VIEWS AND DECISIONS FOR CONSIDERATION BY YEAR OF CARE PROGRAMME BOARD:
wave 2 interviews with key stakeholders

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Abbreviations

DH   Department of Health
GP   General Practitioner
PCT   Primary Care Trust
QIPP   Quality Innovation Productivity and Prevention
QOF   Quality Outcome Framework
SHA   Strategic Health Authority

Executive summary

1.1 Audience and purpose: this report is written for the Year of Care Programme Board as it approaches the third year of the Year of Care programme. The report is based on interviews with 15 individuals selected by the Year of Care team. Interviewees were invited to reflect on the past year of the programme and look ahead to the coming one. This is the second in a planned series of three waves of interviews, conducted to provide fast feedback to support the board in its decision-making.

1.2 Timing: Interviews were conducted during October and November 2009.

1.3 Structure of this report: following a brief account of the project's methods Section 3 provides a summary of the programme's successes during the past year. Section 4 lists nine priorities identified by interviewees for the coming year. Section 5 highlights five features of the broader context, and three features of the programme itself that shape and interact with the Year of Care programme and its potential outcomes. Section 6 summarises experiences and learning from pilot and non-pilot sites where Year of Care has been implemented. Section 7 considers each of the nine priorities in more detail, in the light of contextual features and experiential learning. Views from interviewees are reported that prompt decisions for the Board for the coming year.

2. METHODS

2.1 Interview procedure: Interviewees were purposively selected to include Year of Care Programme Board members, key people from Year of Care pilot and non-pilot sites, leaders engaged in work with long term conditions other than diabetes, and one person from the Tribal evaluation team. Fourteen interviews were conducted in person and one by telephone. Most interviews lasted between 60-90 minutes. All were recorded then transcribed and transcripts sent to interviewees for verification.

2.2 Analysis: the researcher read all transcripts to identify key themes then re-read them to conduct thematic analysis.

2.3 Ethical considerations: formal ethical approval was not necessary for this study. All interviewees signed consent forms that outlined confidentiality agreements and rights to withdraw from the study. Voice recordings were deleted. Transcripts are securely password protected and will not be seen by anyone from the Year of Care Board and team, as promised in the confidentiality agreement.

2.4 Scope and limitations: this study is limited by the narrow selection of interviewees, all from senior positions in their organisations. The Tribal Group Evaluation report will provide a wider perspective: the aim of this report is to provide a strategic overview of the programme and its present and future direction, and not to overlap with the Tribal Evaluation.

3. SUCCESSES

Comments from interviewees about successes during the programme's past year fell into ten key themes. They are listed below, roughly in order of frequency of mention.

- The Year of Care concept has an attractive and inspirational quality for clinicians and is becoming better known
- Culture change for clinicians, towards a more patient-centred approach, has been demonstrated to be feasible
- Care planning has been demonstrated to be feasible in individual practices and in broader groupings (networks or commissioning groups) as routine practice
- The training for practices that wish to adopt care planning has been developed and refined
- A practical model that describes care planning has been developed, which turns the concept into a practical set of actionable steps

- The programme has attracted and maintained ongoing enthusiasm, engagement and commitment from those in pilot sites during its second year
- Learning events have been productive
- The IT template has been developed
- Communication about the programme to the external world has been effective
- A team approach to developing the programme has been effective.

4. ISSUES IDENTIFIED AS PRIORITIES FOR THE NEXT YEAR

During interviews nine main themes emerged as priorities for the coming year. Each priority was raised by a significant proportion of interviewees. They are listed roughly in order of importance.

- Aims for the year: clarify specific aims for Year of Care in the coming year
- Year of Care model: further clarify the Year of Care model and message based on genuine empirical evidence
- Commissioning: gain more understanding about how, practically, to achieve micro/macro commissioning and provider development and promote both as far as is feasible in the coming year
- Evidence and communication: clarify the nature of information and evidence that should and can be available at the end of the programme, consider how it will meet expectations and requirements of intended audiences, and how to communicate it
- Strategic connections: develop links with relevant structures, people, programmes in preparation for the end of the programme
- Long term conditions: explore options for expansion into other long term conditions and decide how far to pursue expansion in final year
- Patient education: clarify what is needed and how it should be provided
- Training: clarify ongoing means of delivery. Clarify relationship between national training programme and Year of Care
- Ongoing support: identify what is required for operational sustainability and development of the programme and potential models for achieving it.

5. CONTEXT AND CONCEPT – ASPECTS TO CONSIDER

5.1 Overview: for every intervention aspects of the broader setting and of the intervention itself interact with the way the intervention develops and the outcomes that emerge. Features referred to by interviewees that may influence decisions made in the coming year, or that may interact with decisions, are briefly discussed.

5.2 Context-related issues:

5.2.1 Policy context: Year of Care benefits from the broad policy context that has, for some years, been moving towards individual care plans and personalisation. Interest in and understanding of the mechanics of care planning is further advanced than that around commissioning. Progress for the Year of Care programme in the area of commissioning is more complex, operating in an environment of hazy understanding and without a shared vocabulary.

5.2.2 Potential change of government: with a looming general election it is possible to predict features of the Year of Care programme that might have a different future if the government changes. Other parties with whom Year of Care might work may lean towards inertia, delaying progress. For the relevant areas Year of Care could decide whether to wait for new policies to become evident or to plan preemptively.

5.2.3 Project and incentive-based nature of NHS: much of the direction of general practice is influenced by targets and projects that have financial incentives attached. Year of Care currently has no national financial incentives, but does involve initial outlay of time and money.

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5.2.4 QOF targets: QOF targets act as a particular challenge to the Year of Care approach. QOF targets can be effectively met for patients with diabetes through medication and firm medical direction. A partnership approach towards patient-identified goals may not necessarily meet QOF targets.

5.2.5 Bio-medical outcomes for diabetes are slow to change: evidence of success measured by health outcomes is slow to emerge. This is problematic for a three year programme. It is also a problem for evidence-based commissioning.

5.3 Programme-related issues

5.3.1 Attractiveness and complexity of the concept: as a concept Year of Care has appeal to many clinicians. This builds interest and a wish to adopt some or all of the approach. At the same time, the programme is complex, and there is a tendency for clinicians to adopt their own interpretation of what Year of Care means.

5.3.2 Iterative nature of the programme: as a feasibility study then a pilot, Year of Care has developed and changed over time. An iterative approach supports adaptation and improvement, but also risks a sense of lack of clarity and diverse interpretations of the current approach or plan.

5.3.3 Limited time and resources: as it enters its third year the programme faces a wide range of opportunities for developing and/or refining aspects of the approach. At the same time there is a need to narrow the focus on forward planning. With limited time and resources priority areas must be identified.

6. OPERATIONAL EXPERIENCES AND LEARNING FROM PILOT AND NON-PILOT SITES

6.1 Overview: this section aims to summarise learning from sites where Year of Care has been implemented, looking first at contextual factors that support change; then at approaches that support Year of Care as it is introduced, implemented, and embedded; and finally at future needs. The findings may offer pointers for identifying sites where Year of Care is or is not likely to develop effectively, suggest approaches other sites may consider if adopting Year of Care, and indicate topics for potential development.

6.2 Contextual features of sites where Year of Care has been introduced

6.2.1 Charismatic clinical leaders keen to promote Year of Care: sites where Year of Care has become established have charismatic clinical leaders who are (a) trusted (b) keen to promote Year of Care (c) prepared to discuss and grapple with the practical implications for practitioners of implementing the programme.

6.2.2 Engaged clinicians who actively network: ideas and enthusiasm spread in areas where there is a culture of engaged networking.

6.2.3 Motivation to change things: motivation is crucial. Sometimes low standards can be an incentive to adopt new approaches while existing high standards can act as a disincentive.

6.3 Supportive approaches for introducing the Year of Care programme

6.3.1 Initial awareness raising and reality check: widespread open discussion should be held about the aims, requirements and readiness of a practice or a site to adopt Year of Care before deciding to do so and before embarking on training.

6.3.2 Training: to maximise the chance of implementation it is crucial that the right people attend training for Year of Care.

6.3.3 Multi-disciplinary engagement: following training the idea and commitment to adopt the programme should be accepted by representatives across the whole diabetes-related team.

6.4 Supportive approaches for implementing the Year of Care programme

6.4.1 Effective project management: skilled project management is crucial.

6.4.2 Engaged partnership approach for developing and implementing the programme: inviting and maintaining active engagement from a wide range of stakeholders supports effective integration of the programme with other local activities. A partnership approach which models the culture change that care planning aims for creates a supportive environment in which to encourage and improve implementation of the programme.

6.4.3 Patient engagement in design and delivery of the programme: wide-ranging patient input is needed to shape communication, education and patient-interaction so that it reaches and responds to the local population.

6.5 Supportive approaches for maintaining and embedding the programme

6.5.1 Links with other programmes: linking or integrating Year of Care approaches to other local or national initiatives supports continuation beyond the programme's lifespan

6.5.2 Checking and supporting ongoing implementation: implementation across practices and across sites is inevitably patchy and requires ongoing monitoring and support. One site monitors care plans; more mechanisms for monitoring and support are yet to be developed.

6.5.3 Incentivising engagement: local schemes may be developed to promote uptake of the approach and/or sanction non-implementation.

6.6 Newly emerging needs for the future

6.6.1 Master classes to tackle the challenges: some aspects of the Year of Care approach remain as unsolved challenges. Inviting external input to focused sessions on specific issues may be one way forward.

6.6.2 Training for and engagement of the extended team: the Year of Care approach could be supported by other health care practitioners who engage with patients with diabetes if the other practitioners understand and refer to patients' care plans. Training is needed to support the wider team to understand and engage with the process.

6.6.3 Support for clinicians as they struggle with the culture change: the culture change required for clinicians to fully adopt care planning brings with it new stresses and challenges. Opportunities for support are needed.

6.6.4 Training and support for family and carers: no involvement with family or carers has yet been built in to the Year of Care programme.

6.6.5 Recognition and acknowledgement: staff in sites where Year of Care has been implemented may feel unrecognised for their efforts by the Year of Care Programme Board or team. It is important that they are acknowledged for their hard work.

7. NINE PRIORITIES FOR THE NEXT YEAR

7.1 Overview: views from interviewees about each of the nine priorities are reported prompting decision-making about the relative importance of each issue and how they should be addressed.

7.2 Clarify aims for the programme's final year

7.2.1 Diverse and changing aims for the programme: the iterative nature of the Year of Care programme has allowed the programme's aims and content to develop and grow, taking advantage of strategic opportunities. For some this is an approach that should continue during the coming year; others voiced a strong wish to contain and define the aims and agenda for the programme's final year.

7.2.2 Key questions for setting aims for the coming year: two issues most commonly raised by interviewees will help define the year's agenda. The first questions whether the focus for the coming year is to maximise effectiveness of the pilot sites, or to spread the approach as far as possible. The second question asks whether the aim for the year is to learn as much as possible from the pilot sites, or to work to embed the Year of Care approach in a sustainable way.

7.2.3 Decisions to be made : although options raised by the two questions above are not mutually exclusive, most interviewees expressed a strong wish for clearly articulated aims and a defined, manageable agenda. Decisions about the following eight priorities would help shape the agenda.

7.3 Clarify Year of Care model and message based on empirical evidence

7.3.1 Central questions for clarifying the model and message: the following four points summarise areas for clarification raised by interviewees about the Year of Care model and message.

7.3.2 What exactly does the Year of Care model include? as noted above, the Year of Care model is both appealing and complex. It has attracted interest among clinicians and general

practices who have adopted their own interpretation of the concept. Many focus only on care planning; some adopt process aspects of care planning but not the deeper cultural changes. If the aim is to maintain integrity of the model it is important that it can be clearly articulated.

7.3.3 What does care planning involve and what defines it? The care planning component of the Year of Care model has been clearly articulated. Two similar but separate three-stage models have been put forward to describe and explain the approach, turning the concept into actionable steps. There is scope for refinement of materials that invite patients to participate in and prepare for care planning, and of the care plan. Attention is being given to ways of demonstrating 'genuine' care planning rather than mere process.

7.3.4 What is known about how the Year of Care model works in reality? Interviewees identified a need for more knowledge about the way that Year of Care is applied in individual practices, wanting to learn about on-the-ground behaviour, barriers and gaps. Better understanding of practical experiences is needed before the model is promoted more widely.

7.3.5 How can the Year of Care model be conveyed? More recent experience from care planning training has demonstrated that the approach is best conveyed when role modelled by an experienced clinician; written toolkits alone are not effective. Other interviewees pointed out that, when promoting Year of Care, benefits to clinicians, as well as those to patients should be emphasised. Finally, the approach is best conveyed by adopting an approach that models the partnership approach of care planning, being absolutely clear of the goal, but flexible and trusting that clinicians have best understanding of how to apply the model in their own context.

7.3.6 Decisions to be made: the Tribal Interim Evaluation Report may have provided enough information about implementation of Year of Care to meet needs identified by interviewees. When enough is known about practical clinical experience decisions can be made about feasibility of the Year of Care model: whether it can be seen as practicable in its current shape or whether changes are needed. Decisions could be made about the extent to which the Year of Care programme aims to define and control integrity of the approach and its processes. A related decision may be the extent to which the Year of Care approach is intended to be selective to certain practices or mainstreamed.

7.4 Commissioning

7.4.1 Clarify how far Year of Care will develop its approach to commissioning: most interviewees considered the commissioning component a central strength in the Year of Care model, but some question how far the programme itself can or should develop the approach.

7.4.2 Increase understanding of micro macro commissioning in practice: many of the practical realities of micro macro commissioning are yet to be understood. Master classes may be on way forward; a Year of Care project, if funded, could provide valuable learning.

7.4.3 How essential is an IT template to the commissioning model? : views are mixed on the centrality of an IT template to support micro macro commissioning. Proponents of the template see it as essential; others are less sure. Most recognise that data collection alone will not resolve commissioning challenges, some of which relate to inadequate understanding of how to move from data to decisions. Some areas are adopting approaches that bypass the need for an IT template.

7.4.4 Decisions to be made: while retaining micro macro commissioning and provider development as part of the Year of Care model the programme could decide what priority to place on understanding and developing approaches to implement it; whether to look for other models to adopt or adapt; of whether to leave development to other programmes. Commissioning and IT development may both be affected by the coming election, prompting further decisions about whether to postpone action or plan pre-emptively.

7.5 Evidence and communication

7.5.1 Clarify realistic expectations of evaluation message: expectations about what the Year of Care evaluation might demonstrate differ with closeness to the programme. Those more distant hope for evidence of positive changes in health outcomes and/or savings in resources. Interviewees closer to the programme recognise the challenge, but suggest approaches for conveying the benefits in terms of the QIPP agenda, and as patient stories.

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7.5.2 Key audiences: GPs, PCT commissioners, decision makers in NHS, decision makers in Department of Health, and people with diabetes were some of the key audiences for evaluation results identified by interviewees. Each will need targeting differently.

7.5.3 Packaging the message: three approaches for packaging the Year of Care message were suggested: demonstrating its relevance to the QIPP agenda; promoting the benefits for staff; and selling its relevance as a solution to problems that are already identified as national challenges.

7.5.4 Decisions to be made: an assessment could be made of all evidence that can or will be collected to demonstrate the programme's impact; decisions made whether any additional evidence could or should be collected; and efforts undertaken to manage expectations about demonstrable outcomes. Having identified the type of evidence that will be available targeted approaches to communicate outcomes to key audiences could be prepared, in advance of the final evaluation findings.

7.6 Strategic connections

7.6.1 Levels of engagement with other programmes and strategies: interviewees referred to the importance of developing close links with other programmes to support further development of components of the Year of Care approach, and to embed the approach beyond the programme's lifespan.

7.6.2 Possible strategic links: suggested programmes or strategies with which Year of Care might link included the broad personalisation agenda; Co-creating Health; NHS Diabetes commissioning framework; IT development and SHAs.

7.6.3 Decisions to be made: the programme could determine the extent to which developing links with other programmes or strategies is a priority for this year then, to the extent to which it is important develop a clear strategy for identifying and pursuing options.

7.7 Long term conditions

7.7.1 Inevitable spread from Year of Care to long term conditions: an underlying intention for Year of Care was that, by exploring an effective approach to support people with diabetes, the programme would highlight potential models for people with other long term conditions. Interest is inevitably growing among those engaged with other long term conditions. Views differ about how engaged Year of Care should be in exploring relevance of the approach beyond diabetes.

7.7.2 Range of views about ease or challenges of extending Year of Care: Some interviewees considered application of the Year of Care model to other long term conditions a simple process. Others identified a range of challenges.

7.7.3 Approaches for exploring applicability of Year of Care to long term conditions: two different conceptual models were suggested for considering ways in which Year of Care would be applicable for different long term conditions, or ways the model might need to be adapted. A third suggestion proposed discussions between representatives from a wide range of health care areas, including end of life, with the aim of achieving 'one person one care plan'.

7.7.4 Decisions to be made: Year of Care needs to decide how involved the programme will be in its final year in exploring and developing its applicability to other conditions.

7.8 Patient education

7.8.1 Different reasons for patient education: interviewees referred to two main reasons for patient education: to educate people with diabetes about their condition and how to manage it; and to help them make best use of care planning. Education for family and carers of people with diabetes is also needed.

7.8.2 Condition-related patient education: structured education programmes meet some of the need for condition-related patient education but is inadequate in its reach.

7.8.3 Patient education to support best use of care planning: some interviewees believed specific education is needed to support people with diabetes to understand and engage with the culture change that care planning requires.

7.8.4 Decisions to be made: the programme could decide whether it has a clear view about needs for patient education, and the extent to which it will be engaged in supporting ways of meeting these needs.

7.9 Care planning training

7.9.1 Current position with training: interviewees recognised development of the care planning training as a success. Some questioned feasibility of the proposed train the trainer approach for delivering the training, believing that delivery through established training bodies such as universities would be more achievable and effective.

7.9.2 Other training needs: there is a need for brief training for the extended health care team; there is also a need for refresher training as noted below.

7.9.2 Relationship of national training programme to Year of Care: some interviewees expressed a need for greater clarity between the national care planning training and Year of Care, to address the challenge of limited time and resources and to ensure adequate focus on Year of Care goals.

7.9.3 Decisions to be made: best approaches for delivering training for Year of Care in the future could be discussed, and decisions made about what priority to place on meeting currently unmet needs for training the extended health team and on refresher training. Clarification of the relationship between the national training and the Year of Care broader programme is wanted.

7.10 Sustainability for the future

7.10.1 Practical approaches for sustaining changed approach: some interviewees raised questions about practical aspects of sustaining Year of Care when the programme ends.

7.10.2 Refresher training and the challenge of staff turnover: in areas of high staff turnover there are frequent needs for care planning training for new staff. Even where staff retention is high, ongoing supported clinical reflection is needed to maintain interest, ensure implementation and refine approaches. More work is needed to develop and deliver refresher training.

7.10.3 Peer support for clinicians: sites where Year of Care is being implemented identify a need for peer support as clinicians adapt to the culture change that Year of Care brings. New approaches that provide peer support are being explored and could be shared.

7.10.4 Systems to reinforce Year of Care approach: more could be learned, developed and shared about ways of reinforcing implementation of Year of Care models.

7.10.5 Central repositories of information about Year of Care: suggested approaches for retaining information and knowledge about Year of Care included identifying acknowledged clinical champions for the model, and ensuring that Year of Care is widely and well documented.

7.10.6 Decisions to be made: the programme could determine what priority to place on developing approaches to support future sustainability and, to the extent that it is a priority, select and develop mechanisms to achieve that aim.

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1. BACKGROUND

1.1 Audience and purpose

This report is written primarily for members of the Year of Care Programme Board, based on interviews with 15 individuals selected by the Year of Care team. Interviewees were selected for their experience of the programme from an operational or strategic perspective, and/or for their experience and views on issues of relevance to the programme. The purpose of the report is to provide fast feedback for the board to consider as it aims to maximise effectiveness of the programme in its final year.

Accounts of the background to the Year of Care programme and its aims and approach have been presented elsewhere and will not be repeated in this report. The aim of this study is to capture reflections on the past year of the programme and views about the coming year.

1.2. Timing

Interviews were conducted during October and November 2009. This period coincides with completion of the Tribal Group's Interim Evaluation Report. Some hopes or concerns expressed in interviews and reported here may already be addressed in the Interim Evaluation Report, which has not been read by the author of this report, in the interests of maintaining an independent view.

This study is the second in a planned series of three waves of interviews with selected stakeholders. The first, conducted by Grace Sweeney, was completed in late 2008 and reflected on the feasibility phase of Year of Care. The third will be conducted in late 2010.

1.3 Structure of this report

Because of the varied ways in which interviewees are connected with Year of Care, their views and comments range from site-specific observations and recommendations to high level strategic proposals for direction of the programme. In order to capture both levels of observation, this report addresses separately reflections based on implementation of the Year of Care, and those that relate to operation of the programme as a whole.

The report starts with a brief summary of successes that the programme has achieved in the past year. Section 4 lists the key priorities most commonly identified for the Programme Board to address in the year ahead. Section 5 then outlines aspects of the context in which Year of Care operates and features of the programme that influence and interact with development of the Year of Care. Section 6 reflects on some of the operational experiences of pilot and non-pilot sites. Section 7 then looks in more detail at views relating to each of the nine key priorities listed in Section 4, taking into account contextual factors and operational experiences.

2. METHODS

2.1 Interview procedure

Sixteen individuals were purposively selected to be interviewed, including people involved in Year of Care at pilot sites and non-pilot sites, Year of Care Programme Board members, people engaged in work with other long term conditions and one person from the Tribal evaluation team.

Each person was contacted by the researcher and invited to take part in an interview which would last between 60 – 90 minutes. When individuals agreed to be interviewed each was sent an information sheet outlining the purpose of the study, the way in which it would be conducted, and ethical guidelines. Fourteen interviews were conducted in person and one by telephone; one potential interviewee did not have time to be interviewed.

Interviews were loosely structured around prompts which invited interviewees to identify successes relating to Year of Care in the past year, areas for improvement, concerns, and priorities for the coming year. As the study progressed later interviews probed areas most frequently raised by earlier interviewees.

One interview lasted only 36 minutes due to shortage of time. All other interviews were close to the expected duration, the average length was 72 minutes. All interviews were recorded and the digital recordings sent to a transcriber. Transcripts were sent to interviewees for verification.

2.2 Analysis

The transcripts were read by the researcher first to identify key themes, then re-read to conduct thematic analysis. This draft report has been written for circulation to interviewees and the Year of Care Board, with the aim of completing a final report before the end of January.

2.3 Ethical considerations

As a study for the purpose of service improvement this work did not require formal ethical approval.

Interviewees were assured that all interviews were confidential, and that anonymity would be maintained except where specific knowledge would be ascribable to particular individuals. All interviewees were told of their rights to withdraw from the study, and asked to sign a consent form.

When transcripts were approved digital recordings were deleted. Transcripts will be held, securely password protected on the NHS Diabetes & Kidney Care internal electronic system until the end of 2012, when they will be deleted. Transcripts are held only for verification of this report or for future evaluation purposes, but, in keeping with the commitment to confidentiality, will not be accessed by any member of the Year of Care Programme Board or team.

Interview excerpts from all interviewees are used throughout the report. To preserve confidentiality interview excerpts are presented free of identification but a password protected version of the report with interview identifiers verifies the breadth of interview excerpts on which this report draws.

2.4 Scope and limitations

This study is limited in its scope by the narrow selection of interviewees, involving only 15 individuals from senior positions within each organisation. While different views may be held by those in other posts, the aim of the study is to collect a strategic overview of the current status of the programme. The external evaluation conducted by the Tribal Group will provide a more comprehensive view of the programme and this study is not intended to overlap in any major way with the work of the external evaluation.

Due to the varied range of interviewee experience and the open nature of the interviews, not all topics were explored with all individuals, so where certain views are expressed it is not always known how widely held those views are. In most cases the report indicates whether a view is widely held or expressed by only one individual.

3. SUCCESSES

Interviewees were invited to comment on successes of the past year. The following points summarise the key themes, roughly in order of frequency of mention.

- The Year of Care concept has an attractive and inspirational quality for clinicians and is becoming better known
- Culture change for clinicians, towards a more patient-centred approach, has been demonstrated to be feasible
- Care planning has been demonstrated to be feasible in individual practices and in broader groupings (networks or commissioning groups) as routine practice
- The training for practices that wish to adopt care planning has been developed and refined
- A practical model that describes care planning has been developed, which turns the concept into a practical set of actionable steps
- The programme has attracted and maintained ongoing enthusiasm, engagement and commitment from those in pilot sites during its second year
- Learning events have been productive
- The IT template has been developed
- Communication about the programme to the external world has been effective
- A team approach to developing the programme has been effective.

Excerpts from interviews provide more detail.

The Year of Care concept has an attractive and inspirational quality for clinicians and is becoming better known

> people like what it stands for and they're interested in it and … they're wanting more information about it ... numerous people who want to do it themselves, even though they don't quite know what it is,.....the mere fact that people want to do it and are interested I think is a success factor in itself.... it's had a catalytic effect amongst health care professionals, which is quite difficult to do that, it's something that they think they can buy into, it's something that is about their practice …

> generally speaking … patients and the clinician involved really like the care planning encounter. You know, I think it, instead of being a kind of QOF box ticking exercise, it's a real encounter … so actually I think one of the drivers that sustained it has been people just feel - I'm practising quality medicine.

Culture change for clinicians, towards a more patient-centred approach, has been demonstrated to be feasible

> [Year of Care has] significantly helped to move the culture change, to move thinking in a sense, towards a more patient centred approach. There's loads of people in the country doing that but I think that we're a definite part of that movement.

Care planning has been demonstrated to be feasible in individual practices and in broader groupings as routine practice

> the success has been the degree to which we've demonstrated a complete culture change and approach to patient centredness, patient education, patient involvement

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and care planning .... . And we have delivered care planning and I think it's now embedded, ... We think it's embedded, beyond the Year of Care practices, so that's our success.

The training for practices that wish to adopt care planning has been developed and refined

what has been achieved is that there is a good, an excellent national training project, programme ...

I think it's great that they've got the training up and running because clearly ... it is important that there is some kind of structure.

A practical model that describes care planning has been developed, which turns the concept into a practical set of achievable steps

Year of Care has … allowed us to … understand this concept. Before it was a philosophy, … it was aspirational, it was policy statements, we kind of got some vague ideas about it was it really should look like and why we were doing it … if we re-wind two years ago, … And the policy was saying to do something and we genuinely didn't know whether we could get it down to actually being able to be clear about what it is. And there is almost a danger now that we forget this massive success of being articulate-able because we'll be constantly you know, uneasy because we haven't quite achieved the ambitious future that we kind of want to see, because we want to change the culture of primary care essentially, primary and specialist care in long term conditions.

The programme has attracted and maintained ongoing enthusiasm, engagement and commitment from those in pilot sites during its second year

the way that people have been involved and engaged in the pilots, at all the different levels of care and I think that's been extraordinarily successful. The fact that … their leaders of those areas are prepared to come to programme boards and that so many people are involved in improving the approach to care planning, at the front line, is really impressive …

the fact that we are still delivering a Year of Care … because pilot sites haven't had much funding at all in comparison to other programmes which try and achieve something as complex as this and they're all still engaged and still we're having regular meetings and we're sharing ideas and the evaluation is still going on …

Learning events have been productive

one thing that's been very good has been the learning events between the three sites, because I think, there have been synergies between the three sites, but also quite significant differences between the three sites. And I think the joint learning events have been useful, helpful, powerful.

The IT template has been developed

[the IT template] I mean there's no question there's been some good things in that, you know, this project has developed the first ideas of what needs to be captured in any IT system anywhere,... obviously its good because it's helped formulate thinking about it and to have it is just a miracle in itself.

Communication about the programme to the external world has been effective

The HSJ supplement, that was really successful, so communications I think they've done really well … in terms of engaging with SHOs and PCTs has been very good. And I think that their campaigning at a national DH level, … So I think they've done a lot of things very well strategically and in terms of communications …

A team approach to developing the programme has been effective.

the fact that we really have been able to identify and express and exchange, the issues where things are not going right. And from my point of view, that's the critical element to getting things improved … we have to have an environment in which we can raise the issues that are not going right, so that they can be addressed.... That is at the board … and in the project as a whole so, so really we've been able to self reflect and then build on these things. And we've been I think able to do that because of the new structure of the board … It's a case of everybody looking at it altogether …

4. ISSUES IDENTIFIED AS PRIORITIES FOR THE NEXT YEAR

The nine priorities are listed roughly in order of the extent to which they were seen as crucial and/or commonly expressed. Each of the issues was named as a priority by a significant proportion of interviewees.

- **Aims for the year**
  clarify specific aims for Year of Care in the coming year

- **Year of Care model**
  further clarify the Year of Care model and the message based on genuine empirical evidence

- **Commissioning**
  gain more understanding about how, practically, to achieve micro/macro commissioning and provider development and promote both as far as is feasible in the coming year

- **Evidence and communication**
  clarify the nature of information and evidence that should and can be available at the end of the programme, consider how it will meet expectations and requirements of intended audiences, and how to communicate it

- **Strategic connections**
  develop links with relevant structures, people, programmes in preparation for the end of the programme

- **Long term conditions**
  explore options for expansion into other long term conditions and decide how far to pursue expansion in final year

- **Patient education**
  clarify what is needed and how it should be provided

- **Training**
  clarify ongoing means of delivery. Clarify relationship between national training programme and Year of Care

- **Ongoing support**
  identify what is required for operational sustainability and development of the programme and potential models for achieving it.

Themes that emerged from the interviews demonstrated considerable agreement on key priorities for the coming year, but views about how each issue should be addressed were more diverse.

In Section 7 views are described about each of the priority areas listed above. The following section outlines aspects of the broader context for Year of Care and characteristics of the programme that shape the setting in which decisions about the priority areas will be made.

5. CONTEXT AND CONCEPT – ASPECTS TO CONSIDER

5.1 Overview

For any intervention, aspects of the broader setting, and of the programme itself interact with the way the intervention develops. Features of the context, and of the Year of Care concept that have potential to support, challenge, or change the programme were mentioned during interviews, and are noted here as factors that may influence and/or interact with decisions taken by the Year of Care Programme Board in the coming year.

Features of the context

- Policy context
- Potential change of government
- Project and incentive-based nature of NHS
- QOF targets
- Bio-medical outcomes for diabetes are slow to change

Features of the programme

- Attractiveness and complexity of the concept
- Iterative nature of the programme
- Limited time and resources

5.2 Context-related issues

5.2.1 Policy context

As one interviewee said, for several years 'all the health policy has been really pointing in the same direction', towards care plans. Another interviewee spoke of a view commonly held by long-practicing clinicians that, in the past five years, there had been a 'sea-change':

> it is moving more towards listening to people and actively engaging people, a different approach …

Receptivity to the care planning component of Year of Care is supported by the fact that care plans and an increased emphasis on self-management has, for several years, been a policy aim.

Commissioning and personalisation of health services are also high profile policy issues, but the thinking surrounding them is less well developed. The challenge of implementation is confounded by the fact that, as relatively recent concepts in health, there are few established or shared understandings of precisely what each means.

> everybody in the NHS is muddled over all the words to do with long term conditions and personalisation … people use a whole set of words, personalisation, patient centred, self-management, self care, care planning, care plans, you know, you usually have a group of eight people in the room and there are eight different versions of all of this. And it is paralysing to action … how can a group of people who don't realise that they've all got these different views, then set about organising something?

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5.2.2 Potential change of government

As the next general election draws closer there is an increasing risk of inertia, while partners and organisations with whom Year of Care needs to work postpone decisions or implementation until the direction of the next government becomes clear.

There are decisions that, as a time-limited programme, Year of Care will not be able to postpone for long, so the programme may choose to predict possible policy changes relating, for example, to IT, commissioning, and the future shape of general practice, and prepare models and evidence that would support the future of Year of Care if the government changes.

5.2.3 Project and incentive-based nature of NHS

> [Year of Care] has come at a time with so many other pressures in practices, … which are all ways of achieving different objectives, but they all have money behind them. And so may not be very much money, but when so many things come along, with a little bit of money attached, the ones that don't get money attached, tend to fall through the net ...

The tendency for the NHS to influence practice by introducing new projects and incentivising targets creates a situation where choice of direction for a general practice may be swayed by financial considerations. This further supports the tendency for current projects to be superseded by new ones.

As an intervention with minimal financial incentives to support it or act as bait, some GPs resist the Year of Care approach, dissuaded (or supported in their resistance) by the initial organisational costs in time and money required to establish it. Comments below from two inerviewees reflect the challenges at a practice level, and at a PCT level.

> I think that there will be a lot of resistance to the whole care planning process from GPs because it's time consuming. I definitely think it's the right way forward, … we've done it in the practice and we're beginning to see some of the benefits from it. But it's a different way of working and I think that a lot of GPs are, will say that they're just too busy and they can't do that and it's not right for them and they can't really see what the benefits are, da dee da dee da, and it's a different way of working, so it's outside peoples' comfort zones.

> it's not easy financially to achieve this. … the reality of implementing this change is expensive, I mean really expensive. So to pull everybody out, hundreds of thousands of health care professionals out of their jobs to go and attend training, and then to come back and attend it again, … even if it's only for half day, is really expensive. And for organisations, you know local health communities to fund all of that, is quite expensive as well and everybody is under the cosh financially at the moment so the incentive to get involved isn't great …

Yet, as a third interviewee reflected, incentivising care planning would bring its own risks.

> *Q: So if Year of Care approach is to spread, does something need to change in the system incentives?*

very much so, we'll have to be careful how we change it because we don't want sort of like, 'you *will* produce a care plan' in there, because it will become a mechanistic approach again.

5.2.4 QOF targets

Several interviewees highlighted QOF targets, not just as another approach that competes for resources and attention with Year of Care, but as a significant perverse incentive to the new power dynamic that Year of Care requires. Views from two interviewees describe this perspective.

> on the one hand we've got this Quality Outcome Framework which is all about what sort of standards, what sort of target levels of HbA1C we should achieve …. So we're desperately trying to get patients to say to them, ok this is what we're aiming for, HbA1C ... And we're going through a care planning process which is about supporting them to make individual choices to make their decisions for themselves, to set the goals for themselves, so it's quite possible that patients will say, 'look I feel great, my HbA1C is 8. I feel great on this ... and as far as I'm concerned I'll just leave it as it is.' ... So there is the dilemma because the patient is making choices for themselves. That means you're not achieving your QOF points because you can't push them down to the target level of 7 that the QOF is expecting of you, so you're losing money!

> our staff … very much felt, in diabetes world at least, that we ought to be doing things differently. We want to find ways of engaging with our patients then, to help them to achieve different outcomes. That's balanced very strongly in practice by the feeling that we need to achieve specific outcomes that we're being driven towards and that actually the priority honestly, is about achieving our QOF targets before outcomes, and that some in our areas would argue that getting people's behaviour change, isn't going to do that much towards achieving our targeted outcomes....Yes, and essential, doesn't feel essential, because we can achieve the levels of target there by the sort of things we're currently doing. We can work really hard and give all the drugs … and when we can't achieve it by that means, we're allowed to exception code people... So we can say, look we've given them three drugs to push it down, hasn't done it now in the appropriate period of time, right, exception code them, so they don't count in the targets.

5.2.5 Bio-medical outcomes for diabetes are slow to change

Change in health outcomes for diabetes is acknowledged to be slow, and unlikely to be achieved in a three year programme. This reality is in tension with the wishes of those outside the programme who want to see hard evidence that the Year of Care approach 'works'.

> My concern would be in time scales ... but we're working for long term conditions so it's very rare, you wouldn't expect any change in health outcomes for maybe a decade, if you're lucky. And we're doing a three year programme, so I just hope that we've managed to communicate effectively enough now that we're not expecting to see any changes during the life time of the programme and that we've put in mechanisms to monitor that longer term.

Other interviewees emphasised that a changed approach to long term conditions would not suit all patients. The culture of passivity and dependence on medical care is well established and it is important to maintain realistic expectations about what can be achieved.

> some people will always have a long term condition of diabetes here, and will not want to change, some people will be actually virtually impossible to change, but people in the middle, who are trying to get a bit of a shift, we're gradually influencing. It's taken us the last whatever it is, sixty years of NHS, to get them to where they are now, the current model, it's going to take us an awful long time to unpick aspects of that model, so we get back to people being feeling that they come in with their own agendas.

The fact that bio-medical markers for long term conditions are slow to demonstrate change is also a problem for evidence-based commissioning.

> the nature of commissioning means that there's always this difficult balance between long term conditions being unlikely to see any changes in the short term and yet commissioning cycles constantly needing short term improvements and you know, this is a common issue with any programme not just ours.

5.3 Programme-related issues

5.3.1 Attractiveness and complexity of the concept

The attractiveness of the Year of Care concept to clinicians is one of its positive features: it sparks interest and activates a wish to work differently.

> when I actually launched the idea of care planning and asked the people who might want to be pilots, it was interesting just how many people put themselves forward and said, 'yes we might like to do this'. Nearly twenty practices out of a hundred practices came forward and said that even without payment they were interested in doing it. To me that reflected the high level of interest that says that we need to do things differently.

Despite the readiness with which the idea of a more patient-centred approach is grasped, the full implications of the programme are far more complex than they initially appear.

> I knew it was a complicated programme but I didn't understand that it was a complex programme ... the breadth of areas of the NHS that it covers ...

Clinicians inspired by the Year of Care concept often re-assess their practice and re-think aspects of their service delivery to people with long term conditions, particularly around care plans and care planning. Integrated links with provider development and commissioning have received less attention and the full implications of the culture shift towards a more patient-centred relationship and the organisational changes required to support the change are less commonly adopted.

As a result, practices that consider themselves to be practicing the Year of Care approach vary considerably in the extent to which they adhere to the model envisaged by the Programme Board.

5.3.2 Iterative nature of the programme

Having started, in its first year, with the aim of trialing the feasibility of establishing a Year of Care in general practice, the model with which the programme was working was inevitably fluid. As it moved into its second year more of the challenges and requirements became clear, and the programme developed to meet them, but also, other facets of the programme continue to develop and change.

> it isn't just say me that changes my mind - everyone in the project - this is iterative in every single possible way.

As an iterative programme Year of Care is able to refine its approach in response to earlier experience, adapt to changing circumstances, and benefit from new thinking.

The more challenging aspects of the fluidity have been a sense, by some, of lack of clarity and unpreparedness.

> there was no clarity around the product right from the beginning … and the concept was made sort of clear, was very clear in the people who understood what they meant by it, but I don't think it was clearly, you know clearly really understood by some of the clinicians that took it on board. And then we started doing all the stuff around Year of Care without having an education programme or the right tools …

As the programme continues to develop and change there is ongoing potential for stakeholders less close to the centre to hold different interpretations of current thinking.

5.3.3 Limited time and resources

As a three year programme Year of Care is limited in what it is possible to achieve, yet there remain a range of opportunities for further development.

As with any project, phases can be identified in the life of the Year of Care programme. The first phase explored the feasibility of whether the programme could be established. The next phase could be seen as the development phase, creating resources, setting up the board, clarifying training. In the next phase the programme became operational: the new board was in place, a strategic plan was set, work streams were identified and acted on, the training started operating and clinicians began implementing the programme. Year of Care can be seen to have now reached another phase where, having become operational, new challenges have been identified. Along with the recognition of 'holes' that need to be addressed, the programme has also reached its final year; a phase which brings its own requirements for reflection and forward planning.

> we had a very operational but now good work programme, we had people who were now committed to really doing it and all working together, and we began to do it, but in that phase … what came out of that was, the beginnings of the real worries and the issues and the things that weren't going right. … that's where we began to identify the absolutely big holes in this project, and then begin to talk about them …And then really by August, when we had the next sort of phase, it was then that we realised that we had to look at this next and last year that was coming up. And that's a time of an absolute commitment … absolutely looking now at a sort of self reflection, right across the programme, what's been good, what hasn't, what can we say, and developing a plan for the last year.

There is an inevitable tension between focusing on refining the programme by meeting the needs that have been identified, and forward planning. Another interviewee expressed their own interpretation of the current phase:

> there is also, a 'so what', in all of this. So we have polished exemplars at the end of the year say, say we put all our energy into that, then what? So what happens as a result? So in any piece of work, there's a development which is around scoping, there's a pilot phase which demonstrates why, and then there's an implementation phase which takes it out widespread. So we've done the development and scoping, then we've done some pilots, so what? So where's our strategic plan? Who's going to pick this up? How's that going to be delivered? Who's going to take responsibility for it? How's it going to be sustainable? How can it be financed? How do we demonstrate, all those things, what's the business case?

As it moves into its final year the programme is constrained not only by limited remaining time, but also by its staff capacity.

Several interviewees praised the work of the project manager, as well as that of the Year of Care initiator, recognising that both have been central to the programme's achievements.

> I think that it wouldn't have happened without having a defined project manager to do this, none of this would happen, and it also wouldn't have happened without X. … And I think that Y has done a fantastic job in being able to keep it afloat this year.

The same interviewee expressed concerns that additional central support was needed to achieve the amount of work required in the final year, and that careful planning for any new support staff is needed to ensure smooth functioning.

> I don't think Y can carry on doing it on his own, quite frankly, there's too much. There's too many things that crop up, that sort of fit with the Year of Care … it's not sustainable. So once a strategy has been worked out and defined, …. We have to look at getting some more resourcing … So the working arrangement needs to be sturdied up a bit. … we need to have plans in for [any new people] coming in, because it's going to be a nightmare for them otherwise.

6. OPERATIONAL EXPERIENCES AND LEARNING FROM PILOT AND NON-PILOT SITES

6.1 Overview

The Tribal Group evaluation will report on individual sites in detail. This summary of operational experiences reflects on what might be learnt from the different contexts, approaches to implementation and stages of progress that pilot and non-pilot sites illustrate.

In this section three aspects of the context in which Year of Care has been introduced that have influenced its uptake or development are noted. Next, supportive approaches that sites adopted as they aimed to introduce, implement, then embed Year of Care are observed. Finally, future steps identified by those in the sites where Year of Care is most advanced are noted.

6.2 Contextual features of sites where Year of Care has been introduced

With the small number of interviews conducted for this study any comparison of the sites where Year of Care has been introduced can only be tentative. Nevertheless, comments suggest factors that may have influenced the way in which Year of Care was introduced and the extent to which it was implemented in each site. Three potentially influential features are noted here.

6.2.1 Charismatic clinical leaders keen to promote Year of Care

In sites where Year of Care has become established the programme was championed by charismatic clinical leaders who are (a) trusted (b) keen to promote Year of Care (c) prepared to discuss and grapple with the practical implications for practitioners of implementing the programme. The following views are from two different sites.

> we had really effective clinical champions, so we had GPs in our areas who were the spokespeople, the spokesmen of the Year of Care project who saw the bigger picture, who did all of the kind of motivation with their peers about trying to get people involved, but also thinking about it from a practical point of view, so coming in with, and some of the models that were developed as part of this project was around kind of this is the kind of theory, this is a model, how will it work in practice? And for people to come in and challenge that, which I think was really helpful.

> And I think the key thing is charismatic clinical leadership …

In addition, support from senior leaders has been helpful to provide backup to the clinical leaders.

6.2.2 Engaged clinicians who actively network

> I belong, there's a network of very engaged GPs, so you know, if I suggest something and then I'll have masses of emails back saying, that's rubbish, you can't do that, or you know, and so there's a lot of very active people around.

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In both sites where the programme has spread, not only are there enthused charismatic leaders, but also a culture of engagement and networking, so that ideas and enthusiasm are spread more widely.

> and we wanted to work with practice based commissioning groups to make this link with commissioned services locally for local populations further down the line, and we didn't expect at the very beginning that we were going to get all of the practices involved. But what happened was we had one GP for a practice based commissioning group that would say, you know, we want to do this as a practice, can we do it as a group? So I think as groups and as groups of local commissioners they've worked well together.

6.2.3 Motivation to change things

> When we bid initially for the Year of Care project, we had seen that diabetes was a major strategic priority, because we had some very poor outcome markers and we also had some of the poorest Picker survey results in the country. We didn't really have a coherent strategy ….
>
> *Q: How much did low standards help?*
>
> ... it gave us an ambition, it certainly gave us an ambition and a drive and a degree of energy and urgency, you know, that this was absolutely, we could not leave things as they were. So I think ambition is key.

The situation above contrasts with the setting in a different site, where Year of Care has been less readily adopted.

> And we're in the middle of a whole system redesign of [diabetes services] anyway … And it's interesting actually, because we probably offer, far more for our patients than they do in other areas, because we had a very comprehensive range of self care, self-management services, so we've got Expert Patients, we've got PAL service, which is about activity for life, for a whole range of people, we've got swimming clubs, you know, as well as the DESMOND and the DAFNE, we've got information prescriptions in the libraries, accessing information points, you know, we've got a whole range of very good self care services. …
> There's a lot going on really ... And that's part of the problem you know, because if you've done certain kinds of, if you've done maybe Co-creating Health and cognitive behavioural therapy, and then you're asked to the Year of Care training, you don't always see the need …

A similar difference has been described on an individual practice level. In a site where all other practices in the area have fully adopted the Year of Care approach, one practice has not.

> There's one practice where I really don't think he is really doing it, and he's a single-hander, who has really, really good outcome measures. And I think he tells his patients what to do. But he's quite hard to shift, he has such good outcomes, do you know what I mean, so it's a difficult one and I think … so it's like, 'I'm doing really well, so why should I change what I'm doing?' So he's a little difficult, but I think we'll see, but I think patient pressure might move him.

6.3 Supportive approaches for introducing the Year of Care programme

6.3.1 Initial awareness raising and reality check

Interviewees generally agreed on the need for open, broad discussion about the purpose, process and implications of adopting Year of Care as the first step, even before embarking on the training. The following interview excerpts outline one person's view of what should be considered at the outset.

> the awareness raising, so you know, what's this all about? What's in it for me? What does it mean for our patients? What does it mean for health care professionals? What does it mean for the admin and support staff? What does it mean for our model of care? What does it challenge? So all of these things that you could almost think about in advance, before you say, right we're doing this for the right reasons rather than this is a good idea, let's go and try it. I think up front, you need to do as much of that as possible … there's an element of a reality check here in terms of where do you start? And where do you see your end point as? So I think as much awareness raising as possible and I mean that with people with diabetes, so what will this mean for them? So if we're going to adopt a care planning approach, but also with our voluntary sector …

The same interviewee recommended that new sites should be given a checklist to help them gauge their readiness to embark on Year of Care, and to consider the potential costs and benefits from a grounded, informed position.

> So I think it's just about taking what we've learned and just applying it into a framework in terms of this is what we would recommend that you look at what's in place, before you embark on this project. Have you got the buy-in? Have you got the vision? Have you got the leadership? Have you got the stakeholders lined up? What's the links with the voluntary sector? What's your local long-term conditions like? What's your regional structures? What are the levers, the drivers, but also what are the barriers in terms of what do you envisage a successful outcome and how would you achieve it? But what do you perceive the barriers to be? So it's some of that kind of preparation up front I think which is the reality check … as a package, there'll be kind of like a checklist of ten things to say actually do you have all of these things lined up before you embark on the process? What is it you want to get out of the process and how long do you think that process is going to be?

This approach contrasts with the situation in one site where, though the Year of Care concept attracted enough interest for practices to choose to adopt it, the description of the model and the understanding of what was involved was open enough for each to interpret it differently.

> Our approach was around … practices that had expressed some interest at the time and have sort of gone along with the project, all of whom have … interpreted it in very different fashion. … And then we started doing all the stuff around Year of Care without having an education programme or the right tools, … And in some ways, I think, with the benefit of hindsight, people just were you know, we'll do Year of Care and we'll, and went along to some action sets, people were quite enthusiastic and then I think each area interpreted the concept differently.

6.3.2 Training

> there's the initial, there's the training programme that's to be delivered, that, we think is core.

Interviewees had clear views on who should attend the training.

> the whole team that delivers the clinical care needs to do the high level training, ok, so your practice nurse, your nurse specialist, your GP and if you've got a specialist practice nurse who's doing diabetes, I think they should all do the training. Because that's the only way you're going to get consistent approach.
>
> *Q … in practices where perhaps one or two people go, how does that then work*
>
> Well it's that doesn't work and I think that's what happens, you have a diabetes specialist GP and a specialist nurse and then if they're not around, nobody else does it, and we've had that in one of the practices. So you might need your clinical champions that are your experts, but then your whole practice has got to embrace the culture just so they can keep it ticking over if something goes wrong. So you might not have all your GPs in one practice attending, although that would be ideal, because they will all have diabetic patients and probably all doing this. But certainly it needs to be multi-professional, you need to have your specialist nurse, you need your practice nurse there, a) because then you get a degree of challenge.

The broad consensus is that at least two members of a practice, and preferably more, should attend; that they should be multi-disciplinary; should include diabetes specialists and also people with the influence and/or decision-making power to ensure that the new approach is adopted and implemented, whether or not those who attend the training are present in the practice on any one day. Another interviewee described a possible approach for maximising attendance.

> I think the senior partner in the practice needs to attend, because the senior partner will be making some of the decisions around you know, whether we do this or we don't do it. So there's something about that decision that needs to be made. And the second thing is, the nurses or the clinicians who will be directly involved in doing the care planning, and delivering the care, obviously need to be involved in that process too. And also I suppose one could say that having some of the admin staff who need to do some of that work, it might be useful for them to understand what exactly they're attempting to do here, and how the whole thing fits together. So maybe two or three people out of the practice for half a day or two or three hours would probably be sufficient....And a better way of doing it is to actually say, 'come for lunch and then after lunch we could spend a couple of hours doing this training and then you disappear back to the practice again'.

6.3.3 Multi-disciplinary engagement

Interviewees from the three pilot sites independently emphasised that after the training, engagement needs to spread to the whole multi-disciplinary team engaged in diabetes, and commitment to an action plan is needed from all involved.

> if you learn from the experience that we had, you need across your diabetes network, you need total engagement. So you know, if it was a project that was led by your specialist team without GP engagement or commissioning engagement, then necessarily all the parts of the jigsaw need to be in place. So I think it needs to be part of a network initiative if there's a network there. If not, it needs to be led or

supported by commissioners, whether that's local groups of practice based commissioning or whether that's PCT commissioners in terms of this is kind of changed management programme. But it's about aligning all of the players in the economy for diabetes to the vision and once you've got the vision it's about what's the action plan that you're going to put in place to achieve where you want to go.

But we had GPs, nurses, psychologists, dieticians, patient representatives and consultants, sat round the table discussing the care package and agreeing how things should happen. That for me is that really engaged, often quite contentious discussion between groups, and it was multi-disciplinary, and it had a patient voice. That's what's made it, I think, for us successful.

it's got to be the approach of everybody in the practice, and therefore that's about the cultural change within a whole practice ... Therefore the receptionist has got to understand what it means and that's got to be about leadership, … the embedding it in the practice culture …

6.4 Supportive approaches for implementing the Year of Care programme

6.4.1 Effective project management

In the site that, to date, has extended and embedded Year of Care most widely, the lead clinician now plays, most of the time, a 'supportive background role' while a project manager does the daily work of project management. As the following two interviewees described, the project manager needs skills that are appropriate not only for the task, but also for the setting.

A key factor has been getting the right project manager, and you know, this kind of project so depends on project management and a project manager who understands the culture of and can engage with front-line practice staff.

But F has been absolutely brilliant, so for me, it's been actually a project that's been handed on to a large extent to F to run with and my role with her, with the project then, has become a much more supportive background role. And so she sort of does the daily running of the project, she's out there in the practices, she's sort of delivering needs. … Well the reason this lady's very good, I mean she's, you know, obviously she's got, you know, a heap of skills and she can write documents and all of those kind of things, but again the thing that I think is very good about her, is that she has worked in [the local area] for a long time … So she's very aware of the huge other pressures on practices in [the area]. … anyone who tried to work with practices without being extremely sensitive to that context, would have a door slammed in their face. What F is absolutely brilliant at, is to maintain relationship and also … she's also able to in a sense, be helpful around things that are tangential to Year of Care a bit, … So I think there's a sense of you've got to give something as well as take something.

6.4.2 Engaged partnership approach for developing and implementing the programme

In a site where Year of Care has become widely implemented a steering group with very wide membership was established at the outset, and has continued to meet monthly. The

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lengthy excerpt below illustrates the breadth of the group and the benefits that emerge from it.

> we have a strong enthusiastic steering group. G is the medical director, we have H who's one of the assistant directors for the PCT provider arm … so in essence she has responsibility for the nurse specialists and the diabetes centre. We have I … his remit is around research and patient information. We have J who's the patient engagement lead and we have a lady called J she came into post around supporting self-management, she's done a lot of work around developing resources for patients about what's out there. K who I mentioned, the community diabetologist, comes sometimes, so he's in the circulation and he comes when he feels like he should. We were having the diabetes nurse specialist come … We've also got the liaison with the research network, because they support us and we've got the people, the public health people sometimes come and who else have we got, so there's a whole network of people. They don't all come to all of them, you know, they're all invited, we've got a patient rep, how could I forget her, I should have said her first. But what I think is fantastically useful, is a lot of these people have got related experience or have worked on projects with related issues. So we've really kind of tapped in to this wealth of expertise of these different people who, you know, have said, well we've done it like this before or are you aware of this thing? Or do you know about that? And so I think that has really enriched kind of the ideas that we've had coming out of it and also we've also been able to partner up with stuff that's going on, to sort of strengthen what's happening.

The steering group is seen as central to the success of programme in the site where it operates, but integrally related is the genuinely responsive partnership approach that proponents of the Year of Care have modeled.

> and across the PCT, … we did meet and greet, so we all sort of listened quite hard to what the practices that we picked on had to say about themselves, and their patients. And we've, you know, we've listened and we've changed things … and actually I think it's just like the care planning encounter, so I mean I think, you know, we've actually just used the same concept which is, you know, we have our agenda, they have their agenda, let's sit down together and actually understand where each of us is coming from, what we're trying to aspire to. … So I think it's always got to be in partnership and all the practices have gone at different paces is the other thing. Because you know, different practices have got different issues, and some of them have got really big other issues that you know, are, it's quite amazing that they've managed to pick up and run with this, when I know that there's all sorts of other stuff that it's incredibly difficult … you have to take on board the context. So I would say, you know, it's like we've got to start where our own people really are.

In the other site where significant numbers of practices are implementing Year of Care the current means of maintaining and developing implementation is through learning events, held roughly quarterly, attended by the diabetes lead nurse, diabetes lead GP, and practice manager from each practice involved in Year of Care. The interviewee acknowledged that thought needs to be given to a more widespread means of engagement.

> as a PCT, we've identified the diabetes lead nurse and the diabetes lead GP and the practice manager in each of the practices, so they're now our main focal points for communication. Each year, the local enhance service specification for diabetes ties them into, I can't recall whether it's three or four shared learning events in a year, so as a group, they come together, so their leads come together and it's actually, it's an evening meeting and people turn up to these evening meetings.   they set the

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agenda … I think we need to take it down slightly and support more informal networks, so almost like a care planning club, so where the practice nurses can come together, you know maybe twice a year to talk about what they're doing, how have they found it, what have been the experiences? So actually there's a structure there that they have to comply with, then I think there [needs to be] something underneath it that's more informal …

6.4.3 Patient engagement in design and delivery of the programme

An interviewee from one site commented on the need for more patient engagement at the outset of the programme than had been conducted in their area.

> having the right programmes, talking to [patients] about what they understand by Year of Care, because have we really asked them what they understand by it before we started? So there's something about what do they really, what do they want out of it? And then designing the whole thing ... we did do some patient education right back in the beginning but we need to go back and revisit that because ... before we roll it out we've got to have much more in place for patients so they understand what it means.

The site that has achieved broad application of Year of Care invited comments from patients at the early stages of developing and implementing the programme. Efforts were made to recruit views from patients beyond those who typically respond to invitations to engage.

> so as we got going with Year of Care, we had the patient engagement events, where we had these massive turnouts and we had a lot of information back about what people wanted. We had some social marketing where we said, well we want to separate out the annual review into data collection, data back to you, think about it and then come in and talk about it. And how do you want that information? And they told us they wanted it in colours, so we got colour printers to go into practices … one of the things Year of Care taught us is if you send out a poster with the PCT logo on it, a certain type of person will read that and attend that. If on the other hand you engage practice receptionists who are day to day making the appointments for people, handing out the prescriptions to people, arranging the appointments for people, and who live in the communities where those patients live, whose children go to the same schools, who shop in the same shops, they are incredibly powerful in engaging large groups of patients.

6.5 Supportive approaches for maintaining and embedding the programme

6.5.1 Links with other programmes

Recognising that Year of Care as a three year programme will soon end, all sites are aware of the need to embed the approach so that the benefits continue.

In the site that maintains engagement in Year of Care through an active and widespread steering group, an additional benefit of the broad membership has been the opportunity to explore and identify links for establishing the Year of Care model beyond the three year timespan.

> we are trying to make sure that we connect Year of Care into as many mainstream on-going work strands as we possibly can, because obviously we're conscious that as a project, we're in our final phase. So we really want to kind of get it latched into

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on-going areas of work. So that partnership and having this very, I mean very engaged steering group, has been incredibly helpful to make sure that we understand what else is going on in the community and in the PCT and to try and make sure we get our foot into as many doors as we can.

In this site aspects of the Year of Care model are being integrated into three other projects or programmes, the largest of which will commission all practices in the area to conduct care planning for their patients with diabetes.

[this area] has decided to roll out the Year of Care model of care as part of something called the diabetes care packages, which is part of … the DH integrated care pilot. … So in essence, we've got this monster project going on which is involving, putting a lot more resource into general practice. And the first one that they chose to do was to deliver a diabetes care package for people with type 2 diabetes, at the heart of which is a Year of Care model, for annual reviews and in order to make that effective, they are requiring that that is delivered not at individual practice level but across a network of practices.

6.5.2 Checking and supporting ongoing implementation

All interviewees directly engaged with sites where Year of Care has been introduced acknowledged the inevitable gap between numbers of clinicians who attend training and those who implement the programme.

Yes, there is a gap there and it's a gap, the gap is there partly because of the inability to influence other people in the practices to thinking the same way, there's partly a gap because of priorities, partly a gap because of resources. They are all things that make it difficult for practices to implement.

Q: would you know, of the [20] practices that have sent people to the training, how much the training has been put into practice?

… I would say it is hard to know, the number of people that you see are definitely doing it is small. The wider influence of that training is probably more significant, but we need to capture it, keep using it and build on it.

Even in areas where the programme is established, proponents of the Year of Care acknowledged that more work and new approaches are needed to increase and sustain implementation.

I think that's one of the key things, this whole project or this whole care planning process and you know, you hear it recurringly, is a complex intervention, everybody will tell you it's a complex intervention. How are we supporting the ongoing implementation and embedding of that complex intervention? And if we don't do that, if we don't support it and embed it, then people are going to tail off at the end of the day. And that's part of it being a whole system programme, so that we continually come back to it, you know, we've got some practices who have been really successful, they've made the changes, they're doing, they're seeing some good results. What are we doing to get everybody else up to that same level?

In this site it was recognised that more opportunities were needed to meet the range of staff involved in the Year of Care approach, to hear their views and give support.

we underestimate the support and the ongoing development that needs to be there at a very local level to kind of help people through that process.

we've got twenty-eight practices who we've delivered the training programme to. We want just to follow that up and say, you know, how have you implemented it? You know sort of, these are the key components that need to be in place to support the house, so that's the theoretical model, so these things need to be put in place. Have you put those things in place? If not, why not? But also, what would it take to put those things in place to move forward?)

as a team, as a kind of service modernisation directorate, we've had to say, what's our role in supporting this... we've had to look at different mechanisms for supporting them, but also we went out after the initial training and set up phase, we went out and asked primary care, what do we need to support you to do this? And some of it was around peer meetings, some of it was about education groups, some of it was about refresher training... it's also about you know, if we've got an enhanced framework in primary care that we're saying, this is the model that we want you to deliver diabetes and it incorporates care planning, then I think there's an obligation for us to go out and talk to people and say, tell us about how you've implemented that. You know, we're paying for an advanced level of primary care led diabetes linked with care planning, what have been the successes? What have you found about the process? And I think use different ways to kind of incorporate that continuous improvement process.

In the other site where the programme has been widely implemented, an interviewee acknowledged that the extent of engagement is still patchy.

having said it's a success, I mean obviously that's tempered with the fact that there are some laggards and some people are doing a lot better than others.

In this site, where practices are commissioned to conduct care planning for patients with diabetes, care plans are monitored as part of a developmental process, revealing the extent and levels of consistency with which practices are engaging in care planning.

We sample the care plans. So, dear practice, you've got a list of four hundred patients of whom 80% have been through care planning, can we have a 10% sample of your care plans, with the patient's name deducted. And we've gone through those, and that's been quite revealing and it's made it, and it's revealed there's a, you know, there's a distribution curve of how well people are doing and some people are doing it fantastically well and other people are doing it not at all as we would like them to, for a variety of reasons. And we found that there are, there are some staff who are quite resistant, you know, there are people who have been to the training who are quite negative about the whole thing, they were saying, oh this idea that has been imposed from above, and I've been forced to go on this training … And that kind of stuff is real, and so we're going to have to get underneath some of that.

As with the other site mentioned above, the need to understand and find ways of addressing lack of engagement is recognised.

6.5.3 Incentivising engagement

In the site where practices are commissioned to conduct care planning it is recognised that, despite commitment from practice partners or champions, a challenge remains to ensure that the new approach is spread throughout the whole team. As a means of reinforcing the commitment to care planning, payment not only for each individual practice, but for all practices in the network of which they are a part, depends on meeting this commitment.

a practice is a bigger organisation than just the champions who come to the meetings, and they vary in how well they disseminate the information throughout the rest of the team, because I think general practice is very different to how it was some years ago. It's not a single entity and you've got more than just partners, partners do things other than just see patients, they're often doing other things like teaching medical students or being on committees or being part-time these days, increasingly. So if you've got a salaried doctor who's only there one day a week, how do they know what's going on? And so that, there's always a risk of erosion of the message into the team, that's the challenge for this coming year, is to embed more fully the ethos of Year of Care working and to make sure that we've got the whole team engaged, not just two or three champions …. so we are very clear that if you don't deliver care planning as part of the package of care, you won't get paid. That's the lever. And within networks, what we're saying is, and by the way if any of you default on this, the whole network loses. So we're applying peer pressure. So it is not just us beating them up with a stick, and waving the carrot of money at them, their peers will say, our share of the loot depends on you doing this.

6.6 Newly emerging needs for the future

All interviewees identified needs for the future; the most significant are listed as priorities for the coming year and described in more detail in Section 8. There are new needs however, that have only become evident as the programme has been implemented, and though each is only representative of one site, they may suggest more general needs for the future.

6.6.1 Master classes to tackle the challenges

I think for the next year, the bits that haven't been done of this project, looking at the hard bits, we've gone away and we've done the easy parts, haven't we? Because that's natural. There's a couple of pieces of work that we actually need to work in partnership with [the Year of Care Board] over the next year to say, 'this is what we think we're doing, what do you think?' And just to kind of use somebody external to kind of challenge our thinking, and I'm not sure how we facilitate that. I think it's kind of like provider development commissioning and just some of those big key themes about how do you actually embed and sustain that change? And think about some of the practicalities … And I think that's going to take a specific piece of work … it might be that they need some sort of master classes in terms of 'how do we take the problem we've got into a wider arena?' Get some other people together and say, 'what are the potential solutions?' And I think that would be hugely valuable.

As this interviewee acknowledged, aspects of implementing and maintaining Year of Care remain unclear. While learning events are valuable for sharing ideas within the programme, input of external ideas and experience could shift thinking towards developing solutions to some of the remaining gaps. The suggestion is not to replace learning events, but to hold 'master classes' as additional focused sessions with specifically selected participants to explore solutions to identified challenges.

I think it's important for the learning events to continue … it's important for that kind of like networking, but also the kind of support we get from other people. I think there are specific things where I would want … to kind of engage our public health people in that, I would also want to kind of say, is there somebody from local authority who we work with in [our area] would want to come and kind of be part of that kind of think-tank almost? Or is there somebody from the voluntary sectors … So the team in

terms of the problem solving around that might be different to the project team and the learning network as it currently is at the minute.

6.6.2 Training for and engagement of the extended team

In the site where all practices are required to conduct care planning a need for more widespread understanding of and more frequent reference to the care plan has been recognised.

> Because if you're saying I want to lose weight, and then we do this very detailed action planning, you know, exactly how you're going to do it, and then nobody talks to you about that for a year, it just doesn't work … it's billed as a once a year thing, but actually if you're trying to do aims and actions with a patient, really that needs refreshing and I think what we haven't really thought through is how do we sustain it, how do we keep it going? Particularly when you've got a big team, you know, so ok, they see a particular nurse practitioner for their care planning encounter, but then they might come back and see a different GP or somebody else or they might see a health care assistant. All of us need to be singing from that same song sheet and it's quite difficult to do that.

In this site a two-hour training session is being trialed, to help staff on the periphery of care planning to increase their understanding of and engagement with the process.

> basically we're doing a two hour training session for people who are not directly care planning, but who are involved around the edges, part of the 'house'. So that they really understand what's happened in that encounter and try and encourage people to then carry on checking with the patient, how they're getting on with their goals, understanding why these letters are so important, you know, understanding why we need to capture things that aren't working or the services that didn't. … so they're HCAs who are doing the first visit, the health advocates and interpreters that we use, some of the administrative staff, some of the other clinical staff, I think particularly some of the GPs who feel a bit disempowered by this process, because it's much more nurse led, than perhaps the way the practices did it in the past.

Those involved in planning the two hour training consider it likely that, as the Year of Care approach becomes established, training will be needed across all components of the 'house'.

> it's actually checking what people think they need … and we definitely think that's going to be quite important. I think that in a sense, we need to think about training up the entire 'house'? And the care planning at the moment, you know, we quite rightly focussed on training the people who were actually doing the care planning in the centre, but actually, as systems work, we need everyone to understand what's going on and be able to kind of do their bit.

6.6.3 Support for clinicians as they struggle with the culture change

Several interviewees acknowledged the challenge involved for clinicians as they hand power back to the patient, especially when the patient is making choices that go against medically recommended practice.

> We are transferring power towards the patient, and that is really hard for clinicians. Especially when the patient is not doing what they should be doing! It causes people to feel very draughty, you know, we've had an encounter where you know, actually the patient's not signing up to any of this.

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As the same interviewee acknowledged, in reality the outcome may be little different, but the requirement for the clinician to accept the patient's choice makes overt what was previously covert non compliance.

> I think that those tensions have always existed and I think what's happened is that Year of Care makes them overt rather than covert. Because what happens, covertly now is the doctor goes, you must take these tablets to lower your cholesterol and the patient goes, ok, and then they go off and they never take them. Whereas the Year of Care makes that overt.

One interviewee described the culture change required of clinicians as a series of changes: first, changing their consultation style so that they no longer engage as an authority figure; second, resisting the habit of racing in with instructions for the patient; but third, finding alternative approaches to help motivate people to adopt and maintain healthy choices.

> So the first part of the change is letting go some of the medical model of me doctor, you patient, I know best, here's what to do. So people will then change and have a very patient centred consultation and then revert to type and say, well that's fantastically interesting, I've now heard all about if from your point of view, now I'm going to tell you what to do. And getting people to stop doing that is quite difficult but then the next skill set … is giving people the skill to let go of some of the medical model, but to still keep the challenge and the motivation back to people … to have the desire to change behaviour and lifestyle, so it may be, ok, well I don't really want to take a statin, I'm going to control that with lifestyle changes, but then add the motivational skills to really make those lifestyle changes happen.

In recognition of the genuine challenges these changes bring for clinicians, the site that has widely embedded care planning has instigated multi-disciplinary monthly meetings to support clinicians who have concerns about individual cases.

> And what we've put into the diabetes care package is … monthly multidisciplinary team meetings, as a forum for people to bring cases that are troubling them. Which will be supported, we hope, well definitely by the community diabetologist and we hope by the nurse specialists. And very much with an idea that if people are struggling with a situation that they actually have somewhere to go to, you know, to deal with that.

6.6.4 Training and support for family and carers

A question that has not yet been addressed is the role of carers and family members in care planning.

> what do we do about carers. And what training do we offer the families of patients with diabetes?

6.6.5 Recognition and acknowledgement

Although most interviewees referred to the significant motivation and effort that implementation of the programme has required from all involved, clinicians and other staff in practices may not know that the Year of Care Programme Board, or anyone else in the central team is aware of their efforts. Recognition, feedback and celebration could support and encourage them.

something about feedback to practices from the national board, because there's been a huge amount of effort and I think they feel they've been feeding the beast. And so some kind of celebration of their effort really, and achievement.

7. NINE PRIORITIES FOR THE NEXT YEAR

7.1 Overview

In the following pages views about each of the nine priorities listed in Section 4 are reported, taking into account the contextual features and the operational experiences reported in the previous pages. Decisions about the relative importance of each of the priorities and some of the issues identified by interviewees could help shape the agenda for the coming year.

7.2 Clarify aims for the programme's final year

7.2.1 Diverse and changing aims for the programme

Possibly the overall highest priority amongst interviewees was the need to clarify specific aims for the Year of Care programme for the coming year. Awareness of limited time left for the programme increases pressure to identify and focus on the central aims, but, arguably, lack of clarity amongst interviewees about direction for the coming year reflects ambiguity, confusion or diverse understandings about the purpose of the programme overall.

Notwithstanding the five questions that Year of Care aims to answer that ostensibly shape the programme, for most interviewees the focus and boundaries of the programme lack clear definition. Nevertheless several interviewees, unsure of their own view about the programme's focus, expressed conviction that the proponent of the Year of Care was clear about the direction.

> we'd go nowhere without her, and she's got this fantastic approach which is very, she's very clear about the focus of where she's going, she's really clear about the detail that lies behind this …

It was generally acknowledged that the aims and overall direction were led by the Year of Care proponent, and that these had extended over time. One interviewee described the continuous growth of the programme, from three pilot sites 'doing their own thing', to the recognition of the need for shared training, then the growing interest in providing training to a broader audience, and now the potential expansion beyond diabetes into long term conditions.

> [the proponent of the programme] may well have had a plan in the back of her mind, but it was never articulated until a year ago maybe … there were three pilot sites went off and did their own thing, and then last summer we realised … there was some reason to do combined learning so we had a day where we brought those three pilot sites together and said, 'well what did you do in your training?' and there was some very clear common elements to it and there was some other elements that weren't so common. … But we then brought it together and then we kind of produced a year ago, in the Getting to Grips, the kind of outline of what the training was and largely that was to just kind of clarify it, there wasn't a clear undertaking at that stage to provide the training, and then X, mainly because again lots of people centrally in DH and other places are very keen on rolling this out, you know, got some more funding and commissioned people … to provide the training more widely. But I think it kind of grew from little acorns if you like. But I think it was mainly in the world of diabetes, which is where most of us were baseline thinking. I think that during that time the issue of long term conditions has been raised … really raised this question of, 'ok fine, but are we talking about diabetes, are we talking about long term conditions?' And again X might, well .. think that of course that was always part of the

plan, it may well have been, but it was never articulated, none of us signed up into kind of doing it.

Another interviewee viewed the national training programme as particularly challenging to the original aims of the programme, its audience extending beyond the original sites. While recognising that the training programme, with its broader demands, brought in valuable financial resources, this interviewee believed the lack of clear definition of the programme's aims allowed for ongoing shifts in perception of what the programme consists of.

> The problem is that the Year of Care, the framework within which it's delivered, has shifted and the reason it's shifted is because there is the development of a national training programme for care planning which is broader than just the Year of Care pilot sites. And that is because different people coming into different organisations and different conditions put on money, that was given to do the work and … there is the development of a national training programme and curricula, which isn't focussed solely on the Year of Care pilot … but that's because needs must at the time, to be able to get some resource to be able to do it, it had to be bigger than just the three pilot sites. And there were new people coming into the partnership from the organisations who hadn't been involved previously. And also, because of the lack of clarity, or the lack of definition around what Year of Care was, it was really easy for that to just happen, because Year of Care is what X thinks it is … And I think it has escaped because of that and it's never been clear about what it is and what it isn't.

The iterative nature of the programme has already been noted (5.3.2), with the benefits and challenges that brings. The value of leaving space to 'go with the flow' and seize strategic opportunities to engage with current issues is described in the following interview excerpt. By remaining flexible about where to apply any extra capacity the whole programme has potential to increase its profile, gain capacity and build support.

> what are the things out there that we need to do that are of benefit to the pilot sites, that's the first thing, and in a sense what we need is things that give general support for the project, … things that are, that are trendy and strategic and give us profile and give us opportunities and give us capacity and help us do all our things. And the thing about long term conditions … that it is coming up so fast as a political interest, that it would be something that within our limited extra capacity, I would be interested in keeping a toe-hold in, just because the more, you have to go with the flow a bit, if you want to succeed with your project.

More frequently interviewees took an alternative view, particularly in the light of limited time and resources, and identified a need for more tightly defined boundaries, wanting a strategy that, in the words of one respondent is:

> clearly defined, and I mean clearly defined, because we've had strategies before that mean nothing, because they're so vague and woolly … There's too many things that crop up, that sort of fit with the Year of Care but maybe don't … because there isn't a clear strategy or a clear vision around it. … it's vital, because otherwise we're all just going to be going off doing our own thing, or what will happen even worse is that people will just gradually disappear from it, because it's too messy and too untidy and too difficult.

7.2.2 Key questions for setting aims for the coming year

Two main questions, one at an operational level and the other at a strategic level, commonly recurred. Excerpts from two interviews illustrate the key questions:

- Is the aim of this year to support the pilot sites to be the best they possibly can or is it to spread the model to new sites?

  I would be saying to Year of Care board now, what is it you're wanting to achieve? Are you wanting to polish the pilot sites so that you're getting the best possible, possible, possible care in [each pilot site] or are you wanting to spread this as far as possible, as robustly as possible, so that actually, if there were mistakes made, other people don't make them again, and a lot of the key learning gets actioned really quickly …

- Is the aim for this year to focus chiefly on what is possible and what can be learned, or is it to embed the approach in a sustainable way?

  because I'm not clear what the, quite what we're trying to do, are we just trying to finish a pilot, in which case we just try and finish the pilots, or are we trying to make this widespread? So if it's finishing the pilots, let's make them great, let's make them demonstrate absolutely that it's worth doing. If we're looking to get it out everywhere, well be more strategic then, and link to the system drivers that really make this work.

The two interviewees most closely connected to the central programme viewed the above options as mutually compatible.

> one of the good things we've been able to do I think, is shift the perception within the pilot sites, to where it ought to be really, which is, this is not whether it works, it's about whether this is feasible. So if people want to do it, then these are the lessons that they can learn from us. And so I think that takes the pressure off a bit, should we just be doing it in Year of Care, or should we be rolling it out? We have been doing a bit of both, I intend that we continue to do a bit of both, the training and in a sense the national agenda in which we work around care planning, means that we will be doing a bit of both, but from my point of view, the Year of Care project … is assessed on what happens within the pilot sites, that's my view.

The other interviewee closely connected with the programme expressed a similar view.

> I think we have a duty to work with the pilot sites that first came on board … to ensure that the Year of Care for them, has been as successful as it could be. We do also have a duty to share that learning but I think that's down to a local level really. We want to make, we want to help other practices be as able to deliver a care planning approach and to … feed into the Year of Care as much as possible, but I think that has to be something that's determined by local priorities, local plans …
>
> *Q: So are you really saying your primary responsibility you feel, is to the pilot sites?*
>
> … I don't see them as being mutually exclusive to be honest, I think all the learning that we've got to date has been from the pilot sites and we're not, we haven't finished collecting that learning from the pilot sites and so it seems almost artificial to focus, you know, to have an either or …

Most other interviewees expressed a need for a choice and clear direction. The case for a broad focus for the year was put by the following interviewee.

> Darzi has said that everybody has to have a care plan by 2010 so there is this national movement for it, so they have to have care planning. But, having a care plan

and care planning are two different things. And I think people don't understand it, so it still needs an enormous amount of, you know, of education and changing the consciousness of people in the country and I mean, it's a lot of people, a lot of practices. So what happens at the end of this year, I don't know, I mean what happens at the end of any project? How do you change behaviour so radically, … If we're talking about, you know, what have we got now … that's about eighty practices we're talking about, all in all, you know, that's tiny compared to all the practices in the country … so you're still talking about a very, very small proportion, you know, maybe we should have been, maybe this year should have been much more about rolling out, rolling out throughout the country, not just within the pilots, I don't know.

Others, and in fact the majority, while expressing lack of clarity about existing aims for the year ahead, believed that the focus should be on pilot sites. Two views are presented below.

> we've probably got plenty of care planning on board, but have we really achieved the other elements of the Year of Care programme? So I think it's making sure that the exemplars truly are exemplary.

> I would prefer to focus on the pilot sites that are already there and put the energy in there to cover the bits that aren't currently being done. So that could be defined as getting better, so around the commissioning areas, around the provider development, things like that, engaging people with diabetes.

As a third interviewee pointed out, within the pilot sites, more is needed to spread the model.

> we continually come back to it, you know, we've got some practices who have been really successful, they've made the changes, they're doing, they're seeing some good results. What are we doing to get everybody else up to that same level? … we have to be really clear in terms of what the project was set up to do and the area in which it was set up to deliver within, because that's our cohort. … And I think there is this element of do it right, and get what, maximise the learning before you actually cascade and transfer that and I think it's really important for us to support the people before they lose interest and go away and do something else.

Even for those who see pilot sites as the focus of the programme, there is lack of clarity about whether the aim for the final year is chiefly to learn from the sites (in which case the question about practices dropping out of pilots is pertinent); or is the aim a more functional one of embedding the approach.

> … is it a project? Is it a pilot that at some point is going to come to an end or are we trying to embed something that's going to be part of a change in culture change process? And I think in some of the pilot sites, because some practices have fallen out or you know … some practices have sort of dropped out of the pilot, well what does dropping out of a pilot mean?

7.2.3 Decisions to be made

Although those most closely involved in the programme at a central level are comfortable with the existing aims, most other interviewees expressed a wish for more clearly articulated aims and defined boundaries for the programme for the coming year.

Almost all interviewees believed that the focus should be on the pilot sites, rather than on spreading the programme further, and greater clarity is needed about how the overall Year of Care programme interacts with the training programme.

> Q: A*m I being too black and white to think that at least what you're saying is, there should be a clear separation between the training and the Year of Care?*

> I don't know that there can be, politically, that's the problem. I don't think they can be....It's not that simple, I wish it was. I think at least … there needs to be agreement as to how these are fitting together.

Overt clarification is wanted about the extent to which the broader aim for Year of Care for the coming year is to look beyond the end of the programme to work towards achieving a more widespread and embedded culture change, or whether the key focus is on achieving maximum development and impact in the pilot sites.

Overall, the wish is for clarity of purpose and an identified manageable agenda, as the following two excerpts illustrate.

> Yes and I think if it's not a narrower task … even when you have defined objectives, they just explode and they expand, and my big fear is that actually we just haven't got the capacity to do it, to do everything and even when it is narrowly defined …

> we have a responsibility to [acknowledge areas that we can't fit in] and to accept that we can't take everything on board.

Decisions about the relative importance and direction for the remaining eight priorities discussed in the following pages would help shape the agenda for the coming year.

7.3 Clarify Year of Care model and message based on empirical evidence

7.3.1 Central questions for defining the model and message

> I think we need to engage broader than just the leaders of the pilot sites, I think we actually need to try and speak to those people that are doing it, just saying, what is 'it'? How is it working? And try and make that evident to people. And I also think we need to be very clear about saying, this is Year of Care and this isn't. And so it is about definition and clarity and evolving it to a point where it is perfectly clear if an area is doing that programme, or is only doing bits of it and even then doing those bits wrong.

The interview excerpt above summarises issues of central importance to most interviewees. By the end of the year the programme will need to know what the key messages emerging from Year of Care are, and how they should be communicated. Questions to help clarify the message include:

- What exactly does the Year of Care model incorporate?
- What does care planning involve and what defines it?
- What is known about how the model works in reality?
- How can the model can be conveyed?

7.3.2 What exactly does the Year of Care model incorporate?

As already noted (5.3.1) the attractiveness of the Year of Care model is both a success and a challenge. For many health care professionals the concept resonates, and they are keen

to apply it. At the outset the model gathered shape and reality as the pilot sites adopted and implemented it, but the concept is fluid and open to individual interpretation.

> it wasn't an off the shelf model away back at the beginning, it was very much around what does this mean for you? And it's quite interesting because we've kind of interpreted that locally in our projects in slightly different ways and fed that back into the national learning set, whereas now I think there's an opportunity for some element of standardisation.

The full complexity of the model is not immediately apparent, and as growing numbers of clinicians and practices consider themselves to be adopting Year of Care, the question of definition (what exactly is Year of Care, and who defines it) and integrity (how close to a specifically defined model should practice be and why does that matter) becomes more pressing.

> Year of Care is a sound bite, it's almost become a single word and people say, are you doing Year of Care? Are you not doing Year of Care? Well Year of Care is a complex intervention that has at least three component parts and one of them of course is care planning and then the other one is the micro to macro and the third one is the commissioning and Year of Care is all of those things. But when you talk in a clinical sense and what's happening, is somebody doing Year of Care? What they often mean is, are they doing care planning? And so we have to unpack as we go around, are you talking about Year of Care, and if you talk about Year of Care, how would you know that people are doing Year of Care, well you'd expect to see that they were doing care planning, they were using it to influence commissioning, and that they had a proper commissioning agenda around it.

As another interviewee said, for many, Year of Care has become synonymous with care planning.

> it's only focused on care planning. It's not focused on the rest of the 'house' around it and even though we preach that this is an integrated infrastructure that needs to be organised, people are just taking the care planning bit out and just saying, right we're going to do care planning. And that involves training up a number of health care professionals or just telling care professionals to do it. They're not doing everything else which needs to be in place, they're not dealing with the commissioning, they're not looking at the user involvement, they're not looking at what IT systems are in place. So they're just picking the easy bits, because care planning, well it's not easy, but it's tight and it's specific and it doesn't have all the old the organisational attributes..... what they're saying is, right we're going to do care plans.

If the Year of Care concept acts as a catalyst to shift clinicians towards an approach that is somewhat more patient-centred, even when they fail to adopt the whole approach, does that matter? As one person said of their own area:

> So the translation [from numbers of clinicians attending training to numbers implementing the approach] is hard to know, the number of people that you see [who] are definitely doing it is small. The wider influence of the training is probably more significant.

And another:

> … but never forget the individual clinician that can just do something else tomorrow, it's a little bit more effective than what they're doing today …

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The case is made in the following excerpt for maintaining integrity of the approach: when practices badge themselves Year of Care but fail to adopt the complete model, any benefits claimed for sites where it has been fully implemented may not be relevant for partial 'tick-box' approaches.

> … another thing to add is that they may not actually think that 'it' is the same 'it' that we're talking about. So there's a slightly different version of that, so people say that 'we're doing Year of Care' but actually in a couple of areas, where the team have gone in to look at it, they're not, they're just using the badge, Year of Care, which is quite problematic to deal with, they're just doing it in a tokenistic, or not even a systematic way. … I think that that is still one of the main challenges for Year of Care, in that if we ever get any evidence to say that it works, it will be in the framework the context within which we've developed the programme with the pilot sites. I don't know that it's something that you can take off the shelf and just dump in another area and expect them to do the same. I think it has to evolve, otherwise it just becomes a tick-box exercise and that I think is what some areas are doing …

Several interviewees said that the model still needed to be more clearly articulated.

> I don't think it's very well articulated really. I think [the proponent] can articulate it very well, but generally across the population, I'm not sure other people, it gets well articulated.

As another interviewee said, while clear articulation of the model would not guarantee integrity of application, at least it would help with definition.

> so what does Year of Care need to do in the next year? It needs to get every single key, key message for all of these elements through, what is care planning in practice? what is micro to macro commissioning and other things in practice? what is part of the training? you know, really clear and articulated and just flood the system with those messages, so that anywhere that decides that it is going to implement care planning and micro commissioning and training programmes and IT systems or whatever else, is not forced but is you know, obliged because they know what's going on …

Another area where interviewees differed in their interpretation of how the Year of Care approach could be implemented was the extent to which it could or should be applied to secondary care.

Questions of how to define, design and deliver micro macro commissioning and the related requirements are discussed below (7.4) as the third priority to consider. Challenges relating to the care planning component of the model are discussed next.

7.3.3 What does care planning involve and what defines it?

Although there is still space for refinement one of the past year's successes has been to turn the concept of care planning into a set of actionable steps.

Two separate but similar three-stage models were proposed by two different interviewees as a means of conveying the care planning approach. Both are helpful as a means of turning care planning from a concept into a practicable process and also, both support clear thinking about potential applicability of each of the three stages to other long terms conditions. As potentially useful models both are described in the lengthy excerpts below.

One model divides care planning into three stages that describe 'what you do before, what you do during and what you do after the consultation'.

So before, you need to (a) prepare the patient by sending results, but for many long term conditions that don't have results, like diabetes does, they might be more about preparing somebody to think about the questions they've got or what it is they want to consider, what they want to get out of the consultation. It's about (b) having planned care, again in diabetes that was automatic, everyone's getting their yearly review, but in airways disease or Parkinson's or whatever else, you don't get that, you just turn up when you have a problem. And it's about (c) making sure that people have information so, before it's about planned care, preparing the patient and making sure that both the patient and the health care professional have got all the previous plans or the previous knowledge, in the consultation.

During, it's mainly about what the health care professional is doing and how they're helping to bring the patient forward in that consultation, so a lot about their skills training, a lot about their approach, whether they truly value listening to what your perspective on your condition is, or whether I'm just going to tell you what to do because I know everything! … using a goal setting action planning approach, so really getting specific down to what is it you want to work on? And having a clear action plan exactly what that's about.

And then afterwards it's about having a care plan, so a piece of paper … it is important but it's the bit that everybody gets lost into, all they want to do is produce the care plan, they don't care what happens to make it. It's a bit about making sure people have got the appropriate follow up and contingency plans, they know who to contact if it doesn't work, they know the things to kind of look out for …

The other three stage model likens care planning to an appraisal process. Using this analogy care planning involves reflection; consultation; and documentation.

The first step is about reflection, the first bit is giving individual people the opportunity to think their own thoughts and that's where the results part comes into it. To begin with, I felt that getting results to patients was the only important issue, but actually it's not … if we can be encouraging - and I'm not sure we are yet - an element of reflection from the individual: 'what's happened to me? How's it going to be?' before I come to my appointment. And I think we need to develop yet a series of reflective tools. And interestingly across the Year of Care pilot areas and others that are like our own are interested, we've all got documents that ask a person to note down things like, what's happening in my own life? What's affecting my diabetes? What do I think of my results? for example. What are the key areas I want to tackle this year? They're the typical sort of questions that come out from it. And I think we can actually develop that much wider across long term conditions as a whole.

... the second stage is the consultation, how we turn that around to become the equal partnership that we talk about in the Year of Care and so on .... I liken this to an appraisal process, in medicine we've all got appraisals and in many other areas of work as well, people have appraisals now. In medicine we have to put forward quite large portfolios of what we've done through the year to keep ourselves up to date, and it's not good enough to say you've just been to a course, you actually have to stop and reflect upon it. What did I get out of it? What did I learn? … I actually see that this is a very good model, for how we could take long term conditions forward. We should have an expectation of information gathering, of reflection from the person themselves with the long term condition. We shouldn't be jumping in making an assumption that we, that we as the doctor or nurse the so called appraiser, know what's happening for that person before they start. They need to tell us what's happening, we need to make it possible for them to tell us what's happening. So then, they say what's happening, we can bring our perspective to it and at the end of

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> it we can come out with a joint agreement. We're a long way from achieving that yet, but that's how I see long term conditions going forward eventually.

> the last stage is this documentation stage, and I think we've got a long way to go to actually achieving this yet. … And essentially we've all come up with some piece of paper which you write something on, which you might keep a copy of in your practice records, either electronically or in paper format and the person themselves goes away with a similar copy. And it's mostly about a single recording, outcomes from a single event which was the consultation. And if you're lucky you get someone to put them together over course of time and you get a set of them coming up and it's mostly focused around diabetes at the moment.

Each of the stages remain open to further development, and as the model is further refined decisions will need to be made about whether improvements are guided, shared or at least encouraged from the central Year of Care programme.

The interviewee above emphasised the importance of design and presentation, and its impact on whether patients engage with information their practice sends them. While practices, following the care planning model, may send patients their results and/or an invitation to reflect on their condition prior to consultation, unless the material is presented in an appealing way it is likely to remain unread.

> Quick word on documentation, for the record really, I was looking at the types of documentation different areas are using to get records out to patients ... it's about the design and the appeal to people. ... how important it is that we design appropriately to appeal to people, to get them engaged. That we move away from what is perceived as the dull grey NHS with information that's printed in unintelligible ways, that has no meaning to individual people. So the leaflet that we produce locally, I'm very pleased to say, is very colourful, very bright and most people who have looked at it, say how easy it is to interpret. … There could be a national model [for this type of material], the only problem with that is people feel more ownership as they develop it locally and general practice is particularly awkward like that … So there are difficulties about choice …

Another area for refinement is the care plan: the medium on which it is developed and stored by the practitioner and the output that the patient receives. Different approaches are being used, new approaches being developed, and more adventurous ideas being proposed. A decision will need to be made about whether or not the Year of Care model is prescriptive about the nature of the care plan.

As with the Year of Care model overall, questions of integrity to the 'genuine' care planning model arise. Most interviewees referred to the difference between the outer 'tick-box' process and deeper cultural change.

> is it a process or is it a real holistic approach to managing the care together? And I think it should be both and I think that, I know across [a certain area] in some places it's a process and in some places, they're starting to get that it's about real co-partnership.

Within the Year of Care programme consideration is being given to ways of demonstrating true care planning. One approach already in use in one site (6.5.2) is an annual audit of care plans. Other ideas, including asking patients at the end of a consultation how they were treated, and/or questions to clinicians about their practice are being explored.

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How do you know if people are doing care planning with the cultural shift? Well that's, you have to, probably triangulate it, there's a lot of discussion at the moment and the bit that we haven't in a sense completed, is the set of metrics for this, … the metrics, they're usually thought of as sort of quantifiable, adding up metrics, and there will be qualitative things around culture shift and so the question is, how do we know?

7.3.4 What is known about how the Year of Care model works in reality?

I think it is very, very important to make sure that Year of Care does actually properly work okay in the pilot sites where it has been tested, to make sure that all of the areas where there are problems get ironed out before we start to say, look we can mainstream this. Collect the evidence for what really works, find out where the problem areas are, look at a strategy for actually dealing with that. We need to find out from each of the PCTs how many practices are actually doing the work. How they're implementing it, whether they're using the standard template, you know, we need some of that operational work doing to get that work out and then have a look at it. Let's learn what's working and what are the barriers to implementation.

The excerpt above captures a view expressed by the great majority of interviewees. Two similar views from different interviewees are quoted below, raising the most-asked questions about what is really happening at practice level: how many practices are actually using the model and of those that are, what are they doing, which parts of the model work and where are the gaps.

we understand what it is we're trying to do, and we're starting to articulate that, but Year of Care could be really clear about that. We need to measure whether or not we're doing it and then we need to work out what the gaps are and improve where the gaps are.

I don't think all pilot sites have demonstrated that all aspects of it are do-able, because it's such a complex intervention, there's so many different strands of it. So no I don't think that they have. … I haven't seen a paper that says, this is what has been achieved in this area, I've seen loads of paper that says, we've done x, y, and z but not in terms of outcomes and impact. … I feel as though we're not getting, I can't access the coal face, I can't access where it's actually happening. I can only access the level who are managing the programme who maybe have more of a bias around it. That's not to say they're doing bad, but it's just you focus on different things.

Other interviewees who had practical knowledge of pilot or non-pilot sites discussed the gap in numbers between clinicians who attend training, and those who go on to apply the programme.

I think there is a gap between the implementation of the structure and actually what happens on the practice level and making it actually happen. Yes, there is a gap there …

As described above (6.5.2) in areas where the programme is established, proponents of the Year of Care acknowledged that it is difficult to know how deeply, within each practice, the approach has been integrated.

we trained 51 of our primary care practitioners, so we've trained two people per practice ... What we haven't measured is, in that practice, those two people trained, there might be a multi-disciplinary team of 10, 20? So we've made an assumption in our project, that those people that we've trained, who are delivering diabetes care, are the change agents or the champions within their practice, and what we haven't

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assessed is, have they transferred or shared any of those learning in terms of their skills? … we've made an assumption that the two individuals we've trained, are the people that can influence all of those changes and we haven't actually measured that.

The general view was that before the Year of Care model can be promoted more information is needed about what exactly is happening on the ground in individual practices and from that, to understand which parts of the model can reasonably be promoted as feasible, and which parts need to be improved or changed.

7.3.5 How can the Year of Care model be conveyed?

The training programme has learned, from experience, that the care planning component of Year of Care is best communicated to general practice in person, modelled by a clinician who fully understands the approach. Written words about the process fail to convey the essence of the model.

> you can tell someone, you can write it down 'til it's coming out of your ears, and they will not get it, if it's about culture change. … you don't get it by telling people, which is what these toolkits are doing. You have to work alongside people, you have to role model it, you have to find ways of holding up a mirror that enables them to self reflect … you have to provide the environment in which somebody can have a look and reflect and examine themselves and see whether they're doing it.

Other interviewees emphasised the importance of making clear to clinicians and other staff not only the benefits to patients, but also how the approach can help them, the practitioners.

> You see with all of this, we're trying to, there's a huge culture change that we're trying to embed with all of what we're doing and with what's happening with Year of Care and I think that the staff need to know what's in it for me? It's alright kind of saying, 'these are the behaviours that we think you need to adopt' and they'll turn around, lots of professionals will say, 'well I already do that' or 'if I want to go further with this, what's in it for me?' So it's motivating people to want to change and to do that they need something around, this is where it's working, this is how it's improved things, not only for [patients] but also for the clinicians themselves that are involved in it.

Returning to the question of integrity, and the extent to which those promoting Year of Care should insist on close adherence to the model, an approach described in 6.4.2 likens the process of spreading the model to that of the care planning encounter: 'we have our agenda, they have their agenda, let's sit down together and actually understand where each of us is coming from, what we're trying to aspire to'. Central to this approach, alongside flexibility, is absolute clarity about the goal that the programme aims for, while trusting that clinicians and practices will take sound decisions based on what is appropriate in each particular setting.

> And hear from them where they are and actually understand which bits of this they feel they can start with. So we were also fairly flexible about, ok, this works for you, let's go for that and … So it's all the time, just offering people ideas. But they've got to work out what they feel they can do as their next steps.

> Well I also think 'it', I mean I think what's important is people understand the 'it' that we aspire to, so the aspiration is absolutely clear. But it's always going to be, I mean there are some patients and we've been doing this, where I wouldn't even begin to try and do a Year of Care encounter with them, it's just not appropriate for that patient. … So it's not, it's not that I'm not doing it, it's about what's the 'it' that works in this particular situation.

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7.3.6 Decisions to be made

Before promoting the Year of Care model enough must be known from 'the coal face': from individual practices and non-champions of the process about how widespread and to what depth the YoC model is being implemented, to assess understanding and feasibility of the whole model and of its various components. The Tribal Interim Evaluation Report may provide this information.

Armed with information about current application of the model, decisions could be made about which parts of the model are effective in their current state, which parts need further development, and whether any parts should be dropped.

Decisions could also be made about the extent to which the central programme aims to define and control integrity of the Year of Care concept (the various components and how to determine whether 'it' is really happening) and the application of it (would Year of Care propose specific approaches to process and documentation, eg care plans, or by design or default allow each practice to develop their own approach).

Implicit in this question may be the extent to which Year of Care is intended to be a mainstream approach, or one that individual practices self-select - or even apply - to adopt. If the latter, a strong focus on integrity, and of spread through role-modeling is feasible. If the aim is to mainstream the approach, overall integrity of a complex model is hard to control, but the model could influence a wide number of clinicians to make changes of some sort.

7.4 Commissioning

7.4.1 Clarify how far Year of Care will develop its approach to commissioning

> We've focused a lot on ... the care planning element … and putting systems in place to make a collaborative environment and we've focussed less on the menu of options in the middle, so provider development, menu development ...how we can take all of that and aggregate it on a population level … I think the last year we really need to focus on that.

> I think [the priority] is closing the gaps of things we agreed to do in the first place, so provider development, public and patient involvement, micro macro commissioning, really understanding where those things fit in and making sure that we are, inverted commas, building the house appropriately, in each of the pilot sites.

Understanding more about how provider development and micro macro commissioning could work as part of the Year of Care model was one of the top priorities for interviewees, as illustrated by the two above. As acknowledged earlier (5.2.1) general thinking around commissioning, beyond the Year of Care, is less advanced than that around care planning,

Some, recognising the difficulty in implementing micro macro commissioning, questioned how far Year of Care should or could aim to develop the approach.

One interviewee suggested that, weighing up relative benefits from each, energy was better spent on developing the care planning component of the model than on micro macro commissioning, and that pursuing the latter was a 'red herring'.

> for me personally I suppose [micro macro commissioning is] a red herring ... it's trying to say, well what is the wide range of things you might want, let's identify them

and then we can see if we can do something about it. But reality says, especially in these economically difficult times, that we're only going to have certain types of resources that we produce at the end of this. And I fear that the influence of the micro macro commissioning is only going to be small in changing what those services might be. We haven't got the monies to produce them, I think much, much more significant from the Year of Care is not the micro macro commissioning, but actually the influence on how we engage with people ... We have other ways of picking up some of those needs, service needs .... We've got a much bigger, a much more important message out of this, than the micro macro commissioning.

While other interviewees could see the case for not pursuing micro macro commissioning, all except the person above thought that inclusion of commissioning was what gave Year of Care its unique appeal.

> [dropping the commissioning component is] certainly an option. My concern about doing that is, then Year of Care just becomes what everything else is. The difference of Year of Care, although people may not verbally say this, because we all have slightly different constructs in our heads, of how we see this. I think the difference is about working to get that micro level of commissioning and taking that information to properly inform local, and use it to ... re-distribute finance. If that disappears, I'm not saying it's worthless, but if it disappears it becomes the focus between the person with diabetes and the health care professional, it's not actually about influencing good commissioning.

Another interviewee who also believed that inclusion of the commissioning component strengthens Year of Care, wondered whether development of the approach for commissioning has to be done by Year of Care itself, or whether Year of Care could benefit from and adopt an approach to commissioning developed by another programme.

> I think the whole story is much more powerful [with commissioning in] But … if [commissioning is] shown to be in an approach elsewhere, then they could probably take their foot off the gas there and concentrate more on the culture shift. Year of Care as a whole, is a powerful concept, people picking up on just part of it is a slight liability… I think the whole concept is powerful. Whether or not it all has to be supplied and labelled under Year of Care, or whether some of that burden can be taken off by for example, you know, the commissioning approach elsewhere, then that might take the pressure off the team having to try to do everything.

7.4.2 Increase understanding of micro macro commissioning in practice
There was general agreement that much remains to be understood about application of micro macro commissioning to the Year of Care model, and in practice generally.

> I think our problem is that we all use this buzz word commissioning, but actually not many of us know the ins and outs of how to do it, because we promote it but we don't have to do it. Therefore, how would we know? … I just think that we need to sit down and say, what is it that needs to happen?

The suggestion of 'Master Classes' (6.6.1) to introduce external experience and knowledge could be a useful approach.

One interviewee outlined some of the practical difficulties provider development and micro macro commissioning raise for a PCT: limited budgets and concerns about raising false hopes; challenges of decommissioning health services; unchartered territory of health budgets buying third sector or public health services

it's a real fine balance between if we go out and do a provider development work-shop, but yet we have no money to invest in any of the services, then we're raising peoples' expectations and not delivering something at the end of the day. So although we recognise that yes, there's something we could do about provider development, we have to be realistic about, you know, … it's a bit of kind of keeping everybody's expectations real …and it's the bit about what would the ideal model be? And the thinking is that once we've introduced care planning systematically, we use the information from that care planning process that informs what services should be there. So there's this almost we need to move from this model to something that's slightly different but the bit in the middle in terms of how do you do that, and how do you make that transition, but how then do you say well actually we don't want to commission this part of your service and that might be from a specialist team, that might be from a community team and that might be about shifting services into the voluntary sector. And that's full of kind of how you manage the politics and how that fits into a commissioning framework and I think all of those things need to be realised in terms of, what's actually physically possible. …there's also a big debate about if we're doing care planning that identifies a particular need for an individual, what's actually commissioned as part of a health budget?... So if you, if you say, well actually there's a local need for an individual to have, they don't want to access a dietetic who's traditionally in a hospital setting, they want to join the local community cookery class that's running in the local school for ten weeks ... So does the health budget cover that?

The Year of Care team has applied for Innovation Funds to explore issues connected with commissioning.

we're looking for Innovation Funds ... to put in some people and to try and have a project which really begins to unpack that. So just as I say now that one of the successes is that Year of Care has actually been the laboratory to test feasibility of care planning, I'm hoping that in the last year, we'll become the laboratory to test feasibility of helping to make these things available for people.

Another interviewee described the same project:

If you think of world class commissioning, you've got an incredibly strategic top level view and what we're talking about for supporting people with diabetes is a local fishing, a group that goes fishing once a week, you know, something very practical, very local and meets their individual needs. So you've got to find a way of marrying up the long term condition commissioner with a budget of however many million and you know twenty quid on a thermos flask and so on and so forth, which is why we're trying to put in this interim element which would be someone whose role it was explicitly to coordinate the commissioning of these small but effective community services. And we're hoping that will provide some answers, should we be successful in our funding application.

Whether learning from this proposal can support development within the Year of Care timescale depends on success in gaining funds and the time taken for the project to reap benefits.

7.4.3 How essential is an IT template to the commissioning model?

Diverse views were expressed about the value, centrality or risk of an IT template to support micro macro commissioning.

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[the IT template is] the major delay, ... We now have that solution but it's only in System One, and there's plans to put it elsewhere but at the moment it's only System One.

As another interviewee illustrated, some who are enthusiastic about the IT template see it as central to implementation of micro macro commissioning, and to the full functioning of the Year of Care model.

> *Q. And do you think it's realistic to think that the micro macro commissioning can happen within the Year of Care time frame?*
>
> Only if everybody takes up the IT templates.

Another practitioner who is using the IT template described the approach with enthusiasm.

> Well the macro micro commissioning is part of the care planning template - So it's actually captured in that. … it's brilliant because what we can do is we can say, ok, the patient would like to set a goal and say they would like to lose weight or whatever, and they wish to lose weight by going swimming rather than going to a weight management clinic for example. But that's not, that's a need that's not met because basically we don't provide swimming. So we can tick that as being in the box which it says that this is a need that's not met. So when you actually analyse a hundred or two hundred or five hundred or thousands of patients on System One, the feedback that you get out of there is that we are commissioning all these weight management clinics and actually patients don't need that. This is micro and macro commissioning.

While the template is seen, by some, to be an essential component of micro macro commissioning, it is not in itself sufficient.

> … This is micro and macro commissioning.
>
> *Q. It is, but have you managed to shift your funding, your budget in a way to commission differently?*
>
> No we haven't, what I'm saying is that the template allows us to be able to do that … We are collecting the data and in the fullness of time that data, the PCT will be able to look at that data and say, ok, we need to de-commission this or we need to commission more of that.

From another interviewee's perspective, the real challenge for commissioning comes at the next stage: knowing what to do with the data that has been collected.

> it's no good just having the information, because the whole problem with commissioning is we're data rich and knowledge poor and so unless there are some, unless we tried it to see, can you actually use this mass of information to commission anything differently, I'm not sure that we can say that that bit has worked … we can't say that actually, this has changed what is being delivered locally, because at the moment, it hasn't … that's always the problem with commissioning, people don't know how to use the data. I'm not saying I do, they don't know how to interpret it, they don't know how to say, well this is this, therefore we need to do y, x, y, and z. That's where commissioning falls down …

Others have concerns about the impact of an IT template on the integrity of the Year of Care model.

> I don't think we should hang everything on the IT template, … I'm sure we will use the IT template but I don't want that to be seen as the Year of Care....because GPs would see a template and they'd think tick, tick, tick and then they've delivered Year of Care, and that's not what it should be about.

Two other interviewees emphasised that training and support to understand the approach underlying Year of Care will be particularly important if a template is introduced, to avoid a 'tick-box' approach.

> Unless health care professionals have been trained in a standardised way to interact with people with diabetes in a certain way, then that's what you'll get on those templates and it will be quite useless in terms of Year of Care. If you use the template *and* train for Year of Care, you will get the big cultural shift that's required. The IT is just a tool, it's not going to be the answer, ever.

Two interviewees described approaches designed to bypass the need for an IT solution. The first approach uses an audit of care plans, backed up with questions to patients, to identify gaps in services.

> if we have to wait for an IT solution that captures the goals and outcomes of care planning, that then we can identify need and unmet need … we'll still be here talking about for whenever, so what we've said is, we need to start then saying, actually the people who have been through the care planning process, we need to audit a sample of care plans to say 'what is that we're picking up? Are there any recurring themes?' We also can triangulate that by speaking to people, you know, 'if you've been to the care planning process, what's been the experience? But what other services could have been in place to help you to support in a better way?'

The second, at a network level, will employ high level public health practitioners to identify gaps in services across health and public health, working in partnership with the local authority.

> the PCT has appointed people from public health background called Healthy Lifestyle Programme Managers who have taken on the responsibility for monitoring what's available in a particular patch … in essence, they are taking on the responsibility of monitoring what is there and they are going to ... channel information about what isn't there, back upstream … so there's a structure has been put in place, humanly, given that we don't have a structure electronically to try and capture some of that, those stories about what is or isn't present … . These are quite high level public health doctors or practitioners and they will be expected to do a lot of the public health analysis, so they will be very hands-on around joint strategic needs assessments, they'll be expected to work in partnership with the down on the ground level people in the local authority … so a lot of it is actually stuff around environment, which is very much the remit of the borough rather than stuff that's necessarily within the remit of health.

7.4.4 Decisions to be made

The great majority of interviewees saw a need to understand more about the practical challenges related to provider development and micro macro commissioning and for workable approaches to be found.

While no one dismisses the value of an IT template, some point to the fact that in itself, it does not solve the problems and brings with it added risk of a focus on process rather than culture change. While some had strongly supported efforts to promote access of the IT

template to all general practices, the coming election with possible changes to IT developments makes efforts in this direction questionable, at least for some.

The most common view is that micro macro commissioning should remain part of the Year of Care model. The extent to which developing approaches to micro macro commissioning should be a priority for the final year of the programme remains a question. Could the programme could look for other models to adapt, or how far does it aim to go down the route of exploring and developing a new approach itself? As with IT, the coming election raises questions about the future for commissioning, suggesting either, postponing efforts in this direction, or alternatively, developing a model ready for a post-election environment.

7.5 Evidence and communication

7.5.1 Clarify realistic expectations of evaluation message

Though not an issue raised by all interviewees, some raised concerns that the message that could emerge from the Tribal Group external evaluation at the end of the programme would not be strong enough to demonstrate success, and others, that expectations for the outcomes may be unrealistic.

> I worry that the evaluation is sound enough to have enough influence, because we spent a lot of time and a lot of money on proving that this works … to government really and other NHS PCTs commissioners to say, this is what, if you did this, you would improve the care of people with diabetes.... so I worry that the research isn't good enough or when it comes back, that it's, the results aren't useful enough to be able to say it works ... we need to have some evidence to say that it has changed things.

Those closest to the Year of Care programme are very conscious of the complexity of managing the message from a programme that started as a feasibility study and now is a pilot study.

> we're constantly caught in this awkward position of we're not advocating roll out of the Year of Care because it's a pilot programme and we've not been evaluated yet, we haven't had the interim evaluation yet, let alone the final evaluation and the final evaluation might not be the final, final evaluation … there still might be a lot of issues that are outstanding. So we're not advocating a roll out, at the same time we're aware of so many areas in which our learning and experience can be of value, and we're aware of so many actual geographical areas that are taking on board our learning or are interested in it or think they're taking on board our learning, and so we're trying to share our experience and knowledge in as useful a way as possible with the constant caveat that this is if you want to go down this way ..., we can't ever stand up and say, you know, Year of Care, yes or no, does it or doesn't it, because that's not what we're evaluating, that's not what it is that we're trying to find out. We're trying to find out, like I say, the five big questions, so how you systematically embed care planning and so on. Not, if I do the Year of Care locally, will my population get x, y, z? And that's a really difficult balance.

Another person, actively involved in the programme, acknowledged that the most evident outcomes from the evaluation were likely to be descriptive, relating to patient's quality of life, rather than quantitative health outcomes demonstrating a change in biometrics.

> I think the trouble is most of what you're trying to measure is fairly soft and I think a lot of it is going to be descriptive, you know anything particularly hard - and my

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personal prediction around biometrics - you know the blood pressure and HbA1Cs is that it's probably not going to make a huge difference because people are already fairly focussed on those because of QOF. But I guess the hope would be that it will make a difference to the quality of the life the people with diabetes, but that's the bit we're not going to be able to measure, so that's the difficulty I think. So I don't know, is the honest answer, that we're going to be able to demonstrate anything terribly wonderful other than, you know, this is what it felt like, which isn't very …

Another interviewee expressed the view that any attempt to demonstrate effectiveness of the overall programme through measuring health outcomes would be unrealistic and potentially detrimental.

it depends what we want to do, we're never going to prove the benefit of Year of Care, and I'm hesitant to even going there, I know that people say, 'oh look at the data, let's see if it got worse or better'. I wouldn't go there, we said we couldn't do it, and we're making it up. If it makes sense we'll say, 'oh we knew that all along' if it doesn't make sense we'll say, 'oh well, we didn't know, it was never going to work. You know, just be clear we were never going to test this. Individual communities can do that, but the Year of Care project in my mind shouldn't, because you've got a danger of undermining the whole thing, all this fantastic learning, all this stuff that we know works.

The further removed from the programme interviewees were, the more concrete their hopes and expectations about what the final outcomes might demonstrate. The following two excerpts are from people not closely connected with Year of Care.

it's getting some of the evidence out in a very clear way to people, that people can understand. So the evidence from the pilots about benefits that it has to people with diabetes, but also if there's any evidence around any savings in resources, in particular in the current climate that we're in around you know, having to look at quality and productivity and efficiency savings. So I would guess, I think it's important that they gather what they can and that any positive evidence that they have is actually sold and disseminated really widely … my only concern, my big concern about Year of Care, is about the evidence around you know, the benefits and benefits realisation and all of that, and what's that going to say and how is that going to be communicated.

The thing I would urge, is to have the sharpest analysis of their data that they can possibly afford. And to have that as rigorously checked across different you know, NHS Diabetes, Diabetes UK, DH, everywhere you can possibly get, get a health economist to give it the closest professional polish that it can possibly get, because the sharper that evidence is, the more it will be helpful both to yourselves and to ourselves. What will kill in my view, the usefulness of Year of Care, is if the reporting of it is bland. So that for me, what I've been consistently saying is that it's not going to be sufficient for us to have an experience of care type, we've really got to link it into the literature, the literature that develops about patient professional collaborations, so what is this, how does this Year of Care advance that literature? And how does it fit into the various literature reviews that already are, how does it advance the quality and productivity agenda, what can you show from a health economist point of view as the savings, if you invest here? … it's got to be so sharp and the sharper it is, then the more use it will be to other long term conditions. But if it's bland, and if it's, well it mostly made a difference and patients liked it much more, then it would be a disappointment to everybody from long term conditions that looks at this as being a real spearhead for long term conditions.

Two interviewees pointed to the value of communicating evaluation findings in terms of the QIPP agenda. As the following excerpt says, ideally strong evidence should be available in at least two or three, if not all four of the QIPP areas.

> in terms of the evaluation, it ought if it isn't, to be demonstrating a QIPP agenda. So how have we improved the quality and in what areas? How have we used innovation, which we have, to achieve that? What have we prevented as a result of doing this? And there are likely to have been a lot of complications you would expect that might well be prevented by doing this. And what in terms of productivity, so what's the health economics benefits of having done this then? We must have some data now which shows how much better off that PCTs that have taken part are, as a result of having done this. And if you can't demonstrate benefits on all of those fronts, it maybe not a problem, as long as you can demonstrate the benefits of having done it are really, really significant, in two or three of those areas, ideally you'd be able to show benefits, significant benefits, in all four areas, because if you can, then there's a huge incentive for PCTs to get involved in the longer term. Unless the evaluation will actually demonstrate four things very clearly, under those labels, I think we're going to struggle to convince people.

Recognising the difficulty of demonstrating hard data one interviewee pointed to the value of patient stories for conveying the value of the programme.

> I personally think that the stories the people have been through it, are the thing that helps the most.

The same interviewee pointed to the difficulties in hearing patient views. Focus groups have been identified as the best approach.

> we still have a real issue about how do we hear from patients how it was for them? And we don't have an answer so I think we're still really struggling with that … So it's actually, I think we're really kind of fumbling around about how do we hear from patients about the issues that they're facing? How do we hear from patients about what the service was like? And I don't think we have an answer ... that's what we've said with Tribal, that you know, what you're going to have to do with us is focus groups, because it's just not going to work in any other way.

As another interviewee described, an approach is being planned for a user representative to speak to patient focus groups, in the expectation that patients may speak more openly to a service user than to evaluators.

> Well there are groups of patients within the pilot sites who've been part of the care planning Year of Care pilot, and … they hold focus groups for those people, the evaluation company, … I think that they might speak in a more relaxed and honest way to me than they would to Tribal, because they know that Tribal are the evaluation team … And I'm just coming from a very similar perspective as those patients, so I'm going to go up and talk to some of these groups.

7.5.2 Key audiences

The following interviewee stressed the fact that outcomes from Year of Care will need to be targeted to a range of different audiences.

> because we should get some results, and we should be telling people what these results are and just having one publication … isn't going to tell it to anyone. I think we're investing this amount of time and effort, the pilot sites, the national organisations, in this, we now have a role to communicate the findings, what worked,

what didn't work, how it's changed lives - hopefully it has changed lives. To get that out there, but then there's going to have to be separate programmes organised by different bodies, different organisations, to deliver it at a local level.

Some interviewees, who saw external communication as a priority, identified key audiences for which Year of Care should prepare targeted messages, to clarify what the programme can offer. The list includes high level decision makers in DH and PCTs, commissioners, clinicians and other front line staff, and people with diabetes.

> I think that we need to translate some of the key findings and target the audiences. Some will be GPs, some will be commissioners, some will be people with diabetes, people from Department of Health ... at PCT level … decision makers in the NHS. ... senior people to take on board some of the aspects or all the aspects of what we say, …I think at a PCT level, delivery level, there are decision makers, there are leaders there are people that make things happen at a local level .... We need to get to those to actually say ... this is what needs to be delivered in a local service for the benefit of your patients. .... clinicians, commissioners, people who have power at a local level …We also need to be getting out to people with diabetes to communicate what it is, so they will demand it themselves. The difficulty we have is, it's complicated … because it's such a big programme, it's really difficult to communicate the complexities of what they need to be asking for … we need to refine those communications and do some more awareness raising.... which means we need to work out what we need to communicate.

> I think PCT commissioners, I think frontline staff need to understand. … GPs, nurses, allied health professionals, anybody that's involved in delivery of care for people with long term conditions.

7.5.3 Packaging the message

The suggestion that findings from the evaluation should be framed to demonstrate their contribution to the QIPP agenda has already been mentioned (7.5.1).

Other advice about conveying the message was to emphasise the benefits of the approach for staff.

> There's got to be an understanding of how practices work, what are the key factors that will really switch them on … So I think that there's got to be some wins in there for primary care, you know, the practices have got to understand that if they embark on something like this, they've got to get something back in return. They're not just spending a whole lot of time on sitting down, speaking to patients and not getting anything back.

Finally, a broad approach to selling the Year of Care message is not so much to promote the programme per se, but to demonstrate its relevance as a solution to the problems that others have identified. From this interviewee's perspective Year of Care will become increasingly attractive as recognition grows of its potential to meet current problems.

> care planning as a concept, as an output, has got to reach mega, mega proportions in the next six to nine months, we've got to really push it from central government, from organisations who've got to hit these targets, and I've started to say, 'look guys, this is an absolute must-do, it's really important because it's in the health care policy, … it's the only way to save the NHS … unless we've got a fully engaged health service, fully engaged population that are not dependent on health services entirely for their care, then we can't afford, can't afford to run services as they are now' ... we need those messages to go out and then [the Year of Care] can come out and say,

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'sure, you've bought the problem and here's a solution for you'. And it's that kind of, we need the problem to get ratcheted up really … I think a lot of our success over the past year, eighteen months has been to be working on selling the problem and then people growing to thinking, 'well ok, fine, you know, and I buy that, we've got to change things' so and then you know, we'll soak up Year of Care as a way of achieving it. And it's getting that balance between being in the last year of wanting to get as many people as possible and just letting it kind of grow as I think it will do just naturally.

7.5.4 Decisions to be made

Although those close to Year of Care have been careful to maintain realistic expectations about outcomes the external evaluation can demonstrate, some beyond the programme are still hoping for firm evidence of health and/or economic benefits.

A close reassessment of evidence that will or could be collected could be useful, and attempts made to either fill any possible gaps and/or to manage expectations amongst wider audiences. Knowing what evidence is available, priority audiences could be selected and the key issues and approaches of most relevance to each identified, so that targeted communication could be prepared when the evaluation findings are available.

7.6 Strategic connections

7.6.1 Levels of engagement with other programmes and strategies

Interviewees considered it important that Year of Care develops links with existing programmes and strategies, to promote and support specific aspects of the programme (eg the IT template) and/or to embed the approach.

> Anyway so I think it's really important that they kind of do connect up with other stuff that's going on and try and kind of transfer learning and experience across the range of other projects that are going on. Because again it's that sense of what you don't want to do is a project that then just sort of fizzles.

One person questioned the extent to which Year of Care aims to remain a separate entity during its final year, or whether it might identify another programme to integrate with, in the interest of sustainability.

> I'm not sure whether they actually want to get on board with somebody else or whether they want to stay independent. At the moment they are an independent project effectively. Working on their own, lobbying on their own, campaigning on their own, developing on their own, doing a good job actually on their own. But it's unsustainable, so what happens at the end of the contract then?

The following two interviewees put the case that, if the aim is to embed the programme, a clear strategy should be developed within the next few months to identify specific 'system drivers' and shape and negotiate ways to embed Year of Care approaches.

> if the Year of Care could actually have a clear strategy around to handle that ... in terms of what's going to happen next, you know, is it going to be picked up by NHS Diabetes or Diabetes UK or someone else, what are we going to give organisations to carry on this …

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If we're looking to get it out everywhere, well be more strategic then, and link to the system drivers that really make this work. So how in the world class commissioners' cycle, do you link this and when? … Who's doing it? How do you get the message in at the right time? How do you drive that forward? How do you link, get the clinical engagement? How do you use your patients and service users to, or carers, to rally for you? … And how do you persuade people that this is the right thing to do? If you're going to do it, then put together a strategy for doing it ….

The point was made that, if Year of Care does intend to embed its approach by linking it with other ongoing strategies, it needs to have finished products that are relevant and ready to adopt.

it helps … far more if we were to say, right here are three finished products, this is how to do it, this is the model, this is the way forward, these are the tools to use, this is the training programme, it's finished, it's accredited, everything is ready, now slot it into a national implementation process.

7.6.2 Possible strategic links

Strategic links suggested by interviewees are listed below.

The relevance of Year of Care to the current personalisation and long term conditions agendas was mentioned by most interviewees.

we really are trying to move the whole personalisation agenda of the NHS … and the national agenda has been to move towards long term conditions … there's the economic argument that you have to do that, this is what people have to do, and the care planning bit is really what people have to do long term. I mean it really, what the government, or the DH … is saying is that care planning or something like it … has to be the new way, there has to be a new relationship between the individual and the NHS, and we're calling it care planning at the moment, and that has to be a change in the way that mainstream care is delivered, so that this isn't a project, this is about mainstream. And the trick will be to see whether we can just about get to that point, partly by, and it won't just be Year of Care … working with Darzi leads and other people and pushing this has got to change, this has got to change, and then what Year of Care will contribute is, this is actually how you do it, we know that this is what works. So I think the issue as to whether Year of Care becomes a passing project or really changes things, depends on whether there is a desire out there to really change the relationship between the patient and the service and in which case Year of Care will have produced the way that you do it, and a lot of information, and will make it possible for it to happen.

Several interviewees referred to the overlap between Year of Care and Co-creating Health; all who spoke of Co-creating Health wished for a closer connection.

Co-creating Health are doing some diabetes projects which are very secondary care focussed and you know they're both linked but they're both, the Health Foundation is if you like, the centre it's part of both of those programmes, but I don't think they're linked enough.

Health Foundation have got a parallel project called Co-creating Health, and I think there is a need for us to come together and share ideas and share learning, because I think having two potentially competing models being promoted, would be quite destructive.

A commissioning framework is being developed by NHS Diabetes and Year of Care could find a way to work as part of it.

> [NHS Diabetes have] produced a set of products around commissioning … linking into … the world class commissioning process … When a priority for improvement in that particular area of diabetes is decided on, that's the moment that we link in and have our set of products and events that we can offer that helps to make that actually happen and ... evaluate it for effectiveness … So all areas of diabetes care, we have a commissioning care guide and a clinical care guide and what care to expect for patients, triangulated the approach in the language which meets each person's sort of needs and key stake holders. We then have a product which is a leading change programme …

Opportunities for embedding the process developed by Year of Care through widespread application of the IT template that links care plans with data for commissioners has already been mentioned (7.4.3).

> They are already trying to engage ... all of the other main suppliers. … in terms of the IT conversation, there needs to be a national conversation, it doesn't need to be limited to Year of Care team, it just needs to be a long term conditions, or you know, a number of people engaged to have this same conversation and lobby for it all over the place. …

Another interviewee suggested that Year of Care should work to influence patient access to medical records, believing that would significantly advance power shifts within the patient-clinician relationship and support genuine care planning.

> our patients need access to their records as well, their own clinical records or a summary … There's work on the summary care record, which is part of the My Health Space national programme, rumbles on a bit slowly … And there's talk that our national IT systems, the computer systems we use, will actually be able to download information directly into My Health Space ... I'm aware that some of the companies are talking about it, but I think an awful lot will depend on whether the Department of Health pushes it. We need that central steer … the Year of Care board, for what influence they carry … I think if we see the Year of Care as the end point, we've missed the main goal really …

From a structural perspective one interviewee pointed to SHAs as a valuable level at which to engage, because of the SHA role, bridging policy directives and implementation.

> I do see the SHAs as a really important part of this, linking between high level government policy and implementation, and there seems to be an appropriate mass of people there to work together to kind of engage, to turn this policy mandate, mantra, into kind of actionable stuff, informed by Year of Care, informed by Cochrane health … not necessarily involved in, but just looking at all these sorts of things, with clear standards …

7.6.3 Decisions to be made

Year of Care could decide how much focus to place on developing strategic links during the coming year and, to the extent that it is a priority, develop a strategy for doing so by identifying programmes or developments with which it aims to explore options and shape itself accordingly.

7.7 Long term conditions

7.7.1 Inevitable spread from Year of Care to long term conditions

> the targets set are that everybody with a *long term condition* will have a care plan by
> - the date seems to change, but somewhere around now - it's not that all people with
> *diabetes* will have a care plan. And so we need to ensure that the best bits of each of
> these integrate, so I think coming up from the Year of Care project, we need the
> essential learning and there are some very specific things in the Year of Care that I
> think are really hugely important in terms of learning there. But ultimately I think any
> care planning for one long term condition is flawed. We have to get to a position of
> care planning for the person who happens to have whichever long term condition it
> is.

> certainly coming from a general practice perspective, where so many of our patients
> have other co-morbidities, I don't think it's realistic to do a diabetes care planning
> meeting and then a COPD planning meeting and then a back pain care planning
> meeting, so I actually … if we're really going to be patient centred, we should be
> patient centred around the whole range of things that they're struggling to cope with.
> Because actually if you start talking to them, you know, you need to lose weight, you
> need some more exercise, and completely ignore the fact that they've got terrible
> back pain, it just actually feels like you're beating them up. So it feels to me that the
> kind of natural flow of where Year of Care is coming from, even though it grew out of
> diabetes, is actually towards a patient-centred encounter … And that may or may not
> feel like something that, you know, the current Year of Care structure feels confident
> to do.

If Year of Care is seen to have merit for addressing issues related to diabetes it is inevitable,
both from a policy perspective and from a general practice one, that consideration will be
given to how it relates to other long term conditions.

It was always the intention that, through its work with diabetes, the Year of Care approach
should have relevance for long term conditions more generally. However, as the interviewee
below states, the focus to date has been diabetes; the programme has not explored which
aspects of the approach are transferrable.

> and it was always long term conditions, the idea was always to find out these
> answers for long term conditions using diabetes as a sort of test condition, but it's
> undeniable that our focus has been on diabetes and so there's, we think we know
> some principles that can be broadly transferred to other long term conditions care,
> but they, I'm sure there are so many different individual operational details and so on
> that need to be changed.

To some extent the Year of Care has already supported thinking about care planning more
generally, at several levels. Excerpts from two interviews described the start of this process.

> we have … a departmental commitment, that everybody with a long term condition
> should be offered a personalised care plan. That commitment was made back in
> 2006 we've done a lot of work with … stake holder engagement about … what do we
> mean by a care plan and we've wanted to draw upon learning in many different areas
> ... and the Year of Care programme is another area that's, the kind of the principles
> and the ethos of what Year of Care is about, are very, very closely aligned with the
> kind of policy intention of offering a personalised care plan and care planning to
> people with long term conditions. So although that's a specific programme that's

been piloted and it's for diabetes, we've drawn an awful lot of learning from, you know, the whole principles of Year of Care and indeed the programme leads that are involved in it …

The minute somebody gets it and starts doing [Year of Care] and likes it, they don't just tell their friends to do it for diabetes … But they will also say, but this ought to apply to all our long term conditions, gosh yes, it must, right? And this is happening at every level, it will happen in the practice, it will happen across a PCT and … within Diabetes UK, the Year of Care people pulled together all the charities dealing with other conditions, … beginning of September and we had a meeting at the charity level, to explain what was going on and they're currently all going away to have a think about care planning for their conditions

A question now, with the self-generating spread of interest in extending Year of Care to other long term conditions, is how involved, in its final year, Year of Care should be in examining applicability of the model to other conditions and/or engaging with other long term condition groups or programmes, or should Year of Care retain its focus on diabetes.

it's one of the real challenges … for Year of Care, is it, 'this is diabetes' own little world and we get everyone doing it in diabetes and hope it spreads', or do we at this stage start to think about well it's going to be different in long term conditions

7.7.2 Range of views about ease or challenges of extending Year of Care

Some consider extending the approach into long term conditions a simple process.

I think the process is very easy to be related to long term conditions. I don't see any real difference … if it's really about setting goals, planning what people need for the year, you know, care planning for the year, understanding people's needs, making sure people get what they need in that year, etc., having a full assessment, then everybody with a long term condition should get that.

The following lengthy excerpt describes the process one practice is taking to extend care planning process to all long term conditions.

Well we started out with diabetes and now I am doing it for all long term conditions in our practice... we've further developed the IT tool that we have with diabetes, to actually extend it out to long term conditions and it needs some further work to it ... this is at early stages, is that we've taken the generic care planning template and then added to it all the long term conditions that you have in the QOF for example. What we've done in our practice is to say, ok how many of our patients have long term conditions? Whether one or more long term conditions, let's identify them, approximately 25% of our population have those long term conditions. Which conditions do they have? How many people have how many conditions? Lump them together. So we've got a break down of the number of people, the number of conditions that they've got. And then we've booked appointments for them, depending on if they've got three conditions, they can come in for a forty minute appointment, if they've got two conditions, they can come in for a twenty minute, thirty minute appointment, whatever it takes under those circumstances. So patients come in, they have an opportunity of having a proper care planning consultation which is generic and would cover all the aspects that they're concerned about, whether it's their epilepsy … diabetes … stroke … heart disease … cancer, whatever it might be. And then at the same time, you're actually clicking on the relevant long term conditions, going into those templates and adding the relevant data. So you're fulfilling the QOF requirements for that particular long term condition. Meanwhile you've also collected the data from the patient, their perceptions from the care

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planning process. You then, when you go into setting their goals and that helps with commissioning as you know the process, the way that it works … So you capture all of that information and then we say to them, 'we're going to give you a print out of this, these are your goals that you have set, these are your perceptions, this is your care plan…

Others consider the extension more difficult, identifying challenges and unexplored differences that need specific attention.

I hear about people talking about rolling out from Year of Care into long term conditions as if it's a very automatic thing … and without contemplating the fact, well, that person hasn't got planned care currently, doesn't get any form of structured care, how on earth are you going to recognise them to give them the preparation they need, you know, all this sort of stuff. It's coming, 'well we just put the systems in place for Year of Care, we put the training in place and we'll be sorted'…. So whether it's a true extension or … a separate project of a separate learning and understanding. And my thinking is, I think it's the second.

Challenges include the risk of overwhelmingly complex consultations if multiple long term conditions are considered at once, and systemic differences between diabetes care and that for other long term conditions, not all of which have specific health indicators (such as HbA1C) and many of which have no current system for annual checks.

when you've got Phyllis coming along, who has got diabetes and that's her main problem, then we understand that, we send her originals beforehand, we can understand the impact of other things on diabetes, it's very much part of our thing. When Phyllis has diabetes and arthritis and airways disease, does she go along to the diabetes care planning appointment one day and another appointment for the non-diabetes stuff another? Doesn't sound very holistic, that. You know, how do we, what do we send Phyllis before her care planning around her airways disease and her things, is it different stuff? If we're doing it in one big appointment, we're sending her diabetes information, the COPD information, spirometry, you know, a kind of quality of life wellbeing thing, how are you doing? What sort of things do you want to work on at the moment? That's a massive and potentially for people with multiple long term conditions, of which many people do have, that's potentially a massive list of things for people to consider. So it's starting to think about what that would look like. …The other key bit … is that actually, Phyllis gets her appointment and there's appointments in between, but she'll automatically get an annual appointment to do this, because she's got diabetes. But Brenda with her airways disease or her arthritis, doesn't get that. ... when you say in the practice, 'ok fine, so how are you going to make sure that Phyllis gets her preparation for the consultation, her results and this care plan? Which consultation are you going to do it in, how do you know it's your day to day rather than just turning up and doing your 10 minute appointment just because she wants to get a new inhaler and you want to make sure it's right etc. And no-one's really thought that through.

Challenges relating Year of Care to cancer care illustrate some of the difficulties. Where self-management is either less relevant, or less evident a different approach to care planning may be needed. Another difference is that for most cancer patients care is provided by secondary rather than primary care.

one of the things that we would wish to do with cancer is also to change... the interaction between the professional and the patient, in terms of their assessment. So we thought [Year of Care] to be highly relevant … that's the difference between ourselves and diabetes of course. In that much of what we're interested in is about

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the acute care … but we are different from diabetes in that there isn't the same measure of control of any individual person affected by cancer and there isn't the same kind of ability to test, as there would be within diabetes, so in some ways, we kind of look enviously at the way that diabetes is structured in the sense that you can get a blood test that will give you a very clear indication of where you are, and a level of control that you can exercise through medication if necessary, through diet or through exercise, is a much higher level of control. People affected by cancer can also exercise some control by diet by medication compliance and by exercise, but it's not the same level of control. ... There are some cancer conditions, tumour types, that are dealt with by GPs, prostate cancer is the easiest example of that, but some of the leukaemias. But the majority of follow up care is currently provided through out-patient department appointments.

Some interviewees believed that Year of Care should be applied to secondary care as soon as possible. Others recognised that, if applied to long term conditions more broadly, ideally the approach would spread to specialist care, but that additional work would need to be done to make it applicable. The following two interviewees illustrate these points of view.

It is however of relevance to secondary care, a diabetologist, because if somebody goes to see somebody in primary care and gets a certain sort of interaction, they might well appreciate a similar sort of interaction on a similarly informed basis in secondary care. So yea, I think that would be fair to say, if you opened it up to more long term conditions, many long term conditions are really secondary care based at present, and so it suddenly become, you know, if you had kidney disease as well as diabetes, you'd be seen in secondary care in a specialist unit. Well absolutely in that case you would want the same approach to be taken there wouldn't you?

I think the principles of the micro level should be taken on board in specialist care. The difficulty of that is that they don't necessarily see individuals for the whole of their year, they see it for bits of it, so if they have a particular problem, they will go to hospital and then come back. I think it would be nice if it was taken on board, but I think the mechanics of doing it, are likely to be different. And so some work would need to happen, I don't think you could just up whole-scale and say, here, you do that in specialist care.

Another interviewee, while able to envisage the Year of Care approach being relevant for at least some cancers, went on to identify other conditions and situations that would be more challenging, for example, dementia, or situations where a patient has a complex mix of conditions.

I can see certain cancers becoming long-term conditions and I can see an annual review of a patient with cancer fitting in very well with the Year of Care house model … that should be part of the discussion between Year of Care and Health Foundation and Co-creating Health, how generalisable is this approach? Because there may be some long-term conditions where it may not be quite right, so does it apply to children with cystic fibrosis? Don't know, may not be. How does it apply to dementia, it might be quite difficult in dementia.

Further questions relate to whether or how carers should be involved in care planning, their role being central in some long term conditions.

And so how do you play in a carer, that's a challenge for some long-term conditions, the carer is key and I don't think we've thought about the carer at all, in Year of Care. … there are times when there's advocacy issues, … we've got patients with diabetes have got three or four other conditions, they suffer with depression, might have

schizophrenia, they may be on a CPO programme, so I think you know, they're another stratification. ... So it's in that complex bit, unpacking … I think there are patients whose ability, because of other conditions, to exercise those choices, maybe constrained.

At a closer look, the cultural and contextual differences between long term conditions may militate against a comprehensive national approach.

Long term conditions is a sort of managerial concept and in fact whereas I think it was sort of right in policy terms around 2003 and 2004 to say, oh look, there's things called long term conditions and they all have the same characteristics and they're all like together, when you look at it … they're actually quite separate in terms of operations and how people work, and they're not the same at all. You can't, a respiratory nurse can't just cover at the weekends for a diabetes nurse and a kidney nurse, they just don't think the same way. And therefore, in terms of facilitating practice, I think what Year of Care has shown is, that it is so context specific, it's about real life, it's real professionals on a real daily basis. It's not some managerial concept and therefore how you facilitate this and coordinate it long term, will depend on how your culture works locally I think.

7.7.3 Approaches for exploring applicability of Year of Care to long term conditions

Three different models or approaches to explore whether or how Year of Care might relate to other conditions have been suggested, none of which are mutually exclusive.

One approach uses the model described in 7.3.3 to ask, for each long term condition that Year of Care might be applied to, what would be done before, during and after the care planning consultation, and how might different conditions add together.

But we think then in terms of the sort of consultation mechanism, the centre of the 'house', that you can reduce it to three things to think about. What do you need to do before the consultation with that person, to activate them, it might be sending results out but in other conditions it might be asking them to reflect on their symptoms, something. So what should be done before the consultation? Then what are these skills which will, in the consultation, and we think they're exactly the same, agenda setting, goal setting and action planning. But they're about a much wider range of symptoms and conditions and pulling them all together. And then what would you need to do after the consultation? And so, as I say, I think the things that are within the consultation are more generic and the things that are before and are after, are probably more disease or condition specific … we're offering up to other conditions or groups of conditions, some structured thinking which we think they could use as a starting point to develop their own ways of working.

Another model for considering similarities, differences and potential relevance of Year of Care to other conditions conceptualises care for long term conditions within a quadrant. The horizontal axis of the quadrant describes the patient's capacity to self-manage, running from one extreme of complex, frail or elderly social and health care where care coordination is essential, to self-management as in Year of Care at the other end of the spectrum. The vertical axis runs from specialist, acute care at the top to generalist care at the bottom.

So you've now got four quadrants and we've started to map various professional groups and people that work in these quadrants. … start with the bottom right quadrant …That is where what you'd call case management takes place and people like community matrons and district nurses are working out in primary care and community settings with individuals who are very symptomatic and need a lot of coordination of their care. And then if you go above that to the top left, there are

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specialist sites where … say specialist nurses in urology or diabetes who were dealing with people who were very symptomatic and they really had problems that needed to be addressed then and there … Its' acute, we also have discharge planning up there now. Then if you go over to the right hand side at the bottom, that's where Year of Care is … We now actually think we've identified some people who we've talked to, actually in the top right hand corner and we think those are people either with very rare conditions, probably looking after children and young people, so they're in the specialist secondary care end. We've just identified cancer nurses who are looking after people who've got over cancer … we think that actually they should all come down into the bottom right hand corner, but at the moment they're being dealt by specialists and specialist services. … all those people need to have the skills of helping people problem solve and things but the different environments in which they work, will mean that they are, that they organise their lives in completely different ways as professionals. And so, but they still have to sort of think, is there something we need to prepare the patient for, is there something they need to go away with, and are we really coordinating care or are we really supporting their self care. And so the 'house' would be very relevant but the actual organisation, the roof of the house is like so different in each of those areas, it's unbelievable. And of course the commissioning, they all have to be commissioned, but the commissioner would be commissioning in quite a different way for these things.

Another interviewee talked about the need to bring together the range of people working in long term conditions, including those involved in terminal care. As this interviewee pointed out, the concept of a 'care plan', which has been used in so many settings, is also of crucial importance in terminal care. The vision of 'one person one plan' should drive discussions to coordinate approaches towards that goal. This interviewee also believed that an electronic approach to presenting the unified care plan should be developed.

we need to bring together all the people from across a range of long term conditions and terminal care, end of life care there, who are also working on very similar issues as well. End of life people are involved in care plans all the time, they're hugely involved in the discussion with people, 'what do you want to happen in the latter stages of your life?' Well end of care is the last stage of long term conditions.... And so we actually need to work very closely with those teams as well. And they're already creating big care plans for people in that phase, it has to be the same care plan, the same documentation which is carrying someone through their entire journey through life, from when they get their first thing that we call their on-going medical problem, a long term condition, right through to when they're becoming an overwhelming medical problem, and often multiple medical problems, to what we're calling end of life. And so we actually have to, I think the next stage is to come back together to get some general working together with a range of other medical disciplines..... it is the concept here that it's one person one care plan. …I see it as a series of chapters, the day to day, the what if, the what if I have an emergency admission, what do we do about my respiratory disease which I also happen to have as well as my diabetes and of course …You can't make a care plan for diabetes without a care plan for the respiratory disease, in fact I think as soon as you talk about a care plan for diabetes, or a care plan for respiratory disease, you've missed the point. A care plan is for a person, it's about a person and the way they live and the medical conditions are the chapter headings if you like.

7.7.4 Decisions to be made

A question for Year of Care is how involved the programme should be in exploring the relevance of its approach for other long term conditions, and/or developing it further for broader use.

While some may envisage a more engaged role for Year of Care in this area over the coming year, most who expressed a view cautioned against it.

The following interviewee made the case that discussions will be needed with a wide range of partners about the future for long term conditions, and that for those discussions individuals and learning from Year of Care will be invaluable. However, like several other respondents, this interviewee did not think now is the time to be doing this. First, learning from Year of Care should be completed and digested, and then relevant audiences brought together.

> I don't think Year of Care needs to do that, …I think the way it's going to happen in the long term is, that there needs to have some common definition around how this and if this is applicable across other long term conditions … I think there is a need to grapple with this and be clear about what are the common principles and what are the specifics for individual conditions as and when. I don't actually think it's the job of Year of Care, but I think that they've got a lot of learning that can help unpack that and one of the things is that some of the board members are very skilled influencers and very skilled at being able to influence other organisations to come more along that strategy rather than just staying in the position that they already are. But that's an influencing job, not a delivery or Year of Care job … ... and also I think there are other partners involved that aren't at our table in there. We can bring partners in, but then they can never be partners in our Year of Care project *...* But we would have to involve other stakeholders from other organisations, other disciplines, to actually see whether it is relevant in those areas...It's not the time to do it now, but it is the time to do it when all the learning has been gathered and thought about and investigated and considered and then actually make a decision maybe, actually we're going to go off in a different direction, working with other stake holders, with other organisations.

7.8 Patient education

7.8.1 Different reasons for patient education

Many interviewees referred to the need for more patient education. Two key reasons for education were mentioned.

- The first is to inform people with diabetes about their condition and how to manage it.

- The second is to inform the public and people with diabetes about the care planning approach so that they can make best use of it, and also, by expecting to be treated differently they help shift the patient: clinician relationship.

Views varied about the extent to which the second reason for education could be combined with the first.

A further distinction in patient education is whether it is designed and/or provided at a national level, or locally. In their comments interviewees covered both levels of provision.

As reported in 6.6.4, another gap is the need for education for family and carers of people with diabetes.

7.8.2 Condition-related patient education

Although the structured education programme, DESMOND, is specifically designed to educate people with Type 2 diabetes about their condition and how to manage it, several

interviewees referred to inadequate provision of the programme in most geographic areas. An equally serious limitation is the fact that it is delivered only to newly diagnosed patients.

> [DESMOND] wouldn't deal with the ongoing aspects, because you only really go to one structured education course, so say you've had diabetes for twenty-five years, you need that ongoing involvement in your own care outside of education as well, because you won't receive any more education.

The impact of inadequate patient education on the care planning process is described by the following interviewee. The culture change that is the essence of Year of Care presumes an informed patient, and in the absence of adequate patient education the task falls to the clinician.

> we had hand-outs, and we had a DVD [about care planning] that went to the practices to show patients and there was input to the patients at patient engagement events, but I think certainly in year one, the experience for many of the practices, the patients turned up for their care planning encounter and actually pretty much the whole of the time was spent on education about what an HbA1C is. And I think that just represents the huge black hole that we had and people just didn't know the most simple basic things about their own diabetes. Often people had to come back again, so you had that appointment and actually never got on to the care planning because you were still explaining why blood pressure mattered. So I think for some patients it's a very big ask, but really highlighted the enormous black hole in terms of patient education understanding.

Another limitation of DESMOND is that, as a national programme, it does not necessarily match local needs. One Year of Care pilot site reshaped and renamed DESMOND to meet local cultural, lifestyle and learning needs, and by doing so, hugely increased attendance.

> We have delivered [diabetes structured] education to seven thousand four hundred and fifty patients in three months of this year … what we found was, the structured education which requires, you know, group work, a psychological approach, and fixed sessions over time, of so many hours repeated at these intervals, for some of our population, just didn't work. The attrition rate was very high, it didn't fit with the Muslim culture of prayer times. Some of the food offers weren't quite right, so we had to completely reconstruct a training package that fitted our community … that was designed specifically with our community in mind and what they wanted. So we had a menu of different options. Some of our patients will not work with a group. They only want one to one. We offered some one-to-one, some of our groups said, actually, putting it on during school hours is no good, it has to be in the evenings, it has to be in weekends, and some people needed some education to know what education was. So we had taster sessions of one hour, we had drop-in sessions and then, but of the people who went to the introductory taster sessions, I think the data showed over 90%, it's about 90 to 95% then converted to [the full course]

At the same site consideration is being given to further developments of the education programme, adjusting it for individual learning styles, readiness to change and personal circumstances.

Alongside the adaptive approach taken at the site described above, there is caution about departing in an unstructured way from the evidence-based approach.

> but I recognise that we need to be quite careful about acquiring an evidence base for what we do, because I accept that DESMOND is the gold standard and if we depart from DESMOND we need to be very clear about what it is that we're doing and why.

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While acknowledging the overall inadequacy of provision, some interviewees believed that, were it more widely and routinely available, the basic approach and material covered by DESMOND or similar programmes would provide patients with much of the information and approach they need to make good use of care planning.

> the core of those programmes is to make them realise that they're the ones that need to understand what to do because they've got to do it themselves … I think education does do that as long as it's delivered in the right way, by the right tutors, according to the right philosophy and it could be formalised a bit more, to say, this is about how we're here to help you, possibly. And most education programmes are there as the bedrock of good self-management

> *Q:… you feel that if there was more structured education like DESMOND around, that would meet that need [for education about care planning]?*

> Not all of it, but it would certainly raise the game for people with diabetes to understand their role in their own care.

7.8.3 Patient education to support best use of care planning

Other interviewees believed that a different type of education is needed to prepare patients for the new skills involved in care planning.

> we're training everybody, but what about the patients? So, there is an underestimate of the impact, so people say they want self-management and self care, but they need the skills to do it, which is why we need things like the Expert Patient Programme, we've got health trainers here attached to people with long term support, available for people with long term conditions, who are non-medical but who will work with people with long term conditions to help them do all of that. So help them-self care, supported self care. And that's what you need you know, you just can't take a whole tranche of people and say, right now we're delivering it like this.

The following interviewee believed that without better understanding by patients, the broad culture change that care planning is intended to bring about would be thwarted. This was seen as a need that extends beyond Year of Care.

> before we roll it out we've got to have much more in place for patients so they understand what it means. And I don't think that's just Year of Care, I think that's a lot around the Co-creating Health that the government's, you know, everybody should have a personalised care plan. Well most people don't know what a personalised care plan looks like. So if we don't help them understand it, again it'll be a paper care plan like we used to have with you know, the patient signing it but it not meaning much.

This interviewee suggested that the need could be met at a local level.

> I think that's about having you know, in your local area getting groups together talking to them about it, maybe running programmes about what, you know as simple as what does the Year of Care mean to you? You know, we don't, we've got all this fancy training for the GPs but as I say, nothing really embedded for patients, so I think that's definitely something we need to focus on.

> Q: *that's much more than just DESMOND, it's about the whole approach?*

> Yes, it is, yes because if the, DESMOND won't give them that will it?

Another interviewee recognised the same need, but suggested that educating patients for the new approach to care planning could be delivered nationally.

> There's something about making sure that patients are actually educated to sufficiently understand that process. ... And I think that if you really wanted to, it could go out through Diabetes UK, it could go out through a variety of different mechanisms to inform patients of the whole Year of Care project and raise their awareness, do it on the television, you know, a range of different media. Use the media to be able to sell this on a large scale ...

Another interviewee from outside Year of Care was concerned that potential misunderstanding among the public about the term 'care plan' risks conveying the very opposite approach to what is intended (paternalism rather than self-care). The solution is not to change the name, but to ensure that people are well enough informed.

> a lot of clinicians have been saying to us, if you use the term 'care plan' it will switch a lot of people off and I guess if you're talking of people newly diagnosed with diabetes for example who could still be very fit, active, don't see themselves as being ill, offering a care plan maybe a turn off to people and it's what we're finding is, it's really important to explain what the process is. It's not about labelling them as needing care, it's not meant to be paternalistic, and actually that's completely the opposite of what care planning and the Year of Care is about ... I think as part of our communications, it's just really important that when we, in every communication that we put, where we go out and talk to the service or to patients and public, we say, 'this is the process of engagement and empowerment and goal setting and it's going to support you and the resulting thing, that like formal record, would be a care plan but it might be called a support plan and it might be called a health plan and it might be called something else and actually it doesn't really matter from a national perspective we're calling it a care plan.' And I just think it's going to be tricky but that's the way we're going to have to manage it I think. I don't see us changing the name, we can't do that, it would be too confusing.

The added value of educated patients would be that they would help drive the culture change by expecting and demanding a changed relationship with their clinician.

> I suppose on the other side of it, another aspect is it has to be driven by demand from patients and public as well. So we need to raise the expectation, raise awareness about what they should expect because at the moment people don't always expect to be asked their views or fully listened to … and I don't know how much in terms of the Year of Care that that's been done … and if it hasn't, then I suggest that that's something else, it's about raising awareness.

7.8.4 Decisions to be made

Several interviewees referred to the need for more education for patients with diabetes about their condition. There was also a widespread view that Year of Care would benefit from more education for the public in general and people with diabetes about the purpose and process of care planning. There was no single view of how best to meet that need. Some think it can be met through incorporating information about care planning into current (but more widespread and routinised) structured education, and others that more generalised education is needed, extending beyond diabetes and Year of Care, to explain the care planning process more broadly.

Some believe that more generalised education about care planning should be part of a national programme and as such, a national responsibility. Others envisage local training programmes.

One interviewee put the case for caution, believing that not enough is yet known about what is needed to be able to respond effectively.

> I think we'd be in danger, like I say of doing something for the sake of doing something years before we know what it is. You know, you sort of miss out a step and you go from premise to an intervention without actually scoping and identifying and so on. And I'm not just talking about an education programme, that was just an example. You know, even an awareness raising campaign or anything, I just don't know what, what we would be hoping to, what gap we would be hoping to achieve by doing that. We don't know whether or not there's a need yet to do it.

Decisions should be made about the extent to which the need for patient education about diabetes and/or about care planning is a priority for Year of Care, and whether enough is known about ways that gap can be met for the Year of Care to make recommendations and/or to lobby about who should meet the needs and in what way.

7.9 Care planning training

7.9.1 Current position with training

Interviewees who discussed the care planning training recognised the achievement and benefits for the programme of having a standardised and potentially accredited training programme.

As one interviewees described in the following excerpt, the training provides a combination of structure (eg sending out results prior to the consultation) and skills, and supports integrity of the Year of Care care planning model.

> The other thing we've been very successful with doing is developing a training programme that's now kind of rolled out nationally … those places that were saying they were providing care planning training are starting to realise the fact … that perhaps they're not or people are not necessarily buying the services of people who say, well yea we'll give you a day on care planning and it doesn't mean anything. Because again part of the care planning training that we provide is the structures as well as the skills …and it's that combination that's key.

As described in 6.3.2, interviewees had clear views about who should attend the training. One interviewee made the point that training could not achieve the goal of culture change in the absence of a supportive context. For this reason, it is not effective for isolated individual staff to attend the training; at least two or three staff from a practice need to be committed to change, and operate in an environment that will allow them to implement the new care planning approach.

> the message of Year of Care is, that it is about this culture change in terms of the relationship … within an individual consultation say, but it really cannot be delivered, it cannot be done outside the context that the person works in, either because they don't have the right amount of time or they don't have the right amount of support or they don't have the right features there to enable them to have a satisfactory consultation. Absolutely utterly context specific and depends on that.

Some interviewees discussed who should deliver care planning training, and though a train-the-trainer approach was acknowledged as the current preferred option, concerns were raised about the feasibility of this approach. Three people proposed that a better approach would be for recognised training bodies, including universities, to deliver the training.

there's an awful lot of pressures on staff to work differently, to deliver projects, to do things and I'm not always sure that we should keep taking people out for lots of time to be delivering training programmes. So personally I'd rather commission people to come and do it for me.... , either have a national training team or make sure that what can be presented by the local university is what the national training team would like. So get the national training team to maybe develop a module, or there could be delivered by, you know, your local university. they don't want to do that because they want to keep the integrity of the training, but you know,..., I think there are ways of doing it. Whereas if you asked two GPs and three practice nurses and a couple of others to do an onerous amount of training for this, it takes them away from their clinical practice .. there's quite a lot of challenge in that, right across the country, you will not get that.

A few interviewees raised questions about the future for care planning training: how would it be continued when the programme ends.

7.9.2 Other training needs

Interviewees mentioned two areas for training that are currently unmet.

The first, described in 6.6.2 above, is the need for a less intense but still necessary level of training for the extended health care team.

The second, described below (7.10.2) is the need for refresher training and training to address staff turnover.

Discussions may be held about whether these should be developed locally or centrally.

7.9.2 Relationship of national training programme to Year of Care

The people most closely connected with the national care planning training programme expressed satisfaction and optimism about its impact.

> there's no doubt that when we now go out to a new place that says, come and tell us and help us with this, mainly sort of care planning and Year of Care, and they want to work with us … this is how I know we've got a very good thing to offer, because we now, you know, we'd start with this, we'll ask them this first and then we'll work with this bit and have a taster session and then we'll get champion practices and then we'll train those up and then, and we know that that works … we haven't been as through as far as we would like, but we're getting a feeling that they will be successful … so we've got a method now and when we apply the method de novo, it appears to work.

As noted earlier (7.2.1) some interviewees wished for greater clarity about the current plans or status of the wider national training, and its relationship with Year of Care.

Others were concerned that demands of the national training programme threatened progress for Year of Care itself.

> it's a big task and again part of the thing for me is, where is the sustainability in that?

7.9.3 Decisions to be made

Questions were asked about the feasibility and longer term future of the train the trainer approach for Year of Care sites. Decisions could be made about best approaches for delivery of the training longer term. Decisions could also be made about how best to meet needs for training for the extended team, and refresher training.

The more pressing priority for interviewees relating to training was a wish for a more transparent relationship between the Year of Care programme and the national care planning training, with the aim of not jeopardising success in the former by draining its energy on the latter.

7.10 Sustainability for the future

7.10.1 Practical approaches for sustaining changed approach

Most interviewees were more preoccupied with current issues than thoughts of sustainability for the future, but some raised ideas or questions about how the Year of Care approach would continue once the programme ended.

Much will depend on the outcome of developments and strategic decisions about links with other programmes (8.6 above), but some questions or suggestions about how the Year of Care approach could be sustained would have relevance whatever decisions are made.

Even were all the proposed approaches for sustainability in place, the following question about how they would be centrally coordinated would still be pertinent.

> I mean the question is, where does the coordination of this happen long term, ...And what you have to do is, you have to have somebody whose job it is to facilitate and improve practice, going round endlessly and all the time.

7.10.2 Refresher training and the challenge of staff turnover

An interviewee from a site with high staff turnover acknowledged that the added challenge of training new staff in care planning acts as a barrier for adopting Year of Care

> [in this area] it's very, very, very difficult to recruit nurses and because they're in great demand, there's quite a high turnover, so I think most of the practices have battled with staff and I know that one of the practices was on the brink of giving up on Year of Care, just because of having to retrain, and obviously the care planning training is just another piece of training that you've got to do.

An interviewee from another site recognised that for reasons both of staff turnover and the general need to maintain focus, ensure ongoing implementation, and refine process and skills, some system or approach for ongoing supported clinical reflection will be needed.

> Some of those professionals have moved on, they've gone to different areas to work, so we need to say, 'well actually maybe that practice has stopped care planning now because the key individual has left.' So I think we need to do much more local work with the individual practices around embedding sustaining the momentum … But also refreshing, refreshing people, because what we've done is, we've developed our providers around … all of the stuff that goes around care planning with the process, so we've invested in that. So we need to kind of say, 'ok, that's been the initial investment, they've gone away, they've tried and tested it, patients have been through the process, this is some of the evaluation'. But we also then need to say, 'well this is what your experience of the whole process has been, how is it going to continue in the future? How do we support that?'

One interviewee suggested that approaches to meeting these needs should be developed by the programme in the coming year:

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it's about habits and things, this is a huge change in what you do on Monday and Tuesday and Wednesday, and therefore it has to be reinforced and so, and I think that one of the big challenges for this next year … what's needed to help people to continue to keep their practice up to date, either by having on-going learning sets, or there are some things, tools and things that I think you can put in.

7.10.3 Peer support for clinicians

The need for support for clinicians practicing a Year of Care approach has already been discussed (6.5.2 and 6.6.3). Successful models could be shared.

7.10.4 Systems to reinforce Year of Care approach

Mechanisms to encourage and maintain implementation of Year of Care were described in 6.5.2 and 6.5.3. Learning more about effective ways to achieve ongoing implementation and developing systemic approaches to embed them could be a priority for the coming year.

> You can do what [one site] is doing, which is that in their … local enhanced service payment system for general practice, they're insisting that they are given a selection of care plans or things that came off the system, and that these will be looked at externally once a year. So that's a sort of mini audit that they're all part of … we have to get a whole collection of ways that are embedded in the system, that enable people to get back, what's happening to their practice, either personally or their general practice in a sense, and their many organisations, so that they can have this process of on-going reflection. …Well you see, we have to have all the levers in line, so the commissioners and the PCT have to be using any financial things that they've got to incentivise these things. They have to, if they have any quality assurance mechanisms, then they should be including this sort of thing within it.

7.10.5 Central repositories of information about Year of Care

Once the Year of Care programme has ended how will the central messages and approaches be accessible?

The following interviewee proposed that one sources of knowledge about Year of Care, once the programme ends, will be trainers, particularly if the train the trainer approach is successful. Another approach is to identify and acknowledge current clinical champions of the approach and establish their availability to share the message. The third is to ensure that the Year of Care approach is well documented.

> how we build that stuff in, is a really important question, and again I think that's a bit about the trainers … It's a bit about establishing that there's clinical champions. It's about getting a lot of our thinking into writing so that when people are thinking this through, they find the article that sets the ten key messages from, if you want care planning on 1, 2, 3, 4 … There will still be when this Year of Care disappears, there will still be a lot of people who are informed, aware, knowledgeable, energetic about this and again, it's about trying to track them down.

Other interviewees spoke about the need to ensure that Year of Care publishes articles widely in journals of relevance to all key professions.

7.10.6 Decisions to be made

Decisions need to be made about what priority to place on developing and implementing approaches to sustain Year of Care practices for the future, and, to the extent that this is a priority, select and develop the chosen mechanisms.

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APPENDIX 1: LIST OF PARTICIPANTS

Bradford and Airedale Teaching Primary Care Trust: GP. Shahhid Ali

Diabetes UK: Head of policy and care improvement. Bridget Turner

Department of Health Directorate of Commissioning and System Management: Lead for self management, long term conditions. Tracy Morton

Derbyshire County PCT: Diabetes clinical lead. Tom Humphries

Macmillan Cancer Support. Lead for Cancer Survivorship programme. Stephen Hindle

NHS Diabetes: Director. Anna Morton

NHS Kirklees: Director of patient care & professions. Sheila Dilks

NHS North of Tyne: Acting associate director of service modernisation. Jill Mitchell

Northumbria Healthcare Foundation Trust: Clinical lead for long term conditions. Simon Eaton

Tribal Evaluation Group: Lead evaluator. Gail Louw

Tower Hamlets PCT: GP lead in diabetes. Isabel Hodkinson

Tower Hamlets PCT: Medical director. Douglas Russell

Year of Care Programme Board: Chair. Sue Roberts

Year of Care Programme Board: Representative patient. Avril Surridge

Year of Care Programme Manager. James Thomas