.

The way that **the external evaluation** has grasped the programme and worked with the pilot sites was seen as a major achievement by interviewees. When evaluation is often viewed as an add-on, the fact that that there was a policy expectation for the pilot sites to engage, does not undermine the work of the research lead to develop strong relationships with the pilot sites. However it should be noted that one of the three pilot sites have, at the time of writing, decided not to collect data in line with that laid out in the national study.

‘Very early on, there was a discussion about what we meant by evaluation and really, you know a concept from many people that we were designing a formal piece of bio-medical research, and a randomised control trial for the Year of Care and care planning, and saying that weren’t doing that was quite challenging to quite a lot of people initially. But what I have observed is that the sort of mixed methodology has developed of, that formative evaluation as well as the observational qualitative and quantitative elements; the people, certainly the steering group and others involved are really very comfortable with that mix’.

‘[The research lead] has been absolutely superb. He has got the ability to distil things into a very simple and usable format; he has been so supportive, it has been you know, just for bouncing ideas off. And helping to sort yeah, formalise ideas. And X makes things simple. He offers clear and simple solutions. He can always see the bigger picture and how change impacts as a whole’.

‘I am very disappointed that one of the sites is basically doing what on earth it wants, and I just think that it could threaten the whole project and I am not quite sure how that happened, and I hope that we can resolve it’.

Finally it was noted that getting high level organisational buy in, as well as getting a **large and diverse group of partners** and funders together has been a massive achievement and could provide an exemplar for within agency and cross agency working. Getting Diabetes UK to champion the Year of Care programme as one of its most important programmes has been a considerable achievement.

‘We have managed to engage critical parts of the Department [of Health] and for our benefit so that they have brought their skills and knowledge and help and explanation and things and to an extent, their oomph, to the degree that the words are in major documents and we’ve got senior support sponsorship in the Department [of Health] that’s been maintained and secured and transferred from senior people to senior people, which is very, very good.’

‘...if the government is really serious about innovative partnerships across sectors in order to develop new methods of delivering care and people self-supporting themselves. Boy! They have got a flagship example here, involving private, public and voluntary, they can really capitalize on this’.

What worked well?

A series of **learning sets** throughout the preparatory phase of the study brought clinicians and other project staff from the sites together to focus on culture and behaviour, share progress, expertise and good practice. The learning sets were viewed as being very positive, helped to re-invigorate the group, and allowed the opportunity to challenge in a safe environment.

The learning sets were organised by the central Year of Care team and were professionally managed and facilitated. Interviewees noted that clarity often came from the learning sets, and that action learning is a positive way to design services; being able to change projects as they develop, by using formative feedback and reflection was seen as valuable. One participant described the learning sets as providing '*a serious anchorage point for us*'.

However, several interviewees from the pilot sites underestimated the commitment required to attend monthly learning sets and other meetings. Some learning sets were described as '*repetitive*' and '*hitting dips*', and it was reported that they hadn't always got the best out of people in the room. Several interviewees noted that the sets sometimes felt turgid, needed to be focused, need to be at a higher level, and should '*push the boundaries*'. These criticisms notwithstanding, there was a strong consensus that the learning sets should be maintained over the two-year delivery phase of the programme, but may be required less frequently:

'Because you go to the learning events and then somebody will say, Oh yeah we have done this, and you think, oh my God we haven't even thought of that. And then you think, oh right! You actually come back from it quite fired up, I mean, we go to these events and you come away feeling absolutely exhausted as you have input so much kind of intellectual thought process into the event and then you come away and you're all fired up because you think, 'oh! We have not done that', and that is really good. And then you go back and make contact with people and say, share with us what you've done about that? It has, it has been this kind of competitiveness, but that has been quite healthy'.

'We tend to focus quite a lot on what is going well...But we should be a bit more honest about what is difficult really. You want to be seen in a good light, the Department [of Health] are there and Diabetes UK are there, and other organisations are there, and so there is the element, a bit of an element of competition, which is good, it is healthy but sometimes we don't always challenge each other'.

'First of all simply being present with others, the coming together in real time with a group of people that are aiming to achieve similar ends. Whether everybody contributed or not, the fact that we came together consistently is just so important. So that is one thing. Secondly we used the events to argue and debate in a very mature way and for people to express their misunderstandings or concerns, and to really chew the cud and to get down to some of the nitty gritty about what these concepts were about and it was through that process that we arrived at the point where we all feel fairly familiar with our theoretically framework and our house and who would have thought it nine months ago that we were going to reach that point'.

The Year of Care programme has been run through **project management processes** from the outset, which has provided clear governance structures and arrangements, clear

expectations from the central team, and clear lines of communication between the pilot sites and the central team. Pilot site interviewees reported that they found the one-to-one meetings with the central Year of Care Project Manager to be generally helpful in maintaining drive and momentum. Many interviewees commented on the quality of the project management, which was described as thorough and intellectually robust; ‘Going back to basics. Dotting every ‘I’ and crossing every ‘t’. In addition, the governance and support structures, including the Evaluation Steering Group meetings, the Knowledge Management meetings, and the Reference Group were considered to be invaluable. Formal project management processes enabled the central team and others to analyse, reflect and react to potential risks to the programme.

‘I think that the whole governance arrangements around the project and the nine-month set-up and the way that it was managed in terms of the project management methodology. I think was really helpful because actually we needed those deadlines to be able to work effectively’.

‘I think what has been critical though in all our project management appointments is the intellectual capacity of these project managers have required to do the job because this is a complex area and so you have got to be quite skilled in handling people as well as having the intellectual capacity to have a debate and understand it; because I think if you don’t have that in that project management role, it would not have been successful as it has been to date. There have been some quite challenging situations to handle in the pilot phase and that has been about managing personalities and I think if you have got intellectual grasp of what this is about; it actually helps you with that’.

However, whilst the majority of interview participants praised the project management structures, there was some concern from the pilot sites that they were too heavily project managed from the central team, that they needed the central team to ‘let go’ and trust the pilot sites and the evaluation team, and that by the end of the preparatory phase the central team needed to hand control over to the pilot sites.

‘I think that we were quite heavily managed in the beginning I think for a 100K project and a big organisation who had just gone through major reconfiguration there was a bit sort of, emails were popping in all the time asking for things. I can understand the need for some of that but I think that it was overdone in the beginning’.

‘At the origin of the project, we felt we were being project managed to death’.

‘X’s style came across as complete control freak, and to the point where it became unhelpful. I think and I suppose that felt like nobody trusted us. And that felt a bit odd. ‘Cause to have gone through the application and scrutiny process we felt that they should have had more confidence in their confidence skills. Having selected us to leave us to get on with it’.

Participants reflected on the **central team** and how they had worked to move a Year of Care forward. The following points were seen as particularly beneficial to the programme:

- Engaging critical parts of Department of Health and getting Year of Care vocabulary on major policy documents;
- Initial focus on vision rather than the mechanics of delivery;
- An expectation that the Year of Care can be achieved;
- Personal enthusiasm and commitment of key players;
- Drive from the central team who work very well together, and work closely with the pilot sites;
- An honest frank team able to challenge each other;
- Support from the National Diabetes Support Team on commissioning;
- Engaging a wide range of stakeholders.

‘We have had the most fantastic team and we have been able to entrain some really important people because of their personal skills or because of their importance. And that is one of the critical factors. The team has been fantastic.’

‘First of all we said infrastructure’s important but we said it’s only important to the degree that it’s there to support the value system, which is different from what most people in the NHS believe is the current way that the NHS is run which is that the infrastructure is almost there for itself and that improvements will occur if you get the infrastructure right and if the system is right then improvements will follow from it’.

‘I think we focused on what we were aiming for rather than the mechanism and so that is quite important, because I think it gives you credibility with all sorts of people, clinicians, patients...’

The enthusiasm from the **pilot sites** was praised. It was acknowledged that the pilot sites worked hard to achieve change and progress on the project within a very tight timeframe. This was facilitated by mature relationships between individuals within the local project team, and their ability to build good relationships between providers, primary care and the teams themselves as commissioners. As time progressed the three pilot sites began to work together as a team; *‘they are all bouncing off each other. And they are much more confident about what they are doing now as they can see where they are going’*.

‘... and the passion and enthusiasm from people who want to make this work in their local area.... Again, it is about people who buy into the vision of what you are trying to achieve and want to try and make it happen and I think those kind of contributions in lots of different ways from people in the field as I would call it has kind of really driven it as well’.

‘We did not go out to primary care and say, “we want everybody to participate” and scare them off with this evaluation framework, training and education, and

you make the transition and all of this stuff. We actually, we sort of fed them bits of information as we progressed along, I think if we had gone out at the outset and said, “we want you to come on 2 days training, we want you to change the way that you work”. If we had dictated that to them we would have lost them’.

‘When the X team fed back that their clinicians were queuing up to become involved. That says something to me, that these clinicians think that this is right. They might not have the evidence base for that but they think that this is right. Usually you would instinctively not get that so I think that that wave of clinical rightness might be the turning point that carries the project through. Because you need to get to them before you can get to the patients’.

Finally, the process of developing and commissioning the **external evaluation** was seen to be successful, as a result of having evaluation expertise on the central team and having a policy expectation that the pilot sites be evaluated. At a local pilot site level, there appeared to be a willingness to participate in the evaluation; at two pilot sites, the evaluation was being sold as helping practices to review and reflect on their services, although by a process of ‘drip-drip’ so as not to lose people. Interviewees from two of the pilot sites reported that the evaluation process seemed clear and simple and the external evaluation team had been careful to shoulder as much of the *‘donkey work’* as they could.

‘The mix of knowledge on evaluation, has been important and so there has been a mixture of people with bio-medical experience, people with qualitative skills, people with improvement and implementation knowledge and skills and I think that that has been a really rich mixture’.

‘And so from that day, first outset, the central team brought the evaluation team in. That enabled us to start building relationships and to start getting the project up and running. I think that also, the original project documents that the sites were required to produce they needed in there to acknowledge their commitment to the evaluation, so even before any personnel were directly involved there was a policy expectation. And I think that was very, very sensible so that was in the project learning documents and the first learning event, hey presto here is your evaluation team. And that was enormously valuable’.

‘So we did not scare them off with the evaluation and we are really keen that the strategy that we adopt in terms of communicating it has to be carefully worded, which means that primary care will get something out of it, which is linking it into the wider agenda’.

What didn’t work so well?

Many interviewees – particularly those from the pilot sites – admitted that in the early stages, they had been **confused about the purpose** of the programme and what was expected of them. There was reported to be a general ambiguity that stretched from the pilot sites, across to the central team and wider: *‘one thing that was clear at the learning*

sets was that it was ambiguous'. There was a reported lack of clarity and misunderstanding of expectations between the central team and the pilots, for example the pilot sites had assumed that the central team would develop the IT template. Early confusion about Year of Care meant different Department of Health departments and others were unclear and there was a constant need for the central team to refresh what the priorities and links were.

'Yeah the learning events; the first few I struggled to keep the clinicians engaged because they were very negative about it - because they came away saying what have we just done? What have we just achieved? Why did we go? And what is it all about? I don't understand it. There was a lot of ambiguity and I was conscious we could have lost those people at that time, particularly clinicians who had taken time out of practice to be there and they didn't understand what was required off them. This improved following the meeting in January'.

'And I did feel a bit bewildered actually about what this was actually all about. What the real aims were, the aims and objectives of the project, and it really took me quite a bit of time to work through everything and because I wasn't there at the beginning of the process, I think that makes a big difference actually and it did take me a little while to just start to digest everything and start to reword things'.

The **speed and scale of change** expected as part of the programme caused some difficulties. Year of Care is an ambitious programme; the size and breadth of the programme and a lack of clarity about its boundaries meant that there were varying expectations from stakeholders, but a strong line from the central team that this was a feasibility study minimised the risk of drift. Participants also reported difficulty in working out what success would look like when the scope of the programme was so wide. It was acknowledged that pilot sites required 'headspace' to get around all of the changes that need to take place to get the programme up and running.

'I think that it was quite counterproductive that we were at the start really pushing them to get project plans in place, to get project managers in place, just kind of forcing them, when actually what they sort of really needed was more clarity about what it was they were trying to do'.

'I think that also regardless of the timing, this project implies or requires quite a lot of change in various different aspects of professional practice attitudes, delivery, research activity, partnership approaches with patients you know, there is a lot of stuff going on, that involve training. That involve new systems for sending out blood tests and other bio-medical indices results and so on. Sending out written care plans, and then on top of that there is an evaluation and all that that is going to entail'.

'How are they going to cope? How much change are we going to expect them to take on board and in what time scale?'

‘...the amount of work and visits and the amount of learning sets and things like that have been absolutely colossal for all project managers that we have had in post. We are doing a lot because we have to in a short time scale but things have to slow down now’.

Year of Care is a change programme for the pilot sites as well as the NHS. There were some concerns expressed that the central team and one of the pilot sites shared a vision that the other sites were given ‘piecemeal’, and a feeling that they were validating an **existing model around care-planning**.

‘And I think something that sort of reinforced this feeling was that the Diabetes UK conference, we are still, we were in theory supposed to be building this model, and we got to Diabetes UK, there were Diabetes ‘Year of Care’ published material, that we had never seen at our groups. We were supposed to be developing it, but we had never seen it before. Yes, we had seen the work that was in it, but we did not know it was happening’.

‘I am not sure if Year of Care is part of a bigger game plan that someone has within the department, or you know, are we pawns in a game? Care planning has now come out and is embedded in this project, which is a formal project, with formal sponsoring and formal governance arrangements, and yet in Darzi’s paper it seems to be kind of, and we are already going with it, and it is being applied to other long term conditions.... but it feels like we are being used as a demonstrator site for care planning in LTC’.

Participants expressed a series of further concerns relating to timing which might have an eventual impact of the programme. These included the timing of Year of Care programme which coincided with the reorganisation at Department of Health and the Office of Strategic Health Authorities Review of Hosted Organisations (insert reference); the fact that a six month period to conduct a feasibility study was considered by some to be too short; and the fact that there was some slippage, as a consequence of some initial time scales being unrealistic. In addition some interviewees were concerned that the central team had spent a lot of time trying to bottom out the concept of Year of Care because the group was made up of ‘ideas people’ and the programme took a long time to get off the ground; there were perceived gaps in skills around commissioning and economic elements; some key people were not able to attend many of the Board meetings; no patients were involved in early discussions; and several interviewees noted that the contribution by service users at the Reference Groups could have been even more valuable. There were concerns about ‘professional patients’; people who were drawn from the same demographic, and who were described as the ‘*usual suspects*’. Getting full engagement from sites where there is a lot of other programme work going on was described as a challenge and some relationship difficulties both centrally and locally were noted as a consequence of differing agendas and different ways of working. There were perceived to be some difficulties in communication because of the size

and breadth of the programme and finally there was some question over how to embed the programme and its outcomes in Department of Health policy and delivery.

‘How is this being fed back to X now? And I know Z goes and sees him a couple of times, but where is this being really embedded in that work and being taken account of? And I think that was one of my concerns in the early days and I think it is still a concern now. So, when we turn this into policy or you know at the end of the study, how did it actually get embedded in policy and delivery?’

Knowledge, skills & support

What skills & support were available at a central level?

Interviewees felt that the following skills and support were available to move the process forward:

- Creative thinking, drive and tenacity from the SRO at the central team;
- Buy-in across the Department of Health and Diabetes UK;
- Robust Project Management framework around whole programme;
- High level of intellectual capacity of the project managers to deal with complex project;
- Health Foundation and links to Co-creating Health project, which proved useful in helping to structure Year of Care site visits.
- Care planning;
- Development of a national IT template;
- National Diabetes Support Team; supporting improvement work;
- Coaching support to Project Manager from National Diabetes Support Team;
- Communications advice from National Diabetes Support Team.

What skills & support were available at a local level?

Interviewees noted that money to purchase a local resource, as well as the central resources and support provided by the central team all helped to move the process forward. In addition, interviewees noted the following:

- Well rounded local project team with good representation from specialist care, primary care, consultants, GPs, clinical psychologist, dietician, and patients;
- A dedicated team rather than being an add-on to people’s job;
- Local facilitation and co-ordination;
- Personal development opportunities; representing organization nationally;
- Time for meeting and reflecting;
- Diabetes UK regional networks to spread the message of Year of Care;
- Specialist services involvement.

‘We had six interpreters, advocates who were then translating and giving us feedback from the population. So, to get attendance we needed a venue that was

very close to people where they lived, we booked it over lunch time, we provided food as an incentive to come, that food should model some of the healthy eating options that we wanted to talk about, we have facilitators, we have a story to tell that is agreed by the team in advance. We have the ability to capture information and feedback from users and we commit to them going back and telling people, ‘this is what you told us, this is what we have done’, and that seemed to work very successfully and as an organization we have learned more about how to engage with our population better, and certainly using the practices themselves rather than at a higher level seems to make a lot more sense’.

‘There has been a single individual at each site that has picked this ball up and decided to co-op their colleagues. It doesn’t mean that they are now absolutely critical and that it is not going to function properly without them as other people have become linked, but at the very beginning there was one person; those 3 women, one at each site were absolutely key. As well as the personnel, there were then the relationships... they have an inspirational vision for how things should be and that is something that is very common between them all, and it is often very different from the traditional way that health service operates...so they have this common culture of progressive development of health services’.

What skills or support was missing at the central level?

We asked interview participants to reflect on the skills and support that was not available at a central level, and that could have moved the process forward more efficiently. The following were identified:

- Project Manager had to actively seek out skills and expertise in some cases e.g. around pilot selection;
- Admin skills and support not available to Project Manager;
- A stronger set of skills to structure and support learning events;
- Technical support on aspects like segmentation;
- Technical skills in commissioning on a whole system basis;
- Economic skill to determine costs and benefits;
- Users on the central team seem tokenistic; an interviewee noted that s/he ‘*Didn’t feel that they were given the opportunity to challenge. There were no central presentations from the user perspective. No stories to influence the way we think or to challenge our thinking. Should use social marketing to get to perceived hard to reach groups*’;
- Lack of integrated data;
- An evidence base for care planning and other components of the Year of Care concept, to share with clinicians who work in an evidence based way;
- Local research data collection and literature searching must tie in with the external evaluation.

‘I mean personally I did quite a lot of admin type stuff which I don’t know that it was the best use of my time and some of the kind of administrative process type

stuff in terms of like going through contracts with a fine tooth comb and stuff like that was probably not my biggest skill but some of that is about working in a new context. I think more widely in terms of the project - areas that I would beef up if I was doing it again, probably the shared learning kind of element of it’.

‘And if you look at the kind of skills of the central team - care planning is something that people knew a lot about, and we kind of had that sort of skill and understanding, but some of the more technical questions around say segmentation, costing and stuff like that, we kind of had to try and get other people involved in that, and I think that there is a combination of people just having too much on their plate. And actually we are trying to do something really new here. And so, there is not necessarily lots of the expertise around that could help you with that’.

What skills or Support was missing at a local level?

Interviewees were asked to reflect on the skills or support that was missing at a local level, and identified the following:

- Skill set of senior managers; reported lack of transformational skills and ability to work with complexity;
- Lack of project management skills in the NHS;
- Difficulty in recruiting a project manager at the pilot site;
- Lack of procurement skills in the NHS;
- Getting good representation across all user age groups, and different ethnic groups;
- Shortage of some staff, e.g. dieticians and how to provide a recognised standard of service across the patch;
- Providing the same messages to all staff regardless of sector.

‘The emphasis was very much on care planning as it still is, and all the time, I have been pushing to say that it needs to link to commissioning – it needs to link to commissioning, if it doesn’t link to commissioning it is not going to have real input and I remember a conversation at the start of the project with somebody and I said, “I am really worried that the commissioning side of this is going to get lost”. I can see the benefits of care planning, but actually the bit that hasn’t happened yet and needs to is the link with commissioning because that is what changes population provision and that is just the nature of the project’.

‘I tend to approach things really thoroughly and so for example when you do research you have a literature review and you have a very clear rationale for why you want to do this. That would lead on to your aims, and how you are going to do this and what you would expect to get from it. Maybe I felt that there was a lack of that clear structure in the very beginning. For example someone said that there is literature around the components of care planning, but what is there around about care planning in diabetes? Something about just backing up the rationale for doing it would have really helped me personally’.

Potential risks and future challenges

1. Loss of national leadership

One of the key risks identified by interview participants was around national leadership of the programme and the potential vacuum if the current SRO for the programme decided to leave. There were concerns that changes in national leadership risked loss of importance of the programme and drive, motivation and momentum could be impacted. In addition, there were concerns about handling the politics and keeping the programme high profile if and when the current SRO left, but interviewees were also mindful of the need to be sensitive to the new National Clinical Director for Diabetes and to make sure not to *'throw the baby out with the bath water'* by starting again. In terms of central leadership, it was noted that the Management Board needs to take a more determined leadership role and not *'just react and respond'*. It was suggested that the Board needs to be clear about what its strategy is and it needs to communicate its strategy to the pilot sites.

'I think that there is a key leadership issue at a national level to keep the drive and momentum going, and also with the insight, and the creativity and the tenacity to keep it on track' .

'In terms of the risks for the team are that you've lost the main driver and the person who set it up, understood it, probably sees the totality of it and has this huge skills base in terms of clinical, managerial and systems mind'.

'You have lost the methodology and the history and therefore I think that potentially the leadership is not going to be as effective. Then locally, everything needs facilitation so the question is have we got it sustainable enough that without our level of leadership, the central leadership, can it be maintained? Have they got it internalized enough to be able to keep up the momentum for the reasons that we've said?'

'The board needs to play a bit more of a leadership role, at the moment I think that we are playing a reactive, sort out problems role. Everything feels like a problem and not everything is quite frankly as things evolve. But I think that we do now need to take stock and take a bit more of a leadership role for the next 2 years, to help the pilot sites. If we are not clear to have a leadership role knowing what we are doing and where we are going and hoping to get to, we can't really expect the pilot sites to. I think that we really need to start looking at how we start communicating across other Long Term Conditions and I don't know how we can do that, some thinking needs to happen around that.'

2. Challenging clinical assumptions

Interview participants expressed concerns about challenging clinical assumptions around consultation skills, and were unclear about how to incentivise GPs to 'bespoke' their care. There was evidence that some clinical staff felt that they are working in a care-planning

way already, and that some clinicians might not be able to handle the consultation in a different way; *'how do you control vast numbers of clinicians in their approach to patients?'* In addition, participants felt that it would be easy to default to old behaviours and that measures needed to be in place to make sure that good practice continues to happen.

'It's one of our major challenges all the way through is about clinical assumptions and challenging clinical assumptions and I think that you have got to be, you have got to work with very skilled people who can do that without getting people's backs up, because a lot of this work is hearts and minds stuff and getting people engaged through a degree of challenging, but also a degree of understanding where they are at, and respecting and recognising the systems that they are already working and have done'.

'Now why do I think that the clinician thing is more important than the patient thing, it's partly because while the co-creating health concept says that in the consultation you're both in charge, and this may be my thinking, the fact is that unless the clinician either gives permission or enables this to happen, even with an empowered patient banging on, it isn't going to happen'.

'So, if we are going to really do personalised care planning it is a whole cultural change in the way that we work with people and it is about active listening. Active listening and really open questions and that takes time. And it is not coming in, I will tell you a few things, I will ask you a few questions and out the door. It should reap benefits but they will be long term, and linked with that some people still feel that they want to be told what to do and that came across in our user groups, and so the big danger for me is, that we can't actually engage with the public in this way, for those two reasons. It is a skill to use all your different levels of perception to work with people. And it is not always the skill that you train people in, and I think that the big issue will be managing the psychology of it all'.

3. The external evaluation

Although there was generally a high level of support for the external evaluation across the pilot sites, and a strong relationship had been developed with the external research lead, there was a recognised risk in getting pilot sites to deliver on the evaluation and a risk that patients might not want to participate in the evaluation. Several interviewees suggested that the evaluation has come quite late in the order of things that people need to do and there was evidence that some were now panicking at the thought of practices being expected to do deliver on the evaluation. There was also some concern at an apparent lack of skills/knowledge of evaluation processes across the three pilot sites and that there may have been an overestimate of the skills that local people have.

These potential risks were mitigated by the external evaluators who worked to help to engage local GPs who had questioned the process of the evaluation, and to develop close relationships with the local project team. There was some concern that the results of the

evaluation wouldn't be available for 24 months, although in fact, emerging findings will be made available on an ongoing basis. Finally some participants felt that there was a risk that the programme would be deemed a 'success' because the sites were being observed rather than because of the process of Year of Care *per se* and a concern that the evaluation may '*not be able to answer all our questions*'. One or two interviewees expressed concerns about promoting and implementing Year of Care before the results of the pilot/evaluation become known.

'But I was very, very concerned about the evaluation process, and whether it was actually measuring the evaluation of the project or something completely different. I was also concerned that given that any such project has a relatively short life span that obviously outcomes in diabetes are by their nature very long term. What actually matters to people is have they got any of the complications of diabetes. Have they got foot problems? Have they got heart problems? And at the end of the day that is all that matters'.

'Because they have got to get their practices to do lots of stuff to make this happen, and so it is kind of like, that is quite a lot of work for them to get, and quite a lot of work for the practices, and so we are like almost managing people at one, two three degrees, in that we have got this goes through the evaluation team, because it is technical and it kind of needs to, then it goes to project team locally, and then it goes to the practices who they are relying on to do it. So there are a lot of stages in the process where it could go wrong. And we are sort of relying on it working'.

4. The commissioning agenda

There was a considerable amount of discussion about the commissioning agenda. Many potential risks and concerns were expressed, for example the following challenges were raised and might benefit from discussion:

- How do you get providers to systematise themselves in a way that fits the consultation, that is, how do you commission the outcomes that the patient wants?
- Is it going to be possible for the commissioner to handle the degree of complexity?
- Will the commissioning process have to be kept simple for the first few years rather than let the programme fail?
- Will the system 'fall over' before it gets off the ground?
- How do we ensure value for money if patients are to hold the money for their own care?
- What if there is 'a run' on one option (e.g. gym membership) – do we set up a waiting list? We need to be able to respond fast once decisions have been made.
- Do we provide choice for patients with diabetes who are admitted as inpatients for another reason (e.g. pregnancy)
- Will patients need access to quality data on the range of options available to them?

- Does a patient have to sign up to a package over a year and then have to ration themselves, so that they don't spend all their money?
- Geographical challenges to commissioners – e.g. range of services in rural areas, demand on services in an urban area.
- How do you commission a service to be spot on? How do you write the specification for that?

Some interview participants noted that there had been little consideration of how services would be commissioned in the early stages of the Year of Care programme; it was reported there had been a focus on care planning because that is what people were familiar and comfortable with, but for Year of Care to work, participants noted that care planning needs to link to commissioning. It was suggested that until commissioning became clearer in health services, commissioners could learn from others e.g. commissioning in social services and in different parts of the country. It was suggested that the central Year of Care team would benefit by getting more commissioners involved in the management structure of the programme. Finally, there was evidence that the pilot sites were not yet feeding back the problems that they were encountering with commissioning and by not yet inviting commissioners to the table *'they weren't then enabling other providers to come into the market'*.

'I think that people need to believe that where gaps in service are identified that they will be acknowledged and met. I have just sensed that some maybe need some reassurance that something will change because they don't want to let patients down, they have got a relationship with the patient and they are asking what they want and what they need, but if they can't then follow it up and say, 'okay well we have got this that may be able to help you in the future', you know whether that is now or in the future, then people will lose faith I think'.

'...what Year of Care has that nothing else does is about taking those individual needs and choices, wishes, plans and whatever you want to call them to really influence the services that are provided at commissioning level. So, that is what I see the Year of Care as, I don't see Year of Care as care planning or commissioning, it is about making that jump...the innovative thing about Year of Care is taking individual needs and aspirations and using this to drive provision at a population level, rather than basing it on historical reasons or assumptions.'

'It is probably a stepwise process isn't it? I think that embedding care planning within the care process is a fundamental first step. Because you can't deliver Year of Care without that, and even for clinicians and patients to even move to that is a big challenge. We are way off it here, we have done work on redesign, which points towards collaborative care planning, but we have not got a robust skill set amongst clinicians and patients to do that consistently, and until you have got that you can't gather the real needs information that will then inform commissioning. I think that it is a natural first step, and what you need, what I hope Year of Care is doing is challenging commissioners to build an

infrastructure that can then respond to the outputs of that. So that is almost phase II it seems to me or even phase III after the commissioners have developed that infrastructure, is to respond to that need.’

‘So the biggest problem I think is going to be how do you commission the outcomes that patients want, are they going to be so complex that it is going to be impossible for the commissioner to handle that degree of complexity? Will we have to keep it simple in perhaps the first two to three years, rather than trying to let the project fail by trying to commission options for patients that are far too complex?’.

5. The IT Template

The IT Template was raised as a potential risk. First of all, there had been a delay in recognising that a template was needed; secondly there appeared to be some confusion about who’s responsibility it was to develop the template; and finally there were concerns that a delay in developing the template could potentially derail the process of Year of Care, including the need for further training. There was a concern that training had been premature in the absence of a template.

‘The biggest gap that nobody ever perceived at the very beginning was this information template and I think you know in hindsight it is a great thing, and I think that there was, I think that we had different expectations, as a pilot site what the central team would bring and I think visa versa.’

‘So we had to get this care planning training in and because of the timescales of the project we could not wait. So we got the care planning training in and done. We needed the template, if I did it again I would go with the full package. Cause what we did was we taught, within the care planning training we taught the principles of care planning mainly around the consultation technique. What I would do if I did it again was I would have the whole package and that is the organisational staff as well with the template. We would give practical advice on how to transfer information to pre-consultation letters and summary letters etc. but the timing was not right’.

‘I know that there is a concern within the team that without that IT template, the momentum, because of the amount of practices that we have got involved, the momentum is going to slow down considerably if we don’t start giving practices tools to be able to record what is happening in their consultations. To be able to record where the gaps are in services; to be able to record what patients needs and wants are so that that can be fed back into the commissioning process. And, services can be provided, and that is not going to happen over night by any means, but that is key I think to making this all pull together and join up and work. I keep calling it the missing link’.

‘The risk of losing momentum now. It should have been delivered in the middle of May, we are still not there, because it is with X at the moment, they are the initial pilots, and they have done a sterling job in pulling this out so quickly but the reason that it has been held up at the moment is that they are making sure that they have got the coding element spot on. Without the coding, the commissioning process is nigh on useless, and so we have got to get that coding. And it has got to reflect the needs of care planning’.

6. Increasing inequalities

Several participants were concerned that the Year of Care programme might have an unintended consequence; that it might actually increase inequality rather than increase access to high quality, personalised care. There were concerns expressed that both professionals and patients might not want/be able to change their behaviour in line with Year of Care, and that we risked re-enforcing existing health inequalities if service users didn’t develop skills needed to negotiate the care that they needed: *‘it could turn out to be a white middle class focused piece of work if we are not careful’*.

‘.....what happens in the next few years, there will be some people that care planning will work for very, very well, there will be others where they won’t want to touch it with a barge pole as that is not how they live their life, they don’t live it in that structured organised way and they don’t want to, and why should they. I think that there is a big issue that this is not for everybody, and at the moment we are making broad statements that care planning and the subsequent commissioning of personalised services will benefit everybody and I just think we haven’t really got to that side of things yet and we can’t until some of the results of the evaluation come out, but there is a risk that in this formalised way that there is a significant proportion of people who just don’t want that amount of hassle.....and some people who are managing their lives relatively well, feel that something else is being imposed on them...’

‘How do we ensure that we have got equity across the patch, because we were saying, if not all patients may want to participate in their management in a care planning process, and we have never really discussed how we deal with that at a local level. Or whether we just adopt this approach and take everybody through it. So some of the learning that has to emerge over the next 18 months has got to be about well, you know, is this suitable for everybody or have primary care managed it for everybody, or what are the variances in the way that care is delivered’.

‘I think that this is a long term thing. If you are changing a whole culture, that is years of culture. And the results from that are not going to appear in two years; it will take longer. It could increase inequalities. I do believe that it can reduce them, because those people that it can potentially most benefit – if it is done right – would be those that aren’t getting access to services currently because no one is informing them. So rather than the emphasis being on empowerment and self management, it could potentially also be a process to ensure access.’

7. Spread and sustainability

Many interviewees felt that spread and sustainability were potentially areas of significant risk; how do we move from a discrete project to mainstream practice? Although the evaluation will not report definitely for two years, some interviewees felt that the central Year of Care team should be thinking about spreading this across all organisations and all long term conditions. There was a worry that other geographical areas wanted to roll out Year of Care but didn't have the funding or intensive support that the national pilot sites enjoyed.

‘One of the other challenges is sustaining it and measuring whether it is being sustained, but one of them, thinking about it on a wider scale, is sort of challenging clinical assumptions with people who have not been directly involved with the pilot and I think that there is some work to be done out there with the opportunity for people who are interested to access the learning in other ways that on the internet. You know, there is some value in having that. It is hearts and minds stuff. It is about understanding from clinicians what it is about and what it means to them and how it works, and so I don't think that it is just a model that you can get in a folder, and read about and apply’.

‘I suppose the biggest risk for me is that it has been over-hyped to policy makers and that if we then get a glitch it then gets discredited. Over-promise and under-deliver. It is a very attractive and persuasive model. But we really don't have the proof in the pudding’.

‘Somehow, I don't think that there is a risk of the enthusiasm waning, but I think that the central team, the central basis, the focus, all the things that we were talking about that would be needed for other organisations to take this on, I think that they are going to be essential for a long time’.

Many participants were concerned for the actual pilot sites: How would they cope with the volume of work required to deliver the programme and the evaluation over the next 24 months, particularly now that central funding for local project management support had come to an end. Would the pilot sites be able to work in a complex system and deal with such complexity? There was a very real concern of losing engagement with primary care and thereby momentum as a result of the scale of the programme. Some were worried that care planning was in reality too time consuming to put in place. Finally competing priorities for PCTs might distract local project teams from delivering or evaluating Year of Care.

‘And I suppose continuity in terms of the thinking and the kind of ideas but also actually this is more like sustainability like what happened to the pilots getting long term kind of plans in place and stuff like that. How are they, when they don't have a project manager or whatever any more, how are they going to drive this forward...and they are going to need to kind of continue to do the evaluation which is going to be resource intensive, but also lots of the other things. The stuff like

engaging practices, supporting practices, and if we want to find out about some of the more kind of technical things around costing and stuff like that, and how they link in on that. I mean all of those things kind of could be quite resource intensive, so how are the pilot sites going to address that? And how are they going to plan for what happens next?'.

'I think that one of the risks is that after we have engaged the practices and delivered the training that they don't make that transition in primary care, and I think that we need to be clear on what our role is in supporting that transition. So I think that that needs kind of careful consideration. And managing, and support and I think that it is a really fine balance between dictating to primary care and supporting them through this process because although people see you have got a local enhanced service in place, is it a stick or is it a carrot, and you don't want to kind of, I don't want to build in too much to an enhanced service that says you need to do that, it is about working for them in a developmental way and for them to have ownership as well'.

8. Individual budgets

Individual Budgets are designed to bring about independence and choice for people receiving care or support. It gives them a full understanding of the finance that is available, in order to empower them to take control and make decisions about the care that they receive. Piloting individual budgets is seen as a core part of the Personalisation agenda and within the Department of Health as a central part of the strategic direction outlined in the NHS Next Stage Review. Individual Budgets are therefore hugely relevant to the Year of Care, diabetes services and the care of all people with long-term conditions. This raising the question as to whether individual budgets be piloted within the provision of care for people with diabetes, we would advocate that this be done within the framework of a Year of Care approach, as a means of supporting facilitated choice.

'The biggest concern that I have had since the inception of this is that it gets used for personalised budgets. This is not about personalised budgets, the trouble with Year of Care is that it is so broad, so wide, it is so, jumbled is not the right word, but it covers so many different things, that people can use it to be a vehicle for whatever they want it to be, and the current thing is individual budgets. Now, Year of Care can not be used for individual budgets because it does not set the cost of individual care, it will look at the cost of services, but unless we do additional piece of work to match those services to individual needs, I cannot see how they are going to come out with a budget. I think that care planning provides a way of identifying options that people can use. Now whether personalised budgets is used as the mechanism to commission that or not is irrelevant, quite frankly if this worked you don't need personalised budgets as you just do the commissioning through the proper commissioning at a population level, through the population commissioning route'.

The Year of Care programme is currently exploring and testing what is needed to support effective use of individual choice as a mechanism to stimulate a wider range of more

flexible service provision, tailored to the needs of individuals with long term conditions. There are two reasons why this is directly relevant to individual budgets. The first reason is that we are piloting how care planning can be used to support individuals to make informed choices about their personal care, working in partnership with a healthcare professional and the establishment of what is needed in a local healthcare system to support this. If individual budgets were to be put into practice then they would need to be implemented within this context. The second reason is that the programme is exploring how to get the right services and support in place for individuals with long term conditions and of particular relevance is the idea that capturing individual priorities and goals from care-planning discussions is fed back into commissioning at a population level. This reflects the idea of a 'notional' individual budget.

From a practical perspective the Year of Care will deliver a number of critical elements which are required to enable effective self-direction¹, in particular:

1. A robust infrastructure within which people with diabetes may be supported to make informed decisions about their care. This could be further extended to provide support to individuals to control the mechanisms through which their personalised care is procured.
2. Systematic documentation of the services and interventions that patients choose. It similarly documents the services and interventions that they would have liked but which weren't available. This knowledge will give an indication of the ways in which individual budgets might be spent and the potential cost of meeting currently unmet need.
3. Detailed data on service receipt at individual level. These units of provision provide the basis for costing patient pathways. The value of this knowledge to the development of individual budgets would be considerable.
4. Within the context of Year of Care, there might also be potential for exploring the use of individual budgets in specific areas where there is a high level of unmet need and / or a lack of a sufficiently wide range of services tailored to individual needs and circumstances. These might include weight management services; education, information and support; or emotional and psychological support.
5. Established fora in which people with diabetes could identify discreet elements of their care / stages of their care pathway where they would prefer to have the option of choosing from a range of service providers.

This is all framed within a wider understanding of issues relating to patient engagement requirements.

¹ Alakeson, V. (2007) *Putting Patients in Control: The case for extending self-direction into the NHS*. London: The Social Market Foundation.

DISCUSSION

The review interviews raise a number of key issues about the Year of Care at both a local and national level.

One of the most consistent themes was the phenomenal amount of work that has been put in to the programme, which for many was over and above their initial expectations. The pilot sites devoted considerable time and energy to developing their local areas, the national team maintained dialogue and input with a range of organisations and policy developments, and everyone involved in the programme contributed to the development of theory and expansion of the evidence base. This enabled a very large amount to be achieved in a very short space of time.

The importance of key individuals and ‘champions’ was a regular theme. The stakeholders all recognise the function that these individuals have had in a wide range of roles, often not quantifiable: Motivating people to put in work over and above their remit, promoting the programme and garnering interest and buy in, and providing support and reassurance on a day to day basis. The awareness of the importance of these people to the programme’s success has been noted at every level and is echoed throughout in concerns about future momentum and leadership locally and nationally:

‘... when [the pilot sites] don’t have a project manager [...] any more, how are they going to drive this forward?’

‘In terms of the risks for the team are that you’ve lost the main driver and the person who set it up, understood it, probably sees the totality of it and has this huge skills base in terms of clinical, managerial and systems mind’.

The review interviews also provide an interesting perspective on the issues that the programme has faced to date, and also highlight areas of significant internal tension.

One of these is the tension between the central team’s role in stimulating and facilitating development at a local level, and a sense that the sites ‘*felt [they] were being project managed to death*’. This reflects the debate at national level about the most successful way to deliver innovation. On the one hand is the concept that devolution to local teams liberates initiatives, and on the other the idea that local skills and knowledge cannot be assumed and local change may not be possible without outside facilitation. This programme may not always have got the balance right and will need to keep this continuously under review. However it emphasises that the ‘art’ of facilitation (defined as achieving results through other people) is one which might be valued and studied in the NHS more generally. The pilot sites have been unanimous in their gratitude for the central team’s guidance, and are clearly aware of how far the extent of the success of the programme can be attributable to the personal intervention of the SRO:

‘She is very clear about what she thinks is needed and has the confidence and the experience and the kudos to stand back and articulate that quite clearly’.

The frequent mention of the importance of funding during the interviews also provides an interesting juxtaposition with the sites' intention and wish to continue to be involved in the Year of Care learning events after the funding has finished. This demonstrates the value that is placed on the theoretical models to facilitate local application and operational development, the motivation of staff to work hard to deliver a programme they believe in, but also the tradition and experience that nothing can be achieved without financial levers.

This way of working has clearly led to widespread recognition that the Year of Care is not a 'discrete project' but rather a vast, complex programme of cultural change and the required interdependencies with local initiatives and associated work streams which feed back to inform further theoretical development. Indeed, one of its undeniable strengths is that it crosses so many fields that it inspires a great deal of involvement and passion from people with a variety of different backgrounds and roles

The sites have had to adapt the central programme intentions to meet their local environment to ensure that the programme is delivered in a way that is practical - emphasising and downplaying the constituent parts depending on local circumstances - which has led to the occasional tension, as with the evaluation:

'I am very disappointed that one of the sites is basically doing what on earth it wants, and I just think that it could threaten the whole project'.

The fact that the three pilot sites have interpreted the Year of Care in different ways – whilst maintaining a standard lexicon – and the relationship between the sites is a further area in which a difficult balance is maintained. The three sites were selected partly on the basis that they were different, and would therefore likely provide different outcomes, and yet it is apparent from the interviews that as well as support there is a degree of competition between the sites:

'You want to be seen in a good light, [...] other organisations are there, and so there is the element, a bit of an element of competition, which is good, it is healthy'.

There is acknowledgement that the Learning Events have provided an excellent forum in which to share experiences and issues candidly, and although the sites '*are all bouncing off each other now*' there is an inference that these sessions can be developed to provide an opportunity for the pilots to further challenge each other's work, and the work of the central team. Although the Learning Events enable sites to communicate what they have done, challenges still appear to be internal rather than cross-site:

'Because you go to the learning events and then somebody will say, Oh yeah we have done this, and you think, oh my God we haven't even thought of that'

Hopefully, once the pilot sites move out of the 'set up' phase and begin to deliver the Year of Care their experiences in different areas will compliment each other and the relationship will be able to develop into one in which they are able to provide more practical support as 'critical friends'. There are accusations that the programme has at times felt like a validation exercise of a care planning model already developed, but as the programme evolves within each site new initiatives and systems will feed into the overall programme. There is acknowledgement within the central team that their current skill set is focused on care planning expertise and may need to be broadened to meet this future need, particularly around commissioning, and it may be that individuals from within the pilot sites are able to fill this gap.

'Care planning is something that people knew a lot about, and we kind of had that sort of skill and understanding, but some of the more technical questions around say segmentation, costing and stuff like that, we kind of had to try and get other people involved in that'.

Finally, there are issues around what the programme can achieve which need to be clarified in the next stage. Pilots, whilst having individual issues about data collection and involvement in mandated aspects of the programme, have different views on the issue of assessing overall impact. As this is a feasibility study rather than a Randomised Controlled Trial, this work usefully highlights that further clarification is necessary.

This review report complements the reports received from the Tribal evaluation. As well as offering an insight into the collective thought of the programme's key stakeholders it raises issues which the national team would be well advised to consider in order to ensure that the next phases of the programme are as successful as the first. The passion for the programme and commitment to ensuring its sustainability is apparent throughout the interviews and this needs to be built on to ensure that the Year of Care continues to inspire such widespread engagement and a framework in which to radically alter the culture and systems of provision of care for people with diabetes.

APPENDIX

List of interviewees in wave 1

1. Avril SurrIDGE (User Representative, Year of Care Programme and Partnership Boards)
2. Bev Bookless (formerly National Diabetes Support Team)
3. Bob Moberly (User Representative, Year of Care Evaluation Steering Group)
4. Bridget Turner (Diabetes UK)
5. Douglas Russell (Tower Hamlets PCT)
6. Helen Dixon (Choice Team, Department of Health)
7. Iain Ryrie (Tribal)
8. Jill Mitchell (North of Tyne PCT)
9. John Dean (Bolton PCT)
10. Kathy Wilson (formerly Project Manager for Year of Care)
11. Rachel Turnbull (North of Tyne PCT)
12. Sheila Dilks (Calderdale & Kirklees PCTs)
13. Sue Page (Cumbria PCT)
14. Sue Roberts (SRO, Year of Care programme)
15. Trudi Akroyd (Calderdale & Kirklees PCTs)
16. Wenda Aitchison (Co-creating Health – Diabetes project)

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