

Progress Report: Evaluation of the National Integrated Care Pilots

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Foreword by the Department of Health

Better integration of providers is increasingly being seen, both nationally and internationally, as an effective approach to delivering services in a way that best meets the needs of individuals and makes effective use of resources. The recent white paper *Equity and Excellence* proposed a vision for health services that included the creation of the Public Health Service, the empowerment of GPs to commission services and new responsibilities for local authorities. For each of these to be successful will require some form of integration and more effective partnership working across all sectors.

The NHS alone cannot tackle health inequalities and challenges such as the ageing population. The Programme of Integrated Care Pilots is an excellent showcase not only of integrated and personalised services, but also of clinical leadership and innovation. The pilots are all locally driven according to clinical need and demonstrate excellent and innovative relationships, which have been established for the benefit of the patient or service user. A number of the pilots are led by Practice Based Commissioning (PBC) consortia and are well-placed for the proposed GP Commissioning arrangements. Such clinicians are in the driving seat on decisions about services and the evaluation is starting to show that GPs (and other clinicians) involved with the pilots are taking on new responsibilities around whole-system care. It is imperative against this changing environment that the lessons learned from the pilots are shared across the health and social care community to help others.

It will come as no surprise to many that better integration is not easy and there can be a number of challenges - from the development of organisational form and infrastructure to cultural difference. However, the benefits can be more rewarding from both a patient and service perspective, and there is an appetite among frontline staff to explore integrated working.

This independent evaluation will provide a valuable addition to the evidence base for integration and will support commissioners in the future. The final evaluation report is expected at the end of 2011. It is key to continue to share the ongoing learning both prior to and following the final report in order to support consortia in considering different options for integration locally.

Preface

This document has been prepared by RAND Europe and Ernst & Young for the Department of Health. The information contained in this document is derived from public and private sources (e.g., staff interviews and Living Documents) which we believe to be reliable and accurate but which, without further investigation, cannot be warranted as to their accuracy, completeness or correctness. This information is supplied on the condition that RAND Europe and Ernst & Young, and any partner or employee of RAND Europe and Ernst & Young, are not liable for any error or inaccuracy contained herein, whether negligently caused or otherwise, or for loss or damage suffered by any person due to such error, omission or inaccuracy as a result of such supply.

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Executive Summary

The programme of Integrated Care Pilots (ICPs) is a two-year Department of Health (DH) initiative that aims to explore different ways of providing integrated care to help drive improvements in care and well being. This report is not intended to contain interim conclusions but to provide information about the evaluation activities conducted, the data collected and the analyses completed. It therefore summarises the evaluation and reflects on the development of the ICP programme to date. It concludes with a summary of impressions and an outline of the following stages of the evaluation. It is primarily of interest to the stakeholders involved in the Pilot programme – the Department of Health, the ICP Measures and Evaluation Steering Group (MESG), and, of course, the ICPs themselves. Others interested in the processes involved in evaluating complex interventions and programmes in health and social care and integrated care in particular, may also be interested.

The evaluation involves both qualitative and quantitative research designed to clarify what the ICPs are doing, how they are going about this, what effort is required, and what are the types and scale of outcomes. We have balanced the need for both breadth and depth by collecting a common set of data across all sixteen ICPs and investigating six in greater depth (the so-called 'Deep Dives').

Some summary highlights as of 1 June 2010:

- Three Living Document data collection rounds have been completed, analysed, synthesised and fed back.
- Interviews have been conducted with 135 ICP staff in Deep Dive sites.
- The first round of patient interviews at Deep Dive sites commenced in April 2010, and interviews at three of the five sites participating are complete.
- Data on hospital utilisation has been collected from national Hospital Episode Statistics (HES) for 11 of 16 Pilot sites.
- Ten sites sent out a structured questionnaire to patients/service users between autumn 2009/early spring 2010.
- All sites have sent out staff questionnaires.
- Local evaluation metrics have been received from 14 of the 16 sites (self-evaluations).

So far, the evaluation activities have progressed to plan. Securing ethics approval, and dealing with the subsequent amendments following the decision to collaborate with The Nuffield Trust, were time consuming and required more

resources than expected. Some further delays arose as some ICPs took longer to establish themselves than they expected. In particular, we were unable to contact patients and service users until the ICPs had identified them. Despite these challenges, on balance we are satisfied with progress to date and the ICP teams have worked closely and effectively with the evaluation team.

Each ICP has completed 'Living Documents' (LDs) on a regular basis, in which they identify and reflect upon their progress. LDs have provided increasingly rich and reflective material. Not surprisingly, early responses were comparatively thin, but these have become more detailed with further rounds. We are also beginning to gain an understanding of what the ICPs know about their costs through the LDs (although this will be substantially supplemented through other means).

Each site has sent out staff and patient/service user questionnaires. Their distribution has been timed to balance the need for Pilots to have begun establishing themselves and identifying target populations, and the need to capture data relating to the situation before the ICPs had made a significant impact. The same is true of the interviews; we were able to interview staff earlier than patients, carers and users. Over 135 interviews have been conducted and analysed.

We have collected aggregated cost data from every site and we will continue to refine our understanding of these costs. We will also carry out a detailed cost analysis on two of the six Deep Dives and supplement this with cost information from all Pilots, based on service utilisation data; the information about activities contained in the staff and patient questionnaires; and the impressions of the ICPs themselves, communicated through the LDs.

Our impressions so far of the progress of the ICPs can be summarised as follows:

- **Context matters:** Each ICP is deeply influenced by the personal journeys of its leaders, the inter-institutional histories of the partners, local geographical, social and economic circumstances and the evolving national policy context. Any generalisations and recommendations will need to be sensitive to this.
- **Clusters not models:** We are not thus far seeing solid and distinctive models of integrated care emerging. Instead we are seeing a more fluid process of adaptation to a changing environment in pursuit of some broad overarching aims and values. Bringing care closer to patients, providing support for more preventive interventions and strengthening and simplifying informed choice are all being pursued, but in different ways.
- **There exists an appetite for collaboration:** In every ICP there are examples of professionals collaborating well and, despite anxieties about standards, professional accountability and governance, the willingness to find integrated solutions is apparent. Whether this will be easy to sustain is yet to be seen.
- **Building the infrastructure can be demanding:** In the early months, the ICPs have focused on building a platform for integration and it will be

interesting to see how the focus of attention can be moved from this activity to a focus on changing the experiences and care of service users.

- **Decision-makers work with limited cost data:** The LDs and our follow-up interviews reveal that decision-makers are by no means careless about costs, but they struggle to find reliable and readily available cost information.

Next steps

Over the next 12 months the evaluation will continue to take shape as the second round (providing the 'after') of various methodologies will be carried out.

The key steps to the evaluation completion are as follows:

National Evaluation

- A systematic analysis of all the completed Living Documents, identifying both changing strategic intent over time and the final cluster of activities adopted
- The second round of the staff questionnaire and a systematic comparison of the ICPs with the national picture
- The second round of the patient/service user questionnaires and a systematic comparison of the ICPs with the national picture
- Further analysis of documentation from the Pilots
- Interrogation of service utilisation data revealing difference (in difference) between ICPs and comparable areas outside the ICPs
- Examination of the local metrics produced by the Pilots.
- Cost data collected through the LDs and computed through service utilisation data and estimated through staff and user questionnaires to be analysed

Deep Dives

- The second round of staff interviews
- The second round of patient/user interviews
- Analysis of non-participant observations
- Models of changing service configuration and their costs and consequences

This report was submitted to the Department of Health (DH) in June 2010 to provide a summary of the progress made on the evaluation of the Department of Health Integrated Care Pilots (ICPs). Since this time the DH has made a number of changes to the evaluation scope which is detailed in the stand-alone Summary entitled: Executive Summary: Progress Report on the Evaluation of the National Integrated Care Pilots. We are confident that the integrity of the approach shaping our evaluation remains intact.

CHAPTER 1 Introduction

This document informs the Department of Health (DH) and the Measures and Evaluation Steering Group (MESG) of progress made by the evaluation team to date. It is intended to provide information about the evaluation activities conducted, the data collected and the analyses completed. It will be of interest to the DH, the Pilots, and all involved in supporting the implementation of the Pilots, but its primary purpose is to inform the DH of progress. The design of the evaluation focuses on understanding the changes resulting from the activities of the Pilots. At the time of writing, some of the Pilots have only recently entered implementation stages, and this document should be read in this context.

1.1 Background

Demands on health and social care are changing in line with demographic change: there are more people with long-term and/or multiple health problems, and more people seeking support from both health and social care agencies. Rising levels of obesity and more sedentary lifestyles may make this worse. People with physical and learning disabilities, carers and multi-agency support for children may all anticipate and demand more integrated care – thus raising expectations of what services can deliver. Services are adapting to meet these changing needs and expectations.

Emphases on early intervention, prevention and support have been apparent in recent decades and these were reinforced in the NHS Next Stage Review led by Lord Darzi.¹ The expectation was articulated that once-fragmented services could be coordinated and ultimately integrated to provide supportive, person-centred care that facilitates earlier and more cost-effective interventions. These interventions should benefit the individual, their carers, the wider system of health and social care and, ultimately, society as a whole. Integrated care has therefore been identified as one way of addressing these changing and growing demands and some (often short-term and disease-specific) evidence is promising. However, there remain significant gaps in the evidence base and we have yet to understand the full dynamics of more widespread and long-lasting efforts. The evaluation is intended to reduce these gaps and to improve our understanding of what can be expected of integrated care, and why. We begin this report with an update on recent policy and literature.

¹ High quality care for all: NHS Next Stage Review. Cm7432. London: Department of Health. 30 June 2008.

1.2 Update on recent policy and literature

Since the commencement of the Integrated Care Pilot programme in April 2009, integrated care has remained both a focus of academic research and a policy interest of all three main political parties.² The DH has continued to provide support for local care integration beyond the 16 Pilots, with practical tools and recommendations for commissioners in planning such services, particularly for people with long-term conditions.^{3 4}

We have always aimed to locate the findings from this evaluation within the wider emerging literature. Our original protocol identified this context but since then further relevant material has been published, and it is worthwhile noting it here. Recent literature has explored the state of integrated care in the UK and internationally, and has contributed further suggestions for improving and implementing such programmes. A few notable reports that we will draw upon in our final report are noted here.

A March 2010 study, published jointly by The Nuffield Trust and the King's Fund examined potential models of integrated care (touching on those enacted by the 16 DH Pilot sites). They concluded that organisations combining commissioner and provider roles offer the most promise for aligning incentives to produce efficient care across primary, community and acute services. (It is worth noting that this conclusion of The Nuffield Trust in no way influences the technical support being provided by Nuffield as part of our quantitative analysis of service utilisation). The authors also noted that if integrated care organisations (ICOs) are to become an effective force within the NHS and succeed as a model of care where others have failed, significant reform to the GP contract may be needed to embed new incentives for integrated care. Another option could be giving Primary Care Trusts (PCTs) greater discretion over the retention of GP contracts.⁵

The Health Services Management Centre at the University of Birmingham organised a seminar in June 2009, focused on the evidence for care integration and the current policy context within the NHS. Reports on key learning points emphasised evidence that integration improves clinical outcomes but that the impact on costs is mixed. There is some evidence that larger physician groups are more effective in delivering recommended care management processes than smaller groups are. The authors concluded that integrated care may not be a panacea, but that it has an important contribution to make in ensuring that

² Humphries, R. 'Election 2010 and Adult Social Care – Policies and Prospects', *Journal of Integrated Care*, Vol. 18, No. 2, Apr. 2010, pp.12–16.

³ Department of Health (DH), *Improving the Health and Well-being of People with Long Term Conditions: World Class Services for People with Long Term Conditions: Information Tool for Commissioners*, January 2010. As of 4 June 2010:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111122

⁴ Department of Health (DH), *Supporting People with Long Term Conditions: Commissioning Personalised Care Planning – a Guide for Commissioners*, 2009. As of 4 June 2010:
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093360.pdf

⁵ Lewis, R. Rosen, R. Goodwin, N & Dixon, J., *Where Next for Integrated Care Organisations in the English NHS?* London: Nuffield Trust, 30 March 2010. As of 4 June 2010:
http://www.nuffieldtrust.org.uk/members/download.aspx?f=/ecomm/files/Where_next_ICO_KF_NT_230310.pdf

resources are used as effectively as possible and that the quality agenda set out for the NHS is delivered.⁶

Syson and Bond examined eight 'integrated health and social care teams' managed by Salford City Council and Salford Primary Care Trust to support older people and vulnerable adults.⁷ Teams are aligned with GP practice-based commissioning clusters. The researchers found that the teams had achieved improved access to and delivery of services; however, challenges were seen in the management and resolution of boundaries between the professions. Overall, co-location and proximity helped generate transfer of knowledge and development of shared practice focused on delivering more appropriate interventions for service users.

A December 2009 paper by Ham and Oldham examined experience in making use of Health Act flexibilities and care trusts.⁸ Flexibilities introduced under Section 31 of the Health Act 1999 allow one authority to transfer resources to the other, which then leads in the commissioning of both health and social care; integrated provision, under which one authority takes responsibility for the provision of both health and social care; and the pooling of budgets where one authority manages a single budget on behalf of both. Concentrating on three areas because of their priority given to health and social care integration – Knowsley, North East Lincolnshire and Torbay – the authors drew on discussions from a series of seminars at which the experience of each area was presented and reviewed, and they identified a number of emerging lessons for the future of service integration. The paper highlighted the need for integration, examined the implications for policy and the need for policy coherency, and urged ministers to avoid prescribing structural solutions and to focus instead on service users. The authors concluded that failure to work in partnership should be viewed in the same light as failure to achieve other objectives, including financial balance and standards of care.

Researchers at the University of York carried out a literature review on international financial and resource mechanisms to integrate care (1) within health care and (2) across health and social care.⁹ Integrated resource mechanisms (IRMs) were identified and assessed from an economic perspective. The researchers found that few studies evaluated the effect of IRMs on health outcomes, and those that did provided mixed results. Improvements in carer burden, carer and patient satisfaction and functional independence were reported, but most studies that assessed health impact found no effect. There was some evidence of improvements in process

⁶ Ham, C. and D. de Silva, *Integrating Care and Transforming Community Services: What Works? Where Next?* Birmingham: University of Birmingham Health Services Management Centre, HSMC policy paper 5, September 2009. As of 4 June 2010: http://www.hsmc.bham.ac.uk/publications/policy-papers/Ham_and_de_Silva_PP_5_pdf_Policy_Paper.pdf

⁷ Syson, G. and J. Bond, 'Integrating Health and Social Care Teams in Salford', *Journal of Integrated Care*, Vol. 18, No. 2, April 2010, pp.17–24.

⁸ Ham, C. and J. Oldham, 'Integrating Health and Social Care in England: Lessons from Early Adopters and Implications for Policy', *Journal of Integrated Care*, Vol. 17, No. 6, December 2009, pp.3–9.

⁹ Weatherly, H., A. Mason and M. Goddard, *Financial Integration across Health and Social Care: Evidence Review*. Scottish Government Social Research. Edinburgh: University of York, Centre for Health Economics, 2010.

measures, such as hospital admissions and delayed discharges, and weak evidence that IRMs could achieve cost savings. In the implementation period, staff satisfaction sometimes fell and costs increased. The review found tentative evidence that financial integration can be beneficial.

Turning Point assessed the economic savings available from integrating a broad range of health, housing and social care services.¹⁰ It identified significant evidence that integration created efficiencies and savings, with early intervention services potentially saving the NHS up to £2.65 for every £1 spent. The report *Benefits Realisation: Assessing the evidence for the cost benefit and cost effectiveness of integrated health and social care* reviews evidence from the UK and abroad. The evidence presented supports the claims that:

- Early intervention through housing-related support is highly cost-effective
- The evidence for case management is positive, particularly in reducing hospital admissions and delaying residential care placements among older people and people with long-term conditions
- There is a strong business case for integrated health and social care teams serving local neighbourhoods and supporting people with complex needs

Atun, de Jongh and colleagues presented findings of a systematic review exploring a broad range of international evidence on the extent and nature of integrating of targeted health programmes and specific interventions into critical health systems functions.¹¹ The authors found that in practice, health systems combine both non-integrated and integrated interventions, but the purpose, nature and extent of integration vary enormously between different interventions in countries, creating a diversity of local solutions to address (with varying degrees of success) emergent problems. They suggested that the modest amount of evidence on programme effect creates the context for strong opinions for or against integration in global health.

The more recent literature reflects a longer-running optimism regarding the intuitive ability of integrated care to deliver improved and/or more efficient services. For policy makers and practitioners, there remain at least two difficulties with the existing state of knowledge: it is not clear how best to remove the barriers in the way of creating more integrated care, and the evidence base showing the costs and consequences of specific efforts to integrate care remains patchy.

Possible ways to overcome some of the barriers to implementing integrated care are captured in a recent review of the literature on the dissemination of evidence-based practices.¹² These identify, from the wider literature, the

¹⁰ Turning Point (2010) *Benefits Realisation: Assessing the evidence for the cost benefit and cost effectiveness of integrated health and social care* London: Turning Point.

¹¹ Atun, R., T. de Jongh, F. Secci, K. Ohiri and O. Adeyi, 'A Systematic Review of the Evidence on Integration of Targeted Health Interventions into Health Systems', *Health Policy and Planning*, Vol. 25, No. 1, Jan. 2010, pp.1–14. As of 4 June 2010: <http://heapol.oxfordjournals.org/cgi/reprint/25/1/1>

¹² Yuan, C. T., Nembhard, I.M et al. *Blue print for the Dissemination of Evidence-Based Practices in Health Care*. New York: The Commonwealth Fund. Pub 1399. Vol 86.

generic characteristics of successful improvement activities (not specifically linked to integrated care, but compatible with the experiences of the ICP so far) and cover:

1. Highlighting the evidence base and relative simplicity of recommended practices
2. Aligning campaigns with the strategic goal of adopting organisations
3. Involving opinion leaders in 'championing' integration
4. Securing a credible coalition of sponsors
5. Achieving a threshold of participating organisations to maximise network exchanges
6. Developing practical implementation tools and guides
7. Creating networks to foster learning opportunities
8. Incorporating monitoring and evaluation milestones and goals

To varying degrees we can see that the ICPs reflect these generic lessons. However, it remains the case that, as Atun, de Jongh and colleagues note, the opinions surrounding integrated care cannot exceed what can be justified by the evidence base. This is partly because many advocates (including some of the leaders of the ICPs) have personal experiences or insights that lead them to believe that their approach to integrated care will deliver benefits. We do not by any means discount these experiences and insights and indeed seek to draw upon them through our interviews, questionnaires and Living Documents. Furthermore, the recent literature reinforces the view that a 'one-size-fits-all approach to integration should be avoided'.¹³ But although there is no single model to be universally adopted, there can be a common pool of evidence and argument to be drawn upon when adapting integrated care to local circumstances. Therefore, we need to build the evidence base as well as draw upon it. Evidence remains incomplete and patchy and we believe that, without answering all the questions associated with integrated care, our final report will contribute significantly to this evidence base, and we will relate this new evidence specifically to the needs of decision-makers in and around the NHS.

1.3 About the DH Integrated Care Pilots and our evaluation

The table below outlines the 16 ICPs selected to participate in the DH programme.

¹³ Weatherly, H. Mason, A. Goddard, M and Wright, K (2010) *Financial Integration across Health and Social Care: evidence review* Scottish Government Social Research.

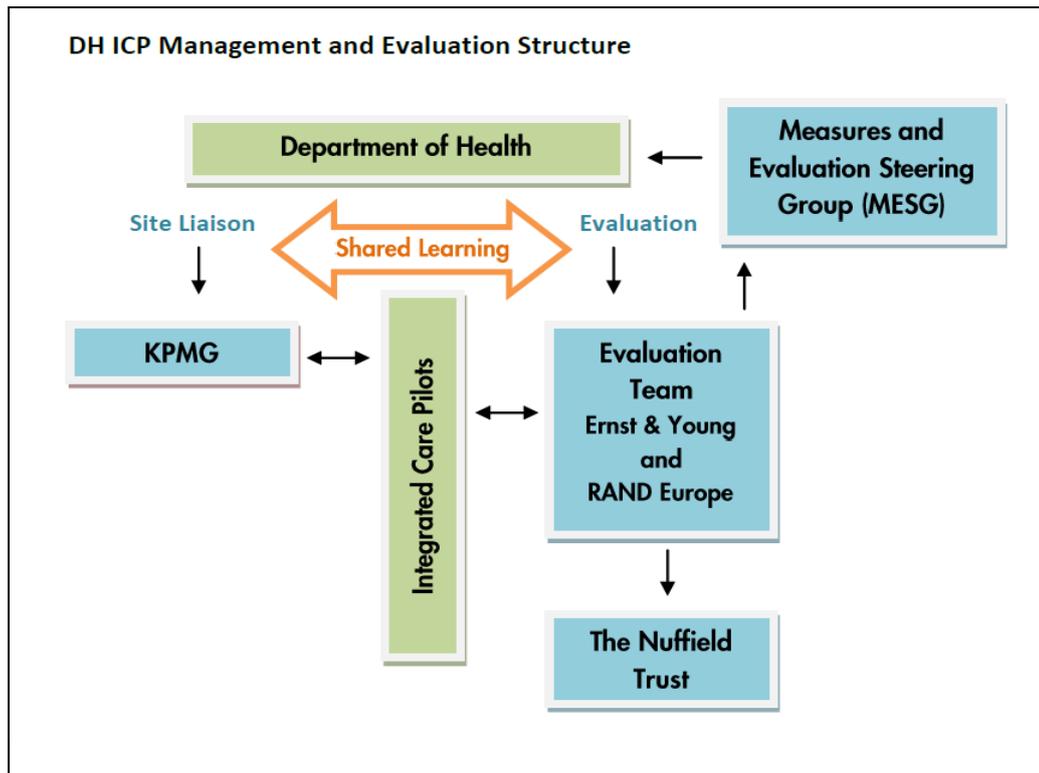
Table 1.1 The 16 initiatives selected to participate in the DH ICP programme

Pilot	Intervention focus/ patient group
Bournemouth and Poole	Structured care for dementia
Cambridgeshire (Cambridge Assura)	End of life (EOL) care and diabetes
Church View Medical Practice (Sunderland)	People at risk of admission (elderly)
Cumbria	People at risk of admission (self-management)
Durham Dales	Reclassification of acute hospital as community hospital Reduction of care inequalities
Newquay	Memory clinic and other support for people with dementia
Northamptonshire Integrated Care Partnership (NENE)	People at risk of admission to hospital (long-term conditions)
Norfolk	Long-term conditions
North Cornwall	Mental health care
North Tyneside	Falls in over-60s
Northumbria	Chronic obstructive pulmonary disease (COPD)
Principia Partners in Health (Nottinghamshire)	People at risk of admission COPD
Tameside & Glossop	People at risk of cardiovascular disease (CVD) People with CVD
Torbay	Elderly in hospital People in nursing homes with COPD/ congestive cardiac failure (CCF) Low-level dementia
Tower Hamlets	Structured care for diabetes (self-management)
Wakefield Integrated Substance Misuse Services (WISMS)	Substance misuse

 *Deep Dive site (see Chapter 2: Methods)*

The ICP programme is led by the Department of Health with programme management support and site liaison provided by KPMG. The ICP evaluation is managed by Ernst & Young (EY), while the evaluation itself is carried out by RAND Europe. Together, EY and RAND comprise the ICP evaluation team. The team has subsequently subcontracted The Nuffield Trust to provide national data for use with quantitative analyses. The DH Measures and Evaluation Steering Group (MESG) oversees the evaluation and provides both external viewpoints and support. All key steps in the evaluation have been discussed and agreed with the MESG. Figure 1.1 shows the organisational structure of the ICP management and evaluation.

Figure 1.1 Organisational structure of the DH ICP management and evaluation



The evaluation of the DH ICPs aims to answer the following questions:

- What approaches to integration have been employed by the Pilots?
- What approaches to integration work well and in what contexts?
- Who benefits from integration, in what ways, and with what consequences for equity (what definitions are there of 'success')?
- What resources are required to make integration succeed and how can these be efficiently used?
- In delivering integrated care in England, what policies and practices are: the most **suitable** (that is, 'fit for purpose'/likely to deliver the intended outcome); the most **feasible** (that is, capable of being implemented given the existing architecture of delivery and accountability); and most **acceptable** (that is, likely to generate the support of patients, users, clinicians, managers and the wider public)?

The evaluation consists of a number of interlocked activities, including the collection of both qualitative and quantitative data, and data collected from all sites as well as more detailed data from Deep Dive study sites (see Chapter 2 *Methods*). The evaluation seeks both to quantify the benefits (and their implications for equity) associated with the Pilot programme and to understand how changes have been brought about, including factors that have enabled change and factors that have acted as barriers to change. The methods are described in detail in the following chapter.

1.4 Significance of the ICP evaluation and what it seeks to achieve

As noted in the background section, the belief that integrated care can deliver efficient and effective improvements in health and social care has arguably outstripped the modest amount of the evidence to support this. The DH therefore determined that an evaluation would be conducted alongside the programme to establish and support the ICPs. It is important to restate three features of this evaluation in order to understand its significance. The evaluation is to be formative, summative and in real time.

First, the evaluation is to have a formative dimension. That is to say, it should deliver, during the life of the programme, a steerage or corrective role. This is characteristically used when a programme wishes to evolve and develop. This process of adaptation rules out some evaluation designs – for example randomised controlled trials or quasi-experimental approaches (but does not preclude their use as one part of the evaluation). The evaluation itself must pay attention to the processes in the Pilots, but must also be able to provide a description of how the evaluators influenced the Pilot.

This role was built into the design of the ICP scheme and into the design of the evaluation. The evaluation team has aimed to communicate with the Pilots, in particular in relation to:

- Clarifying Pilots' goals and surfacing different focuses chosen by sites
- Understanding the different approaches to integration taken by other ICPs
- Understanding how different approaches function in their different contexts
- Identifying successful (and less successful) activities associated with these approaches
- Locating the activities within the wider evidence base, encouraging reflexivity and learning

More specifically, we have supported three areas of learning for the ICPs:

1. Feedback to individual Pilots – allows reflection on progress
 - *Learning within each **project***
2. Feedback to support programme-wide collaborative learning
 - *Learning within the **programme***
3. Comparing and contrasting existing ICP practice with wider evidence
 - *Learning within the wider **scientific community***

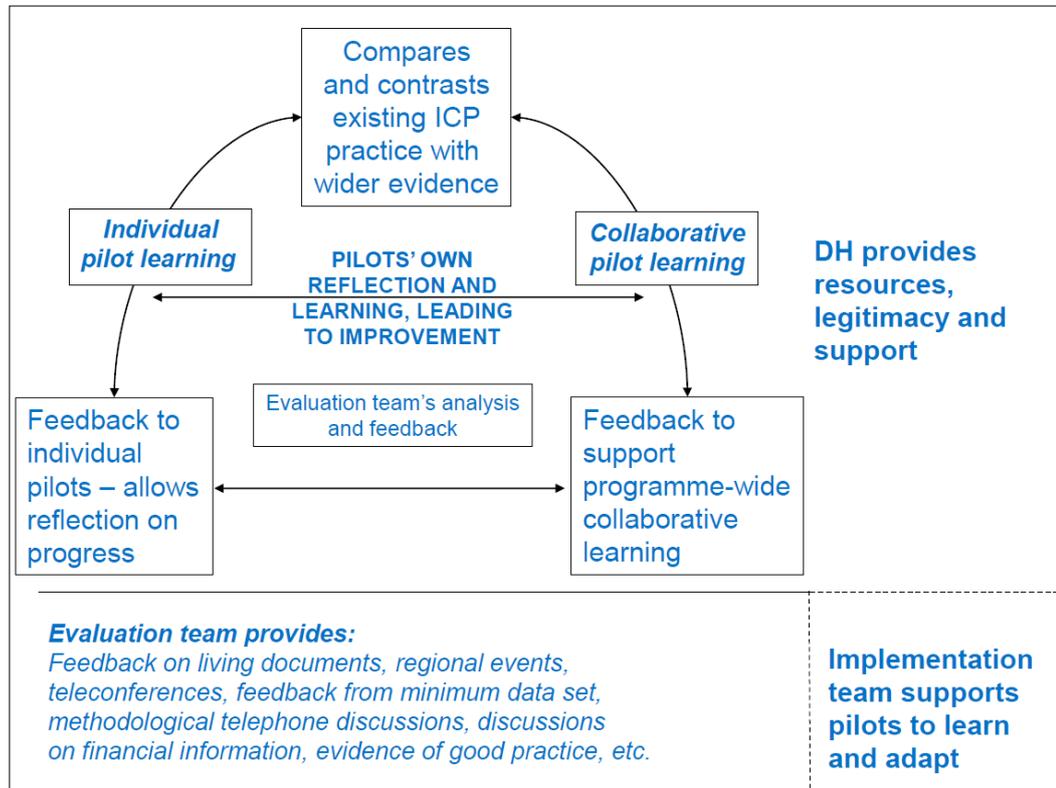
We have used the following tools to support learning:

- Written feedback on Living Documents
- Participating in regional events and learning networks
- Teleconference on evaluation matters with sites
- Feedback from the quantitative data set collected by each ICP
- One-to-one methodological telephone discussions

- One-to-one discussions on financial information
- Providing evidence of good practice

Our approach is summarised in Figure 1.2.

Figure 1.2 Summary of the evaluation team’s approach to supporting learning



The second feature of the evaluation is that it should provide summative conclusions that address the following key evaluation questions: what resources were required; what was done with these resources; what were the consequences; and was it worth it. Of course, fulfilling this role requires the evaluation to be independent. The formative role described above can challenge this independence. However, there is an effective system of checks and balances designed to address this.

Furthermore, the evaluation team aims to publish their findings and will therefore in due course be submitting it's findings to external peer review. The evaluation protocol has already been accepted for publication. The individual analysts conducting the research all adhere to, and expect to be judged by, the highest academic standards. The final check is provided by securing ethics approval, which guarantees that the approach has been independently judged for its ethical content.¹⁴

¹⁴ The evaluation team uses the RAND Europe Quality Assurance process, which provides internal expert peer review. RAND Europe has a long tradition of high quality work, and this is

The third feature that should be noted relates to the fact that the evaluation takes place in real time. The wider evidence base, policy context, and local circumstances have all changed since the start of the evaluation and will continue to evolve. In particular, the wider context of public finances has changed, and Pilots that may have been conceived in times of anticipated plenty are being delivered in a context of financial constraints. Consequently, evaluation questions may also evolve in recognition of these changes.

In the following chapter we outline in more detail the approach underpinning the evaluation and the methods used.

supported by a quality assurance system that itself is subject to frequent review and improvement. The most recent version of RAND's quality standards can be found at www.rand.org/standards/ (As of 4 June 2010). There are two QA reviewers: one a continuous reviewer to ensure quality as the work progresses, and one 'final' reviewer to review products and reports as they are produced.

In addition, RAND Europe has undergone the process of ISO certification. ISO (International Organization for Standardization) is the world's largest developer of standards. It is primarily concerned with 'quality management' through meeting customer and applicable regulatory requirements and continually improving performance in this regard. This means that all of the procedures within RAND Europe, from research process to administration, are independently quality assured.

CHAPTER 2 Methods

In this chapter we revisit the methods used in this evaluation, paying particular attention to developments since the original proposal was agreed, and explaining the thinking behind these developments. It was always anticipated that some evolution of methods would be desirable in the light of experience. The fundamental approach, however, remains unchanged.

2.1 Approach

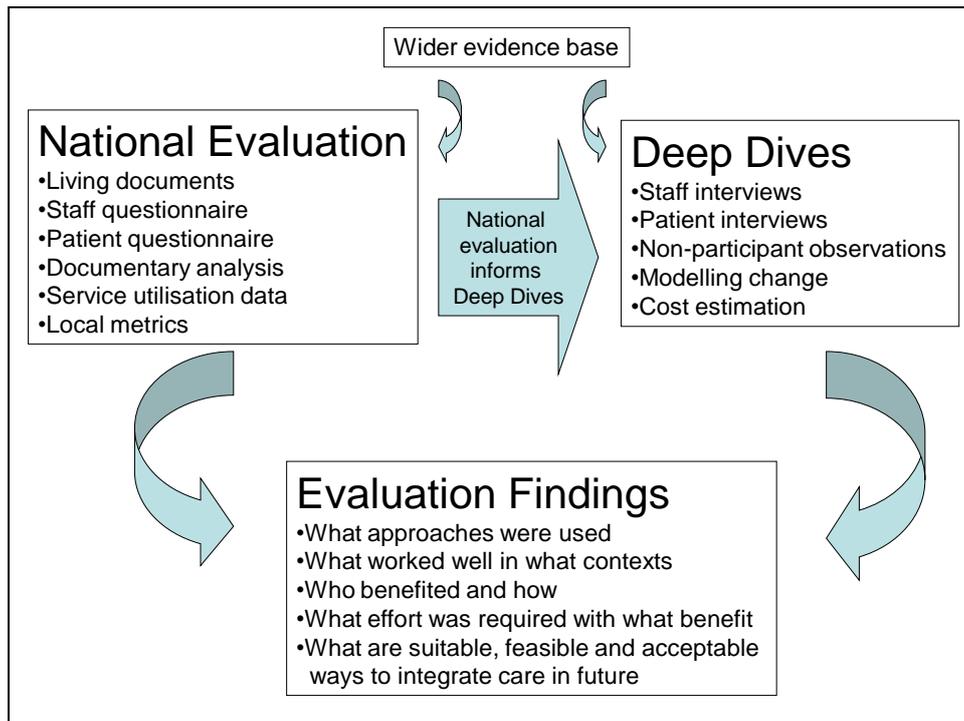
The approach described here is of the **embedded evaluator**, where the evaluation activities are a distinct strand within the Pilot programme, helping to **co-produce** the successful delivery of the programme, rather than being a separate study focused solely on contributing to the scientific understanding of integrated care. However, it is important that this evaluation contributes to scientific understanding and that it generates valid and independent evidence to support decision-makers in judging the implications of the Pilot programme for the future direction of policy. In what follows, the approach is to find a suitable balance between the need to contribute to learning and improvement within the programme as it evolves, and the need to arrive at summative conclusions independently of the other players involved in delivering the programme. As an evaluation process it is equally concerned with providing a stream of 'real time' evaluative evidence and with delivering a single study after programme implementation. It also aims to balance breadth and depth.

For clarity, in this chapter we outline the evaluation approach and methods and in the following chapter we identify the progress made to date.

2.2 Methods

This is a mixed methods evaluation combining data collected across all Pilot sites in the national evaluation, with more detailed data collection and analysis in six detailed case studies (or Deep Dives). We will consider findings in the light of the wider literature before analysing the data to answer the five evaluation questions outlined in chapter 1. These evaluation methods are summarised in figure 2.1 overleaf.

Figure 2.1 Summary of evaluation methods used



2.2.1 Building a minimum dataset for each Pilot: the role of the Living Document

The Department of Health agreed that Pilots receiving funding would be required to collaborate with the evaluation team in developing a minimum data set. This minimum dataset involves the Pilots maintaining a Living Document (outlined below), participating in staff and patient questionnaires by identifying respondents, and supporting the quantitative arm of the analysis through the collection of quantitative data. Figure 2.1 shows the national measures (that is, the quantitative measures to be collected by all ICPs except where clearly inappropriate) feeding into the Living Document, the Living Document summarising local experiences and additional local measures also feeding into the Living Document. The evaluation team is responsible for analysing the national measures, for supporting the ICPs in producing the Living Document and (as described below) conducting more detailed analysis at the Deep Dive sites. It is also responsible for ensuring that the relevant ethics and research governance arrangements are in place. The questions listed in the Living Document are outlined below in table 2.1.

Table 2.1 Summary of questions/themes in the Living Documents

Question/theme	Purpose
Developing the Pilot and background information	To explore the motivations and expectations of the Pilot team
Who is doing what?	To enable the evaluation team to understand who is carrying out specific roles within the collaboration to provide integrated care
Processes	To produce a descriptive account of the processes of integration
Outputs and outcomes	To identify successes and positive developments as the project evolves
Is the Pilot progressing to plan?	To encourage comments on actual progress against planned progress
Sustainability	To understand what plans the Pilot team have put in place to ensure the long-term sustainability of their project and how these plans are evolving as the project develops
What difference is the Pilot making?	To understand the ways in which the project is making a difference to patients'/carers' lives, what positive impacts it is having on the region and how the Pilot activities compare to work being undertaken elsewhere
What are the cost consequences of the Pilot?	What have the Pilot management and activities cost to date and how are expenses being controlled by the Pilot team

ICPs are asked to complete the Living Document in line with the eight questions/themes set out above and to update this throughout the lifetime of the Pilot. Each Pilot has been asked to submit this Living Document (a key component of the minimum dataset as described above) at various times so that we can assess learning and evolution of site management thinking over time. The sequence of Living Documents, and progress to date, are outlined in Chapter 3.

The Living Documents (LDs) provide an important way for the evaluation team to understand the motivations, analyses, experiences and expectations of those leading the Pilots. There will be a total of six rounds of LD collection and analysis. On each occasion, the evaluation team provides specific feedback to each Pilot. There is no intention to comment on the success or otherwise of each Pilot, nor to judge one against the others. Rather, evaluation team feedback focuses on how comprehensible and complete the LD is. In addition, we provide summaries of each round, entitled thematic reviews (examples of the summary documents for rounds two and three are annexed to this report). The thematic review provides the DH with an update on ICP progress and is intended to stimulate learning and discussion within each Pilot and across the programme as a whole.

Prior to each thematic review, two researchers individually read a sample of the LDs and draft their comments and summary feedback. These comments and summaries are then discussed with the task leader and a shared approach is agreed. In preparing this document, all the LDs are read again by the task leader and common themes are identified. The summary comments are then

re-read along with the Site Periodic Reviews to ensure that important themes have not been missed.

2.2.2 National quantitative data collection

The ICP evaluation includes three elements of quantitative data collection:

- Hospital utilisation data
- Patient/service user questionnaires
- Staff questionnaires

The quantitative evaluation seeks to quantify the scale of any changes, focusing mainly on hospital utilisation, and comparing the results with a control group of patients (matched by demographic characteristics as well as by their hospital readmission profiles). Data will be taken from Hospital Episode Statistics (HES), both for outpatient, referrals, accidents and emergency and inpatient care (including emergency admissions, ambulatory sensitive admissions and length of stay for selected conditions). This is an important and innovative aspect of the evaluation that The Nuffield Trust has been supporting.

Since completing the June 2009 version of the protocol for this evaluation, there has been one significant addition to the methodology. This piece of work is to be delivered by The Nuffield Trust and is fully integrated into the overall evaluation framework. The evaluation will now include the use of risk prediction methods to assess the impact of integrated care on service use.

The inclusion of the analyses to be carried out by The Nuffield Trust is:

- Adding to the validity of the findings of the existing analyses
- Enabling new analyses to be carried out which will extend the range of conclusions that can be drawn from the existing analyses.

The data to be collected for this analysis consists of a list of patients included in the Pilot at six-monthly intervals. For each person in the list the Pilot sites have been asked to extract:

- The patient's NHS number (which the evaluation team will not see)
- Year of birth
- Sex
- Post code
- Code of the practice with which they are registered

These new analyses relate principally to hospital utilisation data (admissions, referrals, use of A&E) and not to other parts of the current evaluation. It is well understood that a key problem in the type of evaluation so far proposed (in which there is no, or only limited, use of randomised controlled trials or quasi-experimental methods) is the challenge it poses for understanding whether effects seen are actually due to the intervention.

The original evaluation protocol addressed this problem by proposing to look at overall rates of utilisation for general practices included in the Pilots and

compare them in a before-and-after analysis with matched practices in other parts of the country. It sought to locate these utilisation rates within a set of comparator data and to draw upon the experiences of patients and providers to arrive at a plausible understanding of the contribution made by the Integrated Care Pilots to improvements for patients and for the health system. It also sought to understand these contributions in the light of the wider evidence base and the prior expectations of the Pilot teams.

There are a number of threats to the validity of this design that will be mitigated by carrying out the analyses with The Nuffield Trust.

The first risk is that the number of patients enrolled in Pilots is small, and insufficient to make an overall statistically significant difference to practice rates of utilisation. The Nuffield Trust's analyses will identify individual patients in the Pilots and match their utilisation to individual controls in HES. This allows a new question to be answered, namely "Did the intervention work on patients who received it?" This can be seen as an 'explanatory' or 'on treatment' analysis, in addition to the original question of "Did the intervention have an overall effect?" (which is equivalent to a pragmatic analysis). These are both important questions for the NHS. New methods of pseudo-anonymisation developed by The Nuffield Trust allow us to both track patient journeys and to ensure the anonymity of individual patients. This enables individual patient data to be extracted from HES for this type of analysis in a way that has not been possible before.

The second risk is that the analysis does not adequately account for the tendency of high-risk patients to reduce their utilisation over time (regression to the mean). The approach to risk adjustment developed by staff at The Nuffield Trust enable this risk to be reduced. Furthermore, combining these risk adjustment methods with the pseudo-anonymisation methods described in the previous paragraph enables this problem to be reduced further, by allowing one-to-one matching of patients in the Pilots to patients with equivalent risk of hospital admission in control practices.

These two methods will improve the validity of the analyses already agreed by allowing the evaluation team to include risk profiles of patients in the regression analyses (which are already planned), and they allow a new set of questions to be answered, which are outlined in the previous two paragraphs. This will bring a new and innovative contribution to our wider understanding of how health service innovations should be evaluated.

Quantitative data is also being collected through two standardised questionnaires (both 'before' and 'after' Pilot implementation) for both staff and patient/service users. Some of the questions in the staff survey are taken from the NHS Staff survey and this will allow comparisons to be made between ICPs and elsewhere. In 11 of the 16 Pilots, data has been collected from patients/service users, and, in all Pilots, data will be collected from staff. The patient/service user questionnaire includes questions on numbers of GP consultations, community nurse contacts, social care use, and use of out-of-hours services, alongside questions on their experience of the services offered.

The use of a set of national measures enables a rich picture of the outcomes in the Pilots to be drawn and also enables comparisons between groups of

patients with shared characteristics in Pilot and non-Pilot sites. In addition to the national measures, sites have also chosen a number of very specific measures relevant to the aims of their own Pilot, which have been incorporated into this evaluation: for example, the proportion of people dying in their preferred place of death.

Sampling

Each Pilot site has a designated project manager who has assisted in identifying the sample of patients and the sample of staff participating in their Pilot, who were then invited to complete the relevant questionnaire. For the patient questionnaire, we are sampling up to 500 patients per site to ensure sufficiently large numbers to detect a large effect. A number of smaller Pilots will not require this number of patients. To detect a small effect would require a sample of 2,500 patients, which is more than many Pilots are likely to recruit. Therefore a small effect will only be detected using pooled data.

For sites identifying their populations through their presence on a disease register (eg COPD, diabetes), patients/service users are sampled where the number is not likely to exceed 500, and a random sample of 500 has been drawn in those sites where the identified population is likely to exceed that number. For sites that have identified their target population from some type of risk profiling, subjects are likely to be identified sequentially. In this case, we have given questionnaires to all subjects until the target of 500 has been achieved. Follow-up questionnaires will be sent to all subjects in 2011, and in the analysis we will distinguish respondents in terms of their length of exposure to the intervention.

For the staff questionnaire the targeted sample size is 50 staff, although some smaller sites are able to identify only around 25 staff to include in the questionnaire distribution. A range of staff will be sampled to include all the major stakeholders from both health and social care.

Participation

Participation in both questionnaires is entirely voluntary and patients and staff who have been invited to participate receive a cover letter, explaining that participation is voluntary and that the questionnaire will deliver anonymised returns. In the case of the patient questionnaire, the cover letter as well as the questionnaire itself are also explicit in stating that respondents may accept help from a friend or a member of their family to complete it if they so wish.

We have incorporated a number of measures in the study design to ensure confidentiality of respondents. Each Pilot site will be provided with printed copies of the corresponding questionnaire. Pilot sites will also be provided with a list of codes for both patient and staff questionnaires. It is the responsibility of Pilot sites to administer the questionnaires, including assigning a code number to each questionnaire before posting. Posting will also be undertaken by the Pilot site. In that way the national evaluation team will not receive any identifiable patient or staff data.

Additional data

In addition to the above, each Pilot site is being asked to provide the following data:

- Participating GP practices: list size and age breakdown in five-year age bands (e.g., 0–5, 6–10, 11–15), along with the date on which each GP practice enters the integrated care scheme developed by the relevant Pilot.
- Local metrics: each Pilot site is asked to identify two local metrics – measurements or indicators that they aim to use for their own evaluation. Metrics will comprise one process indicator for year 1 and one outcome measure for year 2. The nature of the measure will vary between sites but the evaluation team will not permit the use of any measures that raise ethical issues above and beyond those already identified earlier.

Additional ICP evaluation activities

All ICPs have shown a willingness to conduct additional pieces of local evaluation, adding to the richness of the learning from the programme as a whole and feeding back in real time to support improvement during the life of the programme. The evaluation team will encourage and, where practicable, support this, for example by suggesting appropriate measurement instruments. Although the evaluation team will advise on local evaluations it will not be responsible for assuring the quality of the data or its analysis.

2.2.3 Diving deeper: data collection in the Deep Dives

The six sites: the Deep Dives, from which we are collecting more in-depth information are: Principia, Torbay, Norfolk, Northamptonshire Integrated Care Partnership, Cumbria, and Church View. These were selected as a purposive sample¹⁵ from the 16 Pilots. Selection factors included Pilot activities that had the potential for high impact if implemented nationally, activities considered to be particularly innovative, interventions for which the evidence was lacking and ensuring the sample contained a variety of intervention focuses and target populations.

From these Deep Dives we still draw upon data from the national evaluation, including staff and patient questionnaires, the quantitative metrics, and the LD; however, additional data is also collected from these sites through three interlocked concepts. First, we aim to develop a deeper and more qualitative understanding of the intended logic of intervention, how this evolves and where the barriers and facilitators to successful intervention lie. Second, we are trying to understand and map the patient experience/journey, how this changes and how it produces benefits and/or disadvantage for different participants in the ICP. Third, we will develop a cost estimation focused on the costs of integration (both start-up and delivery) to the organisations within the ICP, identifying both

¹⁵ A purposive sample is a non-representative subset of some larger population, and is constructed to serve a specific need or purpose – in this case, to ensure a sufficient range of approaches were included rather than to secure a ‘typical’ sample.

what costs were anticipated near the start and what costs were estimated once the ICP was functioning. Deep Dive specific data collection activities will contribute to all three objectives (although they will be focused on one or other of these three at one point or another). These activities will provide significant added depth and meaning to the national metrics and LDs that each selected Deep Dive will also be generating.

The additional activities carried out in the Deep Dive sites are:

- Staff interviews
- Patient/service user interviews
- Non-participant observations
- Focused cost estimation and service mapping in a subgroup of Deep Dives
- Mapping the patient experience and cost estimation

Table 2.2 Focus of interviews by interview group

Patient/Service Users and informal carers	Staff (non-financial)	Staff (financial)
<ul style="list-style-type: none"> • Primary focus on mapping the patient journey (with additional information on the logic model¹⁶): • Patient and user interactions with ICP organisations • Patient/user journey • Patient/service user experience • Additional/reduced costs/opportunity costs externalised onto patients or carers 	<ul style="list-style-type: none"> • Primary focus on logic model (with additional information on the patient journey): • Interactions with other professional groups and organisations within the ICO • Experience of delivering care • Understanding of implications for wide care system • Additional/reduced costs/opportunity costs externalised onto patients or carers 	<ul style="list-style-type: none"> • Primary focus on cost estimation (with additional information on the logic model): • Set-up costs • Running costs (best case, worst case, most likely case) • Distribution of costs • Additional/reduced costs/opportunity costs externalised onto patients or carers

¹⁶ A logic model can be a simple or complicated way of laying out the inputs, processes, outputs and outcomes of any intervention or activity. In particular it can support a consideration of the causal pathway linking these stages, For a classic and clear introduction, see W. K. Kellogg Foundation (2001). [http://www.wkcf.org/W. K. Kellogg Foundation Logic Model Development Guide.](http://www.wkcf.org/W.K.Kellogg.Foundation.Logic.Model.Development.Guide)

Interviews

We have used semi-structured face-to-face interviews with selected staff and Patient/Service Users in each in-depth Pilot. The focus of the interviews varies for different interviewees and these foci are outlined in table 2.2.

Staff interviews

The resulting data, from staff interviews, will be interpreted in the light of the staff questionnaires that will also be conducted. The questionnaires will provide wider comparative descriptions of staff attitudes and experiences, and the interviews provide deeper understanding. We considered and discounted the use of focus groups for two reasons: first, we are uncertain about the extent to which experiences will be shared and we are interested in establishing if there are notable differences within as well as between groups. Second, the health and social care system can involve professional and organisational rivalries and differences that might be discussed more easily with individual members of staff.

It is not possible to predefine the identity of all the staff we choose. The first round of interviews has been carried out and will be repeated in autumn 2010. The interviews are semi-structured. To begin with, a total of 10 staff were interviewed; then, using a snowballing approach, an additional 15 interviewees were identified by our initial respondents as key players who should be invited to contribute. The process will be conducted twice to provide a total of about 50 staff interviews in each Deep Dive (providing some 300 staff interviews in six Deep Dives).

In addition to staff interviews, we are interviewing approximately 15 service users or informal carers in each Deep Dive site. For the first round, we have identified patients for interview by inserting a question into the standard quantitative patient questionnaire, inviting patients to tick a box if they would be willing to be contacted for a more detailed discussion about their care. As with the staff interviews, findings from such interviews can be interpreted in the wider context of the patient questionnaires conducted in each Deep Dive. We considered but discounted the use of focus groups because of concerns that patients and carers might be reluctant to share certain experiences with a wider audience. The purpose of these interviews is primarily to understand how their interactions with organisations within the ICP have changed during the operation of the ICP. We are aware of the particular challenges facing some patients in participating and will seek to be supportive. Fifteen service user/carer interviews will be conducted twice over, resulting in 30 user/carer interviews per Deep Dive or 180 service user interviews, assuming no attrition between interview rounds, which is unlikely.

Both staff and Patient/Service User and carer interviews are recorded, anonymised, transcribed and coded according to emerging themes relating both to practical issues reported and to the subjective judgments of interviewees.

Non-participant observation

In addition to the interviews, we have explored the workings of the Deep Dive Pilots through non-participatory observations of key events in all of the Deep Dive Pilots. The key events do not involve carers or service users in a clinical setting but involve meetings where the representatives of the various parts of the ICP interact. For example, these are internal team meetings or external events designed to promote stakeholder understanding or involvement. Their selection will be opportunistic and determined in collaboration with the ICP. The purpose will be to observe how interactions really work: considering potential issues of power, the allocation and acceptance of roles and underlying areas of consensus and conflict. As with the interviews, they will be conducted on two separate occasions and differences between the two occasions will be identified. Notes have been written up in the form of ethnographic field notes¹⁷ and all participants will be informed in advance of the event and at the start of the event, and told how the data will be used in the final evaluation. Efforts will be made to anonymise both the site and the individuals involved, but it will be made clear that full anonymity cannot be guaranteed as there are only a limited number of Pilot sites. The evaluation team will take particular care to exclude data that could be both traceable to one particular person, and harmful to the career or reputation of that person.

Mapping the Patient/Service User experience

The associated step towards digging deeper and arriving at a more complete understanding of the pathways used by each Pilot will be to map the service user journey before and after the intervention. In the first round, this will focus on the existing situation and how it is intended to change. In the second round there will be more opportunities to consider how this has changed. We will draw upon the staff and user questionnaires and interviews, supported by wider documentary evidence, for each Deep Dive and map the changing patient experience. This will provide a tool to support both evaluation and learning. This task will be conducted when the analysis of the staff and user interviews and questionnaires for each Deep Dive is complete. These maps will also feed into the cost analysis. Where the purpose of integration is clearly focused on changing a care pathway, this will allow a different sort of analysis compared with ICPs pursuing more of a change to the whole system.

Equality

The Pilots' formal strategies relating to equality will be identified through the documentary evidence supporting the application and subsequent delivery of the Pilots along with their elaboration of this in the Living Documents. The impact of these will be assessed not only through the Pilots' own data as demonstrated in the LDs but also through patient and staff questionnaires and interviews. There is also a wider dimension to the evaluation, which concerns how to develop a responsive, personalised service that relates positively to

¹⁷ Ethnographic field notes involve the observer maintaining notes describing the behaviour of groups and sub-groups and the observers' reflections on these.

local communities and allocates resources on the basis of need. This would be a service with equality at its core.

2.3 Service mapping and cost estimation in the Deep Dives and across the wider programme

Our original protocol proposed the collection of cost data only from Deep Dive sites, but we now propose to analyse cost-related data from all sites (using both HES data, and information from the LDs) and to collect more in-depth information from a subset of Deep Dives.

We have yet to have preliminary discussions with the Deep Dive sites in this regard, but we anticipate that we will focus on a wider patient group such as older people at risk of admission to hospital, and on a more disease-specific group such as COPD. We plan to use logic modelling¹⁸ and the processes mapping¹⁹, key informant interviews and documentary evidence to develop a map of service users' changing interaction with health and social care, and to use this to produce estimates of the changing costs of providing integrated care. This will provide relatively firm, but illustrative, evidence of the sorts of costs and consequences that can be anticipated from developing integrated services. We also aim to model how services are transformed from one state (pre-integration) to another state (post-integration); what happens to the patient journey in each; how costs vary in each state; and what was required to transform from one state to another. These costs will also be examined against what is known of costs elsewhere (for example, there is now a developing literature on the costs of care at the end of life).

This in-depth analysis will be supplemented by the cost information we are now collecting from all Pilots through the LDs and the analysis of costs associated with service utilisation derived from the staff and patient questionnaires. With the agreement of MESH, we prefer this route to cost estimation to that of using locally held data from primary care. The reason is that our proposed route would allow a good comparison of costs across the sites; while the cost data would contain uncertainties, these would tend not to vary from one site to another. Using locally held data from primary care, on the other hand, is likely to highlight differences which reflect how the data is collected rather than real differences in cost. Since we want to understand the relative differences in the costs and consequences of different approaches to integration, this was felt to be the preferable route. We will use the Deep Dive costing exercise to illustrate the sorts of absolute costs and savings involved.

The aim of this adapted approach is to produce realistic cost estimates that also accommodate inevitable uncertainties surrounding such estimates. Some of these uncertainties are generic to all cost estimates, and some are more specific to the NHS and to social services (and in particular the difficulties of identifying clear cost data). However, in this context we can more reasonably aim to produce a clear understanding of the main categories of cost (staff by

¹⁸ Logic modelling is used widely in evaluating healthcare interventions. See, for example, <http://www.healthscotland.com/scotlands-health/evaluation/support/logic-models.aspx>

¹⁹ For example, see: http://www.cps.gov.uk/publications/finance/process_mapping.html

grade, equipment, building, travel, etc) and the likely range of costs within each category, and subsequently estimate the best, worst and most likely case scenarios. We will also distinguish between set-up costs and running costs (although in a fluid, adaptive and improving system this distinction may be conceptually simple but operationally difficult). As of June 2010, we have developed a more sophisticated cost categorisation, and this is outlined in the following chapter.

Understanding running costs has a number of challenges, but this is only the starting point of an economic evaluation which must also consider consequences and make a judgement about whether the resources could have been better used to achieve the same benefits for patients and service users. This requires us to compare what has actually happened in the Pilot with what could have happened. Producing this 'counter-factual' might typically involve comparing what happened in the Pilot with what happened in similar health systems which did not have integration. Alternatively, a 'before and after' approach might be used. Our approach will be to form a judgement of what would have happened in the absence of the Pilot by drawing upon both comparative data (especially comparing the differences achieved within the Pilot with the differences achieved outside the Pilots), and before-and-after data, along with the judgements of local decision-makers revealed through interviews, LDs and locally produced documentation.

It would seem that, with regard to the current ICP evaluation, there are a number of different outcomes being measured in many of the projects that do not facilitate direct intra-programme comparison. Costing methods, too, are variable, although the standardisation we have imposed on the Living Document should overcome this to a certain extent and should also permit straightforward external comparison with extant studies.

Furthermore, any of the formal methods such as cost-effectiveness analysis (CEA); cost-utility analysis (CUA) and/or cost-benefit analysis (CBA) will not individually capture the entirety of benefits needed to represent effectiveness in this evaluation with its aim of capturing multidimensional, clinician and patient, whole-system benefits. An incremental cost-effectiveness ratio (ICER) or a net present value (NPV) summary statistic, for example, is only capable of expressing one of these dimensions at any time and would be inadequate for the kind of evaluation ICPs require. Furthermore, defining the baseline, or indeed the new system of delivering care, would not be as accurately defined as it would be had the interventions been carried out in more structured, trial-like conditions (but this is certainly not an argument for saying that only trial-like interventions should be a part of the repertoire of health improvement techniques). Raftery (1998)²⁰ described economic evaluation as 'a half-way technology' because of a lack of a standardised approach, and although the technical aspects of such evaluations have developed very rapidly since this conclusion was drawn, we believe no one technique is sufficient for use in evaluating ICP costs.

²⁰ Raftery J. 'Economic evaluation: an introduction' *BMJ* 1998;316:1013-1014.

Coast and others have therefore put forward the 'cost-consequences' approach.²¹ Mauskopf et al (1998) believes this to be a much more useful and flexible approach.²² Using a cost-consequence approach, the impact of each Pilot may be appraised in terms of a number of its different parameters including specific health care service use and costs, productivity losses and health outcomes, etc.

The cost-consequence format is more likely to be accessible, readily understandable and applied by health care decision-makers than a simple ICER (although our precise approach may differ from that of the example shown here). The decision-maker may use selected items from the cost-consequence analysis that meet his/her needs. It will also allow for adaptation to the perspective taken and can be used flexibly in a number of decision settings. In general, the cost-consequence approach, by making the impact of the new treatment as comprehensive and transparent as possible, will enable decision-makers to select the components most relevant to them and will also give them confidence that the data are credible to use as the basis for resource allocation decisions.

With this in mind, we will continue to work with sites to collect data relating to a cost-consequence analysis.

2.4 Summary

The core of the approach outlined in the original evaluation protocol has remained intact. It was agreed at the initiation that this evaluation would follow a fluid process and that certain methods might need to be adapted; and to a limited extent, they have. The introduction of The Nuffield Trust to the team is allowing us to risk-stratify patients and provide a more textured account of what might happen to different groups of patients. We have also moved away from anticipating a discrete number of relatively fixed models of integrated care as units of analysis in the evaluation. Indeed we are now particularly interested in how the underlying mechanisms of integration are associated with the widely shared aims within what appear to be rather different institutional arrangements. Finally, we have moved away from focusing the collection of cost data within the Deep Dives and adopted an approach which will facilitate more comparisons across the Pilots with some detailed illustrations of the absolute costs and benefits that might be achieved using a sub-set of the Deep Dive sites. We discuss the implications of these developments in chapter 4. However, the approach outlined in this chapter fits closely with the original plans, and we believe this is working well.

²¹ Coast J. 'Is economic evaluation in touch with society's health values?' *BMJ* 2004;329-1233-1236.

²² Mauskopf JA, Paul JE, Grant DM and Stergachis A. 'The Role of Cost-Consequence Analysis in Healthcare Decision-Making.' *PharmacoEconomics* 1998;13(3) 277-288.

CHAPTER 3 Progress and delivery to date

In this chapter we outline the evaluation activities completed and compare this with the original plan. It shows that progress is broadly proceeding as intended.

3.1 Deep Dives

3.1.1 Staff Interviews

From September to December 2009, 135 interviews were conducted with staff involved in the ICPs in each of the Deep Dives: Cumbria, Northamptonshire Integrated Care Partnership, Norfolk, Principia Church View, and Torbay. Interviewees were invited to participate by the Pilot managers, and we were able to review these choices to ensure we were satisfied with the selection of staff representing a variety of professions and roles. Some interviewees were involved in the core team and some were not, but the selection criterion was that work experience of all interviewees chosen could potentially be affected by the implementation of the Pilot. The evaluation team coded and analysed the resulting transcripts using NVivo²³ and produced summary outlines for each Deep Dive. We will return to the original transcripts in a year's time and conduct a systematic analysis of changing staff attitudes and experiences at the very early stage of the Pilot and at a more mature stage in its development. The first round of staff interviews was completed between September and November 2009.

The arrangements for staff interviews, with the assistance of project managers in each of the study areas, went smoothly, and timelines originally set out were met (see table 3.1 overleaf).

²³ NVivo is a qualitative data analysis computer software package. It supports qualitative analyses of text-based data.

Table 3.1 Timeline for the first round of staff interviews

	Jul-09	Aug-09	Sep-09	Oct-09	Nov-09	Dec-09	Jan-10	Feb-10
First-round Staff Interviews								
Preparation	■							
Set up and conduct Staff Interviews			■					
Analyse Staff Interviews						■		
Report writing Staff Interviews							■ ●	
Project management	■							
Deliverable ●								

One hundred and thirty-five staff interviews were conducted across the six Deep Dive sites, as shown in table 3.2.

Table 3.2 Staff interviews in the six Deep Dive sites

Site name	Date of staff interviews	Number of interviews
Norfolk	22–24 September 2009	27 interviews
Cumbria	6–8 October 2009	25 interviews
Principia	10–11 and 24 November 2009	23 interviews
Church View	18–20 November 2009	21 interviews
Northamptonshire Integrated Care Partnership	15–16 October 2009	19 interviews
Torbay	29–30 October 2009	20 interviews

Interviews were transcribed verbatim and analysed using NVivo software. For further details of the findings from the first round of staff interviews and analysis conducted, please see Chapter 4, *Early impressions and plans for the next phase of the evaluation*, section 4.1.

The second round of staff interviews will commence in September 2010 and follow the timeline outlined in table 3.3.

Table 3.3 Timeline for the second round of staff interviews

	Sep-10	Oct-10	Nov-10	Dec-10	Jan-11	Feb-11
Second-round Staff Interviews						
Set up and conduct Staff Interviews	█					
Analyse Staff Interviews				█		
Report writing Staff Interviews						●
Project management	█					
<i>Deliverable</i> ●						

3.1.2 Patient/Service User Interviews

The first round of Patient/Service User interviews commenced in April 2010. Interviews have been completed in three of the six Deep Dive sites and are on course to be completed within the timeline outlined below:

Table 3.4 Timeline for the first round of Patient/Service User interviews

	Feb-10	Mar-10	Apr-10	May-10	Jun-10	Jul-10	Aug-10	Sep-10
First-round Patient Interviews								
Preparation	█							
Set-up and conduct Patient Interviews		█						
Analyse Staff Interviews						█		
Report writing Staff Interviews								●
Project management	█							
<i>Deliverable</i> ●								

The process for arranging patient interviews has proved more challenging than anticipated. Many patients have elected to be interviewed in their own home, which has necessitated greater planning for the research team, for example, through the allowance of additional travel time between interviews. Some patients have also had to cancel interviews due to deteriorating health.

To date, a total of 59 patient interviews have been completed as indicated in table 3.5 below.

Table 3.5 Patient interviews in the six Deep Dive sites

Site name	Date of patient interviews	Number of interviews
Norfolk	June 2010	15 interviews (<i>in process</i>)
Cumbria	20–12, 26–27 and 27–29 April 2010	23 interviews
Principia	22 and 24 March 2010, 14 April 2010, 4–5 May 2010	21 interviews
Church View	7–8 April 2010	15 interviews
Northamptonshire Integrated Care Partnership	June 2010	6 interviews (<i>in process</i>)
Torbay	Not applicable	Not applicable

In Norfolk, 15 interviews are being carried out, and 6 are being held in Northamptonshire Integrated Care Partnership (both taking place weeks beginning 7 and 14 June). The patient population in Northamptonshire Integrated Care Partnership is especially ill, and many patients who originally consented to interview had to decline due to poor health or hospitalisation.

After discussions with the evaluation team, Torbay ICP felt unable to participate in patient interviews due to the high number of integrating activities that take place in Torbay outside of the ICP. The view of the evaluation team was that Torbay staff were involved in such a variety of related activities that interviews would fail to elicit the particular added value of the Pilot. This ‘contamination’ by other activities was complicated further by the fact that the Pilot explicitly built on earlier activities and experiences, making a ‘before-and-after’ analysis problematic. The MESH concurred with the decision to exclude Torbay from this part of the evaluation.

The second round of patient interviews will commence in March 2011 and follow the timeline set out in table 3.6 below.

Table 3.6 Timeline for the second round of patient interviews

	Mar-11	Apr-11	May-11	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	
Second round patient interviews											
Set-up and conduct patient interviews	■										
Analyse staff interviews				■							
Report writing staff interviews								■ ●			
Project management	■										
Deliverable ●											

3.2 National Evaluation

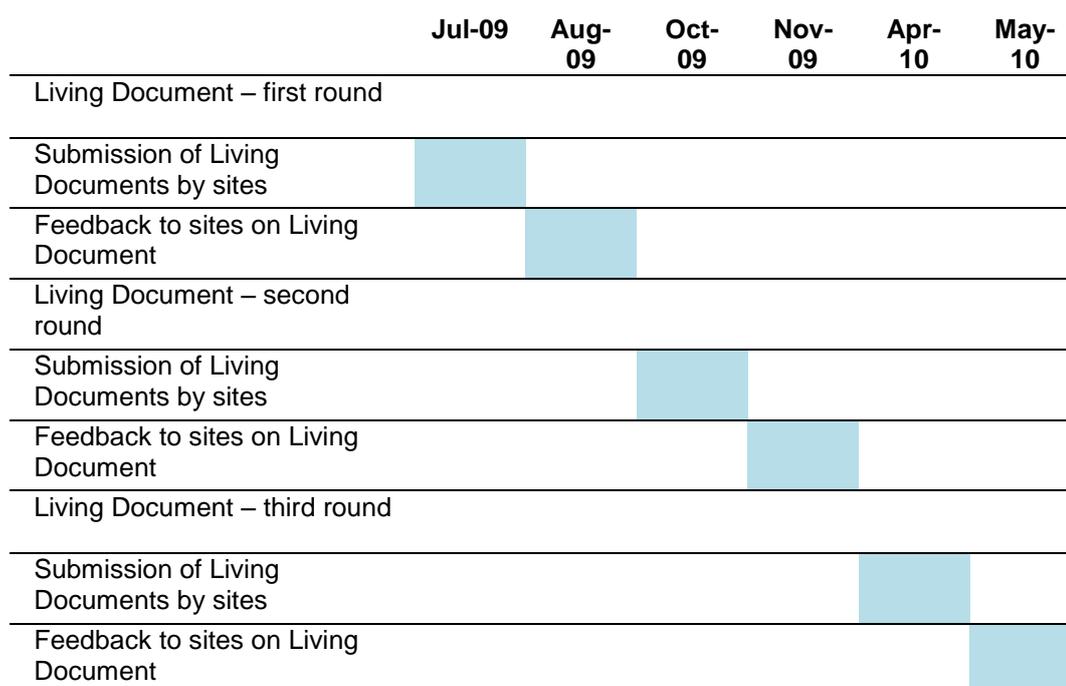
3.2.1 Living Documents

As part of their participation in the national ICP programme, Pilots are requested to complete and periodically update a set of questions contained in the Living Documents (LDs). In the LD (or self-evaluation), Pilots are asked to explore what has happened in their Pilot (the outcomes) and how it has happened (the process). In addition, Pilots are being asked to explain why they think the changes they have identified have happened.

The purpose of the LD is to help the Pilots in at least two ways. First, it should allow them to treat their self-evaluation as a Living Document or diary, for which they can begin to collect data from the start of the Pilot and so permit the documentation of changes over time, thus avoiding the common difficulties associated with pulling together the final report at the end of the Pilot. Second, it should provide a focus for data collection, which may save Pilots from collecting data that are not used. Furthermore, the LD is expected to help researchers, funders and policymakers to develop a deeper understanding about what the Pilots have done and what has been achieved.

Six rounds have been planned for the LDs, with dates now fixed for all. Table 3.7 below provides a summarised picture on the progress of the LDs so far. The third round of the LDs has just been successfully completed.

Table 3.7 Summary of progress on the Living Documents



During the preparation of each round of the LD, Pilots have had the opportunity to ask questions and seek advice from the evaluation team on a per-request basis. Furthermore, once the sites have completed their respective LDs, the evaluation team develops three types of deliverables that aim at providing feedback, thus contributing to the wider feedback loops and learning networks for the Integrated Care Pilot project. The first deliverable is the individual, site-specific, Living Document Feedback Reports, which contain comments as well as feedback from the evaluation team. These reports are confidential and are sent individually to each of the 16 Pilot sites. The second deliverable is the Living Document Thematic Review, which provides a ‘bird’s-eye view’ on the main emerging issues and common themes emerging from all 16 sites. Where relevant, contrasts between sites are also reported. The Thematic Review is distributed more widely among all Pilot sites, so the outcomes and results by Pilot are kept anonymous. The last deliverable is a presentation on the Living Document Thematic Review, at which Pilots have the opportunity to discuss the outcomes, contribute to the wider knowledge of the project and ask for advice. The LDs have formed the basis of both teleconferences and presentations at national learning events.

The preliminary analysis and results of the three rounds of LDs are available in section 4.2 of chapter 4: Early impressions and plans for the next phase of the evaluation, and appendix A: Review of the second and third round Living Documents (November 2009, April 2010).

3.3 Cost

The first stage of collecting cost data involves understanding the categories of cost that are both relevant to decision-makers and collectable through available resources. Achieving both of these may require some degree of compromise. Using the LDs and the first-round staff interviews, we have developed a set of cost categories that we can now use to structure the cost data already collected. At this stage in the evaluation we have identified key dimensions of costs experienced by integrated care organisations, as well as core categories that can be seen within each dimension. These dimensions are:

- Cost dimension 1: Costs (and savings) of being in a funded programme
- Cost dimension 2: The costs of building a platform for integrated care
- Cost dimension 3: Trailblazers' costs and benefits
- Cost dimension 4: Service utilisation as a measure of costs
- Cost dimension 5: Whole system costs

Cost dimension 1: Costs (and savings) of being in a funded programme

Being part of the national ICP programme brings certain costs and benefits for organisations above those associated with simply managing and delivering change. These costs would not be imposed on future efforts to provide improved care through integration and therefore are of less relevance to understanding the costs associated with integration in general. For this reason, we limit ourselves to understanding the Pilots' perceptions of these. The costs include participating in the external evaluation and learning events, and reporting on progress to the DH. The savings include the support and advice from the DH (where this substitutes for advice and support which would have otherwise been necessary in delivering integrated care), the support for effective project management (through the implementation team in particular), and the status and profile derived from being a part of the project. These can be termed 'knowledge capital', which for some sites might have financial as well as non-financial implications. This information is of particular importance to those funding, managing, and participating in similarly funded programmes. We do not propose to collect detailed costs, but we will ask Pilot leaders about their perceptions of the costs and benefits of being part of a funded programme.

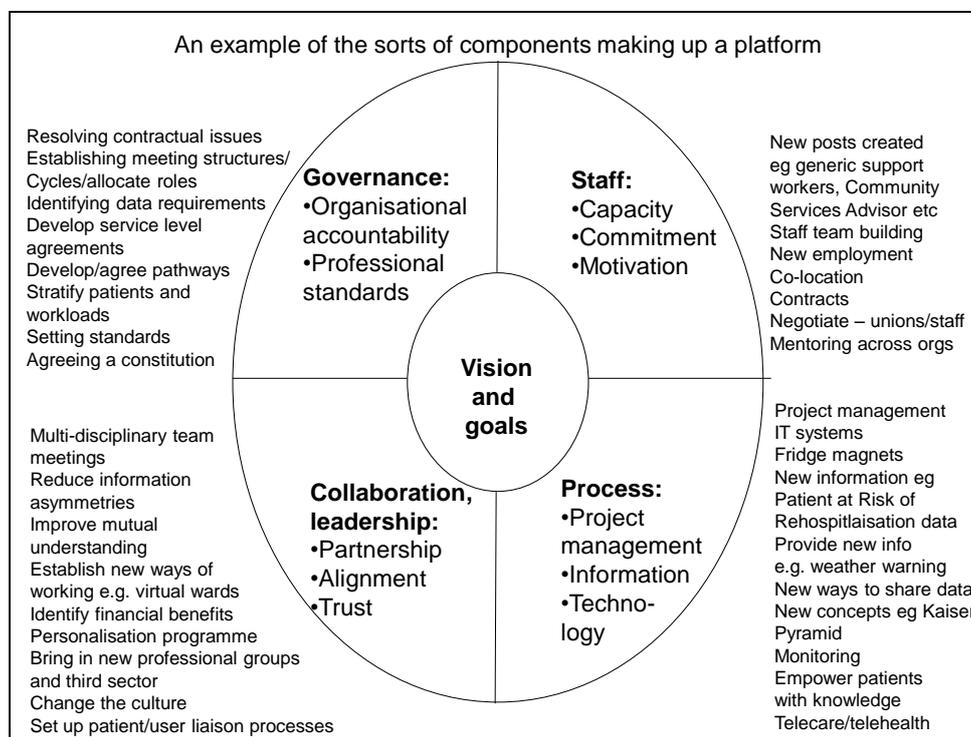
Cost dimension 2: The costs of building a platform for integrated care

The costs and consequences of building a platform for integration are core to understanding the costs of the ICPs and to informing decision-makers about costs they might anticipate if Pilots are extended across the care system. Conceptually, we can identify costs generated by setting up and running the infrastructure necessary to make integrated care possible, but not including the changes in the service utilisation delivered as measured. This is not simply a 'set-up' cost (although one can anticipate that it will have set-up costs) but there are continuing costs to maintain the infrastructure which in turn supports changing service delivery. The Living Documents and staff interviews describe considerable efforts being put into creating governance arrangements, building

the necessary staff capacity, establishing information systems, and building collaborations and partnerships. At the heart of this is the need for leadership, vision and project management. This can be thought of as the entry ticket for playing the integration game, which comes at a cost. It is helpful to conceptualise it in this way because it focuses decision-makers on the sorts of activities and costs they should be prepared for that are separate from the costs associated with service reconfiguration.

Their costs have been captured in the third round of the Living Document as inputs of time and staff planning and other arrangements necessary to establish the most appropriate platform. These categories are illustrative and may evolve as our understanding develops. On the whole these are non-capital-intensive activities. However, it should also be recognised that some specific platform activities may be hard to distinguish from service costs (for example multi-disciplinary teams both build a capacity for inter-organisational working and take decisions about patients, service users and carers which are part of changing the service itself). In figure 3.1 we describe these conceptually. The inner circle describes areas of activity, while activities listed outside the circle capture particular examples specifically mentioned in the Living Document, interviews and discussions with the Pilots.

Figure 3.1 The Components of a Platform for Integrated Care



In practical terms we will cost only the major cost items outside the circle (for example, new IT systems rather than fridge magnets). We already have the first data collection of cost data through the work of our health economist. It is the case that some of these costs are still being established and Pilot sites have reported that they do not have them clearly defined yet. Where there are

particular gaps between these data and the major cost items, we will go back to the Pilots for further information. However, major items such as project management, the time of leadership, IT systems, new buildings, the costs of meetings and so forth are all either available to us now or can be identified in the next round of the Living Document, and more specifically in the cost modelling to be conducted in specific Deep Dives (as outlined in the previous chapter).

This cost dimension will be built up by collecting categories of cost that relate to establishing and running the platform. In practical terms this involves extracting key items of data from the Pilots and it can be expected that some Pilots will find this easier than others. However, the sorts of categories are illustrated in table 3.8.

Table 3.8 Categories of cost associated with building a platform for integration

Cost dimension	Cost category	Costable item	Metric	Incremental capital costs	Incremental running costs	Source
Costs of building a platform for integration	Governance	Agreeing decision-making protocols	Meetings	None	Extra time xhr rate	Local log
		Harmonising clinical/other governance	Meetings	None	Extra time xhr rate	Local log
		Set/agree standards	Meetings	None	Extra time xhr rate	Local log
		Establish new organisational forms	Meetings	Buildings	Staff	New budgets
		New legal/constitutional forms	Legal advice	None	Legal fee/ dissemination	Budgets
	Staff	Contract negotiations	Meetings	None	Extra time xhr rate	Local log
		Training	Fees & materials	None	Time & materials	Local log/budgets
		Creating new roles	Meetings	None	Extra time xhr rate	Local log
		Team building	Meetings	None	Extra time xhr rate	Local log
		Culture change	Consultant fees/time	None	Time & external advice	Local log & invoices
		Transport	Mode & expenses	Vehicles	Mileage/travel	Travel/expense claims
	Information	IT systems	Purchases/leases	New capital spend	Annual fees/leases etc	Local budget
		IT software	Purchases/leases	None	Annual fees/leases etc	Local budget
		Identifying, collecting new info'	Time/meetings	None	Extra time xhr rate	Local log
Reducing info asymmetries		Information/dissem	None	Information materials	Invoices/time	
Advocacy/advice		Staff time	None	Extra time xhr rate	Local log	
Info to support joint decision-making		Meeting & materials	None	Extra time xhr rate	Local log	
New ways of communicating with patients		Fees & materials	System costs/time	Time & materials	Local log & invoices	
Collaboration	MDT meetings	Meetings	None	Extra time xhr rate	Local log	
	Coordinate with third sector	PPI & other meetings	None	Extra time xhr rate	Local log	
	Coordinate with other parts of public sector	Meetings/conference	None	Extra time xhr rate	Local log	
	Establish new ways of working with patients	Mti Meetings	None	Extra time xhr rate	Local log	
	Transport	Mode & expenses	Vehicles	Mileage/travel	Travel/expense claims	
	Supporting self-care	Staff & information	Buildings	Extra time xhr rate	Local log/budgets	

Note: 'Local log' is data held locally by the Pilot (e.g., on the number of meetings).

Cost dimension 3: Trailblazers' costs and benefits

However, one set of costs should, we believe, be considered separately. These are what we categorise as 'trailblazers' costs' and they relate to a number of costs incurred by individual Pilots which, having been incurred once, should not be incurred by those following after. For example costs associated with securing legal advice on alternative legal forms for an integrating entity (social enterprises, issues of liability, employment rights and so forth). However, we are also aware that there are a number of 'trailblazers' benefits that we should consider and these include the possibility that they add to the creativity of local debates and the energy behind local solutions associated with the sense of leading the way.

Cost dimension 4: Service utilisation as a measure of costs

Fourthly, there are the costs measured by changes in service utilisation. Service utilisation can be used as an indicator of resources used in themselves or can be given monetary values using national tariffs where available. Across the ICPs as a whole, data on health care usage will be based on the data we collect on specialist referrals, hospital admissions and length of stay, together with annual data on the costs of the Pilot to the NHS and social services (principally based on staff engaged in the Pilot on a full-time equivalent basis). For the most part we will use national data for comparative purposes.

We have outlined this in our evaluation protocol and these points are reprised here for convenience.

Secondary care usage

Data will be taken from Hospital Episode Statistics (HES) both for outpatient referrals, accident and emergency and inpatient care (including emergency admissions, 'ambulatory sensitive' admissions, and length of stay for selected conditions). These data will be collected for patients enrolled in any intervention, and also for their whole populations.

Our first approach to quantifying impacts of the integrated care Pilots is to focus on groups of patients (e.g., a practice population) by matching to similar practices using national datasets. The main reason for focusing on the population level is because a change in the delivery of services might not only have an impact on those in greatest need, but also upon a wider group of service users (for example if services are re-distributed), and these might have consequences that were not originally anticipated. This research design is most appropriate where the aim of the Pilot is expressed in population terms (e.g., to reduce a practice's overall rate of emergency admission). We will do this analysis by a before-and-after comparison of practice levels' rates of utilisation, using a before-and-after comparison with matched practices from national HES (Hospital Episode Statistics) data.

In addition, we will assess the potential impact on the intervention on individual patients. This answers a different evaluation question, namely what is the maximum effect that the intervention could have, if applied to all those who could benefit. This is essentially an explanatory rather than a pragmatic approach to the analysis. These analyses will be possible through the

involvement of The Nuffield Trust in the evaluation. Their approach will permit the identification of risk-matched individual patients in national HES data which will permit a before-and-after comparison with matched individual patients in the ICPs. Permission for the pseudo-anonymisation required to access these data in this way has been given by the National Information Governance Board and Cambridgeshire ethics committee.

Sites have been asked to provide a number of patient/user details namely NHS number, postcode, DOB and sex in six-monthly phases, starting in January 2010. Downloads of HES data will include retrospective data back to 1 April 2006 for both individuals and for practices. The data will be given by the ICP sites to the NHS Information Centre in Leeds, who will carry out the necessary pseudo-anonymisation required for us to access the required individual level data matching. At no stage will the research team have access to identifiable patient data.

Primary and community care usage

Data on numbers of GP consultations, community nurse contacts, social care use and use of out-of-hours services will be collected from the staff and Patient/Service User questionnaires that has been administered and will be repeated in approximately 12 months, enabling a before-and-after comparison. We considered obtaining these data directly from the NHS, but as there is variability in the availability of such data (especially out-of-hours care), we decided to collect these data from patients and service users to ensure a consistent approach.

Cost dimension 5: Whole system implications

Whole systems approaches allow us to understand the interactions among the different cost generators. Although changes in service utilisation underpin this approach, they provide only a static picture. Modelling the system can help us to understand the dynamic relationships between the various generators of costs. Consequently we should be able to better understand, for example, how transitioning patients from hospital care to hospice care will change overall costs in their final year of life. Therefore understanding how integrated care might reduce the number of hospital admissions, or reduce the average length of stay, becomes an important basis for assessing whether the Pilot was supporting cost-effective forms of integration.

We will focus on evaluating the costs and benefits associated with building a platform for integration (cost dimension 2) and changing service utilisation (cost dimension 4). We will also contribute to understanding of the costs associated with participating in a programme, being trailblazers, and potential impacts on the wider health and social care system.

Supported by these cost data, we will be able to conduct a cost-consequence analysis. The reasoning behind adopting a cost-consequence evaluation is to enable a wider range of outcomes to be considered alongside the resource cost data that has been routinely collected. This approach is wider than the traditional utility-based approaches usually used in economic assessment. This is because i) target outcomes of the ICPs are disparate and ii) a much wider

range of resource costs are being drawn from different sources, sometimes requiring only a modest re-orientation of existing resources, while in other cases, requiring dedicated resources. For example, multi-disciplinary team work may involve exactly the same number of staff doing many of the same tasks, but in a more informed or slightly different way. Additionally, the ICP interventions are less specific and more fluid than more traditional services or service bundles that can be more easily evaluated through methods such as cost benefit analyses (described below). That is to say, such interventions (and their associated costs) may come to be defined only through adaptation as they learn (and may subsequently evolve still further).

3.4 Summary of quantitative data collection

The ICP evaluation includes three elements of quantitative data collection:

- Hospital utilisation data
- Patient/service user questionnaires
- Staff questionnaires

3.4.1 Hospital utilisation data

Data on hospital utilisation is being collected from national Hospital Episode Statistics (HES) for 14 Pilot sites. For one site, Durham Dales, data will only be collected at practice level and will not be collected until the end of the evaluation period.²⁴ As agreed with the MESH, we will not collect hospital utilisation data for Wakefield because primarily, reduced hospital admissions is not a focus of the Pilot's activities. North Cornwall is also not providing data at an individual level, as similarly it is not an aim of this site to reduce admissions for the range of 'ambulatory sensitive conditions' that the national evaluation is studying in most of the Pilots. It was originally planned not to collect individual patient data at Torbay as it was thought that it would not be possible to identify risk-matched control patients for people who were already in hospital. However, recent work done at The Nuffield Trust suggests that this may be possible. As a result Torbay has been asked to participate in the individual data submissions from July onwards and therefore this site will be included in the table of results ongoing.

For 13 sites, data is being collected for individual patients/service users to permit risk-matched controls to be identified from the rest of the HES database.

For these 13 sites, details of enrolled patients/service users are being sent to the NHS Information Centre (NHS-IC) for the data to be linked to HES records,

²⁴ There is no individual patient-based intervention in Durham. The intervention that relates to hospital admissions in Durham Dales is the closure of a district general hospital and the provision of limited on-site emergency medicine in what will become a community hospital. There would be no means of identifying national controls for people exposed to the intervention.

anonymised, and for anonymised data then to be transmitted to the evaluation team.

The table below presents the number of Patient/Service User records communicated by sites to the NHS-IC, and the results of linkage to HES, by site (at 15 May 2010).

Table 3.9 Details of Patient/Service User records and linkage to HES by site

Site	Total number of individuals identified by sites	Number of individuals linked to an HES ID	% of individuals linked to an HES ID
Bournemouth and Poole	98	91	93%
Cambridge	522	507	97%
Church View	917	889	97%
Cumbria	1,100	1,100	100%
Northamptonshire Integrated Care Partnership	353	327	93%
Newquay	222	212	95%
Norfolk	68	56	82%
North Tyneside	207	204	99%
Northumbria	217	215	99%
Principia	155	153	99%
Tameside & Glossop	2,420	1,933	80%
Tower Hamlets	3,827	3,578	93%
Total	10,106	9,265	91%

The linkage rate of 90% or more is consistent with best practice within the area of evaluation of complex interventions. Linkage is not expected to be 100%, as linkage to HES depends on Patient/Service Users having recorded episodes of admission to hospital. So, for example, in Tameside & Glossop, where the intervention involves primary screening for cardiovascular disease, one would not expect to match all individuals to an HES record.

We are currently still investigating the low rates of matching in Norfolk.

3.4.2 Patient/Service User questionnaires

Ten out of sixteen Pilot sites are including a questionnaire survey of patients/service users with a standard structured questionnaire, and all of these sites carried out the questionnaire during autumn 2009/early spring 2010. All new recruits up until 31 March 2010 were included in the survey process. If fewer than 500 Patient/Service Users had been enrolled, all were sent questionnaires. If the site had recruited more than 500, then the evaluation team provided the site with code numbers to enable them to send questionnaires to a random sample of 500 patients/service users.

Distribution of patient questionnaires in the first round began on 30 October 2009, with significant variation among sites in terms of timing. Certain sites did

not start the distribution of the patient questionnaire until February 2010, most often because they had not yet selected patients/service users to receive the intervention. For all sites, distribution of questionnaires continued until the end of March 2010. Table 3.10 below summarises the process of patient questionnaire distribution.

Table 3.10 Summary of patient questionnaire distribution

Site	Start date of questionnaire distribution	Number of questionnaires sent (by 31.03.2010)	Number of questionnaires received back (by 10.05.2010)	Response rate*
Bournemouth and Poole	20/11/2009	205	132	63%
Church View	25/01/2010	150	89	59%
Cumbria	08/02/2010	497	322	65%
Northamptonshire Integrated Care Partnership	Mid-November 2009	65	47	72%
Newquay	14/12/2009	216	96	44%
Norfolk	01/02/2010	248	105	42%
Northumbria	30/10/2009	216	162	75%
Principia	30/10/2009	91	77	85%
Tameside & Glossop	w/c 25/01/2010	491	210	43%
Tower Hamlets	21/12/2009	421	129	31%
Total		2,600	1,369	52.5%

*Note: * Response rate is calculated as the ratio of the number of questionnaires received back and number of questionnaires originally sent (without adjusting for drop-out due to death, refusal or questionnaires received blank).*

The overall response rate of 52.5% is in line with what we expected for a survey of this type. Sites with lower rates of response had often distributed questionnaires late (which generally reflected the Pilot recruiting service users late), sites with mobile populations and sites where there may have been language problems. In our original proposal, we intended to use non-English language versions of the questionnaire for sites where >10% of the population spoke a language other than English. This applied only to Tower Hamlets (Bengali). However, while the site was willing to translate and distribute questionnaires in Silheti, they advised us on the basis of their past experience that this was likely to produce very few responses. Therefore all questionnaires in the end were distributed in English.

The evaluation team had developed an Excel spreadsheet for the management of the patient questionnaire distribution with the dual purpose of (i) facilitating and systematising the process for the sites and (ii) facilitating their own monitoring of the process. Site project managers were sent detailed instructions on the use of this tool and two training workshops were run by the

evaluation team in September and October 2009. The instructions were also summarised in a handbook sent to sites prior to questionnaire distribution.

The use of the Excel spreadsheet was less than ideal in several sites, especially in relation to completion of dates when reminders were sent out, and in the start date of the intervention (which was designed to be recorded for each individual Patient/Service User). We are currently in the process of clarifying the intervention start date with a number of sites so that we can accurately assess the extent to which these questionnaires were sent out (as intended) before individuals had received an intervention.

Hard copies of completed patient questionnaires have been sent to the evaluation team during May 2010, and data entry will be carried out in June 2010. At this point in time no information is available about the actual quality of data in returned questionnaires.

A simple summary analysis of the Patient/Service User questionnaires will be carried out and sites will receive frequency distributions of their own Patient/Service User responses. However, the main analysis of these questionnaires will be carried out in Summer 2011 following the distribution of the second round of questionnaires in Autumn 2010/Spring 2011.

3.4.3 Staff questionnaires

All 16 sites are taking part in a staff questionnaire. A consultation exercise with the sites took place in January-February 2010 to work out how easy it would be to identify staff involved in the Pilots. Following this, we decided to ask all sites for two lists of staff members:

- List A: staff directly involved in the Pilot (for example, appointed to or seconded to work on the Pilot).
- List B: staff indirectly involved but likely to be affected by the Pilot (for example, local GPs, community nurses, social workers).

We then surveyed all members of staff belonging to list A, and randomly sampled from list B up to a maximum of 50 staff members per site. By the 1 May 2010, 11 sites were in a position to start the questionnaire and 4 had actually sent out questionnaires. All will have been sent out by the end of June.

As with the patient questionnaire, the evaluation team developed an Excel spreadsheet to assist sites in the management of staff questionnaire distribution, and a set of instructions was summarised in a handbook sent to sites prior to questionnaire distribution. A simple summary analysis of the staff questionnaires will be carried out and sites will be sent aggregate frequency distributions of the staff responses from all sites. However, the main analysis of these questionnaires will be carried out in Summer/Autumn 2011 following the distribution of the second round of questionnaires in Summer 2011.

3.5 Local metrics

Each site has agreed two local metrics that are to be reported as part of the national evaluation. In general, this forms a subset of more extensive local data collection being carried out by sites.

We are currently collating data on these local metrics. The main purpose of this is to ensure that there is agreement between the site and evaluation team about the data that are to be collected and reported. A second set of data from local metrics will be provided by sites in spring 2011.

The role of the evaluation team is to report on these local metrics as an adjunct to the national data collection: **we will not be conducting analyses of the data for sites.**

The currently agreed local metrics are as follows:

Bournemouth

- Number of people seen in the period by Specialist Intermediate Care Team and Dementia Advisor. This will be measured by recording and collecting the data relating to the number of referrals to each service.
- Are service users valued and supported? This will be measured by an audit of patient and service user records for evidence in care plans of relevant discussions, exploring their wishes, views, interests and ethnic and religious needs.

Cambridge

- Number of patients expressing choice of place of death, as a percentage of all patients in the Pilot practices
- Percentage of people who express a choice of place of death dying in that place of choice (overall target for Pilot 50%)
- Number of people dying at home as a percentage of all deaths in the Pilot
- Number of admissions in the year prior to death in the target population compared with numbers identified in a retrospective audit
- Number of people dying in hospital, admitted from nursing homes, as a percentage of all deaths among nursing home residents dying in the Pilot

Church View

- Number of care plans completed and shared across primary and secondary care (process)
- Significant event audit of people admitted to hospital who are being actively case managed (intermediate outcome)
- Qualitative analysis of patient/user experience (separate funding application through the local Knowledge Transfer Partnership, outcome measure)

Cumbria

- Review discharges and A&E attendances of patients aged 70+ and diabetics, and record avoidable factors

- Inpatient resource allocation audit. Application of a method of attributing unnecessary inpatient costs to the services for which patients are waiting before they can be discharged

Durham Dales

- The number of referrals to the Hot Spot scheme in Durham Dales compared to referrals from the rest of County Durham. (The Hot Spot scheme aims to identify people at risk of fuel poverty mainly through social services but also with some GP identification. The scheme addresses their needs in relation to keeping warm, including advice on allowances, insulation, etc. The main aim is to reduce health consequences of hypothermia.)
- Reviewing recommendations that had been made for a sample of people who had been referred to the Hot Spot scheme, and contacting the people to see how many of the recommendations had actually been carried out

Northamptonshire Integrated Care Partnership

- Percentage of complex patients receiving medication review (clinical and compliance based) within one week of hospital discharge
- Percentage of people dying at home increased (target from 21% to 26.5%)

Newquay

- Number of people on Quality and Outcomes Framework (QOF) dementia registers
- Reports of significant event audits of people on register admitted to hospital, especially acute hospital and Cove Ward

Norfolk

- National Social Services measure NI135 – carers who have been assessed and in receipt of services
- National Social Services measure NI136 – people supported to live independently through social services

North Cornwall

- Change in number of referrals and waiting time to see a therapist assessed by: (i) number of referrals, and (ii) mean and median waiting time from referral to time of first appointment
- Improving Access to Physiological Therapies (IATP) measure of recovery rate, using IATP standardised questionnaire. Client scores will be compared before and after treatment, and compared to national data that are being captured as part of the IATP programme

North Tyneside

- Follow up in the GP patient records to check recommended referrals have been made
- Patient questionnaire, using a modification of one they are already using in the hospital outpatient falls service

Northumbria

- Patients with FEV1 <60% on triple combination therapy with Tiotropium, ICS and LABA. This is a measure of the treatment quality: patients with very restricted lung function should be on triple therapy.
- A measure of the quality of assessment: people with reduced oxygenation of their blood (<92%) should be assessed for Long-term Oxygen Therapy (LTOT).
- Patient questionnaire results (site using its own questionnaire)

Principia

- Audit of people who are being case managed in the community wards and who are nonetheless admitted to hospital as emergencies (process measure)
- Patient diaries for people with COPD (outcome measure)

Tameside and Glossop

- Increase in the number of patients on CVD risk registers greater than in non-ICP practices
- Patient questionnaire to measure improvement of patient's perception of care (locally developed open-ended questionnaire to be completed 15 months from the development of care plan)

Torbay

- Reduction in average length of stay of patients aged 65+ in Torbay Care Trust using South Devon as controls and providing a more detailed analysis of people with very long stays to understand the reasons behind the inability to discharge them
- Increase in the number of patients (or carers) advising that they felt involved in discharge planning (questionnaire)

Tower Hamlets

- Percentage of patients with controlled blood pressure, cholesterol and HbA1 (HbA1 is a measure of long-term blood sugar control.)
- Document of care planning consultations that have been completed

Wakefield

- Output of the Wakefield balanced scorecard
- Patient/service user questionnaires (site using its own questionnaire)

3.6 An evolving approach

Progress and delivery to date have gone largely as planned. As our learning has evolved through primary analysis and site feedback, some methods have been amended, and all changes have been discussed and implemented under the guidance of the MESH. These changes relate primarily to the greater involvement of The Nuffield Trust in provision of hospital utilisation data, but also to the continuing development of effective ways to identify costs. We are currently exploring ways to account for various benefits within cost-consequence analyses of Pilot activities.

CHAPTER 4 Early impressions and plans for the next phase of the evaluation

As mentioned, this report is not intended to provide a mid-term analysis of results but rather to detail the progress made on the evaluation to date. This is primarily because our analysis depends on ‘before-and-after’ pictures of the Pilot experience, and at this point we have completed only the first round of the evaluation. That said, in this final chapter we present some early impressions of the ICPs to date and thoughts about how the evaluation will develop.

4.1 Impressions

We have completed the first round of interviews with staff in the Deep Dives, reviewed three rounds of Living Documents, interacted with every Pilot regarding their costs, participated in various national events and feedback activities with the sites, reviewed documents from the implementation team, conducted non-participant observations in the Deep Dives, and have begun to explore the quantitative data on service utilisation. From this we have some emerging impressions which may or may not be confirmed and developed in our final report.

Staff views from interviews

Staff interviewees perceived the national/global context of the Pilots to be helpful, providing examples that influenced planning in the Pilots and encouraging optimism that integrated care would bring benefits. However, other national features (such as the volume of reform initiatives) were thought to be less helpful, potentially creating confusing or conflicting drivers.

In each area, staff identified examples of early successful collaborations to deliver more integrated care, and expressed an appetite to ‘lead the way’ nationally. Pilot status was widely thought to have been helpful, raising visibility and support both locally and nationally.

We found agreement across and within Pilots concerning what integrated care should deliver. The pursuit of integrated care was perceived to be relevant to a wide range of problems, creating high expectations among some staff. However, some aims and processes identified as desirable were (often implicitly) in tension with others. Staff were broadly in agreement about what was required to create a platform for integrated care and what the facilitators and drivers of integrated care look like. These are summarised below.

- There was a widely shared understanding about what the platform (the leadership, organisational infrastructure, staff, relationships and governance arrangements) for integration should look like. The key dimensions of this platform are: governance; staff; information; and collaboration. At the heart of all four is effective leadership, a clear vision and sound project management.
- Similarly, there was a shared sense of what success would mean (quicker, more person-centred, more informed care delivered to more choice-making users closer to home).
- A wide range of (not always compatible) facilitators and barriers to integrated care were identified. Facilitators included: securing Pilot status and raising the local profile; past experience of successful integration; good communication; co-location; effective use of IT systems; leadership; 'fit' with national drivers; perception of necessity (the lack of a 'plan B'); and improving job satisfaction. Barriers included: inertia; a perception of constant reforms; external shocks knocking Pilots off course; lack of trust; IT failures; fear of putting patients at risk; GP resistance; and financial pressures.
- Staff were clear that they regarded good relationships as being crucial to success, but were much less clear that staff empowerment (often thought to be an important part of integrated care) mattered. More junior staff in particular wanted empowerment only where they felt they had the personal and technical skills and competencies. Training to improve skills in mutual understanding, creativity and learning was given a high priority, but the need for training in specific technical skills was also identified. Staff were less clear about how to change health and social care services with measurable benefits.

In conclusion, Pilots, the DH and the evaluation team are left with some important questions arising from the staff interviews. It may be that, having become skilled at setting up and running the platform to deliver integrated care, all of those involved in the ICP now need to add to this skill-set by implementing service change. The sense that staff (and their organisations) need creativity and the ability to learn from others may be a tacit recognition of this need. This might also indicate the complexity sensed around the theme of empowerment.

Some potential challenges include:

- Learning and adapting to translate findings from the evaluation into action.
- Factors shaping health and social outcomes are driven by many factors other than service change – what is the best way to use this knowledge?
- Staff say that important training includes creativity and innovation – is this available?
- Staff say that relationships matter – are they being addressed?
- Staff are ambivalent about empowerment – what does this imply for the future of Pilots?

The staff interviews provide some grounds for confidence: a shared perception of what patients should expect from integrated care; a shared sense of what sort of infrastructure might be required to deliver this; reported benefits from being part of the Pilot programme; and early examples of working well together. Insights about how to take this forward included a belief that relationships will be key to success, that skilled face-to-face working is needed to complement IT and organisationally mediated relationships and that a focus on the service user can be a good way to unlock local tensions. However, there was less clarity about how services were to be reorganised in ways that users and their families would notice and that would have measurable benefits. Either the teams leading the Pilots know the answers to this but are not communicating them, or plans have yet to be developed. Either way, it should provide a focus for urgent action.

4.1.1 What the Pilots told us in the Living Documents

It is important to note that the LDs can provide only a partial account of Pilot progress, reflecting the perspective of those leading the Pilots. However, we have a strong sense that these are completed in good faith and with a genuine wish to present an authentic picture (a widespread observation of qualitative researchers is that when asked people want to ‘tell their story’). In addition we have triangulated the material from the LDs with the Periodic Reviews completed by the implementation team and found that the accounts in each are highly compatible (although highlighting different aspects). As a further check, in the final report the evidence from the LDs will be compared and contrasted with the evidence from staff and user surveys and interviews, and with the quantitative evidence of impact. In the following sections we provide a flavour of the themes that the LDs have given rise to. In the final report, there will be a more comprehensive analysis of what the LDs tell us and how the views of the Pilots evolved over time.

Clusters, not models

At the outset of this evaluation, and based on our understanding of the literature, we anticipated finding that distinct models of care would become apparent and that they could be classified in relation to two criteria: structure and function. These dimensions are outlined below.

1. Structure

Integration can be seen as occurring at three levels^{25 26}:

- *Micro-level integration activities* – these promote integration among individual practitioners within a single organisation (e.g., between doctors and nurses in a primary care practice setting).

²⁵ Epping-Jordan, J.E., S.D. Pruitt, R. Bengoa and E.H. Wagner, ‘Improving the Quality of Health Care for Chronic Conditions’, *Quality and Safety in Health Care*, Vol. 13, 2004, pp.299–305.

²⁶ Grone, O. and M. Garcia-Barbero, ‘Integrated Care’, a position paper of the WHO European Office for Integrated Health Care Services, *International Journal of Integrated Care*, Vol. 1, June 2001. As of 4 June 2010: <http://ijic.org/index.php/ijic/article/view/28>

- *Meso-level integration activities* – these promote care integration among practitioners working in different organisations (e.g., between GPs and specialists).
- *Macro-level integration activities* – these promote integration designed to facilitate organisation-to-organisation working (e.g., across different sectors). These may include policy agreements and financial arrangements. Examples of these are joint budget holding between health and social care services or structural changes to facilitate work across two or more organisations.

2. Function

Integration can be classified²⁷ in terms of:

- *Organisational integration*, where organisations are brought together by mergers or structural change.
- *Service integration*, where different clinical services or support/back-office functions are integrated.
- *Clinical integration*, where the focus is on care for a particular disease.

This gives the following matrix, which we originally intended to use to help understand the nature of integration proposed in the selected Pilots.

Figure 4.1 Matrix to show the nature of integration proposed

	<i>Micro-level integration</i>	<i>Meso-level integration</i>	<i>Macro-level integration</i>
<i>Organisational integration</i>			
<i>Service integration</i>			
<i>Clinical integration</i>			

It is now evident that the picture on the ground is more complex, fluid and subtle than this. What we are seeing is less that distinct models are emerging tidily within the boxes of figure 4.2 and more that Pilots have adopted a 'pick and-mix' approach, which combines different elements (often responding to local circumstances) and may possibly change over time (although this is too early to confirm).

The concept of a model implies something that can be demarcated (the boundary separating the model from the context is clear), that is relatively fixed over time and that has a degree of internal coherence. It also implies something that can be applied in a variety of contexts. It aims to capture the essential (and therefore simplified) structure of an activity or process, usually

²⁷ Fulop, N., A. Mowlem and N. Edwards, *Building Integrated Care: Lessons from the UK and Elsewhere*. London: The NHS Confederation, 2005.

with the intention of duplicating or evaluating interventions according to how faithful they were to the model.

However, in light of the LDs, this language seems unhelpful. Although there are undoubtedly dimensions of systemic integration (for example in information systems, assessment, access, standardised communication and finance), each Pilot is also embedded in its local areas in different ways, making such integration very context-dependent. Rather than a discrete set of models, broadly comparable across the Pilots, what is apparent from the LDs is a more fluid process of change and evolution. Furthermore, the activities of the Pilots are often difficult to demarcate from related but non-Pilot activities with, for example, a variety of schemes all designed to provide more personalised care. Similarly, the focus of activity within each Pilot changes over time as circumstances evolve. Each Pilot also carries out a number of activities that are not part of a single coherent model. Integration is a process and not a model. Furthermore it is a process that is to a degree self-limiting (that is, there will never be complete integration). Information-sharing, pooled budgets, shared communications protocols and so forth all have practical limits to scale and scope beyond which they become suboptimal. These limits will manifest themselves differently in different contexts.

We found that, rather than identifying a discrete set of models of integration, the LDs described a wide range of skills and resources used to conduct a variety of integrating activities in pursuit of many different outcomes. Each particular combination of resources, activities and intended outcomes appears to depend upon local leadership and context at least as much as upon the adoption of models (although many started with a good understanding of models of integration learned from US or UK examples). A more accurate term than 'model' might be a 'cluster' of activities that evolves over time as learning takes place, relationships mature and the environment changes. Clusters are made of elements tied together in space and time, which may mutually reinforce and support each other, but which are not logically or causally unified. It is also apparent that each locality has developed its own distinct cluster. This sensitivity to local history and context was anticipated by Chris Ham and John Oldham in their recent publication on integrating health and social care in England.²⁸

Intended outcomes

The intended outcomes are described in many different ways, adding to the difficulties of comparing and contrasting the Pilots. However, they can be placed under three broad (but not mutually exclusive) headings. The first heading is a **concern with technical efficiency**. Intended efficiencies mentioned include improved cost control, more effective deployment of the workforce, leaner and more effective organisations, a learning and self-improving system, integrated commissioning and reduced institutional dependency among service users. One Pilot also suggested that integrated care would make any potential future 'slash-and-burn' response to financial

²⁸ C. Ham, and J. Oldham, 'Integrating Health and Social Care in England: Lessons from Early Adopters and Implications for Policy', *Journal of Integrated Care*, Vol. 17, No. 6, December 2009, pp.3–9.

pressures less likely and a more coherent response more possible. By implication, kinder cuts can be better made where more subtle, needs-driven and evidence-based steerage is possible.

The second heading concerns the **quality of services**. Issues mentioned include making services easier to access and, once accessed, having fewer 'hand-offs' and being simpler to use. Speed of response was also mentioned, especially where this could improve the clinical outcomes by early diagnosis or more quickly identifying a sudden deterioration. Most considered that integrated care would support better-informed decisions and many asserted that more personalised care, delivered closer to home, would improve the quality of that care. It was also anticipated that more preventive work and earlier treatment would improve the quality of care that could be provided. Many saw a strengthened user voice in decision-making as also contributing to improved equality. Most issues related to improving equality were in the particular sense of ensuring that resources were focused on those carrying the greatest burdens of disease rather than by chance or related to power. However, others identified more specific measures to reduce inequities focused on specific and vulnerable social groups.

The third heading concerns **user and carer experience**. Better premises, more responsive services, strengthening the users' voice, having to give the same information less often, greater continuity of care and getting answers sooner and more easily were all mentioned. The number of issues brought up under user and carer experience may be fewer than those regarding value for money, but across the 16 Pilots there is a fairly even balance of attention given to each of these three overarching anticipated outcomes.

Evolving views about skills and resources

In pursuit of these aims, ICPs have marshalled a wide range of skills and resources. Skills required were said to include: negotiation, trust-building, communication, project management, facilitation, data analysis, leadership, workforce development, financial management, redeploying under-used resources, managing change and understanding systems. National support from the DH and the opportunity to relate delivering integrated care to achieving other national priorities were also said to be a key resource. The Periodic Review for January has already identified some improvements in outcomes associated with the application of these skills in the areas of:

- Communications and engagement
- Implementation of services
- Data management
- Bridging the gap between different cultures

The LDs support this interpretation, and because relatively few additional staff have been brought in, it appears that these skills have been developed within the Pilots.

Knowledge of certain key methods has also shaped behaviour. Understanding of key concepts such as the one-stop-shop, multi-disciplinary team work; the virtual ward; and lean methodology have all informed local decisions.

Not surprisingly, given the stage of development of the Pilots, there is more awareness of change within the life of each Pilot and a sense that each is managing an unfolding process of change rather than (simply) implementing a model. Skills are drawn upon to manage this process of change. However, from the LDs, this does not appear to involve a change away from the intentions and spirit of the original proposals; indeed, these aims have remained fairly consistent. On the contrary, there appears to be a process of adaptation to a changing environment and to learning from experience, in order to continue to pursue relatively fixed aims.

4.1.2 What does the Pilot prioritise (and has this changed)?

In the document summarising the second round, we identified, from the LDs, three problems that it was hoped integration would mitigate:

1. The first concerns the worry that information about patients and users is not made available where it is needed in a timely and efficient manner, and that service users find themselves repeating the same information. Proposed solutions are intended to ensure that information about the patient/user/carer (and ways of helping the patient/user/carer) are more effectively shared and used across disciplinary and organisational boundaries. Achieving this may involve one of a number of approaches, including the use of information and communication technology, better team work through multi-disciplinary or multi-agency decision-making, reducing the number of 'hand-offs', and empowering service users to articulate their needs more effectively at each stage of their journey through the system.
2. A second type of perceived problem is that staff are believed to be inappropriately constrained by the organisational settings in which they work. This results in staff delivering poorer services than would be justified given the resources allocated to them. In response, the solution in some Pilots is to empower (however defined) staff (clinical and non-clinical) to be less constrained by previously narrowly defined organisational or professional parameters. The aim is to relax these parameters, thereby empowering staff to both carry out a wider range of tasks and contribute to a wider range of decision-making, where they can use their knowledge and skills more effectively.
3. A third perceived problem apparent in the LDs is that accountability and financial systems previously drove behaviour to defend organisation-based incentives rather than patient benefits or wider benefits for the health care system. It is recognised that for reasons of effective management of public resources, and for reasons of accountability, there will have to be budgets, budget holders and reporting arrangements, but it is believed that by exploring how pooled or shared budgets might be amended, or by creating new organisations with different responsibilities, it might be possible to

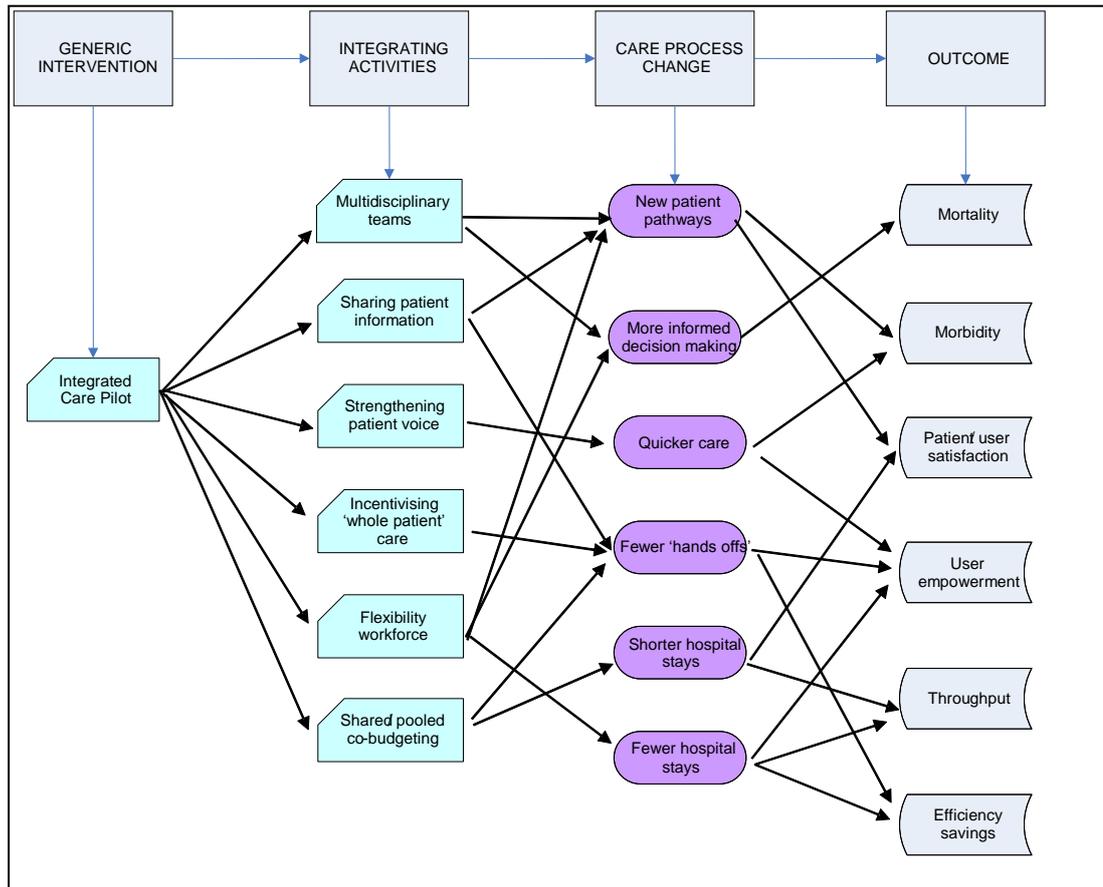
reward behaviour that supports integrated goals (such as reduced hospitalisation).

These three themes are still strongly present in the third round of LDs; however, some other themes are now a little stronger. Unsurprisingly, the anticipation of downward pressure on expenditure has focused attention on the role of integrated care in not only achieving cost control but also establishing a more rational basis for managing spending constraints and resisting a 'slash and-burn approach' (as one person called it), which might achieve savings in one place only to create additional costs elsewhere.

Linked to this, perhaps, is a greater sense that systems thinking and the softer skills of change management (either formally or tacitly) underpin how Pilots describe what they are doing and in particular when describing what facilitates and what hinders the projects. There is a growing interest in the skills and approaches needed to help delivery. Facilitators often mentioned concerns over leadership, building shared interests, creating appropriate incentives and developing good relationships (as well as more traditional emphases such as project management and senior support).

In conclusion, through the three rounds, the LDs display a growing sophistication and clarity about the skills and activities needed to deliver integration. However, the concrete routes to improved outcomes remain unclear. In the previous round we suggested that many of the arrows in figure 4.2 were unclear (at least as presented in the LDs). This is now becoming clearer to us but there is still more work to be done to properly understand the causal chains.

Figure 4.2 Mapping the causal chains between ICPs and outcomes (also see appendix A)



4.2 Summary and next steps in the evaluation

In summary, through our analysis of the early stages of the ICPs we are clearer that within each Pilot there is a cluster of inter-related activities' which include activities. Some of these, such as service reconfigurations, are delivered through 'traditional' project management (such as might be identified through a logic model). Others are more similar to negotiations and involve compromise and tactics among different agencies, including service users, (such as might be identified through process mapping). A third feature involves repeated cycles of learning and adaptation, for example as professionals come to understand each other better, modify their behaviour, and then stimulate further changes in others. We have preferred to refer to this as a cluster of activities. To evaluate these will require a set of evaluation approaches that can match the complicated and varied nature of the activities.

Fortunately the mixed methodology underpinning the evaluation is capable of generating a sufficient variety of data. During the next and final stage of this evaluation, this data will be derived from the following sources:

National Evaluation

- A systematic analysis of all the completed living documents, identifying both changing strategic intent over time and the final cluster of activities adopted
- A before and after study of the two rounds of the staff questionnaire and a systematic comparison of the ICPs with the national picture
- A before and after study of the two rounds of the patient and user questionnaire and a systematic comparison of the ICPs with the national picture.
- Further analysis of documentation from the Pilots.
- Interrogation of service utilisation data revealing difference between ICPs and comparable areas outside the ICPs
- Examination of the local metrics produced by the Pilots.
- Cost data collected through the LDs and computed through service utilisation data and estimated through staff and user surveys.

Deep Dives

- A before and after analysis of staff interviews.
- A before and after analysis of Patient/Service User interviews.
- A before and after analysis of non-participant observations.
- Models of changing service configuration and their costs and consequences.

Policy Review

We will work with the DH and the ICPs to develop further our efforts to review and develop evaluation findings into policy recommendations that are suitable, feasible and acceptable.

We anticipate that once these data are analysed we will be able to show:

- What approaches and clusters of activities were used
- What worked well (efficiently, effectively and equitably)
- Who benefited and to what extent
- What costs and non monetary efforts were required
- What are suitable, feasible and acceptable ways to integrate in the future

APPENDICES

Appendix A: Review of the second- and third-round Living Documents (November 2009, April 2010)

Second round thematic review

This report provides an overview of the responses from the sixteen Pilots to the **second round** of the Living Documents (LDs). It provides a general summary of the responses given by the sixteen Pilots to a series of questions asked by the Evaluation Team. The purpose of the report is to provide the Department of Health with an understanding of progress in the Pilots and to promote reflection and discussion within and amongst the Pilots about their activities. It builds upon the first round review of those Living Documents submitted in July 2009.

Overview of wider themes apparent in the Living Documents

In the LDs, the Pilots articulate a sense of the problem they intend to address by their various integrating activities. 'Pre-integration' (if we may use that clumsy term to describe services in the Pilots before the ICPs were established) local health and social care systems are perceived by the Pilots in various ways – some reporting that they are building on existing integration and others less so. A variety of weaknesses are identified in these 'pre-integration contexts' and, alongside identified weaknesses, a number of proposed measures. These wider problems and proposed solutions are more developed in the second round of LDs than in the first and might be summarised into three main dimensions:

The first type of problem which integration is intended to address concerns the anxiety that information about patients and users is not made available where it is needed in a timely and efficient manner, and that service users find themselves repeating the same information. Proposed solutions are intended to ensure that information about the patient/user/carer (and ways of helping the patient/user/carer) are more effectively shared and used across disciplinary and organisational boundaries. Achieving this may involve one of a number of approaches including the use of information and communication technology, better team working through multi-disciplinary or multi-agency decision making, reducing the number of 'hand-offs', and empowering service users to articulate their needs more effectively at each stage of their journey through the system. (However, as we discuss below, the precise meaning and content of 'empowering' and 'reducing hand-offs' can be abstract if not vague).

A second type of perceived problem is that staff are believed to be inappropriately constrained by the organisational settings they work in. This results in staff delivering poorer services than would be justified given the resources allocated to them. In response, the solution in some Pilots is to 'empower' (however defined) staff (clinical and non-clinical) to be less constrained by previously narrowly defined organisational or professional parameters. The aim is to relax the organisational and disciplinary parameters thereby empowering staff to both carry out a wider range of tasks and contribute to a wider range of decision making where they can use their knowledge and skills more effectively.

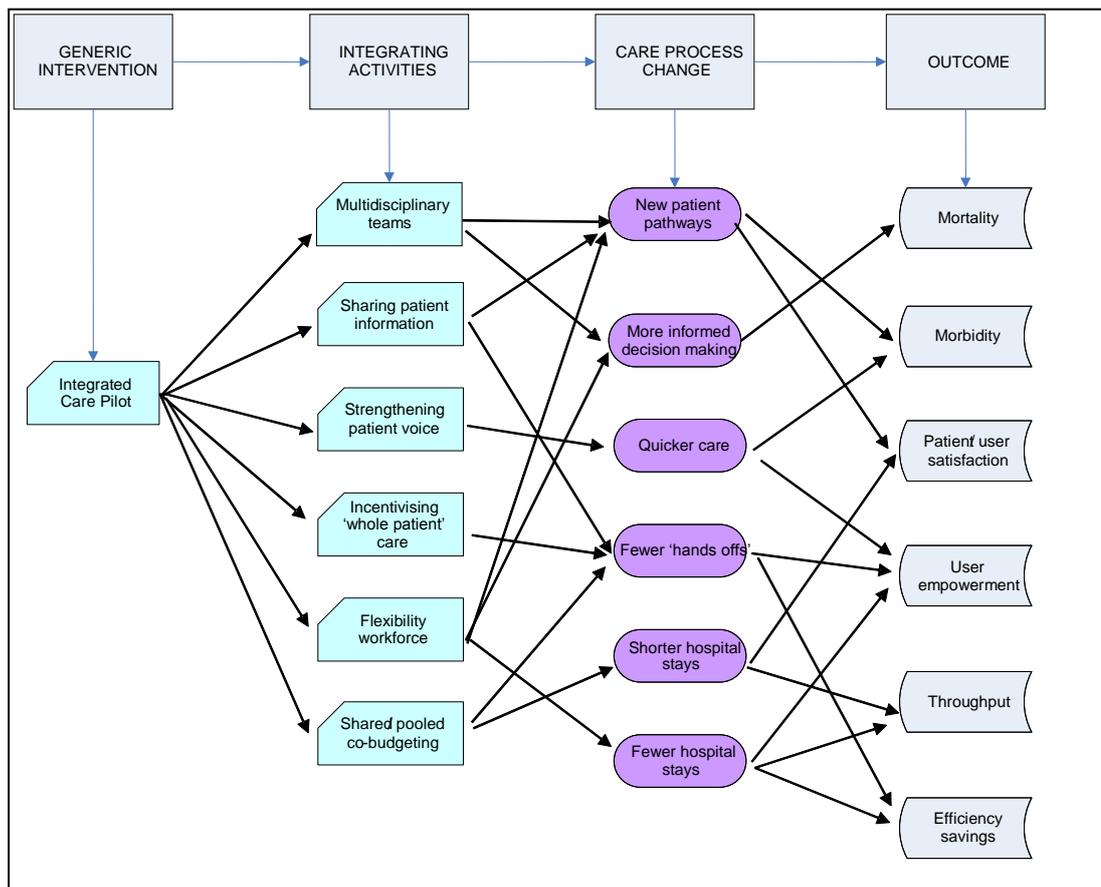
A third perceived problem apparent in the LDs is that accountability and financial systems previously drove behaviour to defend organisation-based incentives rather than patient benefits or wider benefits for the healthcare system. It is recognised that for reasons of effective management of public resources, and for reasons of accountability, there will have to be budgets, budget holders, and reporting arrangements but it is believed that by exploring how pooled or shared budgets might be amended, or by creating new organisations with different responsibilities, it might be possible to reward behaviour which supports integrated goals (such as reduced hospitalisation).

The Pilots therefore suggest an increasingly clear sense of, at a general level, what the problems are and what needs to be done. The LDs, among other things, address the question 'what might integration as a health and social care system look like and what should be its consequences?' The writers of this report believe that an integrated health and social care system is built and sustained through a variety of activities and these include communicating, sharing data, arriving at joint decisions, co-financing and so forth. However, although we have a developing understanding of what these activities in the Pilots are, at this stage in the evaluation we know much less about the detailed ways these activities are being organised and nor is it always clear whether and how they successfully contribute to sustaining and developing integration. It is also at this level of granularity where we can better understand what local contextual factors support or limit these activities. For example, it is important and relevant not only to understand that district nurses, social care professionals, GPs and consultants plan to share information about individual patients but also to know if this will be done electronically, through paper-based forms kept with the patient, or through a different method, and if this information will be in addition to all the information held separately by each team. Therefore we are now at the stage where we want to develop a more detailed understanding of these activities and how they relate to local circumstances.

Abstractly, we might describe what the LDs describe in the following way. The Integrated Care Pilots (conceived as a system-wide intervention) are giving rise to a number of identifiable integrating activities, such as setting up Multi-Disciplinary Teams, sharing patient/user information, and creating a more flexible workforce. These are then expected to create changes in the care service users receive. This might be clinical care, health care or social care and includes changes such as the creation of new patient pathways, fewer 'hand-offs' and fewer hospital stays. It is then anticipated that these changes in care will lead to improved outcomes in areas such as morbidity, user satisfaction

and hospitalisation. The causal chains that connect these (the arrows in Figure 1) are as yet unclear in two ways. First, it is not clear what integrating activities will change which care process changes and then influences outcomes. Second, it is not always clear how this will happen. The arrows in Figure 1 are indicative of what could not be predictive of what will be. There may also be other causal linkages which are more subtle – for example, it is possible that by creating multi-disciplinary teams this leads to a cultural change which independently influences outcomes. This complexity is suggested in figure 1.

Figure 1: Mapping the causal chain between ICPs and outcomes



The questions asked

Turning to the more specific questions asked, the topics in the second round of the Living Document covered the same assessment areas as the first round, with some small changes. As with the previous round, there were a number of sub-questions asked within each of subject areas. These questions will be posed on a further four occasions during the lives of the Pilots and will provide evidence of how the projects perceived themselves to be progressing throughout the Pilot Programme. The topics covered in this evaluation round were as follows:

- Q.1. Developing the Pilot and background information (exploring the motivations and expectations of the Pilot team)
- Q.2. Who is doing what? (to enable the evaluation team to understand who is carrying out specific roles within the collaboration to provide integrated care)
- Q.3. Processes (producing a descriptive account of the processes of integration)
- Q.4. Outputs and outcomes (to identify successes and positive developments as the project evolves)
- Q.5. Is the Pilot progressing to plan? (encouraging comments on actual progress against planned progress)
- Q.6. Sustainability (what plans has the Pilot team put in place to ensure the long-term sustainability of its project and how are these plans evolving as the project develops?)
- Q.7. What difference is the Pilot making? (in what ways is the project making a difference to patients/carers' lives and what positive impacts is it having on the region; how do the Pilot activities compare to work being undertaken elsewhere?)
- Q.8. What are the cost consequences of the Pilot? (what have the Pilot management and activities cost to date and how are expenses being controlled by the Pilot team?)

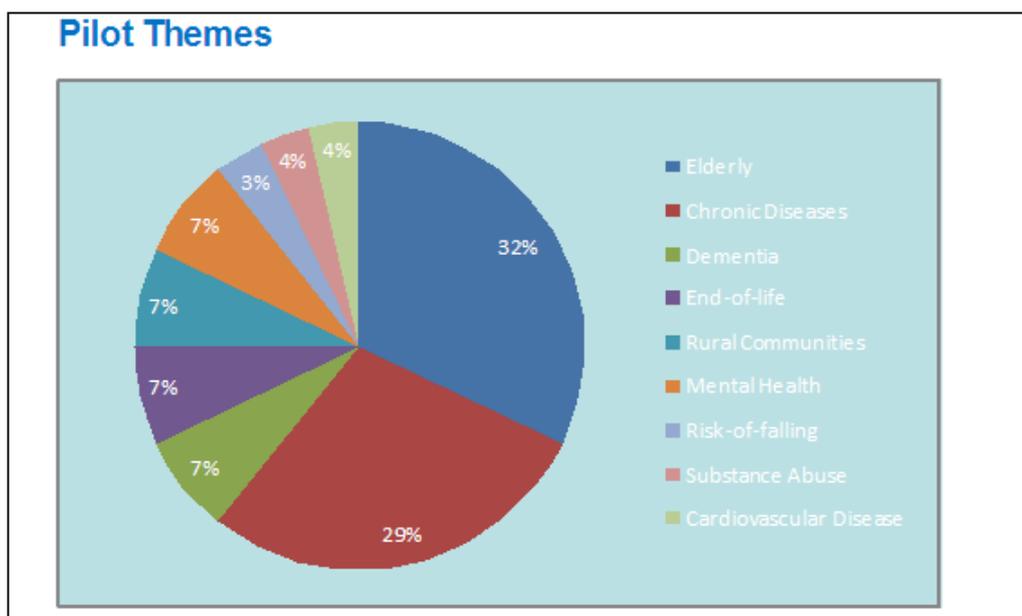
The responses to the questions

The second round of the LD provided a considerable level of insight into sites' progress, with Pilots providing very helpful information. Both the number of questions answered and the quality of responses were more developed than in the first round of documents. We are very grateful to all the Pilot sites for the effort and time that has clearly been invested in responding to this evaluation round. In particular, we are impressed with how many Pilots attempted to answer all questions in the LD.

Question 1 concerned the aims and objectives of each Pilot and these are now fully covered in the responses. The range of aims and objectives was reported with growing clarity about the origins of the Pilot team's approach. Inspiration has come mainly from two sources; examples of successful integration in the US, and local experiences of successful working. In one case, it came from a

university-delivered OD event. Being part of a national programme is viewed positively and has helped to encourage local buy-in. Important repeated themes are about treating the whole patient, supporting patient choice, improved screening, providing new patient pathways, and underpinning joint working (presumably through organisational change). If successful, patients should anticipate quicker, better care and an improved patient experience. An approach for delivering this mentioned by four Pilots is community wards and all but one of the Pilots aim to reduce emergency admissions and hospitalisation. In one way or another, 14 Pilots also indicate that reducing inequality is an aim. Pilot themes are unchanged from the first LD and are outlined in figure 2 below.

Figure 2: Pilot Themes



All the Pilots started with at least some good local relationships amongst partner organisations and wider stakeholders and in general these have been reported as improving across the sites. These are associated with quite varied efforts to develop the organisational and governance arrangements. These range from exploring new legal entities to function as employers of an integrated workforce through to bringing primary care resources into the formal governance of the hospital. More commonly, setting up integrated care board (or equivalent) for local leadership and direction is widely reported. In general, the language of collaboration, networks and change management programmes describe the intent, at least, of developing the integrated care through agreement rather than hierarchy.

There are still, however, wide variations in the level of detail and information provided. There is a tendency to use broad overarching terms to describe activities that are, however, not further illustrated in the LD by evidence or practical examples. For example, the integration process is frequently described as the 'streamlining' of existing services, but without providing detail

to allow us to understand the precise arrangements and activities that characterise such streamlined services.

In response to **Question 2**, it is clear that the Pilots have secured the engagement of clinicians and more than half of the Pilot projects could be described as clinician-led. Primary care clinicians are strongly represented but so too are commissioners, community nursing, user representatives, adult social care and in general there is a clear relationship between the key participants in the integrating activities and the roles described as leading the Pilots. This includes representation from management. As described above, these are typically organised within a board (or equivalent) and Pilots are also exploring the appropriate organisational and governance arrangements to sustain and strengthen these relationships.

As the Pilots have reached the stage where they are taking a growing number of crucial decisions about delivering integration, we would also like to learn more about the rationale behind choices made by these leading figures. For example, why have specific services been selected for integration but not others? Are decisions in practice dominated by one particular professional or organisational viewpoint? We hope that being explicit about this will not only support the national evaluation but also help to share understanding within the Pilot.

Question 3 concerns the processes and activities being developed and delivered. These describe a range of both vertical and horizontal integrating activities. These may be categorised as: operational activities; workforce development activities; governance-related activities; information and communication (both the 'hard' technology and the 'soft' relationships); and commissioning arrangements. All Pilots are committed to conducting some form of local evaluation outside the national evaluation. The facilitators of these activities are mainly 'softer' such as 'a shared belief and value base', trust, and leadership. Employment issues appear as something hindering integration in seven Pilots as does a lack of information regarding the total budgets that will be available to the integrated services. In most Pilots, these activities are focused on setting up processes but as they become embedded, it will be useful to find out more about their operation.

In response to **Question 4**, a number of Pilots also state that they have measured the success of some activities or have carried out some evaluation activities, but Pilots neither make these available nor have they cut and paste from them. We would like to hear more about emerging findings from the Pilots local evaluations or other local studies, including how these findings are being analysed and how they are being used in the subsequent design and development of the project. Similarly, when Pilots refer to successful outcomes they have achieved, for example, better standards of care or positive feedback from patients, we would like to know what evidence has been used. We are happy to discuss with Pilots how this might most easily be achieved.

As with the previous round of the Living Documents, some Pilots have noted that it is still too early to answer questions about outputs and outcomes, although overall there has been a significant increase in the response to these questions. Outputs already achieved include the creation of teams, the

development of a shared understanding, some early sharing of knowledge and skills, and developments in IT. In almost all cases this describes a context where Pilots are preparing to go 'live' but have not yet done so. Outcomes achieved reported so far are primarily about a 'mindset shift' or similar cultural change.

Question 5 asks Pilots about progress to date and most can report that progress, by the date of submission, is broadly on target. The main difference has been where projects have a relatively short chain of relationships to mobilise, progress has been quicker and has gone further. Where complex workforce issues or 'whole system' changes are required, progress has almost inevitably been slower. Progress has been facilitated by a national environment emphasising patient-focused services, and the 'air cover' Pilots perceive they have to be innovative and develop disease-specific initiatives (e.g., the National Diabetes Year).

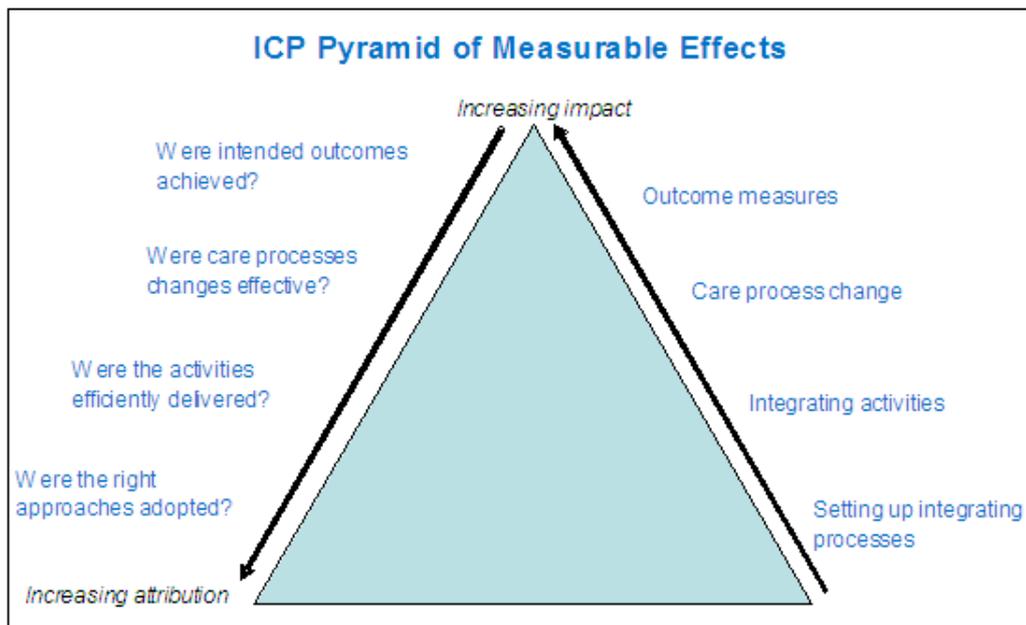
Question 6 concerns the future sustainability of Pilot projects. In the first round of the Living Documents, a large number of Pilots did not discuss plans for the long-term sustainability of their project. In this round, there has been a much higher response rate, with the vast majority of Pilots attempting to answer questions on future sustainability. A common response is that the future sustainability of the project will depend either on the success of the Pilot and/or the financial viability of continuing the work after the Pilot period. This is an understandable response, but we would encourage greater consideration by Pilot sites of different ways in which sustainability can be achieved, by strengthened relationships between partner organisations, improved working arrangements between different service providers, and planning for additional funding where necessary. A key trend is that Pilots are often still not willing or able to consider the cost implications of future sustainability and are not addressing whether or not their project is financially viable in the longterm. This is particularly relevant for those Pilots that are reporting they have already overspent and we would hope to hear more about the implications that current out-goings and expenditure will have for the potential sustainability of the project at the end of the Pilot period.

Question 7 asks Pilots to comment on the difference their project is making, as an individual initiative, and also in the context of all the other work that is being undertaken at Pilot sites across the country. As it is still a relatively early stage in the Pilots' progress, the majority of Pilots struggled to answer this question, with three Pilots failing to provide any response at all. A common trend was the inability of Pilots to identify and separate any successes they have achieved from other initiatives, such as the Transforming Community Services agenda. This made it difficult for Pilots to speak authoritatively about the particular impact their individual project has had. This problem of 'attribution' is a common one where parallel programmes are taking place in the Pilot region but we would encourage Pilots to consider more carefully the contribution being made by their project to the positive outcomes being seen more generally in their area of care. Nonetheless, all but four Pilots attempt to describe some key differences that are already being made by their project. Improvements in patient safety, better use of resources, and increased cost-effectiveness were some of the impacts reported. As the projects develop, we expect that it will

become easier for Pilots to respond to this question. In particular, we hope that Pilots will be able to assess the difference they are making in the context of the work being done elsewhere in the country. This element of the question seemed to have been confusing for some Pilots and it was sometimes not clear which other initiatives were being referred to. This question was intended not just to understand what the impact of the Pilots has been to date, but also to give Pilots an opportunity to reflect on their work progress in comparison with work being undertaken at other DH Pilot sites. Given that all the Pilots are working on broadly similar projects, it is expected that Pilots will engage with the projects being undertaken elsewhere in order to compare their own experience and see how work systems are progressing elsewhere under similar circumstances. We would be especially interested in hearing whether Pilots have been inspired by or drawn any lessons from the successes or failures of any of the other Pilot sites.

There is an important challenge facing the Pilots in trying to assess the scale of impacts. It will be relatively easy to identify changes in setting up and running the ICPs, and establishing integrating activities. It will be less easy to identify the impact on changes to care processes and even harder to attribute changes in patient outcomes to the ICP. The national evaluation will provide quantitative evidence on this but until that point in the LDs, it may only be possible for the Pilots at this stage to provide partial or even anecdotal evidence of impact. This 'pyramid of measurable effects' is described in figure 3.

Figure 3: The ICP Pyramid of Measurable Effects



Question 8 concerns the overview of cost data and financial information. The financial information relating to setup (fixed) and running costs (variable) is contained in Question 8.1 and Q 8.2 of the Living Document (LD). This was the first time that such information has been sought from the Pilot sites. Individual

comments on this section of the LD have now been fed back to each Pilot. The intention of this short section of the report is to appraise the data as a whole for emerging trends, variations and potential problems collecting this type of economic information. Each Pilot will also have the opportunity to discuss their data with the Economist leading these aspects of the study (to date two of these centres, on multiple sites, have discussed the information provided).

We anticipated that these questions might not be as easy for some Pilots to complete as other questions because NHS costing systems are complex, especially when looking at programmes not budgets, as is the case in the Integrated Care Pilots programme. Bringing together different organisations and agencies was expected to add several new layers of difficulty. We expected the information might not be readily available or was at least incomplete. Also, some of the Pilots are still in the process of establishing and finalising their integrated care models and some costs may still be unknown. However, in total, 11 sites provided some information. Four of the Pilots did supply adequate (and in some cases exceptional) information about both fixed and variable costs. Four other sites supplied the variable cost information only and three sites supplied only their fixed cost information. The remaining sites have mostly indicated that this information is being worked on and is expected to be forthcoming in the next few months.

Of those sites responding to this section, the majority of the fixed costs were comprehensively reported, although some were still being finalised. Some sites still did not know the precise financial value of all the resources being used but managed to identify what they were. Although we might have expected buildings and equipment to play a prominent role, it was actually setup and planning costs (mainly one-off staff time spent in meetings, etc.) that consumed the largest amount of these resources and, consequently, a surprisingly high proportion of total fixed costs. Professional fees and computer systems also played a major role in setup costs.

In terms of the key variable costs, staff employment was the most prominent; however, associated travel was also significant. Clinical audit and performance costs were perhaps surprisingly important as the second most important category. Training and marketing costs were also a significant factor in the ongoing delivery of most of the programmes. There was considerable variance in the running costs between sites which, to some extent, probably reflects the scale of projects. However, more comprehensive data will provide a more complete picture on running costs and their variation in the future.

There seemed to be no aspects of Question 8 that appeared to be problematic (for respondents at least!) and most were completed comprehensively (although some still require further confirmation). It was also reassuring that these questions appeared to capture the full range of actual relevant costs in the Pilots. No additional cost categories were identified in the process of talking to coordinators (however, this will be confirmed shortly by separate telephone follow-ups).

It is hoped that the five centres that have yet to supply any costs information can be assisted with their task and that the information they are still seeking can be found within the next six months. Overall, the exercise has produced

confidence that all relevant cost information can be obtained as part of the ongoing ICP evaluation. This will be particularly useful when assessing both outcomes and effectiveness data relative to the resources required to effect these changes.

Emerging Trends in Living Document responses

A key theme in the Living Document responses relates to the varying degrees of experience the Pilot sites have had with previous integration activities. A number of Pilots have prior experience of integrated care initiatives and this appears to have put them at a distinct advantage to get up and running quickly in the planning and management of their current project. For other Pilots, this is their first experience of integrated care and, as is to be expected, some sites have experienced problems persuading stakeholders and organisation partners of the value of their project objectives. Anxieties from some staff to the changes being implemented are still being reported by a number of Pilot sites. In these cases specifically, we would like to hear more about the steps the Pilots concerned are taking to allay these concerns and to ensure that all relevant partners and stakeholders are supportive of the project and its aims. It is expected that such information would be useful not only to the individual Pilots concerned, but to other schemes that may be implemented in the future so that lessons learned may be shared with others and help future projects to be implemented with a minimum amount of internal conflict.

Strong senior management and clinical leadership were once again cited by the majority of Pilots as being an internal factor that has facilitated the overall progress of the Pilot. For the Pilots, the models of integration selected all require a degree of clinical leadership. Recruitment matters emerged again as a key issue, with Pilots reporting variously that the inability to recruit staff with the right skills at different levels has hindered their progress or, alternatively, that the employment of a project manager has been a significant positive factor in the Pilot's development. Prior working relationships and dedicated input from senior partners were also cited as contributing internal factors to Pilots' progress. A small number of Pilots have been hindered by delays, with unplanned hold-ups in finalising contracts, gaining approval from key stakeholders, and consolidating management structures between participating groups being reported as setbacks. Of particular concern are problems stemming from failures to agree on what exactly 'integration' means or should look like when implemented. Often these kinds of problems can be linked to either poor internal communication, whereby staff are unclear about the rationale behind particular changes or the overall purpose of the project. However, we found that many Pilots are still developing their own explanation of what integration means in detail.

While a small number of Pilots report that it is still too early to outline what integrated activities have achieved for service users and carers, a range of outcomes and outputs have been identified and reported by Pilot sites. Specified outcomes include reductions in hospital referrals, reductions in the length of hospital stay, and improvements in the quality and effectiveness of working relationships between organisation groups. Other positive developments include the completion of training programmes and workshops,

wards 'going live', establishment of multi-disciplinary teams at co-located sites, and a range of positive feedback and anecdotal evidence in support of integration activities.

The majority of Pilots report that, overall, their Pilot is making good progress in line with the project plan, although most Pilots have experienced delays in a number of different areas; for example, following recruitment hold-ups, delays securing the release of funds, or staff absences as a result of the swine flu outbreak. Other procedural problems have been linked to the adoption of the PbR tariff and the move to HRG 4. As with the previous evaluation round, a number of national factors were reported to have contributed to the success of Pilot projects, including the Darzi Review, the National Dementia Strategy, the Transforming Community Services Policy, the Social Care Green Paper, and also the project's initial selection as a Department of Health Pilot site.

Processes for the third round 3 – some issues for discussion

More granular information

In general, we have a developing understanding of how the Pilots are variously giving their local health and social care systems different, more integrated characteristics. However, as indicated above, for the next stage, and through the Deep Dives, it will be necessary to develop a more fine-grained understanding. For example, and to illustrate the kinds of evaluative evidence that will be needed, if we return to the question of staff empowerment, the references in the LD to giving staff more power are not located within a discussion of the issues which will most probably be associated with staff empowerment: how to avoid the dilution of professional expertise in decision-making; how to support a culture and local leadership where different disciplines can work collaboratively; how to create sufficient time to meet and communicate and yet spend sufficient time with the client. These are the sorts of detailed activities whose successful performance will be key to determining whether the wider 'systemic' characteristic of staff empowerment will be delivered.

Similarly, to understand the systemic characteristics of integrated care we will need to examine, among other things: the interdependence of agencies and activities; how goals are set and communicated; whether the whole system takes on characteristics and has consequences which were not intended by the participants; how resources are transformed into outcomes; how the system engages with the wider regulations, professional relationships, and accountabilities characterising the wider health and social care system; and how specialist skills and organisations can protect their expertise and specific contributions while at the same time contributing to the smooth working of the whole system.

However, finding data to answer these questions needs to be balanced with the constraints facing the Pilots. The evaluation team is well aware of the demands on the Pilot Team's time associated with delivering the 'day job', the Pilot and in addition participating in the national evaluation. The Pilots have remained committed and enthusiastic about this participation but we also recognise that

as we look for more detailed information that we need to do so in a way that limits the demands being placed on Pilots.

On some more mechanical points, we would encourage Pilots to spell out all acronyms when you first use them (and especially when these relate to local organisations). Although some acronyms are well-known, others are very specific to particular localities or assume a more specialised clinical knowledge. We would also request that you provide names and job titles in the 'author' column for all those providing the responses. Finally, a small number of Pilot sites were late in returning their completed evaluation forms. We would kindly ask that greater care is taken in the future to ensure that the Living Documents are returned before the submission deadline.

Link with quarterly reviews

It has become increasingly clear that the quarterly reviews produced by the Implementation Team provide an additional and rich source of information about the progress and achievements of the Pilots, and challenges being experienced. This is a useful source of evaluative evidence and we intend to integrate this into the evaluation. We would also like to discuss with the Implementation Team how the evidence emerging as part of the evaluation might be used to support implementation (contributing to the formative aims of the evaluation team).

Appending documents

We are very happy to explore ways of managing the flow of data from the Pilots. The reflections of the Pilots in response to the questions in the LD remain crucial to our evaluation plans but it may be that evidence to support these reflections could be appended, or cut and pasted from other documents.

More use of telephone discussion

It has been suggested that it might in some cases be more helpful to have a telephone conversation with the evaluation team rather than communicate through the slower process of providing individual feedback. It was suggested that this would both allow the Pilots to provide more tailored responses and allow the evaluation team to clarify their comments.

Third-round Thematic Review- April 2010

This report provides an overview of the responses from the sixteen Pilots to the **third round** of the Living Documents (LDs). It provides a general summary of the situation described by the Pilots as of April 2010 and has a particular focus on the new issues or themes that are becoming more apparent. As far as can be achieved whilst still producing a coherent and meaningful document, it clearly distinguishes what was said previously with what has changed.

Methods and processes

All LDs appear to be produced in good faith and all provide an increasingly clear outline of what the Pilots are hoping to achieve, what they are doing, and why. They vary in length and quality. In some the updating from the previous round is, in places, limited and the overall length of responses range from 27 pages of updated material to 127 pages of new material.

Prior to this thematic review, two researchers each read a sample of the LDs and drafted their comments and summary feedback. These comments and summaries were then discussed with the task leader and a shared approach agreed. In preparing this document all the LDs were read again by the task leader and the common themes identified. The summary comments were then re-read along with the February Site Periodic Reviews to ensure that important themes had not been missed. This document represents the outcome of this process.

Link with Periodic Review

In our summary of the 2nd round of the LDs we suggested that we would make a link between the LDs and the Periodic Reviews. The Periodic Review process is designed to provide:

- Each Pilot site with opportunity to reflect on their participation in the programme
- The implementation team with an opportunity to assess support needs among the Pilot sites, make amendments to management processes as appropriate, and highlight learning network learning opportunities.

It therefore serves a rather different function than the LDs which encourages the Pilots to reflect more on their local histories, reasons, and expectations providing a deeper insight into motivations, identities and calculations. However, the exercise of triangulating the Periodic Reviews with the LDs provided a very useful way for us to check our interpretations and where there were apparently rather different accounts to check these.

Responses to questions

The questions asked in the LDs

Turning to the specific questions asked, the topics in the second round of the Living Document covered the same assessment areas as the first round, with

some small changes. As with the previous round, there were a number of sub-questions asked within each of subject areas. These questions will be posed on a further four occasions during the lives of the Pilots and will provide evidence of how the projects perceived themselves to be progressing throughout the Pilot Programme. The topics covered in this evaluation round were as follows:

- Q.1. Developing the Pilot and background information (exploring the motivations and expectations of the Pilot team)
- Q.2. Who is doing what? (to enable the evaluation team to understand who is carrying out specific roles within the collaboration to provide integrated care)
- Q.3. Processes (producing a descriptive account of the processes of integration)
- Q.4. Outputs and outcomes (to identify successes and positive developments as the project evolves)
- Q.5. Is the Pilot progressing to plan? (encouraging comments on actual progress against planned progress)
- Q.6. Sustainability (what plans have the Pilot team put in place to ensure the long-term sustainability of their project and how are these plans evolving as the project develops)
- Q.7. What difference is the Pilot making? (in what ways is the project making a difference to patients/carers' lives and what positive impacts is it having on the region; how do the Pilot activities compare to work being undertaken elsewhere)
- Q.8. What are the cost consequences of the Pilot? (what have the Pilot management and activities cost to date and how are expenses being controlled by the Pilot team)

Responses

The Pilots were encouraged to build on their contributions in the previous round and, as anticipated, many of the responses to the questions (especially the earlier questions) remained at least in part unchanged.

Question 1 concerned the aims and objectives of each Pilot and these are now fully covered in the responses. The responses to these questions are largely unchanged. Inspiration for integration has come mainly from two sources; examples of successful integration (mainly US and UK), and local experiences of successful working. In one case it came from a university-delivered OD event.

Being part of a national programme is viewed positively and has helped to encourage local buy-in and this view is undiminished in the third round. Important repeated themes are about treating the whole patient, supporting patient choice, improved screening, providing new patient pathways, and underpinning joint working (presumably through organisational change). If successful, patients should anticipate quicker, better care and an improved patient experience. An approach for delivering this mentioned by four Pilots is

community wards and all but one of the Pilots aims to reduce emergency admissions and hospitalisation. In one way or another, fourteen Pilots also indicate that reducing inequality is an aim. Most of these pursue the aim of equality by seeking to ensure that all service users (and potential service users) have equal access on the basis of their health and social needs (as opposed to specific community based or otherwise targeted initiatives). Implicitly, the hope is that by bringing all services closer to the users, those previously most disadvantaged have the most to gain.

All the Pilots started with at least some good local relationships amongst partner organisations and wider stakeholders and in general these have been reported as improving across the sites. These are associated with quite varied efforts to develop the organisational and governance arrangements. These range from exploring new legal entities to function as employers of an integrated workforce through to bringing primary care resources into the formal governance of the hospital. More commonly, setting up an integrated care board (or equivalent) for local leadership and direction is widely reported. In general the language of collaboration, networks and change management programmes describe the intent, at least, of developing the integrated care through agreement rather than hierarchy.

In response to **Question 2** it is clear that the Pilots have secured the engagement of clinicians and more than half of the Pilot projects could be described as clinician-led. Primary care clinicians are strongly represented but so too are commissioners, community nursing, user representatives, adult social care and in general there is a clear relationship between the key participants in the integrating activities and the roles described as leading the Pilots. This includes representation from management. As described above, these are typically organised within a board (or equivalent) and Pilots are also exploring the appropriate organisational and governance arrangements to sustain and strengthen these relationships.

As the Pilots have reached the stage where they are taking a growing number of crucial decisions about delivering integration, we would also like to learn more about the rationale behind choices made by these leading figures. For example, why have specific service been selected for integration but not others? Are decisions in practice dominated by one particular professional or organisational viewpoint? We hope that being explicit about this will not only support the national evaluation but also help to share understanding within the Pilot.

Key participants and organisations involved in the leadership of the Pilots, as reported in the LDs, have remained stable. There is no evidence that, faced with the hard miles of delivering integrated care, the alliances behind it have begun to fragment.

Question 3 concerns the processes and activities being developed and delivered. A typical response is that 'The main activities of the Project Office are around building relationships, setting up systems, obtaining information/data'. Another describes their activities as 'Communication to and engagement of internal stakeholders...Communication sessions...Data collection and information sharing...Community work stream'. Where

mentioned, the aim of integration is more typically seen to be about 'relationships and shared vision which are critical rather than organisational form'. Indeed, a more typical response is that integration concerns staff in their existing organisational settings working differently and according to a shared vision: 'It is worth highlighting that the actual delivery of the Pilot intervention itself rests with the existing practice nurses, community nurses, some social care staff and their wider teams in general practice/community care. These staff have taken on the Pilot approach as a part of their normal job and incorporated it into their workloads – there are NO staff (beyond the project manager) who are specific to the project'.

Pilots have different ways of coordinating this work across separate but participating organisations: 'The agreements to integrate are made as part of commissioned and specified services rather than relying on 'gentlemen's agreements'. Likewise the integration is not leading to organizational integration as a means to protect the vibrancy within the market...' Others stress the importance of locating formal inter-organisational agreements within 'softer' relationships: 'The main mechanisms for integration are shared or complementary contracts; integrated team structures; and sharing the values and vision of the partnership'.

The importance of organisation as well as shared values is implicitly or explicitly repeated in each LD (but with a different balance between the weights attached to each). One sees integration as 'The action of incorporating organisations, and teams, delivering care to the local community, into a whole or entirety, where there is no segregation, to deliver seamless care'. However, the same Pilot goes on to note 'it has become clear that not everyone within the Pilot has the same working definition of "integration" and reported on planned activities to 'ensure a common understanding'. One comments that 'The phrase "culture eats strategy for breakfast" comes to mind here'.

Integrating activities are described as: operational activities; workforce development activities; governance-related activities; information and communication (both the 'hard' technology and the 'soft' relationships); and commissioning arrangements. All Pilots are committed to conducting some form of local evaluation outside the national evaluation and in some cases these are extensive. The facilitators of these activities are mainly 'softer' such as 'a shared belief and value base', trust, and leadership. Employment issues, which were reported in the previous LDs to be hindering integration in seven Pilots, and lack of budgetary information, are both improving.

In response to **Question 4**, a number of Pilots report the collection of significant data to support local evaluations. They also report the engagement of both commissioners and managers both of who expected to see hard evidence of costs and consequences. Through learning events, training, team meetings, electronic information folders, and the development of communications and media strategies, Pilot sites are building and sharing a local evidence and information base. Few can make the claim that 'We have been able to demonstrate phenomenal improvement in throughput for our community hospital, while simultaneously reducing staffing costs' (although some of this improvement preceded the formal launch of the Pilot) but this sort of solid evidence is likely to be needed to overcome the fact that, for one Pilot

at least, 'We have yet to convince many of our medical colleagues in general practice and the acute trust of our abilities to manage patients effectively at home'. Most Pilots also recognise that their sites 'are being closely watched by neighbouring localities' and that clear indicators of success would spread integrating activities.

One instance of how this might be done is reported as: 'There are 26 performance measures being reported against [which] measure the projects effectiveness and impact on patient outcomes and this is being monitored in the bi-monthly stakeholder meetings'. In addition they also collect and share information about the demographics, routines, life events and preferences of each service user and use this information to help in communicating. Perhaps supported by this information, they report increased engagement from commissioners and managers as well as clinicians. In this case, local evaluation is not carried out as an afterthought, or external to the Pilot, but as part of the routine flow of information at the heart of integrating activities. This Pilot has developed further than most but almost all the other report that they are also seeking to generate local evaluations (although not always so extensively) and it is recognised that comprehensive financial and clinical data will be needed to demonstrate to the PCT and others that commitments are being delivered.

As with responses to Question 3, there is a sense in the LDs that Pilots are moving beyond planning and meeting and beginning to put together the nuts and bolts of delivery.

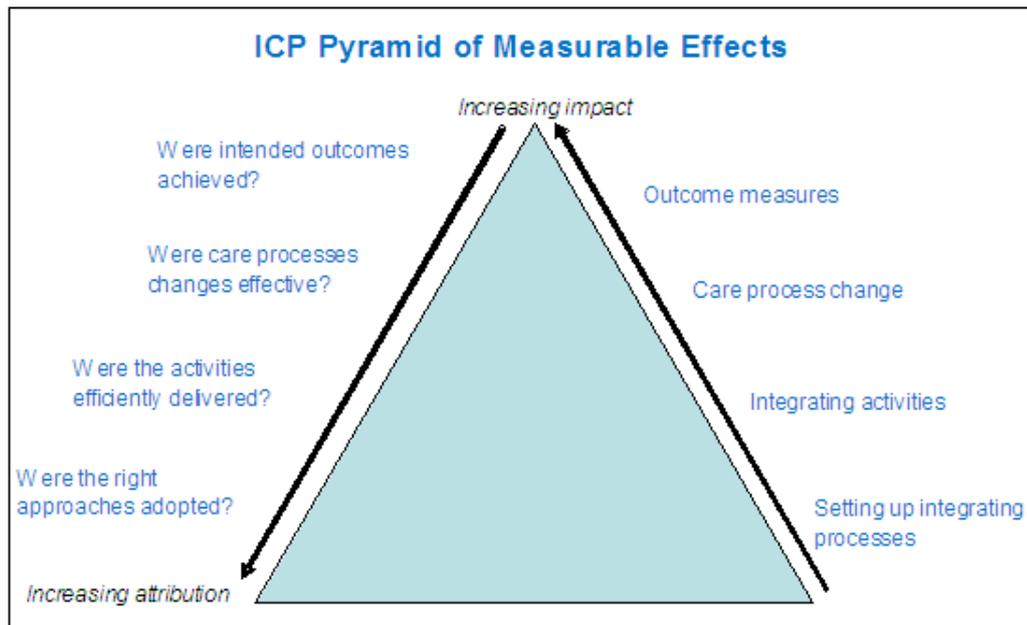
Question 5 asks Pilots about progress to date and most can report that progress, by the date of submission, is broadly on plan. The mood is well captured by the view that this has been a 'Period of intense activity to set up the Pilot with a sense that a lot going into the sausage machine'. Progress is reported across all the Pilots and this is supported by the reporting through the Periodic Reviews. However almost all Pilots note with concern the wider financial context and locally there remain groups that have yet to be won over – the late adopters, possibly. From the LDs it is hard to understand the basis for the resistance and whether it is based on reasoned concerns or a general antipathy to change. One reports that a minority of local practices 'are luke warm and a couple are reluctant'. The main difference has been where projects have a relatively short chain of relationships to mobilise, progress has been quicker and further. However, even where 'Extremely supportive PCT' and other good relationships are reported this does not guarantee rapid progress. Where complex workforce issues or 'whole system' changes are required progress has almost inevitably been slower. Progress has been facilitated by a national environment emphasising patient focused services, the 'air cover' Pilots perceive they have to be innovative, disease specific initiatives (e.g. the National Diabetes Year).

Question 6 concerns the future sustainability of Pilot projects. In the first round of the Living Documents, a large number of Pilots did not discuss plans for the long-term sustainability of their project. In the second round, there was a much higher response rate, with the vast majority of Pilots attempting to answer questions on future sustainability. This attention has continued in the third round.

Whilst almost all sites note likely future financial constraints with anxiety, many see that budgetary pressures will make integrated care even more important with future plans highlighting ‘the need to build on and expand the work being developed in the Pilot’. An interesting and important question concerns what sustainability means – it is less about organisational forms and more about integrated services yet there is an anxiety that centrally driven organisational tinkering could undermine integrated working: ‘An integrated organisational form does not guarantee integration of services and usually leads to a large organisation that is later seen as unable to reflect local needs so we go back round the circle of breaking up organisations and still do not have integrated services’. Perhaps the important point is that sustainability is more likely to come through organic locally developed organisational forms rather than the imposition of central models.

Question 7 asks Pilots to comment on the difference their project is making, as an individual initiative and also in the context of all the other work that is being undertaken at Pilot sites across the country. Even at this more developed stage of the Pilots, most recognise the difficulty of attributing change to the Pilot when so many other initiatives also have similar or related goals. ‘The proposed new model of care is aimed to make a difference but that said, it will be difficult to separate the success entirely from the benefits’ of other activities. This problem of ‘attribution’ is a common one where parallel programmes are taking place in the Pilot region but we would encourage Pilots to consider more carefully the contribution being made by their project to the positive outcomes being seen more generally in their area of care. Nonetheless, all Pilots attempt (even if vaguely in some cases) to describe some key differences that are already being made by their project. Improvements in patient safety, better use of resources, and increased cost-effectiveness were some of the impacts reported. However, the ‘pyramid of effects and attribution’ mentioned in the previous thematic review and described in Figure 2 remains relevant.

Figure 2: The ICP Pyramid of Measurable Effects



Question 8 concerns the overview of cost data and financial information. The financial information relating to set-up (fixed) and running costs (variable) costs is contained in Question 8.1 & Q 8.2 of the Living Document (LD). This was the second time that such information has been sought from the Pilot sites (following a revised pro forma). Individual comments on this section of the LD have now been fed back to each Pilot. In the thematic review we do not discuss each Pilot but it is important to understand the sorts of financial data that are becoming available. All the sites have provided at least some information. Generally more set-up costs have been identified than variable costs. Some have made considerable progress towards at least identifying the categories of cost and two have produced comprehensive and justified descriptions of their costs. However, even the best of these fall short of what would be needed to make a compelling business case and allow an analysis of which parts of the cluster of activities were especially expensive and which were not.

We anticipate that fully understanding these costs, and being confident that variations reflect not simply differences of interpretation and data collection, will require further work. We have prepared a short paper for the DH on how this might be achieved and we will return to this question in our interim Progress Report.

Overview of wider themes in the Living Documents

'Clusters' not 'models'

At the start of this evaluation, it was speculated that by this stage in the life of the Pilots certain models of integrated care would be becoming apparent. For example, we considered that there might be models of horizontal or vertical

integration, on the one hand, and models of service and structural integration, on the other. It is now evident that the picture on the ground is more complex and subtle than this. The concept of a 'model' implies something that can be demarcated (the boundary separating the model from the context is clear), something that is relatively fixed over time, and something that has a degree of internal coherence. It also implies something that can be applied in a verity of contexts. It aims to capture the essential (and therefore simplified) structure of an activity or process, usually with the intention of duplicating or evaluating interventions according to how faithful they were to the model.

However, in the light of this evaluation in general, and the LDs in particular, this language seems unhelpful. Although there are undoubtedly dimensions of systemic integration (for example in information systems, assessment, access, standardised communication, and finance) each Pilot is also embedded in its local areas in different ways making such integration very context dependent. Rather than a discrete set of models, broadly comparable across the Pilots, what is apparent from the LDs is a more fluid process of change and evolution. Furthermore, the activities of the Pilots are often difficult to demarcate from related but non-Pilot activities with, for example, a variety of schemes all designed to provide more personalised care. Similarly, the focus of activity within each Pilot changes over time as circumstances evolve. And each Pilot carries out a number of activities which are not part of a single coherent model. 'Integration' is a process and not a model. Furthermore it is a process that is to a degree self limiting (i.e. there will never be complete integration). Information sharing, pooled budgets, shared communications protocols and so forth all have practical limits to scale and scope beyond which they become suboptimal. These limits will manifest themselves differently in different contexts.

We found that rather than identifying a discrete set of models of integration, the LDs described a wide range of skills and resources used to conduct a variety of integrating activities in pursuit of many different outcomes. Each particular combination of resources, activities and intended outcomes appears to depend upon local leadership and context at least as much as upon the adoption of models (although many started with a good understanding of models of integration learned from US or UK examples). A more accurate term than 'model' might be a 'cluster' of activities which evolves over time as learning takes place, relationships mature, and the environment changes. 'Clusters' are made of elements tied together in space and time, that may mutually reinforce and support each other, but are not logically or causally unified. It is also apparent that each locality has developed its own and distinct 'cluster'. This sensitivity to local history and context was anticipated by Chris Ham and John Oldham in their recently published study of integrating health and social care in England.²⁹

Intended outcomes

The intended outcomes are described in many different ways adding to the difficulties of comparing and contrasting the Pilots. However, they can be

²⁹ Ham, C and J Oldham (2009) 'Integrating Health and Social Care in England: lessons from early adopters and implications for policy' *Journal of Integrated Care* 17:6 December 2009

brigaded into three broad (and not mutually exclusive) headings. The first heading is a concern with **technical efficiency**. Intended efficiencies mentioned include improved cost control, more effective deployment of the workforce, leaner and more effective organisations, a learning and self-improving system, integrated commissioning, and reduced institutional dependency among service users. One Pilot also suggested that integrated care would make any potential future 'slash and burn' response to financial pressures less likely.

The second heading concerns the **quality of services**. Issues mentioned include making services easier to access and, once accessed, having fewer 'hand-offs' and being simpler to use. Speed of response was also mentioned, especially where this could improve the clinical outcomes by early diagnosis or identifying earlier a sudden deterioration. Most considered that integrated care would support better informed decisions and many asserted that more personalised care, delivered closer to home, would improve the quality of that care. It was also anticipated that more preventive work, and earlier treatment, would improve the quality of care that could be provided. Many saw a strengthened user voice in decision making as also contributing to improved quality. Most related to improving equality in the particular sense that ensuring that resources were focused on those carrying the greatest burdens of disease rather than by chance or power, was itself contributing to equality. However, others identified more specific measures to reduce inequities focused on specific and vulnerable social groups.

The third heading concerns **user and carer experience**. Better premises, more responsive services, strengthening the users' voice, having to give the same information less often, more continuity of care, and getting answers sooner and more easily were all mentioned. The list of issues under user and carer experience may be shorter than the list for value for money but across the 16 Pilots there is a fairly even balance of attention given to each of these three overarching outcomes.

Skills and resources (and how these have changed)

In pursuit of these aims, ICPs have marshalled a wide range of skills and resources. Skills required were said to include: negotiation, trust-building, communication, project management, facilitation, data analysis, leadership, workforce development, financial management, redeploying under-used resources, managing change and understanding systems. National support from the DH and the opportunity to relate delivering integrated care to achieving other national priorities were also said to help. The Periodic Review for January already identified some improvements in outcomes associated with the application of these skills in the areas of:

- Communications and engagement
- Implementation of services
- Data management
- Bridging the gap between different cultures

The LDs support this and the fact that relatively few additional staff have been brought in, it appears that these skills have been developed within the Pilots.

Knowledge of certain key methods has also shaped behaviour. Understanding of the one-stop shop, multi-disciplinary team working, the virtual ward, and lean methodology have all informed local decisions.

Not surprisingly given the stage of development of the Pilots, there is more awareness of change within the life of each Pilot and a sense that each is managing an unfolding process of change rather than (simply) implementing a model. Skills are drawn upon to manage this process of change. However, from the LDs, this does not appear to involve a change away from the intentions and spirit of the original proposals and indeed these aims have remained fairly consistent. On the contrary, there appears to be a process of adaptation to a changing environment and to learning from experience, in order to continue to pursue relatively fixed aims.

New Model Professionals?

It is sometimes easy to miss significant changes that are implicit rather than explicit. One reading of the LDs is that the progress of the ICPs is bound up with changing professional roles in health and social care. The LDs describe a context where, for GPs in particular, there is (implicitly) an enhanced role for the professional, including advocacy, community involvement and leadership, human resource development, whole systems thinking, and change management. Other professionals also face enhanced roles (and in particular for nurses in delivering care for the people with chronic conditions) but there are clearly power asymmetries involved where GPs, in particular, may feel they have more control over the development of their enhanced roles. For some, there might not be enhancement so much as substitution as efforts are made to use the workforce more effectively. With substitution, tasks previously carried out by one group of professionals are carried out by another (typically less qualified) group.

It is interesting, perhaps, that these issues are not articulated through the LDs and this may reflect the fact that these are GP-led and that GPs appear to have been developing an enhanced skill-set and role, learning 'on the job', almost without noticing how their role has changed.

However, reading the LDs closely, it appears that we have a new type of professional emerging. The enhanced roles include: taking responsibility not only for the individual client but also for that person's journey through the whole system; collaborating in teams and developing soft skills of leadership and influence; both helping those who have already accessed the system and ensuring that unmet needs are addressed; and not only diagnosing and telling but also listening, sharing information and discussing. A very important caveat to this is that the LDs are either written by, or are influenced by, professionals who embrace these changes. Presumably there are many other professionals who do not but they are not represented in the leadership of the Pilots.

Making the business case for change

Some of the benefits of integration are beginning to be identified or, at least, anticipated. These include reductions in acute admissions, increased early detection and weather information for people with COPD (who may choose to stay at home in certain weather conditions, for example). We are also seeing that problems identified in previous rounds in relation to, for example, data sharing and implementing information systems are felt to be improving and, among other benefits, this should allow improvements in efficiency, quality, and user experience to be monitored and communicated. However, given the size of the investment, there is still a lack of clarity about the sorts of sustainable and measurable cost and quality improvements that might be expected. This is an important issue in the wider context of making the business case for integrated care because the experience of the ICPs suggests that integrated care costs money before it delivers benefits. Unless the future (or intermediate) benefits can be made visible, and costs identified, it may prove hard to maintain the commitment of managers, practitioners and users.

What is the focus of concern (and has this changed)?

In the document summarising the second round, we identified, from the LDs, three problems which it was hoped integration would mitigate:

1. The first type of problem which integration is intended to address concerns the anxiety that information about patients and users is not made available where it is needed in a timely and efficient manner, and that service users find themselves repeating the same information. Proposed solutions are intended to ensure that information about the patient/user/carer (and ways of helping the patient/user/carer) are more effectively shared and used across disciplinary and organisational boundaries. Achieving this may involve one of a number of approaches including the use of information and communication technology, better team working through multi-disciplinary or multi-agency decision making, reducing the number of 'hand-offs', and empowering service users to articulate their needs more effectively at each stage of their journey through the system.

A second type of perceived problem is that staff are believed to be inappropriately constrained by the organisational settings they work in. This results in staff delivering poorer services than would be justified given the resources allocated to them. In response, the solution in some Pilots is to 'empower' (however defined) staff (clinical and non-clinical) to be less constrained by previously narrowly defined organisational or professional parameters. The aim is to relax the organisational and disciplinary parameters thereby empowering staff to both carry out a wider range of tasks and contribute to a wider range of decision making where they can use their knowledge and skills more effectively.

A third perceived problem apparent in the LDs is that accountability and financial systems previously drove behaviour to defend organisation-based incentives rather than patient benefits or wider benefits for the healthcare system. It is recognised that for reasons of effective management of public resources, and for reasons of accountability, there will have to be budgets,

budget holders, and reporting arrangements but it is believed that by exploring how pooled or shared budgets might be amended, or by creating new organisations with different responsibilities, it might be possible to reward behaviour which supports integrated goals (such as reduced hospitalisation).

These three themes are still strongly present in the third round. However, some other themes are now a little stronger. Unsurprisingly the anticipation of downward pressure on expenditure has focused attention on the role of integrated care in not only achieving cost control but establishing a more rational basis for managing spending constraints and resisting a 'slash and burn approach' (as one person called it) which might achieve savings in one place only to create additional costs elsewhere.

Linked to this, perhaps, is a greater sense that systems thinking and the softer skills of change management (either formally or tacitly) underpins how Pilots describe what they are doing and in particular when describing what facilitates and what hinders the projects. There is a growing interest in the skills and approaches needed to help delivery. Facilitators often mentioned concern leadership, building shared interests, creating appropriate incentives, and developing good relationships (as well more traditional emphases such as project management and senior support).

In conclusion, the LDs display a growing sophistication and clarity about the skills and activities needed to deliver integration. However, the concrete routes to improved outcomes remain unclear. In the previous round we suggested that many of the arrows in Figure 1 were unclear (at least as presented in the LDs). This is becoming clearer to us but there is still more work to be done to properly understand the causal chains.

Figure 1: Mapping the causal chain between ICPs and outcomes

