

**YEAR OF CARE:
REFLECTIONS ON
INTRODUCING A COMPLEX
INTERVENTION INTO A
COMPLEX ENVIRONMENT**

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EXECUTIVE SUMMARY

1. INTRODUCTION

1.1 Audience and purpose: this report is written primarily for the Year of Care Programme Board. It is based on interviews with 11 individuals, all actively involved with the Year of Care programme. The report summarises interviewees' reflections at the end of the programme's three years about achievements, areas of weakness, and factors that supported or limited implementation and spread of the programme. The report explores issues of process rather than content, with findings intended to be of interest to a broader policy audience, beyond Year of Care. The central, somewhat cumbersome question underpinning this study was: what are the key learnings about implementing, embedding and mainstreaming into a complex environment a complex intervention that requires significant cultural change?

1.2. Timing: interviews were conducted between October and December 2010, the date when the pilot phase ended. Funding for the Year of Care programme ends in February 2011 and funding for the training programme ends in June 2011.

1.3 Structure of this report: after a brief outline of the research methods used, Section 3 describes features of the broader context and of Year of Care that influenced development and impact of the programme. Section 4 addresses the question, what is Year of Care? Section 5 discusses aspects of communication relating to Year of Care. Section 6 identifies enabling factors that supported the programme. Section 7 discusses ways that benefits from Year of Care might be sustained and views from interviewees of the future. Section 8 considers evaluation.

2 METHODS

2.1 Interview procedure: interviewees were purposively selected by representatives of the Year of Care Programme Board for their active engagement in design and implementation of the programme. They included key people from pilot sites and from the Year of Care Programme Board. Nine interviews were conducted in person and two by telephone. Most interviews lasted 60-80 minutes. All were recorded then transcribed and transcripts sent to interviewees for verification.

2.2 Analysis: all interview transcripts were read by the researcher and thematically analysed to address the underpinning question for this study.

2.3 Ethical considerations: formal ethical approval was not necessary. 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 in senior positions and all engaged in and committed to the Year of Care. The intention is not to provide a comprehensive review of the programme: that is the purpose of the final Year of Care report which will draw on an external evaluation of the work at pilot sites. The aim of this report is to reflect views from those most closely involved with development and implementation of Year of Care.

3. CONTEXT

3.1 Overview: the impact of any intervention is influenced by characteristics of the intervention itself, and by aspects of the environment in which it operates. Four qualities of the intervention and three features of the context are noted here for the impact that they have on issues discussed later in the report.

3.2 Iterative nature of the Year of Care programme: Year of Care has demonstrated ongoing readiness to learn and change leading to active development and refinement of ideas and activities. Because of its changing nature a temporal element is often necessary for descriptions of the programme. In this report three temporal phases are identified, though in reality each overlaps chronologically. The first phase (Year 1) was the development phase. The implementation phase began in Year 2 when three pilot sites began to introduce their practices to the programme. This continued during Year 3 with roll out to further practices in the pilot sites. Activities of the third phase, described as spread, started in Year 2 then continued with more rigour in Year 3, when Year of Care was spread to sites beyond the pilots.

3.3 Time-limited project: as a three year project Year of Care was an ambitious undertaking.

3.4 Limited budget: the overall budget for the project was relatively small. Pilot sites received funding from Year of Care for their first year only.

3.5 Nature of the pilot sites: the pilot sites provided three very different contexts. The differences, as intended, led to varied and valuable learning but also created challenges for summarising progress and outcomes.

3.6 Culture of NHS, general practice and diabetes care: Year of Care challenged and was challenged by the target driven culture of the NHS and the tendency for general practitioners to adopt a paternalistic approach to patient care.

3.7 Limited common understanding of concepts central to the programme: as a widely used term with many meanings the concept of care planning is prone to misinterpretation. Commissioning and development of non-traditional providers, the other components of Year of Care, are less familiar concepts.

3.8 Broader economic and policy context: for most of the project's three years Year of Care has been operating in a well-resourced environment. Current and future economic and policy environments will be challenging, bringing change and uncertainty.

4. CONCEPTUALISING YEAR OF CARE

4.1 Overview: throughout the project there has been no single or simple description of Year of Care, partly due to its ongoing development but also because the programme's conceptual nature defies simple summaries. This section outlines the essence of the programme by first, reporting key qualities that characterise Year of Care; second, describing development of the concept, and third, outlining the impact that has been attributed to the programme.

4.2 Concept of Year of Care

4.2.1 Relational aspect of Year of Care: Year of Care is an intervention that aims to change relationships between patients and healthcare professionals, moving from a hierarchical to a partnership approach. Lasting shifts of this nature require underlying changes to organisational structures, attitudes and culture.

4.2.2 Year of Care embodies central qualities underpinning general practice: building on the more equal relationship between patient and clinician the other components of Year of Care: education, information, organisational processes and effective commissioning embody the principles on which general practice is built.

4.2.3 Year of Care as a concept, an ethos, a philosophy with inbuilt self-reinforcement: as an intervention that aimed for an ethos-driven cultural shift, Year of Care was introduced to pilot sites as a practical model to be empirically tested, rather than as a policy document to be implemented as a mechanical process. Many practitioners who adopted Year of Care found the approach developed motivation and inbuilt rewards for them and their patients.

4.2.4 Potential for Year of Care application to depart from ethos and lose impact: if Year of Care is adopted as a process, without the underlying ethos, it loses its impact. There is a fine balance between encouraging sites and practices to own and interpret the ethos and intervention, while ensuring that they understand and maintain the model closely enough to gain benefits from it.

4.2.5 Commissioning and provider development: alongside care planning, commissioning and provider development were complementary components of the original Year of Care model, yet, due to challenges with design and support they received less attention than care planning. Consequently the Year of Care profile is closely associated with effective care planning but processes for commissioning and provider development, at the time of writing, are not yet fully developed.

4.3 Developing the Year of Care Concept

4.3.1 Process for developing the concept: the central team that initiated Year of Care deliberately entrusted leadership for development of the approach to key people in the pilot sites who would be responsible for implementation.

4.3.2 First year: five set questions and framing the concept: the central team initiated the development phase by setting five questions relating to diabetes care for the three sites to consider. Key people from the three sites were regularly brought together for facilitated learning events where participants shared ideas, with added input from the central team. At these events conceptual models were developed that proved useful throughout the whole project. All interviewees valued this phase, but some believed additional time would have been beneficial.

4.3.3 Second year: developing clarity: having developed the concept each site started introducing their practices to Year of Care. At this early stage the introductory training and resources were basic and experimental and, inevitably, early sites failed to receive the benefits that later ones did, as the process and resources developed over time.

4.3.4 Third year: achieving clarity on Year of Care approach to care planning: experience gained from working with pilot sites and other sites to which Year of Care has spread has confirmed essential requirements and components for effective care planning. Those involved in spreading the concept now feel confident in their approach.

4.3.5 Ongoing development of care planning: as application of the care planning approach continues those using it go on identifying refinements to the model and additional ways in which it might be used, including extending it to other long term conditions.

4.3.6 Development of provider & micro-macro commissioning components of Year of Care: unlike the work on care planning, application of the commissioning component of Year of Care has remained unclear. During the third year new funding has been accessed for one pilot site to develop a model for provider development. Findings are expected to coincide with completion of the overall project.

4.4 Impact of Year of Care

4.4.1 Changes for clinicians: shift to patient-centred care: those implementing Year of Care have observed a change in the power balance between patient and clinician.

4.4.2 Changes for patients: increased understanding and engagement: patients in the pilot sites are said to be becoming more familiar with the Year of Care process and at the same time, gaining better understanding and control of their condition.

4.4.3 Changes in clinical indicators: although few people closely involved with Year of Care considered it realistic to expect clinical evidence of changes among patients within the project time span, those implementing Year of Care at one pilot site believe their data demonstrates a marked improvement in biomedical markers from their Year of Care cohort compared with other patients.

4.4.4 Roll out from initial practices to other practices in the sites: in each pilot site the Year of Care approach has been rolled out to ever increasing numbers of practices, though not all have entirely grasped the concept.

4.4.5 Changes in diabetes care more broadly: as Year of Care becomes more widely adopted the relevance of its approach has become more evident, with the model being used by other healthcare professionals, and the principles influencing design and perception of diabetes services more generally.

4.4.6 Wider impact on other long term conditions and healthcare in general: the Year of Care model has been described as a paradigm shift that will influence and shape health services for other long term conditions, and healthcare more broadly.

4.4.7 Little impact on micro-macro commissioning or provider development: lack of progress with development and implementation of micro-macro commissioning and provider development is a disappointment for the project. Awareness and understanding of the issues involved has grown and those involved in the more recent project to develop a model for provider development are optimistic about its potential to complement Year of Care's care planning component.¹

4.5 Summary: Year of Care is described as an ethos or philosophy that aims to change relationships between patients and clinicians resulting in a more equal partnership approach and more appropriate access to services. Achieving the change requires an underlying change in attitudes, organisational structures and culture. Year of Care was developed experientially in three pilot sites, with support from the central team who initiated the project. Key people from the sites were supported to share experience and ideas as they developed the concept. During the second and third years the concept was implemented in practices in pilot sites and more broadly. Impacts are evident for clinicians, patients, and changes in healthcare delivery. The commissioning component of Year of Care that aimed to develop non-traditional providers and link micro-macro commissioning has not, at the time of writing, been fully developed.

5. COMMUNICATING YEAR OF CARE

5.1 Overview: the changing, iterative aspect of Year of Care brings challenges for communication, compounded by the conceptual nature of the programme. Engagement with healthcare professionals is described, illustrating ways of introducing clinicians to a new project. Other aspects of communication are discussed, including how to capture and convey conceptual aspects of the programme and how to maintain its integrity.

5.2 Engaging sites in Year of Care

5.2.1 Challenge for a new project: as a new undeveloped project with no evidence of outcomes Year of Care needed, at the outset, to attract participants to turn the idea into reality.

5.2.2 Engaging initial pilot sites to participate: the initial appeal of the project to potential pilot sites was not the description of a specific solution, but the promise of an approach that would address problems that had already been recognised within the site. Once involved, the process of presenting participants with questions to contextualise in their own setting built engagement that, when shared with others, led to development of the programme and of diagrammatic models that represented key components of Year of Care.

5.2.3 Engagement during implementation phase: early efforts to introduce practices to the programme struggled when resources and understanding were not fully developed, leading to disillusionment in some practices. On reflection an approach more like the one used to engage initial participants, identifying needs and skills and supporting practices to recognise Year of Care's potential relevance may have been more productive than promoting the programme as an entirely new approach.

5.2.4 Engagement during roll out and spread to other sites: along with more refined approaches to introducing the programme, roll out to other practices in pilot sites and spread to new sites has been supported by financial incentives for uptake, increased confidence that the programme is effective, and practical examples of the programme's implementation elsewhere.

5.2.5 Addressing staff turnover: engaging staff who join the programme later: key staff who join Year of Care as a result of staff turnover need to fully and accurately comprehend the programme ethos and its implications. Communication from the central team has been crucial for helping new staff grasp a broad understanding of the programme that helps them engage effectively.

5.3 Capturing the concept

¹ Progress on the provider development model subsequent to the writing of this report is summarised in the Foreword.

5.3.1 *The need for 'hooks':* conveying a complex concept and maintaining it over time is a challenge. The 'hooks' described here demonstrate ways that the essence of the concept has been captured.

5.3.2 *Diagrammatic representation of the concept:* diagrammatic models designed by participants from pilot sites during the development phase of Year of Care have delivered ongoing value, partly as a tool for conveying the concept to new audiences, but also as a source of the foundational principles to which participants can return to reassess ideas, challenges and potential developments.

5.3.3 *Real-life stories and examples:* descriptive stories of people's experience of Year of Care, and DVDs showing patient encounters based on the model, effectively capture the essence of Year of Care.

5.3.4 *Systematic procedures:* while the essence of Year of Care depends on a change in attitude and culture, tangible practices such as sending patients letters in advance help lock the change in place as systems develop around them.

5.3.5 *Responsibility assigned to a designated position:* when a position is created to support a change in practice, in addition to tangible support gained from the person in the position, the very fact of the position gives the concept recognition and raises its profile.

5.3.6 *Training programme that embodies the approach:* in a similar way to the cues gained from a designated position, the training programme brought intangible benefits in addition to its tangible ones. As well as conveying the Year of Care concept to new audiences the very fact of its existence helped crystallise the approach for those already familiar with it.

5.3.7 *Badging:* alongside the intention to integrate the Year of Care concept into standard practice some people recognised the need to hold Year of Care in the mind of practitioners and maintain use of the programme name as a reminder of the cultural shift involved.

5.4 National training programme

5.4.1 *Challenge at outset of limited practical experience of implementation:* as an empirically driven programme Year of Care had no local concrete experience of implementation on which to draw for its training when it began. Some of the training received by the first practices that adopted Year of Care was not fully effective.

5.4.2 *Training programme based on experience:* during the first year of implementation experience grew and the training programme developed into a codified approach for assessing sites, introducing them to the programme and training local trainers.

5.4.3 *Attitude-based focus:* as well as conveying information the training programme addresses attitudes, asking participants to examine their approach. Training is only delivered by people practically engaged with Year of Care themselves.

5.4.4 *Training for the whole team:* ownership of the shift in ethos towards adopting Year of Care is supported when all members of the healthcare team who have any connection with patients with diabetes receive a brief introduction to the Year of Care training.

5.5 Maintaining integrity of the Year of Care message

5.5.1 *Challenge of approach being 'tarnished' by distorted or incomplete application:* Year of Care attracts interest and from the start, practices and practitioners have been interested to adopt it. As a complex concept it is not always adopted thoroughly, raising concerns that the programme's reputation will be 'tarnished' by inaccurate or incomplete applications of it.

5.5.2 *Introduction to Year of Care given only by central team members:* in order to ensure that new sites interested in adopting Year of Care understand accurately the ethos and implications of the programme, only members of the central team deliver introductory sessions to new sites and, when sites are selected for training, only members of the central team deliver the first training session.

5.5.3 *Quality assurance for Year of Care trainers:* local trainers for Year of Care undergo a thorough programme of training that includes intensive contact with central trainers, ending with an assessment of the required competencies.

5.5.4 *Central protected resources:* Year of Care resources are available online, clearly badged as belonging to the programme. They are not intended to be changed in any way, or used by anyone who has not successfully completed the Year of Care training

5.5.5 Support for trainers over time: the ideal approach for maintaining integrity of the approach for local trainers would be to hold occasional collaborative events for mutual support and learning.

5.6 Communication to wider audiences

5.6.1 Communicating Year of Care to health decision makers: local and national Year of Care leaders have effectively maintained contact with health decision makers, actively re-framing the profile of the programme to demonstrate ongoing relevance as the policy agenda shifts.

5.6.2 Communication with patients: the risks and benefits of promoting Year of Care to patients beyond sites that have already adopted the programme have been debated and no agreement reached. As a result there has been no awareness raising of the programme to patients in general.

5.6.3 Communication with other related projects: another project addressing a similar theme piloted its approach during a similar time period as Year of Care, yet until recently there was little interaction between the two projects. Particularly during the early phase of a project the tendency to take a protective stance appears difficult to overcome.

5.6.4 Communication with the wider public: at an earlier stage in the Year of Care project staff from the central team communicated news about the programme more widely, but were not able to address the interest raised, consequently little broad communication has been conducted in the latter phases.

5.7 Summary: Communicating Year of Care to new sites was initially challenging, with no tangible experience on which to draw, but with time and experience a codified national training approach has been developed which proved effective in assessing readiness, conveying the programme and its underlying attitudes, and training local trainers. As a complex concept specific 'hooks' have proved useful for capturing the essence of the programme; these include diagrammatic models, stories, systematic procedures, and the training programme. The appeal of Year of Care brings the challenge of practices and practitioners adopting aspects of the programme without fully understanding and applying the underlying ethos. Maintaining integrity of the approach is crucial for the programme's reputation and for its effectiveness. This has been addressed by ensuring that when new sites are introduced to Year of Care they hear the message directly from the central team. Year of Care has maintained good communication with policy makers about the relevance of the programme to current concerns. Contact with patients, other projects and the wider public has, for various reasons, been less active.

6. ENABLING FACTORS FOR YEAR OF CARE

6.1 Overview: factors identified here are those that supported Year of Care during its development and implementation phases. The majority were noted by interviewees because of the evident benefits they brought; a few were noted because of their absence.

6.2 Enabling factors at central level

6.2.1 National leadership and direction: an innovative national project needs a leader who is committed, experienced and passionate about the cause.

6.2.2 A team approach at national level: from the outset a team approach was applied to development of the programme, with pilot sites central to that task. Increasingly, over time, governance of the project was opened up to a team approach, with progressively more key people from the sites becoming members of the programme board which oversees the project. Roles and relative responsibilities between the central team and programme board have never been explicitly clarified; this could have been a useful exercise.

6.2.3 Funding: As a project with a relatively small budget the advantage gained by accessing additional funding, which enabled development of the training programme, is very evident. The same may prove to be true with new funding granted to develop a model for provider development. Lack of funding to develop IT support was a barrier to development of the micro-macro commissioning component of Year of Care.

6.2.4 Support from centre for sites: sites benefitted from supportive facilitation and input from the central team during development and implementation phases. Members of the

central team gave direct support, and possibly could have provided more input when new project managers came into post as a result of staff turnover.

6.2.5 Approach congruent with current direction: the project benefitted from the fact that its aims were in keeping with current national policy directions.

6.2.6 Common recognition of an issue and shared language: multiple meanings attached to the term 'care planning' bring the risk of misinterpretation. Lack of general familiarity with issues relating to commissioning and non-traditional provider development created difficulties for shared conceptualisation of the problems and for exploring potential solutions.

6.2.7 Appeal and effectiveness of the project itself: the appeal and effectiveness of the underlying ethos is a bonus. Having understood and applied the approach it often becomes self reinforcing.

6.3 Enabling factors at site level

6.3.1 Commitment from relevant positions: with experience Year of Care has learned that new sites can only proceed if people in the right positions demonstrate interest. This generally requires money (from commissioners) and influential clinicians who can engage other practitioners.

6.3.2 Senior leadership in relevant positions and organisations willing to be actively involved: in addition to availability of money and clinical interest, support is needed from senior leaders throughout the organisation who will be actively involved if necessary. It is particularly valuable if both secondary and primary care are involved.

6.3.3 Team approach and steering group with committed representatives: at site level a multi-disciplinary team with a representative steering group has been proved to be an effective way of implementing Year of Care.

6.3.4 Effective project management: experience in pilot sites demonstrated that a dedicated position for a skilled project manager was essential for implementing the programme and for providing support to practices. New sites have fewer demands, not being part of the main external evaluation, but most believed that an initial need exists for a designated position to support implementation then an ongoing role to support maintenance of the approach.

6.3.5 Financial incentives: each site developed its own incentive scheme, offering financial benefits for practices that adopt Year of Care. In one site, where financial incentives were introduced prior to supportive systems being available, this led to later disengagement but where support is established financial incentives attract additional uptake and, depending on the nature of the scheme, can maintain application of the approach.

6.3.6 Systems that support implementation: the first sites to adopt Year of Care struggled with lack of training, documentation, IT and other supportive systems. The time taken to develop IT systems to support commissioning has proved an ongoing barrier, providing not only a block to necessary data collection, but also acting as a diversion that limited conceptual development of the challenges related to commissioning.

6.3.7 Readiness to change organisational structures to meet needs of relevant stakeholders: sites that fully adopted the Year of Care ethos have reassessed the way they organise their services, re-shaping them to better meet needs of patients and clinicians operating within a partnership context.

6.3.8 Shared learning: during the first two years of the project members of pilot sites benefitted from learning events when they were brought together to share ideas and learning. Mutual learning has continued during the final year, with site members meeting to discuss project closure.

6.4 Additional factors that give added support

6.4.1 Practical examples of the approach in practice: although not available until more recently, stories and DVDs of care planning in practice are useful tools for demonstrating the approach.

6.4.2 Evidence of success elsewhere: interest in the model grows as more sites adopt Year of Care.

6.5 Summary: enabling factors from the central team that supported Year of Care included strong leadership, an inclusive team approach to governance, and individual support from members of the central team when needed. Extra funding enabled additional development which met needs that only became evident as the project progressed. Circumstantial factors that helped were the fact that the project has appeal of its own, and that its aims support national policy directions. Lack of clarity about the programme's central concepts were a hindrance. Supporting factors at site level included commitment from leaders who could arrange financial input and from influential clinicians; genuine support from senior leaders; creation of a multi-disciplinary team and committed steering group; and dedicated skilled project management. Sites benefitted from opportunities for shared learning. Implementation also required supportive systems including IT, training, documentation; and willingness to re-think and re-shape organisational structures in line with the new ethos. Financial incentives supported uptake, and stories of care planning and evidence of success elsewhere provided added support and interest.

7. SUSTAINABILITY AND THE FUTURE

7.1 Overview: interviewees believed that benefits from Year of Care should be sustained but lack of clarity about the future policy context limits capacity for planning. Roles currently played by the central team and sites will be important if the ethos, practice and benefits from Year of Care are to be embedded and sustained in the future.

7.2 Role of the central team in sustaining Year of Care

7.2.1 Current role of central team: if benefits from Year of Care are to be sustained consideration will need to be given to which key functions currently conducted by the central team must continue, and how they can be maintained. Currently the central team relates to three main audiences: sites already conducting Year of Care; external audiences; and new sites that might adopt the programme.

7.2.2 Relationship with sites conducting Year of Care: much of the work that the central team aimed to achieve with pilot sites has been completed. Two aspects of project development are still in progress: IT systems for commissioning, and development of a model for provider development. Though designs for both are expected to coincide with the end of the Year of Care project this leaves no opportunity for further development. The central team's facilitation and support were crucial to mutual learning that benefitted the care planning model as it was trialled, refined, and later, spread. Maintaining integrity of the Year of Care message has been another central team function, with key people who are new to the programme hearing the Year of Care message directly from a central team member, ensuring an authentic and complete version of the programme, and avoiding the risk of deterioration through 'Chinese whispers'. Skills maintenance would, ideally also be a role of the central team.

7.2.3 Relationship with external audiences: the central team has maintained a relationship with policy makers, maximising the opportunity for Year of Care to become embedded within standard practice. If this is not achieved by the end of the project time span it is not clear how this role will be continued. Communication with patients and the wider public are other potential functions to be fulfilled.

7.2.4 Relationship with new sites: spread to new sites has been largely ad hoc, resulting from interest raised by occasional promotional events or requests from new sites. Members of the central team effectively assess and train new sites, using the training programme that has been established. If this approach is to continue an ongoing training team would be needed. An alternative route to sustainability would be through embedding Year of Care into mainstream regular processes.² Training and skills maintenance would still be necessary.

7.3 Role of sites in sustaining Year of Care

² As described in the Foreword, in developments that took place after the writing of this report Year of Care care planning has been approved as RCGP policy; work will be undertaken to incorporate care planning into GP training programmes.

7.3.1 Embedding Year of Care in practices: pilot sites had each integrated Year of Care into their existing programmes, linking it with other aspects of service provision so that it became embedded as standard practice.

7.3.2 Role of sites in supporting Year of Care: support for the Year of Care process and training in its skills and ethos will remain important, even when Year of Care has become embedded in standard practice. As other programmes evolve and change if the benefits from Year of Care are to be maintained support for the approach would need to remain a designated component of a specific role, held by an individual or, possibly, a committee.

7.4 Views of the future

7.4.1 Broad views of future context: doubts and concerns were expressed for the future of health services, though some interviewees expressed optimism about opportunities future changes may bring.

7.4.2 Perceived opportunities for Year of Care: maintaining the training programme would be one way that Year of Care could continue to spread and sustain its impact.

7.4.3 Perceived risks for Year of Care: if the Year of Care approach became compulsory for all practices there would be a risk of it being adopted as a process rather than an ethos. Until now the only sites adopting Year of Care have been those deemed ready, having high levels of organisation and motivation. It is not known how the approach would be applied in situations where interest is low and systems less well organised.

7.5 Summary: aspects of the role played by the central team that appear important for the future include refinement and spread of newly designed processes; maintaining integrity of the Year of Care ethos and message; skills maintenance; promoting Year of Care to policy makers; and introducing Year of Care to new sites. At site level sustainability can be maintained by embedding Year of Care into other programmes and ensuring support for the approach, even when it becomes integrated into existing processes. While it is conceivable that some individual sites may independently maintain Year of Care, for the programme to sustain its ethos and impact essential central team functions will need to be fulfilled. If the training team found a way to continue after the project ends the crucial work could be conducted by that team. The future is too unclear to predict how changes will impact on the outcomes from Year of Care.

8. INTENDED AND ANTICIPATED OUTCOMES AND WAYS OF MEASURING THEM

8.1 Overview: external evaluation of Year of Care has been a significant component of the project. As an iterative and conceptual programme Year of Care illustrated challenges for design and implementation of evaluation.

8.2 Intended outcomes: views of those involved

8.2.1 What would evidence success?: although interviewees from the central team articulated changes that would demonstrate that Year of Care had been successful, interviewees in the sites were less able to identify indicators that would demonstrate success.

8.2.2 Few expectations of clinical evidence in project timespan: most interviewees believed it would not be realistic to expect biomedical markers to demonstrate success for Year of Care within the project time span.

8.3 Expected outcomes from outsiders

8.3.1 Expectations of clinical and/or economic outcomes: external stakeholders tend to hold expectations that Year of Care will be able to demonstrate its effectiveness through changes in clinical indicators and/or through demonstrated financial benefits.

8.4 Views of the evaluation that was conducted

8.4.1 Frustration and disappointment with evaluation: participants in pilot sites have struggled with the main external evaluation, finding it demanding and cumbersome. They are also disappointed with what they believe the evaluation findings will be capable of demonstrating.

8.5 Challenges for evaluation of Year of Care

8.5.1 Challenge of designing evaluation for an iterative, changing project: the main external evaluation was conducted in two phases: the first covered the development phase of the

project and the second started in Year 2 with the implementation phase. Year of Care continued to develop and change, but the need to agree on evaluation design and data collection at an early stage led to decisions being made to collect a wide range of data with inadequate prioritisation, leading to challenges with interpretation, and gaps where alternative data could usefully have been collected.

8.5.2 Challenge of intangible and varied outcomes: in addition to not expecting to be able to demonstrate clinical evidence of change within the available time period, some interviewees believed that clinical outcomes were not a reasonable expectation for some patients and instead, outcomes could better be indicated by tracking individual cases. Similarly, starting points and circumstances were very different for the three pilot sites, creating challenges for summarising outcomes.

8.5.3 Challenge of implementing a complex evaluation: the process of collecting data identified as potentially useful proved complex and demanding, creating additional work for sites and practices, leading to frustration and dissatisfaction. Patients also reached limits in their willingness to participate in evaluation.

8.6 Alternative approaches to evaluation

8.6.1 Establish shared view of evidence of success at outset: shared and explicit agreement at the outset about how success could be demonstrated would have been useful. Mutual agreement about the balance between internal and external evaluation would support ownership of the evaluation.

8.6.2 Establish realistic approaches to collecting indicators: having determined the indicators of success, it would have been productive to assess existing data sources to determine whether new data collection was necessary, or whether existing information or simple processes could inform the essential questions. The most appropriate timing for the evaluation could also be considered.

8.6.3 Establish realistic expectations at outset: interviewees agreed that external pressure for simple answers to complex questions should be rebuffed and that realistic expectations of what might be achieved should be explicit and evident.

8.7 Summary: although one site did collect data that suggested clinical benefits from Year of Care, this was unexpected and most of those closely involved with the programme did not anticipate evidence of this type. Participants at site level were sometimes unable to articulate how success for the project would be demonstrated. People external to Year of Care tended to anticipate clinical or financial evidence. The nature of the programme created difficulties for the evaluation, leading to a complex design that was problematic to administer. A more collaborative and comprehensive approach to evaluation design could have included shared agreement about indicators of success, a mix of internal and external evaluation, and greater use of existing data sources to measure effectiveness.

1 INTRODUCTION

1.1 Audience and purpose

This report is written for the Year of Care Programme Board. It is based on interviews with eleven individuals nominated by representatives of the Programme Board. Each interviewee was selected for their overall view of the programme and their active involvement in both influencing and implementing Year of Care.

The purpose of the interviews was to capture reflections at the end of the programme's implementation phase and to provide feedback to the Year of Care Programme Board that will enhance learning from the three-year project, with a specific focus on learning relevant to policy-makers.

The aim of the report is to summarise key lessons about Year of Care's achievements and areas of weakness, and factors that supported and/or limited effective implementation and spread. The intention is to explore the underlying processes involved rather than focusing on specific detail or content, aiming to identify learning of relevance to a policy audience broader than Year of Care and, potentially, broader than health.

The central and somewhat cumbersome question underpinning this study, and at the heart of the interviews, was: what are the key learnings about implementing, embedding and mainstreaming into a complex environment a complex intervention that requires significant cultural change?

This report does not include accounts of the background to Year of Care, nor descriptions of the programme other than issues that relate directly to points made in the report itself. Information about the programme's aims, approaches and development are presented elsewhere.

1.2. Timing

Interviews were conducted between October and December 2010. The pilot phase for Year of Care ended in December 2010; funding for the programme ends in February 2011; and funding for the training programme ends in June 2011. Though interviews were timed to summarise views at the end of the project, during the period that interviews were taking place additional developments and realisations continued to emerge.³ As one person observed, the process of closure is an active part of the project; articulating summary thoughts clarifies thinking and prompts more to emerge.

This study completes the intended three waves of interviews with key stakeholders, planned during the first year of the programme. The first, conducted by Grace Sweeney and completed in late 2008, reflected on the feasibility phase of Year of Care. The second, conducted by the same researcher as this one, reported in January 2010 proposing factors for the Year of Care board to consider as it aimed to maximise effectiveness of the programme in its final year.

³ A major development subsequent to the interviews on which this report is based was the acceptance of the Year of Care care planning model as a professional standard by RCGP. Work will now be undertaken to incorporate care planning into GP training programmes.

1.3 Structure of this report

Following the introductory sections this report sets the scene in Section 3 by identifying qualities of the programme and aspects of the context in which Year of Care operates that impact on the way in which the programme developed and the impact it has.

Section 4 explores how the Year of Care Programme is perceived: what is the essence of the programme. The concept is explored first, through key characteristics used to describe Year of Care; second, by exploring its development over time; and third, through considering the impact attributed to the programme, and areas where impact was anticipated but not delivered.

Section 5 addresses communication about Year of Care. This section incorporates five related topics. The first considers ways in which people were introduced to the programme and how they became motivated to get involved; the second addresses ways in which a complex concept can be captured and conveyed; the third describes the training that has been developed for communicating the programme approach; fourth, issues of maintaining integrity of the message are explored; and finally this section considers ways in which the message is conveyed to a wider audience.

Section 6 identifies and considers the key enabling factors raised by interviewees. This section relates only to factors that supported the set up and roll out phases of the project.

Section 7 reports on sustainability and the future. Roles currently played by the central team that may be important for retaining the benefits from Year of Care are noted, and ways that sites can and do support sustainability. Views are presented about the future of the environment in which Year of Care operates and possible implications for the programme.

Finally, Section 8 looks at evaluation, considering first the views of interviewees about how they would identify success for Year of Care; second, expectations from outsiders; third, views about the external evaluation that was conducted and fourth, suggestions from interviewees about alternative approaches to evaluation.

Most sections of the report include a temporal element, reflecting the fact that the programme developed and changed over time. Within each section aspects of Year of Care that interviewees considered successful are reported, followed by interviewee comments about areas they viewed as unfinished or less successful.

2. METHODS

2.1 Interview procedure

Eleven individuals were purposively selected by representatives of the Year of Care Programme Board for interview. They included senior leaders and project managers from each of the three Year of Care pilot sites and Year of Care Programme Board members.

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, ten questions around which the interview would be based, and ethical guidelines⁴. Nine interviews were conducted in person and two by telephone.

Interviews were loosely structured around the ten questions listed on the information sheet, inviting interviewees to reflect on successes, disappointments, barriers and enabling factors for the programme, and to consider key lessons about embedding a complex intervention into a complex environment. Questions were also asked about the future of Year of Care.

Interviews lasted between 40 and 96 minutes, the average length was 66 minutes. All interviews were recorded digitally and the recordings sent to a transcriber. Once transcribed, transcripts were sent to interviewees for verification.

2.2 Analysis

All transcripts were read, noted and coded by the researcher, then re-grouped into topic categories. Categories were then re-read and re-coded in a process of thematic analysis to address the question at the centre of this study. This draft report has been written for circulation to interviewees and the Year of Care Board, with the aim of completing a final report by mid February.

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 2013, 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.

⁴ The information sheet is attached at Appendix 1.

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 eleven individuals, all at senior levels and all committed to implementation of the Year of Care programme.

The aim of this report is not to provide a representative view of Year of Care but to reflect the views of some of those most closely engaged with development and implementation of the programme.

The final Year of Care report will provide a comprehensive review of the programme, drawing on the main external evaluation which collected extensive data from pilot sites.



3. CONTEXT

3.1 Overview

Every intervention is shaped, supported and limited by interaction between qualities of the intervention itself, and the context in which it operates. The conceptual nature of the Year of Care programme is discussed in detail in Section 4.2, but here, four other defining features of the intervention are noted followed by three aspects of the broader environment that shaped implementation of the programme and that, potentially, will influence the future. These seven factors are raised here as those most frequently mentioned by interviewees when considering development, implementation or future of the programme and for the way that they impact on issues discussed elsewhere in this report.

3.2 Iterative nature of the Year of Care programme

A central feature of the Year of Care programme has been, and continues to be, its ongoing development and change. The readiness of those most closely involved in developing the programme to adapt and change has led to ongoing refinement and development of ideas about what can be achieved and approaches for achieving it. Those close to the programme recognise the benefits and success of this responsive approach, yet it also brings challenges for those who struggle to implement a still-developing programme.

I mean I think the successes of Year of Care are very much around the fact that it's been a project that's been prepared to learn from itself and change if need be ... the fact that nobody takes for granted that we got it right, that the project got it right from day one and has just continued to reflect and learn and refine and reiterate things.

Because of the changing nature of the programme a temporal element is integral to any description of Year of Care. The challenges, lessons learned, and experiences of those developing and implementing the programme differed, depending, amongst other things, on the time at which they were involved.

In this report three temporal phases for the programme are identified, though in reality each overlaps chronologically. The three phases are:

- development – developing the concept was the primary task of Year 1 of the programme (2008) though, as described in Section 4.3, development has continued throughout the whole project period;
- implementation – during Years 2 and 3 (2009/10) the pilot sites introduced the Year of Care concept to their practices. In two pilot sites a staged approach was used, with a limited number of practices involved in Year 2. Later, mostly in Year 3, a second phase of implementation, referred to here as roll out, took place, as further practices in these sites adopted Year of Care.
- spread – during Year 2 but more intensively during Year 3 the programme has been introduced to new sites that were not part of the original pilot.

3.3 Time-limited project

The Year of Care programme set out to achieve its aims within a three year period. Most interviewees acknowledged how ambitious a challenge this was.

But it was just too short a time scale to do all the different elements of such a broad programme that was really trying to change absolutely everything.

3.4 Limited budget

As a three year project Year of Care operated with limited funding. Pilot sites were each given £100,000 in their first year, but no financial support was provided to sites in subsequent years. Training was provided free of charge.

And then the plan was ... they had no money then from then on because we wanted to see ... This has been about can we change the way that services are delivered main-stream for the majority of people that we're dealing with? And so if we'd given people in the pilots, money to do this, others would have said, well anyone can do this with the resources. So no money was given.

Overall, the programme has operated with a relatively small total budget (approximately £1 million over 3.5 years, including training and evaluation). Money to develop the national training programme, included in this total, was received after the start of the project in a separate sum from NHS Diabetes. The training programme is discussed in Section 5.3 of this report.

3.5 Nature of the pilot sites

The three pilot sites each faced different challenges and each developed their own approach to implementing the Year of Care programme. These differences have, over time, allowed broad learning to take place but initially, and in some ways ongoingly, it is difficult to pool or summarise progress and outcomes for the programme as a whole.

... the base line of where we're starting from is all different in the pilot sites, so one thing that needs to be taken into account, where do we sit? So if you're looking at the Healthcare Commission survey results, where did we all sit at the beginning of this process? And some of us have had more to achieve than others ...

3.6 Culture of NHS, general practice and diabetes care

Several interviewees referred to the way in which Year of Care interacted with, challenged and was challenged by the broader culture of the NHS and general practice, where targets have shaped service delivery and the professional stereotype for general practitioners is to adopt a paternalistic approach towards their patients. Each of the following three interview excerpts supports this picture.

... and we've been working in a culture in which everyone is used to simply being performance managed, told what to do, targets, priorities set externally ...

... but a medical education programme that starts with telling people they're great and they're fantastic and they can lead the way and sometimes it should be telling them that as leaders, they need to actually not to be leading, but following them. So it is a huge cultural change.

And diabetes care has become a bit of a QOF check list for lots of clinicians and a lot of patients receiving that, understandably find it of no use whatsoever ...

3.7 Limited common understanding of concepts central to the programme

An additional challenge for Year of Care is the broad and varied application of the term 'care planning', leading many general practices to claim that they already apply a care planning approach.

... the lack of national clarity about what care planning is ... whether it's related to empowering people with long term conditions to live better and self-manage, or whether it's about keeping people with multiple long term conditions, essentially the frail and elderly, out of hospital to save money. And the documents that come from the department muddle the language ... And so huge, huge lack of clarity ... a big frustration is that actually many many GPs believe they are doing it now, in a very, sometimes nice but holistic way, sometimes nasty, patronising way, but very very few understand that this is a new paradigm, patients going off being coached and supported to live their life with diabetes..

As the following interviewee described, even less clarity exists for the other components of Year of Care: commissioning and provider development.

... commissioning is still a vague, woolly word that means lots of things to lots of different people. There were components within it, but most of the commissioning that's really done locally is through contracting and this isn't about contracting, this is the broader public health philosophy of commissioning.

Another interviewee described a survey conducted by a previous Year of Care project officer that found very low levels of understanding of non-traditional provider development in PCTs across the country⁵

3.8 Broader economic and policy context

As the following two interviewees commented, although Year of Care provided limited funding to pilot sites, nevertheless the project started under optimal conditions.

... in the last four years, we've had the resources, more resources in the NHS than we've had before, so we have had resources to put into it. Into the future, you know, if this had happened ten years ago or five years hence, you wouldn't get so much dedicated project management time. I mean, Year of Care was funded for the first year. The rest has been funded basically by other PCTs that have taken it forward. So there's been a lot of goodwill involved in this that might not be there in the future.

... when we started, we were in a growth situation. But now I think, for somebody else to pick it up, you're in the context of NHS trying to create twenty billion pounds worth of savings.

The implications of the harsher economic climate may not be entirely negative for broader spread of Year of Care. As the interviewee quoted above recognised, along with a well-

⁵ This view was consistent with the analysis of world class commissioning conducted by the Department of Health.

resourced NHS came the challenge of multiple competing priorities, leaving Year of Care as one of many projects vying for practices' attention. The interviewee quoted above went on to emphasise that the current need to reduce spending highlights the value that Year of Care offers with its potential to influence the area most in need of money-saving.

My answer to that is, well if you're going to make any savings, it's only by transforming long term conditions ... It's the non-elective recurrent admissions for complications of long term conditions is where the big money is and therefore we have to address that. If we don't address that, then we'll be bankrupt.

Several interviewees commented on the uncertainty of the future.

... the whole culture of politics and policy has changed in the last six months, nine months ...

At the time of writing proposed policy changes towards commissioning by GP consortia are not far enough advanced to predict the impact.



4. CONCEPTUALISING YEAR OF CARE

4.1 Overview

Throughout the development and implementation of Year of Care there has been no single, uniformly adopted, specific statement that describes exactly what Year of Care is. The challenge of definition is partly accounted for by the iterative, changing nature of the programme but another key difficulty arises from the fact that, as several interviewees said, Year of Care is not a mechanical model, it is a conceptual one.

As a means of describing the programme this section reports comments from interviewees that address three questions. First, what are the key qualities that characterise Year of Care? Second, how did the concept develop during the course of its three years? Third, what impact has been attributed to the programme?

4.2 Concept of Year of Care

4.2.1 *Relational aspect of Year of Care*

I want to know what it is, and I'm still not sure we do know what it is. I see Year of Care as this mechanism for bringing about change in relationships at a local level and changing access. Other people see it as care planning, other people see it as commissioning, other people see it as a national training programme. I think the only one thing that we do all agree on, is that the product we have is the national training and Year of Care as a brand, but it's not a product. It's an intervention ...

This interviewee sets the scene by identifying the range of activities associated with Year of Care: care planning, commissioning and national training, whilst acknowledging mixed views about what exactly the programme is. As Interviewee 5 sees it, the programme itself is an intervention that aims to change local level relationships and service access.

Almost every interviewee referred to the relationship or partnership aspect of Year of Care. Two are quoted below.

... it's that true working in partnership that's important with sometimes the patient leading the goal setting or always leading the goal setting and the professional understanding how they can support the achievement of those goals, through better control or better management and supporting them to manage their condition.

... trying to change the relationship between the person with diabetes and the healthcare professional The relationships between people. ... I've heard people say things like, it puts the humanity back into medicine, because we've forgotten about it for a long time. And I've heard people, you know, nurses doing it, say that, actually this is why I went into care.

The interviewee quoted above described the ongoing ramifications that emerged from Year of Care's intention to re-shape relationships: recognition of the need to look more broadly at

factors that influence and support the relationship between patient and healthcare professional, leading to an expanding focus on organisational aspects and culture.

And what's happened over the last three years actually, it's of course come to light, that you can't just change a relationship in health, you have to change the whole system around the relationship and so in a way it's become a system-wide programme whereas perhaps originally, it was only really seeing one bit of that system, but you can only change that, if you change the rest of it around it. Therefore it's become more organisational, more about culture, more about the environment and that wasn't necessarily where we were where we started three years ago.

4.2.2 Year of Care embodies central qualities underpinning general practice

Another portrayal of the intervention frequently mentioned by interviewees, which also emphasises the relational aspect, is the conceptual diagram developed during Phase 1 of the programme: 'the house'. This model is attached at Appendix 2. Development of the model is described in 4.3 below, but essentially, the central components are an elaboration of those described in the first interview excerpt in this section : an equal relationship between a patient and clinician supported by education, information, organisational processes and commissioning. As the following interviewee said, the emphasis that Year of Care places on trust, care and local setting is the basis on which general practice has been built.

... at its heart is 'the house'. The educated and informed patient who's been assisted in accepting their diagnosis, understanding their diagnosis and supported in living with their diagnosis, and the engaged and informed and educated clinician who comes armed with the knowledge as an expert and to have that dialogue of partners, equal partners, around goals and actions and negotiating what those are, as equals rather than hierarchical. And for the commissioning arrangements, whatever they are, surrounding that to have all the systems and processes and infrastructure in place. ... and for me, that is what British general practice has as its strength, a registered population, over time, based on trust and knowledge of the person in their context: physical, social, psychological and spiritual. And with care and compassion as part of the equation and not simply by medical markers and valuing the person as a human being In a way I wonder why Year of Care had to be invented. Why is it that professional training doesn't embed this as an approach? Why did Diabetes UK have to come up with it as a model to teach doctors and nurses how to talk and listen, how to talk to patients, importantly, how to listen to patients?

Although, as several interviewees pointed out, the Year of Care approach reflects the true underlying nature of general practice, they also recognised how far from that model many have slipped.

No I think until you're doing it and until you start thinking about that way, you don't realise the value of it and you think you're doing it and you're not. So a lot of our GPs, especially the ones at the start, felt they were very good at diabetes care, felt that they were already doing the Year of Care planning, and all it needed was a bit of you know, rubber stamping to get them this wonderful accolade of delivering Year of Care as a new innovation. The reality is it was not that. It was very much a new concept and a new way of working that was quite difficult to grasp, because it was a concept. It wasn't hard fact.

4.2.3 Year of Care as a concept, an ethos, a philosophy with inbuilt self-reinforcement

The interviewee above points to a central challenge for Year of Care: that as a concept it was not easy to convey. Interviewees, including the following two, commonly spoke of Year of Care as a culture change, a system change, an ethos, or a philosophy.

It needs to be a system change, not just skills training.

I think you know, if you're asking me about what the success of Year of Care is, that it has a philosophy behind it, that makes it, that helps the project lay its wares out from the beginning about where the ethos of the people that are involved in this are coming from ...

Closely linked to its conceptual, ethos-driven nature was the way in which Year of Care was introduced. Unlike many new models, it was not presented as a written policy document, but as a practical model to be empirically tested and developed.

... normally a lot of the healthcare delivery work that goes on in the NHS is a lot of theorists sitting in a room or having a brainstorm, writing a policy document that's saying, thou shalt, or thou wilt. But this hasn't been like that, this has been very much, here's an idea, here's a philosophy, here's a model, can it work? You tell us if it works. So from the perspective of doing it with pilots, there is more benefit doing it like that because you can see whether it's real, whether it really can work. It probably could have been rolled out [as a policy document] but then ... it wouldn't have become so relevant and so real, it would have probably just become a document that sits on a shelf, like everything else does.

Another interviewee, also referring to the empirical way in which the programme was introduced and developed, pointed to the self-reinforcing quality of the approach that Year of Care promotes.

... this is a grass root project, this is about real clinicians and people working together absolutely in the grass roots, in the clinics and in the surgeries. And that's where they've got the oomph from it and that's where they've got their motivation from it ... I mean at a time when no-one can have a good word for the NHS, these people have done masses and it continues to be motivating for a lot of people.

As the following person commented, once clinicians had adopted Year of Care they expressed enthusiasm to maintain it.

Now I think it's just that people much prefer working this way. I mean we ask the practice, would any of you consider stopping doing this? And they all said: Oh no!

4.2.4 Potential for Year of Care application to depart from ethos and lose impact

While Year of Care is much valued by practitioners who adopt and apply the approach and is often described by interviewees as transformational, they also acknowledge that Year of Care is not universally accepted amongst the practices that have adopted it.

... when the GPs actually do it, they come away feeling differently about the conversation that they had with their patients. That, I think just experiencing that, would make a difference. I think the challenge is not necessarily everybody experienced that, I think there's always some people who wouldn't maybe have delivered it in the same way or maybe have different expectations. ...I think that it has

done in pockets, but it takes longer than a two year programme to change cultures of organisations.

The following interviewee attributes the fact that Year of Care fails to motivate some practitioners, and/or that motivation fades, to a failure to implement the Year of Care approach in its true form.

... unless the motivation is actively maintained, then even that sort of dissipates a bit. So there is this continual paradox that when it's done according to the method, ... Year of Care method ... when it's done that way, it is motivating and then it works. But when it's not done that way, it doesn't motivate and it doesn't work and it sort of atrophies and therefore the challenge is to keep it on course without of course, controlling it because the thing that's motivating, is that it's about real people working in a really flexible way.

The interview excerpt above highlights a crucial challenge for the programme: that it is the empirical, malleable nature of Year of Care that allows it to be relevant, practicable and meaningful in different settings, yet there is a central core to Year of Care without which the approach loses its impact. It is this balance between, or combination of, a specified process and an underlying ethos that creates much of the difficulty in conceptualising or articulating Year of Care.

4.2.5 Commissioning and provider development

A more specific area of confusion about the definition of Year of Care arises from changing and varied views about the centrality of commissioning and provider development to the Year of Care concept. Several interviewees made no mention of micro-macro commissioning or provider development when discussing Year of Care, while for others, including the following two, they were a crucial component of the programme.

... one of the challenges for this project is that it's not tangible and everybody brought to it their own perspectives of what they thought could or should be happening. And although there was some work undertaken in the initial phases about defining it tightly, they're still quite broad, so the nuts and bolts of what happened and what needed to happen, I think were not seen up until about three or four months ago, which is quite a long time to go through a project without being absolutely clear what was going on in every area. And I've been challenged by that because ... the project has been very focussed on care planning, not on the commissioning end and I've always been challenged by that

... because Year of Care was the totality of provider development, and in fact the Year of Care came out of the *Choosing Health* White Paper, which was all about developing providers to match peoples' need. Now of course you couldn't do that without finding out what their need was via care planning. However, in a sense for this to be Year of Care we have to deliver on provider development. And that's an area in which overall in the project at this moment, we have been less successful. ...

4.3 Developing the Year of Care Concept

4.3.1 Process for developing the concept

The central team initiating Year of Care decided, at the outset, that rather than directing development of the project from the centre, leadership for turning the idea of Year of Care into reality should be given to those in the pilot sites who would be responsible for implementing the programme. In handing over leadership the central team trusted the

readiness of the healthcare professionals involved to recognise and value the ethos behind the programme and trusted their ability to develop it.

... it wasn't about us going down and doing a lovely two hour presentation and saying, this is how it should be, it was actually about the people doing the work doing it and believing it and shifting it. I think many of those individuals had that perspective, they might not have used those words, but they had that ethos. And we gave them space to come out, to think about it, to talk about it, to bring some of those passions that maybe get lost in team meetings or tick box exercises, which healthcare runs on, it thrives on, mechanistic theory ... So I think we gave them the space, we gave them local support and facilitation and help to actually encourage that space, encourage that speaking, that thinking, and I think we gave people responsibility for leading it and doing it themselves, as well as having the national, we said, this is for you to work out, you need to lead this at a local level in the best way that'll work for your area.

4.3.2 First year: five set questions and framing the concept

Looking back, one interviewee recalled the open-ended initial challenge from the central team to the pilot sites. The sites were each asked to address five questions relating to diabetes care, care planning and commissioning in their own setting.

I think the project at the beginning was prescriptive in terms of it posed five questions, so each of the three sites were posed five questions and part of the project was how do you answer all of those five questions as part of the Year of Care programme? And I think what happened was, the translation of those five questions was down to the individual sites, so we were all left with a high degree of autonomy, to interpret those five questions and to put that into context. Then part of the learning sets and learning events was actually our interpretation being shared with the others and then coming up with some common understanding. So it was quite a clever way of constructing the support for the project, sharing the maximum learning and people's intellectual capacity within the process ...

Another interviewee reflected on the open nature of the early stage of the project, recalling the challenge, but also the value of it.

In the beginning it was seen as being for a selective group of practices and ... I don't think there was real clarity on what we wanted to achieve ... in some way, people might think the first year was a waste of time, we should have started from a different place, but actually that was real action learning. So it's a positive for me. At the time, that's when we lost some people, but actually we learnt so much that has helped embed it. And that's I think a key lesson, so I expect people to drop off, but don't give up.

The following person emphasised the importance of the learning events for focusing attention, sharing ideas and developing thinking in order to concretise interpretation of the concepts.

I think what's been helpful is the focus of the learning events so as we've gone through this process, and certainly in year one and year two of the programme, we had quite a commitment in terms of the base sites to the learning events ... And I think where we've been able to kind of concrete some of our conceptual thinking has been from taking part in those discussions and then coming up with something to say you know, some of the illustrations that have been sort of proposed through the

project, does this sort of visually represent what we're trying to do and does it make sense? So I think that's been really helpful facilitating some of that learning.

As noted earlier, interviewees saw the 'house' model as a central component of Year of Care.

And then the whole system around the house was developed and macro commissioning and good care planning and goal setting etc. That developed over the first year about what we really wanted out of it.

A member of the central team confirmed that the 'house' model emerged in response to needs identified by the sites, rather than as an outcome of central planning.

I'm not even sure we always knew exactly what we wanted, to be honest. It was actually the listening and engaging and shaping up the house model, came from people working in the pilot sites saying, we actually need to frame this. We need to have a framework to communicate it. ... I don't ever remember somebody [in the central team] saying, we need a framework for this. So it actually came from them about what they practically needed and was worked up with them together.

Another interviewee described the process of developing the model and the value of participants being involved in developing it, rather than having it imposed on them.

We didn't start with an entirely blank sheet of paper ... we were given a starter and we had a facilitated learning day where we explored whether the concept [of the house] was useful or not and part of the learning was to, 'and now describe your local environment as if it were a house and what does it look like and draw your house' and so the house had some pretty flimsy walls and a ricky racky roof and lots of tiles missing and a foundation with some holes in it. And I think that exercise got us into the understanding, because I can see that if you use that as an approach on another project and you said, this is your model, people would say, no it isn't ...

Along with valuing the development phase, some interviewees believed that phase was too short, and that more time was needed to fully develop and grasp the concept before attempting to convey it to practices.

... the first three months were more like, in a sense getting our heads round what we thought the job was, which was good, I mean don't get me wrong, that was an absolutely essential part of the process. But in theory, then going to go live in April, and that was just unrealistic. And I think that actually a little bit more time, ... we took about three months to build, I mean obviously the central team did most of it, but we had monthly away days and sort of you know, interactive conversations. I don't think that the house model was actually firmed up until about the end of November and beginning to get our heads round what that meant, probably took a while. So we were doing visits into practices into the January February, and I don't think we were really clear what we were asking them to do.

4.3.3 Second year: developing clarity

Building on early development of the concept, pilot sites continued to develop their understanding as they introduced practices to Year of Care. There is broad agreement from pilot sites that practices introduced early to Year of Care struggled to understand the concept because of inadequate support. As noted elsewhere in this report (5.3), time and experience were needed to develop relevant training and support systems. Inevitably, the

first trial sites were unable to benefit in the way that later ones did. The following interviewees commented on two different sites.

And then the whole system around the house was developed and macro commissioning and good care planning and goal setting etc. That developed over the first year about what we really wanted out of it. So we started something without the training and education programme, without actually all the necessary, if you like, basics like good information for the GPs in place. So it was almost we learnt on the job in the first year. Our practices that were involved in the first year, consequently struggled because they didn't really get it, or if they got it, there weren't the props to help them do it. I think from that, there's been a lot of work driven by [the national team] around getting the right training and education in place to deliver it. But that came on-stream much more latterly.

So in essence I think it was like too many steps collapsed together, because in fact almost I would say that in a way, this whole phase of these two years is almost more like a test of concept than actually a test of implementation ... So for example, a lot of the practices have said, well when we started we didn't know what we were supposed to be doing, and they'd had some training but the training wasn't really very integrated and didn't in itself, the trainer wasn't fully understanding what Year of Care was asking people to do. So I think a lot of people were trying to implement something they were very unclear about what it was.

During the second year while pilot sites worked with practices the national team worked with other interested sites, observing and developing their understanding about what did and did not achieve, constitute and convey the Year of Care approach.

... in the second year and we left [the pilot sites] to their devices a huge amount and ... we went out to the other sites that had originally been partners and said they were interested ... and spent a huge amount of time with these sites. And that's where we got very great validation for our method and way of working. Huge frustration, because the way you go about things is clearly very important and ... there were many sites who believed that this was a tick box intervention, that they didn't properly understand, that they tried to put in using what I'd call non-facilitative approaches and in some places put in money. And they've almost nothing to show for it. ... And I think we are now confident in the third year, that we know what it is ... so one strand was going out and getting all this experience and learning about how other people were doing and also learning about how to describe what we were doing, ... so all the time we were learning.

4.3.4 Third year: achieving clarity on Year of Care approach to care planning

Those working closely with the programme now agree that they know the necessary components that support a practice to engage in care planning using the Year of Care approach. The following two interviewees expressed their confidence in the care planning approach.

... we now know what we're talking about and that if you don't have certain things, it won't work, if you then put them in, it does work.

I think the work around care planning over the last year has got stronger. I think it's got more structured, it's become more organised and people have become clearer around what it is and what it means and what you have to do to say that you're doing it ... I also think it's informed the organisations that are close to it, what change is, in health and how to do it more broadly in terms of the education, the training, the team-

working, having the leadership at a local level, and unless you have all these things in place that interacts on the system, you're not going to be able to effect any change between the patient and the healthcare professional ...

4.3.5 Ongoing development of care planning

While satisfied that the programme is achieving much of what it meant to achieve, those engaged with it continue to refine their understanding of the concept and to identify areas for further development.

One interviewee identified a need to re-shape the emphasis on care planning as a process, rather than on care plans as an outcome in the 'house' model, and to acknowledge that for some patients the process of achieving a meaningful care plan may take several years. Only time and experience of working with the model could bring this degree of greater clarity.

... even now I'm clarifying what my understanding is and ... I think the house model has some limitations and needs to have further explanation or slightly different wording ... I think that there was ... an under-stress on the care planning encounter as part of an ongoing process of care. Because now I think everyone's put a huge amount of effort into delivering care planning, but I think there wasn't very much thought about, and then what do you do with the patient who had their care plan? And that's partly because, when you look at the picture of the house, it says, collaborative care planning. But people read that as a single encounter and actually for it to work, it needs to be an ongoing way of working with this person ... But I think there's also a conceptual thing about ... you can't necessarily get people far enough through the process to produce a care plan in the first or second iterations. And again what many of the practitioners see when they see that house, is that care planning, they've got to actually produce a plan. Whereas actually, for some patients, and I have this image of them being outside the house and up the garden path ... A lot of them have been used to being told what to do by their clinicians. So they need to be kind of reeled in ... I think absolutely this is a complex change, yes it's going to take time, I mean I would say two to three years running. But I also think there are some gaps in the way that we presented the concept. And I think that's just because we hadn't done it ourselves.

Interviewees referred to other specific areas where they intend to develop the Year of Care concept. One is to extend Year of Care beyond diabetes to other conditions.

... one of the things we have to get smarter at is this business of not duplicating for disease specific conditions. I think we need to be person specific not necessarily totally disease specific. So that we try and get that annual care planning down to one long consultation that takes in the totality.

4.3.6 Development of provider & micro-macro commissioning components of Year of Care

Although initial visual representations of micro-macro commissioning were designed, as already noted, the aspects of the Year of Care concept that remain under developed are those connected with provider development and micro-macro commissioning. A separately funded project has been undertaken at one of the pilot sites to explore and design an approach to address this gap in the Year of Care concept. The end of the separately funded project may coincide with the end of the Year of Care period, but there will not be time to trial the new model before the three year timespan ends.

... we've got a separate arm of the project ... is there a model ... that can take some of the community based lifestyle programmes, local authority commission programmes, voluntary sector programmes into a more systematic model for the community based solution to support for self management of long term conditions? So it's just about extending the boundaries because what we learned from this project from the commissioning perspective was that commissioning on the scale that we're doing at PCT level can be quite inflexible, because of historic commissioning investment, because of contracts that are in place. But in order to shift the focus away from the acute, the specialist medical model into a different model, it takes a very different level of thinking. So what we're proposing to do is look at is there a framework that we can suggest to a GP consortia that they go and commission, that embeds the community aspect into kind of like the medical model, so there's a bridge across the two ...

4.4 Impact of Year of Care

Alongside information about how those involved in Year of Care conceptualise it, the programme can also be understood from the impacts attributed to it.

4.4.1 Changes for clinicians: shift to patient-centred care

Most interviewees referred to the fact that the Year of Care approach supported and achieved a different relationship between healthcare practitioners and patients, resulting in more patients who felt more empowered. Three views are quoted below.

... passing ... the ownership back onto the patient, so empowering the patient ...

Because I think the power balance is a better, I think it's just much more respectful of people. One of the nurses, it was so touching, we went round and she said, oh it's great, there's no more telling off! It's like, Halleluiah! That has to be a success.

... one of the key successes is the introduction of patient centeredness because I think the GP contract overall, with its focus on the financial reward for the quality and outcomes framework, tended to be a reductionist, non-patient centred computer centric data exercise that left many patients feeling spectators of a process designed to increase the remuneration of practices. And I think the care planning element coupled with consultation skills element and the capacity of practices to understand their own disease register ... all that skill has really been very beneficial.

4.4.2 Changes for patients: increased understanding and engagement

While acknowledging that the culture change that Year of Care aimed for would take time to develop, as the following three interviewees described there is already evidence of patients changing their levels of participation in the process and, in some cases, actively engaging with their health.

But we've got a very nice example ... in which I think this woman ... the GP said, well the first year she got her letter, even though she'd been told all about this, she got her letter and she didn't know what it was for, in fact she thought it had come to her by mistake and it was for the GP. So she didn't open it and she took it with her to the GP. The second year she opened the letter and had a look at it, and brought it back to the consultation. And the third year, she came back and she'd written some things down and thought about some of the things that she could do. Now that I think is very

realistic, and is about this whole people learning and thinking and it's a big change in culture and loads of people are saying this.

... we've now made good progress towards people understanding how not to get sick in the first place, understand their condition when they've got it, know that they're not powerless, and they've got options and that they'll be supported and respected in dealing with those options and the data is showing that we might actually be helping them to live a bit longer_... Well the figures appear to demonstrate that people are getting better. Not only are they feeling they're more in control, they seem to be in more control and if we believe the evidence, then the long term complications will be less.

... it might have been hard work at the beginning to set up and do all the templates and the coding and stuff, but once that's all been done, they're then realising the benefits in that the patients aren't coming back as often so they're having maybe a slightly longer consultation but they're not having as many appointments ...

4.4.3 Changes in clinical indicators

As discussed elsewhere in this report (8.2.2) there were mixed views about whether it was feasible to believe that the programme could, by the end of its three year period, demonstrate tangible evidence that suggested a change in health outcomes. Many of those closest to the programme thought it would not be possible in the short timespan.

... not enough people with diabetes have been through enough cycles of care planning for us to tell us whether this has made a difference.

Nevertheless, at least one of the sites has analysed its data and found what appear to be promising results.

... the challenge in things like diabetes and long term conditions is to measure outcomes. ... so we tend to focus on outputs and process measures. But the outputs that we've got, such as glycaemic control, blood pressure control, renal function, cholesterol level, the data on those is looking very promising. And one of the things that we've noticed, that the cohort in the Year of Care cohort, the care package has been commissioned across the whole borough, but the Year of Care cohort started from a lower starting point and have improved more rapidly than the rest, is what the early data shows and it's been validated and we think it's statistically significant. So we think more observation, it needs to be done over a long period of time ... we think that the trend is there and it's robust. ...

4.4.4 Roll out from initial practices to other practices in the sites

In each pilot site the Year of Care approach was spreading to practices beyond those involved in the initial implementation phase. Roll out is not ubiquitous, not everyone adopts the approach absolutely, but as the following interview excerpt says, it is an evolutionary process.

... what we're getting now is much more of a roll out of Year of Care than we envisaged in the beginning. We hoped for it, but we didn't expect it to be quite as successful in the way it is. The failure is that not every practice is doing it in the right way. Every practice or most practices are saying that they want to do it, many have been on the training, some are at the stage of starting to implement it and working with [the project manager] to take it forward. So it's an evolutionary rather than revolutionary process if you like, but evolution is gathering pace. So that's been very

positive for us ... the possible element that slowed it down, were people seeing it as an isolated innovation for a particular group of people, rather than a systematic cultural and behavioural change that should influence a whole care pathway ... It was a step on the way to a much more comprehensive review of services for people with diabetes.

In another site an interviewee described the success of all practices having made some changes in their understanding of good practice, but still the challenge of fully grasping the concept of Year of Care.

I think it's just such a huge conceptual model and I think it was just trying to do too much too quickly in some ways ... I actually feel amazed that we managed to get all of the practices doing at least some of it and actually being positive about it, in the main. And all of the practices have shifted at least in part, their views of the ways that they work and what's a good way of working. But I still feel that actually most of them are in process and not really getting it. I mean almost I feel that we didn't really clarify what is this really really about? If in a nutshell you had to say, what this is about, I'm not sure that the practitioners at practice level would find that very easy.

4.4.5 Changes in diabetes care more broadly

As well as supporting change in the practices where Year of Care has been introduced, interviewees spoke of wider changes, both in the sites where the programme is active and in general practice as a whole. Three interviewees below describe local and broader changes.

... another success for us is that we've been training the community nurse teams as well So we did like a hybrid training that was half a day, that concentrates on the essence of Year of Care really. And we've rolled that out to I think, well we've completed a list of about 200 nurses ... also they've got the SystmOne, clinical system where they record all their data, so they're recording the goal setting, action planning, in exactly the same place as the practices. And eventually we're going to have a shared model so that the practices share the patient record with the community teams and they'll be able to see each other's goal setting and action planning then ...

... the care package we commissioned across the borough, embedded care planning ... that was informed by the learning from Year of Care. So what we tried to avoid was more of the feed the computer without thinking about the person and so the care planning consultation is this much longer patient centred patient focussed interview with the patient having had the data collected separately and had the time to think about it and the education beforehand. It's difficult to attribute all of that to Year of Care alone, but I think the energy that we got from being appointed a site for Year of Care, helped underpin the drive and thrust diabetes up the commissioning agenda. So it gave it a profile that it wouldn't have otherwise necessarily have had ... I'm not sure that we've got care planning embedded in the hospital. But we certainly do have it embedded in general practice and in the community and a specialist care team in the community ...

... the big successes are that we have developed, codified, described, tested in every possible way, a model for care planning and a complete support package ... And I think ... that we've raised the awareness of self management support within the diabetes community and maybe a bit more widely, an enormous amount and I would expect that to last ... it would be much much harder now for people to talk about diabetes without talking about the need for support, for self management, care

planning, a collaborative approach and that sort of thing. So the basic, the limited ledge that we've got to, is a change in culture.

4.4.6 Wider impact on other long term conditions and healthcare in general

In each of the pilot sites interviewees spoke of the broader impact of Year of Care on the way that healthcare is being planned and/or delivered. Interview excerpts below are from each of the three pilot sites.

I think in some of our younger GPs, definitely get that ... they then take that whole way of working with people, to other areas, which is important as well. Because GPs are not diabetes specialists, they manage a whole generic range of conditions. So now, a lot of our GPs are using it in that way of working to manage other areas ...

I think we've done more than we hoped that we would. I think the patient experience in diabetes has been transformed and diabetes has actually been an example of a paradigm shift in how we do things. ... Well within long term conditions, so it's being extended to other long term conditions like respiratory disease, cardiac disease, urological disease, so it's become how we do things round here for long term conditions. But I think some of the skills will have knock-on effects into short term conditions, acute conditions: how do we frame this problem and what does the patient want to happen?

... the momentum that we've achieved and the cross fertilisation to other strategic programmes - we never envisaged three years ago that we would be designing a model for the delivery of COPD, aligned to what we'd learned from diabetes Year of Care. We never envisaged that we would construct our NHS health check programme to be delivered in a care planning format similar to what we had for diabetes. What we're doing is through some of our other service reviews around dementia then how are the care planning principles embedded in that? We've sponsored local projects into care homes around areas of proactive care planning, ... So in terms of embedding change ... we've now got three strategic programmes that have been delivered by primary care with a care planning ethos. So it is and we never envisaged three years ago that this tiny little project with the five questions at the beginning would have had such an impact.

4.4.7 Little impact on micro-macro commissioning or provider development

Interviewees acknowledged, often with disappointment, that developments in the areas of provider development and micro-macro commissioning had not been achieved. Several reasons were offered but the size of the undertaking of the whole Year of Care project was commonly acknowledged, as was the fact that people now have a greater understanding of these areas. Views from four interviewees are presented below.

I'm anxious that we won't be able to show that much impact around commissioning. I think we will be able to show it around one to one care planning. ... So I'm slightly saddened by that, in all honesty. But, but, there is work going on, I don't know what's going to come out at the end, I just think it's a shame that we weren't able to really wave the flag for this is how it really changed commissioning, when that was part of the original scope for the project.

... we're only doing [Year of Care] in the context of the training, we're not doing it in the context of the whole of Year of Care and that's where it gets a little bit muddy for me. Because the commissioning side, because you can only say you're doing Year of Care, I believe, if you are doing the care planning and the micro to macro ... But

quite frankly nobody has really done the micro to macro properly, therefore you could question whether anybody has done the Year of Care properly ...

I personally think, as a project, that that bit has completely not got off the ground and we haven't done it. ..., we really have not been able to deliver in anything other than a very loose kind of narrative way between groups of practitioners on the micro to macro. ...each locality ... has their own network and those practices meet monthly for multi-disciplinary team meetings. And there definitely is conversation going on about oh, I can't get, I've got a Bengali woman who wants to go swimming but you know we can't get that. So at that level, but that's not going anywhere very powerful at this point ... I would say that that very powerful vision of micro to macro has not been delivered ... I think it was a fairly big chunk to bite off so actually we've learnt a lot about what the barriers to doing it were and I think that in a sense conceptually people are in a place much more when they understand.

It is disappointing that we haven't been able to deliver better on the micro to macro commissioning.. ... clinicians delivering diabetes care, like the idea of Year of Care because it allows them to reflect on their own skills and put the person at the centre of their care. They see the benefit in doing the micro to macro commissioning, but for many of them it's a new concept and it's also different people who are going to be organising that.

The site hosting the project to explore further development of provider development was optimistic that an applicable approach would soon be available.⁶

... we've got a bit to do around micro to macro, because ... we haven't got a systematic IT solution to identify unmet need at the care planning consultation. That's a bit of work that needs to be integrated into the agenda as well. But then also provider development, so if we're really going to achieve a major behaviour change for long term conditions, we need to crack this bit about how do we link people's ongoing management and life style intervention and advice into a more community based programme. And that's the bit that when we finish our provider development project, will actually complement this.

4.5 Summary

While there is no single description of Year of Care used by those closest to the programme, there is broad agreement on some of its defining qualities.

First, its aims are to achieve a respectful relationship between an informed patient and a healthcare professional who is committed to working in partnership with the patient. While this type of relationship is central to the concept of British general practice many practitioners feel it has been pushed aside in favour of a paternalistic model. When the partnership approach is re-established practitioners gain motivation and the Year of Care approach becomes self-reinforcing.

In order to re-establish relationships between practitioners and patients Year of Care has recognised that not only individuals need to be influenced and changed but that systems and culture need to be reshaped. It is in this broader approach that the underlying unifying essence of Year of Care becomes evident, leading people to describe it as an ethos or a philosophy.

⁶ The Foreword to this report provides an updated account of progress on the provider development model.

While the Year of Care approach has a transformational impact for some practitioners and practices, not all practitioners embrace the approach and some who do let it fade. One explanation when Year of Care fails to motivate is that unless applied according to the 'Year of Care method' the approach loses its influence. Yet at the same time it is acknowledged that 'the method' cannot be applied too rigidly, or it will lose its essential qualities of flexibility that allow it to be owned, adapted and adopted in different settings. Finally, descriptions of Year of Care vary in the extent to which they acknowledge provider development and/or micro-macro commissioning as a central component of the concept. For some it is central, others make no mention of it.

Another of the defining features of Year of Care has been its approach to development. At the outset leadership was handed to those in the pilot sites responsible for implementing the programme to interpret the notion and make it reality, with support from the central team. The facilitative approach was initiated by giving the sites five open questions relating to diabetes care, care planning and commissioning for them to address. During the first year representatives of the sites met frequently to share ideas and develop the concept, with ongoing input from the central team. A diagrammatic representation of the programme developed during that time captured the crucial components of Year of Care for those involved and has continued to hold meaning for them.

As the concept took shape pilot sites were also required to make contact with selected practices to prepare them for implementing the programme. Participants from the pilot sites felt unready, not yet able to convey the concept when they themselves were still developing their understanding. During the second and third years experience of working with practices deepened understanding of what the concept was, how it worked, and what was needed to support its introduction and maintenance.

While those close to the Year of Care programme are confident and clear about the care planning component, aspects of the concept relating to provider development and micro-macro commissioning are not, at the time of writing, fully developed.

As the project reaches the end of its three years Year of Care may also be understood by the impacts that are attributed to it. Those involved say that where the Year of Care care planning approach has been implemented patients are offered a more empowering approach to their care, leading to increased participation and engagement in their health. Some practices may have early evidence of improved clinical indicators. The ethos behind Year of Care has spread beyond the original practices and practitioners to influence diabetes care more broadly, other long term conditions, and other aspects of the health service, with its emphasis on a patient-centred approach. Developments in the areas of provider development and micro-macro commissioning are still ongoing and though understanding of these issues has grown, there is no evidence of significant practical change.

5. COMMUNICATING YEAR OF CARE

5.1 Overview

As a complex programme Year of Care illustrates challenges for projects that need to convey the nature and progress of their work while accepting that the iterative and conceptual nature of aspects of the programme limits the extent to which any succinct description will be complete or final.

In this section comments from interviewees are presented relating to six aspects of communication. The first is the way that the programme was communicated to healthcare professionals to engage them in the programme. The second addresses ways that conceptual aspects of the programme have been captured to communicate them to others. Third, the national training programme is described, as the solution found for conveying care planning to practices and professionals. Fourth, the challenge of maintaining integrity of the Year of Care message is explored, along with solutions that the programme has applied. Next, communication with other projects is discussed and finally, comments about ways that Year of Care can be communicated to wider audiences are presented.

5.2 Engaging sites in Year of Care

5.2.1 Challenge for a new project

Comments from interviewees are reported here about the way that Year of Care was conveyed to healthcare professionals to initially engage them in the programme at each of the three successive stages of the project: early development; roll out to other sites; and spread to new areas. Starting as a new concept with no evidence of outcomes, how did Year of Care sell itself to sites and practices in a way that encouraged them to participate?

5.2.2 Engaging initial pilot sites to participate

A member of one pilot site described the initial motivation to become involved with Year of Care. The interviewee was attracted to Year of Care, not because of the specific approach it offered, but because the programme appeared feasible and addressed issues with which the site was struggling

... certainly within the diabetes commission group, we had been having conversations about concern that patients didn't understand their diabetes and weren't supported with it and a lot of concerns about that ... it wasn't that I particularly was sold on the idea of whether care planning could or couldn't do this. But I think what it came along as actually something that looked potentially possible and you know, ticked a lot of the kind of concerns or the boxes that you would say, oh yes, well that's something. These are areas that we're concerned about, I don't know how to move this forward. And then along comes this idea ... and it's like, ah, that looks like it, meshed really quite nicely with a lot of the areas of concern or that we'd been trying to work on but feeling not very successful.

As noted above (4.3.2) having become involved in the programme pilot sites were presented, not with a description of Year of Care, but with five questions to address.

You know it's about how do you embed care planning? How do you commission? What's your population assessment? I can't remember, there was five at the very outset of the project. and we kept coming back to them and we would have to contextualise what we thought it meant, discuss it and then try it and test it. But we kept coming back to them because that was our project brief, so the five key questions that were set each of the base sites, and as a steering group we kept coming back and saying, these are the five things we need to address over the next couple of years as part of the project. What actually do we mean by that? [another of the sites], they've interpreted it in this way, you know, how would that work for us?....

A member of the central team later reflected on the value of this approach.

I think there is a very strong lesson which is, if you really want to change practice, actually you have to get into the areas that need the practice changing. And it's no good just sending them a document, there has to be something there to help that, to inspire that, to encourage it, to engender enthusiasm, to actually make that change, because change is really hard.

Emerging from this level of engagement came the models that represented the shared understanding of those involved in the project during the development phase.

The house, the windmill, all of the stick man diagram, the commissioning triangle, all of the illustrations that's come out of the project, has come out of the combined learning, questioning reflection, through the learning events and through feedback from the local sites into the project team. So from the project it worked well, so it served a really good purpose and people's clarity of thinking, so we came up with a model and then that was the message ...

In response to a question about whether the models emerged from the central team or the sites, this interviewee emphasised the shared way in which the concepts were developed and the effectiveness of the approach.

... you got kind of like devolved autonomy, it was a bit of a laboratory, we fed it back in, we clarified the messages and then the messages came back out again and we were all on message to what the key thinking was around the key concepts around commissioning, training, you know, all of those other things ... And I think then the learning events was kind of capturing all of that back up again, crystallising people's thoughts and then the redistribution of those key messages ... I think it's a really interesting model and I think we've learned loads from that approach.

5.2.3 Engagement during implementation phase

Having grasped and developed some of the models for Year of Care, sites then went on to introduce selected practices to the programme.

An interviewee described the disillusionment created in one site where practices were offered incentives to participate and introduced to Year of Care with a half-day training session but no further training or support was offered until much later. Those initially most enthused felt cheated by lack of support.

... it took a while for the national training to develop and because we were rolling out, or trying to roll out care planning quite early from here, and waited for training for a

long time and that is why a lot of the practices disengaged with Year of Care or care planning. So our incentive scheme, we certainly got a lot of angry practices who came on board really early on, through the scheme and then got fed up of waiting for trainers, so went off and did what they thought, which didn't include everything, or just abandoned it ... they ran a lot of half day awareness sessions early on for practices, linked to the scheme again. And some of them did do a lot of great work and they formulated letters and leaflets and stuff and then because not anything much happened, they disengaged and they came a bit angry really, so they've been difficult to get back on form. It's only a few of them but they're the key ones probably. Anyway, having the training ready to roll out, is key and ... and having some kind of evaluation as well, so practices can evaluate how they're getting on and are they really doing it, and some kind of mentorship or support for the practices in implementing this.

The situation was similar in other sites with those introducing the programme feeling under-prepared.

... it was a shaky start. So I think something around more opportunity to kind of share understanding kind of where people are starting from on the ground, would have been helpful.

This interviewee believed that a different style of introduction to Year of Care during the implementation phase could have been more productive than the one used. The following excerpt contrasts the situation at site-level, where Year of Care readily chimed because it appealed to a need previously identified in the PCT, with the situation in general practices where some of the skills that the programme offered were ones with which practitioners were already familiar. If, instead of promoting Year of Care on the basis of its novelty, practices had been asked to identify ways that the programme matched and made use of their current skills and approaches the interviewee suggests they may have been more ready to engage.

... we didn't spend time understanding kind of where people started from. So I'm saying that at PCT level ... we sort of already spent time worrying about the gaps and understanding what we needed to change and in fact we were in the middle of a gap analysis I think, when we got told that we'd been shortlisted. But that hadn't really happened at practice level ... But actually within general practice, there's a lot more experience around motivational interviewing, consultation skills. And so some of the stuff that was coming new and exciting to them, was actually stuff that I think kind of was already in practice and having it presented as something new and different, was actually unhelpful ... again that was a missed opportunity where perhaps if we'd been able to say to people ... there was some conversation about the ways the care planning consultation echoed the normal consultation if you like. But I think that we didn't then have that conversation down in practices very much. So I think that there was some sense of 'this is completely different', but actually it isn't really, and I think a lot of practitioners in primary care have actually had quite a lot of training around some related skills and I think that we perhaps by badging it as something so new and different, in a sense almost kind of cut people off from some of our resource ... Something around an understanding of you know, actually helping practices to look at themselves ... But actually we didn't really get people to think about what kind of skills and resources they had which resonated with this.

Reiterating this point the interviewee highlighted the importance, for engagement, of an organisation understanding and believing that a new approach will meet their needs or address an identified problem, and the sensitivity needed to do this well, by first getting to know what skills and approaches practices already have and use.

... for them to understand the resonances and also for them to understand the ways in which, because what drew us in at PCT level was that sense of, we can see we've got all these problems and difficulties. We don't really know how to go forwards, but this sounds like a really good idea and we could see that if it works, it's going to sort out a whole range of things that we're struggling with. Hence the energy that is worth putting in. And I think the same is true at practice level, you know, where I think that people, and I think that we only had one practice, a high flyer practice, who sort of more or less said, well I don't need to do that, because I'm doing my own thing and much better already, sort of thing. But even with him, I think that actually, there are elements of the Year of Care process that he does do and there are elements that he doesn't do. But I think if he'd felt less kind of imposed on, I think actually there could have been perhaps more interesting conversations with him around, ok, so this bit works for you, so tell us about this bit. What's happening here?

5.2.4 Engagement during roll out and spread to other sites

Following the early implementation phase each pilot site has continued to roll out the programme to other practices in their area, building on their experience, as described in 5.4 below. Engagement and uptake in each of the sites has been encouraged with the introduction of financial incentives. As the following interviewee says the incentive scheme has played a large part in promoting uptake among practices that might not otherwise have engaged.

Well I suppose the key success was that we've managed to take it from being a pilot to implementing and we have got like 80% of practices through some training. Now how well they're all implementing, we're not sure yet but we know that a lot of them are and as they're doing the incentive scheme data we will be able to see that, but it's going to be a while before we can really evaluate it ... Without the scheme I think we wouldn't have been successful, we'd have only engaged with those practices who were very keen on diabetes care. So the scheme has made a big difference. And the training has made a big difference.

During the second and third years of the programme Year of Care has also been promoted to and requested by areas beyond the initial pilot sites. Some areas are enthusiastic to adopt Year of Care even before evaluation results are available.

I mean I suppose the main differences now from my point of view are that we're beyond the pilot sites. So within the pilot sites they've rolled out and beyond the pilot sites there are new sites who are coming on board and are at various places down the process and that's I suppose the achievement. I mean I suppose that's been ahead of some of the evaluation, but people have enough faith in this and have seen how it seems to work ... to want to kind of go on with it really. So I think, you know, that's the major success for me, is that it's starting to roll out.

Introducing new practices to the programme has become easier over time, partly because of greater familiarity with the concept, but also with experience of implementation the programme is easier to describe through practical examples.

I'm sure it's easier for people coming to it now. I think if nothing else, because we can go and tell a clinical story ... We can go and tell a story that's kind of this is what happened when we did this ... or this is what happened to this patient, those kind of stories of experience I think work very well, on the whole ... Whereas the kind of much more kind of you know, and the research says that, you know, supportive self management, that just doesn't really work I think for us clinicians. We're used to stories and I think the problem is that there weren't any stories when we started.

Nevertheless, as another interviewee said, other practices and sites are waiting to see evaluative evidence before being persuaded to adopt Year of Care.

... maybe with all the evaluation that's gathered, that will help, because we've implemented it without any evaluation really. And a lot of people ask, where's the evidence? What are the cost reductions? And they want to know those things before they take something like this on.

5.2.5 Addressing staff turnover: engaging staff who join the programme later

Any programme of significant size and duration will experience staff turnover. Providing adequate support quickly enough to help new staff engage with the programme is crucial, and the more complex the programme the more demanding the requirement that they grasp the concept and its implications accurately. In each of the three sites the project manager's position was refilled during the course of the three years.

Each spoke of the challenges.

... you have to be in on the inception to have that excitement, you know, when a project first kicks off and you're involved in it from the beginning, you're in a different place. As soon as you come and take it over from somebody else that's done it, you've lost the momentum ... And the momentum was lost and there was other people that had left ...

Project managers spoke of the value of learning about Year of Care from people in the central team. Not only did they dedicate time to helping the new staff member learn about the programme, their knowledge and understanding of Year of Care was accurate and wide-reaching.

I was completely new to this project and obviously you've got to get your head round it, and I think for me personally, for me being able to move forward in the post, was [someone from the central team] who came and spent some time with me and was there at the end of an email or to phone. So I think it was actually having that support from somebody at the centre, in the central team, I think that's really helped ... obviously people [working in the local site] have other work to do, so I think it was having that person who'd been there and also worked with the other two sites as well.

I think probably working closely with [two people from the central team] has really helped me and they did come down and helped quite a lot. And that's how the messages have got conveyed I think, and their understanding what's happening in [the local area] and them understanding what Year of Care model is, probably has been evolved through that close working.

Project managers also benefitted from communicating with each other.

... as well for me, at the time one of the other sites had a fulltime project manager. ... from what she said, although she'd been in post longer, she felt it helpful that ... we communicated fairly regularly as well.

5.3 Capturing the concept

5.3.1 The need for 'hooks'

As a complex programme Year of Care demonstrates not only the difficulty of conveying a concept to those not familiar with it, but also the challenge of how to sustain the essence of the concept over time. While more mechanistic programmes can be locked into place with tangible materials or measurable behaviours, an ethos change is by nature more ephemeral and less readily monitored or maintained.

Those involved with Year of Care are aware of this challenge and during interviews references were occasionally made to 'hooks' that help lock Year of Care into place. Six approaches are described here: diagrammatic representations of the concept; real-life examples of the model in practice; systematic procedures; assigning responsibility to a designated position; a training programme that embodies the approach; and badging.

5.3.2 Diagrammatic representation of the concept

Development of the 'house' and other visual interpretations of aspects of Year of Care has already been described (4.3.2). These diagrams, and the 'house' in particular, proved useful not only as tools for conveying the concept to others, but also as a means of capturing the ethos of Year of Care so that those involved could come back to re-examine their current approach to implementation and match it against their original portrayal of the programme.

... having a description of things that were I suppose quite high level concept, so the conceptualisation of the project around the house. Throughout the project we kept coming back, when we got into difficulty, we'd go back to the diagram and that would help keep us kind of grounded in what we were trying to do and so that we then started to say, ah, we've run into a problem with the clinician knowledge or this is a problem that is about the foundation of the commissioning process, or this is part of the roof that's missing. So we could then agree as a team, where the problem was, because it is a complex system, we could then start to decide and what do we need to do about it, so if it's a missing roof tile that is a procurement issue. If it's a problem with the foundations, then we need to go and talk to the commissioners and maybe find some money or write a service specification. If it's the clinicians, then it's the care planning training and we need more time and more facilitation. And if it's the patient, then we need community engagement. So all of that helped us frame what we were doing.

The evident attachment interviewees demonstrated for the 'house' model raised questions about the extent to which the diagram held meaning for those who had not been part of its development.

Q: I was wondering if part of the value of a conceptual tool is that you've had input into it.

... the facilitation and the adoption and the ownership definitely was important ... It's a risk, because you say here's a project initiation document and chapter one is a conceptual model that you haven't been part of developing, you might say, well, that's a load of management clap-trap, I'm not going to believe it.

Another interviewee acknowledged the added value of conceptual tools for those who developed them, but observed that nevertheless, the 'house' model effectively encapsulates the Year of Care for people new to the programme when it is explained by people involved in the programme.

My view is always that it matters that people are part of creating it, would be my guess. I think if you create an analogy and it works for you, I think you're part of the thinking ... but I suppose the issue is that people who were involved in the project had the opportunity to navel gaze and had the time out to do that and spend hours doing it. You couldn't really afford for each practice, each person that we train to go through that process again ... but I suppose all I can reflect on is that people working in the NHS get the idea of it. I guess that's partly by how it's explained to people. I don't suppose they feel as passionately about it as we do, the trainers get it and the team who are responsible for rolling this out in their site get it. They need to get it because if they don't, they're not going to be able to make it work, given that the house is at the heart of it all. Thinking about the meaning of this for other areas, any other future project, the point is you can't expect that same level of input and devotion after the first round really. So as long as you've got a workable concept, then that's what you can go with.

5.3.3 Real-life stories and examples

So I think there were bits that they showed well, but I actually don't know that anybody at that stage really, and even now, I'm not sure any single person could really deliver that. Because I think it's such a complicated model, in a sense you need to hear far more stories around the process, because I think there are so many perspectives. I mean that's one of its fantastic strengths is that it does talk about this process from a whole range of perspectives. So almost I think, as a testament to the complexity of the model, I'm not sure that any individual person or only an individual person perhaps telling a number of different stories, could really do justice to it.

In the excerpt above an interviewee described the experience of hearing the Year of Care concept described at the very beginning of the programme. At that stage there were no real-life examples of Year of Care operating anywhere in England, but more recently, as noted (5.2.4) stories capture and convey the concept. DVDs are another valuable tool.

... and I suppose one of the big successes has been that we're using DVDs of consultations now, so people can actually see what care planning looks like. So they know ... what they're trying to achieve in their own heads. Because if people can see it being done, I think that's the only sure fire way of people understanding what it's about.

5.3.4 Systematic procedures

While Year of Care is essentially about a change of attitude, there are some tangible practices that support and encapsulate that change. A central component is sending patients letters with their results prior to their appointment. As one interviewee said, this practical behavioural tool has the potential to act as a 'hook', prompting then locking in a whole organisational change.

The letters are going out and the odd thing is that that is enormously powerful practical thing, it's not just about consultation skills. You completely, they have to completely reorganise their practice, they then send the letters out, quite a lot of the sites have put in special clinics and groups, so people can understand them. Then people come back and they talk in different ways. And I absolutely know that that's transformational really. And it's brilliant because it's transformational, based on a practical thing, not on an attitude change, which is a lucky hook, for my point of view, because I don't think it would have worked otherwise.

IT systems and templates have this same capacity to lock change into place.

5.3.5 Responsibility assigned to a designated position

During the development phase Year of Care pilot sites were assigned funding for one year only. In each site much of the money was spent employing a project officer. As well as conducting essential functions, the project manager's position played a valuable role in highlighting Year of Care as a reality, or, as the following interviewee said, giving it profile.

Yes, through that engagement, that team working, pulling the teams together, coordinating things. I mean that's the most time consuming thing in health, is actually leading and coordinating other people to do things. At the local level. Therefore having a role, also gave it profile.

5.3.6 Training programme that embodies the approach

During the third year of the programme a national Year of Care care planning training programme has been operational, which conveys and codifies the care planning approach. Section 5.4 discusses the national training in more detail. As the following interviewee said, training can convey meaning and support change in a way that written documents cannot.

... that just giving people a policy document doesn't change anything, just giving people a list of things, doesn't really change anything, but maybe training does, because it's about people and it's real, it builds that confidence to enable them, one to be confident to do it, but also to carry on doing things.

Another person spoke of the power of the training to embody the programme and establish a sense of concreteness, something that can be described and to which people can relate.

... then the training programme, and we've now got thirty trainers and there will be forty five by the end of January ... they have been through formal training Year of Care ... and the programme in a sense, builds up camaraderie and brand loyalty for these people and so all the time I think, we're building up that this is an entity, it's Year of Care, this is what it is, we can describe it, it's codified, here it is.

As well as conveying the concept of the Year of Care approach to new audiences, the training programme has played a role for those already familiar with the concept, by helping to crystallise the approach for them.

There was education and learning through the care planning training ... but I think that that has helped to crystallise in people's mind, what this is and what the shift is.

5.3.7 Badging

While the aim for Year of Care is that it should become embedded into standard practice, some interviewees pointed out that this should not happen so fast that the approach loses its identity. When promoting a culture shift it is not realistic to lose touch too soon with the emblem that signifies the essence of the shift. In the following interview excerpt from a site that aims to integrate the Year of Care approach into other long term conditions, the need to hold on to the Year of Care badge is emphasised to avoid losing touch with the qualities that the programme represents.

... a lot of our GPs are using [Year of Care] in that way of working to manage other areas, so that's good ... started to get embedded for change, but I think it needs a hook and that's why we have to keep hooking it onto Year of Care at the moment.

And we do need to keep reinforcing it, because it is, you know, it is quite a big difficult step ... So it is a huge cultural change ... I think it still needs Year of Care as the sort of driver. So we are still undertaking Year of Care training, Year of Care development, Year of Care this, and that is helping us embed it constantly. It's a bit as I spoke about before, it's this constant cycle of use Year of Care to get people back on all the time.

5.4 National training programme

5.4.1 Challenge at outset of limited practical experience of implementation

As noted above the national training programme is now the main means of communicating the Year of Care approach to care planning. It is a commonly shared view that Year of Care suffered in the first year of implementation from not having a well developed training programme with which to introduce practices to the programme.

... some of the early practices who engaged with this, and again they're the ones who value the diabetes care, want to improve, went off and kind of tried to implement Year of Care without any training, with very little information, right at the beginning of the project and when we talked to those practices, they saw the care planning partnership side of it and they saw the goal setting action planning side of it, but they didn't completely buy into the whole concept and certainly haven't been sending results out to patients either ...

Nevertheless, as most interviewees agreed, time and experience of trialing the programme was the only way that enough knowledge and understanding could be gained to develop a meaningful and effective approach to training.

... [not] having the training ready, which we couldn't have done anyway because it's been a learning experience, so it's not really a failing, it's evolved, the training hasn't it, over the pilots.

5.4.2 Training programme based on experience

During the second year the project accessed additional funding to develop a national training programme for care planning.

... in the second year ... we got money for the national training group, which is one of the massive successes ... they gradually learnt all about this and began to train and it was like they were other troops going out to see what happens when you go out to new people, what helps to train better or not. And so in parallel, we were both getting experience and gradually ... the training initiative has become bigger and bigger ... for instance, it turned out that if you just went to train in a place that hadn't thought this through and didn't know what they were doing, they sent the wrong people on the training. So that they developed something that explained who should come on the training. Then it turned out that even though you gave that instructions to people, if they didn't have a service organised to be able to identify these people in these roles ... still the right people didn't come, they didn't know what they were meant to be doing and afterwards there was no structure to support them. So we then put in, ... we ended up with the ... steps to the Year of Care! Which was the steps that you were most probably advised to go through to get this whole thing into place. At the beginning the steps were mainly about the work that needed to be done locally, before training, and the steps at the end were about how to identify people who had the skills to do this and could become trainers. And so as we moved from the second to the third year, they began to put in a training the trainers programme.

With experience gained during development of the training programme Year of Care now has a codified approach for introducing, assessing, educating and training new sites to deliver the Year of Care approach to care planning.

Building on experience, the programme is selective about sites where they will deliver training, insisting that a site must fulfil certain requirements before being ready to participate⁷.

I think a lot of the success of the training is about how we've rolled it out, which is to insist that it's only going to be delivered in areas that have got their act together. And that's actually very difficult because it puts us in a position whereby it takes a long time for a site to be ready for training. But if they're not ready for training, the chances are we go down there, we do the training and then actually nothing really changes in practice.

5.4.3 Attitude-based focus

A key distinguishing feature about the Year of Care training, in keeping with its conceptual nature, is that it addresses attitudes, as well as facts and structures.

I suppose the thing that's different about our training is that it does focus on clinicians' attitudes, because if you don't kind of change those a bit, you're not going to get anything to happen, you're not going to change the culture. It also looks at kind of the organisational aspects that you need to put in place to allow the care planning consultation to be embedded in the care. And I think that some lessons in all of that, if you don't get the training right, and it's not good enough quality, you can't really be sure, or sure as you can, that what's then delivered in the practices, is actually what is care planning. And I suppose one of the lessons for the whole project is that people aren't sure what care planning is. When we go to new sites and they still think it's pieces of paper and plans made by health care professionals for people with diabetes. And I think it's not until people actually have the training, that they kind of get what its all about.

Another defining point about the training is the fact that it is delivered only by people practically engaged with Year of Care themselves, usually clinicians. In this way the message and attitudes are conveyed by people who are committed to the approach, with practical experience of the challenges and benefits.

I think the training is successful because of the way that it kind of works as an integrated part of the project ... So I think that's one of the successes, is that it's by people who are actually doing it.

5.4.4 Training for the whole team

One final point about the training is the recognition that staff beyond those who will be delivering care planning need to be introduced to Year of Care.

... one of the other things about ownership is very interesting hearing from the practices ... even where somebody in the practice took on the lead role and was even possibly wanting to champion it quite actively, that they had enormous difficulty getting the practice team to understand it or show any interest in it ... we needed to train or somehow get this message out to the whole practice team. Whereas we just

⁷ Specific points learnt from the training programme about factors that enable new sites to adopt Year of Care are discussed in Section 6.

trained the people who were going to be doing care planning, to start with ... anyone who impinges on the process tangentially, so that's pretty much all the GPs and many of the, depending on how you do your call and re-call, many of the reception team, have to understand what's going on here. So even if it's just an hour's explanation ... pretty much everybody has to understand something about this, because people will then see that person who's had the care planning and unless they kind of pick up and reinforce that model, it slides back into something paternalistic and doctor centred again ... so there is something about actually being very clear about who is this change going to impact on?

5.5 Maintaining integrity of the Year of Care message

5.5.1 Challenge of approach being 'tarnished' by distorted or incomplete application

The Year of Care approach has ready appeal for many health practitioners and, from the outset, practices and practitioners have expressed interest in the programme and been pleased to claim that they are using the approach. Early in the life of the programme, when the essential qualities of Year of Care were clear to those developing it but, because of its changing and conceptual nature, open to mis-interpretation by those external to the programme, this posed a potential threat to the way Year of Care was perceived. As one interviewee said, the risk of Year of Care becoming associated with incomplete or inaccurate applications of the programme raised questions about whether and how the programme should restrict and control use of the approach it was advocating.

... we got very worried in the second year that Year of Care would get tarnished by this problem. And that created more tensions about how control freak-y could we be about what it was and what it wasn't.

5.5.2 Introduction to Year of Care given only by central team members

By the third year the programme had clarified and codified the Year of Care approach to care planning through the training programme. Along with increased clarity an approach has been developed to minimise 'dilution' of the message and/or 'Chinese whispers'. When the message about Year of Care is being delivered to potential training sites for the first time, as an introductory session, the message is always delivered by members of the central team.

We've tried to take the risk of Chinese whispers out as much as possible by things like, we [the central team] deliver the tasters so that there's, it's pretty clear what we're looking at, from an early point.

Similarly, once sites are recognised as ready to receive training, the first training session is delivered by members of the central team.

We deliver the first lot of training on site, so that it's important that the people who are going to be trained, see it being done as it's meant to be and that there isn't any dilution there.

Another interviewee expressed a wish that the Year of Care approach could always and only be introduced by members of the central team.

... the training has put a bit of a stamp on it. It's still roll-able over because anybody can still call themselves Year of Care and use the logo and everything, so there's still some vulnerability there ... one of the ways of doing it would be to have key people

who give, key front people, who give the same messages out all of the time, where they are, so that that message is not diluted. You can't help it getting diluted once it gets past them, but if you have key front people having a consistent message and then working closely with other organisations, the chances of it getting diluted lots are less ... yes actually we have [that approach currently], but we have kind of touched on other people maybe giving the messages, people not in the central team, and I don't know if that worked as well.

The value of people from the central team introducing new staff to the programme has already been mentioned (5.2.5).

5.5.3 Quality assurance for Year of Care trainers

Part of the codified approach for developing new Year of Care sites included a well-developed approach for training new local trainers.

... to become a trainer it is a national training, you do the one and a half days training [which introduces Year of Care to clinicians] ... it's one full day and then you go away and reflect and come back about six weeks later for half a day and really feed back what you've done since then ... discussed it in the practice team, actually implemented it in your practice ... There are then three days intense training sort of induction training – 'train the trainers' it's called ... there's usually three members [of the national team leading the] training ... You then deliver the one and a half days, one day and then six weeks later the half day, to local healthcare professionals and somebody from the national key team comes and assesses the competencies ... you're assessed and you've got feedback ... then you do another one and a half days to different participants, again one full day, half day six weeks later, and you're quality assured by that same person who did the peer support. ... And then if you do actually get through, if you achieve the competencies then obviously you qualify to be a trainer.

The thoroughness of the training approach with high levels of contact with the national team and final assessment maximises the chances of trainers repeating the message with high levels of integrity.

5.5.4 Central protected resources

Year of Care currently has resource materials available online to be used by people who have successfully completed the Year of Care training programme. As the following two interviewees described, they are not intended to be used by people who have not received the training, and they are not intended to be altered in any way.

... we now say that they've had the Year of Care approach to care planning, and in fact we're putting a little Year of Care © symbol on all our materials and getting very heavy about this, partly because the word has been misused in different places ... you cannot take our resources now, they're out on the web ... but usually people say, this is a Year of Care resource. But we would be really worried that they will be used in training [by people other than Year of Care trainers]. They're not allowed to use our resources in training, in case they're used the wrong way. And I would occasionally ring up somebody ... and make that quite clear to them.

We're currently trying to set up a sort of a share point site for administrators which will be password protected, for new sites to access the documents. Now what they have been told is that if they alter anything they should take the Year of Care logo off it. Because it's possible that people might want to alter things because a local target

has been a little bit different, that sort of thing ... We wouldn't glibly share our resources with somebody just because they said could we have that? For me it's a package, you don't get one bit without the other ... the last thing we want to do is produce a resource, somebody gets a hold of it, they change it, they change the words and in changing the words, they change the philosophy of it and that's not Year of Care ...

5.5.5 Support for trainers over time

In response to a question about whether or how trainers could be monitored to ensure that their approach remained close to the original message over time, an interviewee from the central team expressed the view that ideally ongoing maintenance would be best provided through mutual support at centrally organised collaborative learning events.

I don't think personally ... that I would go down the route of quality assuring people to the nth degree, I think you'd have to trust them to a point. But ... people who are trainers are now saying, they'd quite value the opportunity of having learning sets ... So I think it would be decided to have some kind of collaborative event, how that would happen, I don't know, that requires money and funding and organisation. So there's a desire from trainers already that they'd like to meet up and share and problem solve ...

5.6 Communication to wider audiences

5.6.1 Communicating Year of Care to health decision makers

I think it has been a very successful programme PR wise, in terms of tentacles into different bits of the policy world, into different parts of the healthcare system, particularly nationally. For a long time it had very high profile, I think it dipped for a while and it's starting to come up again.

I think we have managed, even if it's just in pockets, to get Year of Care and the patient centred approach on the national agenda. So it's there, even if it's just a little seed or whatever, that's good.

At both national and local levels Year of Care's success at maintaining a profile was attributed to the programme leaders' ability to frame then re-frame the programme as necessary to retain interest by aligning it with priority topics or policies.

... my biggest learning around all of this, is that the leadership who were involved, whoever that might be, actually spent their whole time aligning things ... aligning things to policies, aligning things to local changes, aligning things to get the system, so that the core of Year of Care carried on, but that it became aligned to whatever was going on in the system.

This approach is modelled in excerpts from two interviewees below.

... when the PCTs were going through the assessment process for world class commissioning ... So there was a whole competency framework that was developed and what we did ... was map the elements of the project according to a world class commissioning competency framework. So, have we met all of these needs, which fitted with the political environment at the time. And I guess now, because everything has to be integrated into the QUIPP programme ... what we're doing is looking at the elements of this project that clearly needs to fit into QUIPP whether it's from quality

or productivity perspective. So I think some of the learning is that the people who have been leading the local pilot sites have had to adapt and change and look at where we integrate this project, the context of this project, into what it means for our local economy ... And I think it's just about having that strategic vision to see where it actually fits in the context ... it's equally applicable in terms of the agenda for long term conditions, and it's just about where we fit it in and where we have it on the agenda going forward.

... so I would say that that leader aligned [the care planning training] to be able to get more and more sites aware of Year of Care and sort of start running it out by the back door, to a certain extent. That to me is seeing an opportunity, aligning what it is going on around it, to actually get that opportunity up and running without actually worrying too much about the nuts and bolts and details, which is great leadership. However when you're having to manage that, it's very difficult. We're now seeing it again with the new government coming in. We're now shifting it slightly to say actually this is about 'nothing about you without you', so re-shaping the policy contents to keep the consistency of the programme going. So it's about having somebody who has wherewithal enough and is bright enough, to actually be able to make those shifts without really changing too much, what's going on in the programme. And I admire that ... I think the challenge is bringing everyone else with them, at the same time, so they can get their heads around it and work out exactly what's going on. And that's quite difficult for people who work in different contexts and different environments and have a different perspective

As the interviewee above pointed out, while reframing the approach is important for keeping the programme on national and local agendas it brings challenges, partly in communication, with a risk that not everyone stays abreast of the shift, but also at an operational level where re-framing may have practical implications.

Maintaining the interest of health decision makers also relies on ongoing relationships with people in specific positions. Personnel and policy changes require a readiness to rebuild relationships as the situation shifts.

I think that there was a significant gap actually when there was a change at the department of health, when the link between the Department of Health became weaker. And I think that we've had to spend some time picking up the profile ... there's different politics, different methods of engagement and different amounts of buy-in as well. So I think that makes it challenging.

5.6.2 Communication with patients

During the programme's three years mixed views have been expressed about the extent to which Year of Care should promote itself to people with diabetes in general practices beyond those where it is already operational.

Some interviewees believed that communication with patients would be a constructive way of advancing Year of Care: once patients understood care planning and self management as their right they could demand it from practitioners.

I think we could have done more to raise the profile of Year of Care with patients ... I don't think that every diabetic person in the country knows about Year of Care and is demanding care plans and wants to self care and self manage. And I think a lot of them probably don't know what it's about. To me, maybe we should have, or maybe now, we should be really marketing it in that way as, 'this is your right, this is what you're entitled to, this is what you should embrace', in a way that really turns people

on. And I don't know how you do that, but that's something ... So people need to think differently. So I think that's a not so much failure, maybe a next step.

Another interviewee recalled the Year of Care board debating whether to promote the programme to patients. The case against was that it would not be available to all patients and that raising expectations risked being damaging.

And actually, a year ago, this was a conversation that a few people on the board had had, which was about, how do we do this, how do we promote this to people with diabetes, how do we engage? And there was a real debate, there was a tension around whether we should do that, because what would it be up to us to promote? Not everyone would get care planning, therefore what role have we got to actually promote it? How do we do that awareness raising out of the context of a pilot site where they're running it? And my perspective is, that we didn't, we just left it. Other people may feel as though we did a little bit here and there, but I think we just didn't deal with that.

The debate was not resolved and no significant patient awareness-raising beyond sites where Year of Care operates has taken place.

5.6.3 Communication with other related projects

Concurrent with Year of Care the Co-creating Health initiative has also been active. Interviewees spoke of a relationship between the two projects that felt more competitive than communicative.

Also an added challenge was the fact that there were two projects going along in parallel and some of the time we felt they might almost be in opposition rather than in synergy. So that was the Health Foundation, Co-creating Health and Year of Care and at one time it felt as if they were in competition really as to which - we're the best one, no we're the best one - rather than do you know what, there's learning from both that could be complementary. So I think we've got to the latter phase now, which is more constructive.

One Year of Care site is also a site for Co-Creating Health. As the following interviewee described, in recent months a collaborative approach to determining how the two projects fit together has been achieved. Until this time both projects appear to have felt too protective of their work to be able to communicate.

And I suppose the other thing is the Co-creating Health pilot ... so we've now started talking to each other more and again the pilots run very separately and they're all offering training and they were getting GPs to go on training around goal setting, yet we were getting GPs to go on training about goal setting, so the two needed to speak to each other and coordinate who they were aiming their pilot at. And we've only just done that, very recently and the people from Co-creating Health, the trainers, have come in and sat on Year of Care training and I went and sat on some Co-creating Health training and all kind of worked out where we feel then, the training fits... we have got there but again it's only very recently, so perhaps we could have been doing it earlier on, but there were barriers or whatever, each pilot was very protective ...

The same site is also hosting the IT SystemOne pilot, which is of significant interest to Year of Care for its application in the micro-macro aspect of the programme. Yet, despite the relevance, in a similar way the two projects have only recently begun to communicate.

... here we've been very lucky because we were already a pilot for the IT side anyway, so we've kind of brought those two projects together here ... And the two pilots haven't really talked much until this last year ... the Year of Care, we started talking to SystmOne probably when I picked this work up, but prior to that they were very separate, so the SystmOne pilot was piloting templates for care planning, but never talked to Year of Care, so the terminology they used, the way that the care planning bits recorded, didn't fit quite with Year of Care and it would have been a lot better if they'd have talked with each other ...

5.6.4 Communication with the wider public

Several interviewees spoke of the need to communicate Year of Care more widely. The following interviewee believed that the programme could have been building awareness and sharing progress beyond the pilot sites during the course of its three years.

I don't think we've got enough output around Year of Care over the last three years, around what is actually happening in the sites. I think we've done very well in sharing across the sites. We've been a little bit protective for various reasons around what we put out there into the big wide world around the learning ... in terms of making more information available on the website, it could have been previous evaluation reports that haven't really seen the light of the day for various reasons. It could have been actually having sharing events where people not doing Year of Care could come along. Sometimes I think that it feels a little bit like a club, rather than being there to really promote it and say what we're doing, not as a 'we're best', but this is what we're learning. And we didn't do that very much.

Nevertheless, the same interviewee acknowledged that at the start of the project Year of Care did communicate more widely, but was unable to cope with the interest the communication stimulated.

... we did start doing that and we did have a Year of Care network with lots of communications, lots of contacts, with newsletters and things like that, so I think it's happened to a certain extent, however in a way it was shutdown after a while, simply because we were getting a lot of people saying, we want to do it here. And we couldn't cope with it, the number of people actually involved in holding hands to be able to disseminate it and do it 'right', in inverted commas, whatever right means, just meant it was very difficult to do that ... That makes it very challenging in terms of how do you promote it when you can't actually get or synthesise all the messages tight enough ...

Other interviewees, considering ways of communicating to wider audiences at the end of the project, emphasised the importance of finding relevant approaches and frameworks within which to package the message.

I think we have learnt about embedding change, well certainly I have. But we are continuing to learn that all of the time, and I think that we've got to think about a way of sharing that and I know when the final report will share that, but in terms of sharing it practically as well and having a bit of a voice around it.

Actually it will demonstrate savings, but that's the sort of world we live in now, is really not only having your clinical effectiveness outcome, but your cost effective outcome. And marrying the two together and having the people who've got the analytical skills to understand that. So one of the things we really need to improve upon is, the ability to demonstrate through analysis, the benefits both clinically and

cost effectively, to the system ... And [knowing] what other people need to hear, is important.

5.7 Summary

Responses from participants throw light on the changing ways that potential participants are effectively attracted to engage in a project, as the project develops over time.

At the outset, before Year of Care was fully developed, initial participants did not need to fully understand the approach that the programme offered; the information that attracted them was an indication of the needs it met and the challenges it addressed. At this stage in the programme participants became engaged by responding to an invitation to explore and develop what the approach meant for them and how it might work in practice, rather than being presented with a prescribed programme. This exploration was conducted within and between sites, with designated time for collaboration, facilitation and support from the central team.

As the approach developed initial participants were required to introduce Year of Care to practices. This being the first stage of implementation there was no experience on which to draw and no established resources. The initial participants felt insecure in their understanding of the programme and this, combined with lack of resources led to disillusionment and disengagement in some of the early practices where it was introduced. On reflection, a more productive approach to introducing the programme could have been to replicate more of the approach that worked for the first participants, working with individual practices to identify needs and skills and indicate ways that the programme could meet their needs and build on their skills. More time to allow initial participants to develop confidence in their understanding of the approach could have been valuable at this stage. Although experience was necessary to develop fully appropriate training and resources, more time could have allowed early stage prototypes to be developed.

As the programme was adopted in more practices, supported partly by financial incentive schemes, it attracted sites that wanted to adopt it themselves, while others expect to see evidence before engaging with Year of Care. Stories effectively convey the approach and impact of the programme; these are inevitably not available until some time after implementation has started.

As the project continues staff turnover risks loss of organisational memory and diminished understanding of the programme. Contact with and guidance from people in the central team who are steeped in understanding and experience of the programme is invaluable for maintaining integrity of the message.

As a programme that incorporates conceptual components, Year of Care risks having its message lost over time. The programme demonstrates six approaches for capturing the conceptual aspect of Year of Care: developing diagrammatic representations; telling stories; introducing procedures that lock the changes in place; a training programme that embodies the conceptual shift; appointing a position that gives the programme profile; and badging the approach, even while working to integrate it, highlighting it in people's consciousness.

The training programme that introduces new practices to care planning has developed over time and is built on experience. Those delivering it are confident that they can convey the message and its underlying culture change, but also that they can diagnose when a site is ready to adopt it and when not. They have codified the training into a series of steps that include training new local trainers. Rather than just provide information the training aims to bring about an attitude change among those who participate. Over time it has been

recognised that all involved in the practice team need to be aware of the Year of Care approach, not just those being trained to deliver it.

As an attractive programme Year of Care has risked its image being tainted by association with practices and practitioners who claim to be applying a Year of Care approach, but who are in fact not doing so thoroughly. This apart, over time and as new people join the programme there is always a risk of a message deviating from the original. Approaches to reduce this risk include only people from the central team introducing Year of Care to new sites; badging Year of Care materials; and the quality assured training programme.

Year of Care has maintained good communication with health policy makers, largely due to the skill of programme leaders at central and local levels to frame the programme in the light of current agendas. This sometimes requires re-framing, to keep abreast of new agendas, especially in the current political context. Though necessary, these changes can create challenges for people implementing the programme.

The programme has not engaged in communication with people with diabetes beyond the pilot sites. Some of those engaged in the programme believe this would have been productive, raising awareness and bringing added demand to practitioners to engage in the approach Year of Care proposes. Others were afraid of raising false expectations.

Until very recently little communication has taken place between Year of Care and other related projects. While recognising the value of communication, it appears to illustrate the cautious, protective approach that develops during the early stages of pilot projects. This study offers no suggestions on how to address this.

Finally, Year of Care will need to consider ways of communicating its findings with the wider public. At an earlier stage broader communication was conducted, but the programme was unable to cope with the interest raised. Since that time little broad communication has taken place. The importance of framing messages in the light of themes that interest key audiences was emphasised.

6. ENABLING FACTORS FOR YEAR OF CARE

6.1 Overview

The enabling factors discussed in this section are those relevant to Year of Care during development and implementation of the programme. It is too early to identify factors that support sustainability. Enabling factors are presented here in three main categories: those relating to the work of the central team; those relevant to Year of Care sites; and factors that were not available in all situations but provided additional support when used.

The list of enabling factors presented here is not exhaustive and the headings under which they are presented are not clear cut, but the aim is to identify the key supportive elements highlighted by interviewees. The order in which factors are presented is based on logical follow-on rather than frequency of mention or significance. The relative importance of each enabling factor depends on the stage of the project, however factors listed at the top of each category were those most crucial to getting the project underway.

The importance of most factors identified here became evident because of the valuable role they played in supporting Year of Care, but a few were recognised because of challenges caused by their absence or incompleteness.

Almost any input into a project brings with it the risk of negative as well as positive impacts and, for some enabling factors, interviewees discussed potentially damaging outcomes as well as productive benefits.

6.2 Enabling factors at central level

6.2.1 *National leadership and direction*

Several interviewees emphasised the need for committed, experienced and passionate leadership at national level if an innovative project is to be established in more than one site.

... people, drive, particularly [the project leader] ... she drives these sort of things. I think the people that were around did have a lot of experience and passion about it, but needs commitment and passion.

It would never have happened from the ground up. It would have been in a practice and stayed within a practice, because remember, the GP culture is not particularly one that shares across practices their individual successes ... You wouldn't I think have got it if you just sent a consultant out and said, this is the way we're going to work. It needed national focus, it needed national direction, it needed solid thinking ...

The challenge of strong leadership was also acknowledged. Strong views and leadership can be unsettling until relationships and expectations are established.

... we learnt to understand where [the project leader] was coming from and she learnt to understand where we were coming from ... we had a sort of typical forming storming norming cycle.

6.2.2 A team approach at national level

Throughout, Year of Care was led by a central team, sometimes called the national team, and by the programme board.

Membership of the programme board expanded during the course of the project, with an increasing emphasis on inclusion and input from representatives of the pilot sites. As already noted (4.3), from the outset sites were actively involved in development of the concept, but their participation in governance has gradually extended. The following interview excerpt from a member of a pilot site illustrates the changing experience of governance over time.

I think the project management structure from the centre was a lever to achieve the momentum. Yea, it was quite difficult living through it because it felt like we were responding to the central team, but without that focus I'm not sure we would have achieved what we achieved ... I think initially at the very outset, because the project was funded at set up, it was very tightly managed and controlled ... and I think the project has emerged over time and it's emerged to be more encompassing ... to pick up some of the themes that have emerged as part of the local learning ...

At the end of the first year the programme board was extended to include the Senior Responsible Officers (SROs) of the three pilot sites and strong emphasis was placed on the collaborative and team-based expectations underpinning the Year of Care project.

... I brought the SROs of the project onto a completely re-figured steering group, central steering group, and made the point endlessly and repeatedly and behaved in this way, that we were all in this together and if the project succeeded, it depended not just on what they did themselves, but it depended on the whole project and they were now, each of them one quarter of the responsibility for that.

During the second year some interviewees observed that input into the project from the pilot sites slackened, but more recently, in the third year, interest and input have been regained. Several interviewees attributed the renewed sense of engagement at least partially to the inclusion of project managers from the sites on the programme board, bringing a more operational perspective to combine with the strategic and policy considerations. Another interviewee also suggested that increased engagement was due to more active input from the central project manager, and the fact that sites now have outputs to demonstrate which gives them an enhanced sense of participation.

And I think part of the shared learning and part of the more inclusive approach to the board is that we are getting people's perspectives so the project managers will tell us about operationally this has happened on the ground. They feed that in and then you've got kind of like a strategic spin on things and making strategic connections but then you've also got a policy context. So I think it has been helpful and it's been important I think to gain the momentum to keep people engaged to the end of the project.

I mostly think it's the external push, it's that engagement, it's the relationships, we had a period where the project manager ... wasn't as engaged for various reasons and I think putting that back to the forefront of the programme has engaged people. I do also think that people have got things to show now, and have got things to say and feel ... I think they do feel as though it's more of a team approach now, to getting it delivered, whereas previously it wasn't, it was, 'well central team are doing the evaluation, you know, that's different to what we're doing'. It wasn't as integrated. So

I think the relationship building has helped to do that, but it is also that they've got things to tell, they've got things to show ...

A local project manager who had recently joined the programme board spoke of the benefits of being included, leading to an increased sense of rapport and team spirit.

I sort of did wonder sometimes initially if the central team was holding that power and perhaps not always sharing everything. But as time's gone on, there has been that mutually working together and that sharing, so I think its just building that rapport really ... you just build that rapport all the time. I think that's it and perhaps both parties sharing lessons learnt, the good and the bad ... I think again being invited to the project closure groups, again I think there's been a lot more culture shift really. Which I can understand why, because although I've always felt that we should all be working as a team trying to make it work, I suppose I can understand in a way, although it's a project that the national central team whatever they're called, in a way ... there was an element of assessment. I mean there had to be I think. I think we've got to accept that it takes a while to build up rapport and trust. So probably we may not have it from the beginning but I suppose we're three years into the project that perhaps had it a little bit sooner.

Other interviewees also suggested it would have been beneficial to include local project managers earlier and to focus more on a genuine 'core team' with active input from the local sites, rather than a sense of tokenistic representation.

As one interviewee pointed out, roles and responsibilities of the various governing bodies were not explicitly defined.

... governance had never been that clear, we've sort of muddled along with it in all honesty. We have a partnership board, we have a programme board, that has changed a couple of times, we then have another working group around one bit and it's never been tightly defined. I think it's been well managed and the budgeting and things like that have been well managed, but because if we weren't clear about the remit and the roles and responsibilities, it's difficult to know how the pilot sites would have been clear about that as well.

As membership of the board grew over time there was flexibility and lack of clarity about where exactly power for the project lay.

I think we never really clarified what the team, the central team was for and who was on it.

Q. So you're saying, there's the central team which was those of you who were just national, the board included the SROs and now the project managers. But it's not clear what the team and the board, where the powers lie, is it that?

No, it's never clear, we juggle it. It's never been really clear. It may well be clear to the extent that, the national team is probably perceived to have the power, however the team focus, i.e. what is it we're actually here to do, what are we, a team, to achieve? Is it a national team here to achieve delivery of what the national team want, or is it a team approach to deliver Year of Care? That's been a little bit hit and miss, I think, over the years ... But because of the breadth of the programme and the fact that it was national and local and there was care planning going off over here, and new pilot sites going off over here, it wasn't ever really clarified ... people are unclear, one, unclear of roles and responsibilities, but two, you know, when they get in a request saying, we want you to do something, thinking well actually, I haven't

agreed to it, or things are going on in my life ... It would have been better if we'd have spent some time clarifying what the national team was and what exactly it was there to do and building almost a temporary organisation around that activity properly in terms of objectives and aligning values and principles and working practices and things like that. But we didn't do that, but it's only in hindsight that I'm learning that ... But we didn't think about it beforehand. It was just a group of organisations coming together and we'd work it out as we went along.

The interviewee above believed, with hindsight, it would have been beneficial at the start of the project to specify roles and responsibilities of the various groups, and their relationship to each other and to the project's goals. While acknowledging the importance of the collaborative team-based approach adopted by Year of Care, the same interviewee believed it would have been productive to have had a clearly outlined project plan at the outset, highlighting the tension between establishing a framework within which to operate as a central team, and inviting input based on empirical experience as a collaborative developmental project.

But when you were talking about the importance of the team approach?

I know it's contradictory, it's contradictory, I think that that has made it difficult for us as a team to grapple with it. So I actually don't think everything should be written down but if you have the bare bones of a plan, and we did have a plan but that was for year one ... But we never really had a plan since then, we didn't really have a framework. We had lists, we had the odd strategy, but they weren't used as the mechanism for managing the process, even if it's a flexible process.

Q: So you would like to have some sort of template you're working from and then be willing to be flexible?

Yes, because then at least you know what the expectations are and where to flex. If it's not really solid, then I think that that's quite difficult.

One person commented on how the project had benefitted from stability of board membership, retaining the same senior officers throughout its three years, supporting retention of organisational memory.

I think the real beauty is that the three SROs have been consistent through the project, so ... we're quite fortunate ... Because at the moment we're fortunate, we're recounting our experience.

6.2.3 Funding

The fact has already been noted (3.4) that as an ambitious project Year of Care operated on a relatively limited budget. Pilot sites received funding for their first year only, modelling what could be achieved in a real, rather than ideal, world.

... most of the funding [at site level] was for a facilitator or project manager, to actually rope people in, engage them in some shape or form.

Many interviewees referred to limitations the sites experienced due to lack of an IT system to support the commissioning element of Year of Care. As discussed later in this report (6.3.5) because the programme was new and experiential it would not have been relevant to design an IT system prior to implementing care planning, but had Year of Care had access to more funding it is possible that a specially tailored IT programme could have been designed to match needs as they emerged during the first year of implementation.

So we couldn't have put the IT in first and I think we all knew that ... if we had had in a sense, more central money, I suppose, this has been done on a shoestring ... But if we had had money, I suppose what we should have put in was a whole time IT person to do the pulling together and the working in the second year .. [the project has] had to just beg and borrow from people all the time to get that done.

As described in 5.4, during Year of Care's second year access to additional funding enabled a comprehensive approach to care planning training to be developed.

... another enabler was funding from NHS Diabetes ... it was a discreet piece of funding that came from NHS Diabetes to develop ... the training package and training the trainers and to deliver it in some areas.

Almost every interviewee spoke of the value gained from the training programme. It is difficult to imagine that the training could have been developed to such an advanced level had additional funding not been received. It is not possible to determine the benefit gained by the additional funding being designated for a specified task (ie developing training) or whether an equally successful outcome would have been achieved had the same amount of money been incorporated into the original budget. It is difficult to imagine, however, how the need or budget required to develop the training could have been estimated when Year of Care started.

Separate funding has also, more recently, been accessed to develop a model for provider development.

Because we've got some external funding from our SHA, we've got a separate arm of the project that's ... is there a model that can take some of the community based life style programmes, local authority commission programmes, voluntary sector programmes into a more systematic model for the community based solution to support for self management of long term conditions?

As with the IT component, it cannot be known whether, had the Year of Care budget been larger at the outset, the provider component might have been developed earlier, or whether added benefit may be gained from development of the model being funded separately.

6.2.4 Support from centre for sites

During the development year members of the central team worked closely with members of pilot sites to develop the programme, providing facilitation, support and input.

It was very much a supportive environment in terms of take things to the table, so an update in terms of what we've been doing, so these are the practical things we've been delivering operationally. But then also to kind of say, how have other people tackled these problems? What can we learn?

During the third year, in some cases members from the central team have worked closely with the sites, sharing lessons from other sites.

Appreciative comments have already been noted (5.2.5) from project managers who joined the project midway about the value they gained from contact with the central team. One interviewee pondered whether more support should have been offered from the centre to local project managers, modelling and promoting the important facilitative role project managers could play in building relationships with general practices.

... maybe we needed to have invested more time in facilitation of the sites or working with the project managers on the sites about facilitation. So we needed to facilitate them which we did in a way, but then you've got all the people changing and things ... that we didn't have facilitation high on the list, I don't think, early on. We kind of knew it was there but we didn't make it explicit and so I think when, certainly early on ... we didn't emphasise the need for facilitation as much, and we didn't facilitate, help them enough ... To do the things, you know we talked about relationships with the practices and getting the feel and put the links, things like that ... And I think that maybe we didn't dig deep enough there ... I think maybe we needed to be a bit more clear ... and maybe they needed some one-to-ones ... just in the early stages, not many, because they'd missed out on a lot of the thinking and stuff.

6.2.5 Approach congruent with current direction

Care planning, in various forms, has been a policy theme over recent years and though, as noted in 3.7, multiple interpretations of the term create confusion, Year of Care was supported by the fact that it was moving in a direction congruent not only with care planning but with the broader interest in long term conditions and self-care.

... congruence with a lot of other pieces of work that were going on, so that we weren't trying to paddle against the tide. It does fit together with loads of other stuff, so a need to get general practice really effective and providing good quality consistent service. And we've started diabetes, but that's an issue across the board [of long term conditions] ... I shudder to think what it would have been like if we were in an environment where in fact there was a centralising hospital thing going on and you were trying to do something that was about encouraging practices. I think if there were tensions and pulls like that, it would be very difficult to get people on board.

Because Year of Care matched national policy directions each pilot site had its own strategies, schemes, pathways and packages which Year of Care complemented and into which it could be integrated. As the interview excerpt above points out, a project that was paddling against the tide would fare differently.

6.2.6 Common recognition of an issue and shared language

While Year of Care has been supported by broad recognition of and agreement with the general direction of its aims, it has been hampered by lack of a shared language around care planning, bringing challenges of misinterpretation and complacency among those who believe they already do care planning.

As discussed in 3.7 the area of commissioning and provider development is less developed with little shared language or debate. In these circumstances a pilot needs not only to find solutions but also to define the problem in ways that resonate and bring it to the attention of the intended audience.

6.2.7 Appeal and effectiveness of the project itself

Reference has been made already (4.2) to the appeal of the Year of Care approach for practitioners and patients and the motivation it builds. The underpinning philosophy gives the care planning component coherence and its attitudinal base offers practitioners the opportunity to relate to the approach at a personal level.

... all the documents are written in a certain style, I think the presentation of the taster and the style of delivery of the taster is of that same ethos and philosophy and people might not get that at that stage. I think when people come to the training, they

do and that in part is because we actually have a 40 minute activity getting people to think about their philosophy and where they are in relation to their philosophy of Year of Care ... and we have a really big debate about that, so that we can, and actually some of the activities we do are quite attitudinal, because to be honest for me, if you can't impact on people's attitudes about this, then the intervention will be a bit shallow and hollow ...

Another supportive factor that is inbuilt into the Year of Care project is its iterative nature. In keeping with this quality the project leaders demonstrated ongoing willingness to learn and change, supporting ongoing adaptation and development.

6.3 Enabling factors at site level

6.3.1 Commitment from relevant positions

Experience gained from Year of Care care planning training has increasingly confirmed factors that must be in place before a new site is ready to adopt Year of Care. The first requirement is interest and enthusiasm from individuals who, together, have the necessary influence to enable adoption of the approach. In the current situation this generally requires interest from commissioners who can fund the project and clinicians who can influence their colleagues.

... we get an expression of interest from somebody within an organisation and we kind of need to suss out who they are and how likely they are to be able to take this forward, because sometimes you get an interested individual who has no influence to make this happen across an organisation. And that's really a shame but that's the way of the world isn't it? But normally when we're approached by an organisation which would be some sort of commissioning person with some enthusiastic clinicians, hopefully from primary care but some actual secondary care as well ...

6.3.2 Senior leadership in relevant positions and organisations willing to be actively involved

Having confirmed that a site has commitment from funders and clinicians to adopt Year of Care, it is also essential that senior leaders and/or influential people in relevant positions throughout the system are willing to provide genuine support for the project.

The following two interviewees described the need for enthusiastic and active support from senior leaders.

... we've learnt that it needs to be in at all levels. We've already said that it's got to be kind of buy-in from chief exec and all the way down ...

... it needs people at the top to embrace it and drive it from that as well. And that's really vitally important ... I think where there isn't that, you won't get anybody doing it, and at a high level. Here, because I'm an exec director and I can drive it, I think you need that, and in [the other sites there are leaders], they're all very, very senior people who can drive the organisation forward. Otherwise it just becomes one of many competing projects that you know, many people that are commissioning services here and doing pathway redesign, would be doing. So it does need very senior buy in to succeed.

Another interviewee pointed to the need for involvement from people with practical understanding of the system who are willing to engage in a pragmatic way when necessary.

... it's a complex intervention and embedding it is part of the ongoing sustainability. You need to understand primary care, how it's configured and we've been really fortunate that the project people that we've had in the project have had that understanding. So there's been synergy in terms of working with primary care, understanding the practical solutions and sometimes you need to get your sleeves rolled up to find a practical solution. So I think we've had that level, we have had levers, we've had commissioning levers ... there's been a lever to achieve some of that change.

Clinical leadership is another essential component. Several interviewees spoke of the need to have a GP champion for the project who is respected and willing to be thoroughly engaged with the project. Two interviewees are quoted here.

... we've had this charismatic leadership of [the GP Year of Care lead], so I think a clinical champion who's really credible and believed and trusted by the local GPs, has been crucial.

... it also needs [leadership] at a local level. A champion, somebody who is going to muck in, get their hands dirty, and actually knock a few heads together, to make things happen, to push it and to promote it.

Another level of support emphasised by some interviewees was secondary care. In some sites a specialist has provided clinical leadership for Year of Care. As the following interviewee explained, if secondary care is part of the initial decision and drive to adopt Year of Care and specialists engage in the training, a shared area-wide approach can be adopted. This is a preferable situation to the alternative where primary care adopts Year of Care and then tries to match its new model to secondary care after the event.

... we've also seen where there's a good relationship between specialist care and primary care and the commissioners, that that's driven it in a more organised way ... it seems to be that relationship is really important ... If you have primary care setting off on a journey with the commissioners, which is great, and doing all this kind of work, what about people who go to the specialist service, either for their diabetes care or who actually go into the specialist service for, to have something sorted out and then come back to primary care. They have the potential to get treated differently when they go into the specialist service. And that kind of undermines the philosophy. ... And what it seems to be is that where places can start looking at it together, it just appears to go through from the beginning much more easily... so they've trained their specialist team as well. So that they know about and they're going along the same philosophy and way of work, as primary care ... where there is this kind of leadership ... about diabetes care for an area rather than, this is what you do, this is what we do, and we'll work together to do it. That's just rolling along much better.

As happened in one pilot site, if staff turnover leads to loss of support in key positions the project can founder.

I think [the commissioners] were originally, when they put the bid in to do the pilot, they were engaged. But staff have changed, the project officer [for the area] has changed ... [we] did meet with the senior people to try and move it forward ... But her job changed ... when she left it kind of took a backward step really ...

Genuine engagement from a range of relevant areas across the organisation can provide some guard against lost energy when one position changes, if others stay stable.

6.3.3 Team approach and steering group with committed representatives

Reflecting on experience from the pilot sites interviewees, including the two below, commented that as well as needing support from senior leaders, a team approach across a range of disciplines was needed to maintain active engagement.

... those areas that did it very much by team approach, found it a lot better and easier to implement than those that didn't have that buy in and that sign up to actually push it out at a local level.

I think a multi-disciplinary approach, the valuing nurses and therapists as equal colleagues ...

The following interviewee illustrated the importance of a multi-disciplinary wide-ranging team by describing the potential barriers that need to be overcome.

Organisational barriers and [the evaluation company] barriers, you know, the tribes of doctor, nurse, therapist, GP, consultant. And the organisational stuff about, oh well we work for community health services, you work for general practice and I work for the hospital.

As part of the team approach another essential component is a representative steering group of individuals genuinely committed to participating and making the project work. One interviewee described a new site that was ready to adopt Year of Care.

... and they've done everything that they need to do to put this in place and working very coherently as a team and they've got a steering group to take the process forward, working really with commissioners and clinicians to try and embed this in practice ... they need the right people in that team and a steering group to manage the project.

A member of one pilot site spoke about the challenge to maintain momentum in their steering group but nevertheless, the essential ownership and accountability to Year of Care that members felt.

We set up a steering group at the very beginning of the project with the key people who were signed up to the project in the first instance. We've carried on with the format of that steering group ... there have been times when because some of the key people ... haven't been able to turn up for meetings, so you know, keeping the momentum ... I think people have seen it as their responsibility to see the project through to the end. And you know, people's commitment have come and gone over the time, but generally it's the same people at the beginning of the process that are still there and taking the accountability for it ... potentially a year ago we could have let it fail because of key people being diverted to different projects, so yea, we've been quite lucky... I think we've all approached this with a very kind of can-do attitude, so never did we think that we would ever going to kind of fail, so I think people have been genuinely very positive and I think having that positive attitude has been really helpful.

The same person acknowledged that though the steering group now works together well it has sometimes been challenging and takes time for a team to develop trust and good working relationships.

... from the very outset we were really clear that the project steering group had to be representatives from all of the areas because that's what we signed up to deliver as part of the bid ... so you've got people who are motivated and enthusiastic and have the vision ... so we've got some senior people signed up to the project. But also it's been quite a close knit ... I think we have good relationships across the steering group, I think if something's not right I think people are quite open to say ... And you know, just be open to challenge ... Be critical of ourselves as well, because it hasn't been all sunshine and roses, there's been some difficult conversations we've had. There's been some challenges in terms of you know, what is it we think we're here to do? So yea, I think, and people respect each other, so I think some of those softer things around relationships, trust, all of that stuff. And that takes time to work on. Yes, if you've got a new team coming together, then that takes time to kind of develop ...

Another interviewee described the steering group in a different pilot site, with its wide-ranging membership and similarly high levels of commitment and enthusiasm.

Locally we've had very committed or should I say the majority of the members of our project board have been very motivated and committed. We've never cancelled a meeting ... we started with eleven project members which has been a mix of provider and commissioner, which is a good mix. Obviously [the medical director and GP lead] ... We've obviously got a service user representative who's been very good, very keen. We have the manager of the [local] diabetes research network ... we've got AD for older people who is also AD for diabetes ... we had an AD for community engagement which initially with patient events, that was really helpful. Commissioning manager for self care and healthy lifestyles, who's actually also had quite a bit of involvement in expert patient groups, so obviously she's been able to see it from self management point of view. And the commissioning manager for diabetes obviously. We had somebody in research ... the lead nurse for diabetes ... as I say, we've never had to cancel a meeting, there's been that commitment ... it's a way of getting people together (a) to feed back but also to from a strategic point of view, look at the forward direction of the group ... most members were really keen and enthusiastic, wanted it to work.

6.3.4 Effective project management

Interviewees from the three pilot sites emphasised the critical importance of an effective project manager for introducing Year of Care.

As one person said, it is crucial to have someone whose role it is to be constantly supporting, reviewing, maintaining and reinforcing the Year of Care message not just to clinicians but across the system to all relevant stakeholders.

You can only do that if you have somebody that is constantly focussing on it and if you like, marketing it. You've got the complex change, you know it's right, some clinical people will buy into it ... But to get the whole system to change or to get it embraced by a whole group of GPs or consortia, you need constantly to be reinforcing the message and showing and demonstrating the success and looking at the messages and offering support. So, and that needs to be an iterative cycle so you're constantly going back and reviewing, right things are falling down, right what do we do to get them back on track? So if you think of DiClimente's Cycle of

Change, it's that kind of people fall off and you have to get them back on all the time with this, and you just transfer that to the whole system and that's exactly what you've got to do. So you've got to constantly remind your board of the success, constantly remind your commissioning directors of success, constantly remind your GP consortia of the success, constantly go back to your stake holders. It's that evidence and evidencing and evidencing, that's really important and evidence, demonstrating and marketing, I think are the three elements that I think make it successful.

The same interviewee emphasised the time, effort and skills needed to perform this role.

I think the key lesson is, that you've got to just constantly keep at it, because the other thing is, don't underestimate engagement, the time it takes to engage, the amount of effort you have to put into engagement, and that your project leader and her skills, her political skills ..., her negotiating skills are absolutely crucial in this ... I think they do need to have proper project management skills, we put far too many people into project management roles that are clinicians that have never done project management in their life before, without giving them ... proper skills and competencies to do it, so that's really important. I think that they have to be at the right level, because they have to earn, you know, you have to earn your respect and keep the respect ...

An interviewee from another site emphasised the valuable role the project manager had played and the importance of her sensitivity to the culture of general practice.

I don't want to just skip over the project management [it] is absolutely fundamental. Without, this project wouldn't have gone anywhere and I think, I say ... the skills that she had were coming from a background that really understood the culture of general practice as independent contractors, whom you could ask to do things, not tell to do things ... And her understanding how to get past the front desk and into the practice manager's office to get them engaged. And then being able to deal with and being sensitive to neighbouring practices that might have some history between them ... So there's all that kind of emotional intelligence that's needed, and understanding the local community, so I think it's a skill set that pure project management ... doesn't give you, that's a valuable add on. And without your project manager, the whole thing will not succeed ...

Another pilot site integrated the project management role into a different existing position and reflected that, with hindsight, it was clear that a dedicated position was needed for the role,

... one of the learnings for us is that it needs dedicated time as opposed to being part of somebody's portfolio, because of it being a large project, a complex project ... I don't think you can underestimate the level of hands-on support ... to be a key resource for the practices because part of embedding and sustaining change at primary care is that it's not just a short intervention, you go in and you do something, it's about how you embed some of those behaviour changes and how do you sustain it and it's just being that key person to do some of the follow up and all of the kind of like the groundwork, I think is really important learning ... developing the relationships, following through, working through problems with individuals and then feeding that back up where necessary.

Q if you were advising a site that was taking on Year of Care now, would you say they needed a fulltime project manager?

Initially yes ... having that dedicated resource, if it's even part time dedicated resource, I would say is more beneficial than actually having it part of a wider portfolio, to gain some of the specific focus that you need.

Project managers spoke of the challenge of their role. One described what she believed was needed, though time constraints had prevented her in working in this way.

Keeping all the practices, finding out exactly where they are and again, it would have been really nice to have got to know them better, gone to visit them once a month, keep them going: what are you doing? how are you learning? Having a bit more of a collaboration between the practices, so they could learn from each other and support each other, ... but I think if at the beginning there could have maybe been I don't know, monthly meetings, a monthly update, to kind of keep them enthused, because I think once you've done the training, that's fine, but when they actually go back into reality, it almost seems like they need something else to keep coming back at them and keep them ticking over, keep them enthusiastic, have a buddying system with a different practice that's done it well,

Another project officer who had the opportunity to offer more interaction with practices spoke of the importance of individual contact with practice staff: open offers to access support were not taken up but face to face visits proved useful.

... we're offering, when we send out the evaluation form after three months [after the Year of Care training], we're saying, would you like any support? We actually give them the choice to tick which they prefer, so we say things like, a practice visit, a group session with practices in the locality, we've got a few options. But so far they've all said I'll let you know if I need you. They've not taken us up on it, but at least they know where to come to ... and the practice visits I think do help and often when I do a practice visit after the training, I usually have the practice manager or certainly anybody who does the IT or admin side, in the meeting along with maybe a GP if they've not done training, and then the nurse who's done the training, we talk through a lot of the practicalities, and that makes a difference I think. And then everybody knows my face and knows where to come for help really I think, it's only doing the hands on bit does make a difference.

While interviewees from the three pilot sites were agreed on the importance of the project manager's role, their requirements to maintain involvement with the central team and to participate in the programme evaluation made their situation different to sites that were part of the roll out or spread of Year of Care. For the latter, while agreeing there are definitely project management tasks to be fulfilled, interviewees considered how these tasks could best be allocated.

The following interviewee envisaged that project management could, possibly, be performed by a site's Year of Care steering group, but that at the outset at least, the work needed to be a distinctly identified part of someone's role who understands the programme and can coordinate what is needed to implement and maintain it.

Q. Yes, so when you go out to new sites, do you recommend that they have a project manager?

We sort of recommend that they have a steering group, because if you think about it, some of the role of project manager was about this being a pilot and needing to do a lot of the evaluation and learning. They need a coordinator of some kind to pull together meetings, training, learning, to do some of the across other patch stuff, so for example in [one site] they've identified they need to do some healthcare assistant

training, that she's going to have to commission bits of that so you know, they need someone to have learnt that and pulled it together and then to coordinate providing that. So I'm sure you actually do need somebody, now whether it's a person or it's a committee of people, I'm not sure, but it has to be substantial enough part of someone's role for a while ... there maybe people within organisations whereby this role would fit quite nicely. They might already exist and they take it on as part of their role.

Another interviewee who agreed it was unlikely that new sites could appoint a full-time position specifically to implement Year of Care nevertheless stressed the importance of the role being a designated part of someone's position, and that the person needed to fully understand, value and feel enthused about the programme's value.

... Actually it's much much harder engaging people if for example it's just being put on somebody's job and they don't see it as being important or they don't quite see the whole impact that it might have. Whereas, if ... the person who is doing it has it, and is passionate and keen, then that's much more likely to succeed than somebody else who doesn't see it as being as important or kind of seeing it as, blimey I've got something else to do.

As noted above for the pilot sites, as well as supporting implementation of the programme, project management requires an ongoing facilitative role. As the following interviewee suggested, this would be a demanding and time-consuming position, but it need not be specific to Year of Care, it would be a position that supported the whole integrated package at site level into which Year of Care fits.

... there's a much more facilitative role there as well. It's not just about delivering the project, it's about having a feel for the practices, having really good relationships not just the practices but the other teams delivering diabetes care, specialist teams for example. And having a feel for those and enabling them and supporting them to develop and go forward, not just about delivering the project ... it would have a bigger impact if you like, so it might be about embedding this philosophy and project or whatever, whatever you want to call it, but it could encompass other organisational and strategic things to do with whichever condition you're looking at, diabetes for example. They would be facilitating the practices and teams, they might be organising some training, they would have a feel for which practices and who was struggling and kind of doing some buddying, you know, all those sorts of things that they could do.

6.3.5 Financial incentives

Pilot sites each designed their own system for building in financial incentives to promote uptake and maintenance of the Year of Care approach.

As noted in 5.2.4 one site established an incentive scheme during the second year of the project which was effective in attracting interest from practices but, due to a delay in accessing training and other supportive systems for Year of Care, led to disillusionment and disengagement. Nevertheless, with training now available the same site has currently achieved high rates of practices accessing Year of Care training and anticipates equally high implementation rates because of the incentive scheme.

We've got about 80% of the [local] practices now have been through training, so now I wouldn't say they are implementing. We're sending them an evaluation after three months, after coming on training, to say how are you doing? What are the successes? What are the barriers? But because we're paying them a financial

incentive scheme again, it's likely they will all implement ... because of the scheme. So the scheme was to cover the training and then start implementing a report of some of the goal setting. So we expect that they will carry on with it.

Another site that successfully implemented Year of Care in many of its practices has established a scheme that aims to maintain application of the approach by building it into a commissioned package that operates within networks of practices. If any practice fails to incorporate the component parts the network as a whole will incur a financial penalty.

... one of the things we've done ... that makes it more likely to be sustained is the fact that the project has been translated into a commissioned package of care with money attached to it. So that package is unlikely to be thrown away because it carries a financial penalty with it as well, if it goes ... The training and care planning, the disaggregation of the annual review, the package of care designed around the four stratifications and the care planning approach and the patient evaluation satisfaction and the education, are all embedded within that. And that's over and above the national contract, so I think the local GPs are now wedded to that, because it's tied into the way of doing things in networks and so networks is a key component, working out above practice level using data and disease registers ...

6.3.6 Systems that support implementation

As an experiential project Year of Care faced an inevitable challenge of not being able to prepare, prior to implementation, systems that would support the pilot sites in the first iteration of the programme. As a result, sites felt held back by not having the tools they needed to move ahead.

... you must, must have the systems in place to enable people to do it. So you need to have your training, your education, whatever paperwork you need, whatever IT systems you need, you need to have that in place.

Almost every interviewee referred to the restrictions that lack of an IT system placed on development of the commissioning element of the programme.

If you're going to involve commissioning, you've got to have a method of doing that, now whether it's through IT or a paper method or whatever, but having some kind of method, process to evolve commissioning ...

The importance of support systems is undeniable and, as two other interviewees pointed out, lack of an IT system did not only limit the tangible work that without an IT system could not go forward, it acted as a diversion that closed off conceptual development of the whole area to which it related.

But it's been a huge problem and a frustration ... it's turned out to be a real barrier. And a real barrier therefore to people thinking about what sort of services people need to support them. However, I would say that I don't think lack of IT was the main reason people don't think about that, they don't think about it because it's not on their horizon ...

... the people that are being trained to do [YoC training], are not actually the people who do the commissioning ... but there isn't a mechanism to get that into commissioning really, partly because of the challenges that the team have had in terms of getting IT up and running. Partly I think because commissioning is still a vague, woolly word that means lots of things to lots of different people.

Many of the systems required to support Year of Care have been developed and implemented; work on IT is still ongoing.

6.3.7 Readiness to change organisational structures to meet needs of relevant stakeholders

The intention that Year of Care should stimulate a system change has already been noted. In order for a system change to happen decision makers at site level must be willing to adjust and make changes as they recognise the potential to improve services following the introduction of a new intervention.

One interviewee described the way that the underlying ethos behind Year of Care had prompted changes to organisational procedures in one practice, which paved the way for reshaping the relationship between patient and clinician, while still meeting the clinician's needs.

... where it has worked, it's revolutionised the way people are getting their care. If people actually don't just use the care planning bit but actually use the learning that comes out of that to develop services for people ... it's amazing what can be achieved. And I think you know, what's clear to me is that the way clinicians behave can really make a difference to how patients engage with them. But equally how services are structured that allows clinicians to behave in a different way, is equally part of the equation in terms of changing things really ... one of the practices told me that they just got much more focussed on diabetes because they're now thinking about some of the structures and organisation of some of the appointments and clinics, and that kind of focus seems to help. But I think, I suppose that concept of taking all of the checks out of the care planning appointment and moving them to having been done a couple of weeks beforehand and shared with the patient, means that actually in your care planning appointment, you're not checking blood pressure and everything else, you're actually, you've done all of that and you can really focus on what matters to the person ... but equally it has fulfilled the agenda of the clinician around QOF, because that data has gone in, so that worry about, oh my god, we'll not get our QOF collected, isn't there, because it's already been done.

Similar organisational changes have happened in another site.

So a lot have moved to having two appointments for patients anyway, so they bring them in, perhaps the healthcare assistant if they're lucky enough to have one, and get all the bloods done and then the nurse sees them two or three weeks later. So if they've got that model up and running, it's not much more for them just to have some added time around the results going out. They're probably doing it quite easily. The smaller practices often do crack on with it quite quickly as well, because if it's a small practice and they're quite motivated and are a good team, then there's only a few people to involve and it works. It's probably, I find it more difficult in the larger practices where they have a few nurses who all work different hours or are shifts that pass in the night, getting them meeting with everybody, you know, practice team, practice manager etc. It's difficult and then they've got that much on the agenda, finding time to discuss Year of Care. So in the smaller practices it often does work well.

As the previous interviewee said, practices also have to think about further ramifications for patients and be willing to make other changes.

That's not the entirety of it because I think you know, you've got to then have the ability to then look at changing systems that don't work for patients. So for example, I

think in [one of the sites] if you look at some of the issues they've raised around culture, as part of this they've actually done some work to bring in the health advocates to sit down with people and explain what all the results mean in their own language.

Another person spoke about the potential to restructure contact with patients, responding to different cultures and needs and reshaping the way in which diabetes patient education is delivered to provide more specifically for different groups.

I think being really connected into the community through our patient involvement teams and understanding the culture aspects and not falling into the trap of one size fits all ... So being prepared to chop and shape what we've commissioned and provide to suit different groups.

6.3.8 Shared learning

Interviewees from each site referred to the benefits they gained from the opportunities for sharing learning with members of the other sites at the learning events.

I think one of the benefits of being part of a multi-site project is the shared learning and the kind of knowledge that gets transferred across the different sites ... We learnt a lot by getting together, so the facilitated study days with the other sites, was very helpful. I think we benefited a great deal from being able to go and showcase what we'd achieved and also share struggles. So we got a different perspective from somewhere else. Oh yea, we had that, and this is how we fixed it.

For some, the learning events also created an opportunity for learning within sites, as the travel involved led to designated time when those involved could discuss the programme.

One of the best things was having meetings in York because it meant that the team had three and a half hours a day to talk to each other on the train. That's not a facile comment, it's protected time with each other and an excuse to be, not an excuse, a justified reason to be out of the office, thinking purely about this and not shoe-horning it into just a half hour meeting. So those days were very very useful.

The benefits of learning from other sites have continued with the project closure group.

Project managers also benefitted from learning from each other, and wondered whether more opportunities could have been created for doing so.

I think we can learn from each other, and there are things we'll share with each other ... so we do email each other and share, we probably don't have enough time to do that or enough time to share experiences of everything, but we do see each other, we're usually at a meeting with an agenda and then we're back on the train and off. So I think probably a buddying support would have been useful.

Finally, as noted in 5.6.3, when related projects (eg Year of Care and Co-Creating Health) are not only happening simultaneously but are also co-located there appear to be significant opportunities for mutual learning, yet these have not been realised until recently.

6.4 Additional factors that give added support

6.4.1 Practical examples of the approach in practice

The educational and persuasive impact of stories and DVDs that demonstrate the approach and benefits of Year of Care have already been noted (5.2.4 and 5.3.3).

Obviously these tools were not available to sites that were introduced to Year of Care early in the implementation phase, but as experience of the programme grows stories and practical examples can support effective uptake.

6.4.2 Evidence of success elsewhere

As an interviewee from one pilot site reported, when Year of Care moved from initial implementation to roll out the attraction of the programme grew, as its application and benefits to a wider range of practices became increasingly evident.

I think what can happen is when you have a particular pilot type project that's small, people think well it can work there but it won't work here. And I think as it's grown, we've been able to demonstrate the benefit of it across the whole system rather than just in a couple of practices.

In the same way, as more sites adopt Year of Care interest in the approach grows.

6.5 Summary

Committed and experienced leadership is needed at national level for an intervention to be adopted across a range of geographic areas. Year of Care could not have developed or progressed without passion and enduring commitment from the programme leader. Alongside this strong leadership the programme demonstrated the motivating impact of adopting and maintaining a team approach between those at the centre who initiated the project and people at the sites implementing it.

As well as adopting a team approach to development of the project, Year of Care aimed to adopt a team approach to governance. The latter is more challenging than the former and changed over time with an expanding circle of people joining the programme board. Motivation appears to have increased with expansion of the board, and some believe it would have been beneficial to have extended membership of the board earlier.

There is an inevitable tension between balancing the aim for shared decision making with the underlying recognition that essentially the central team holds power. Equally, there is a tension between, on the one hand, a perceived need for a framework that specifies project aims and objectives, and, on the other, the intention of iterative development as a team.

Money proved to be an enabling factor when later input was needed to develop aspects of the programme that could not be foreseen ahead of time; barriers arising from lack of IT support could, possibly, have been addressed had additional funding been granted specifically for that purpose. There may be benefits in accessing additional funds earmarked for specified tasks, rather than needing to predict at the outset the total project budget.

The central team has an enabling role to play in providing support to those at site level, sharing information, guiding, updating and ensuring those at the sites fully understand their roles. It was suggested that more support could have been given to project officers.

Two circumstantial factors affected Year of Care, one supported it and one hindered it. The programme benefited from its congruence with national policy directions, but was challenged by lack of clarity around the term 'care planning', and even more by the lack of clear thinking around commissioning. In thematic areas where problems have not yet been recognised and named the challenge of identifying and developing solutions is far greater.

The nature of the programme itself was an enabling feature, having appeal for many clinicians and creating motivation when applied thoroughly.

At site level similar enablers applied: committed support and ongoing active input was necessary at senior levels to instigate and maintain Year of Care. A team was needed with broad representation and a steering group comprised of committed members from a wide range of relevant organisations. Project management is crucial. Though, possibly, the project management task may be performed by a committee rather than an individual, the general view was that a dedicated role was needed to support uptake of the programme, and later, to provide support and encouragement. If, as intended, sites integrate Year of Care into wider approaches to health, a broader position could be created to provide facilitative support, or, alternatively support for Year of Care could be integrated into an existing position that has that role.

Sites have introduced financial incentive schemes to support uptake and implementation of the programme. One site offered financial incentives to encourage uptake of training and implementation. This achieved high rates of attendance, though levels of implementation are not yet known. Another site has included care planning as part of its commissioning package, resulting in financial penalties if practices opt out.

Implementation was hindered initially by lack of necessary support systems, including training, templates and IT. As an exploratory project it was inevitable that systems would be developed and refined as the project progressed. Development of IT support has been a lengthy process; possibly additional funding could have brought faster outcomes. Although conceptual development of the commissioning component of Year of Care is still required, the lack of IT systems has, in most cases, diverted attention from the topic and provided a reason to focus elsewhere.

In practices and sites where the Year of Care ethos has been absorbed, readiness to re-shape organisational structures has supported significant changes to the way that patients and practitioners experience their services. In these cases Year of Care has demonstrated its ability to prompt system change.

As a multi-site project Year of Care has illustrated the benefits of shared learning as those in different pilot sites met to explore and discuss their experience. The supportive and well facilitated environment in which they met encouraged an open approach in which solutions and struggles were shared. The lack of shared learning until recently between Year of Care and other related projects (SystemOne pilot and Co-Creating Health) suggest the need for specific attention and facilitation before mutual learning can occur with other pilot projects.

Two additional supportive factors have been available more recently. Practical examples of the Year of Care approach, and evidence of success elsewhere were not available until midway through the third year, but Year of Care has now been operational long enough to record practical demonstrations of its application. These DVDs and stories provide useful tools for promoting uptake and for training. Uptake is also promoted as more sites adopt the programme.

7. SUSTAINABILITY AND THE FUTURE

7.1 Overview

Interviewees were convinced of the importance of embedding and sustaining the benefits from Year of Care, but the uncertain policy context for the immediate future limits options for clear planning or predicting.

In this section comments are reported about the role of the central team in sustaining Year of Care, the role of the sites, and views of the future.

7.2 Role of the central team in sustaining Year of Care

7.2.1 *Current role of central team*

The role of the central team during Year of Care's three year period as described in earlier sections of this report could be categorised into work that interacts with three main audiences.

The first involves relationships with sites that have agreed to adopt Year of Care. Initially this audience comprised the three pilot sites. The central team's role has been to engage and stimulate the sites; facilitate and support learning and maintain ongoing development of the programme; support design and/or distribution of tools and resources; ensure learning is shared and that sites benefit from what has proved effective elsewhere as they roll out the programme to their local practices.

The second area involves communication and relationships with external audiences: the central team has maintained relationships with funding bodies, evaluators, policy makers and a wider audience.

Finally, with its aim of spreading Year of Care, the team relates to potential new sites. A codified process has been developed for assessing the suitability of new sites, introducing them to the Year of Care care planning approach, then, if appropriate, training them and preparing local trainers.

If benefits from Year of Care are to be sustained, as the programme and its central team reach the end of their three year period it will be necessary to assess which of the functions currently conducted by the central team need to continue, and how they can be achieved.

I suppose the loss, there's a potential loss of momentum as we get to the end of the project ... like all projects the worry is about how do you sustain it. And how do you keep that corporate memory, call it what you want, that learning and keep it embedded, because whenever your project ends, you lose momentum potentially, so there needs to be something about sustainability

7.2.2 Relationship with sites conducting Year of Care

Much of the central team's work in relation to the three pilot sites has now been completed with the three pilot sites fully engaged, the care planning model established and the Year of Care approach, to varying degrees, implemented in practices across the sites.

In the area of project development two aspects are yet to be completed: the IT systems for commissioning are still being developed and work is underway to design a model for the commissioning component of Year of Care.

Optimism was expressed that by the end of the project the IT systems would be complete:

So really probably by about March, we will have credible support for IT for all the three major systems.

The project to develop the commissioning model involving development of non-traditional providers (referred to in 4.3.6) is currently underway and, again, there is optimism that it will be finalised, though not trialled, by the end of the Year of Care period.

... all three pilot sites applied, for SHA innovation funds, because there seemed to be an innovation that was needed ... It's a major project in which we have given the money to a partnership between a burgeoning commissioning consortium that was developing in the sites that had care planning, so they are very keen now to have the services, because they're doing the care planning and they want the services ... And on the other side of [the city] is ... a very community orientated community development social enterprise which knows how to develop community services, and has been working on the tariff for them, how you pay for them, how you'd monitor them, how you would link them with practices ... so we have two organisations each doing the bit of the Year of Care stick man diagram ... We've employed somebody ... who has worked in the community. And she is actively going around the country, pulling together all the Year of Care stuff that was just lying out there, and is going to use the models that are there, to come up with a way in which Year of Care sites could in the future develop and put in all their things ... and that will deliver in March. So ... we will have a manual of how you do provider development of small flexible services in the community to support self management.

The role that the central team has played until now of coordinating the programme board and facilitating debate has supported integration of new developments with national policy and local practical experience.

I think that the benefit of the programme board and sharing some of the thinking, is that we hear what's happening on a national policy perspective in terms of emerging policy, and it's just how we feed through some of the thinking at a local level into the national and vice versa, so there's a two way process ... it's very much kind of working out at a very ground level, what's a practical solution. Looking across the pilot sites and then feeding that back in. So it's been a two way process, but it's been a learning process both down the way and up the way.

Without the central team to play a facilitating and coordinating role the question of how the new model would be trialled and, if effective, spread, was not discussed in interviews. Similarly, if any work is needed to encourage further development or application of the IT systems it is not clear how this will be conducted.

There is one area of the central team's current work with sites that have adopted Year of Care that will, if application of the approach continues, grow over time. This is the task of maintaining integrity of the message (discussed in 5.5), and more particularly, supporting

staff who have a key role in maintaining Year of Care, who join a site as a result of staff turnover. With time, as more sites adopt the Year of Care approach and as staff turnover increasingly brings new staff to the programme, the role of supporting new staff members to gain an accurate understanding of the ethos and application of Year of Care will become increasingly important.

As described in 5.2.5, the role of central team members has been invaluable for helping new project managers understand the programme and their role in it. Until now, contact with the central team has been the means by which the Year of Care message has maintained its integrity. The potential for the Year of Care approach to lose its impact if it departs from its underpinning ethos has been noted (4.2.4).

... that second year in a sense, things did slip ... And what I observe is that when they're not doing it properly, the patients don't get the buzz and they therefore don't come back and see the clinicians who don't get the buzz. So it's actually not something that it's safe to do half cock, because it's not that you just don't get the benefit, you don't actually get the motivation. You get everything that's difficult about it with none of the goodness ...

In order to retain the approach intact there appears to be a need for a core repository (a person or a team) from which people or sites new to the Year of Care approach first hear it, avoiding the risk of 'Chinese whispers' leading to deterioration of the approach and of motivation to apply it.

Similarly, for those already engaged in Year of Care, maintenance of their skills is important. One interviewee acknowledged that if the programme were to continue more work would be needed in this area

... a structured approach, to ongoing skills support, because it's quite clear that these skills atrophy ... And so basically, we've got evidence that if you do not maintain things there, they tend to atrophy.... this is so different conceptually for clinicians, that there's no way that it will be maintained without continual reinforcement and some ways of doing things ... and if we were going on, you would have community of practice and all this sort of stuff, that you would pull together ...

7.2.3 Relationship with external audiences

Communication with external audiences was discussed in 5.6. The central team has actively maintained a profile for Year of Care with policy makers. As the following interviewee observed, retaining a place on the policy agenda requires intelligent reframing in order to hold the attention of health decision makers, but also demands communication and explanation to people actively engaged in the programme, maintaining continuity of the programme while the outer message adjusts to the changing climate.

So it's about having somebody who has wherewithal enough and is bright enough, to actually be able to make those shifts without really changing too much, what's going on in the programme. And I admire that and I think that's how leadership works in healthcare generally ... I think the challenge is bringing everyone else with them, at the same time, so they can get their heads around it and work out exactly what's going on. And that's quite difficult for people who work in different contexts and different environments and have a different perspective.

If Year of Care becomes effectively embedded by the end of its three years there may be no further need to promote the approach to current policy makers. That, however, appears a challenging target. If further embedding at national level is needed the task will need to fit

within the remit of a person or team with the necessary skills, knowledge, networks and ability to communicate the programme not only to policy makers but also, as the interviewee above said, to those implementing the programme. As staff and policies inevitably will change again in the future, the communication role is, ideally, an ongoing one.

For the Year of Care approach to continue there will also be a need for communication with patients and the wider public.

7.2.4 Relationship with new sites

One interviewee spoke of the lack of ready cross communication channels within the health system. In the absence of central leadership there is little opportunity for Year of Care to spread horizontally across PCTs.

I'd like to see it really well embedded, so that when PCTs disappear, it's seen as a norm. But it hasn't quite got to a norm yet, well certainly not nationally. And if it gets embedded as a norm here, that ain't going to influence the PCT next door. No, and I think in the future without leadership, so in the future, [our area] has got Year of Care, they're delivering it, they know what they're doing, they've become you know, a beacon for that. But will that influence [adjacent PCTs] to do it? How can they? Why would they? So how then, are you going to do it ... so what's going to happen in the future, without that sort of top down approach ... to drive it? ...

When asked how new sites currently learn about Year of Care another interviewee described occasional promotional events but acknowledged that, until recently, promotion had been limited.

It's all sorts of different ways, it might be publicity that we've done; it might be little events like the Long Term Conditions events, we've done a couple of workshops there; we've been at Diabetes UK; there's been a couple of articles in the kind of Health Services Journal and other sort of publications and things like that; word of mouth ... I think we could have done better in packaging the project, doing a better or different communications plan. Now I think part of that is because in the early stages we weren't really sure to be honest, what it was, what Year of Care was. And there was a huge expectation from people as to what we could deliver and actually we were just developing it ourselves.

Another interviewee expressed a view that there had been no specific plan for rolling out the programme and described a situation where, following training in Year of Care, new sites have received no further support.

... it's not clear where they quite fit. To have non-pilot sites means that you've got a roll out plan, really, I think. But we don't really have a roll out plan, we have a couple of people going round to talk to them, making an assessment of whether they're good enough, or whether they're set up enough to be able to work with it, and then having the care planning training. But they didn't get the level of support around sharing building blocks, things like that, they just got the training.

As the following excerpt from the earlier interviewee suggests, an alternative approach could have been to give more support to new sites that adopted Year of Care and then to spread the approach on a more geographical basis, introducing it to sites nearby so they could share support.

... it does raise questions about sustainability and I've kind of toyed with this ... Maybe when we did the spread, had we known what we know now, we might have

done it in a slightly different way ... Because if you do this spread and then work more with the people who you've spread it to, if you don't leave them, but you keep in touch and help them work through their bits, then that's much more likely to support sustainability than if they go off and do it, and then that's it, well you've had your stuff with the central team ... by doing kind of the next group of people, the next natural group of people who might actually be next door or something like that ... Then it would have been good if they'd had things like ongoing workshops and checking on philosophy, doing organisational stuff, contact with the central team, that sort of thing.

As interviewees commented, if the current approach continues where the Year of Care approach is spread to new sites in response to promotion and/or a request for training, a national team or organisation or central role will need to conduct that function.

But it means something, somebody, at a national level, has to adopt it. So somebody has to take over what [the project leader]'s been doing really ... because I don't think it's sustainable enough yet to leave it to float free. Well, in a complex change environment now, it's even more at risk

An alternative route to achieve spread and sustainability of Year of Care is to integrate the approach into a larger established framework.

But, what you need is then people like the [NHS Diabetes] and [Diabetes UK], all the people that have been involved, to make sure that it's part of the future and maybe it will link it to the new outcomes framework, so that it becomes a delivery linked to an outcome, that's going to be measured into the future.

Interviewees spoke of discussions currently underway with bodies, including the RCGP, who have capacity to integrate the Year of Care approach into ongoing processes in a way that would sustain it. Training and skills maintenance would still be required.⁸

7.3 Role of sites in sustaining Year of Care

7.3.1 Embedding Year of Care in practices

Interviewees in the pilot sites spoke of the importance of embedding the Year of Care approach into existing or planned models of general practice in order to achieve sustainability.

Yea, the long-term sustainability is an issue, but that will get less of a problem the more we embed it. Over the next couple of years, I'd like to see it really well embedded, so that when PCTs disappear, it's seen as a norm. But it hasn't quite got to a norm yet, well certainly not nationally.

As noted in 6.3.5 sites supported adoption of the Year of Care approach into general practice by building it into broader existing schemes which were financially incentivised. The following interviewee spoke of linking Year of Care with the QUIPP programme and engaging in deliberate planning to ensure ongoing impetus.

... so we've just drafted our sustainability plan, embedding care planning, so what ongoing support do practices need and what should that take? So if it's been linked into our QUIPP programme and we recognise it and need to roll out our existing

⁸ As described in the Foreword, Year of Care care planning has, since the writing of this report, been approved as RCGP policy. A National College Lead in care planning will be appointed, a community of practice established, and work conducted to incorporate care planning into GP training programmes.

programme but also to kind of look at what's the master class element that we need to kind of like keep this momentum going. Then that needs to be planned for and resourced. So I think that's certainly tied into our agenda.

In keeping with comments made earlier the interviewee above described broader embedding of the Year of Care approach by extending it to other long term conditions.

Linking it to other long term conditions, so what are the options to learn from, what we've achieved here into some of the other programmes and some of them I've already mentioned. But then you know, the COPD was about trying and testing it, does it work? ... so that then we're kind of like, we're making the strategic link between embedding the training, provision for the care programmes. So it's not just about one thing at a time, it's about a whole system coming together.

7.3.2 Role of sites in supporting Year of Care

The important and essential role that local site-based project managers play in supporting practices to implement and maintain Year of Care was noted in 6.3.4.

As the following interviewee commented, the task of managing a stand alone project, such as Year of Care, is time consuming and demanding but when the project is integrated into a broader system the challenge of sustaining it becomes more complex.

I don't think you can underestimate the level of hands on support to support practices ... That's time consuming, that's based on face to face eyeballing people, developing a rapport, developing relationships, and on the scale of [large numbers of] practices, that's significant. And that's almost like, it's fine if it's a stand alone project but if it's part of a modernisation programme, then it's about how you sustain that going forward.

Another interviewee endorsed this theme: if Year of Care is effectively embedded into a larger system, support, maintenance and training will remain essential, with the need to check for changes and adjust as the system evolves. For this reason the interviewee believed that support for the Year of Care approach should remain a designated component of a specific role.

... but bearing in mind it may not be a defined project when implementing some sort of complex intervention, if you want it to be permanent, it won't be a project in its truest sense ... if people decide they want to do this, it won't have a beginning, a middle and an end. The integration of it might, but actually it will go on forever ... but I have a feeling that it's an evolving thing, because if you implement something like Year of Care, a year or two down the line, you're in a different position because the people who are working in a particular way have done it for two years, the organisation has experienced it for two years, all that sort of thing. So I think that it does need to be in somebody's brief to drive it, keep doing the cross checking, you know, what's happening? What's different now? The skills are different. We need to start thinking about how that goes forward. How do we integrate with other things that are happening locally and regionally and such like? And it could be in a kind of board remit I suppose, but I don't know, I get the feeling that it's being somebody's job.

7.4 Views of the future

7.4.1 *Broad views of future context*

At the time when interviews were taking place little was known about the future for the health service. Most interviewees expressed concern about the coming changes.

The following interviewee, like several others, believed that aspects of the care planning ethos were well enough embedded in some areas to survive the new environment, however the future for commissioning was too uncertain to predict any outcomes.

I'd hope definitely that what's left would be certainly people having their results in advance and certainly having a more equal partnership in the consultation and maybe the goal setting action planning coming out of it. The feeding it into commissioning, that's another big ask really. I mean that's working for us as a PCT right now, because we've got the financial incentive scheme, but without that, when it devolves down to consortia, it's if they're interested enough to do that and when they first take over, they're going to have so much on their plates, is this high enough profile for them to bother with it or will they shelve it for a while, until they sort everything else out. I suppose keeping it high on the agenda is important.

The following excerpts from another three interviewees outline some of the concerns expressed about changes to commissioning and to the social care budget.

... we're going over to GP commissioning you know, so that's going to be a real spanner in the works, because their views of the future and what needs to be commissioned and how things need to be done, might take their focus away from innovations such as this. So they might say this is almost a done deal, or not to be bothered with it, because they're too busy worrying about the £580 million pound contract we have with our two acute providers and how we're going to manage it. So there's a huge risk to any innovation I think, over the next few years, in terms of people losing their grip and taking their eye off the ball.

I think it's perfectly possible that the changes in the White Paper and the broader aspects, really sweep more or less all of it away ... We simply don't know what's going to happen about commissioning do we, whether privatised firms are going to come in. ... then the rhetoric will stay and the substance will disappear ...

... a worry that the learning that we're currently trying to crystallise and share is going to get lost in the upheaval of the most fundamental reorganisation of the NHS since its inception ... the other difficulty is the business about, in this economic climate, our third sector and social care budget, is it going to be able to sustain the onslaught and will things that we have now commissioned in those sectors, be able to be continued and will we end up getting stuff handed back to health, because social care budgets and housing and day centres and other care budgets, benefits budgets, all will be coming under pressure.

The interviewee above also voiced concerns about the potential for patient preferences to give way to doctors' choices in the new health model.

I'm less certain of how sustainable this is, those patients who've been through this process, have now had their eyes opened to a different experience ... so we've got ...11,500 patients, who've now been through this experience, coming up twice, third time some of them, and I think they're unlikely to accept going back to a 'now I'm going to tell you what to do in ten minutes' approach. That's what one hopes, but it's a very fragile child, this thing of patient voice and again we've got this thing called

Health Watch coming along and I have a worry that we will, GP commissioning could become a very doctor dominated, doctor model, doctor centric, this is what you get, take it or leave it. And I think that's a worry.

A minority of interviewees expressed some optimism.

... if we can influence some of the thinking around doing things differently from a health and wellbeing perspective, then not only are we looking at kind of like community based solutions, but it's more kind of integrated working. So it is exciting, there are opportunities, and I think it's just about how you look at it. Potentially people feel threatened, but it is an opportunity.

7.4.2 Perceived opportunities for Year of Care

Efforts to retain the benefits from Year of Care by integrating the approach into general practice have already been noted (7.2.4).

The other means by which Year of Care could be sustained for the future is by preserving the training programme. The following two interviewees spoke about the broader benefits that can be gained from the training, with its learning around how to change systems and culture, as well as its specific content relating to care planning.

I find it very difficult to map out what's going to happen to health generally at the moment, to be honest, without [thinking about] Year of Care. I think it's got something to leave, I think if we can find a place for the national training to go, I think that that will be a real legacy for it. I think that it will talk about, I think there is potential for it to promote lessons learned around how to change culture and how to change organisations, if we manage to grapple with that. How we make that tangibly happen in a complex environment that we currently live in, I don't know ... In terms of the ethos, I think there's a lot more to be done around the ethos in healthcare generally and as long as care planning and partnership working sits somewhere, I think that that will be a good thing ...

It would be really brilliant to think of a way that we could come up with continuing to do this [training], because I think where it has worked, it's revolutionised the way people are getting their care. If people actually don't just use the care planning bit but actually use the learning that comes out of that to develop services for people.

The interviewee above reflected further on whether the training programme could continue on a user pays principle. As the excerpt below described, staff who complete the training programme provide their organisation with an ongoing way of maintaining the care planning approach and could, potentially, extend the training to introduce it to other staff and expand it other conditions.

... at the end of the day, we can't provide a service for free ... that would have to be on a kind of fee paying basis. I think what the training that we provide does for an organisation ... our training methods provide a way of giving them a sustainable way of delivering training that is of quality and fits with the programme. And I think the other part of that is, you're always going to have workforce movement, you need to have people locally who can be responsive to that ... there's other ways that the training might go on site, in that you might want to do some awareness raising for some staff around care planning, so for people who aren't going to be doing the care planning but need to know that it's happening. So there might be some training for that group of staff. Healthcare assistants probably need a little bit of extra training

and there's the whole gamut of multi conditions. If any organisation wanted to expand this into long term conditions, there's going to be a more vast need ...

7.4.3 Perceived risks for Year of Care

I think [the trainers in the Year of Care training programme] learnt that you can't start a training without talking to the sites, making sure they've got things in place, and they realise the enormity of the model and what it requires ... because otherwise people think it can become a tick box exercise and I think if you want to do Year of Carefully, you do need to have a good understanding of what it entails. I think some people may look at the Lord Darzi and other reports and say that we've all got to do a care planning and they'll try and find the quickest easiest route to do that ... so I think there's a real danger that we'll lose some of the high quality of the work we've done in [our site] and nationally with the training, if people just think, oh, we've decided to supply a template. So I think the risk is, people will go for the easiest most simplest method, what they need to implement, and Year of Care is not this hugely most simplest method ... but my concern is that people will opt for those other options given to them, they're going to pick those rather than what we've done with Year of Care ...

The interviewee above voiced concern that if aspects of the Year of Care model became required practice the rigour of the approach could be lost if practices adopt formulaic approaches and implement the actions without the underlying ethos.

Another interviewee endorsed the point made in the previous excerpt, stressing the importance of sites being ready to adopt Year of Care. As this interviewee described, not all sites have clarity around their system of diabetes care and where this is the case, Year of Care training would be wasted.

I think it needs to be clear what the model of care is for diabetes, in this case, that people need to know who's going where for what and then it's written down somewhere and agreed. But that's a little bit about the organisation and how it's commissioned ... there are some places, PCTs where I just know that we wouldn't be able to necessarily start embedding this sort of thing, because nobody knows who goes where for their care and it might happen that they're referred to this place but actually it's a different day or they're full, they'll go somewhere else and there's no planned way of doing it.... And I think that embedding anything that's complex like this, if there's not a shared protocol or planning or whatever you want to call it, that makes it much more vulnerable. ... I would get the feeling that what would happen would be that the interested group of people, say the primary care, would pick it up ... they'd get the training, it would be good in the practices but it would never become, once they left, everything would just stop. It would never become embedded.

The same interviewee went on to discuss the implications of this type of unreadiness for spreading Year of Care more widely. Until now sites adopting Year of Care have been those that are more forward thinking and organisationally advanced. Having worked only with these sites there is no experience of addressing potential challenges in sites where systems are less well organised or where interest is low.

... originally we thought that we would spread this, but actually it's more tricky. We thought, oh yea, we'll just do this, and we'll do it more of these places, and it's not as easy as that, because some of the people that have put their head up and said, we'll do that, aren't ready ... so [sites that have already adopted Year of Care] are better

prepared and they've done these things before and they're more advanced in their thinking and I think if they're more advanced in their thinking, they'll probably be ... more advanced in their organisational way of doing things. ... There are some other people who think they're there and they're probably half way there, but actually have a way to go to get there. And then there are other people who kind of say, or somebody in their organisation says, this is a good idea, let's do it. And nobody has even thought about how you might do it.

It should be noted that the comments above relate to the readiness of sites to adopt Year of Care, not to the readiness of practices. Experience in pilot sites demonstrated that with enough support even less well-organised practices effectively adopted Year of Care. Crucial to this is commitment to the approach by local leaders at site level (as described in 6.3.2) so that practices receive whatever level of training and support they need.

7.5 Summary

While most of the roles played by the Year of Care central team will have been completed by the end of its three years, there are some aspects of the team's work that, if not conducted by a central person or team, will leave Year of Care less well adapted and less resilient to withstand time and change.

As an experiential project Year of Care has continued to develop new tools and new approaches. Completion of IT systems to support micro-macro commissioning, and of the provider development model will both coincide roughly with the end of the project. During the active stage of Year of Care sites have been coordinated, by the central team, to meet to compare experiences of trialling new developments, and facilitated to explore and further develop models, combining empirical experience with knowledge of policy and strategic interests, some of which comes from the central team. The new IT systems and the provider development model would almost certainly benefit from similar opportunities for discussion and refinement. It is not clear how this will occur, in the absence of the central team. Ideally, opportunities for those involved with implementing Year of Care to meet for ongoing development and refinement of tools and skills would continue indefinitely.

The central team has played a valuable role holding intact and untarnished the current version of the Year of Care method and message. The message underlying any intervention has a tendency to wind down or change as it gets passed along. Year of Care has maintained integrity of its message through activities of the central team, who introduce new key staff to the approach, when, through turnover new staff replace those who experienced the initial training. Maintenance of the message and development and ongoing upkeep of skills will be an increasing need as time goes by. Unless a person or group take over this role, with time it is likely that the impact of Year of Care will be blunted as it departs from its ethos.

Embedding Year of Care into mainstream policies is a key means by which its benefits can be sustained. Throughout the life of the project members of the central team have maintained relationships and re-framed the Year of Care messages to facilitate attention, understanding and interest from health policy makers. Work on this is continuing, with members of the central team engaged in discussions to achieve an embedded approach. Ideally however, even if this is achieved, an ongoing role would exist to convey to those who implement Year of Care how the newly embedded approach matches their current understanding, and to be prepared to re-sell or re-package the benefits from Year of Care when the next set of changes occur.

Sustainability of Year of Care would also be supported if the Year of Care approach and benefits were communicated more widely with patients and the general public, maintaining and raising interest and demand.

Until now, Year of Care has spread to new sites based on ad hoc interest expressed mostly by sites themselves, rather than through a systematic central plan. Use of this approach has enabled those introducing Year of Care to assess and select sites based on their readiness to proceed. It was suggested that, had a geographic approach to spreading Year of Care been taken, and more support given to sites after they had undergone training, sites may have been more resilient and better able to support each other on a neighbourhood basis.

At site level, sustainability will best be supported by embedding the Year of Care approach into existing broader schemes, generally with financial incentives, but also with support from a project manager or a person or team playing a similar role. Once Year of Care became integrated into a broader approach, locally and/or nationally, the need would remain for an identified person to take specific responsibility for adapting and maintaining the message and ethos of Year of Care as it and the system around it evolved.

At a time of uncertainty about future developments in the health system it was difficult for interviewees to predict how Year of Care would fare in the coming changes. If the Year of Care training programme could be retained after the project ends that would provide a central source for sharing and maintaining the ethos.

Future challenges will come from the tendency for sites less enthused by the Year of Care concept to adopt a simplified formulaic version if adoption of the approach becomes essential, thus losing the underlying ethos; and from the fact that until now, only sites that are well organised and motivated have engaged with Year of Care, so the approach has not been trialled in sites that are less advanced. With strong committed leadership at site level even less well-organised practices can effectively adopt the approach, provided they are given adequate support. Without commitment and good organisation at site level this may not be the case.

8. Intended and anticipated outcomes and ways of measuring them

8.1 Overview

As with most funded projects a considerable portion of the Year of Care budget was spent on evaluation for purposes of accountability, to demonstrate outcomes, and to provide broader learning. The iterative and conceptual nature of the programme brought challenges for design and implementation of the main evaluation, which was conducted by a major business services company. This section explores first, views held by interviewees about intended outcomes for Year of Care and second, perceptions of the expectations that external stakeholders held for the project. Views about the evaluation that was conducted are then reported, the challenges involved, and finally, views about alternative approaches to evaluation.

8.2 Intended outcomes: views of those involved

8.2.1 *What would evidence success?*

Interviewees shared a common understanding of the broad intended aims for Year of Care but varied in the extent to which they could articulate expectations they held at the start of the project about specific outcomes that would provide evidence that the programme had achieved its aims.

One interviewee who was involved at the outset provided a clear outline of intended outcomes as remembered from that time. These included the possibility of improved clinical indicators; improved relationships between patients and healthcare professionals; patients with a sense of increased ownership of their health and healthcare; better organised local healthcare systems; healthcare professionals better connected into the healthcare system and patients receiving most appropriate services.

... we may well still get some intermediate outcomes in terms of markers of care. We were never going to get reduced blindness or cardio vascular disease. I mean you need a twenty year programme to be able to show that.

I would have seen success as feedback from people with diabetes saying 'this has really made a difference to the way that I relate to my healthcare professionals, to how I feel about my care, to how I engage in my own care'. I think success would be perspectives, you know, I think it would have been around improved clinical outcomes, if we could ever have got hold of any of that data. It would have been in the form of a more organised and structured system of care at a local level. So a care service that worked, that actually people were getting the services that they needed to have access to, that healthcare professionals knew exactly what they were meant to be doing and what somebody else was meant to be doing. And that was then fed into a process that was prioritising diabetes through commissioning.

Having identified ideal indicators of success, the same interviewee acknowledged that, in the absence of clinical evidence, positive patient views would provide adequate indication of effectiveness.

... if it does make a difference to patient experience, then I do believe that there is a role for supporting other areas in rolling it out ...

Q. So if you saw a difference in patient experience but no difference in any markers, if there's no evidence about that, that's still ok?

Absolutely yes, that's a marker in itself, that's patient outcomes ... Absolutely, and if they feel something has shifted and has shifted for the better, then it should stay and it should be built on ...

Another interviewee, also involved at the outset, expressed very similar intended outcomes.

... that you would have had fully empowered informed knowledgeable self managing patients ... the ideal outcome is that patients would be comprehensively heard and feel comprehensively heard and that there would be a system that could direct them to a service ... the outcome would be that they would have adapted, that they would know they had diabetes, that they had adapted to it, that they had accurate conceptions about what was likely to happen, what they could do about it, that they had integrated it into their lives and that they were doing the best that they could to ameliorate its problems and live a good quality of life ... and they would have available services that they could use flexibly and they would know about them and they would be using them.

Interviewees at site level found it more difficult to express their expectations at the start of their involvement in Year of Care.

Q. Did you have a clear idea at the outset of, even though it's difficult to put into words, the sort of outcome you were looking for?

To be honest, probably not and I think that's just because there was so much to do and there were so many areas that we had to tackle. So I think at the beginning, I don't really think I could see the wood for the trees and I think we were, we had so little infrastructure around the process in place.

8.2.2 Few expectations of clinical evidence in project timespan

An interviewee from a different site also acknowledged lack of clarity about what might indicate success, having accepted that clinical outcomes were unlikely to show changes within the two year implementation phase.

Q. And I don't know by the time you started, if you felt there was a clear message about what the outcomes *would* be by the end?

I don't think there probably was, and probably still isn't in a way, because we know that the outcomes are the long term outcomes. I think we did do a little bit of data collection, [the evaluation company] asked us for it at one point, but they didn't get very much back, so I think they gave up. ... But you couldn't say, because the nature of a care plan is that it's not all about medical markers and the benefit, they might improve but it might take a long time to see that, it's not always going to happen overnight, so I think people who understand the Year of Care, appreciate that. And once it's explained ... they don't expect to see vast reductions in anything. They just

see a more engaged patient really ... getting patients engaged, takes some time and they don't understand the process, they don't understand the changes, they don't understand why they've got the results in a letter form. They bring them into the practice and say, oh I think you've sent me this by mistake! And so if they're only seen once a year or twice a year, it's going to take a couple of years before it really starts working properly for everybody. And then maybe not everybody, so they see that, you can't expect change overnight I think.

Another interviewee expressed a similar view that clinical evidence could not be expected within the two year implementation phase of the project. This interviewee believed that evidence should be sought by tracking patients, with success being indicated by people owning their care plans and, as a result, modifying their behaviour.

I think what you need to then is triangulate with what's the service user's perspective of this, because you might not actually see a change in clinical outcomes over the two years of this project. And the difficulties that we have with quite a lot of our projects linked to long term conditions, we don't give it long time enough to be able to evaluate it. So if you've got some examples whereby you've got individuals who have gone through the care planning process, who have changed their approach to owning their care plan, who have modified their behaviour. So if you're actually tracking people like that where you've got successful outcomes, then I think that's a success story. I don't think you're going to get the clinical indicators in this year of the project .

8.3 Expected outcomes from outsiders

8.3.1 *Expectations of clinical and/or economic outcomes*

I'm a bit concerned that people think, thought when we started it was going to be different learning, because of the whole issue around clinical outcomes and research and what evaluation means ... One of the challenges for health I think is, they may get feedback instantly from a patient saying, well actually I really gained now, or being able to get on an education course or whatever it is. But it won't necessarily have what I would call the research perspective, which is, has it made any difference to clinical outcomes?

As the interview excerpt above says, those involved in Year of Care were aware of external expectations that success should be evidenced by clinical indicators. Another two interviewees spoke of a range of external expectations, including evidence of reduced costs.

There are people out there who only believe that if you save money it's significant, there are other people who still only believe that biomedical outcomes are significant ... different stakeholders and indeed just different observers, you know, from any form, all have their own view on what this was meant to achieve ...

And a lot of people ask, where's the evidence? What are the cost reductions? And they want to know those things before they take something like this on ... but again, it's early days for a lot of the sites, and a lot of the cost benefits are going to be long term cost benefits, not short ...

Another interviewee, as well as endorsing the view of external expectations, commented on the convenience of this expectation for practices that are reluctant to adopt change.

... in terms of evaluation, some people and I put this in as a barrier, want kind of evidence in terms of bio-medical evidence, which isn't unreasonable to think that people might want that. But actually you know, you're not going to get lower HbA1cs when people have been in this once, it's just not going to happen. But I think that's been a little bit of a trick for some places, because you know some GPs, I think it's because they probably just don't want to do it, they're only going to do it if there's lots of evidence ... it would be great if we could get some evidence, but you know, it will be three or four years down the line I would guess.

8.4 Views of the evaluation that was conducted

8.4.1 Frustration and disappointment with evaluation.

Interviewees from each site spoke, often at length, of their frustration and disappointment with the evaluation process and product. The following four interviewees provide some representation of the general views expressed.

I honestly think the evaluation, the way all the forms and people filling it in and doing it, I just don't think that was friendly, user friendly enough and I think it put a lot of people off... I mean it took my head a long time just to get round the forms themselves and the way that it was written up and you kind of think, well I haven't learnt anything from that. And then we had to do it again! I ended up going out to practices delivering all the materials, photocopying, writing laborious stuff on these millions of forms, took them to practices and they gave them to patients and patients have looked at them. And even the practices themselves, the forms to fill in on their consultation with the patients and their skills and stuff like that. They said it was a nightmare to do. So I don't think that's helped ...

I think in September one of the [local] pilot sites pulled out ... But they pulled out largely because of the evaluation of the project, it was too much for them.

I think the greatest weakness has been the evaluation. I mean we refused to do what [the evaluation company] proposed. I think that there was worrying lack of grasp of information governance and my impression from [another site] was that it was punitively hard work and in fact two practices could no longer stand it and that even the data that [the third site] did collect, because they couldn't actually join it up per patient, it's difficult to know that it was of much value ... But I think in terms of, if you view it purely from a project perspective, you could say well that was disappointing because the planned evaluation couldn't or didn't happen or happened and didn't really tell us anything very useful.

I think there was an expectation that we would somehow have a mechanism whereby we capture over time practice outcome data and I'm not sure, I mean we have got mechanisms to do that locally through our availability of QOF data, but on an individual basis I think there was an expectation, I don't think that's been achieved ... But yea, if we were designing the evaluation in hindsight, would you have the same methods? No you wouldn't, you would use a different approach.

8.5 Challenges for evaluation of Year of Care

8.5.1 Challenge of designing evaluation for an iterative, changing project

The main external evaluation was designed in two phases: the first phase, conducted in Year 1, evaluated the development of Year of Care and the second phase, designed to start in Year 2, evaluated implementation over the subsequent two years.

As already noted, one of the strengths of Year of Care has been its ability to learn and change over time. With its iterative approach and learning events as an ongoing feature throughout the implementation phase, it is inevitable that the objectives and nature of the programme were re-shaped over time.

The need to determine and design an evaluation programme at the start of the implementation phase does not sit easily with a project that develops over time.

One interviewee discussed some of the meta-level shifts that had taken place in how Year of Care was perceived: was it a policy theme, a service improvement activity, or a research project? While acknowledging that a level of ambiguity offered strategic advantages, lack of clarity brought problems for design of the evaluation and with expectations that had developed.

... but I think the challenge with that is that many people have seen Year of Care as being something other than what it is. I mean it started off as a policy theme, it then turned into an activity around service improvement ... I see it as service improvement; other people have seen it as a research project to actually define a model of care. How you do that, I don't know, but there are different perspectives around what it is, the whole of Year of Care. And we are I think are equally to blame for that, because we use it according to what argument we want to make at any particular time, whether it's around service improvement, so if its delivery, evaluation or policy, it becomes a little bit of an amorphous everything ... that's how the world works to a certain extent, but sometimes that means that messages are a little bit inconsistent and it's then, you pay for that, when you come back to the evaluation stage!

As perceptions changed about the nature of the Year of Care project, so did the shared understanding of what Year of Care aimed to achieve. As the following interview excerpt describes, although the initial intention was to impact on clinical indicators, as the programme developed the focus shifted towards the underlying need to change organisations and culture. These changes happened over time, after the evaluation had been designed.

I think this project started off being about clinical markers, not in terms of evaluation, but in terms of making the case for change, because of clinical markers, in terms of poor HbA1c control and poor blood pressure control. It did also have the issue of, it's about changing the relationship, but I think to a lot of people, probably me as well, that was not seen as the bottom line that is the thing that it is trying to change ... So I think the way I'm looking at it, it's actually all those other things around the leadership, the culture shift, the organisational change, are far more interesting, but we're not going to get a lot of that, from the evaluation.

The same interviewee, on reflection, believed that Year of Care should have been more clear at the outset about what exactly the evaluation should measure, and equally, more firm with sites about data they should collect.

At the beginning we weren't tight enough around exactly what we would show and what this evaluation was doing. But we also weren't directive enough, I think, to

actually say, no you need to have this, we need to have this and we need to deal with this, so learning on both sides.

Q: It's tricky because you're building a relationship at that stage, aren't you?

It's true and at what point do you actually push that relationship hard, to say, we need this otherwise it's very difficult for us to continue? And I think that there were at times we just stepped back and just let it, see what happened happened and you can do that over a three year project!

The discussion above highlights the tension brought by the need for early decisions about evaluation design and data, at a stage when the central team was attempting to develop a partnership approach with the sites, and when aspects of the programme were still emerging.

Amidst these challenges the central team asked the evaluation organisation to collect a wide range of data with no prioritisation of key topics. As a result a large amount of data has been collected, bringing the challenge of interpretation, and inevitably, gaps where data could have been valuable.

I think there will be gaps in a lot of the evaluation evidence. I think there will be big gaps, with costs, that's another area we should have been more specific on, in terms of, what did your service cost initially? To be able to compare it afterwards, and we weren't focussed on that ... we asked the evaluation team to collect so much data, we didn't prioritise exactly what was the most important and now we have so many different data sources, it's proving quite challenging to be able to interpret it in any shape or form....

Another interviewee highlighted a further way in which early design of the evaluation limited the value and representativeness of the learning that will emerge from it. Although, starting when it did, evaluation of the programme took place in the first practices to adopt Year of Care, in the two pilot sites⁹ that adopted Year of Care as a two-stage process those practices that adopted the programme later have benefitted from lessons learned in the earlier sites. As this interviewee suggests, it is the later (roll out) practices that might offer best evidence of Year of Care in action, yet the evaluation has not covered these practices.

... although maybe there were hiccups in some of the sites with their original cohort of practices who were part of the pilot, that actually they've all really learnt from that and are now doing things maybe a bit differently now that they're rolling out. And I guess that's one of the problems with the evaluation of the project actually ... it's probably the roll out practices within sites that are more successful, if that makes sense, because they've had the benefit of bringing in the learning from the pilot sites.

8.5.2 Challenge of intangible and varied outcomes

The nature of potential outcomes for Year of Care brings challenges for the evaluation. While clinical indicators would be a desirable outcome, as noted in 8.2.2, few interviewees anticipated clinical evidence within the time span of the project.

One person described the nature of possible outcomes, illustrating the challenge of summarising success.

⁹ As noted in 3.2 two sites introduced Year of Care to their practices in a two-stage process while the third introduced the intervention to most sites at the outset. In the third site most practices were encouraged to participate in the evaluation.

... there might not have been any kind of improvements but the fact that they haven't got worse is an improvement. But it's how do you quantify that? It's the quality of the consultation, giving the patient the skills or the tools, the confidence to do something about it, because they can do something about, because it's their problems, their condition and they're the only people that can do something about it.

Another interviewee spoke of the importance of realistic expectations, graded to reflect individual situations. For some patients changes in clinical outcomes may be feasible, others may not demonstrate clinical changes but could experience a change in their outlook as a result of a different approach to service delivery. On this basis outcomes could not be generalised, but should take individual starting points into account.

... for me, that's more important than whether we actually make a difference to HbA1cs or cholesterols or whatever. And my personal view is that actually for people particularly with quite long term diabetes who have kind of got into a rut, I suspect we won't make a huge difference about the bio medical measures, but I'd be very interested to see what happens to people who we catch early on in the first few years of their diabetes and work the Year of Care way and actually they learn to do diabetes and chronic disease differently. So for me, the optimism would be around that group ... And not everybody has the capacity to make changes or the resources, so you know, I think it's really important that it's about how far does the process of care facilitate somebody feeling empowered in self caring and how much do we actually strap people down or tell people off or actually the process of care itself, is demeaning or undermining. So for me, that's the heart of it.

In a similar way, as noted in 3.5, differences in the three pilot sites bring difficulties for amalgamating or generalising outcomes.

8.5.3 Challenge of implementing a complex evaluation

Administration of the evaluation at site level and at practice level proved extremely demanding, as the following interviewee described.

... on evaluation, I think some of the tools that we've used, it's been an industry servicing that, because [the evaluation company] haven't been able to support us in the way that I think we probably envisaged in the first instance and sending out was it four or five questionnaires to [all our] practices, in the right order, making sure that they know what they're doing, it's been huge, it's been a huge pull on our resources, physically, but also from the questionnaire perspective, ... It's something we could have done without ... and I think practices haven't really seen the benefit of it, so for them, huge piece of work to complete the questionnaires in the sequence, in the time, all of that, and I think upon reflection, is there a different way we could have done it, could it have been more sort of action based? Could it have been more qualitative? I don't know, but certainly from our perspective, administering the questionnaires and coordinating it, we had people driving all over with boxes of stuff and just the practical aspects of that, I don't think we can underestimate ... and patients would phone, so we would have to field that. So again, if we were doing it again, were the expectations too high in terms of the tools that we required as part of the evaluation?

An interviewee at another site spoke of the fact that there is a limit to the amount of evaluation that patients will accept.

What we're now getting from patients is, 'if you ask me another question, I'll kill you!' We're up to here with evaluations and questionnaires and feedback and so we evaluate the education, we evaluate the experience of the care planning interview, we evaluate the retinal screening interview, so there's almost too much evaluation.

8.6 Alternative approaches to evaluation

8.6.1 Establish shared view of evidence of success at outset

One interviewee expressed clear views on ways that the evaluation might have been conducted differently. As this person said, at the outset it would have been valuable to engage all players, including the central team, sites and practices, in establishing agreement on the balance between internal and external evaluation, and on indicators of success.

... so this was all about ownership, I suppose it's difficult because there are tensions. There's also something about to what extent when we're trying to work out if it worked or not, do we have to kind of measure it from the outside and to what extent are you going to actually say to the people doing it, you tell us. And I think you need a mix, I'm sure you need a mix. But I think that also the way that the evaluation was originally set up was very much external, big brother was going to come and watch us. And I think that actually getting more on the ground engagement with how we're going to tell and how we're going to do this, might have been another way of actually getting people engaged.

The same interviewee discussed the importance of a shared clear understanding of how success with Year of Care could be described, as a 'punch-line'. As the interviewee said, rather than rely on analytical tools designed by the evaluation company, a broadly agreed qualitative statement of what success would look like would have been useful.

But pinning that down ... so it may be something that's not strictly speaking measurable in a kind of scientific way, but it's the sort of thing that one GP would say to another at a meeting. What's the kind of punch-line on this? And I kind of feel we could have done a bit more thinking ahead of about well what are, so rather than thinking in that rather sort of intellectual sort of analytic measurable way that perhaps [the evaluation company] did, I think we should also think about what are the, what is that we hope at the end of this project we'll be able to say to people. Even if it's stuff that you can't measure and it's an atmosphere or if you like, it's just an attitude.

I suppose there's also something about at the end of the day, what's the point of all this? So having this all-singing very complicated collaborative model, yes, so what's the point? And that's where I come back to something about outcomes. So not necessarily a complicated questionnaire that has to be filled in, but something around what are the simple at the heart of it questions that you would say to people, you know, what do you think of this? And it's very interesting, because the practices have said things like, it works. And I'm kind of thinking, how do you tell what is works? And it's very woolly and it seems to be something around the dynamic in that consultation is more positive, feels there's more potential. So it's something kind of quite potentially vague but actually that's actually the heart of what we're trying to do.

8.6.2 Establish realistic approaches to collecting indicators

The same interviewee had further thoughts about practical approaches to gathering data that could indicate the extent to which intended outcomes were being achieved. As the interview excerpts below describe, the data gathering processes designed by the evaluation company introduced additional work and pressure to the Year of Care intervention. The interviewee

suggested that, had sites and practices been invited to participate, internal data already collected could have provided indicators of success.

And I think the other thing that we could have done much better if we'd spent a bit more time kicking it around both across the implementation teams at the PCT level, but also with more dialogue down to practices ... was stuff around how you're going to measure how you're doing. And I think that there was a sort of, oh [the evaluation company] will do that. But actually, for a lot of reasons what [the evaluation company] wanted to do was just unrealistic. I mean that was kind of formal research project type stuff, and it's just unrealistic in an essentially unfunded day to day NHS setting. I mean because the amount of money that came through from Diabetes UK was not anything like what it's actually cost to do this. And I think you know, so start about, what's a realistic kind of measure that you can use in everyday practice without it costing an arm and a leg? So for example, there are lots of things about, we could have used DNAs as a measure for patient engagement. Well I know that now, but that didn't at that time come up.

So I mean if there is something that is measurable and that's collected as routine data, so we're not doing any additional collection, but what's new is the extraction and reporting function. And that's motivating for most people, they do like to see what's happening.

Another interviewee suggested that key people involved with implementation could have recorded their experience, as part of the evaluation process.

...maybe one of the things we needed to do or if we were to do differently, is around the action learning, so how do we capture action learning more effectively? So is there something we need to write up on? Is that a kind of six monthly progress report?... have a living document and the living document is updated on a six monthly basis. So all of the learning from the previous six months or quarter, whatever it is, is captured, so that you've got a log frame of the project as you go along ...

A third person proposed a different timescale for the evaluation. Whereas the current evaluation was conducted in two stages, with the development year being evaluated in Year 1 and implementation evaluated in Years 2 and 3, this interviewee proposed allowing a two year gap for the evaluation during Years 2 and 3 while implementation was established, then evaluation resuming in the subsequent two years, when the programme should be operational.

I probably would have had a gap in the middle to actually give a couple of years to really embed this, although the risk of doing that is that when you go back in two years time, nobody is doing anything ... [wait] two years and then go back for evaluation ... So we could have done that, or just set up a separate programme to have reviewed it two years later.

8.6.3 Establish realistic expectations at outset

High expectations from people external to Year of Care have already been noted (8.3). Interviewees spoke of the pressure they felt from the external wish to hear simple explanations or outcomes from the project.

We found it very difficult to extrapolate information in a meaningful way because it's so complex. Because people mainly want easy sound-bites, we found it very difficult to get the information that is being, what has happened at a local level, into a format

that people, that will chime with people, because it's so complex. ... I think that we probably should have nailed the evaluation earlier than we did

Q By that, do you mean you might have got, you might have been able to measure different outcomes? Or that you should have stated more clearly what your actual outcomes could be?

The latter mainly ...

While acknowledging external pressure for simple messages, another interviewee stressed the importance of counteracting these demands and instead, conveying the understanding that complex challenges require complex interventions.

I think the other thing is that the people will want to have simple answers out of something that is complicated and it should be set up in such a way that people know that it's not about having a simple answer, when something is so complex. You know, people want to know where's the evidence? Where's the RCT? Well do you know what, there are all sorts of things that might make a difference to the outcome for patients and putting Year of Care in, in the long term I think could make a big difference but when people are just getting their head around it, just trying to get the intervention in place, are they really going to be doing it quite right? And how long will it take patients to get used to it? So there was something about complex interventions need to be described as such and observers of that or policy makers or people that matter, need to have an understanding that it's not going to be A plus B equals C. You know we're constantly being plagued for, where's the evidence? You know, it's from all sorts of places.

A further person recalled that the action proposed above, of clearly stating anticipated outcomes, was, in fact, followed during the second year of the project. It seems however, that more widespread knowledge of decisions made at that stage would have been useful.

... but I do know at the very very beginning ... of the project, we discussed all of these things as to what you could expect and what you couldn't expect in great detail. What we I don't think did discuss to the same degree is what our stakeholders would think about this ... it would have been a good lesson that right at the beginning you should make it very public, what you would expect from this and we didn't do that. But we did recognise about a year in, that we needed to do this ... there is a document on the website in public, what we intend to achieve. And that's what we're going to be measured by and we're not going to be measured by all these other things So we sort of had a handling strategy, but I'm not sure how effective it's going to be and I would recommend that other people gave it more seriousness earlier.

8.7 Summary

While all interviewees understood the broad aims of Year of Care most of those involved at site level did not, at the outset, have a clear view of what, within the project time span, would count as evidence that the project had succeeded in achieving its aims. Many people external to the project expected that success for Year of Care would be demonstrated by changes in clinical indicators and/or financial savings. Most of those engaged with the project believed that the implementation phase was too short for these to be realistic expectations.

The external evaluation commissioned by Year of Care was experienced by the pilot sites and individual practices as onerous, over-complex and disappointing in its lack of evidence.

Difficulties with the evaluation illustrated challenges for any iterative project that is required to establish an evaluation programme while the intervention is still developing and changing. In the face of uncertainty and change the tendency is to collect a wide range of data, adding complexity to data collection but not necessarily providing answers to specific questions. The lack of tangible, readily-agreed measures for demonstrating success added to the difficulty, resulting in a third challenge: the design of an evaluation process that was more complex and onerous than was realistic for sites and practices to implement or for respondents to engage with.

Alternative approaches proposed for the evaluation included clear agreement at the outset between those designing, co-ordinating and delivering the intervention about what would constitute success for the programme and how it would be indicated. It was suggested that all parties should also be involved in agreeing the balance between internal and external evaluation. Closely linked with these points is the need for agreement on data that would need to be collected, considering first the option of using data already in existence. Finally, it was proposed that messages should be clearly conveyed to external stakeholders about the type of evidence that will emerge from the project, pre-empting and correcting unrealistic expectations that a short project exploring complex challenges can provide simple answers or clear-cut evidence.

APPENDIX 1: INFORMATION FOR INTERVIEWEES

Reviewing key learning from Year of Care for Diabetes Project:

Study Information Sheet

Aims

1. To capture reflections from key stakeholders in the Year of Care project at the end of the project's implementation phase.
2. To provide feedback to the Year of Care Programme Board that will enhance learning from the project and supplement final reports and project summaries, with a specific focus on learning for policy-makers.

Sampling

Interviews will be conducted with a purposive sample of individuals who have an overall view of the programme and who have been actively involved in both influencing and implementing it.

Interviews will be conducted during October and November 2010.

Procedure

- Interviewees will be contacted by the researcher and invited to select a time for the interview. Interviews will be conducted face to face or by telephone. Interviews will last approximately 60-90 minutes and will be taped.
- Tapes will be transcribed and transcriptions will be thematically analysed by the researcher.
- A draft report will be written and sent to interviewees for validation.
- A final report will be produced by the end of January.

Questions covered in the interview will include the following:

- What have been key successes in the Year of Care project locally and nationally in the past year and over the whole project period?
- What have been the disappointments or failings in the Year of Care project locally and nationally in the past year and over the whole project period?
- What did you most hope for from the project, locally and nationally?
- What have been the main barriers for the project, locally and/or nationally?
- What have been the key enabling factors?

- What are key issues from Year of Care that you would not want to be lost?
- What are key lessons from Year of Care about how to embed and mainstream a complex intervention into a complex environment?
- Are there ways in which you think differently about Year of Care now to how you did one year ago?
- What are the most effective ways of helping people shift from a mechanistic approach to Year of Care to understanding it as a shift in ethos?
- Looking ahead five years from now, what do you envisage will be left of Year of Care in its broadest sense?

Outcomes

The final report will summarise key lessons about Year of Care's achievements and areas of weakness, and the underlying mechanisms that supported or limited effective implementation and spread. The focus will be on the underlying processes involved rather than the content, aiming to identify learning of relevance to a broader policy audience.

Ethics

It is important to be aware of the following:

- These interviews are entirely voluntary and you do not have to take part though obviously we will be delighted if you do.
- If you agree to take part in the interview, you will be asked to sign a Study Consent Form.
- Everything that you tell the interviewer will be treated in strict confidence - nothing will be attributed to you as an individual or your organisation unless you agree so in advance.
- The digital recording will be transcribed 'out of house' (to protect confidentiality) and will be wiped clean as soon as it has been transcribed.
- All typed transcripts will have identifiers (names, place names) removed and will be stored in a password protected computer.

To maintain the quality of the data that we collect we will do the following:

- Minimise 'research fatigue' for interviewees by sampling appropriately, being clear about the purpose of the interview, avoiding unnecessary duplication of questions, and give genuine choice to decline the invitation to be interviewed.
- Balance the demands of confidentiality with the need to share learning.

If you would like any further information please contact:
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APPENDIX 2: THE HOUSE MODEL